

# **Measuring child maltreatment in community-based trials**

**Gwenllian Moody**

**A thesis submitted for the degree of Doctor of Philosophy**

**May 2019**

**Cardiff University**



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## Acknowledgements

Firstly, I would like to thank my PhD supervisors, Professor Mike Robling, Dr Rebecca Cannings-John, Professor Kerry Hood, and Professor Alison Kemp. I am truly grateful for all your encouragement and patience.

Thank you to my colleagues in the Centre for Trials Research. To Andrea Meek for double-coding qualitative focus groups and interviews, the CTR qualitative group for your help with piloting the qualitative chapter, to Sam Clarkstone for designing and building the online focus groups forum, and to Fiona Lugg-Widger for assisting with data access. Thank you to my office friends, in particular Dunla Gallagher for assisting with qualitative data collection...and your fantastic company!

A very big thank you to all the participants who gave their time to help with this project.

Thank you to all those who provided training to help me conduct this work. I would also like to acknowledge the various researchers who have provided valuable feedback on the work presented in this thesis, at conferences and through peer review of the journal article.

Finally, and most importantly, I would like to thank my friends and family. I Mam a Dad, am eich holl gefnogaeth, hebddo chi, byddwn ddim mewn sefyllfa i allu astudio am y PhD. Most of all to my husband Jonathan, for all your help, encouragement and support, I couldn't have done this without you. I fy annwyl Undeg, am fy atgoffa am y pethau pwysig.



## Summary

### Background

Nationally and internationally, there has been a growing recognition of the importance of identifying, documenting and reporting suspected and confirmed child maltreatment. Formally collected data on the extent of child maltreatment in social services and criminal justice records are likely to be an underestimate of actual cases.

### Aims

The aims of this study are firstly to introduce the problem of child maltreatment. Secondly, to explore mothers, care-experienced young people and professional attitudes regarding the collection and linkage of maltreatment data for research. Thirdly, to investigate how markers and risk factors of maltreatment relate to outcomes that may indicate maltreatment, and to illustrate this using case studies.

### Methods

The study involves formally reviewing the background to each research question by structured literature review. The study takes a mixed-methods approach. Secondary regression analysis of data explored potential risk factors and markers of outcomes that may indicate maltreatment. Exploratory focus group interviews with mothers, care-experienced young people and professional stakeholders were conducted.

### Findings

When exploring mothers, care-experienced young people and professionals' attitudes towards collecting and linking maltreatment data for research three major themes were identified: consent, trust and understanding. Mothers with outcomes that may indicate maltreatment in their child were more likely to have higher parental stress, be more deprived, and show their child negativity. They were also more likely to have a child attending A&E with a nerve, contusion, head or ano-genital injury, with a congenital abnormality, and themselves had a higher number of antenatal check-ups. When collecting data on child maltreatment researchers should not utilise a dataset containing a subset of participants as the main population. They should not utilise a dataset less complete than another, and be mindful that self-report *may* be less reliable than routinely collected data. Case studies were useful in gaining a deeper understanding of the pattern of variables that could be related to outcome.

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## Acronyms

A&E	Accident & Emergency
AHT	Abusive Head Trauma
ALF	Anonymous Linking Field
ALSPAC	Avon Longitudinal Study of Pregnancy and Childhood
CAG	Confidentiality Advisory Group
CAP Trial	Cluster randomised trial of testing for Prostate cancer
CIN	Child in Need
CLA	Child Looked After
COVER	Coverage Of Vaccination Evaluated Rapidly
CPP	Child Protection Plan
CPS	Child Protective Service
CSV	Comma Separate Values
CTQ	Childhood Trauma Questionnaire
CTR	Centre for Trials Research
DAAG	Data Access Advisory Group
DMAP	Data Management Advisory Panel
EDD	Education Data Division
EMRs	Electronic Medical Records
EU	European Union
FNP	Family Nurse Partnership
GP	General Practitioner
GUM	Genitourinary Medicine
HES	Hospital Episode Statistics
HRSS	Health Research Support Service
HSCIC	Health and Social Care Information Centre
ICD	International Classification of Diseases
IMD	Index of Multiple Deprivation
IPA	Interpretive Phenomenological Analysis
IPV	Intimate Partner Violence
IQ	Intelligence Quotient
ISPCAN	International Society for Prevention of Child Abuse and Neglect
LONGSCAN	Longitudinal Studies of Child Abuse and Neglect
MMCS	Maltreatment Classification System
NHS	National Health Service
NICE	National Institute for Healthcare Excellence
NIS-2	Second National Incidence Study
NKPS	Netherlands Kinship Panel Study
NPD	National Pupil Database
ONS	Office for National Statistics
PEARL	Project to Enhance the Avon Longitudinal Study of Parents and Children (ALSPAC) through Record Linkage
PSI	Parenting Stress Index
SAIL	Secure Anonymised Information Linkage



SES	Socio Economic Status
TTP	Trusted Third Party
UAT	Unlinked Anonymous Testing
UK	United Kingdom
UNICEF	United Nations Children’s Fund
US	United States
WHO	World Health Organisation



# Chapter 1. General Introduction

## 1.1 Introduction

The World Health Organization (WHO) has defined child maltreatment as 'All forms of physical and/or emotional ill-treatment, sexual abuse, neglect or negligent treatment or commercial or other exploitation, resulting in actual or potential harm to the child's health, survival, development or dignity in the context of a relationship of responsibility, trust or power' (1). The four types of maltreatment are grouped as physical abuse, sexual abuse, emotional or psychological abuse, and neglect (1). Referrals to Social Services for the year ending in March 2017 were 646,120 in England (2) and 37,618 in Northern Ireland (3). For the year ending in March 2016 there were 33,536 referrals in Wales (4). Preventing child maltreatment is an important focus for United Kingdom (UK) Government. Statutory guidance on child protection and safeguarding has been published for all four UK countries.

### 1.1.1 The problem of measuring child maltreatment

Child maltreatment can be measured in a number of ways, by counting data from formally collected sources, or by asking individuals to self-report their maltreatment experiences.

Formally collected data on the extent of child maltreatment can be found in child protection agencies records (5; 6; 7; 8; 9; 10; 11), criminal justice records (12), and medical records (13; 14; 15; 16). Formally recorded cases of maltreatment however are only a portion of the true numbers of all maltreated children (17; 18). These data are likely to be undercounts because they solely rely on system indicators, created for bureaucratic and tracking purposes as opposed to research purposes (19). They are likely to be more crude recording only the minimal amount of information. For example, the geographical area covered by the agency could also affect count, cases where children or families move between areas could be double-counted or missed altogether (20).

Researchers have conducted studies to attempt to capture the prevalence of maltreatment using self-report. Considerable variation in prevalence rates of self-reported maltreatment have been found (21; 22; 23; 24; 25; 26; 27). Some of this observed variation may actually reflect true experiences by children. However, some of the differences observed may result from differences in methods used (28, 17, 29). The casemix of the participants may have an

effect on prevalence rates, including participant age, gender, and the type of population included such as clinical or population samples. As an example, prevalence estimates tend to differ for some types of participants than others. They are lower for samples drawn at random from general populations and convenience samples than those based on research with volunteers or service user (e.g. recruited from GP practices) samples (28; 30). Method of data collection can artificially influence participant response. Studies have shown that face-to-face interviews result in higher reporting rates compared to self-completed questionnaires (31). Finally, definitions of child maltreatment can have an effect on both counts in formally and self-reported data on child maltreatment. Definitions in formally collected data sources, specifically those from child protection agencies, are decided after consultation and negotiation between various professionals therefore do not appear in a vacuum. The behaviours and events that lead to these classifications could be variable within and between settings (32). Definitions in research measuring self-reported child maltreatment can also be problematic. Some studies focus on perpetrators as family members, which may lead to possibly missing perpetrators outside the family.

### **1.1.2 Theoretical framework, a mixed-methods study**

This study uses a 'mixed methods' approach to address the research questions. This is where the researcher mixes or combines quantitative and qualitative research techniques, methods, approaches, concepts or language within a single study (33). This was utilised as the philosophical assumptions of quantitative and qualitative techniques recognise that certain types of research questions are best answered by qualitative methods, while others are best answered with quantitative methods. Quantitative and qualitative research differ in many ways and have strengths and weaknesses. Quantitative methods typically are associated with a positivist approach and qualitative methods are typically associated with an interpretative or constructivist approach (33). A positivist approach purports that social observations should be treated in much the same way as physical phenomena, should be objective, and that the observer is always separate from the participants they observe (33). An interpretative or constructivist approach purports that time- and context-free generalisations are neither possible nor desirable. It purports that research is value bound, that causes and effects can never be differentiated, and that the observer can never be separate from those observed (33). Qualitative and quantitative research approaches also differ in the ways that they generate and test theories. Traditionally quantitative research focuses on deduction, confirmation, theory or hypothesis testing, explanation, prediction, standardised data

collection, and statistical analysis (33). Qualitative research includes such characteristics as induction, discovery, exploration, generation of hypotheses or theory, the researcher as the primary instrument of data collection, and qualitative analysis (33). Interpretative research is focused on exploring people's experiences and attitudes, or the underlying reasons that they might behave in a certain way. It is concerned with the meanings people attach to their experiences of the world and how they make sense of it (34). Qualitative research is often seen as "giving a voice" to the participants (35).

It is important to understand the strengths and weaknesses of qualitative and quantitative methods as this will put the researcher in a position to combine methodologies. To do what Johnson & Turner (2003) call the 'fundamental principle of mixed research', researchers should collect multiple data using various methodologies in a way that means that the resulting mixture will result in complementary strengths and reduce weaknesses. By combining the two approaches, it is possible to answer complex research aims and questions more comprehensively (37). It is also possible to 'offset' the weaknesses of the two approaches while utilising their strengths (37). Creswell (2009) argues that more insight can be gained from the combination of both approaches than either by itself. Johnson & Onwuegbuzie (2004) argue that mixed-methods research is less restricting for researchers and allows them to be creative. They also argue that the research questions should be fundamental. The methods used should follow the research questions in ways that offer the best chance to obtain useful answers (33), whether qualitative, quantitative or both.

The problems addressed in health and social care research are so complex that either qualitative or quantitative approaches alone would not be able to address the research questions adequately. Research questions that profit most from a mixed methods design tend to be broad, complex, multi-faceted and address social phenomena (39) such as those addressed in the current study. The decision to include a qualitative study, as well as being the best method to utilise for the research question, was made as the researcher is committed to representing the voice of participants in this work. The quantitative component aims to utilise health and social care data to investigate how markers and risk factors of maltreatment predict maltreatment. Attitudes towards such studies being conducted was important to capture to ascertain acceptability and views of groups who may be involved (or have children involved) in such research in the future.

### **1.1.3 The Building Blocks Trial and the Building Blocks: 2-6 Study and rationale**

The Building Blocks Trial (40; 41) was a pragmatic randomised controlled parallel-group trial based in community midwifery settings at 18 sites in England. Pregnant women under 20 were randomly allocated to receive the Family Nurse Partnership (FNP) programme plus usual care or to receive usual care only. The FNP programme is a nurse-led home-visiting intervention where participants received up to 64 visits from a specially recruited and trained FNP nurse during pregnancy and up until 24 months post-partum. The programme aims to improve pregnancy outcomes, child health and development (including reducing child maltreatment), and to increase maternal self-sufficiency. The first aim of the trial was to evaluate the effectiveness of FNP. There were four primary outcomes; biomarker-calibrated self-reported tobacco use by the mother at 34-36 weeks gestation, birthweight of the baby, the proportion of women with a second pregnancy within 24 months post-partum, and emergency attendances and hospital admissions for the child by 24 months old. The second aim was to assess the incremental costs and consequences of the FNP programme compared to usual care. The third was to model possible longer-term costs and effects of the programme. The fourth aim was to evaluate what processes influence FNP outcomes to explore applicability to other settings and optimise further implementation of the programme. Self-report data were collected at baseline, at 34-36 weeks gestation, and at 6, 12, 18, and 24 months post-partum. Routine data were collected from primary care centres and maternity units, and via direct data download from the Health and Social Care Information Centre (HSCIC, later named NHS (National Health Service) Digital), from the Department of Health for abortion statistics, and from COVER (Coverage Of Vaccination Evaluated Rapidly) contacts from primary health-care authorities. 1618 women were randomised to the trial. Researchers found no evidence of the effectiveness of FNP for the four primary outcomes. In light of this FNP could not be considered to be cost-effective, however the programme was found to be delivered mostly in line with fidelity goals.

The Building Blocks Trial assessed the short-term impact of FNP programme. The Building Blocks: 2-6 Study (42) assessed the medium-term impacts of the programme for mothers and children. The Building Blocks: 2-6 Study was a data linkage study. Data collected during the Building Blocks Trial were linked to routinely collected data collected from NHS Digital, Office for National Statistics and the Department for Education's National Pupil Database. This was done by a process of pseudonymised data abstraction. Participants who consented to be part

of the Building Blocks Trial were included in the cohort, unless they chose to opt-out of the study prior to data transfer. Participants recruited to the Building Blocks Trial (40; 41) and retained in the Building Blocks: 2-6 Study dataset (42) will be referred to from now on as the Building Blocks cohort.

Details of the Building Blocks Trial and the Building Blocks: 2-6 Study can be found in the Trial protocol and results papers (40; 41), and the Study protocol paper (42).

Participants in the Building Blocks cohort were selected for the current study as they have some characteristics that are likely to place their children at high risk of maltreatment. The mothers are young in age (e.g. 43), and are living in socially deprived geographic areas (e.g. 44). The cohort are also very well characterised with detailed demographic and psycho-social variables collected at baseline and follow-up.

Child maltreatment can be identified and reported by various health and social care professionals in the UK. Indicated and confirmed child maltreatment data can be collected from various different organisations including from contacts with child protection services i.e. Social Services, data on offenses against children in the criminal justice system, and data from medical and education records (12; 44; 14; 45; 46; 16; 47). Cases of maltreatment that come to the attention of health and social care professionals are only a portion of the true numbers (17; 18). There are many more that go undetected, unreported or unrecorded (28).

#### **1.1.4 Objectives of the thesis and research questions (overview of the study design)**

##### **1.1.4.1 Objectives**

###### First objective

To review the reported prevalence of self-reported child maltreatment in the UK and worldwide.

###### Second objective

To explore the attitudes of mothers, care-experienced young people, and professionals regarding the collection and linkage of maltreatment data for research.

### Third objective

To investigate how markers and risk factors of maltreatment, identified from a variety of data sources, predict an outcome that may indicate maltreatment (in this thesis defined as Child in Need (CIN) Status) for children in the Building Blocks cohort. Markers of maltreatment are features such as physical signs of abuse or injuries. Risk factors of maltreatment are those factors that may be associated with causing child maltreatment.

### Fourth objective

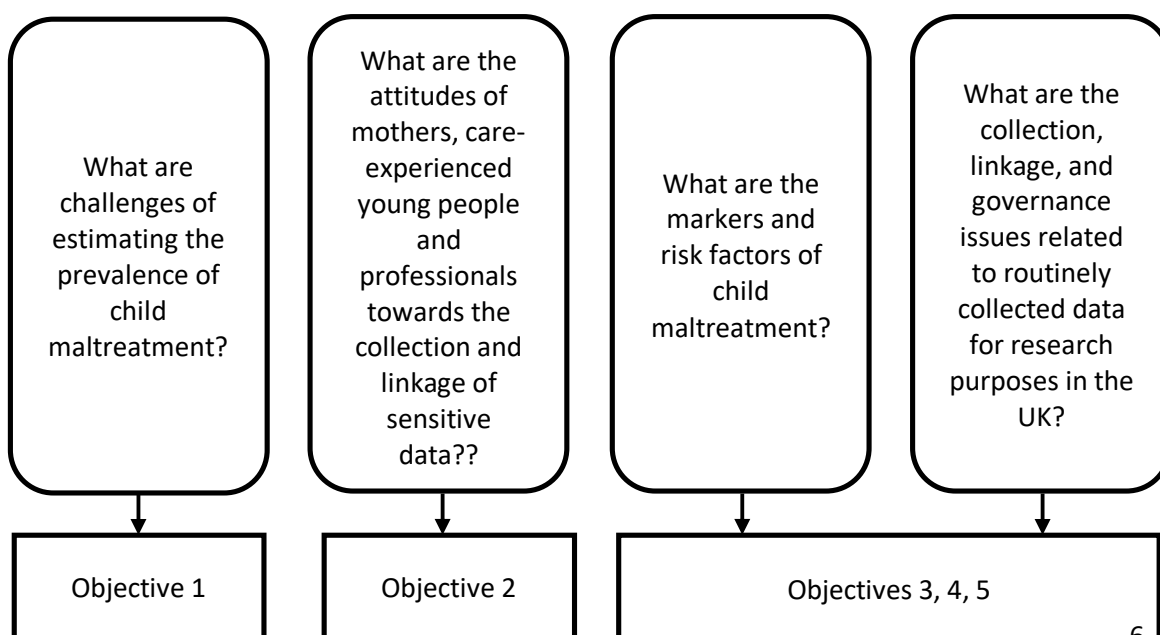
To investigate how risk factors and markers of maltreatment predict *different* outcomes, varying in severity, that may indicate maltreatment.

### Fifth objective

To illustrate how risk factors and markers of maltreatment predict outcomes that may indicate maltreatment using examples from the Building Blocks cohort and the analysis undertaken in this project (case studies).

The study involves formally reviewing the background to each research question by literature review. The study takes a mixed-methods approach, with qualitative and quantitative data being obtained for analysis (Figure 1). The use of a mixed-methods approach is discussed further on in this chapter. The quantitative data were collected in the Building Blocks Trial (40; 41) and Building Blocks: 2-6 Study (42), and qualitative data are collected by the researcher.

**Figure 1.** How the study objectives relate to each research question





#### **1.1.4.2 Thesis structure**

##### Chapter 1: General introduction

##### Chapter 2: Setting the scene

This chapter introduces the problem of child maltreatment and provides a literature review examining other researchers' findings concerning the prevalence of child maltreatment in the UK and worldwide. This seeks to address the first objective.

##### Chapter 3: Exploring attitudes on the collection and linkage of maltreatment data for research.

This chapter contains the qualitative component. It contains a literature review to introduce the research question. Qualitative methods, i.e. focus groups and interviews, are used to address the second objective. That is to investigate mothers, care-experienced young people and professionals' attitudes towards the collection and linkage of routinely collected sensitive data for research purposes.

##### Chapter 4: Building a clearer picture of the relationships between markers and risk factors of maltreatment and later maltreatment outcomes.

This chapter contains the quantitative component. It contains two literature reviews, and the analysis that seeks to address the third objective. That is to investigate how a variety of data sources can be combined to build a clear picture of confirmed maltreatment, markers of maltreatment, and risk factors of maltreatment for children in the Building Blocks cohort. As part of the third objective the advantages and disadvantages of using various sources for collecting data that may point to maltreatment will be evaluated.

There are two additional objectives in this chapter:

- Objective 4: To investigate which risk factors and markers of maltreatment predict different outcomes that may indicate maltreatment, varying in severity.
- Objective 5: To explore how markers and risk factors of maltreatment predict maltreatment outcomes using case studies.

##### Chapter 5: Bringing it all together

This chapter reviews the key findings from the qualitative and quantitative portions of the study and how these can be integrated. Methodological considerations are discussed as well as strengths and limitations. Directions for future research and the implications of the research are outlined, before finally reviewing the conclusions and giving recommendations.

### **1.1.5 Addressing gaps in the current literature**

Three chapters of the study will seek to address gaps in the current literature and two additional chapters will serve as an introduction and discussion.

#### **Chapter 2**

This chapter provides a background to the problem of estimating the prevalence of child maltreatment. The chapter also includes the review of studies using self-report to capture prevalence rates of child maltreatment in the UK and worldwide. Formal estimations of the prevalence of child maltreatment based mostly on self-report have been conducted by other researchers. These however have focused on one type of abuse only, mostly sexual abuse, and contain older studies. The current review expands on these works by reviewing more contemporary studies and presenting studies on prevalence of the four different types of maltreatment in one review.

#### **Chapter 3**

So far there has been no study exploring the attitudes of mothers, care-experienced young people and professionals towards the collection of child maltreatment data specifically. Chapter three explores views about data collection for research and linkage issues for child maltreatment data. This is important as child maltreatment data are considered particularly sensitive. This may be especially true if parents are asked about their consent preferences to collect data on their children, i.e. they would be consenting on behalf of another.

#### **Chapter 4**

Many risk factors and markers for maltreatment have been reported in the literature. These literature however have mostly focused on a single risk factor or marker, or a small group of these. Chapter four reviews literature on many different risk factors and markers of maltreatment, and analyses which of these are most predictive of maltreatment using data collected in the Building Blocks Trial (39; 40) and the Building Blocks: 2-6 Study (41). The chapter also provides a background and context to routine data collection in the UK for research purposes. This was included to familiarise the reader with various issues around the collection, linkage, and governance issues related to routinely collected data.

### 1.1.6 Design of a mixed methods study

This study uses a 'mixed methods' approach to address the four research questions. The first research question is addressed by literature review and by summarising data on the prevalence of child maltreatment. The second research question is addressed using qualitative methods, and the third and fourth using quantitative methods.

The mixed-methods design of the current study consists of a qualitative chapter exploring mothers, care-experienced young people and professional attitudes regarding the collection and linkage of maltreatment data for research using focus groups and interviews. It also consists of a quantitative chapter to investigate how a variety of data sources can be combined to build a clear picture of outcomes that may indicate maltreatment, markers of maltreatment, and risk factors of maltreatment for children in the Building Blocks cohort. Several aspects influence the design of a mixed-methods study, four of the most important to the current study are weighting, timing, mixing and theorising (38).

#### Weighting

The weight or the priority given to quantitative or qualitative research in a particular study should be considered in the design of the study (38). Bryman (2006) suggested that those conducting mixed-methods projects should consider if they want to prioritise the qualitative or quantitative aspect. Creswell (2009) amongst others however disagree with this and argue that an equal weighting is possible if desired. In the current study, the quantitative and qualitative chapters have *somewhat* similar weighting, although the quantitative chapter is considered the primary method. The best method for each research question was chosen without a priori ideal of weighting.

#### Timing

The timing of the qualitative and quantitative data collection also needs to be considered. It may be done sequentially in phases or gathered concurrently (38). The quantitative data had already been collected during the Building Blocks Trial (40; 41) and Building Blocks 2-6 Study (42). The qualitative data were collected during the current study. The data are analysed concurrently as they were addressing different research questions and were not required to be analysed in phases.

## Mixing

When and how to mix the quantitative and qualitative components is another important design consideration. This can occur at many stages including data collection, during analysis, and interpretation (38). In the current study the mixing of the quantitative and qualitative aspects are done during interpretation, through 'embedding' (i.e. embedding a secondary method within a larger study having a different primary method, and the secondary method provides a supporting role in the study) (38). It should be kept in mind however that the qualitative and quantitative aspects are addressing different research questions and this will limit the extent to which the results can be integrated. The current study's primary aim is to collect quantitative data, and qualitative data will provide supporting information.

## Theorising

Several researchers have identified and classified types of mixed-methods strategies (38; 46). Creswell (2009) identified six major types to choose from in designing a mixed-methods study. The current study has a 'concurrent embedded design' (38). In this design quantitative and qualitative data are collected simultaneously. There is a primary method that guides the study and a secondary method provides a supporting role. In the current study the secondary method is qualitative and is embedded in the quantitative method. This embedding may mean that the secondary method addresses a different question than the primary method (38), and this is certainly the case in the current study. The mixing of data from the two methods is done to integrate the information, typically during interpretation (38). The quantitative and qualitative data *can* be compared, however this does not have to be the case as the data can also provide two different pictures that help to answer the overall problem (38). In the current study the qualitative and quantitative data sources will not be compared as they are used to answer different research questions, but will be brought together during interpretation to address the overall problem.

A concurrent embedded design will be used in the current study for two reasons. Firstly, as Creswell (2009) claimed, using this design allows the researcher to gain a broader perspective because more than one method is used. In the current study the qualitative chapter allows exploration of participant attitudes towards the sort of data analysis that will be completed in the quantitative chapter. Secondly, qualitative data can be used to describe an aspect of the quantitative chapter that is not quantifiable (38), or that is simply not quantified. In the current study, the qualitative data explores feelings and attitudes about the collection of child

maltreatment data, and as child maltreatment data are collected in the quantitative chapter via routine data, attitudes towards this were not measured. It should also be reiterated that it is possible for one method to be used within the framework of another (38).

An issue with using a typology such as a 'concurrent embedded design' is that the decision to use that typology is made at the start of a study. The outcomes however of the qualitative and quantitative aspects are not always predictable and so surprising findings or unrealised potential in the data may suggest unanticipated consequences of combining them (37; 48). The details of the various components of this study can therefore be described as 'emerging'. The exact methods and materials that will be used will be developed through the study (49), for example, the design of the qualitative and quantitative components cannot be completed until the literature reviews have been done.

The next chapter introduces the problem of child maltreatment using a literature review as well as a detailed examination of other researchers' findings concerning the prevalence of child maltreatment worldwide.

### **1.1.7 Publications list**

Moody, G., Cannings-John, R., Hood, K., Kemp, A., & Robling, M. (2018). Establishing the international prevalence of self-reported child maltreatment: a systematic review by maltreatment type and gender. *BMC Public Health*, 18, 1164.

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## **Chapter 2- Setting the Scene**

### **2.1 What are the challenges of estimating the prevalence of child maltreatment**

The aims of this chapter are to introduce the reader to the problem of maltreatment, particularly in the UK setting, as well as providing an estimate of the problem in terms of prevalence. This chapter will seek to address the first objective of the thesis. This chapter describes both the nature of maltreatment as well as the problem in identifying or monitoring it. It discusses definitions of maltreatment, current legislation relating to maltreatment, and formally collected data on maltreatment. Prevalence rates of maltreatment in the UK and worldwide will also be reviewed, and why there are variations in these. See appendix 1 for a detailed plan of how the review was conducted.

Nationally and internationally, there has been a growing recognition of the importance of identifying, documenting and reporting suspected and confirmed child maltreatment (1). The WHO in collaboration with the United Nations Children's Fund (UNICEF) called for maltreatment to be recognised as a global public health concern (2).

#### **2.1.1 A formal definition of maltreatment in the UK**

Having a clear definition of child maltreatment is recognised as fundamental (3). The WHO has defined child maltreatment as 'All forms of physical and/or emotional ill-treatment, sexual abuse, neglect or negligent treatment or commercial or other exploitation, resulting in actual or potential harm to the child's health, survival, development or dignity in the context of a relationship of responsibility, trust or power' (4). The four types are grouped as physical abuse, sexual abuse, emotional or psychological abuse, and neglect (4). The four countries in the United Kingdom (UK) have some variation in wording and categorisation of what constitutes the different types of maltreatment (see appendix 2 for definitions). In Northern Ireland for example physical abuse involves 'wilful or neglectful failure to prevent injury or suffering'. This adds a neglectful dimension to physical abuse that is not specified in the other countries. Therefore a child who suffers an injury where the parents have failed to prevent it would be deemed physically abused in Northern Ireland, and neglected in England, Wales and Scotland. In Wales, it is not specified that some level of emotional or psychological abuse is involved in all types of maltreatment. In the definition of neglect there is no mention of the psychological

as well as the health and developmental needs of the child. In Scotland a consent dimension is added to the sexual abuse definition by including that it does not matter 'whether or not it is claimed that the child either consented or assented'. In England a severity dimension is included in the sexual abuse definition. Sexual abuse does not necessarily have to involve 'a high level of violence', suggesting that sexual abuse does not always have to be of a physical nature. Differences such as these can make comparisons of statistics difficult, but does not change the overall classification or designation of maltreatment. It should also be kept in mind that formal classifications that describe various forms of maltreatment are arrived at after much consultation and negotiation between various professionals and even in consultation with family members. Therefore these formal classifications by child safeguarding services do not appear in a vacuum and the behaviours and events that lead to these classifications could be variable (5).

Different definitions for the types of maltreatment exist in different contexts, for example in legal and clinical contexts (6). There are also inconsistencies and variations in definitions used in child welfare legislation and by agency officials as well as researchers (7). Examples in the preceding paragraph illustrate that legal definitions of maltreatment also differ by country (1). The WHO in collaboration with the International Society for Prevention of Child Abuse and Neglect (ISPCAN) has called for common conceptual and operational definitions of child maltreatment to enable identification of cases across sectors involved in child maltreatment response and prevention (3).

In all four countries in the UK a child is defined as anyone who has not yet reached their 18<sup>th</sup> birthday (8; 9; 10; 11), following The United Nations Convention on the Rights of the Child. The terms, 'young person' and 'adolescent' are also sometimes used to describe some of those in this age group, however for the purposes of this study, the term 'child' will be used.

### **2.1.2 Current legislation regarding maltreatment in the UK**

There is no single piece of legislation that covers child protection in the UK, but rather a number of laws and guidance that are continually being amended and updated (12). Statutory guidance on child protection and safeguarding has been published for England, Wales, Scotland, and Northern Ireland. These guidance documents are informed by the requirements of various Acts which share similar principles. The current child protection system in England and Wales is based on the Children Act 1989 (12). After the Children Act 1989 the United

Nations Convention on the Rights of the Child (UN, 1989) was ratified by the UK on 16 December 1991. The Convention on the Rights of the Child combined minimum and aspirational standards for civil, political, social, cultural and economic rights for children, including special protection measures, and has been ratified almost universally (13). The Children Act 2004 was introduced following an inquiry by Lord Laming into the death of eight-year-old Victoria Climbié in 2000 (14). The Children Act 2004 does not replace the Children Act 1989 and covers England and Wales in separate sections. The act updated various pieces of legislation, for example that on physical punishment. It limited the use of the defence of reasonable punishment by carers, so that when a child sustains an injury serious enough to warrant a charge of assault occasioning actual bodily harm, this can no longer be considered to be as the result of reasonable punishment. In England, child protection guidance is set out in the document 'Working together to safeguard children: a guide to inter-agency working to safeguard and promote the welfare of children' (8). In Wales 'Safeguarding children: working together under the Children Act 2004' (9). In Northern Ireland the current child protection system is based on the Children (Northern Ireland) Order 1995 and Safeguarding Board for Northern Ireland Act 2011. In Scotland the Children (Scotland) Act 1995. In Northern Ireland the guidance is 'Co-operating to safeguard children' (10), and in Scotland is 'National guidance for child protection in Scotland' (11). The guidance in all four countries also reflects the principles contained within the United Nations Convention on the Rights of the Child, as well as various other legislation such as The Human Rights Act 1998. The guidance documents include the processes to be followed by professionals and steps to be taken to assess children who are referred to the Local Authority with concerns regarding maltreatment. They also include the services that should be provided for these children (see appendices 3 and 4 for flowcharts depicting these processes).

### **2.1.3 Formally collected data on child maltreatment in the UK**

Formally collected data on the extent of child maltreatment in the UK can be found in records documenting contacts with child protection services i.e. Social Services, and in data on offenses against children located in criminal justice records (15).

Data related to contacts with Social Services include the number of referrals accepted by Social Services, when a child is recorded as a CIN (assessed under section 17 of the Children Act 1989, article 17 of the Children Order 1995, Section 12 of the Children (Scotland) Act 1995), and/or has suffered or is likely to suffer 'significant harm' (section 47 of the Children Act 1989, articles

2(2) and 50(3) of the Children Order 1995, Children (Scotland) Act 1995), and/or the child is the subject of a CPP or on the 'child protection register', and when a child is being 'looked after' (CLA). A CIN is thought to be unlikely to achieve or maintain a reasonable level of health or development without the provision of additional services. Formal data related to contacts with Social Services for recent years include:

- The numbers of referrals to Social Services:

In **England** (population under 18 approx. 11,000,000) for the year ending in March 2017, there were 646,120 referrals relating to 571,000 children (16).

In **Wales** (population under 18 approx. 633,000) there were 33,536 referrals to Social Services for the year ending in March 2016 (17).

In **Northern Ireland** (population under 18 approx. 372,000) there were 37,618 referrals to Social Services in 2016/17, and a total of 4,021 related specifically to child protection referrals (18). These are referrals where the initial assessment indicates that there may be child protection issues (18).

Data on referrals were not published in **Scotland** (population under 18 approx. 1,000,000).

- The numbers of CIN:

In **England**, for the year ending in March 2017, the number of children commencing a period of support for their need was 374,640 (16). The number of children in need throughout the year was 721,730 (16). These figures relate to all children in need and not just those in need for abuse and neglect (16). Abuse or neglect were however the most common primary need at assessment for CIN at 31<sup>st</sup> March 2017, with 52% of children with abuse or neglect as their primary need (17). Bentley et al (2017) reported the episodes specifically relating to children with an in need status at any time due to abuse and neglect for the year ending March 2016 as 199,720.

In **Wales** there were 10,060 children in need due to abuse or neglect at 31<sup>st</sup> March 2016 (17; 19).

In **Northern Ireland** 22,737 children were known to Social Services as being CIN (18). These figures relate to all CIN and not just those in need for abuse and neglect.

Data on CIN status were not published in **Scotland**.

Not every referral to Social Services and child given an 'in need' status is due to a child protection issues. Children are referred and can be given a CIN status for various reasons including if they have a disability. Maltreatment data can also be collected by examining the numbers of children subject to CPPs, these plans are likely to be related to maltreatment only.

- The numbers of children on a CPP or equivalent:

In **England**, for the year ending in 31<sup>st</sup> March 2017, there were 51,080 who became the subject of a plan (16). This includes all children on CPPs and not just those being looked after due to abuse and neglect and other reasons.

In **Wales** 3,059 children were on the child protection register on 31<sup>st</sup> March 2016 (17).

In **Northern Ireland** at 31<sup>st</sup> March 2017, 2,132 children were listed on the child protection register (18).

In **Scotland** in the year ending on 31<sup>st</sup> July 2016 there were 2,723 children subject to a CPP (17).

Data on the reasons why a child is subject to a CPP or on the child protection register is also collected. Neglect was the most common reason in all four UK countries in the year up to March 2016, with emotional/psychological abuse being the second most common (17).

- The numbers of CLA:

In **England**, the number of CLA at any time during the year ending 31 March 2017 was 102,590, and 72,670 were being looked after at 31<sup>st</sup> March 2017(20). These numbers relate to all children being looked after and not just those being looked after due to abuse and neglect. The numbers of CLA due to abuse and neglect in the year ending March 2016 were 42,470 children (17).

In **Wales**, at 31<sup>st</sup> March 2016 there were 3,720 CLA on account of abuse or neglect and there were 1,305 children 'starting' to be looked after in this time period (17; 19).

In **Northern Ireland** there were 2,983 CLA at 31<sup>st</sup> March 2017 (18). These may or may not have been looked after due to abuse or neglect.

In **Scotland** in the year ending on 31<sup>st</sup> July 2016 there were 15,317 CLA (17).

The above data for England and Wales illustrate the numbers of children who are looked after specifically due to abuse or neglect. Reasons for being looked after are not specified in the Northern Ireland and Scotland data (17).

Researchers have used data relating to contacts with child protection agencies to measure the prevalence of maltreatment (21; 22; 23; 24; 25; 26; 27). Sidebotham et al (2006) collected data from Child Protection Services records for children under six years old born between April 1, 1991 through December 31, 1992 participating in the Avon Longitudinal Study of Pregnancy and Childhood (ALSPAC). They found that 2.1% of children were investigated by Social Services and 0.8% were placed on the child protection register (24). This was an incidence rate of 97.5 per 10,000 for registrations (24).

The rates of children subject to CPPs has increased in all four countries over recent years (17). The increase may be partly due to the very high profile case of the killing of Peter Connolly in 2007. Two reports on child protection followed, one by Lord Laming (14) and another more recently by Professor Eileen Munro (28). Governments have taken forward some of the recommendations of these reports (29; 30) such as those in the aforementioned guidance 'Working together to safeguard children: a guide to inter-agency working to safeguard and promote the welfare of children' (8).

Statistics on offences against children include data on homicides and child deaths (17). These crimes could be considered the most extreme examples of child maltreatment. Homicide figures have consistently shown that children under the age of one are at most risk of homicide in the entire population (31). To illustrate this, in England and Wales in 2010/2011 there were 25 homicides per million for children under one compared to 12 per million in the general population (31). Rates of homicide for children in other age groups are lower than for



the general population, however, for children between the ages of one and five there were six homicides per million, and for children between five and 16 there were three homicides per million (31). In 2015 across the UK there were 65 child deaths due to 'assault and neglect' and 'undetermined intent' for children under 15 (17). Homicide rates and child deaths are recorded by the police. Data related to homicides specifically may be undercounts, as the police will only record cases where there is sufficient evidence of homicide (32). Where there may be a lack of evidence, cases are sometimes recorded as child deaths. These however are still likely to be an undercount of children killed as a result of maltreatment (32). Child death figures are normally only published for children in five year age groups, for example, ages 10 to 14. This means that figures which are readily available only cover children up to the age of 14, therefore there may be many more between the ages of 14 and 18 not being counted (32).

Data on the number of sexual, cruelty and neglect offences are also recorded by the police. In 2015/16 in England and Northern Ireland there were 47,045 and 1,809 recorded sexual offences against children (under 18) (17). For the same period in Wales and Scotland there were 2,329 and 1,182 sexual offences against children under the age of 16 (17). These offences do not however equate to unique individuals and therefore one child could have been maltreated on several occasions. For the same time period there were 12,354 recorded cruelty or neglect offences against children in England and 585 in Wales, 341 in Northern Ireland, and 822 in Scotland (17). Sexual, cruelty and neglect offences tend to suffer from under reporting, and it is also the case that as the figures tend to focus on the offence and not the victim. It is very difficult to establish total numbers as offence types cover different age groups, for example the majority of sexual offences relate to children aged under 16 only (32). For some neglect cases it is agreed sometimes that the best interests of the child are served by a social care led intervention rather than a full police investigation and these are therefore not recorded in the data (32).

Data on maltreatment can also be collected from medical records (1; 33; 34; 35).

Sivarajasingam et al (2013) found that in 2013 689 children between birth and ten years old attended emergency departments in England and Wales following violence-related injury, 8119 children aged between the ages of 11 and 17 also attended. González-Izquierdo et al (2010) collected data from Hospital Episode Statistics (HES) in the NHS in England between 1997–2009 on injury admissions that had been coded to denote or indicate maltreatment in children under five years old. They found that 2.6% of injury admissions in children under one

years old, and 0.4–0.6% in older age groups were coded to show that the child had been maltreated (33). When codes that indicated maltreatment-related features were added then the incidence was 6.4% in children under one, 1.5–2.1% in older age groups (33). It may be the case however that professionals do not routinely identify, document, and report suspected maltreatment in medical records (1), and so, it's likely that any information on child maltreatment gathered from medical records are an underestimate.

Cases of maltreatment that come to the attention of Social Services or the police are only a portion of the true numbers of all maltreated children (36; 37). There are many more that go undetected, unreported or unrecorded (30). Fallon et al (2010) likens this to the tip of the iceberg analogy.

Researchers have examined the level of concordance between self-reported maltreatment and formally collected data and have found some concordance, especially in the case of sexual abuse. McGee et al (1995) used interviews to collect adolescents' ratings of the occurrence and severity of five types of maltreatment and compared these with severity ratings by their caseworkers and with ratings from an independent review of agency records. Concordance between adolescent reports and official sources on the occurrence of maltreatment averaged around 75%. They found that sexual abuse had the highest agreement (90%), and neglect had the lowest agreement (60%). Bernstein et al (1997) administered the Childhood Trauma Questionnaire (CTQ) to adolescents on a psychiatric unit. They found high correlations between self-report and therapist ratings of the likelihood the adolescent had experienced maltreatment (done by using patient and collateral interviews and mental health, Social Services, and court records). Sexual abuse again had the most agreement (0.72), and physical neglect had the lowest agreement (0.42).

Although some level of agreement between sources has been found, other researchers have found when examining concordance that there is still a large gap between the number of participants who self-report maltreatment, and maltreatment recorded in formally collected data. Everson et al (2008) examined the concordance between adolescent reports of abuse and from Child Protective Service (CPS) agencies records. Participants were 350 adolescents, between 12 and 13 years old, who were identified as being at elevated risk of maltreatment before age two. Self-report using an audio computer assisted self-interview was used to report lifetime prevalence of physical, sexual, and psychological abuse. The self-report elicited

prevalence rates of four to six times higher than those found in CPS records. It should be noted however that 44.4% of the adolescents with CPS records containing abuse data failed to self-report this abuse. MacMillan et al (2003) used the results from a large community survey given to residents of Ontario, Canada aged 15 or older to examine how many of those who self-reported a history of child maltreatment had also self-reported contacts with CPS. A face-to-face interview included a question about contact with CPS, and the Child Maltreatment History Self-Report, a self-administered questionnaire, was used to assess history of physical and sexual abuse. Only a very small percentage of respondents with a history of abuse reported contact with CPS; 5.1% of those with a history of physical abuse, and 8.7% of those with a history of sexual abuse. Runyan et al (2005) examined the concordance between CPS classifications of *type* of maltreatment. The determinations of type came from two research coding systems (CPS Maltreatment reports were coded using LONGSCAN's modification of the Maltreatment Classification System (MMCS) and the Second National Incidence Study maltreatment coding system (NIS-2)). Participants were 545 children who had experienced maltreatment (collected from CPS records) who were enrolled in Longitudinal Studies of Child Abuse and Neglect (LONGSCAN). Runyan et al (2005) found that there were a total of 1980 reports of maltreatment; however, only 1593 CPS reports specified at least one type of maltreatment. There were differences between the type of maltreatment recorded in CPS records and the conclusions reached by either research classification system; especially for psychological abuse and neglect.

As described in the previous paragraphs, recording child maltreatment can be problematic. There are also some issues with collecting child maltreatment data. Collecting maltreatment data from routine data only can be problematic because of the sole reliance on system indicators, created for bureaucratic and tracking purposes as opposed to research purposes (42). Even when data are collected from several different organisations and combined, this is likely to still be an undercount (27) due to underreporting. It must be kept in mind however that this method of data collection may be no less superior to research data collection as both methods have their difficulties. This is further explored in the review of lifetime self-reported worldwide prevalence of child maltreatment later in this chapter. Fallon et al (2010) note that how a child maltreatment event is measured will affect counts of maltreatment cases by agencies. If provided in the aggregate, agencies can use either a child-based or family-based method of tracking cases. For child-based methods, each investigated child is counted as a separate investigation, while for family based investigations the unit of analysis is the

investigated family regardless of the number of children involved (38). The number of children investigated for maltreatment may be hard to detect as this will depend on data collection and aggregation methods. In some agencies children investigated several times in a year may be counted several times, each time as a separate investigation (38). The area covered by the agency could also affect count, cases where children or families move between areas could be double-counted or missed altogether (38). Formally collected data are especially likely to under represent child maltreatment in middle-and upper-income families (43). Agencies may be less likely to intervene in these groups, or middle-and-upper income families may be more likely to challenge intervention. As well as using formally collected data, some researchers have surveyed professionals working at child safeguarding services for their personal estimates of prevalence relating to their agency (21; 22; 38; 44).

When using formally collected data on maltreatment for research some thought also needs to be given to the variable used as a marker of a maltreatment outcome. The strength and certainty of the data source and variable need to be considered. As described previously, contacts with child protection services (i.e. Social Services) can be used as a proxy for maltreatment. Contacts include whether a child was referred to Social Services, if they were given a CIN status, whether they were subject to a CPP, and whether they were looked after (CLA). Some of these outcomes, along with others such as obtaining a conviction in a criminal court against a parent, or self-reported maltreatment, can be considered hierarchical. The strength of the evidence pointing to maltreatment will be stronger in some rather than others, and as the strength of maltreatment increases the numbers generally decrease. The strength of the evidence is likely to be superior for a conviction in a criminal court, followed by a child being subject to a CPP, followed by child being recorded as in need, followed by child being referred to Social Services. It may be argued that the strength of evidence from self-reported maltreatment by an adult or child is lower still on a hierarchy, possibly because of no corroborating evidence, however this devalues what victims of maltreatment may report. There may therefore be some limitations in using an outcome such as CIN as a proxy for maltreatment, for example not every child given an in need status is due to a child protection concern.

It should be kept in mind that where a maltreatment event falls in this hierarchy or continuum may be to do with strength of the evidence available which may or may not be entirely reflective of whether maltreatment actually took place. Recognition of neglect is notoriously

difficult (45) compared to sexual or physical abuse. Therefore, a case where a child has been neglected may be less likely to result in court proceedings, but the child may be no less likely to be maltreated. Time is also a factor to be considered. When variables (for example, CIN status) are collected at a specific time point, this gives researchers a snapshot of where a child or family may be in the child protection system at that particular time. This will change over time. For example, a dataset may capture that child A was referred to Social Services, and child B had a CIN status at a particular point in time. It may be the case however that child A goes on to be the subject of a CPP post data collection, and no further actions are taken in the case of child B.

The specificity of the evidence needs to be weighed against the sensitivity of the variable. Some variables are more likely to be specific, for example a child being subject to a CPP may be more likely to have been truly the victim of maltreatment. This variable however may not be as sensitive as a less specific one such as self-reported maltreatment.

#### **2.1.4 Other sources of maltreatment data**

As well as being formally collected, data on maltreatment can be collected from other sources. Direct observation of children or of child-parent interaction can contribute to understanding of maltreatment. This method does not rely on potentially biased memories of the respondents and documents child abuse from the view of a trained observer or expert (46). Drawbacks of this method however include the fact that maltreatment may be difficult to detect by observation (46), is obtrusive, and requires extensive training of observers (47). It is also unlikely to ever directly detect abuse, only neglect and indirectly indicate abuse.

Counting contacts made to ChildLine and NSPCC helplines can also provide sources of child maltreatment data (32). These data however are still only a snapshot, and it is not possible to determine counts as a child is not always identified and may make multiple contacts (32). This fact is true however for all methods of data collection where data are collected at a single point in time. The number and reasons for contacts can also be affected by news coverage, marketing and the introduction of new ways to contact the helplines, such as online counselling (32). Who makes the reports to these services may also be important, i.e. the victim, perpetrator, or other informants? In each case the relative value of the report as a good indicator of maltreatment may vary. It is still likely however that the underlying rates of maltreatment are greater than observed rates.

Some studies have included parents as proxy reporters on abuse experienced by very young children (30; 48; 49; 50; 51; 52; 53; 54). It is probable that these studies may suffer from some bias and undercounting (30). Social desirability bias may have an effect; this is the tendency to give answers so the respondent avoids looking bad (55). The effect of social desirability bias could lead to parents being reluctant to disclose their own abusive behaviour (30; 54). This is of course likely to be less influential than the risk of prosecution or their child being removed. Parents might also be unaware of their child's maltreatment (30). Some researchers have found however that proxy reports by parents may be more accurate than agency data (25; 50). Moreover, recent research shows moderate correspondence between parent reports of young child maltreatment and later reports by youths of that same maltreatment (56). This suggests that parent reports may not be as biased as is often assumed (54). Even if parents under-report incidents where they themselves are the perpetrators, they may still be accurate reporters of other types of maltreatment involving other family and non-family perpetrators (54). Turner et al (2007) found no major differences between self-reports and proxy reports about the experiences of children under the age of 10. The only small discrepancy in rates showed lower overall rates of victimisation for self-reporting 10 and 11 year olds than for eight and nine year olds where caregivers also provided information. There was some evidence therefore of possible recall or disclosure problems among the younger self-reporting respondents than among caregivers (54). In general however, there is a considerable body of research that supports the need for the evaluation of collecting self-reports from children in addition to those obtained from parents (47).

## **2.2 Review of the prevalence of lifetime self-reported child maltreatment in the UK and worldwide**

Many have conducted studies to attempt to capture the prevalence of maltreatment using methodologies that use mainly self-reporting. A conceptual difference between 'incidence' and 'prevalence' should be noted. Prevalence can be either the lifetime prevalence of child maltreatment, that is the number of individuals having experienced maltreatment at some point during childhood, or can be period prevalence, that is the number of individuals having experienced maltreatment at some point during a specified period of time, for example, the past year (38; 46). Lifetime prevalence rates are generally assessed in self-report studies, since participants are usually asked to report on their experiences of abuse during their entire childhood (38; 46). Incidence refers to the number of cases of maltreatment during a very

specific period of time, useful when counting new cases, these are normally collected by looking at official figures from agency records (38; 46). Incidence studies tend to capture fewer maltreatment experiences than prevalence studies. This is partly because of the aforementioned underreporting issues, but also because the time frame of incidence studies is more limited than the life-time reports in many prevalence studies (46). In both incidence and prevalence counts the failure to document multiple forms of maltreatment can lead to underestimating some forms of maltreatment. Some measures of maltreatment include only cases where the child has been harmed, while others also consider children maltreated if they are at substantial risk of harm (57).

The prevalence of child maltreatment worldwide captured via self-report will be reviewed in the next portion of this chapter. How methodological differences may explain differences found in prevalence figures will be explored. This work was published in a journal article (58) (Appendix 5).

Formal estimations of the prevalence of child maltreatment based mostly on self-report have been conducted by other researchers. Barth et al (2013) conducted a systematic review with a meta-analysis of the prevalence of child sexual abuse worldwide in studies published between 2002 and 2009. Fifty-five studies from 24 countries were included and prevalence estimates ranged from 3% to 31% (59). Pereda et al (2009b) conducted a meta-analysis of self-reported child sexual abuse in community and student samples worldwide. They included sixty-five articles covering 22 countries, and found that the mean prevalence was 7.9% for men and 19.7% for women (60). Both of these studies included meta-analyses of data from studies of child sexual abuse only. The current review seeks to expand on this by including prevalence rates of physical, emotional/psychological abuse, and neglect. Stoltenborgh and colleagues have conducted meta-analyses of data from studies that addressed the four types of maltreatment (46; 61; 62; 63), all of these included studies published up to 2008. The current systematic review expands on these works by reviewing more contemporary studies, and presenting studies on prevalence of the four different types of maltreatment in one review.

### **2.2.1 Methods**

#### **Literature review**

A literature search took place between May and June 2014, and was updated in March 2017. Electronic literature databases (PubMed, OvidSP) as well as literature from other organisations

(NSPCC, UK Government, WHO, UNICEF) were searched for potentially eligible studies and grey literature. The combined search strategy included terms for the population (children and young people), the incident (maltreatment) and various terms to convey 'measurement'. Duplicate literature was removed using a standard de-duplication function in EndNote. Titles and abstracts were reviewed. The detailed search strategy can be seen in the publication (58) in Appendix 5.

### **Study selection**

The search terms in appendix 1 relate to this original search. Studies before 2000 were not included as the researcher was interested in relatively contemporary data. The studies included in this focused review are those that relate to *lifetime* prevalence of child maltreatment by *self-report*. For the purposes of this review, 'lifetime' prevalence refers to true lifetime prevalence of child maltreatment i.e. in this case up to 18 years old, as well as studies that include children and their lifetime prevalence to the point of self-report. A reference list checking technique was used when ascertaining potential studies (i.e. reference lists of studies identified using the search terms were searched for other relevant publications). Details of the inclusion and exclusion criteria applied to the literature can be found in the publication in Appendix 5.

Included in the search was any study where a participant (adult (18+) or a child (<18)) self-reported lifetime child maltreatment occurring before the age of 18 years. Inclusion criteria for study design was restricted to the primary data collection (i.e. no routinely collected or secondary data sources). Excluded were any study restricting child maltreatment to a specific time reference period (e.g. in the past year) rather than the entire 18 years of childhood, and any study where a secondary person reported childhood maltreatment on behalf of the victim (e.g. parent).

Initial stage of review for inclusion: All titles and abstracts found were reviewed by the researcher. A random selection of 100 titles and abstracts were triple-screened against the inclusion/exclusion criteria by two PhD supervisors. Agreement for inclusion/exclusion between the three reviewers was ascertained using Fleiss' Kappa (64), and achieved a very high level of 0.97. Fleiss' Kappa, as opposed to Cohen's Kappa was used as Fleiss' Kappa should be used when there are more than two raters.



Final stage of review for inclusion: As agreement was high, full papers were retrieved for all selected abstracts and then screened again with more detailed inclusion criteria. Confirmation of inclusion was performed at this stage by the researcher as this related to criteria that could usually only be ascertained with the whole publication.

### **Data extraction**

The following data were extracted from the included studies: authors and year of publication, country, age and gender of participants, population, total number of participants in study, mode of self-report completion (self-completed, interview), type of maltreatment, description of maltreatment, and prevalence rates. Prevalence rates were recorded by type of maltreatment and split by gender where possible. Appendix 5 presents these data for each study included. A PhD Supervisor verified the data extraction for a random selection of 10 studies. The data extraction process was found to be satisfactory.

### **Presentation of data**

Box and whisker plots are presented to show the median (alongside 25th to 75th centiles and outliers) of lifetime prevalence of maltreatment by gender and geographical region (i.e. continent) for each of type of maltreatment (emotional/psychological abuse, neglect, sexual, physical) (figures 3-6). Where a study reported results from more than one country prevalence rates were represented from these countries separately where possible. In two studies which involved countries spanning two continents (Turkey, Russia) categorisation by continent was based on the location of the majority of the study population (i.e. to Asia and Europe respectively). Separate prevalence rates were generated for studies that involved separately self-reported maltreatment by adults and by children. Ranges of rates are presented rather than pooled prevalence due to the high level of heterogeneity observed. Data has also been presented for UK studies only (Appendix 5).

Prevalence rates were apparently higher in some clinical samples compared to samples drawn from a general population. Therefore, for presentation purposes the same figures showing rates for each type of maltreatment by gender and continent for general population samples only were produced (Appendix 5). This excludes those sampled either due to specific socio-demographic or clinical characteristic (including specific professional groups) but includes those recruited from natural sampling frames such as schools, universities, broadly-based

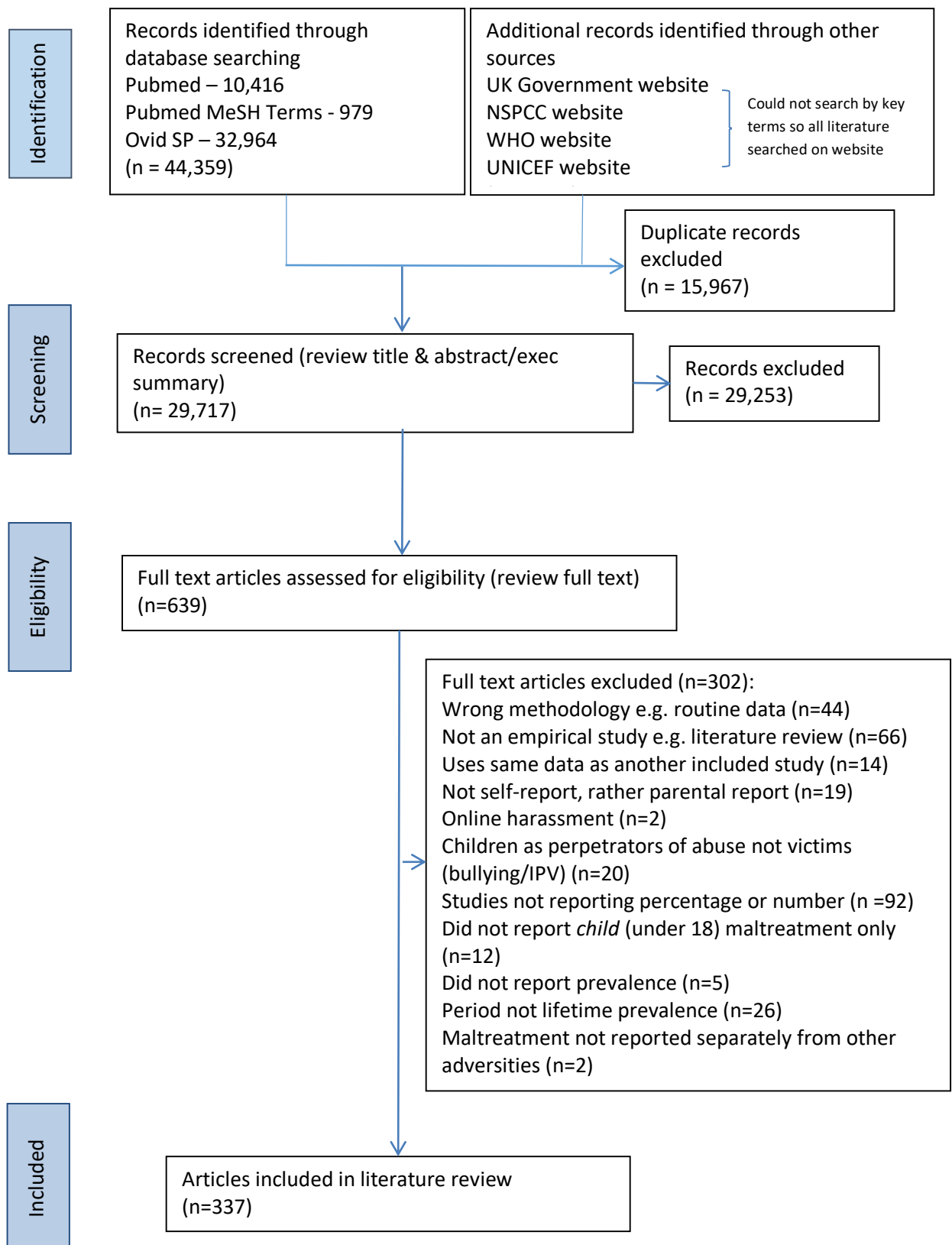
healthcare or primary care organisations and epidemiological cohorts (e.g. population-based pregnancy cohort).

To aid clarity, the following assumptions and changes were made in order for data to be depicted in figures 3, 4, 5, and 6. Where prevalence figures were available for more than one country within a single study, a prevalence rate was reported for each separate country. The same was done for studies presenting separate self-reported prevalence rates for adult and child participants, these assumptions lead to there being a total of 343 'prevalence rates' (within studies) relating to 337 articles or studies. For studies that reported on witnessing family violence, this was grouped under emotional/psychological abuse. As gender splits for prevalence rates were unspecified in many studies, 'male', 'female' and 'unspecified' genders were included in the results. The age of the victim of maltreatment was defined as being under 18, however, it is important to note here that some studies included in this review specified a lower upper age limit.

### **2.2.2 Results**

Of the 44359 records identified through database searching and 1325 through additional sources, 15967 duplicates were removed and a further 29253 excluded at title and abstract stage (Figure 2). A further 175 articles were identified through citation checking and 639 articles were assessed as full texts, of which 302 were excluded as not meeting eligibility criteria. A total of 337 articles were retained for inclusion.

**Figure 2.** PRISMA flowchart depicting literature searched, included and excluded.

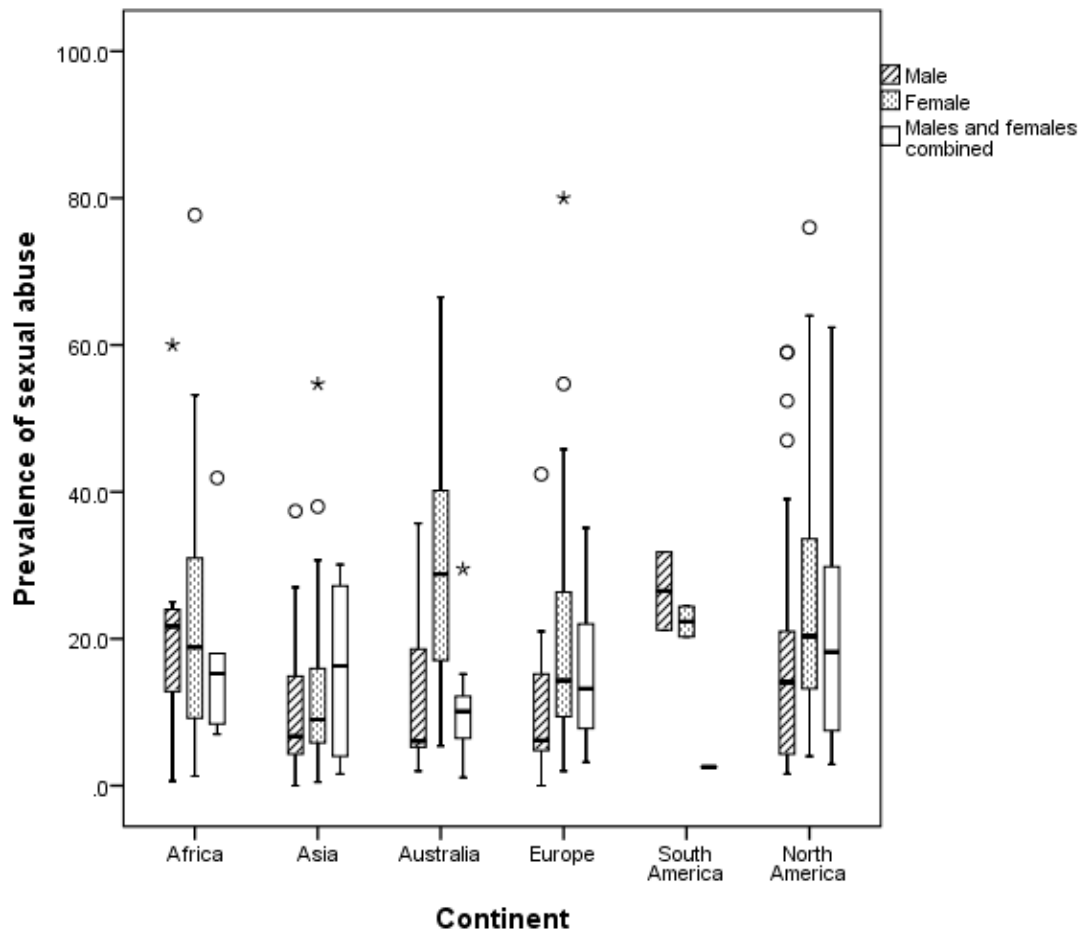


There were more studies including retrospective reports from adults only (n=216, 64.1%) (adults being defined as aged 18 years or over), rather than children only (n=28, 8.3%). The remaining studies included self-reports of both adults and children (n=93, 27.6%). The majority of studies used self-completed data collection (n=213, 63.2 %), some included data collected via interview (n=120, 35.6%). A very small number collected data via both interview *and* self-completion (n=3, 0.9%), or interview *or* self-completion (n=1, 0.3%).

Figures 3-6 show prevalence rates for each type of maltreatment. In addition, there were studies where form of maltreatment was not distinguished and these have been excluded from presentation. Approximately a third of all studies did not report the gender of participants (n=108, 32.0%). Some studies included only female participants (n=109, 32.3%), some had a mixture of males and females (n=101, 30.8%), and a minority included males only (n=17, 5.0%).

*Prevalence of sexual abuse:* When assessing study samples, a single study may comprise separate combinations of continent and gender (i.e. one study may report data for four samples, boys and girls in two different continents). In this context the most commonly studied form of maltreatment was sexual abuse and half of all such study samples (171 of 337) were found in North America. The second largest set of study samples was found for Asia and in contrast the least in South America. Where gender was distinguished, prevalence rates were generally higher for female samples apart from South America (but which had only a small number of studies) and Asia. In the three continents with much higher numbers of studies (North America, Asia and Europe), median prevalence rates still varied considerably for girls: 20.4, 9.0 and 14.3 respectively and for boys: 14.1, 6.7 and 6.2 respectively. When excluding studies focusing on clinical / sub-group samples (Appendix 5), median prevalence rates were generally similar apart for that for North American boys (median 6.5).

**Figure 3.** Self-reported lifetime prevalence of child sexual abuse (n=287 studies reporting 402 prevalence rates)



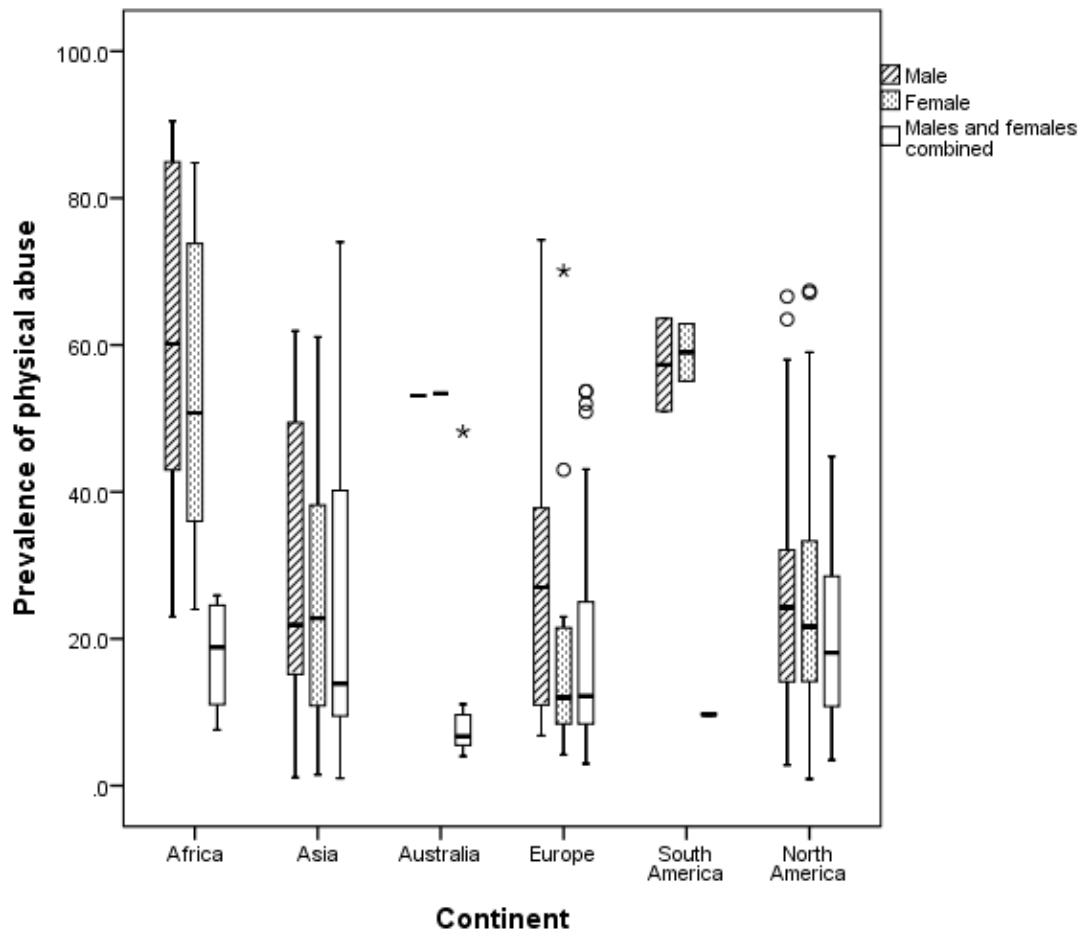
o = Outliers. Between 1.5 and 3 times the height of the boxes (25<sup>th</sup> to 75<sup>th</sup> centile)

\* = Extreme outliers. Values more than 3 times the height of the boxes (25<sup>th</sup> to 75<sup>th</sup> centile)

	<b>Africa</b>	<b>Asia</b>	<b>Australia</b>	<b>Europe</b>	<b>S America</b>	<b>N America</b>
<b>Males</b>						
N studies	9	21	8	18	2	56
Median (25th to 75th centile)	21.7 (12.8 to 24.0)	6.7 (4.3 to 14.9)	6.1 (5.3 to 18.6)	6.2 (4.8 to 15.2)	26.5 (21.2 to 31.8)	14.1 (4.3 to 21.0)
<b>Females</b>						
N studies	14	43	12	27	2	106
Median (25th to 75th centile)	18.9 (9.2 to 31.0)	9.0 (5.7 to 16.7)	28.8 (17.0 to 40.2)	14.3 (7.8 to 28.0)	22.4 (20.3 to 24.4)	20.4 (13.2 to 33.6)
<b>Combined</b>						
N studies	6	8	11	21	2	36
Median (25th to 75th centile)	15.3 (8.4 to 18.0)	16.3 (4.0 to 27.2)	10.1 (6.4 to 12.3)	13.2 (7.8 to 22.0)	2.6 (2.5 to 2.6)	18.2 (7.5 to 29.8)

*Prevalence of physical abuse:* Median rates of physical abuse similarly varied across continents. This was especially true between Africa, Australia and South America but these were based on a very small number of studies in each case. In North America, where most studies had been undertaken, median prevalence rates were similar for boys and girls at 24.3 and 21.7 respectively. Rates were similar (and for both genders) in Asia, which had the second highest number of studies. In European studies, physical abuse was much higher for boys at 27.0 than for girls at 12.0.

**Figure 4.** Self-reported lifetime prevalence of child physical abuse (n=200 studies reporting 280 prevalence rates)



o = Outliers. Between 1.5 and 3 times the height of the boxes (25<sup>th</sup> to 75<sup>th</sup> centile)

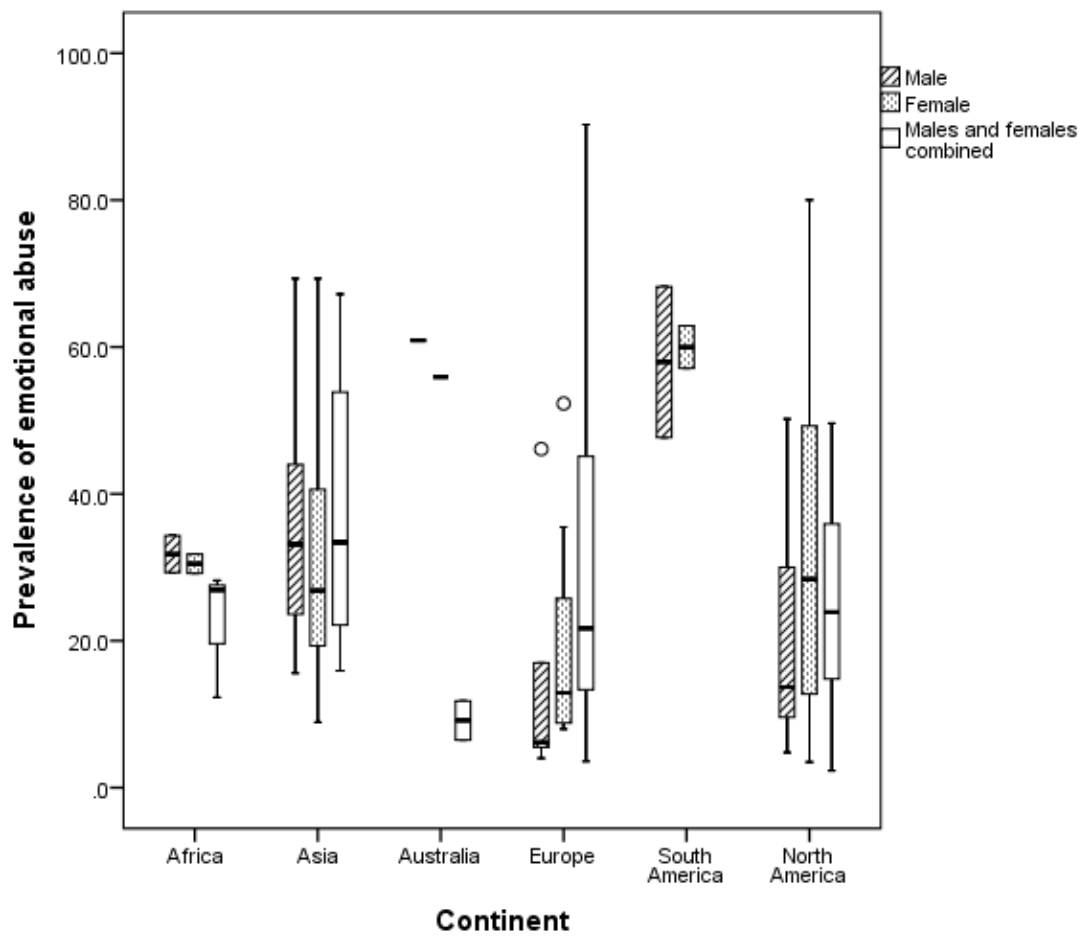
\* = Extreme outliers. Values more than 3 times the height of the boxes (25<sup>th</sup> to 75<sup>th</sup> centile)

	Africa	Asia	Australia	Europe	S America	N America
<b>Males</b>						
N studies	6	15	1	7	2	40
Median (25th to 75th centile)	60.2 (43.0 to 84.9)	21.9 (15.0 to 54.0)	53.1	27.0 (7.0 to 43.0)	57.3 (51.0 to 63.6)	24.3 (14.1 to 32.1)
<b>Females</b>						
N studies	6	20	1	11	2	78
Median (25th to 75th centile)	50.8 (36.0 to 73.8)	22.8 (10.9 to 38.2)	53.4	12.0 (6.9 to 23.0)	59.0 (55.1 to 62.9)	21.7 (14.2 to 33.3)
<b>Combined</b>						
N studies	4	18	7	25	2	35
Median (25th to 75th centile)	18.9 (11.1 to 24.5)	13.9 (9.5 to 40.2)	6.7 (5.0 to 11.1)	12.2 (8.4 to 25.0)	9.7 (9.6 to 9.8)	18.1 (10.6 to 28.6)

*Prevalence of emotional abuse:* Studies of emotional abuse were less commonly found and only in North America and Asia were there more than ten studies for each gender category reported separately. Prevalence rates amongst girls (28.4) in North America were twice that for boys (13.8) although there were twice as many study samples for girls found. Prevalence rates in Europe were approximately half those reported in North America for both genders (boys: 6.2, girls 12.9) and based on a smaller number of studies (boys n=5, girls n=8). In Asia, where there were more study samples involved, median prevalence rates were higher for boys (33.2) than for girls (26.9). Prevalence rates elsewhere were high for both boys and girls but were based on a much smaller number of studies in each case. When reviewing non-clinical samples only, the rate of emotional abuse in North American girls was much lower (15.9) but little different for boys (12.3).



**Figure 5.** Self-reported lifetime prevalence of child emotional/psychological abuse (n=105 studies reporting 146 prevalence rates)



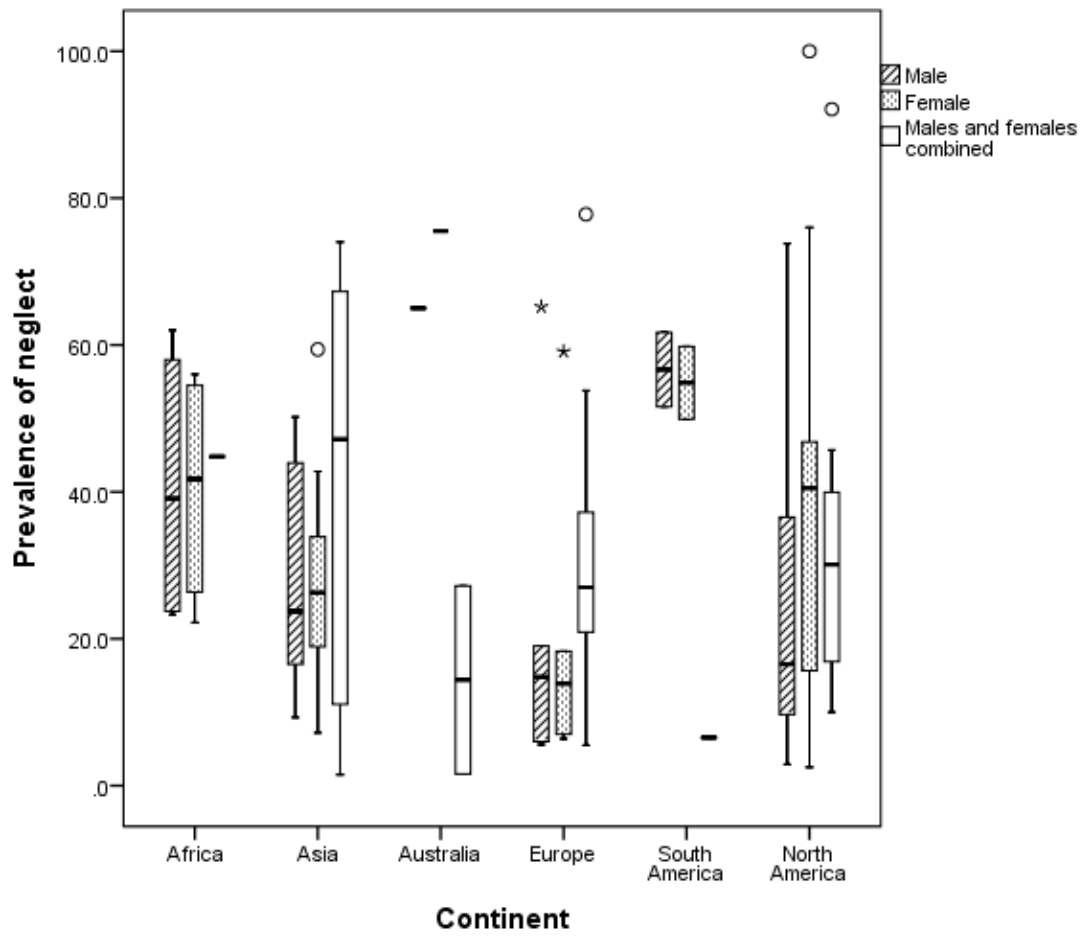
o = Outliers. Between 1.5 and 3 times the height of the boxes (25<sup>th</sup> to 75<sup>th</sup> centile)

\* = Extreme outliers. Values more than 3 times the height of the boxes (25<sup>th</sup> to 75<sup>th</sup> centile)

	<b>Africa</b>	<b>Asia</b>	<b>Australia</b>	<b>Europe</b>	<b>S America</b>	<b>N America</b>
<b>Males</b>						
N studies	2	10	1	5	2	17
Median (25th to 75th centile)	31.8 (29.3 to 34.3)	33.2 (23.6 to 44.0)	60.9	6.2 (5.5 to 17.0)	58.0 (47.7 to 68.2)	13.8 (9.6 to 30.0)
<b>Females</b>						
N studies	2	14	1	8	2	32
Median (25th to 75th centile)	30.5 (29.2 to 31.8)	26.9 (19.3 to 40.6)	55.9	12.9 (8.8 to 25.8)	60.0 (57.1 to 62.9)	28.4 (12.8 to 49.3)
<b>Combined</b>						
N studies	3	8	2	20	0	17
Median (25th to 75th centile)	26.9 (12.3 to 28.2)	33.4 (22.2 to 53.8)	9.2 (6.5 to 11.8)	21.7 (13.4 to 45.1)	-	23.9 (14.8 to 35.9)

*Prevalence of neglect:* There were fewer studies of neglect than for any other category of maltreatment. North America provided the largest number for both boys (n=8) and girls (n=15). Prevalence rates were much higher for North American girls (40.5) than for boys (16.6). Prevalence rates in Asia were similar for boys (23.8) and girls (26.3), which was also the case in Europe but at a lower rate overall (boys: 14.8, girls: 13.9). There were only a very small number of studies across the remaining continents (Africa, Australia and South America) and prevalence rates were very high for each gender group (median from 9.2 in Australia to 33.4 in Asia).

**Figure 6.** Self-reported lifetime prevalence of child neglect (n=72 studies reporting 103 prevalence rates)



o = Outliers. Between 1.5 and 3 times the height of the boxes (25<sup>th</sup> to 75<sup>th</sup> centile)

\* = Extreme outliers. Values more than 3 times the height of the boxes (25<sup>th</sup> to 75<sup>th</sup> centile)

	<b>Africa</b>	<b>Asia</b>	<b>Australia</b>	<b>Europe</b>	<b>S America</b>	<b>N America</b>
<b>Males</b>						
N studies	4	8	1	5	2	8
Median (25th to 75th centile)	39.1 (23.8 to 58.0)	23.8 (16.6 to 44.0)	65.0	14.8 (6.0 to 19.0)	56.7 (51.6 to 61.7)	16.6 (9.7 to 36.6)
<b>Females</b>						
N studies	4	10	1	6	2	15
Median (25th to 75th centile)	41.8 (26.4 to 54.5)	26.3 (18.9 to 33.9)	75.5	13.9 (7.0 to 18.3)	54.8 (49.9 to 59.8)	40.5 (14.6 to 48.0)
<b>Combined</b>						
N studies	1	6	2	15	2	11
Median (25th to 75th centile)	44.8	47.2 (11.1 to 67.3)	14.4 (1.6 to 27.2)	27.0 (19.7 to 42.0)	6.6 (6.5 to 6.6)	30.1 (15.4 to 41.5)

*Prevalence rates from UK studies:* There were 18 UK studies. Lifetime prevalence rates of self-reported maltreatment in childhood varied considerably. Prevalence of physical abuse ranged from 3.6% (65) to 32.6% (66). Prevalence of sexual abuse ranged from 0.7% (30) to 27.8% (67). Prevalence of emotional or psychological abuse ranged from 4% (15) to 66.7% (67). Prevalence of neglect ranged from 5.6% (15) to 77.8% (67). Finally, the prevalence of unspecified maltreatment ranged from 9.5% (68) to 48.4% (68).

### 2.2.3 Discussion and critical appraisal

A total of 337 study reports were reviewed, which provided 343 prevalence rates, based on self-report from either adults or children. North American studies were most numerous across each category of abuse, whereas South American studies were least numerous. In approximately two-thirds of studies prevalence rates were available for either or both genders. Where differentiated, studies of girls were more common than for boys across all maltreatment categories. Prevalence rates were most commonly available for sexual abuse, then for physical abuse and least commonly for neglect. Median rates of sexual abuse were higher for girls than boys in the three continents with the highest number of studies (North

America, Europe, Asia). There were big differences between continents in rates of sexual abuse (for example median of 20.4 and 14.3 for girls in North America and Europe respectively). Median rates of physical abuse were similar for boys and girls in all continents (for example median of 24.3 and 21.7 respectively in North America) apart from Europe and Africa where it was higher for boys (for example, median of 60.2 and 50.8 respectively for Africa), while rates varied considerably between continents for both girls and boys. Few studies of emotional abuse were found for Africa, Australia and South America and rates were much higher for girls than boys in North America and Europe but more similar in Asia (median of 33.2 for boys, 26.9 for girls). Finally, a similar picture of study frequency was found for neglect and median rates were much higher in North American girls (40.5) compared to boys (16.6) but similar across gender in both Europe and in Asia.

Pereda and colleagues (60) found substantial differences in prevalence of self-reported sexual abuse in their 2009 review of 65 studies. Their data suggested a ratio of 2.5 females for every one male victim. More recently, Stoltenborgh and colleagues (46) reported estimated prevalence for self-report studies of child sexual abuse in 2011 similarly across continents and by gender. They found gender made a substantial difference in difference in rates of self-reported abuse worldwide. While gender differences were not statistically assessed on the current study, the findings might suggest something similar. The paucity of studies in some geographical regions makes it more difficult to affirm such gender differences. The number of studies retrieved where gender was not specified also confounds any assessment of differential effect of gender. The pattern of lower rates of sexual abuse Stoltenborgh found in Asia is also consistent with the current findings, as was the highest rate of sexual abuse overall for Australian girls. This may be partly due to the inclusion of some of the same studies in both reviews.

Considerable variation in lifetime prevalence rates of self-reported child maltreatment was found between studies, particularly between studies conducted in any country (between 0.0% and 100.0%). The variation in rates reported in UK based studies was still very large (between 0.7% and 77.8%). It is perhaps important to provide some context to the studies that reported the rather surprising extreme rates of 0.0% and 100.0%. Harkness and Monroe (2002) found that all the females in their study reported that they had suffered neglect at some point. This was a clinical (depressed) sample, and so that may have had a bearing on the results (68). The effect of population of study participants on prevalence rates is discussed in detail below. The

population included in the Khamis et al (2000) found that no males in their study had reported sex abuse. The respondents were boys aged 12-16 who were interviewed by school counsellors, it is possible that they may have been reluctant to disclose a history of sex abuse due to discomfort or embarrassment (69). In both UK and worldwide studies, the greatest variation in prevalence rates reported was for neglect. While some of this variation may reflect actual different experiences that children have, there are methodological differences that exist in the research that are likely to give rise to these variations (30; 36; 70). A broad approach was adopted to inclusion for the review resulting in a heterogeneous sample of studies and prevalence rates. The approach in the remainder of this section is to identify themes that may reduce the quality of the included studies and also lead to variation in prevalence rates. Examples of studies identified in the review have been utilised to illustrate this.

### **Study participants**

The age of the participant at time of reporting may have an effect on prevalence rates. One of the most common methodological approaches for collecting maltreatment data involved the use of retrospective adult self-reports of childhood experiences (71). Some researchers have raised concerns about the reliability and validity of retrospective recall in adult respondents, especially about childhood events and about events that are emotionally charged (72). This is what is known as recall bias (27; 73; 74). Concerns include forgetting an experience that happened many years ago (75). Length of time since the abuse occurred may impact reliability (76), and adults maltreated as children may experience memory impairment related to the event (77). Dietz (2009) interviewed homeless adults aged 50 and older about their experiences of physical, sexual abuse and neglect (78). Pluck et al (2011) interviewed homeless adults who were much younger (18 to 53 years old) about their experiences of sexual, physical, emotional abuse, emotional and physical neglect (67). Rates of abuse reported were much lower in the Dietz than the Pluck study, for example 4.0% and 28.8% for sexual abuse respectively, and 10.0% and 53.7% for physical abuse respectively. It may be easier for the younger participants in the Pluck study to recall the abuse, and specific details of it. Although these are similar studies, these differences in the rates of maltreatment reported could be because of other methodological characteristics (e.g. one was in the US the other in the UK), however age at self-report may still play an important role in the differences observed. Characteristics of the abuse may influence recall, including the type of abuse, the kinds of acts committed, or severity or chronicity of abuse (79). It may be the case however that maltreatment is much more likely to be under-acknowledged rather than forgotten (80).

Respondents may actively choose not to think about or disclose maltreatment experiences to avoid being reminded of them (81, 82).

Children are also asked to self-report maltreatment, and studies sometimes included both adults and children. Many of the methodological issues related to retrospective recall by adults can also be problematic for children. Some researchers have also been reluctant to question children directly about their experiences on account of ethical and procedural complications related to reporting requirements (83).

Comparison of prevalence rates from studies that collected self-reports from adults with those that involved children is problematic (42). For example, a study conducted in 2017 may include self-reported maltreatment as far back as the 1930s or 1940s for adults, but only as far back as the 1990s for children. The time lapse may have an effect, as well as social and legal changes in the definition and recognition of child maltreatment (80). What individuals consider to be abusive behaviour may change between generations, for example, smacking a child was socially acceptable in the UK as recently as the 1980s (29), and still may be today in some communities. In principle however it may be possible to compare adult and child reports for time periods that coincide.

Gender of the participant may influence reporting. Some evidence suggests that men may be less likely to reveal a history of maltreatment (76; 83). The results of the current review seem to support this notion, particularly in relation to sexual abuse. It should be kept in mind that the number of studies however found concerning sexual abuse in men was relatively low at 33% (115/345) compared to those concerning sexual abuse in women (56%, 195/345). It may be the case that there are true differences in prevalence rates between males and females (84). It has been suggested that definitions of maltreatment do not capture the experiences of males adequately, specifically sexual abuse (60). Fear of being labelled as weak or being flagged as homosexual might underestimate prevalence in males (85).

The population of study participants may affect prevalence rates (46). Studies variously derived their samples from the general population (30), clinical or service user samples, convenience samples such as university students, school pupils, or self-selecting volunteers. Prevalence estimates tended to be lower for samples drawn at random from general populations and convenience samples than those based on research with volunteers or service

user samples (30; 85). For example, Cawson et al (2000) (86) found lower prevalence rates in all four types of maltreatment when using a population sample as compared to Fisher et al (2011) who included a clinical population (87). It's unsurprising that the Fisher study reported a higher prevalence of abuse in their population as they were individuals presenting to mental health services with psychosis. Other researchers have found that mental health problems can occur after maltreatment (88). University students may also be more aware of the study's aims and thus more liable to response biases (46). Goldman & Padayachi (2000) somewhat controversially suggested that university students may be a psychologically healthier group which may be associated with lower sexual abuse prevalence (84). Drawing inferences from clinical samples can be problematic if the clinical setting from which the respondents are sampled is related to child protection intervention; it may be difficult to sort out causal order among the variables (42). To demonstrate the impact that such variation can have on prevalence rates our additional figures showed results based on 'non-clinical' study samples. This did not always reduce the prevalence rates, although this was the general direction of effect. The study design, sampling framework adopted (for example, the application of staged and sub-group over-sampling) and the eligibility criteria applied could still exert a substantial effect of apparent prevalence rates even in non-clinical samples.

### **Data collection mode**

The measures used to collect data in self-report studies can be broadly divided into those that require the presence of a researcher presenting questions to a participant, and those that are self-administered. Method of data collection can artificially influence participant response. Some studies have shown that face-to-face interviews result in higher reporting rates compared to self-completed questionnaires (89). Amodeo et al (2006) found that the prevalence of sexual abuse in their sample was higher based on a combined questionnaire and interview rather than a questionnaire alone (90). It should be noted that a particular strength of the Amodeo study was the use of multiple methods and measures to collect data. The researchers utilised this technique, amongst others, to reduce the likely of recall bias. Face-to-face methods can also give opportunities for clarification, probe ambiguous responses and remind participants of expectations for honesty (91; 92). Face-to-face interviews have the advantage of allowing for greater rapport, participants may prefer this method (91), disclosure may be promoted (92) through understanding and support on the part of the interviewer. Others however have not reported such a difference (89). It may also be the case that interviewer presence may hamper disclosure if participants are reluctant to reveal sensitive



information directly, the effect of social desirability (27; 42). Not everyone is equally prone to discomfort relating to sensitive questions, even at a young age (80).

### **Definitions of child maltreatment**

Participants' ideas of what constitutes maltreatment can vary (15), and this may affect self-reported prevalence rates. Participants make a personal judgment about whether what took place was abusive if the questions asked are not specific (80; 93; 94). Answers provided will therefore be influenced by participants' subjective perceptions of abuse (46). This may be influenced by intergenerational changes in attitudes and cross-cultural differences, amongst other things. Previous studies have found that many people do not perceive childhood experiences such as 'being whipped or beaten to the point of laceration' as maltreatment, and there is a tendency to believe that discipline experienced as a child was normal (95; 96). This however, should not affect responses to descriptive questions (15). Direct and specific questions tend to be used in validated measures, and are tested for internal consistency and pre-test reliability (30). Paivio and Cramer (2004) utilised the Childhood Trauma Questionnaires to collect data on maltreatment experiences of the participants in their study, this is a validated measure. Other researchers did not use validated measures, for example, Gratz et al (2002) devised their own questions about experiences of neglect. The populations in these two studies were similar, both studies included males and females and were conducted in the US with university students. The findings of both studies differed however, Gratz et al (2002) found the prevalence of neglect to be 7.0% for males and 3.0% female, whereas Paivio and Cramer (2004) found the prevalence of neglect to be 16.0% for males and 14.6% for females. The differences in these prevalence rates may be partly due to the measures utilised and the validity of those. Age-appropriate questions that give behavioural descriptions of events help respondents to think about specific incidents and are preferred over questions that use legal terminology or ask respondents to label themselves as maltreated (99). Some have found that using broad questions are associated with lower prevalence rates of sexual abuse than more specific questions (100). Furthermore, both the context and the number of questions asked can affect number of reports (89).

Some researchers specified an age range when asking participants about their maltreatment experiences. Bebbington et al (2011) defined child sexual abuse as occurring before the age of 16 (80). Some did not specify an age range, Diaz-Olavarrieta et al (2001) asked participants if as a 'child' they experienced physical or sexual abuse (101). This may affect reported prevalence

rates as one person's idea of a 'child' may vary from another's. When researchers define child maltreatment as something that happens before the age of 16, those who were maltreated at ages 17 and 18 are missed. The definition of the perpetrator of the maltreatment may also affect prevalence rates. Most studies do not specify details about the perpetrator, however, some focused narrowly on perpetrators as caregivers and family members for example Annerbäck et al (2010) (102). Focusing only on maltreatment within the family may be problematic. Radford et al (2011) found that experiences of maltreatment outside the family are less common than those within, but still of a significant concern. They found that for children aged 11-17 21.9% experienced maltreatment within the family, and 7.8% experienced maltreatment outside the family (30). It should also be noted that studies will underestimate infant and toddler abuse as the reporters may not recall these events.

Some studies focused on one form of abuse, for example 34% (114/339) of the studies reviewed here focused on sexual abuse only, with 56% (189/339) including more than one form of maltreatment. Although Bentley et al (2017) reported that neglect was the most common reason for a child being subject to a protection plan or on the child protection register in the four UK countries (17), a greater number of studies have been conducted on the prevalence of sexual and physical abuse. Perhaps this is a reflection of perceived or actual seriousness of the various types of abuse, or possibly the understanding of what emotional abuse is or thresholds for neglect and whether neglect is always physical neglect or emotional neglect. The definitions used to assess the prevalence of abuse and neglect vary greatly between studies, and this will affect prevalence rates (73). Radford et al (2011) asked participants a series of very specific questions about experiences they may have had as a child (30). Diaz-Olavarrieta et al (2001) simply asked participants if they had experienced persistent physical/sexual abuse as a child (101) which allowed participants to impose their own definition of abuse. Most studies, such as that by Diaz-Olavarrieta et al (2001) (101) do not present their maltreatment definitions in enough detail in published papers (38).

Pereda et al (2009) noted differences in definitions of what constitutes sexual abuse, including the age difference between the perpetrator and the victim, the age used to define childhood, and the type of sexual abuse (89). Edgardh and Ormstad (2000) (103) and McCrann et al (2006) (104) defined sexual abuse as when the perpetrator was at least five years older than the victim, this is often done to rule out sexual activity among peers (46). Doing this may be problematic as this will miss the experiences of those who have been maltreated (as well as

consensual experiences) by a person of a similar age. There are also cultural and legal differences between countries in the age of consent to sexual intercourse which affects definitions (86). The acts that constitute sexual abuse are a crucial part of a definition and would almost certainly affect prevalence rates. For example, non-contact abuse such as exhibitionism can be more commonplace and may yield higher prevalence rates than contact abuse only (46).

Definitions of physical abuse may suffer from cultural preconceptions. As previously mentioned smacking is still legal in the UK (with the exception of under 3's in Scotland) but outlawed in some parts of Europe (29). In spite of this often too much is made of cultural differences, and there is a general consensus in many cultures about what constitutes maltreatment (29). Cultural differences may therefore only play a small role in differences in reported rates of maltreatment.

Recognition of neglect can be difficult. Children who are victims of neglect experience multiple types of neglect and it is mostly persistent and rarely traceable to a single incident (45).

Definitions of neglect have been criticised for imposing middle-class values on lower-class families (105), and that they do not take cultural differences into account (45). There has been debate on whether the focus of the definition should be around either caregiver behaviours, or of the experiences of the child, regardless of who is to blame (42). Risk and protective factors can change with age and developmental ability; this can affect definitions (42). Some researchers have purported that definitions of neglect should consider the frequency, duration, and severity of the neglect, the age of the child, and potential consequences to the child's development (45; 106; 107). Tonmyr et al (2011) noted that emotional or psychological abuse can also have particularly ambiguous definitions (108).

Some forms of maltreatment overlap, for example, sexual abuse often also involves physical abuse. All forms of maltreatment include an element of emotional or psychological abuse, this can complicate definitions (86).

Some of the reasons for differing prevalence rates described are expected. For example, it is unsurprising that there are variations in self-reports of different types of abuse and neglect, these expected reasons are less likely to represent error. Some of the differences in prevalence

rates found however are more likely to represent error, for example, whether data collection is self-administered or requires the presence of an interviewer.

### **Strengths and limitations**

The literature was reviewed and data collated on the lifetime prevalence of self-reported child maltreatment worldwide. PubMed, Ovid SP and grey literature from the NSPCC, UNICEF, The UK Government, and WHO from 2000 to 2017 were searched. These databases were selected as they were thought to likely contain literature on the prevalence of child maltreatment, and indeed yielded a large amount of papers on the subject. It is recognised however that other databases not utilised could have yielded additional papers. Literature that was not in the English language was excluded due to budget restriction on translation work. All four types of child maltreatment were included in this review, and studies which did not specify the type were also included. Including all types of child maltreatment in the same review has not been done for some time and this is a strength of the current piece of work. For some studies no upper age limit was provided, contacting the authors of these papers was not justifiable given the current resources and so upper age limit of 100 was assumed for those studies. A meta-analysis was planned on the reported prevalence rates, however the studies were too heterogeneous. Studies varied considerably in the data they collected, the tools used to collect the data, and the populations included. It was therefore not possible to form sufficiently large groups to warrant a meta-analysis.

Although a portion of all titles and abstracts were triple-screened against the inclusion/exclusion criteria, the researcher only was responsible for reviewing all the other abstracts. Reviewer agreement however was very high and the review process was completed systematically.

### **Conclusions**

This review focused on the lifetime prevalence rates of maltreatment observed through respondent self-report. Differences were found by gender and geography which are broadly consistent with previous reviews of child sexual abuse. In addition, the focus was expanded to include other categories of maltreatment. The different number of studies across categories of maltreatment and settings makes it harder to have similar levels of confidence about summary rates of prevalence, especially in Africa and South America. The lack of distinction by gender in many studies is concerning given the sizeable differences observed here and in previous

reviews between boys and girls. Methodological differences between the studies may go some way towards explaining the differences found in prevalence rates. Methods and techniques for collecting data about experiences of maltreatment have advanced in recent years (30), and further research is required to optimise use of data from a variety of sources.

Recommendations for future work include, given the range of methodological differences in studies observed, that researchers may need to be more precise when selecting studies to include in a review such as this one. For example, by excluding studies that have used broad, non-specific labels of maltreatment which require a high degree of interpretation by the respondent. This may be a way to arrive at more useful rates of child maltreatment which will allow better comparisons between studies.

Studies reporting period prevalence were not included in the review. Both lifetime and period prevalence rates are generally assessed in self-report studies, since participants are usually asked to report on their experiences of abuse during their entire childhood (38; 46). The author thought it would be interesting to report some brief findings from these studies as a comparison to those reporting lifetime prevalence.

26 studies reporting period prevalence were reviewed, with just two studies reporting period prevalence of maltreatment in the UK (30; 109). Period prevalence for child maltreatment ranged from as low as 0.0% for sexual abuse within the family to as high as 48.0% for physical punishment within the family (30). Whereas worldwide the range was from 0.3% for sexual abuse of school pupils in China (110), to 89.6% for physical abuse of female high school students in Israel (111).

More thought needs to be given to the best ways to capture data on different forms of maltreatment. An example would be that neglect that is inherently tied to parent-child interactions may be better measured using observation. This can only happen after a family have come into contact with Social Services, whereas neglect related to age-inappropriate demands on children may be better measured using a self-report measure that captures knowledge of child development (42).

## **2.3 Collecting multi-source multi-method maltreatment data**

Each of the methods described above to collect maltreatment data have their limitations.

Some researchers have suggested that due to these limitations it may be that that most prevalence figures are likely to be underestimates (112). With advances in researchers' ability to link various sources of data using identifying information on children and their families, a combination of different data sources can be used capture maltreatment data (42). Methods and techniques for collecting data on experiences of maltreatment have advanced in recent years (30), such as the increasing use of routine data. Further research needs to be done on the best ways to use a variety of data from a variety of sources to collect maltreatment data.

This chapter described the nature of maltreatment and explored prevalence rates of maltreatment in the UK and worldwide. Although data on what is defined as 'maltreatment' are being widely collected, it may also be important to focus on data not defined as maltreatment, including factors that may increase the risk of maltreatment or markers that may give a clue as to the presence of maltreatment. These are described in a later literature review 'What are the markers and risk factors of child maltreatment?'

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## **Chapter 3- Exploring Attitudes on the Collection and Linkage of Maltreatment Data for Research**

### **3.1 What are the attitudes of mothers, care-experienced young people and professionals towards the collection and linkage of sensitive data?**

This literature review was conducted to explore attitudes towards the collection and linkage of maltreatment data for research purposes. This will provide a background and context as well inform the topic guides for the focus groups and interviews conducted for the qualitative chapter of this study. See appendix 1 for a detailed plan of how the literature review was conducted.

Firstly, the review will describe why researchers may want to collect routine data. Next, the issue of seeking consent will be addressed, and various consent models will also be described. The review will go on to discuss the factors that may affect the consent preferences of potential participants. These include whether data are anonymised, the type of data collected and the purpose of these, security and the way that the data are stored and transferred, who has access to the data, knowledge of the participant about the research process, and finally, the characteristics of the participant. The final section of the review will address ‘professionals’ attitudes towards data collection. Finally, the review will end with a paragraph describing how the work to be conducted in the qualitative chapter of this study differs from work already conducted.

#### **3.1.1. Routine data are useful for researchers**

Although routine data are collected mainly for the purpose of clinical care, many researchers have highlighted the benefits of collecting data from routine records, specifically medical records. Routine data can also be collected from non-medical records, for example from education. Most of the literature thus far however has focused on routine data from medical records. Data collected from medical records can be of great benefit to public health studies (1). Electronic medical records (EMRs) are important because of the level of detail that they contain (2). Retrospective review of medical records has also been carried out to improve research coverage and equity of healthcare (3), and epidemiological research that requires representative samples and high response rates (4). Important advances in our understanding

of aetiology, risk factors, and prognosis have been made through the use of population surveillance, disease registries, longitudinal cohorts, and case control studies. These have often involved using data about large numbers of people, sometimes without their consent (5).

### **3.1.2 Seeking consent**

Currently in the UK researchers must seek informed consent to look at any *identifiable* routine data that is collected (1). Identifiable data are sometimes required during research, such as for record linkage using secondary data sources, identification of individuals during follow-up, and the avoidance of double counting (6).

### **3.1.3 Consent bias**

Informed consent requires potential participants to opt-in to allow researchers to look at their routine data. Opting-in or excluding potential participants because of their lack of consent can introduce bias (1; 6). This phenomenon has been variously termed consent, selection, response, refusal, participation, and authorisation bias (1; 6). This means that those individuals who consent to researchers using their data may be in some way different to those individuals who do not (1). This bias may threaten the validity of research results that requires consent for use of data from medical records (3; 6; 7; 8).

The term consent bias is usually used when applied to surveys and medical records research (6). The effect of consent bias has been shown in a number of studies (3; 5; 7; 8; 9). In their systematic review of informed consent and bias in observational studies using medical records, Kho et al (2009) found significant differences between those who consented to participate in research and those who did not. Although Kho et al (2009) found significant differences in their review; there was a lack of consistency in the direction and the magnitude of effect. Macleod and Watt (2008) re-analysed data that were collected for an earlier study where in the first instance consent for review of medical records was not required, but was later required for the questionnaire portion of the study. They compared the whole sample with those who later provided consent and found that there was an effect of consent bias (3). In the Canadian Stroke Registry (10), investigators identified important differences between participants and non-participants in prognostic characteristics. They found that consent bias jeopardised the validity of the study (10). This meant that investigators effectively shut down the registry by discontinuing follow-up surveys and record linkage studies (10). Requiring consent does however not always lead to biased samples (11; 12). It is possible to

observe differences in individuals who do or do not provide consent. It may also be the case that the presence of bias may not adversely affect the research, for example, if a sample retained a higher than expected proportion of males versus females the outcome of interest may still be wholly unrelated to gender.

#### **3.1.4 Other reasons to refuse consent aside from consent bias**

Having to gain informed consent can have a huge impact on the validity of some types of research such as observational studies (7). Some have argued that explicit consent to collect data from medical notes for research should not be necessary because of the difficulties in gaining consent (4; 5; 13). There are other reasons that researchers provide for not gaining explicit consent. Some argue that because the research does not include the use of experimental medical treatments, there is no intervention and therefore the research has no effect on the potential participant (1; 14). Studies which involve abstraction of data from medical records do not influence practice or individuals' outcomes and therefore present no risk and no benefit to potential participants (7). Some researchers have gone as far as to call for a blanket exemption for minimal-risk observational research (15). Some have reasoned that as NHS medical records are funded by public money then these should be made accessible to researchers so that they can conduct research for public health benefits (14; 16; 17; 18). Campbell et al (2007) remind us that clinicians routinely conduct audit-based reviews of their patients' medical records without requiring consent. Explicit consent can be very difficult to seek, reasons include the costs associated with contacting and then consenting a very large number of potential participants can be high (20; 21; 22). Noble et al (2009) sent consent forms from General Practitioners (GPs) or secondary care clinicians to ask for permission to review the medical records of men who had been notified to the trial by cancer registries as having prostate cancer. The cost of this for each consented man was estimated to be £123 per man; this was mostly due to the cost of the development of a secure and encrypted database system. Clinicians sometimes deny access to records, potential participants often don't respond to letters requesting consent, and some individuals refuse to consent (3; 6; 21). Potential participants who are particularly difficult to consent include those who are untraceable or deny their diagnosis, those of the greatest importance such as those who are cognitively impaired, or have a comorbid mood disorder (6). Some groups of individuals can be deemed too distressed to be approached for their consent (5). Iversen et al (2006) state however that true refusal to consent rates are actually quite low. Response rates to consent requests do not stem from people objecting to the research topic or protocol, but

rather from inability to trace individuals. Nair et al (2004) however found that for some individuals, the sponsor and the research topic were factors that would influence decisions to provide consent. Kho et al (2009) found in their systematic review that most studies failed to explore the reasons for refusal, non-response, or inability to contact. Kho et al (2009) suggest widespread education aimed at clinicians, researchers, and research ethics boards on the conditions under which studies can proceed without individual consent.

### **3.1.5 Opting out**

An option that is becoming more widespread now is the use of opt-out. This is where researchers are required to first contact the potential participant for permission to review records, and asking them to reply if they object to their records being reviewed (3). The drawback of the opt-out model is that it can easily 'fail', resulting in mass-exodus of potential participants. This can happen if the community does not have trust in the EMR system or if trust is damaged by a compromise of medical records (24). Another drawback of the opt-out model is that it is never certain that the individual has received the communication informing them of the option to opt-out (25), and therefore their right to confidentiality has not need respected.

### **3.1.6 Identifiable data**

To address such issues, methods such as anonymisation and de-identification of data can be used. These methods have been suggested to protect individual identities (14). At present, a confusing range of terms are used to define the level and identifiability of data, for example, anonymised, de-identified, coded, pseudonymised and identifiable (26). Anonymised data does not include any identifiers, and although data are either provided at an individual level, or can be aggregated, there is no way of establishing a link with the original, identifiable clinical record (26). De-identification or pseudonymisation is similar to this; however, this can include situations in which identifying information is preserved which could only be re-linked by a trusted party in certain situations. A 'key' is available that enables the identity of the participant to be re-linked to the data. Alternatively, the data may become identifiable when used together with other data sources (26). It may be possible for individuals to be identified from a combination of characteristics. It has been shown that about 87% of the United States (US) population can be uniquely identified based on their gender, data of birth and ZIP code alone (27). Even when data cannot be linked to data from other sources, it is still possible to correlate results of various queries to work out confidential information about some

individuals (24). In cases where data relate to individuals with rare illnesses or they belong to small or unusual populations, data can become identifiable (24; 26). Some researchers have highlighted that clinical data can rarely be anonymous (26). This is very much dependent however on the position of the researcher relative to the data. For example if a researcher has access only to one dataset that is itself de-identified then the risk of identification is very limited, however if they can link it themselves to other datasets, the risk rises.

Although many researchers argue that explicit consent need not be sought, in the current ethical and research governance climate it is often viewed that an individual being asked to explicitly consent to research using their medical data holds more importance than the public benefit of conducting the research (3; 14). In Section 251 of the NHS Act of 2006 provisions were made to allow identifiable data to be used in research without consent where disclosure of identifiable information is necessary and consent is not practical (28; 29; 30) (further explored in the literature review 'The governance of collecting and linking routinely collected data in the UK for research'). Blanket requirement for consent has however become the 'default position' for most regulatory bodies and doctors in primary and secondary care (6). Macleod and Watt (2008) claim that the tide may be changing and that the past decade has seen a shift in attitude towards using data derived from records without consent. Al-Shahi and Warlow (2000) suggest that public consultation is needed to determine the ideal balance between, on the one hand, individual confidentiality and data protection and, on the other, the legitimate use of data without consent.

### **3.1.7 Public attitudes towards data collection for research purposes**

Some researchers have examined public attitudes towards collection of medical data. Willison et al (2009) found that there was substantial variation in the control that people wish to have over use of their personal information for research. Views of individuals with regards to consent range from wanting to be consented every time their data were used, to wanting to be consented as a one-off so that researchers can access their data as much as they want, to some saying that researchers should not seek to gain informed consent (1). There has been no consensus found on a preferred consent model in many studies (23; 32; 33; 34; 35; 36). Factors that may affect the consent preferences of potential participants have been discussed in the literature. These include whether the data are anonymised, the type of data collected and the purpose of this, security and the way that the data are stored and transferred, who has access

to the data, knowledge of the participant about the research process, and finally, the characteristics of the participant.

### **3.1.8 Anonymisation and consent**

Researchers have found that potential participants are more likely to consent when data are anonymised. It must be kept in mind that, as mentioned above, that there variations on this and understanding of this concept will be quite broad. Haddow et al (2011) questioned whether individuals in Scotland are sufficiently well informed to realise that their anonymised data are routinely used in research projects, as it is assumed that the public are not only informed but are also supportive of this practice. Results of research to gather public opinion on routinely collected data are unclear about whether this relates to fully anonymised data, the use of weaker forms of anonymisation, such as de-identification, or indeed fully identifiable data (37). There is even less known about public views on the processes for reversing pseudonymised or de-identified data (37). Haddow et al (2011) investigated the public's understanding of the process of anonymisation and the way that anonymised medical data are transferred to researchers. Focus groups with UK participants were conducted to explore attitudes towards the traditional 'warehouse' model commonly used in medical research for delivering anonymised NHS data to researchers. The warehouse model is a system in which the processing of data is performed on behalf of the NHS in regulated centres which store the identifiable information and then make it anonymous. The focus groups were generally supportive of medical research even if data were not always viewed as '100% safe'. It was felt that excessive restrictions on research should be avoided, and participants were surprised to hear that anonymised health data could be used for research in Scotland without consent (37). Datta et al (2011), using an anonymous questionnaire, found that 89% of users of two genitourinary medicine (GUM) clinics in England said they would agree to their blood being tested using unlinked anonymous testing (UAT) for HIV. However 74% wanted the opportunity to consent (the UAT programme measures the prevalence of HIV in the population, including undiagnosed prevalence, by testing residual blood which is anonymised and irreversibly unlinked from the source). Only 14% however were aware that blood leftover from clinical testing may be tested anonymously for HIV (38). Armstrong et al (2007) in their research into public perspectives on biomedical research found that participants felt that if data were identifiable, then the dataset needed to be protected from misuse. Aggregate level data and data about an individual that could not be linked to that individual, so anonymised data were seen to be safer (39).



A study of inner-city Baltimore patients found 30% of respondents agreed that medical researchers should be able to access their medical records without permission (40). When it was suggested an anonymous database could be created for conducting the research, support increased to 86% (40). In New Zealand, less than 20% of individuals attending five primary care clinics indicated a willingness to share their personal health information with researchers without their permission. This increased to 55% when asked for explicit permission. If the data were anonymised, willingness was approximately 45% without being asked and 85% if asked permission (41). It may be that assuring people about anonymising personal information can reduce concern about the necessity of consent for releasing data for research purposes (24). This was shown when comparing the results of two surveys. One conducted by the Australian Government in which individuals were given these assurances found that 64% of respondents believed that permission should be sought to collect health information for purposes other than medical treatment (42). Whereas when assurances were not given in a study by King et al (2012), 92% of respondents said would like to be asked for permission before their health information was used for any purpose other than medical treatment. Other researchers have however found that anonymisation of data does not affect consent preferences. Through focus groups conducted in the UK, Robling et al (2004) found support for medical record research from GP records but a general wish to be informed of the activities, even if the data were aggregated or anonymised. A similar theme of consent for use of data, regardless of whether the data were anonymous, emerged from a pilot Canadian study (43).

### **3.1.9 The type of data collected**

The type of data that is collected may affect participants consent preference. Some data items are considered more sensitive than others. Individuals may not give consent based on the topic of the research or the possible use of the findings (44). Medical data items may be considered sensitive by some individuals. Powell et al (2006) conducted a study that was concerned with the accuracy, security, and confidentiality of electronic primary care records. They wanted to identify the extent to which individuals would allow data from their primary care electronic record to be shared on a national database. They asked patients at a GP surgery to look over their full primary care electronic health record and asked them to highlight any information that they would not want to be shared. The majority of items that patients were not happy to be shared included items related to pregnancy, contraception, sexual health and mental health. It must be noted however that this study had a very small sample size of 31

participants only. While conducting focus groups and surveys in Australia, King et al (2012) found that data related to sexually transmitted disease, abortion and infertility, family medical history, genetic disorder, mental illness, drug or alcohol incidents, list of previous operations or procedures and current medications were considered sensitive items. Items considered less sensitive were date of birth, native language, religion, sexual orientation, blood group, blood pressure status, allergies, diabetes status, and cancers (24). The type of data that records can be linked to may also affect consent preferences. Willison et al (2007) found that participants were more willing for their education data to be linked with their health record than their income data.

Not all researchers have found that the collection of medical data items affect consent preferences. Campbell et al (2007) investigated individuals' preferences about whether and how doctors should seek permission for the use of specified items of anonymised information from their hospital records for clinical audit, teaching, national data collection and research. Most patients had no preference or preferred not to be asked permission for doctors to use their data. The purpose for which information was requested, for example, research or audit did not affect patients' preferences (19). For those who did want to be asked permission for use of their anonymised data, the type of data collected did affect consent preferences. Most wanted permission to collect data on medical history, and reasons for treatment (19). Barrett et al (2006) found a high acceptance (72%) among UK residents of the practice of using personal information, including directly identifying information, without consent for a national cancer registry. Willison et al (2007) suggested that this may be because the cancer registry may have been seen by respondents to be more like a public health service activity than research, which could affect perceptions of the acceptability of use of this information. It may be that cancer itself may hold a special status in the mind of the public, distinct from other health research. It may be that people regard samples differently from information in their health record. In his survey of the literature, Wendler (2006) concluded support for a one-time general consent for research on biological samples. Wellcome Trust (2013) found using focus groups that health data are perceived to be different from other kinds of data, and although sensitive, there was a general feeling that it was important to collect and link this data for various reasons including for research.

Sociodemographic data items have been found to affect consent preferences by some researchers. Willison et al (2009) found that participants felt that research involving profit or

requiring linkage of health information with income, education, or occupation was less acceptable. People were more willing to link their health information with biological samples than with such data. Davidson et al (2013) conducted two literature reviews, one looking at international benefit-sharing models arising from the value of data sharing; and one looking at different methods that have been used to empower the public in decision making about how their data are used. Davidson et al (2013) later held deliberative events with the public to investigate public acceptability of data sharing in Scotland. In the deliberative events concerns were raised about the potential for individuals to be identifiable from shared datasets. Data items that raised concern included postcode and sexual orientation. It was thought that a focus on postcode data in research could result in areas being negatively labelled, for example, as deprived (49). Armstrong et al (2007) found that some data were seen by individuals as private and therefore to be provided only with a good reason, such as name, address, occupation and marital status. Individuals did not feel such data were relevant in research and as such voiced reservations about providing these kinds of data. Individuals were not necessarily reluctant to provide access to sensitive data items such as matters relating to sexual health and behaviours and other potentially stigmatising conditions such as mental health problems (39).

### **3.1.10 Data security**

The perception of security of the data during storage and transfer may affect potential participants' consent preferences. News stories which depict data loss and security breaches in health care have alerted the public to data security concerns in the context of health information exchange (49; 50). Willison et al (2007) conducted a telephone survey of 1,230 adults across Canada to measure attitudes toward privacy and health research; trust in different institutions to keep information confidential; consent choice for research use of one's own health information involving medical record review; automated abstraction of information from the EMR, and linking education or income with health data. Almost all respondents felt protection of the privacy of their personal information in health research was somewhat (23%) or very (74%) important. Over fifty percent expressed increased concern over their privacy in the past five years. Almost all were either somewhat or very concerned that allowing health researchers to access their data made it difficult to control how their information was being used. Clerkin et al (2013) found in focus groups that participants were positively inclined towards the idea of both anonymous and identifiable information from their records being used in research. There were some security concerns however, specifically of

personal information being 'leaked'. Concern regarding security of data during storage and sharing may be especially pertinent for electronic data or records (36; 40; 52). Willison et al (2007) found that four percent of respondents thought information from their *paper* medical record should not be used at all for research, and nine percent of participants felt that their information should not be used from *EMRs* for research. In the deliberative events held by Davidson et al (2013) it was found that there was significant concern about the potential for shared personal data to be hacked or otherwise obtained by unauthorised individuals or groups. When reminded however that data shared for research purposes would be anonymised, most participants appeared to feel reassured that this would mitigate against personal details falling into the wrong hands, though a significant minority were more sceptical. Haddow et al (2011) found that views of the public on the use of a computer or human programmer to anonymise data were mixed. Some were concerned for the level of responsibility for the person undertaking the anonymisation, whilst others were more suspicious that identity could be re-established through unauthorised links between the programmer and researchers. Participants recognised the value of computers in processing large amounts of data quickly, but felt that they would not trust a completely computerised system (Haddow et al, 2011). There were concerns about the storage of data. This focused on the physical location of the person undertaking the anonymisation, the location of the anonymised data with respect to identifiable data, the location of archived data rather than keeping copies, and the transfer of data by disks or memory sticks (37). Hill et al (2013) found in their focus groups that participants thought that safeguards that could be put in place included encryption of data and anonymisation.

### **3.1.11 Who has access to the data**

Which professionals will have access to data may also affect participants' consent preferences. Participants wish to be informed about how their data are being used and by whom (32; 33; 34; 35; 36; 43). Information about the user of the data was seen as more important than the intended use in determining whether to offer consent in some studies (53). Hill et al (2013) conducted focus groups with participants who were part of the CAP Trial (Cluster randomised trial of testing for Prostate cancer) and found that participants felt that it was more acceptable that data were collected for research undertaken by the NHS than by pharmaceutical companies. Acceptability of data collection by university researchers was somewhere between the two (54). The Wellcome Trust (2013) also found in their focus groups that sharing health data for research was beneficial, as long as this was not for commercial gain by pharmaceutical

companies. Perera et al (2011) found that even though most individuals supported the sharing of health records among health care professionals and to provide clinical advice. University or hospital based researchers were less favourably viewed, but still 22% did not want researchers to have access to health records, and 67% and 45% did not want private insurance companies and the pharmaceutical industry to have access respectively. Whiddett et al (2006) similarly found that whilst respondents were generally willing to have their information shared between health professionals, they were increasingly unwilling for it to be distributed to other stakeholders, including researchers.

Many studies have found that the public are concerned that data would be sold for commercial profit. This was generally seen as less acceptable, commanding a higher requirement for informed consent (32; 33; 34; 35; 43). In their focus group work Hill et al (2013) found concerns from the public over insurance companies obtaining information. This was still an issue even after the concept of anonymisation was introduced, and the general feeling that pharmaceutical companies should not be accessing data related to profitability and benefit for the general public than study design or ethical aspects. Stone et al (2005) had similar findings. Haddow et al (2011) found in focus groups that concerns were expressed about the use of aggregate data to a group's disadvantage. These concerns were about insurance companies accessing data and increasing premiums in an area known to have a high level of a disease (for example diabetes), or use of the data by the government to increase pension age in particularly healthy areas. They found however that the use of data for research by pharmaceutical companies was accepted, subject to adequate ethical permissions (37).

Stevenson et al (2013) investigated the acceptability from both patients and GP practice staff in the UK of The Health Research Support Service (HRSS) pilot project that sought to extract EMRs and social records on a national basis. Interviews with practice staff and focus groups with individuals were conducted. Many appeared to have incomplete understanding of the processes involved despite having received the information pack, but once explained there was support for the principle of the HRSS. Concerns were voiced about private companies getting access to data and there was an awareness of the commercial value of data. Most individuals however were no more concerned about health data than any other data (56). The fact that the documentation about the pilot HRSS was addressed from the practice and carried the NHS logo was an important factor in many individuals' willingness to be involved, as was familiarity with research (56). Willison et al (2007) found in their Canadian telephone survey

that trust to keep information confidential was highest for university researchers, hospitals, and disease foundations. It was lowest for insurance companies, drug companies, and the Canadian Government. Davidson et al (2013) in their deliberative events found that data sharing was seen as most acceptable in the public sector, least acceptable in the private sector, with the third sector being in between the two. There was near universal acceptance of public bodies, including the Scottish Government, the NHS, local authorities and the police, having access to *anonymised* personal data from other organisations for research purposes (49). Davidson et al (2013) found that there was an assumption that public bodies had more stringent data protection and security processes in place than other types of organisations. They were thought to be more accountable to the public if a security breach occurred. There was some suggestion that the private sector should be required to pay for access to data or share profits resulting from research (49). Haddow et al (2011) found that the public thought that keeping the data within the NHS was seen to be preferable; as this was seen to keep control of the data. Trust was greatest for clinicians and researchers.

There was a preference to involve as few people as possible in the anonymisation process (37). Luchenski et al (2012) asked patients in outpatient clinics at a hospital and GP surgeries to complete a questionnaire to investigate views and acceptance of the development of universal EMRs for healthcare and research. These are EMRs that simultaneously use data for multiple purposes, such as personal healthcare, policy and planning, as well as health research. They also examined how patients' views are correlated with personal experiences of healthcare and research, patients' health conditions, and sociodemographic characteristics (57). There were high levels of support for use of integrated EMRs in research (81.4%), although close to 60% of respondents would prefer their personal identifiers to be removed (57).

### **3.1.12 Knowledge of the research process and public engagement**

Many studies have found that members of the public believe that collecting and sharing data for research is important (32; 33; 34; 36; 43). Nair et al (2004) found that potential participants often considered the balance of obtaining consent against the public benefit incurred by unrestricted research. In their telephone survey Willison et al (2007) found that 68% agreed somewhat (37%) or strongly (31%) with the statement that 'research that could be beneficial to people's health is more important than protecting people's privacy'. Stone et al (2005) found that individuals usually viewed health research as valuable and generally had altruistic

views about participation in research that might benefit the future health of the population. Most however preferred to be consented before they were willing to share identifiable data.

It is clear that there is a need for increased public education and awareness about research processes and safeguards (35). The amount of knowledge a potential participant has and the attitudes towards the research process, governance, and ethics may affect consent preferences. There is a lack of knowledge about how data are used for research and safeguards to protect data (33; 34; 35; 36; 43), and the public are poorly informed about the governance safeguards currently in place (33; 23; 39;40; 43). It is more likely that potential participants will be satisfied with not providing explicit consent if they have a better understanding of issues involved in carrying out research that requires consent such as those outlined previously (1). A recommendation of The Academy of Medical Sciences (2006) was that increasing public awareness and ensuring more engagement in research using medical data would increase public acceptability of research without explicit consent. Stone et al (2005) conducted interviews with patients, GPs, practice nurses, health visitors and practice managers from GP practices in the UK to explore the knowledge and attitudes of patients and members of the primary healthcare team to data sharing for research, and the impact that this may have on trust between patients and health professionals. They found that many patients had not previously considered confidentiality issues relating to data sharing and thought about registering at the GP practice purely in terms of health and not data collection for research. Patients were unaware of, or unclear about, the ways in which data are shared both within and outside the practice (55). In their focus groups with participants from the CAP Trial, Hill et al (2013) found that members were evenly split between agreeing that using medical records for research without consent for the greater good and therefore no consent was needed, and those that thought that it was important to gain explicit consent. Hill et al (2013) then went on to give a presentation to participants explaining consent bias and how this could affect consent to participate in research. Participants were then asked after the presentation whether the new information given to them had changed their opinions about viewing records without explicit informed consent. Following the presentation participants could appreciate the difficulties for researchers to gain consent and how costly this was in terms of money and time, and many of those who were not happy with the idea of not gaining explicit consent were more accepting of the idea after the presentation (1). No participants spontaneously mentioned ethics committees, NHS research governance procedures, or legislation when considering potential safeguards to data collection (1). Other research has found however that

although providing information and research scenarios to aid understanding of consent issues could alter individual opinions, aggregated opinion showed little change (33; 34).

Davidson et al (2013) in their deliberative events found that the public felt that there should be greater transparency around research involving shared data and that participants should receive feedback on how their data has been used. There was agreement that public involvement in decision making on data sharing was important. Most members of the public did not have the knowledge and expertise to contribute to more specific decisions about the types of research that should be carried out (49). Berry et al (2012) found in a telephone survey of Australian adults that an opt-out system or no consent was preferred (70%) to one using opt-in consent for data linkage for vaccine safety surveillance (linking childhood immunisation and hospital attendance records for the purpose of vaccine safety surveillance research). They later conducted a study looking specifically at parents' consent preferences and understanding of an opt-in or opt-out invitation to participate in data linkage for safety surveillance of childhood vaccines. Parents of babies born at a South Australian hospital in 2009 were sent information at six weeks post-birth explaining data linkage of childhood immunisation and hospital records for vaccine safety surveillance, and were given four weeks to opt-in or opt-out. Parents were followed-up six weeks later and researchers found that over 70% of parents preferred either opt-out consent or no consent. In both the opt-in and opt-out arms four-fifths recalled receiving the information, three-fifths reported reading it, however, only two-fifths correctly identified that the purpose of the study was to link their children's vaccination and hospital records (58). The parents who opted-in were more likely than those who passively consented (did not opt-out) to recall the information, report reading it, and correctly identify the purpose of the study. This study showed that most parents, specifically those who did not actively opt-in, had a poor understanding of the information sent to them regarding the purpose of a data linkage study.

Some researchers have investigated specifically how individuals' attitudes towards data *linkage* for research purposes. The Wellcome Trust (2013) found that participants were not too concerned about research that involves linking health and other data, provided that the aim of the research was to improve health and increase knowledge. Davidson et al (2012) found when conducting workshops to discuss a proposed Data Linkage Framework that most participants felt that research involving data linkage was beneficial if it was in the 'public interest' and had benefits such as medical advances. In 2011 the Welsh Government (59)



commissioned research to test a new procedure seeking consent from individuals to link answers they provided on a survey with information held about them elsewhere. Individuals who were happy to provide their consent reasoned that they wanted to help with the research to improve the health service, and were contributing to a 'bigger picture'. Some individuals were concerned however about giving researchers 'carte blanche' to do whatever they wanted. A further report indicated that 59% of respondents would give permission for data linkage, with varying degrees of how anonymous they would prefer this data to be (60). With regards to demographic findings, there were no differences between men and women. Those with different socio economic status (SES) in the likelihood to give consent to this but younger people were a little less likely to consent (60). Xafis (2015) found while exploring public views of data linkage for research that following an in-depth discussion on data linkage using diagrams and scenarios that there was a good understanding and support for data linkage for research, but that privacy protection was a very important concern. The ALSPAC project through Record Linkage (PEARL) sought to enrich the ALSPAC cohort through linkage between ALSPAC participants and routine sources of health and social data. Audrey et al (2016) conducted qualitative research to examine participants' views on data linkage for research. They found that participants were concerned about the sensitivity of the research question, were more supportive of research that had benefits for health and was in the 'public interest', and there were concerns by many about the effectiveness of anonymisation. Most preferred to be asked for consent whether the data were anonymised or not. Audrey et al (2016) however did mention that views changed after participants were presented with scenarios and did not remain consistent.

### **3.1.13 Characteristics of the participant**

Certain characteristics of participants may make them more or less likely to consent. Some researchers have found that younger people were more likely to consent to data from medical records being used in research (8), specifically those aged 16 to 24 (11), and those over 50 were less likely to consent (8). Luchenski et al (2012) found that levels of support for EMRs decreased with age. Others have found however that those who consented were more likely to be older (32; 36). King et al (2012) found in their Australian focus groups and surveys that 18 to 19 year old respondents were significantly different compared to older age groups, except participants over 60, in their attitude towards the privacy of their health information. This researcher was not looking at whether groups were more or less likely to consent but investigated attitudes towards privacy of health information. The 18 to 19 year old group and

those in the over 60 group were less privacy concerned. Those in the over 60 group are more likely to have passed the prime of their career and therefore under less scrutiny in relation to employment than younger individuals (24). The authors suggest that it may be that teenagers are less privacy concerned as they are typically carefree and less likely to have had adverse experiences regarding privacy, as suggested by the popular perception of their willingness to share personal information on social networking sites such as Facebook (24).

This suggests that being at ease with technology may have an effect on the consent preferences of participants. This is related to the earlier discussed theme of security and consent preferences. Perera et al (2011) found that individuals who were frequent computer users were less concerned with computer security issues and more likely to believe that the benefits of computers outweighed the risks. Frequent internet users and those with a higher level of education were also more likely to value the benefits over the risks of computers (2). Gaylin et al (2011) found that US participants with more positive attitudes towards EMRs were those with greater comfort using electronic technologies.

It may be that those potential participants in poor health or with medical records that contain more stigmatising information are less likely to consent to data collection. This may also be related to concerns about security of records. Merz et al (1999) found that those who consented to data abstraction from their medical records were more likely to have records that contained less sensitive or stigmatising information, this was not just providing consent for data abstraction for research however but for a number of purposes. Knies et al (2012) found that recent users of GP services are underrepresented among consenters. Dunn et al (2004) in their systematic review of UK surveys however found that the patients with the symptoms under investigation were more likely to consent. It could be hypothesised that this may be on account of a perception that that they may benefit personally though from such activity. Clerkin et al (2013) found that females in their study emphasised the risks of information from their medical records being used in research in relation to social discomfort and embarrassment. Other researchers have found however that those in poorer health (64), with long-term disability (32) and people with cancer (65), were more likely to consent than the general public. In their focus groups and surveys King et al (2012) found that there was no evidence that there is a relationship between respondents' state of health and the level of their privacy concern.

Some researchers have found an association between consent preferences and employment or socio-economic status (SES). Kass et al (2003) found in a study with patients with various conditions including cancer and diabetes that those on a lower income were more likely to consent. In contrast to these findings, higher SES has been associated with higher consent rates (32). It is possible however that the association is between consent and employment and not consent and income or SES. King et al (2012) found that respondents who were not currently employed tended to be less privacy concerned than other employment groups. Clerkin et al (2013) found that the males in their study were concerned with the risks of information from their medical records being used in research in relation to employment and finances.

Other characteristics that have been associated with consent include gender and ethnicity. Many researchers have found that males are more likely to be consenters (8; 11; 33; 55). Luchenski et al (2013) found that respondents self-identifying as Black British were more likely to report being undecided or unsupportive of using data from national EMRs for research.

Some have however reported no significant differences between those who consented and those who did not (12; 41). Al-Shahi et al (2005) found that consenters were similar to non-consenters in age, sex, and SES, however, consenters were less likely to be cognitively impaired. Kho et al (2009) found in their systematic review which looked at international studies there were no differences between consenters and non-consenters in age, sex, race, income, education, or health status.

### **3.1.14 Professional attitudes towards data collection**

Professionals' attitudes towards the collection and linkage of data from medical and other records have also been studied. It may be possible that there are factors that affect attitudes in a professional rather than a personal capacity towards sharing participant information for research and other purposes. These may be similar to factors that affect individuals including to whom the data will be transferred and who will have access to the data, and the security of the data during storage and transfer. Perera et al (2011) conducted a survey of patients and physicians in practices using EMRs in Ontario, Canada. They found that even though over 90% of both patients and physicians supported the computerised sharing of patient's health records among their health care professionals and to provide clinical advice, with university or hospital based researchers being also quite favourably viewed. Seventeen percent of

physicians specifically did not support the computerised sharing at all, and 79%, 70% and 23% respectively did not want private insurance companies, the pharmaceutical industry, and the government (source of public insurance in Canada) to have access to their patient's information (2). Perera et al (2011) found that there were mixed views on whether the privacy of electronic medical records could be maintained when transferred. Many were concerned about information security if it travelled over the internet. In their work with the HRSS pilot project Stevenson et al (2013) found that practice staff generally expressed support for the principle of the HRSS, and it was thought the HRSS would lead to more robust and representative samples and make more efficient use of data (56). Concerns from staff were expressed at the idea of data being shared at a national level; mainly to do with the amount of identifiable data going to the HRSS (56). Staff views about an opt-out model were split. Those who supported it thought that it was likely to increase sample size and representativeness. Others were concerned about future repercussions if patients believed their data had been used without their explicit consent, particularly as it was not possible to be sure patients had received and understood information about the HRSS (56). Stone et al (2005) found in their interviews with professionals that GP practice staff were concerned about data sharing with employers and insurance companies, and university research was seen in a more positive light than research by pharmaceutical companies (55). The practice staff were concerned with changes in everyday practice for example writing insurance reports and sharing information with relatives (55). Geissbuhler et al (2013) reported the findings of the 2012 European Summit on Trustworthy Reuse of Health Data convened by the International Medical Informatics Association. Delegates from 21 countries represented national governments, academia, patient groups, industry, and the European Commission. Delegates agreed that the 'Government' (not country specific but general) should provide oversight to the secondary use for the purposes other than direct care of health data, that this secondary use should be fully regulated, and that the patient should be fully informed (66). Hopf et al (2014) conducted a literature review on healthcare professionals' views on the linkage of routinely collected healthcare data. Papers addressed data sharing, that is the shared use of information about an individual patient across settings, or data linkage, that is the secondary use of aggregated, merged data across settings of healthcare data. The studies were conducted in North America or Europe. In the Hopf et al (2014) literature review the use of data for public health purposes was described by four papers. Rudin et al (2009) described the views of clinicians about sharing their data with public health departments. AbdelMalik et al (2008) discussed the need for patient identifiable data for public health and the restrictions imposed by current legislation. El

Emam et al (2011) and Heidebrecht et al (2010) discussed the use of data for assessing immunisation coverage. These studies indicated that healthcare professionals' attitudes were positive about data sharing for a public health purpose (68). El Emam et al (2011) however found that healthcare professionals' attitudes towards the secondary use of patient data would depend on whether the data were identifiable. AbdelMalik et al (2008) found that barriers towards data sharing or linking included start-up and maintenance costs, including remuneration for participating providers. El Emam et al (2011) found that physicians often suggested possible interference with their patient–physician relationships as barriers. Concerns about data governance were common, including data security, legal restrictions, and data quality (69; 70; 71). Technical problems such as lack of interoperability between Information Technology (IT) systems were also identified (69). Privacy issues were cited in all four studies (68). Consent was seen as necessary, although this was deemed impractical to obtain for large anonymised whole population studies (71). There were concerns from staff about an increased workload associated with uploading, verifying, and updating data (72). Some advantages of data sharing were also mentioned, including improvements in patient care and safety (69), and providing timely access to comprehensive whole population trends and longitudinal data (72). Some factors were considered to be both barriers and advantages. Rudin et al (2009) identified trust in the system as both a barrier and a facilitator as concerns of physicians about the sharing of clinical data appeared to be less in those who used linked IT based patient information systems.

### **3.1.15 Critical appraisal**

The above literature review was completed to explore attitudes on the collection of child maltreatment data for research. This is to provide a background and context and also to inform the topic guides for the focus groups and interviews to be conducted in the quantitative chapter. Some critical appraisal of the literature was conducted in order to help determine the strength of the evidence presented in the literature review.

Some thought was given to whether the samples used in the studies were appropriate to answer the research questions. Most of the studies in the literature review were conducted with the general public or with patients, and a small number were conducted with professionals. Utilising patients to provide data may be considered a more specific participant population than the general public, therefore the results may be less generalisable. Utilising patients however was entirely suitable for studies that were gathering attitudes about

collection and linkage of medical or health data. An example of such a study was conducted by Clerkin et al (2013) who asked patients about their views regarding using data from their general practice records in health research.

The current literature review also sought to gather literature on the attitudes of professionals regarding collecting sensitive data for research. Just a small number of papers have been published on professionals' views p (2, 55, 56, 66, 68, 69, 70, 71). Some of these however did not use rigorous methods to collect data, for example, Geissbuhler et al (2013) reported the results of a meeting rather than conducting a formal study. Very little information about how (or if) the results of this meeting were analysed, they do not report that analysis was conducted in a systematic or formal way. Some of the literature reporting the views of professionals include views from mixed populations, which may limit the validity of some of the conclusions. For example, Stone et al (2006) included health care professionals and non-clinical managers. These different professionals might have varying views on, for example, providing data which may be related to their profession.

Detailed information regarding methods was not present in a small number of studies. Some didn't include a topic guide or description of the questions contained in a survey e.g. Chhanabhai and Holt (2007). Buckley et al (2011) failed even to report the number of participants included in their focus groups. Therefore there is little insight into how the data were generated, this makes it very difficult to ascertain whether the methods used were appropriate and robust. Most studies however did contain very clear methods sections, for example Hill et al (2013) provide a very detailed account of the topic guide used in their focus groups.

A criticism of the literature included is that there is a lack of evidence for reflexivity. This is an issue in many qualitative studies. It may be the case that reflexivity has been used but not reported, or simply has not been used at all, both of which are problematic. The authors of the literature have thought little about the effect of the researcher at every step of the research process, or if this has been done it certainly has not been reported. This may be particularly problematic for those employing qualitative methods to capture data. This is surprising as some of the literature reports participants' lack of trust in researchers. The presence of a researcher during these discussions should perhaps have been considered and reflected upon.

In a similar vein, whether the qualitative data were analysed appropriately was also be considered. In the vast majority of the studies appropriate methods were used. Some however suffered from a lack of information which made coming to such conclusion difficult, for example Stevenson et al (2013) noted that all members of the team performed thematic analysis but gave no further details such as if this was done as a group, or coded individually and compared. Some qualitative studies did not report use of double-data coding or any form of triangulation when analysing the data when this should have been performed e.g. King et al (2012) did not double-code any data from their focus groups. Others did report utilising such techniques but did not report on how successful they were, for example by providing the results of Kappa calculations e.g. Nair et al (2004).

Consideration was given as to whether the results of the studies included in the review can be transferred to the work to be completed in the current qualitative study. It should be noted that results of other studies not being transferrable to the current study is not a limitation as such. Some of the results can indeed be transferred, for example, we might expect to find similar themes in the current study as those found in the literature, particularly those that focus on sensitive data items. It may be the case however that novel themes may be found in the current study as so far there has been no study exploring attitudes towards the collection of *child maltreatment data* specifically.

In spite of some of the methodological issues discussed in this section the evidence presented in the literature review is largely considered to be robust. Despite the research being carried out in different countries (with different healthcare systems) similar themes were found. For example, news stories can negatively affect whether participants will give consent in both UK (e.g. Davidson et al (2013)) and the US (e.g. Simon et al (2009)). The same is found with the studies containing differing participants. Stone et al (2005) found that GP practice staff (non-clinical) were concerned about data sharing for research by pharmaceutical companies, and Perera et al (2011) gathered similar results from a study containing clinical professionals (physicians). Similar themes were also found in studies collecting qualitative and quantitative data. Willison et al (2009) found in their survey that data items related to occupation or income were particularly sensitive, with Armstrong et al (2007) reporting similar findings from their deliberative events. Observing such similarities between studies with qualitative and quantitative methodologies is a form of triangulation.

### **3.1.16 Evidence synthesis**

To date, the vast majority of the research on attitudes towards the collection of routinely collected data has focused on medical or health data. Just four studies examined attitudes towards the collection of non-medical data items. Audrey et al (2016) conducted interviews with young people to gather views on data linkage between health and other records such as criminal records data, but they did not ask about linking health with any social care data. The Wellcome Trust (2013) used focus groups and telephone interviews with members of the public to look at whether health data are viewed differently from other types of data, for example personal data such as bank details. Davidson et al (2013) held deliberative events with the public to gather opinions on acceptability of data sharing, including health, social care and many other records for research purposes. Examples of data that could be gathered from social care records were used but these did not include child maltreatment data, and these data were not discussed in the deliberative events. The Australian Government (2004) gathered views via telephone survey on community attitudes towards privacy in both public and commercial bodies including some questions on health data. No study has so far explored attitudes towards the collection and linkage of child maltreatment data.

Three of the studies described in the preceding paragraph were conducted in the UK and one in Australia. Although the inclusion criteria of the review did not exclude any literature by country, this is somewhat reflective of the geography of the literature included in this review as a whole. The vast majority of studies were conducted in the UK and the rest conducted in Canada, the US, Australia, New Zealand, and Ireland. The majority of the studies also focused on attitudes and views of the general public or of patients towards the collection and linkage of data. Far fewer studies included attitudes of professionals. The methods used to collect data in the studies reviewed were split fairly evenly between being quantitative in nature using surveys and questionnaires, and qualitative including focus groups and interviews, or a combination of both.

The descriptions of the literature above point to some gaps in evidence that may indicate the need for further research. No studies have explored attitudes towards the collection and linkage of child maltreatment data specifically, with most focusing on the collection of medical data. The vast majority of studies were conducted in the UK and North America, less is known about views and attitudes of those living in other countries. Finally, most of the literature



explored attitudes of the general public towards the collection of child maltreatment data rather than professionals who may be responsible for recording these data.

### **3.1.17 Qualitative chapter and how this differs from previous work**

Much of the literature described above discusses data collection and linkage issues for sensitive data items, mostly in terms of data stored in medical records, however, there has been no study exploring the attitudes of mothers, care-experienced young people and professionals towards the collection of child maltreatment data specifically. These could be considered particularly sensitive data items. In particular if parents are asked about their consent preferences to collect this data on their children, i.e. they would be consenting on behalf of another. The qualitative chapter of this study will explore this. Most of the work to date has been conducted with 'public' participants, and the attitudes of 'professionals' had been explored to a lesser extent, therefore in the current study focus groups and interviews will be conducted with both professional and mothers and care-experienced young people exploring the themes described below. Some of the themes will be common to both groups and some will be more relevant to one group of participants over another.

The most pertinent themes to come from the literature include the following:

- Attitudes towards various models of consent, including opt-out, and preference for consent
- Attitudes towards data security and transfer
- Attitudes towards and preference for anonymisation
- Acceptability of collection of child maltreatment data from various sources
- Acceptability of collecting data on: confirmed cases of child maltreatment, markers of maltreatment, risk factors for maltreatment
- Discussing the importance of research and any risks or benefit of conducting research on child maltreatment

These themes are both independent of each other but also in many cases linked. How these are linked to each other will be explored further in the results of the qualitative chapter, as well as how any new themes that arise from the focus groups and interviews fit with these into a thematic map.

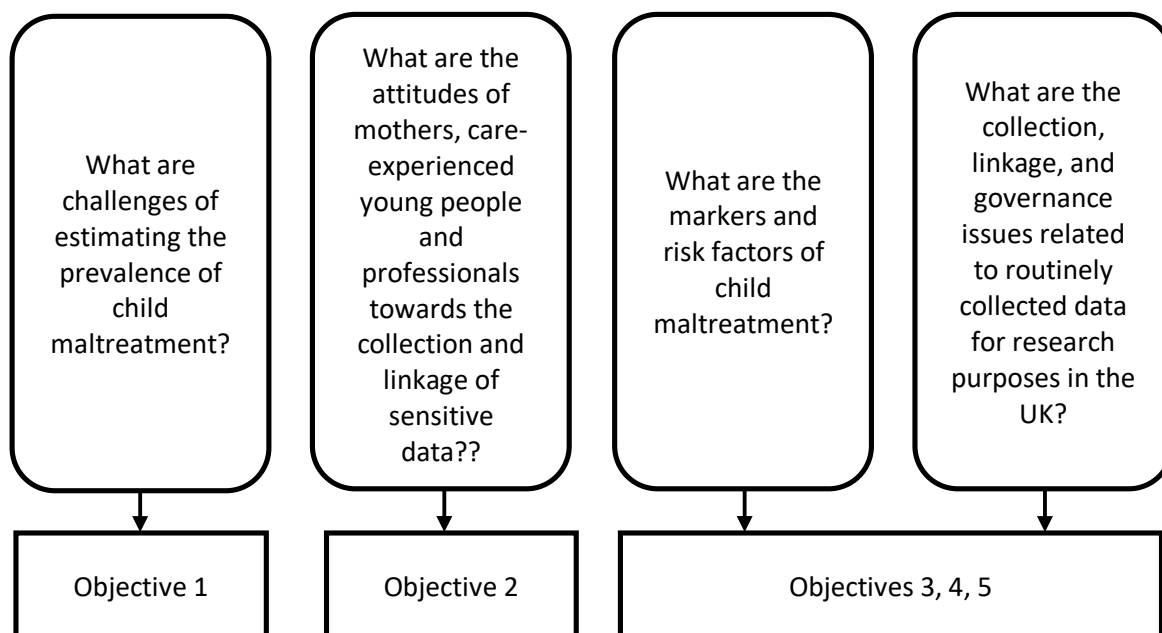
## 3.2 Methods

### 3.2.1 Introduction and objectives

This section is part of the qualitative chapter of the study (figure 1). This focuses on the qualitative methods used to gather an in-depth understanding of mothers, care-experienced young people and professionals' attitudes towards the collection and linkage of routinely collected sensitive data, specifically child maltreatment data.

An asynchronous online focus group methodology was used to gather professionals' attitudes towards the collection and linkage of child maltreatment data. Three face-to-face focus groups were conducted on the same topic for three groups of participants (younger and older mothers and care-experienced young people). Semi-structured telephone interviews were also conducted with participants from the professionals' group.

Figure 1. How the study objectives relate to each research question



### 3.2.2 Participants

#### Approaching and recruiting mothers and care-experienced young people

Three face-to-face focus groups were run. One with younger mothers, one with older mothers, and one with young people who have had some experience of the social care system.

- Younger mother group

These were an existing group of younger, mostly teenage, mothers with young children who attended a drop-in centre for young parents at the Y.M.C.A. in Pontypridd (called 'Our Place'). This group was recruited through an existing relationship that they have with the Building Blocks: 2-6 Study. The group was involved with the study's Public and Patient Involvement activities. They acted as advisors on communicating data linkage issues with study participants. An approach letter was sent to the drop-in centre asking them to hand out a leaflet to mothers advertising the focus group. A pre-selected time and date was arranged between the researcher and the drop-in centre staff. Any mothers interested in attending made this known to the centre staff who invited them to attend the group and handed them an information sheet. Once participants registered an interest to be in the focus group a confirmation letter was distributed to interested mothers by the facilitator of the Y.M.C.A group. The researcher was interested in gathering this participant groups' views and attitudes on the topic in question to gain an understanding of the views of a group that share similar demographic characteristics to the participants in the Building Blocks cohort: they were aged 25 or under, and had at least one child under 6 years old.

- Care-experienced young people group

These were members of an existing group called CASCADE Voices, a collaboration between Voices from Care Cymru and CASCADE, Cardiff University. Voices from Care Cymru are an independent organisation who aim to bring together young people from Wales who have been looked after, and to provide them with opportunities, improve the conditions of being in care, promote the view of young people and to protect the interests of young people in care. The CASCADE Voices group are a group of care-experienced young people who advise on research projects from design to dissemination. This group was recruited through an existing relationship between CASCADE Voices and the Building Blocks: 2-6 Study. An approach letter was sent to CASCADE Voices staff asking them to hand out a leaflet (appendix 6 contains the leaflet circulated to the young people as an example of such material) to the young people advertising the focus group. A pre-selected time and date was arranged between the researcher and CASCADE Voices staff. Any young people interested in attending made this known to staff who invited them to attend the group and handed them an information sheet. The researcher was interested in conducting a focus group with this group of participants in order to understand more about how young people who have had some experience of the care system feel about researchers collecting and linking child maltreatment data. Due to the

personal circumstances of many of the young people who attend this group, the researcher was advised by CASCADE Voices staff that it could not be guaranteed that enough young people would turn up on the day to be enough for a focus group. Indeed this was the case, therefore a focus group consisting of a mixture of some care-experienced young people and staff members from CASCADE Voices was run. A second focus group was then arranged to consisting of care experienced young people only.

- Older mothers group

This was a group of mothers whose children attend a local primary school in Cardiff. They formed an existing informal group who regularly meet for coffee. They had at least one child of primary school age but they also may have other children of varying ages. This group was recruited thorough a personal connection of one of the PhD supervisors with the school. They approached the group to ask if they would be interested in taking part in a focus group and handed leaflets on the topics discussed at the group and an information sheet. The group invited the researcher to attend one of their weekly meetings. The researcher was interested in the views of this participant population to gain a perspective of mothers who are older than those in the Building Blocks cohort: members of the group were 25 or older.

The decision to select participants from existing groups for all three face-to-face focus groups was based on the feasibility of finding participants. Existing groups were also selected as the participants may have better rapport with each other and be more comfortable discussing sensitive topics such as child maltreatment if they are already somewhat familiar with one another. Morgan and Krueger (1997) advise that building on existing contacts is a useful way to recruit participants.

Recruiting a group of fathers was also attempted, but the researcher was unable to identify an existing group to use.

The researcher planned for each face-to-face focus group to contain 6-8 participants (72). El Emam et al (2011) assumed a 33% no show rate for their focus groups, which seems reasonable, therefore as a contingency plan at least 9 participants were recruited to each focus group.

Before each face-to-face focus group the researcher checked that all participants had received the information sheet (see example information sheet in appendix 7) and had a chance to read this. Before the groups began, the participants were provided with a further verbal explanation of the focus group process and given the opportunity to ask any questions or discuss concerns. They were asked if happy to proceed with the focus group, and asked to sign consent forms (see example consent form in appendix 8). Participants were also asked to complete eligibility screens to ascertain if they were competent to provide consent and did not need a translator to be part of the focus groups. Demographic data were also collected including age group, age of child(ren) (if in either of the 'mothers' groups), and whether they were currently in education (for the 'care experienced' group). At the end the participants were thanked for their time.

### **Approaching and recruiting professional participants**

One asynchronous online focus group was run consisting of UK professionals who are responsible for recording maltreatment data in records. They were currently working in the UK and reporting and recording data on child maltreatment as part of their job role. They were approached through the researchers' professional contacts, i.e. people who had worked with the researcher in the past or known to the researcher in a professional context. They were approached via email. A 'snowballing' technique was also used; every participant who agreed to take part were asked if they knew of anyone else suitable to be approached. It should be noted that this method produces a biased sample as the group consists of members who are comfortable with the concept of electronic data sharing.

Participants who registered an interest to take part in the online focus group were emailed an information sheet and asked to register on a website (described in detail in the interview schedules section 3.2.3.2). When registering on the website they were asked to complete an eligibility screen and the consent process by reading an online consent form and ticking a box. Demographic data were also collected through the website, including age, gender and occupation.

The plan was for the online focus groups to contain 6-10 participants, and as a contingency plan approximately 12 participants were recruited allowing for attrition (a greater amount of attrition is to be expected when asking participants to take part in an online group than a face-

to-face group). In the contacts with participants prior to the focus group the importance of their contribution was emphasised to minimise attrition.

On completion of the online focus group each participant was approached via email and offered the opportunity to take part in a follow-on telephone interview. They were asked to contact the researcher if interested in taking part. Participants who registered an interest were contacted directly by the researcher who sent them an information sheet and a convenient interview time was arranged.

Before the telephone interview the researcher checked that the participant had received the information sheet and had a chance to read this. They were then asked if they were happy to proceed and verbal consent was audio recorded along with the rest of the interview. At the end of the interview the participant was given another opportunity to discuss any points of interest, to discuss the interview or to express any concerns.

The younger mothers and the older mothers were offered a children's book to the value of £15 per participant to thank them for their time. The care-experienced young people were not offered children's books as they were paid for any time they gave to working with researchers by CASCADE. The professional participants taking part in the online group were not offered compensation for their time. All face-to-face focus group participants were handed expense forms to complete for travel and sustenance.

### **3.2.3 Procedure and piloting**

Why use focus groups and telephone interviews to answer the research question?

Focus groups are a good methodology for exploring attitudes and needs as well as experiences of participants (73). Exploring attitudes is a key component of the research question. Focus groups are useful when exploring issues that may be relatively new or unfamiliar to people and can allow participants to explore ideas that they have not considered before (73). This was especially relevant to the mothers and care-experienced young people in the face-to-face focus groups. Nair et al (2004) noted that during interviews about consent for medical record reviews participants were still formulating their thoughts and did not have mature opinions. It is likely to be the case that the concepts of data collection and linkage in medical and other records are unfamiliar to the participants in the face-to-face focus groups. The focus group methodology also allows participants to explore and clarify their views in ways that would be

less easily accessible in a one-to-one interview (73) as participants are given the opportunity to listen to the opinions of others. Focus groups are also useful for generating new ideas through group interaction and can facilitate access to a diverse range of opinions in a short space of time (51). As some of the mothers and care-experienced young people were relatively young in age, focus groups as opposed to interviews was a suitable methodology to use as they can facilitate conversation in those that may be initially shy or lack confidence when faced with an interviewer (51). Focus groups can also be considered a non-threatening environment that will help participants understand the issues and allow participants to bring up issues in discussion (51). Child maltreatment can be considered to be a sensitive topic and focus groups are a good methodology to use when discussing sensitive topics (72; 74).

An asynchronous online focus group is where participants can discuss topics in an online forum not in real time. Participants can post comments at any time, but still have the ability to have discussions in real-time if more than one is logged on at once. The asynchronous online group methodology was chosen as a face-to-face meeting would be less feasible due to time pressures and likely geographical spread of professional participants. See appendix 9 for a detailed rationale for the online asynchronous focus group methodology.

Following on from the data collected in the focus groups, telephone interviews were conducted with some of the online focus group participants who indicated an interest in further contributing to the data collection. This piece of work was included to improve data richness and also allow the researcher to gain a deeper understanding of some of the professionals' opinions on the topics discussed during the online focus group. Telephone interviews were also a suitable methodology given the geographical spread of participants across the UK and the cost-effectiveness of not being required to travel.

### **3.2.3.1 Research ethics**

The study was approved by the Cardiff University School of Medicine Research Ethics Committee. All participants provided informed consent before taking part in the focus groups and telephone interviews. Written consent was provided from face-to-face focus group participants, online focus group participants consented by ticking a box on the website, and telephone interview participants provided verbal consent. Participants were made aware of their right to withdraw from the study at any point. Participants were asked to give permission

for the focus groups and telephone interviews to be digitally recorded. Interview transcripts were anonymised.

### **3.2.3.2 Interview schedules**

A semi-structured topic guide was used during both the online and face-to-face focus groups. This was to ensure that the focus of the discussion was directed towards the selected topics, but to also allow participants to steer the discussion. The telephone interviews followed the same semi-structured topic guide as the online focus group, but delved deeper into participants' attitudes and responses to the topics presented as these were one-to-one interviews.

- **Face-to-face focus groups**

The face-to-face focus groups were guided by a topic guide which was developed prior to the first focus group meeting but allowed some flexibility to address newly arising issues. The question schedule was designed in light of some of the issues identified through the literature review of attitudes towards the collection and linkage of sensitive data. The following topics of interest were chosen, from which questions were developed (full interview schedule and accompanying presentation available in appendices 10 and 11):

- Attitudes towards various models of consent and preference for consent
- Attitudes towards data security and transfer
- Attitudes towards and preference for anonymisation
- Acceptability of collection of child maltreatment data from various sources
- Acceptability of collecting data on: confirmed cases of child maltreatment, markers of maltreatment, risk factors for maltreatment
- Discussing the importance of research and any risks or benefit of conducting research on child maltreatment

The face-to-face focus groups involved discussions that took place around various scenarios. These were designed to embed the discussion in a concrete 'story' as many of the concepts discussed such as data linkage are complex and abstract. Other researchers have used discussions based around scenarios and have had success in this method in terms of participants' understanding of the concepts discussed and to facilitate lively discussion (44; 35). See appendix 11 for the PowerPoint presentation given at the focus groups which included the scenarios used.



The face-to-face focus groups were facilitated by the researcher and a co-facilitator. The co-facilitator for the younger mothers group was a PhD supervisor. Another PhD supervisor co-facilitated the older mothers group. A staff member from the CTR with qualitative experience co-facilitated both groups of care-experienced young people.

In the face-to-face focus groups verbal prompts were used to encourage participants to repeat and expand on their responses, when there was hesitation about question meaning or to ask for clarification, or if a yes/no response was provided. Verbal prompts were used to explore meaning and verbal cues were used to reassure participants that the researcher continued to be present and captive, and non-verbal cues were also used to this effect.

- Face-to-face focus groups piloting

The face-to-face focus group work was piloted in two ways. Firstly, participant materials were reviewed by a group of parents with children at the local school where the older mothers group were recruited. Those who took part however in this pilot were not part of the eventual older mothers focus group. Secondly, the researcher's moderating skills and the running of the focus group, including the scenarios and questions presented in the topic guide, were piloted with the researcher's supervisory team and with members from the Centre for Trials Research (CTR) Qualitative Research Group.

#### Pilot 1: Participant materials reviewed by primary school parents

The participant materials (see list in table 1) were piloted by a group of parents from a local primary school in Cardiff; they reviewed and commented upon these. This was done to ensure that the materials were presented clearly, the language was appropriate, and that they were easy to understand. The PhD supervisor with contacts at the local school handed sets of participant materials to ten parents, three sets were returned.

As a result of the piloting work with the parents a number of changes were made, these are summarised in table 1.

**Table 1.** Changes made to topic guide following pilot 1 face-to-face focus groups

<b>Observation from piloting work with primary school parents</b>	<b>Changes made to the participant materials</b>
<b>Changes to the Invitation Leaflet</b>	
It was felt that the wording about needing to be fluent in English could be clarified, and that the Invitation Leaflet should include that books will be provided as a 'thank you' for attending the focus group.	The wording was changed to clarify English language being a prerequisite and added that books would be provided in the Invitation Leaflet.
<b>Changes to the Confirmation Letter</b>	
Clarification on the meaning of the term 'child maltreatment' was requested, and it was thought that including the detail that the focus groups will be audio recorded would be helpful.	A sentence was provided to clarify what was meant by 'child maltreatment' and a sentence was added to note that the focus groups would be audio recorded.
<b>Changes to the Information Sheet</b>	
It was felt that the wording about needing to be fluent in English could be clarified.	The wording of the Information Sheet was changed to clarify English language being a prerequisite.
<b>Changes to the Demographic Data Collection Form</b>	
It was felt that clarification on how to record a child's age if they are under one year old was needed.	A sentence on how to record child's age if under one years old was added to the Demographic Data Collection Form.

Although only a small number of parents reviewed the materials the piloting was very worthwhile as the comments returned were quite detailed and very useful in terms of amending the materials to ensure that they were clear to participants.

#### Pilot 2: Topic guide content piloted with Qualitative Research Group

As suggested by Morgan and Krueger (1997) the scenarios presented to participants and accompanying questions were initially circulated on paper to the researchers' supervisors for comment. Some changes were made at this point. Originally the questions were asked in a series, however the idea to include scenarios presented between sets of questions emerged at this time. The scenarios would become increasingly complex and perhaps controversial as they

introduced the idea of collecting data on child maltreatment gradually. This was a similar idea to work done previously by Robling et al (2004).

Five participants took part in the pilot focus group, four members from the CTR Qualitative Research Group and one student on a summer placement at CTR. A short version of the topic guide was used during piloting due to time restrictions; one hour was allocated for the piloting session. The researcher facilitated the group and a colleague who is also a member of the Qualitative Research Group co-facilitated and took notes. As suggested by Morgan and Krueger (1997) after the focus group was piloted there was a discussion with the group members about any changes or improvements that they could recommend with regards to the scenarios and questions presented as well as the researcher's skills as a facilitator. Morgan and Krueger (1997) suggested various ways to improve or pilot facilitator skills, these included audio or video recording a pilot focus groups and listening to/viewing the recording. The pilot work was also conducted to test the technology used to record the focus groups, and if presenting the scenarios was useful. Unfortunately the audio recording of the pilot focus group failed, this was disappointing, however it was a lesson to ensure that two audio recorders would be taken to the running of the focus groups and that they would be tested thoroughly beforehand.

As a result of the piloting work with the CTR Qualitative Research Group a number of changes were made to the topic guide document. These changes are summarised in table 2.

**Table 2.** Changes made to topic guide following pilot 2 face-to-face focus groups

<b>Observation from piloting work with CTR Qualitative Research Group</b>	<b>Changes made to the topic guide document</b>
<b>Changes to the presentation</b>	
It was felt that a few slides on the PowerPoint presentation did not need to be presented visually and verbally and would be better presented verbally only. These slides included one which detailed of the purpose of the focus group, one about how data are collected in the UK, and one about who might use data for research.	Slides removed from the PowerPoint Presentation, these were to be presented verbally and details added to the topic guide document.
<b>Asking participants for their thoughts</b>	
The group felt that the researcher could ask if any participants had any thoughts about the scenario presented before any questions are asked. It was also felt that the researcher should ask the group if anyone had any more thoughts they would like to add at the end of the focus group.	Some additional prompts were added to the topic guide document.
<b>Prompts</b>	
Some of the questions presented to the group included a prompt that was asked immediately after the question which made it sound like there were two questions being asked, this was confusing for participants.	These questions were separated into an initial question and a prompt that was only to be asked to help clarify the question if there was no response from the group.
<b>Question wording</b>	
The group felt that some minor changes to the wording of some of the questions would help with the delivery of these questions.	The wording of some the questions was amended without changing the meaning of the questions.

Despite the disappointment at the pilot focus group not being recorded, and the fact that the topic guide could not be piloted fully, the pilot was sufficient to allow the researcher to make the changes and adaptations necessary to prepare for the focus groups. This was invaluable as a

way to improve the researchers' facilitating skills. The pilot also highlighted that the ordering of the questions presented was appropriate as on most occasions the pilot participants moved spontaneously to the each topic of discussion before it was presented by the researcher.

- Online focus groups

The online focus group was guided by a topic guide which was developed prior to the focus group. The group was run over 5 weeks with one topic discussed per week, and only one topic was open at a time. The question schedule was designed in light of some of the issues identified through the literature review described previously. The following topics of interest were chosen, from which questions were developed (full interview schedule available in appendix 12):

- Acceptability of collection of child maltreatment data from various sources and whom receives the data
- Attitudes towards recording maltreatment data
- Attitudes towards data security and transfer
- Attitudes towards and preference for anonymisation
- Discussing the importance of research and any risks or benefit of conducting research on child maltreatment

The telephone interviews were based on the same topic guide as the online focus group.

Typed prompts were used in the online groups to clarify questions, and to facilitate participants to expand on particular topics where the literature has suggested this was an important theme. In the telephone interviews verbal prompts were used in the same way as described above for the face-to-face focus groups.

- Online focus groups piloting

A website was built over two days by an Assistant Developer at the Centre for Trials Research. They used free open source software, PHP (Hypertext Preprocessor) Bulletin Board. This is an internet forum package written in the PHP scripting language. It was validated using standard, built in validation that performed basic checks for text and numbers such as setting minimum and maxim lengths and values, and checks on usernames, email addresses, and passwords. Data were captured and retrieved from the system by using a built in data extract feature which uses a PHP script to open an excel file and output the data as a Comma Separate Values (CSV) file.

The online focus group work was piloted with six participants, two CTR staff members and four Institute of Primary Care & Public Health staff and PhD students. The questions from the topic guide document were presented in their entirety to the group over five weeks. The researcher facilitated the group and there were no co-facilitators.

When the pilot was completed the researcher asked the participants for comments regarding the technology (website) used to run the group, the participant materials presented, the questions presented in the focus group, and the researchers' skills as a facilitator. Comments were received both verbally and via email.

As a result of the piloting work a number of changes were made to the website used to run the group, these changes are summarised in table 3.

**Table 3.** Changes made to website following pilot online focus groups

<b>Comments regarding the website used to run the online focus group</b>	<b>Changes made to the website</b>
Functionality on website forces participants to change their password after one month, this was found to be inconvenient to participants.	Change this functionality to ensure that passwords are changed after three months, by this time the focus group would be completed.
Participants could contact each other directly through email, this may be a breach of data protection as it could lead to participants identifying each other although participants are told that they will be anonymous to other participants when they sign up.	Remove ability of participants to contact each other directly through email.
Participants felt that notification could be sent out when other participants commented as a reminder to stay involved in the discussion.	Email notifications set up to be sent every few days to remind participants to comment on discussions, a link to the website included in these emails.

No comments were made regarding the participant materials presented, the questions presented in the focus group, or the researcher's skills as a facilitator. Each participant commented on the discussion threads but commenting was generally limited. The researcher queried with the participants what could improve this. Some said that sending email reminders to comment would help, some said that the lack of comments may be due to the topic and that it was particularly aimed at professionals who record maltreatment data. Piloting allowed the researcher to improve the website and raised concerns about participants' motivation.

### **3.2.3.3 Data Saturation**

Ideally in the focus group work, the aim is to reach a point of data saturation. This is the point at which no new themes or concepts relevant to the topic of interest are interpreted by the collection of further data (75). This is however an ideal that may not be achieved due to the time constraints and funding of this project. The number of focus groups chosen, three face-to-face focus group and one online focus group, were based on the specific participant populations whose views the researcher was interested in capturing, one focus group from

each participant population. Analysis was conducted alongside data collection, and a decision was made during collection that no more groups were needed to reach data saturation.

#### **3.2.3.4 Equipment**

The face-to-face focus groups were recorded using audio recording equipment. A laptop was also used to present both PowerPoint slides depicting the scenarios and some initial slides used to define the various technical terms that may be used during the focus group e.g. 'anonymisation'. Telephone interviews were captured using audio-recording equipment.

The online focus group data were captured on a website on a server owned by Cardiff University.

All participant materials were provided in English but were also available in Welsh if requested by a participant.

#### **3.2.3.5 Duration**

Focus groups were expected to last 1-2 hours, and the online focus group was run for five weeks. The telephone interviews were expected to last approximately 40 minutes.

#### **3.2.3.6 Data Storage and Transfer**

The face-to-face focus groups and telephone interview audio recordings were transferred to secure password protected computer systems which were backed up to the Cardiff University server daily. Once transferred and checked, the recordings were deleted from the recording device. Transcription was completed by a staff member at Cardiff University, and adhered to the standard procedure devised in house by the CTR administrative team. Access to folders containing audio files was restricted to the researcher, and access to the folder was made available to the transcriber for the period of transcription only. Online focus groups data were captured on a password protected website designed by Cardiff University. Only participants who registered on this website had access, and registration was controlled by the researcher. Online focus group transcripts were downloaded directly from the website. Completed transcripts were received and saved to the same secure password protected computer systems, separate from audio files. They were then imported to Nvivo10 software by the researcher for analysis. The project was password protected and only accessible to the



researcher. All data will be kept for 15 years in line with Cardiff University's Research Governance Framework Regulations for clinical research.

### **3.2.4 Data analysis and validation**

An inductive methodology was used to analyse the data. Inductive analysis is where the themes identified are strongly linked to the data, and the data have been specifically collected for the research (76).

Forms of inductive analysis include Grounded Theory, Interpretive Phenomenological Analysis (IPA), and Thematic Analysis. Grounded Theory is concerned with generating a plausible and useful theory of the phenomena grounded in the data; grounded theory is also theoretically bounded (76). IPA seeks to understand people's everyday experience of reality in great detail in order to gain an understanding of the phenomenon in question. IPA is also theoretically bounded and provides an entire framework for conducting research, whereas Thematic Analysis is more flexible (76). During the analysis of the focus groups and telephone interviews the themes identified were somewhat driven by literature on the topic and topic guide. They were not however driven by a specific theoretical perspective, or the researchers' analytical preconceptions (76). The researcher was not planning on devising a theory; and rather was focused on investigating attitudes and looking to create broad themes from the data. IPA tends to focus on direct detailed experiences of an individual (77). This method was not suitable for this analysis as the researcher was interested in patterns in opinions and attitudes across all members of the focus groups and the telephone interviews as well as their experiences. IPA is thought to be more suitable for collecting data that are individual accounts rather than group discussions such as interviews or diaries (77). The researcher therefore used Thematic Analysis as opposed to Grounded Theory or IPA to analyse the data.

Thematic analysis has theoretical freedom, its flexibility can provide a rich and detailed, yet complex, account of the data (76). Thematic Analysis can be used to highlight similarities and differences across the data set, and can also generate unanticipated insights (76). Thematic Analysis can be used to address the research question of interest, i.e. about individual experiences, people's views and opinions, the reasons why people think or feel or do particular things and the processes that underpin experiences and decisions (76).

This was a transcript based analysis (72). The thematic analyses followed the methods as recommended by Braun & Clarke (2006):

#### Familiarisation with the data

The interviews were transcribed by a Cardiff University Staff member working at CTR due to constraints on the researchers' time. The interviews were anonymised. The researcher familiarised themselves with the data by reading all of the various transcripts for the focus groups and telephone interviews and then re-reading these transcripts before coding each one began.

#### Initial coding

The next stage was to code the data. This involved reading through the transcripts line by line and assigning initial codes, these initial codes often used the participants' exact phrasing. Although the coding followed the topic guide for the focus groups/telephone interviews, coding was also data-driven to identify interesting emerging themes. Coding in this way can be referred to as in vivo codes (78), and are a way to avoid interpreting participants' comments strictly through the use of existing concepts or theories. The researcher looked for repeated patterns in the data that may be later formed into themes.

#### Grouping codes into themes

The next step was to reduce the initial codes into a smaller set of themes, by grouping thematically similar codes together. A thematic map was produced as a visual tool to assist in this process. The researcher met with an experienced qualitative researcher from CTR at this point to read through the transcripts and discuss the themes to identify any areas of consensus and disagreement and to aid the process of re-defining themes if required.

#### Review of Themes

Themes were reviewed by firstly reviewing the coded data extracts and looking for any issues with how the codes had been assigned to the themes, and whether they would be better placed in a different theme or if there was a clear overlap in themes. This involved de-coding extracts and also changing or collapsing more than one theme together. The thematic map was re-drawn at this stage. The entire dataset and themes were then reviewed to ensure that they were accurate. This phase was repeated until the thematic map was thought to accurately reflect the dataset.

### Defining and naming themes

A coding framework was produced to define what each code meant in relation to the data.

The coding framework was validated by an experienced qualitative researcher from CTR by reviewing 15% of the data and determining if the coding framework was a suitable description of the data.

Themes from the work will be presented in the results section of the qualitative chapter using quotes from the data to illustrate the meaning of themes.

### **3.2.5 Researcher credentials and reflexivity**

It should be noted that the researcher recognises that the focus group and interview work consists of a social interaction between the facilitator (or 'interviewer' in the case of the telephone interviews, but will hereby be referred to as facilitator) and participants, and that this may play a role in participants' responses. The main facilitator was the researcher (a PhD student) and full time employee of Cardiff University who is a female in her 30's. Her educational background includes a BSc in Psychology and an MSc in Forensic Psychology, and so has an interest in qualitative research, behaviour change, and child maltreatment. She undertook further in-house training in focus group and interview methods in the CTR and also attended a focus groups course run by Oxford University. Previous to this PhD work, she had been a co-facilitator to assist other qualitative researchers in CTR. She had worked on many studies in the unit, including as a Data Manager on the Building Blocks Trial, the Building Blocks: 2-6 Study, and as a Trial Manager on the Confidence in Care Evaluation. All of these aforementioned studies had a qualitative as well as quantitative component, and were focused on behaviour change. The Building Blocks Trial and the Building Blocks: 2-6 Study had a particular focus on child maltreatment.

The facilitator hoped to build rapport with members of the focus groups and interviews to allow them to freely discuss the sensitive subject matter. Some of the focus group participants were familiar with some of the studies mentioned in the paragraph above or have a relationship with the facilitators' colleagues. The care-experienced young people group and the younger mothers group assisted the research team on the Building Blocks: 2-6 Study previously, the older mothers group had a personal connection with one of the PhD

supervisors, this familiarity should help build rapport. With regards to the professional participants, the facilitator attempted to build rapport through shared knowledge of the topic. Limitations include the fact that at the time of data collection the facilitator had no children of her own and was not care-experienced. This may have limited her ability to relate to some of the participants. All of the participants knew that this was part of a PhD study, and they were also made aware that the facilitator had been part of the Building Blocks Trial and the Building Blocks: 2-6 Study. It should be kept in mind that although some of those taking part in the focus groups and interviews acted as advisors on these studies, they were not participants and so this was not expected to limit their responses in any way.

### **3.3 Results**

#### **3.3.1 Demographics**

One online focus group was completed with professional participants, and two additional one-to-one telephone interviews were conducted with members from this group. In total, four face-to-face focus groups were conducted. One with younger mothers, one with older mothers, and two were conducted with care-experienced young people.

There were ten members in the online professional face-to-face focus group, seven of these were female. The group was a mix of professionals, the vast majority of which were health professionals. There were four GPs, three paediatricians, one health visitor, one dentist and a secondary school teacher. They were mostly working in Wales, with two in Northern Ireland and one in England. The young mothers group consisted of six participants and had a median age group of 16-25. Four had one child, one had two children and one had three children, the average age of the children was five. The older mothers consisted of 10 participants and had a median age that lay between two age groups, 26-35 and 36-45. Two had one child, three had two children, four had three children and one had four children, and the average age of their children was also five. The first group of care-experienced young people were a mix of young people and CASCADE Voices staff and consisted of six participants, three young people and three staff members. Two of the young people were currently in education, the median age was 25 across staff and young people, with an even gender split. The second group contained care-experienced young people only and had five participants, with a median age of 23. None of which were in education, and there were four males and one female.

### **3.3.2 Data validation**

Fifteen percent of the data collected during the focus groups and interviews were reviewed by a CTR qualitative researcher. The data were in transcript form which had been coded. The qualitative researcher was asked to review these codes along with the coding framework (figure 7) and to note their agreement next to each code on the transcript. The qualitative researcher agreed with 98.7% of codes (i.e. disagreed with 1.3% of codes); this was thought to be an acceptable agreement rate.

### **3.3.3 Results**

Figure 7 depicts the coding framework devised by the researcher, this illustrates the major themes and sub-themes developed from the focus groups and interviews. The major themes were:

- Consent
- Trust
- Understanding

The first two of these themes, consent and trust, are closely related to the topic guides used to steer the focus groups and interviews. Much of the topic guide was based around themes of consent, specifically the conditions for providing consent and which factors may influence this, and trust, specifically in discussions regarding data security. The understanding theme is less related to the topic guide, and mostly comprises newly emerging sub-themes.

These themes are discussed in detail in the following section. Quotes have also been included to illustrate the most common discussion points as well as to highlight more unusual cases.

#### **Key:**

OM – Older mothers

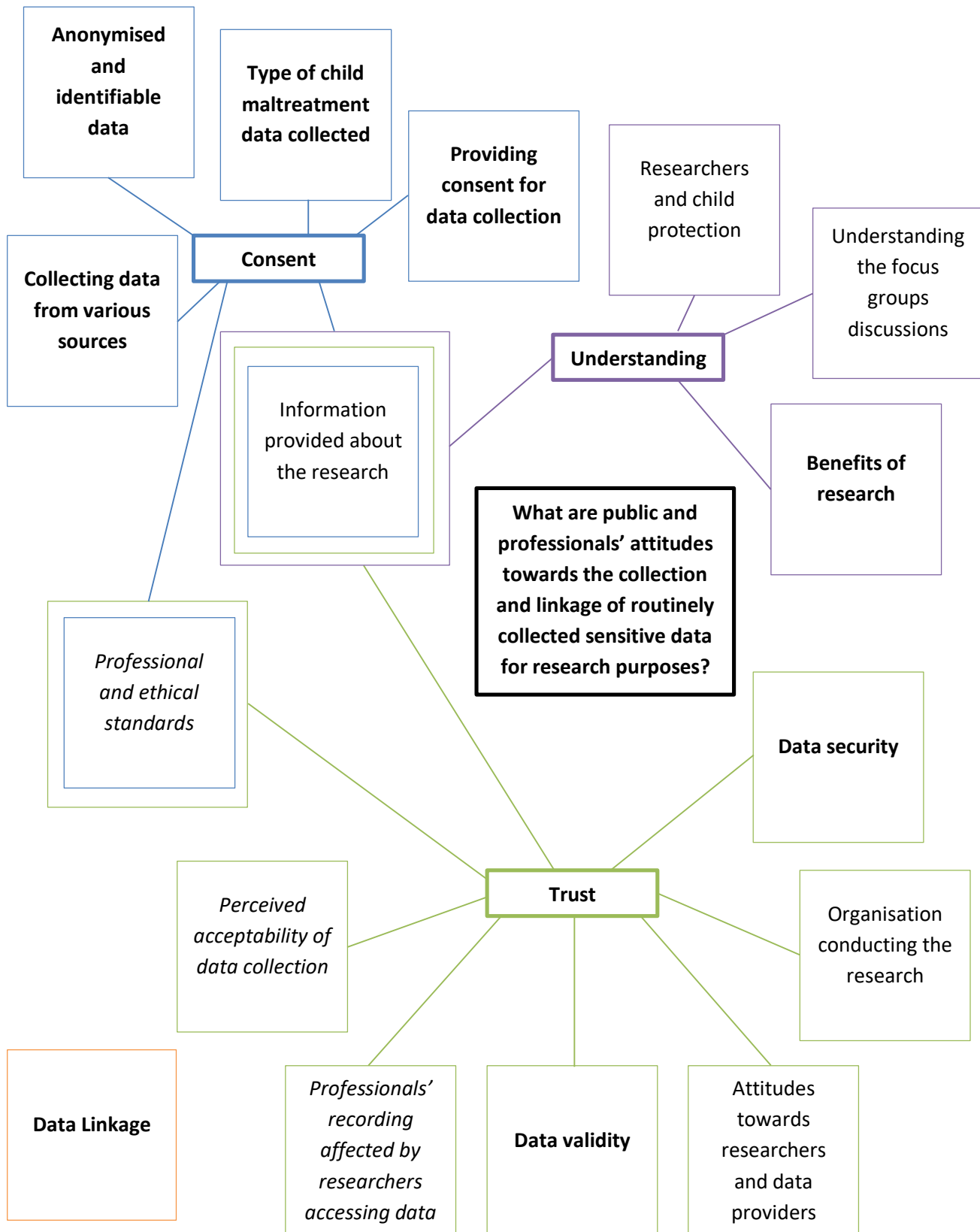
YM – Young mothers

P – Professionals

CE1 – Care experienced young people group 1

CE2 – Care experienced young people group 2

**Figure 7.** Coding framework - major themes and sub-themes



**Key**

- Themes derived from the professionals group
- Themes derived from the public group
- **Themes derived from both groups**

### **3.3.3.1 Theme 1: Consent**

During analysis of the focus group discussions and interviews it became apparent that many of the discussions centred around issues of consent, specifically the conditions for providing consent and which factors may influence this. A number of sub-themes were developed, the mothers and care-experienced young people focused on how the information provided to participants about the research shapes attitudes towards the collection and linkage of child maltreatment data. This was a sub-theme that actually fitted under all three major themes. The professional participants discussed professional standards and ethical issues that should be taken into account when collecting and giving access to child maltreatment data. This sub-theme also fitted under the major theme of trust. Sub-themes that were derived from discussions in both mothers and care-experienced young people as well as professional groups included attitudes towards the type of child maltreatment data collected, attitudes towards asking for and providing consent for data collection and other consent issues, the acceptability of researchers collecting data from various data sources such as data from hospitals or Social Services, and discussions about the collection of anonymised and identifiable data.

#### **Information provided about the research**

The information provided by researchers to participants about the research was found to be very important in how the participants viewed the research and whether they would be happy to provide consent for the collection of their or their child's data. This sub-theme was related to all three major themes. This sub-theme didn't feature prominently in the topic guide used to guide the focus groups and interview discussions.

Participants mostly wanted justification for data collection. They wanted to know *why* these data needed to be collected, as illustrated by the below quotes. They were also interested in what would happen to the data after the project finished, if participants would be provided with the outcomes or findings of the research, and finally, who would have access to the data.

CE2: 'It's like I would want to know first of all why you need my information or why would you like my information and I would like to know if I could be updated and what outcomes you've had from my own information and how that's helped you as a researcher.'

YM: 'Why is it so important, why my child? What are you going to do with it?'

### **Professional and ethical standards**

The professional participants often mentioned professional and ethical standards that they would take into account when discussing the collection of, and providing access to child maltreatment data. This fitted under two major themes, consent and trust.

P: 'Um, but of course the thing that we felt from a (job role) perspective um, the thing that we constantly filter um, that decision making through is the Children's Act, and the needs of the child are paramount, so you know we are more likely to share, is this the right direction for you?'

P: 'I agree with the previous opinions; medical records should be accurate and factual, as per GMC good medical practice guidelines, irregardless of whether they will be seen by researchers.'

There was a feeling from some participants that allowing researchers to access data was the right or proper thing to do from an ethical perspective.

P: 'Um, so it shouldn't really alter what you write, how you behave, because you should be behaving properly 100% of the time.'

P: 'I think we have an obligation, I do feel quite strongly about that, we have an obligation to do that.'

For clarification, the above participant was referring to allowing researchers to access child maltreatment data.

There were some concerns over ensuring that patients were aware that their data could be accessed by researchers and that litigation could arise from this.

P: 'Would there be any issues over consent? If records are shared for research would written consent need to be given by the child's parent/guardian? If not, would we health professions be liable for any compensation claims against us? There is so much emphasis these days on gaining written consent just for a patient to more or less walk through the door not sure if this would put some clinicians off sharing research.'



### **Type of child maltreatment data collected**

The *type* of data collected i.e. whether researchers wanted to collect markers, risk factors, or if they want to collect data indicating status of confirmed and unconfirmed cases of maltreatment was important to participants. Some participants felt that collecting data related to markers and risk factors for child maltreatment, as well as confirmed cases, could be beneficial to the researcher. Others felt that collecting any data that were not related to confirmed cases could be problematic, for example because of diverging views from various health professionals.

CE2: 'Because they could, that could be intriguing actually because they could actually find that there is a higher percentage of if there's domestic abuse going on in the family then it could lead to, well there's more likely a chance of the child getting abused as well if that shows up then yeah that's really interesting data, really interesting information so'

CE1: 'For example, one like doctor, you know a doctor could say "there was a mark", another doctor could say "oh no it's something else", so then how, you know, unless you know "yes that is definitely, that is definitely a mark or an injury" then I don't think that it should be looked, like part of the research.'

YM/P4: 'I don't know if I agree with that because, say like Baby P for instance.'

Interviewer: 'Yeah.'

YM/P4: 'That poor boy had so many bruises and doctors didn't pick it up, I think maybe, I think maybe if like, like researches did look more into things like that, maybe they could've picked it up and thought "oh hang on now, maybe we should look more into this", because maybe they didn't see the same doctor every time.'

One of the professional participants was concerned about *perceived* acceptability, so what the public would think about collecting unconfirmed cases, or markers and risk factors verses confirmed cases to the public.

P: 'As previous posts have said also would depend on what this data actually would be, if cases of proven maltreatment where there is already known information sharing across services I

wonder if this would be more socially acceptable than collecting data on every minor injury in a child for example.'

### **Anonymised and identifiable data**

This sub-theme centred on the collection of anonymised and identifiable data and attitudes towards the conditions in which anonymised or identifiable data should be collected.

Interestingly it was found that anonymised data collection was not necessarily preferred to the collection of identifiable data, and that this was very much dependent on the context. For example, there were concerns from some participants that if enough anonymised data are linked then this could render a participant identifiable, this may partly be about knowledge of what anonymising data actually means.

CE2: 'Yeah I can understand that but then what if it was just like little you know dribs and drabs of thing then you were anonymous it doesn't then become anonymous and technically they've taken it without your consent and I'm sure that's against the rules.'

YM: 'But would there be some links towards like, you, even though your names not on there, the information, it's all linked to you anyway, so they can .....Because they'd be able to find out it's you, because everything on there is about you.'

This was linked to whether outright consent was sought; some thought it was important for consent to be sought even if data were anonymous.

OM: 'I personally, if it's anonymised data, I wouldn't mind it being collected without my knowledge.'

OM: 'Personally I would like to know, even if it's anonymised, I would like something that says "your data has been collected, this is what we will do with it.'

YM: 'I think you should still have to ask, I think they should, if someone, if, just say like you had asked to look at my child's data, I'd want you to come up to me and say "I'm [name], and show me a card or something", I'd want to know if you're looking at my child's records, even if you don't know her, because you're not going to know her anyway, but.....'

This was also true of one of the professional participants.

P: 'This is a difficult question to answer. On a personal level I would wish to know that my personal data is being collected, even if anonymised. Obviously this is not always practical.'

The preference for anonymisation was dependent on the data items being collected.

CE1: 'I think it all depends on the information, if like, I wouldn't mind my name being used if it was for what my blood type is, that doesn't bother me, but as [NAME] says, if it's something to do with any illnesses you have that other people might not know about, I wouldn't want my name being put to that, so I suppose it totally depends on what information.'

Some were unhappy by the revelation that legally a researcher does not have to seek consent to collect anonymised data

CE1: 'Yeah, even if, because if I've already said "no" they should listen to the people and people have their rights to participate or not, so I was using my right to remove my participation by saying "no" to the original trial, so they should respect that, that I've said "no".'

CE1: 'I don't really agree with it, I suppose in terms of how it's put across, like if someone says they don't want to consent and then you're kind of just doing it anyway, I feel like ethically there's, there's kind of a grey area really, well in my opinion at least.'

### **Providing consent for data collection**

The attitudes towards asking for and providing consent for data collection and other consent issues was discussed widely in the focus groups and interviews, including many discussions around consent bias.

P: 'I think, well the trouble is, I think with a sensitive, with something that sensitive, you're less likely to get consent, so then you're going to have, you're going to skew your data completely, um so it can go both ways can't it? Yes it, I suppose in one way more important to get consent but at the same token you're very much less likely to get a decent or a good amount or, of

relevant information because of the nature of the subject, I don't think many people would consent to it.'

P: 'I agree that this is an interesting and important issue. Consent is important but getting consent can be difficult in some circumstances and this can lead to unreliable results being obtained during research. One of the issues is that those the researchers are most interested in are probably the ones who wouldn't give consent.'

Most participants wanted the choice of whether to give permission for data to be retrieved for use in research. This is related to the discussion in the above section about participants being unhappy that anonymised data can be collected without consent.

CE2: 'As long as I was given that choice because everybody's different.'

Discussion about whether giving the option to 'opt-out' is a good idea also took place. In this context the discussion surrounded opting out in the way done in the Building Blocks: 2-6 Study where participants were written to and given the option to opt-out of further research.

OM: 'I don't know, do people actually opt-out, you know? You may get a letter but how many times do you get a letter and you won't do it there and then and you put it to one side because it's not that important and you forget about it.'

Many of the professional participants discussed practical difficulties of obtaining consent for large samples. This was not to do with consent bias necessary but to do with the challenge of obtaining informed consent from a large number of potential participants. Some participants also noted that people should be informed that their data are being used even if they are not consented.

P: 'Interesting question. I don't think researchers should have to gain consent on an individual basis as this would be impractical, but I wonder if there should be generic consent in relation to for example health data. I suppose this might be meaningless, may raise concerns, but I think individuals should know that their data is shared anonymously for the benefit of patients/ clients as a general principle.'

Interviewer; 'And what about letting people, not necessarily asking consent but letting people know, sending them a letter to say.'

P: 'No, because I think, that's just creating a rod for your own back, that's when people kick off and, yeah, no.'

In the young mothers group, there was much discussion about the differences between providing consent to collect data related their child, rather than consenting to their own data being collected. There was a general feeling that they were much more likely to consent to their own data being collected than to that of their child.

YM: 'Because I said yeah to them, they could research me all they wanted, but if they said anything about [name], I'd be like "no".'

### **Collecting data from various sources**

This sub-theme was about the acceptability of researchers collecting data from various sources such as from medical or social care records. There was less support for researchers accessing Social Services data in the group of care-experienced young people compared to the other groups, however not all of the care experienced young people took this position.

CA2: 'Yeah, I wouldn't want anyone to look at my care file, because that's my private business that's where all my information lies regarding my family, why I was in care, things that have happened while I was in care compared to like hospitals and stuff like that so I don't think you're going to get any like... there's not much to research only like why young people go into care but then obviously people with knowledge and a brain cell would understand why people go into care but then like you know researching types of cancer and researching why the waiting list is so long and you know in hospitals and doctors and stuff.'

Many participants did consider Social Services data to be more sensitive than medical data.

OM: 'Medical records should be sensitive but it's you know not necessarily that sensitive for a small child that Social Services things there's a lot more at stake.'

Some participants discussed this in terms of whether the data would be identifiable or anonymised.

CE1: 'I think it all depends on the information, if like, I wouldn't mind my name being used if it was for what my blood type is, that doesn't bother me, but as [NAME] says, if it's something to do with any illnesses you have that other people might not know about, I wouldn't want my name being put to that, so I suppose it totally depends on what information.'

Most of the professional participants discussed this issue in terms of practicality, which source has the most reliable or valid data, and not in terms of their feelings about how sensitive the data items were.

P: 'I agree with the above comments. When considering child maltreatment all possible sources of evidence should be used to collate a more thorough picture. Although in theory all professionals should be sharing concerns regarding both potential and actual maltreatment, the practice may not reflect this and therefore accessing all sources of information, including medical notes and LA records should give more accurate information.'

### **3.3.3.2 Theme 2: Trust**

The next major theme to be identified was that of trust. This concerned trust in data security and validity, the organisations and individuals involved in providing and using the data, and how information provided to participants shapes attitudes towards the research. A number of sub-themes were developed, two of which were related to the mothers, care-experienced young people and professional participants, namely data security and data validity. Sub-themes derived from the data provided by the professional group only included the perceived acceptability of data collection and professionals' recording affected by researchers accessing data. The sub-theme of professional and ethical standards also appeared under the consent major theme and is described above. Sub-themes, that were derived from data provided by mothers and care-experienced young people only, included organisation conducting the research, attitudes towards researchers and data providers, and finally, information provided about the research which also appears under the consent major theme and is described above.

#### **Professionals' recording affected by researchers accessing data**

Most professionals were unconcerned that entries they make into records related to child maltreatment would be 'judged' by researchers, and stated that this would not affect their recording practices. Some conceded however that this may not be true for all professionals.

P: 'This is a non-issue in my view. As professionals I believe that all information gathered in relation to child maltreatment should be recorded in the same way no matter what could happen with the data afterwards. All data that may be relevant should be recorded no matter how small or insignificant it may seem.'

P: 'In another vein, I suppose if the clinician thought the information might be used by a third party, they might be more likely to withhold sensitive data. E.g. some GPs still choose to not document HIV tests thinking they might affect life assurance applications (they don't - of course unless you enter an HIV positive diagnosis in which case you advise patients to look for policies that cover HIV and they exist).'

### **Perceived acceptability of data collection**

This is the perceived acceptability of the public, as judged by professionals, of researchers collecting child maltreatment data. There were discussions around the type of data collected that professionals felt would be more acceptable to the public.

P: 'Um, well it's difficult, I would probably say um, maybe as a population people are more prepared for medical data to be used for research purposes because they feel its um, going to benefit, sort of, medical issues, that they may be more used to it um, but I don't think there should be that much of a difference um, between the two they should be the same really.'

There were concerns from the professionals that the public may not find data collection by researchers acceptable, and that this would damage the relationship between the public and professionals if they realised that data being collected by the professionals were being given to researchers.

P: 'I would like to think as an objective clinician and researcher this should be a good thing, for the greater good. However, I do wonder what would happen to trust between parents and doctors especially if parents might feel their childcare might be judged by someone who might not know them. E.g. minor injuries, head injuries - would that be judged as neglect if the information were passed to someone else?'

P: 'Yeah um, again it sort of comes down to, I think the majority of the population now know that if a medical person or anybody suspects some sort of maltreatment to a child then they have the right to involve third parties in order to investigate that, um whether research then comes under that bracket is, is difficult to know but I think, I don't think it, well apart from, in some people yes it might upset them because they haven't given consent for that information, but I think the majority of the population would accept it, but there will be a small proportion of the population that, that might take offense to the fact that information was passed on, anonymised or not, to another party, um but yeah, no I think in general I think people will be accepting of it, but um a small proportion of people might take offense and it might then effect the doctor patient relationship, but that tends to be relatively small proportion of the population, well where I work anyway, I would expect it not to really impact in it too much.'

### **Attitudes towards researchers and data providers**

This sub theme was derived from participants' attitudes towards the researchers collecting the data and the individuals and organisations who provide the data. There was some suspicion about whether researchers were going to look at data items that participants were not aware of. There was general lack of understanding about the type of data researchers' view i.e. many participants thought that researchers would be handed entire medical or Social Services files and not specific data items from these.

CE2: 'Because it's not like if you go into the Local Authority now and you've said oh I need to look up so and so's name and a bit of information about them it's not going to be all on the front page is it? They are going to go through all the thing and pick up what you need, by the time you pick out what you need you've read what's...'

Many in the care-experienced young people groups believed that their own personal data collected by Social Services could not be accessed by researchers, and that if Social Services provided data to researchers they would be breaking the law. This idea originated from the fact that many of them had been explicitly told by their social workers that their data would be completely confidential, to them this meant that their data would not be shared. Much of these views are less about researchers but a different understanding of what confidentiality means and also a suspicion that anonymisation may not work.



CE1/P4: 'No I seen that in the news as well, there was a social worker who give out um, some stuff on a young person and they can't work with children or nothing no more, because it's all confidential.'

CE1/P6: 'You can get a social worker done for it.'

CE1/P2: 'As researchers I would think it would be very hard to pass through the committee that says yes you can do research.'

Interviewer: 'Even if it's anonymised?'

CE1/P2: 'Yeah because it's technically, I would, its borderline breach of confidentiality to even know that, that young person is, to identify them as being in care, I would say it is anyway.'

CE1: 'Well I think that in like LAC reviews and that, which are like meetings, they say that everything is confidential, so where the researchers are doing it, even though its anonymous, I would feel like it's not as confidential as what they say in the LAC review as well, because you've got your social worker and aftercare worker and support work saying everything's confidential, nothing leaves this room, then it's obviously left the room in a way because researchers have got that information.'

Some participants felt a general lack of trust towards organisations sharing data because they felt a loss of control over what was being shared about them.

CE1: 'And then the other thing that I was thinking about is that, young people um, who have been looked after have, kind of had very little control over the information that's sort of, passed around about them um, you know I think you were saying that social workers and you know, there's the chairs and there could be police, there could be lots of different agencies and very little control over that and then this adds another layer that can feel a bit problematic and out of control, a bit unsafe.'

CE1: 'Yeah I feel like people like me and other looked after children and people whose left care, like they should be able to talk to like, their social workers or after care workers, but then when information's being passed on, they might feel like they don't want to anymore, like they have no one else to speak to them.'

Some of the younger mothers group were concerned about researchers' intentions and why researchers would want to collect data on their child.

YM: 'I suppose like in that it's like the child, like um, I don't know, I'd wonder why as a parent, like "oh have I done something wrong, why are they using my child" like do you get what I mean?'

### **Organisation conducting the research**

This sub-theme originated from discussions about preferences and trust in various organisations (for example the Government, university researchers, pharmaceutical companies) that might collect these data. Most participants were happier to consent to data being collected by an organisation that was familiar to them, and who could use the research to improve circumstances or services.

CE1: 'I don't, for like me personally, I don't tend to like do anything unless it's got like something I recognise, for instance like today, I know Cardiff University is a trusted source so it makes you want to take part, but if it was like somebody like on the street, like when they do the, like when people stop you for surveys, if I hadn't heard of that place, I wouldn't want to give my information, so I think it helps like, not just in this scenario that we're talking about, there's like, you'd know who's doing it.'

CE1: 'I think as well it depends on where it's, like [NAME] said that you wanted something to be done with it, but say it was someone like Welsh government doing this, asking your permission and so on for this research because they want to improve such and such and such, you know, that would make me a bit more, make me happy giving my information if it's coming from someone who can actually do something about, make that change.'

YM: 'I just, I don't know, I think it depends on the name really doesn't it, you know, it sounds silly, but it does depend on what the company's called.'

### **Data security**

This sub-theme originated from discussions about the security of electronic data transfer, data linkage, data storage and access to the data. Some participants voiced concerns about the security of data transfer from the data providers to the researchers, this partly arose from hearing negative stories in the news about personal data being lost or stolen. The vast majority however of the mothers and care-experienced young people did not have many security

concerns and trusted the procedures that researchers would put in place to ensure data security.

OM: 'I'd be happy to take the risk, you know, things do go on and you here about people leaving files on trains or whatever, but I would want lots of assurances first because as much as people want to keep data safe and it isn't safe necessarily. People can say what they want it doesn't necessarily mean it's true.'

OM: 'I think the fact that it makes it to the news when something like that happens, shows how rare it happens, so yeah I think it doesn't really....'

Most mothers and care-experienced young people would prefer that their data were transferred between data provider and researchers via the internet rather than paper-based files, and generally had a good understanding of data protection.

CE2: 'I think online is safer to be honest because you can encrypt it so it's pretty much impossible to actually get that data if its encrypted whereas you can't exactly encrypt a piece of paper unless it's in a made up language.'

There was a general feeling in the young mothers group that sending data via a work email was safer than a personal email, even if this is not the case.

YM: 'Like anyone can get access to that, email is, your email, but then like a works email is probably better as well because, like my email, anybody, like my brother or something could get the password for that or something, whereas a work email it's only you in an office.'

Following data protection procedures was seen as very important to both mothers, care-experienced young people and professional participants.

CE2: 'I would be fine with it being sent anywhere as long as long as it was within data protection.'

P: 'The data has to be treated with the greatest confidentiality as all clinical information would in health. If data for research, there has to be evidence of ethical approval so that the information required is considered as required for the project.'

Professional participants said that there should be no difference between the security of child maltreatment data compared to any other kind of personal data. The care experienced young people however viewed child maltreatment data as more sensitive than other data and so believed that there should be a higher level of security.

CE1: 'I think they should secure because it's not fair on that, the young people if you collect their information, saying young people had been hurt, and then, don't know, it got back, or like there was a way of, you know, identifying or if like, you know, say they could take part in something further down the line and that could be the way the young person found out about, don't know, that's way, you know, (life would go on like the way it is) so I just think it need to be more secure'

P: 'Security and confidentiality should be the same for any of the data -utter confidentiality according to the ethics approval.'

Concerns about data getting 'into the wrong hands' was mentioned a couple of times in the young mothers group.

YM: 'Because then if you were concerned then it, do you know what I mean, it could get into the wrong hands.....'

This participant did not specify who the 'wrong hands' were.

### **Data validity**

There were many discussions surrounding the validity of data in records and how validity may affect research findings and conclusions. There were some concerns from professional participants that accessing the 'right' data would be difficult for researchers when collecting data on child maltreatment from records. There was a strong feeling that Social Services records were the best place to collect any data on child maltreatment. Some professional

participants had concerns about the objectivity of other professionals and that this may affect their recording of child maltreatment data.

P: 'I feel it is appropriate to collect data from these sources. However, it could be potentially difficult to ensure all appropriate data was collected from medical records. There could be a huge variation in the entries or 'codes' used to record such data particularly within GP patient records. Particularly if undertaking research on suspected child abuse/maltreatment. In this situation it is likely to be entered as a clinical finding e.g. 'bruising'. Only following confirmation by paediatricians and Social Services investigations would it be coded more specifically e.g. 'non accidental injury' within the medical notes. The Local Authority records will be easier to localise the required data as they hold details of those children who have been investigated for maltreatment including the confirmed cases and those who were referred but on investigation no grounds for concern were found. All GPs who have suspicions of child being maltreated SHOULD make a referral to the social service and as a result there should be a record of such a referral even if on investigation nothing of concern was found.'

P: 'I agree that it is appropriate to collect from medical records however due to inconsistencies between different health professions in recording such data there will be variations in whether actual maltreatment has occurred or whether it is speculation. I also believe that the majority of clinicians will be very good in recording all relevant evidence but unfortunately not all clinicians are as thorough in their record keeping.'

Concerns from the mothers and care-experienced young people came about accuracy of the data and a belief that there was some inaccurate data in medical and Social Services records

CE1/P3: 'So are you thinking that the information that Social Services have might not be, in some cases, right.'

CE1/P6 'Yeah, as far as like um.'

CE1/P1: 'So they might not be accurate?'

CE1/P6: 'They can um, it's like when social workers chuck words in, say if you have been in homes, you might have things you've told them, but then, they overlap them and say what they want to say, chuck some words in, so it makes it seem worse than it should be, or whatever.'

CE1: 'Some of it, the data, will be good, and sometimes it's just bullshit.'

There were also some concerns voiced that what was in the records did not show a full picture of the family's circumstances and that this would lead to unfair judgements made by researchers.

YM: 'Because they're just looking at statements, they're not looking at you as a person, they're looking at basically the paragraphs that you've seen a doctor for 5 to 10 minutes, do you know what I mean, and they're not...'

### **3.3.3.3 Theme 3: Understanding**

The final major theme was understanding. This concerned participants' understanding of the topics discussed at the focus group, the benefits of research, the researchers' role in child protection, and how information provided by researchers can influence attitudes. Sub-themes derived from data, provided by mothers and care-experienced young people only, included researchers and child protection, understanding the focus groups discussions, and information provided about the research which also appears under the consent major theme and is described above. The sub-theme concerning the benefits of research was also devised and related to mothers, care-experienced young people and professional participants.

#### **Researchers and child protection**

This sub-theme arose from discussions about whether researchers are responsible for flagging child protection concerns. Many of the mothers and care-experienced young people believed that it was the duty of researchers to flag concerns about children if they noticed maltreatment cases in data. If, for example, a case of possible maltreatment was spotted by a researcher that may not have been spotted by others, such as when data from various bodies are linked maltreatment may be uncovered. There were concerns that researchers could not identify a maltreated child if data were anonymised.

CE1: 'I would just wonder as well, like imagine if they collected your data in this scenario, and you notice, going along with the theme of this that, "Child A" have been in there 5 times with said injuries, different injuries, the hospital might not have picked it up, how would the researchers stand on an ethical point of view of, say what would they do, would they have to go to somebody like and say "oh we've noticed that Child A have been there" because I

couldn't do this research knowing that I was sitting there and I'd found this out and not taken it anywhere.'

CE2: 'On the flipside of that I do worry that if you anonymise this kind of data and a child needs to be taken out of a situation where they have been maltreated really, really badly and it's anonymised, how the hell are you supposed to...'

### **Understanding the focus groups discussions**

This sub-theme is concerned with the participants' level of understanding of the topics discussed at the focus groups. During the mothers and care-experienced young people focus group discussions and later analysis the researcher became aware that many of the participants did not always understand the concepts being discussed. Some of the concepts discussed such as 'data linkage' were new to them and can be quite abstract. These concepts were discussed and defined at the beginning of the focus groups and were also framed around scenarios, however some participants still failed to have a good understanding of what was being discussed. There were attempts to clarify when participants' stated that they did not understand, and the researcher believes that this was helpful to aid understanding. This is very important to keep in mind when designing participant materials, and also when interpreting the data gathered in this study.

The below participant was asked their thoughts about the type of data being collected, and if it would matter what type of data researchers are asking for?

Interviewer: 'Ok, and what do you think?'

CE1: 'I don't know, I don't understand it really'

One participant was unhappy about providing consent for a scenario involving a researcher collecting identifiable data from the medical records of all children in Wales (this was not child maltreatment data), although they conceded that they didn't fully understand what was being asked of them.

OM: 'I don't understand, ok but I, I wouldn't be happy.'

For one participant, they asked what we meant by the term 'child maltreatment' about 30 minutes into the discussion on the topic.

YM: 'Can I just say, what does maltreatment mean then?'

### **Benefits of research**

This sub-theme addresses the benefits of research in this field. Many participants were happy for research of this sort to be conducted as they could appreciate the benefits.

P: 'It is in children's best interests but you can imagine a public outcry. If the data is anonymised, the children can't be identified, and the research has gone through appropriate ethical approval, I think it is a good thing for the overall greater good.'

OM: 'And again I would assume that you would only, you know a researcher would only ask for the data, you know, in a bid to try and help you know.'

OM: 'To help the kids you know.'

YM: 'Yeah, I think if like um, like um, healthcare better and also like the way they look after children as well.'

For some of the mothers and care-experienced young people however, the benefits of collecting child maltreatment data for research was not always clear. There were also concerns about it being too late to help a child at this stage who had been maltreated. On the whole they were happier for the research to be conducted if it could have a direct impact on policy.

OM: 'Well, but, so with your, with the researchers findings, can, what can that researcher do with that findings that will help? Because, you know, as far as I'm concerned, if somebody is going to mistreat a child, they're going to do it, you know?'

OM/P1: Participant 1; 'It can influence policy or you know.'

OM/P2; 'Yeah but it.'

OM/P4; 'It's too late for the child when it's happened.'



OM/P2: 'It's too late yeah, but we can also, even for the future though, because people can, you know, it doesn't have to be.'

YM: 'Because I feel like, like no offence but I feel like researches only do, do, you know research things.'

#### 3.3.3.3 Data Linkage sub-theme

This sub-theme does not fit under any of the major themes and stands alone. It came about because of discussions about issues surrounding data linkage. Some participants believed that the idea of data linkage was more useful for clinical care and prevention of maltreatment rather than research, and thought it might be helpful if different organisations were to have access to one others data sets.

CE2: 'Because it can help to have this integrated data when dealing with cases of severe child maltreatment because the Local Authority might not have anything, but the NHS might do.'

CE2: 'Now if they had integrated dataset like this where you can look at NHS and look at education records and look at Local Authority records etc. then you would be able to come up with a better picture of how that child actually is and to prevent maltreatment before it becomes extremely serious. Same thing with Baby P.'

OM: 'The only thing I would say is cases spring to mind where things haven't been linked up in the past, you, you know and they're all in the press aren't they like Daniel Pelka and Baby P and those sorts of things, when agencies in their reviews, they found agencies weren't speaking to each other so I suppose.'

There was also some discussion about the mechanics of linking *anonymised* datasets and how this was done in practice.

OM: 'So how could they link it to Social Services records if it's non-identifiable?'

OM: 'Well that's, well yeah, that's ok, because it's still anonymous to the researcher so any of your, you know, any of the researchers finding will still be anonymous, you know, child 'X' wont it?'

The next section will be a discussion of the results presented above.

## **3.4 Discussion**

### **3.4.1 Key findings**

The aim of this chapter of the study was to better understand mothers, care-experienced young people and professionals attitudes towards collecting and linking routinely collected sensitive data, particularly maltreatment data, for research purposes.

Three major themes were identified, consent, trust, and understanding.

#### **Theme 1: Consent**

##### **Information provided about the research**

This sub-theme was actually related to all three major themes, and was newly derived in that it did not form part of topic guide. The information provided by the researchers affected the decisions of participants to provide consent. Other researchers have found that there is a need for increased public education and awareness about research processes and safeguards (35). It has also been found that the amount of knowledge a potential participant has about the research may affect consent preferences, and that participants may be more likely to be satisfied with not providing explicit consent if they understand the actual research that is being done (1). In similar results to the current study, Davidson et al (2013) found that participants would like to receive feedback on how their data have been used. Other researchers also found that who has access to data was an important consideration for potential participants, and that they would like to be informed about how their data are being used and by whom (32; 33; 34; 35; 36; 43). Information about the user of the data was seen as more important than the intended use in determining whether to offer consent in some studies (35). All of this is important to consider when designing materials such as the participant information sheet. To ensure that truly *informed* consent is obtained, it is vitally important that participants fully understand complex concepts such as data linkage and how to provide this information can be very challenging for researchers. Participant or public involvement can be used to aid with conveying these complex ideas.

### **Professional and ethical standards**

Professional participants were concerned with professional and ethical standards; this came under two major themes; consent and trust. This was discussed in terms of an ethical perspective as well as concerns about how participants would react to their data being collected and fear of litigation.

### **Type of child maltreatment data collected**

The *type* of data collected i.e. whether researchers wanted to collect markers, risk factors, confirmed and unconfirmed cases of maltreatment was important to mothers and care-experienced young people. Other researchers have found that some data items are considered more sensitive than others, and that this may affect consent (44). Discussion in the literature has mainly focused on medical data items and this is the first piece of research to focus on child maltreatment data in this way. Professional participants were more concerned with the perceived acceptability of the collection of various types of data to the public, this was an unanticipated sub-theme for the professionals group.

### **Anonymised and identifiable data**

Interestingly this study found that collecting anonymised data was not necessarily preferred to collecting identifiable data, and that this was very much dependent on context. In the literature there is a mixed picture. Some researchers have found that potential participants are more likely to consent when data are anonymised (24; 39; 40; 41), where some have not found this (35; 43). There were mixture of views in the current study. In findings similarly to Davidson et al (2013), some participants were concerned that if enough anonymised data are linked then this could render a participant identifiable. This may arise from a misunderstanding of what can and can't be done with truly anonymised data. Some participants were unhappy at the revelation that researchers can collect anonymised data without explicit consent. Haddow et al (2011) also found that participants were surprised to hear that anonymised data could be used for research without individual consent. Participants in the current study were selected to be from specific populations i.e. younger/older mothers, care-experienced young people and professionals. Most of the studies mentioned above however contained participants from the general population/primary care patients (35; 37; 39; 41; 43; 49), and so there are some similarities and well as differences in the population samples used.

### **Providing consent for data collection**

There was much discussion and some concern about consent bias by mothers, care-experienced young people and professional participants, but no consensus over whether this was an important enough reason not to ask for consent each time. Most participants however wanted the choice of whether to give permission for data to be collected. Hill et al (2013) found that providing information about consent bias to participants made them more accepting of collecting anonymised data. Others have found, like in the current study, that although providing information and research scenarios to aid understanding of consent issues could alter individual opinions, aggregated opinion showed little change (33; 34). Many of the professional participants discussed the practical difficulties of obtaining consent for large samples; this was a similar finding to El Emam et al (2011). This was interesting as after these focus groups and interviews were conducted in May 2018 NHS Digital did indeed introduce the 'National data opt-out programme', a facility for individuals to opt-out from the use of their data for all research purposes.

### **Collecting data from various sources**

The type of data that is collected may affect participants consent preference; some data items are considered more sensitive than others. Individuals may not give consent based on the topic of the research or the possible use of the findings (44). When designing a study, thinking about the participants and how they may feel about the collection of specific data items from various sources is very important as this may affect consent preferences. It is for example understandable for care-experienced young people to be less supportive of data collection from Social Services records as these participants will have a personal experience of having such a record compared to participants in the other groups. This should be addressed in study materials such as participant information sheets.

## **Theme 2: Trust**

### **Professionals' recording affected by researchers accessing data**

Most professionals were unconcerned that entries they make into records related to child maltreatment would be 'judged' by researchers, and stated that this would not affect their recording practices. Some however conceded that this may not be true for all professionals. This last point is of course an assumption on the part of some of the professional participants, therefore less weight should be placed on this. Speculation in focus groups discussion can be

dealt with by encouraging participants to talk about their own views and experiences rather than what others *might* think.

### **Perceived acceptability of data collection**

There were discussions of the type of data collected that professionals felt would be more acceptable to the public. This is also discussed in the 'type of child maltreatment data collected' sub-theme above. Stevenson et al (2013) and El Emam et al (2011) had similar findings to those in the current study that there were concerns from professionals about future repercussions if patients believed their data had been used without their explicit consent, and that this may affect the patient–physician relationship. This was another newly emerging theme, the professionals were asked about their own feeling towards data collected but often instead gave their thoughts about the *perceived* acceptability of the public, they were speculating about how others would feel. The point in the paragraph above about assumptions made about others' views is also applicable to this this.

### **Attitudes towards researchers and data providers**

There was some suspicion about researchers and a general lack of understanding about the type of data researchers view. This was a sub-theme that did not appear in the topic guide but in hindsight was not entirely unexpected.

### **Organisation conducting the research**

Other researchers found that university research tended to be less trusted than clinicians but more trusted than pharmaceutical companies (1; 2; 26; 33; 37; 41). In findings similar to those in the current study, familiarity was an important concern for participants in the Stevenson et al (2013) study. Documentation carrying the NHS logo was an important factor in many individuals' willingness to be involved in research. This sub-theme was not discussed by the professionals group, but Perera et al (2011) and Stone et al (2005) found that although university or hospital based researchers were quite favourably viewed, not all professionals were happy to share information with them about patients or clients.

### **Data security**

In findings similar to those of Clerkin et al (2013) and Davidson et al (2013), some participants had concerns about the security of data transfer from the data providers to the researchers. Some of this concern arose from hearing negative stories in the news about personal data

being lost or stolen. Other researchers also found that news stories which depict data loss and security breaches in health care have alerted the public to data security concerns in the context of health information exchange (49; 50). The vast majority however of the mothers and care-experienced young people did not express security concerns and trusted the procedures that researchers would put in place to ensure data security. On the whole they preferred the method of data transfer to be online rather than through paper based records, which differs from findings of other researchers that concern is especially pertinent for electronic data or records (36; 40; 52). This may be because many of the participants in the current study were slightly younger (care-experienced young people and younger mothers) than those in the aforementioned studies and therefore have known nothing but electronic systems being used in everyday circumstances. Professional participants did not believe that there should be a difference between the security level of child maltreatment data compared to any other kind of personal data, and they were not particularly concerned with security of data. Others have however found that professionals' concerns about data governance were common, including data security, legal restrictions, and data quality (68; 69; 70). The care-experienced young people viewed child maltreatment data as more sensitive than other data; and so believed that there should be a higher level of security. In practice, some restrictions, such as allowing only certain members of the research team access to data and/or using anonymisation could be used to ensure a higher level of security for certain data items.

### **Data validity**

There were some concerns from professional participants that accessing the 'right' data would be difficult for researchers when collecting data on child maltreatment from records. This was a newly emerging sub-theme, was not discussed in the literature review for this chapter and was therefore not included in the topic guide. There was a strong feeling that Social Services records were the best place to collect any data on child maltreatment. Some professional participants had concerns about the objectivity of *other* professionals and that this may affect their recording of child maltreatment data. Concerns from the mothers and care-experienced young people included accuracy of the data and a belief that there was inaccurate data in medical and Social Services records, and that this may have an effect on any conclusions a researcher came to about them or their child.

### **Theme 3: Understanding**

#### **Researchers and child protection**

Many of the mothers and care-experienced young people believed that it was the duty of researchers to flag concerns about children if they noticed cases of maltreatment in data. There were concerns that researchers could not identify a maltreated child if the data were anonymised. This was a very interesting newly emerging sub-theme to the researcher and was quite unanticipated. Participants on the whole wanted anonymisation and yet want to be able to take action if abuse is detected by research, and these are, in general, incompatible.

#### **Understanding the focus groups discussions**

Similarly to the findings in the current study, Berry et al (2012) found that most parents had a poor understanding of the information sent to them regarding the purpose of a data linkage study. This perhaps should not be surprising on account of the complexity of many of the topics discussed in the focus groups and interviews. This sub-optimal understanding of the discussion topics, as well as being an important consideration in its own right, should be kept in mind when interpreting any of the findings of this study as opinions of participants could conceivably be different if all participants in each group had a firmer grasp of all of the concepts being discussed. Much of the participants' comments were very context dependent, and in a very complex context, it may be that several related factors are being considered (or not being considered or fully understood) by participants and interpreting their attitudes correctly is very challenging.

#### **Benefits of research**

There was much discussion about the benefits of collecting and linking child maltreatment data and whether these were clear. Nair et al (2004) found that potential participants often considered the balance of obtaining consent against the public benefit incurred by unrestricted research. Many other studies have found that members of the public believe that collecting and sharing data for research is important (32; 33; 34; 36; 43). Benefits of a research study could be relayed to potential participants as part of participant engagement. This is not simply about participants' understanding of concepts but also about providing them with concrete examples to draw upon.

### **Data Linkage sub-theme**

There was some discussion in the groups about the mechanics of linking anonymised datasets and how this could be done in practice. The main discussion related to this sub-theme however was related to the idea that data linkage may be more useful for clinical care and prevention of maltreatment rather than for research. More than one participant referred to cases in the media such as Baby P that they felt could be better prevented if organisations could access each other's data. Most of the participants were not too concerned about researchers linking datasets, this is a similar finding to Wellcome Trust (2013). These researchers however found that participants noted the benefits of linking data for research to increase knowledge and for the benefit of the public, and although the idea of linking data was on the whole uncontroversial in the groups in the current study, the benefits were rarely mentioned. It is possible that this could be explained by the fact that, as mentioned above, some participants did not have a full understanding of the concept and this may partly explain the lack of controversy surrounding it.

### **Characteristics of the participant**

The literature review on attitudes towards the collection and linkage of sensitive data discussed how certain characteristics of participants may make them more or less likely to consent. Some general observations about attitudes and participants characteristics are that younger participants (care-experienced young people and young mothers groups) did not seem to be more accepting of child maltreatment data being collected for research than the older participants (older mothers group and professionals). This is in contrast to some researchers' findings that younger people were more likely to consent to data from records being used in research (8; 11). Not all researchers found this however, others found that those who consented were more likely to be older (32; 36).

This finding is therefore more likely to be due to the nature of the data collected in this study and how that relates to the populations included i.e. care-experienced young people and younger mothers. Care-experienced young people and younger mothers had greater concerns on the whole about researchers accessing Social Services and maltreatment data. For the care-experienced young people this is likely to be because they themselves will have a Social Services record. Similarly, it has been found that potential participants with medical records that contain more stigmatising information are less likely to consent to data collection. Merz et al (1999) found that those who consented to data abstraction from their medical records were



more likely to have records that contained less sensitive or stigmatising information. Clerkin et al (2013) found that females in their study emphasised the risks of anonymised information from their medical records being used in research in relation to social discomfort and embarrassment.

Some researchers have found an association between consent preferences and employment or socio economic status (SES). Kass et al (2003) found in a study containing patients with various conditions including cancer and diabetes that those on a lower income were more likely to consent. In contrast to these findings, higher SES has been associated with higher consent rates (32). In the current study, those who are thought to have higher SES (professionals) were less concerned about researchers collecting and linking child maltreatment data than the other groups.

Many researchers have found that males are more likely to be consenters (2; 8;11; 31). On the whole males and females did not voice different attitudes in the groups containing males in this piece of research (care-experienced young people and professionals). This is similar to other research which has found that no significant differences between those who consented and those who did not in terms of demographic characteristics (12; 41). Al-Shahi et al (2005) found that consenters were similar to non-consenters in age, sex, and socioeconomic status. Kho et al (2009) found in their systematic review which looked at international studies there were no differences between consenters and non-consenters in age, sex, race, income, education, or health status. Caution should be taken however as males were not present in all groups in the current study.

### **3.4.2 Strengths and weaknesses of the study**

The strengths and weaknesses of using focus groups and interviews to answer the research question has been addressed in the procedure and piloting section of the methods section (section 3.2.4). A criticism of the current study is the omission of the views of fathers and social workers. There was an attempt to recruit social workers to take part in the professional group, however the researcher failed to obtain any social workers willing to take part. Including fathers and social workers, as well as other populations, in future qualitative work would enable researchers to gather data on their views and attitudes on the collection and linkage of maltreatment data for research. Another criticism of the study was that perhaps more could have been done to ensure a better understanding of the particularly challenging

concepts discussed at the focus groups. Although concepts were explained and scenarios presented to provide concrete examples, it was clear that some participants still did not understand the discussions. Perhaps the researcher could have checked understanding and meaning behind opinions and views as the discussion went forward. This has implications for the validity of the interpretation of the results. It should also be kept in mind that these were self-selective small groups from specific populations and so views may not be generalisable, however, the aim of the study was to explore views rather than produce generalisable results.

### **3.4.3 Data quality and limitations**

Many have criticised qualitative research for lacking methodological rigour (79), others have described qualitative research as being unscientific, exploratory, and full of bias (80).

To ensure rigour in quantitative research the principles of reliability and validity are applied. Reliability is the extent to which an experiment or study can yield the same result on repeated trials. Validity is an indicator that shows that something is measuring what it purports to measure (81). There has been much debate if these criteria can be adequately applied to qualitative research (82). Denzin and Lincoln (1994) argued that reliability and validity should not be used in qualitative research because they are central to the belief that there is an objective truth which can be measured and that this is incompatible with qualitative research. Others have argued that qualitative research should use the principles of reliability and validity to ensure rigour (83).

Some alternate methods to measure rigour in qualitative research have been proposed, and there is no accepted consensus about the standards by which to judge qualitative research. One of the most commonly used is Lincoln and Guba's (1985) concept of 'trustworthiness' which should be measured using four criteria: credibility, transferability, dependability and confirmability. The current qualitative chapter of this study was considered in relation to these criteria and this is explored below.

#### **Credibility**

Credibility is somewhat analogous to the concept of internal validity in quantitative research. The criteria involves establishing that the results are a true picture of the phenomenon under scrutiny (79), in this case that the results accurately reflect the reality of participants' experiences. Various techniques, have been suggested by Lincoln and Guba (1985) to ensure

and to demonstrate credibility, many of which have been utilised in this current qualitative portion of the study.

One is 'persistent observation', this is when the researcher explores details of the phenomena under study to a deep enough level to enable them to decide what is important and what is irrelevant, and focus on the most relevant aspects. The current researcher did gain an in-depth knowledge and explored various themes and topics that were most relevant by completing the literature review that served as the basis of the topic guides for focus groups and interviews conducted.

Another technique is 'triangulation', this involves using multiple data sources to aid better understanding; this is seen by some as a test for validity. This view is controversial however and assumes that there must be a weakness in one method which can be compensated for by another method (84). Triangulation can also be seen as a method to validate or verify and can be used to ensure that an account is rich and comprehensive (84). It may be the case that using different methods can facilitate deeper understanding. Researchers such as Patton (1999) have identified various types of triangulation. In the current chapter of the study the triangulation technique was utilised. Data were collected from more than one participant population (source triangulation) using more than one method (face-to-face and online focus groups, and telephone interviews) (methods triangulation). It should be noted however that although more than one method was used, these methods are still quite similar to one another compared to other methods of qualitative data collection for example observational approaches. Data should be viewed by using multiple analysts to review findings (analyst triangulation). This was achieved in the current research by utilising another researcher to review 15% of the data and also by ensuring that PhD supervisors reviewed the analysis plan and results.

A third technique is described as 'Peer debriefing'. This is the process of discussing the research with peers or superiors with the aim to hear other experiences and perceptions and discuss alternate approaches, as a sounding board for ideas and interpretation. Probing from peers may help researchers recognise their own biases. This technique was utilised in the current research both during and after data collection. Following each face-to-face focus group the facilitator and the co-facilitator would review the discussions held in the group and talk about our own experiences and perceptions of the discussion as well as any ideas had during

the discussion about ways to adapt the topic guide or the way topics were presented. An example of a change made after one of these discussions was that a new slide was included into the presentation given at the start of the focus groups to better illustrate what 'data' may look like to researchers. The analysis and results of the research was also discussed with PhD supervisors. Results were presented at conferences, including during data collection, when the analysis was still ongoing. This allowed peers to reflect and comment on the work and for the researcher to consider if changes needed to be made. Although discussion during analysis and later feedback from peers did not affect findings as such, it was of great assistance in thinking about how to present findings. As an example of this, it was noted at a conference that there was great interest in the online groups and how conducting a 'focus group' was possible online. A detailed rationale for the online asynchronous focus group methodology was therefore completed on this aspect and is presented in appendix 9.

A fourth technique is 'negative case analysis', this is the process of revising hypotheses with hindsight, and can be done through an iterative process of data collection. This involves searching for and discussing elements of the data that do not support or contradict hypotheses that emerge from data analysis. Topic guides can be changed over time using concepts and ideas from earlier focus groups and interviews that can be tested and then redefined, this is analytic induction (83). During the telephone interviews, the participants were asked more direct questions relating to themes already discussed in the online focus group. For example in the online focus group it was mentioned that it was possible that some professionals felt that a researcher judging their entries and any subsequent actions or inactions related to child maltreatment in records, and interview participants were probed for any further thoughts on this. This allowed the researcher to test some of the themes and emerging hypotheses from the earlier focus group.

A fifth technique is 'referential adequacy', this is when a researcher earmarks a portion of the data to be archived but not analysed, and then the data analysis is conducted on the remaining data to develop preliminary findings. The researcher then returns to this archived data and analyses it as a way to test the validity of the findings. The researcher cannot state that this technique was used in the current study. A similar function was performed however as analysis begun after the collection of the first focus group, a preliminary thematic framework was created from this point, and then the rest of the focus group and interview data were analysed

against this as and when it was collected. The thematic framework was modified a little from the first draft but did not change drastically.

Finally, a sixth technique that can be utilised to demonstrate credibility is 'member checking'. Member checking is when data, analytic categories, interpretations and conclusions are tested with participants from whom the data were obtained. This is different to 'peer debriefing' in that participants from whom the data were collected are consulted and not peers or supervisors. This technique is somewhat controversial however and has been criticised by some researchers including Angen (2000) and Sandelowski (1993). Reasons for criticism include the fact that participants may disagree with researchers' interpretations, and then the question of whose interpretation should stand becomes an issue. Participants may also change their mind about an issue, forget what they have said previously, view issues differently with the passage of time, or the data collection process itself may impact their views, this can lead to confusion. Participants may also go along with the member checking process to be 'good' participants and agree with an account to please the researcher. Some of these criticisms are borne from the issue that member checking relies on the assumption that there is a fixed truth of reality that can be accounted for by a researcher and confirmed by a respondent (88), and many do not believe this to be the case. Those with a nonfoundationalist view argue that understanding is co-created and there is no objective truth or reality (87). In spite of these criticisms this technique is important as it provides researchers opportunity to understand fully the participants' views, allows them to volunteer additional information, and allows researchers an opportunity to summarise preliminary findings and participants the opportunity to hear and confirm preliminary results (79). Member checking was utilised during the telephone interviews, as these were conducted with participants from the online focus groups to clarify and expand on the views given the focus groups. During the face-to-face and online focus groups the facilitator and co-facilitator would ask participants to repeat earlier views, and paraphrase responses to assess if they had correctly understood. At the end of each face-to-face focus group a summary of the discussion was read out by the co-facilitator and participants were asked to confirm if this was accurate.

Credibility could also be demonstrated using other techniques than the six listed above. For example the researcher could consider whether participants gave honest accounts and views during the discussions. There is always a risk in research that participants will give 'socially

acceptable' answers rather than being honest. To address this the researcher ensured that participants who were approached to take part were given opportunities to refuse to participate, this ensured that the research involved only those genuinely willing to take part and prepared to offer data freely. This of course affects sample characteristics and therefore the range of views expressed. At the beginning of each focus group and interview participants were reminded to be as open as possible and it was explained to them that there were no right or wrong answers to any of the questions. The researchers' independent status was emphasised, and that they were interested in gaining participants' honest views even if they felt that this was contrary to what the researcher would like to hear. This technique was deemed to be successful, as there were many accounts of participants giving their views that could be viewed as less socially acceptable. For example, some said they believed that researchers 'should' be allowed to collect child maltreatment data without consent on account of consent bias, however they would not provide consent for a researcher to collect data on them or their child in this way. Participants were assured that the results were anonymous and it was made clear to participants that they could withdraw at any point without providing a reason for doing so. The researcher attempted to establish rapport to encourage honesty, this is described in detail in the methods section (section 3.2.6). It may also be the case that the online focus groups and telephone interviews offered more anonymity which may encourage honesty.

### **Transferability**

Transferability refers to the extent to which the findings can be said to be applicable to other contexts. This is analogous, but according to Lincoln and Guba (1985), very different to, the concepts of 'external validity' or 'generalisability'. The main technique to utilise to ensure transferability is 'thick description'. This is the process of describing a phenomenon in enough detail as to enable the researcher to adequately evaluate the extent to which the conclusions drawn from the results are transferable to other times, settings, situations, and people. The findings of the current piece of research may not be generalisable to all populations and was quite narrowly focused, which is appropriate for the purposes of the current study. Future work may focus on gathering the views of fathers, and social workers, these are groups who would have interesting opinions but were not represented in the current research. Four face-to-face focus groups were conducted, one online focus group and two telephone interviews. The researcher believes that these groups provided enough detail and rich data to adequately draw conclusions, some of which may be generalisable. A criticism of the current piece of

research is that it is unknown exactly how many potential participants were *approached* to take part in this work, this part of recruitment was completed by staff members from the groups where the participants were recruited or by a 'snowballing' technique. It may be the case that those who agreed to take part were somehow different from the eligible population, and given the absolute numbers of participants concerned and the numbers of groups this is to be absolutely expected. Quotes from participants have been provided in the results section of this chapter with the aim of allowing other researchers to be able to decide for themselves how far the results may be transferrable to other settings.

### **Dependability**

Dependability refers to showing that the findings are consistent and could be repeated, this is analogous to the concept of 'reliability' in quantitative research. A technique that can be utilised to achieve this is 'inquiry audit'. This is the process of having a researcher who is not involved in the research process examine both the process and product of the research study, to evaluate dependability. In the current study dependability can be evidenced. The face-to-face focus groups and telephone interviews were digitally recorded and then transcribed by the same CTR staff member, and the online focus groups transcript was downloaded directly from the website, thereby providing consistency of method. The researcher read the transcripts while listening to the recordings immediately after they were transcribed to ensure accuracy. The researcher then coded and devised the themes and as previously mentioned a member of the qualitative team in CTR performed a 15% review of the data. Analysis and results were discussed with PhD supervisors.

### **Confirmability**

Confirmability refers to the extent that the researcher maintains a degree of neutrality to ensure that the findings of the research are shaped by the participants and not researcher bias, this is similar to the concept of 'objectivity'. The risk of the results being shaped by the researchers' personal bias has been mitigated to some extent by the techniques listed above i.e. the qualitative researcher performing a 15% review of the data, the PhD supervisors providing input and advice during analysis, and results being presented at conferences which allowed peers to provide feedback on the findings and alternative viewpoints. Before starting data collection the researcher was aware of best practice in terms of methods and running focus groups and conducting interviews. Open rather than closed questions for example were used. Some of the themes in the qualitative chapter were unanticipated and novel, this

evidences the fact that the findings of the researcher were shaped by participants and not the researcher.

The technique of keeping an 'audit trail' can also be used to evidence confirmability. This is ensuring that there is a transparent description of the methodology from start to finish and accurate records are kept of this. The researcher developed themes from the very beginning of analysing the data and before all of the data had been collected, the researcher kept detailed notes of where the major themes and sub-themes were evidenced in the transcriptions. Listening to the transcriptions also allowed the researcher to review her facilitator skills and role in the conversation. Regular notes were made during analysis which allowed the researcher to reflect and improve her skills as time went on as a facilitator. 'Reflexivity' and 'Triangulation' can also be used as techniques (79). Triangulation is discussed previously under the 'credibility' heading, and reflexivity is the process of considering the effect of the researcher, at every step of the research process. How this was achieved is described in great detail in the methods section of this chapter (section 3.2.6).

#### **3.4.4 Conclusion**

This chapter explored mothers, care-experienced young people and professionals attitudes towards collecting and linking routinely collected sensitive data, particularly maltreatment data, for research purposes. Utilising focus groups and interviews to collect data three major themes were identified, consent, trust, and understanding. The findings may be useful to understand potential participants' views and concerns when designing information sheets and considering how to relay information to potential participants when asking them to consent. Participants clearly had strong views about what was and not acceptable in terms of researchers collecting sensitive data. A more co-productive approach to research design could therefore be taken by involving members of the public in the design of research studies from the beginning. Ensuring that researchers listen to their views on which data items are acceptable to collect from which sources, whether data should be anonymised, and how data should be transferred.

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## **Chapter 4 - Building a Clearer Picture of the Relationships Between Markers and Risk Factors of Maltreatment and Later Maltreatment Outcomes**

### **4.1 What are the markers and risk factors of child maltreatment?**

#### **4.1.1 Introduction**

The aim of this review is to examine and bring together the literature on risk factors and markers for maltreatment. Markers and risk factors for maltreatment have been discussed widely in the literature. No attempt however has been made to combine these in order to produce a comprehensive list. Markers of maltreatment are any maltreatment-related *features* that indicate the presence of maltreatment. Risk factors of maltreatment are any factors that may be associated with *causing* child maltreatment. This review includes both studies that have *demonstrated* various risk factors and markers to be associated with maltreatment, and also those that are *suggested* to be associated with maltreatment. This review will serve as the introduction to the quantitative section of this research study and will inform a selection of quantitative outcomes. This review will draw on a broadly international evidence base. See appendix 1 for a detailed plan of how this literature review was conducted.

#### **4.1.2 Markers of maltreatment**

There are many markers for maltreatment reported in the literature. Markers of maltreatment can include physical signs of abuse or injuries (1; 2), clinical presentations other than injuries, and signs of maltreatment visible in the emotional, behavioural, interpersonal or social functioning of a child or parent.

Being aware of markers of maltreatment can be very useful for clinicians and can trigger further investigation if there are concerns for a child (2).

Some of the markers of maltreatment discussed here can also be considered to be risk factors for maltreatment. For example an unusual or frequent pattern of presentation at Accident and Emergency (A&E) (3; 4) can be said to be both a marker and a risk factor for maltreatment.

Many of the markers discussed below are typically recorded in medical records. In the UK the information contained in the medical record is coded according to the International

Classification of Diseases (ICD) and Related Health Problems system developed by the WHO (3). These are rigid coding requirements and can result in identifying very specific cases but are not very sensitive. Collecting data on markers in this way is likely to result in an underestimate of the true number of cases of markers of maltreatment (4).

#### **4.1.2.1 Physical signs of abuse and injuries**

When a child presents with an injury, factors that are indicative of maltreatment and should be considered include vague or inconsistent explanation for the injury, providing no explanation at all, or the explanation is discrepant with clinical findings or child's developmental stage (1; 6; 7; 8). Other markers indicative of maltreatment include no witnesses to a child's injury, a sibling being blamed for the injury, a delay between injury and seeking medical attention without credible explanation, other injuries being present, evidence of neglect, previous safeguarding concerns for child or siblings, the injury is unusual (for example a thermal injury from a stun gun), or there have been repeated attendances with injuries (7; 8). Maltreatment may also be considered if the parent gives evasive or aggressive responses when quizzed, the parent or child is displaying adverse or inappropriate behaviour, or there is a concern with the parent-child interaction (1; 7). This section will provide a combination of collated guidance and some specific examples of research evidence regarding specific types of maltreatment. Some collated guidance includes evidence-based guidelines by The National Institute for Healthcare Excellence (NICE) rather than clinical suspicions.

#### **Head injuries**

A head injury may be a marker for child maltreatment. Abusive Head Trauma (AHT) is variously described as shaken baby syndrome (when concerning infants), violent head trauma, non-accidental head trauma, or inflicted head trauma. It can be difficult to measure as there is a lack of consensus about the definition, as well as the codes of the International Classification of Diseases (ICD) to be used for its characterisation (9; 10; 11; 12; 13). The main signs depicting AHT include subdural hematoma, brain edema, and retinal haemorrhage (14; 15; 16; 17). NICE Guidance (2017) advises that a head injury indicative of maltreatment includes intracranial injury in the absence of confirmed accidental trauma or known medical cause with no suitable explanation, the child is under three years old, there are also retinal haemorrhages or rib or long bone fractures or any other injuries, or there are multiple subdural haemorrhages with or without subarachnoid haemorrhage with or without hypoxic ischaemic damage to the brain (damage due to lack of blood and oxygen supply).

Brown and Malone (2003) reviewed the medical records of children under four years old admitted for head injury to a hospital in Vermont between 1993 and 1999. They found that of the 85 records reviewed, 14% had head injuries due to maltreatment. 42% of these suffered serious central nervous system injury compared to only 10% among the unintentionally injured. Lee et al (2012) conducted a population-based cross-sectional study in NHS hospitals in England in children under five years old admitted with a head or neck injury or fracture. Data were collected from HES between 1997-2009 and ICD-10 codes were used to determine if the admissions were maltreatment related. Of the 260,294 childhood admissions for fracture or head or neck injury, 3.2% (8,337) were maltreatment-related (2). Half of the maltreatment-related admissions occurred in children older than one year, and 63% occurred in children with head injuries without fractures or intracranial injury (2). González-Izquierdo et al (2010) collected data from HES in the NHS in England between 1997-2009 on injury admissions of children under five years old that had been coded to denote maltreatment, or codes that indicated markers of maltreatment. They found that the type of head injury was strongly predictive of maltreatment in infants but not in older children. In infants, codes for maltreatment were recorded eight times more frequently for intracranial injury than for head injuries without skull fracture or intracranial injury. Almost two-thirds of admissions for intracranial injury in infants occurred in children under six months of age, and 19% of these had codes recorded for maltreatment (1).

## **Fractures**

Fractures are the second most common injury caused by child physical abuse, bruises being the most common (19). These have been found to be present in about a third of all physical abuse cases (20). NICE Guidance (2017) recommends suspecting child maltreatment if a child has one or more fractures in the absence of a medical condition that predisposes to fragile bones, or an absence of a suitable explanation. In infants and toddlers maltreatment is likely to be the cause of between 12% and 20% of all fractures (21). Children with fractures due to maltreatment tend to be younger. Carty and Pierce (2002) found in a retrospective study of 467 children presenting or referred with a suspicion of non-accidental fractures that 91% were less than two years old. Worlock et al (1986) found that 80% of children with abusive fractures were less than 18 months old, whereas 85% of all *accidental* fractures occurred in children older than five. Fractures are fairly uncommon in children under one (23; 24), and when they are present, they are a strong indicator of maltreatment (24). The kinds of fractures that may

be indicative of maltreatment include fractures of the metaphyseal, rib fractures, scapular fractures, vertebra fractures, spinous process fractures, sternal fractures, fractures of the outer end of the clavicle, digital fractures in non-ambulant children, fractures of different ages (i.e. from varying points in time), multiple fractures, bilateral fractures, epiphyseal separations, complex skull fractures, and any unusual fractures (8; 22; 25; 26; 27). It must be kept in mind that although some fracture types are indicative of maltreatment no pattern can exclude maltreatment (8).

Bulloch et al (2000) studied the causes and clinical presentations of rib fractures in infants. They reviewed the medical notes of all children under one years old in a three year period admitted to hospitals in Ohio, US and Manitoba, Canada. There were 39 with rib fractures, of which 32 (82%) were thought to be caused by maltreatment (24). In the study referenced above Lee et al (2012) found that of 260,294 childhood admissions for fractures or head or neck injury, 3% (8,337) were maltreatment-related. Valvano et al (2009) reviewed the notes of children with fractures seen between 1997-2005 in a Chicago hospital by the child abuse team. They identified a total of 150 cases of fractures, 93 (62%) of which were maltreatment related. They also found that the femur was the most common fracture location in both maltreated and non-maltreated groups, and rib fractures were significantly more common in the maltreated group (28). Valvano et al's finding of 62% of fractures being maltreatment-related are in stark contrast to Lee et al's of 3%. This may be because these are a selected group of children referred to the child abuse team in the hospital. More research may need to be done on the usefulness of fractures as a marker for maltreatment.

### **Thermal injuries**

Burns and scalds, also known as thermal injuries, may also be indicative of child maltreatment. Thermal injuries can occur because of neglect or physical abuse, and most inflicted thermal injuries are scalds, contact and flame burns (7). NICE Guidance (2017) advises doctors to consider maltreatment if there is no suitable explanation for burns and scalds including if the child is not independently mobile, if the injury is on any soft tissue area that would not be expected to come into contact with a hot object in an accident, or it is in the shape of an implement (for example a cigarette burn is deep and circular) (7). Other signs of maltreatment may be injuries that indicate forced immersion for example scalds to limbs, symmetrical injuries, and scalds with sharply delineated borders (3). Scalds of uniform depths should also be considered as when a child is deliberately immersed in hot water the burn will be of

uniform depth with less splash marks (7). NICE Guidance (2017) also advises doctors to consider child maltreatment if a child presents with a cold injury, for example, with swollen or red hands or feet, or hypothermia.

Geoghegan (2013) performed a retrospective audit in the Emergency Department of Waikato Hospital in New Zealand to review patients under the age of 15 who were admitted with burns from January 2010-July 2012. They found that the most common type of burn sustained was a scald followed by contact burn. Just under half of these cases were suspected to be due to maltreatment as the Child Protection Service within the hospital received referrals regarding 49% of the cases (29). Andronicus et al (1998) found in a retrospective review of 507 consecutive admissions to a tertiary burns unit that 1% of burns were identified as intentional injuries while 6% were attributed to neglect. The non-accidental burns did not always have distinguishing features except that they were more likely to be symmetrical. Geoghegan's findings differed greatly from those of Andronicus, this suggests more research should be done on burns as a useful marker for maltreatment. Thombs (2008) reviewed records from 15,802 paediatric admissions to burn centres across the US and found that 909 children had burns due to suspected maltreatment. Compared with children without suspected maltreatment-related injuries, children with suspected maltreatment-related injuries were significantly more likely to have larger total body surface area burns, and more third-degree total body surface area burns, to have been admitted with a scald, and to have required intensive care, but were less likely to have incurred an inhalation injury. Thombs (2008) also found that children with suspected maltreatment-related injuries were four to five times more likely to have a burn on their buttocks and three to four times as likely to have a perineum burn. They were less likely to have a burn to the head or neck or anterior trunk, but significantly more likely to have a posterior trunk burn. Children with suspected abuse were over two times as likely to have a lower extremity burn, and almost three times as likely to have both lower extremities burned. They were less likely however to have a burn to only one of their lower extremities (30). Children with accidental burns were significantly more likely to have an upper extremity burn (30).

### **Bites and Bruises**

Both bruises and human and animal bites have also been reported as markers of maltreatment. A characteristic adult human bite mark consists of oval or circular marks that may form two opposing arcs, and the inter-canine distance measured will be greater than

three centimetres. Other children can also be responsible for bites, and several of these would suggest supervisory neglect (7). Neglect may also be present if a child is seen with an animal bite (3). Bruising is likely to be the commonest physical injury caused by child maltreatment (7). Research has found that bruises indicative of maltreatment tended to be found away from bony prominences on padded areas of the face or body (such as the eyes, ears, buttocks). Additionally, bruises indicative of maltreatment include multiple bruising and those that occur in clusters, bruising in the shape of a hand, ligature, stick, teeth mark, grip or implement, bruising if the child is not independently mobile, and if there is no satisfactory explanation or medical condition for the bruising (3; 31; 32; 33; 34). Valvano et al (2009) reviewed the notes of children with fractures seen between 1997-2005 in a Chicago hospital by the child abuse team. They found that head or neck bruises were the most common bruise location in both maltreated and non-maltreated children and that torso bruising was more common in maltreated children (28).

#### **Lacerations, abrasions and scars**

NICE Guidance (2017) suggests that a clinician should consider maltreatment if there is no suitable explanation for lacerations, abrasion and scars, especially those on a child who is not independently mobile. If they are multiple, symmetrical, on areas usually protected by clothing, on the eyes ears or side of face, or on the neck, ankles and wrists that look like ligature marks (3).

#### **Ano-Genital signs, symptoms or injuries**

Markers that may indicate that a child has been sexually abused include if there is a genital, anal or perianal injury with no suitable explanation, or persistent or recurrent genital or anal symptom (for example bleeding or discharge that has no medical explanation) (3). The guidance suggests that sexual abuse should also be suspected if a child has an anal fissure, is suffering from constipation that is not due to a medical explanation such as Crohn's disease, has a gaping anus, dysuria or ano-genital discomfort that is persistent or recurrent and has no medical explanation (such as a urinary infection), or evidence of one or more foreign bodies in the vagina or anus (3). Other markers include if a child is younger than 13 and has a sexually transmitted infection. Particularly if there is no clear evidence of mother-to-child transmission during birth or non-sexual transmission from a member of the household or blood contamination, or has an underage pregnancy (3). It must be kept in mind however that for most sexual abuse victims the results of the physical examination are normal (35; 36).



### **Other physical injuries**

Other physical markers of child maltreatment that have been found in the literature include epistaxis (37), traumatic duodenal perforation (38), injuries to the torso (39; 40), and lower extremity injuries (41). NICE Guidance (2013) advises to be aware of any physical injuries that are present in the absence of major confirmed accidental trauma or a known medical explanation, including birth-related causes. A delay in presentation may also be indicative of maltreatment (3).

Boscardini et al (2013) reviewed the medical notes of all children under two who were admitted with epistaxis in a region of Italy over two years and found ten cases of epistaxis, four of which had attendances for head injury or facial trauma. This may point to a relationship between epistaxis and neglect, and epistaxis and domestic accidents (37). Bowket and Kolbe (1998) studied seven case reports of children admitted to a hospital in Auckland, New Zealand between 1980-1994 with traumatic duodenal perforation and found that all perforations were due to either blunt trauma due to road traffic injury (a lap seat belt injury) (two cases) or due to child maltreatment (five cases) (38). DeRoux and Prendergast (2000) reviewed all child-abuse cases at the New York City Medical Examiner's Office over a seven year period. There were 121 homicides relating to child maltreatment with 64 sustaining blunt injuries to the head and torso, of these 50 sustained severe injuries to the torso. Five infants (10%) had adrenal laceration, a marker of major blunt-force injury (39). Coffey et al (2005) reviewed records of children admitted to a paediatric trauma centre with lower extremity injuries from 1998-2002 and found that among the 5497 records reviewed, the incidence of abuse was 104 of 4942 (2%) children 18 months or older, and 175 of 555 (32%) children younger than 18 months. They concluded that among children 18 months or older, abuse is an uncommon cause of lower extremity trauma whereas in children younger than 18 months, lower extremity injuries, particularly fractures, are highly associated with maltreatment (41).

#### **4.1.2.2 Clinical presentations other than injuries**

Clinical presentations other than injuries that may be markers of maltreatment include a seemingly fabricated or induced illness, inappropriately explained poor school attendance, dental decay, poisoning, evidence of submersion, and gastrointestinal complaints (3; 42). van Tilburg et al (2010) found that lifetime CPS allegations of sexual abuse and self-report of ever

having been psychologically, physically, or sexually abused were associated with abdominal pain at age 12 years, and self-reported maltreatment was also associated with vomiting.

NICE guidance advises that a fabricated or induced illness should be suspected if a child's symptoms and signs only appear or reappear when the parent or carer is present, if symptoms are only observed by the parent or carer, if there is an inexplicably poor response to prescribed medication or other treatment. A fabricated illness should also be suspected if new symptoms are reported as soon as previous ones have resolved, if a history of events is given that is biologically unlikely, if the child's normal daily activities are being compromised, or if the child is using aids such as a wheelchair more than would be expected for a medical condition that the child has (3). NICE Guidance also suggests that neglect should be considered if a child has persistent infestations, such as scabies or head lice, a child's clothing or footwear is consistently inappropriate, a child is persistently smelly and dirty, a child is malnourished including 'failure to thrive' (3; 6). Another feature of neglect is inadequate supervision. Examples of this are a failure to administer essential prescribed treatment for the child, there is a failure to attend essential follow-up appointments that are necessary for the child's health and wellbeing, or there is a failure to engage with relevant child health promotion programmes including immunisation, health and development reviews, and screening (3).

Other markers of maltreatment are if there is evidence of poisoning, for example if there are unexpected blood levels of drugs that have not been prescribed, reported or biochemical evidence of ingestions, the child was unable to access the substance independently, repeated presentations of ingestions in the child or other children in the household, or abnormally high levels of sodium in the blood (3).

Poor oral health and dental neglect is a marker for child maltreatment (3; 43). Dental neglect may exist in isolation or may be a proxy indicator of broader neglect in children (44). This suggests that neglect can then be very specific to certain types of childcare responsibility. Indicators of dental neglect include repeated non-attendance for dental check-ups, attendance for emergency pain relief more than once, and requirement for dental extractions or care under general anaesthetic more than once (43; 44; 45). Abused and neglected children have higher levels of tooth decay than the general population. A case control study in Canada found that five year old children with maltreatment history experienced almost twice the number of

caries lesions as controls (46). A US study found that maltreated 13 year olds had eight times as many untreated, decayed permanent teeth than controls (47).

#### **4.1.2.3 Emotional, behavioural, interpersonal and social functioning**

There are some emotional and behavioural states in children that may be markers of maltreatment. These include a departure from what would be expected for the age and developmental stage and not explained by a known stressful event such as a bereavement (3). These may include recurrent nightmares, extreme distress, oppositional behaviour, becoming withdrawn or withdrawing communication, being fearful or aggressive, having low self-esteem, and habitual body rocking (3). Other behavioural or emotional states indicative of maltreatment include indiscriminate contact or affection seeking, over-friendliness to strangers, excessive clinginess, persistently resorting to gaining attention, demonstrating excessively 'good' behaviour to prevent parental or carer disapproval, failing to seek or accept comfort when significantly distressed, coercive controlling behaviour, very young children showing excessive comforting behaviours when witnessing parental or carer distress, emotional responses not in proportion to a situation or developmental stage for example a temper tantrum in a school-aged child, and a response to a health examination or assessment in an unusual way (3).

Other markers of maltreatment that may indicate maltreatment include self-harm such as cutting, scratching, picking, biting or tearing skin to cause injury, pulling out hair or eyelashes, and deliberately taking non-prescribed or prescribed drugs at higher than recommended doses (3). Other markers include disturbances in eating and feeding behaviour such as food hoarding, secondary wetting (wetting when a child has been dry for a prolonged period e.g. six months) that persists with no medical explanation, deliberately wetting, encopresis or repeated, deliberate smearing of faeces (3). Behavioural markers of maltreatment can also include running away from home or care, and sexualised behaviours including if a pre-pubertal child displays sexual behaviours, or a young person's sexual behaviour is indiscriminate, precocious or coercive (3).

#### **4.1.2.4 Parent- or carer-child interactions**

Finally, some parent- or carer-child interactions that may be markers for maltreatment include a carer showing negativity or hostility towards a child, rejecting or scapegoating of a child, and developmentally inappropriate expectations including inappropriate threats or methods of

disciplining. Other parent- or carer–child interactions that may be markers are exposure to frightening or traumatic experiences including domestic abuse, using the child for the fulfilment of the adult's needs such as in marital disputes, failure to promote the child's appropriate socialisation, punishing a child for involuntarily wetting, being emotionally unavailable or unresponsive, and refusing to allow a child or young person to speak to a healthcare professional on their own (3).

#### **4.1.3 Risk factors for maltreatment: Models of the causes of child maltreatment**

Factors that may be associated with *causing* child maltreatment have been widely discussed in the literature. These have focused on psychiatric or psychological models of maltreatment centred on the individual such as characteristics of the perpetrator, and occasionally the child. They have focused on the perpetrator being either criminally inclined or psychiatrically disturbed, or on the relationship between the abuser and abused (e.g. 48; 49; 50). Other models have focused on the family (e.g. 51). Sociological models have focused on external factors and the context that increase the risk of maltreatment (e.g. 52; 53). None of these models have dominated as each only focused on one aspect or determinant (54), and there is no single, necessary or sufficient cause to child maltreatment (50), rather many risk factors usually interact (55).

Ecological models were proposed to include the impact of risk and protective factors from the individual, the family and the community and culture, and how these determinants are nested within one another (50; 56; 57; 58; 59; 60). Four different system levels are included in ecological models. The ontogenic level is concerned with individual factors, this is how an adult, mostly a parent, grows up to behave in a manner that is neglectful or abusive (56; 61; 62). The microsystem level is related to the immediate family and household (56; 61; 62). The exosystem level concerns those social systems in which the family is embedded, but not intimately related to, for example the local community (56; 61; 62). Finally, the macrosystem level concerns the cultural beliefs and values in a particular society (56; 61; 62). Other ecological models include the developmental-ecological model (50), concerned with risk and protective factors for child physical abuse only. It specifies three conceptual domains. The developmental-psychological domain includes factors that caregivers and children 'bring with them' to the family setting, the immediate domain includes factors in the family environment and the way caregivers interact with their children, and the broad domain includes neighbourhood characteristics, available resources, involvement in the neighbourhood, and

access to peer networks (50; 63). Cumulative risk models have also been proposed (e.g. 64; 65). These models assume that the more risk factors are present, irrespective of their nature, the higher the potential for child maltreatment (66).

Although these ecological models have been proposed, the tendency in the literature is still towards studying variables in small groups or separately (60). The research literature does not yet enable us to determine precisely which variables, or targets of intervention, are most likely to prevent or remediate child maltreatment or which are most easily or effectively modified (50).

Numerous child, parent, and societal risk factors for child maltreatment have been identified (60). It should be kept in mind however that children with the same risk and protective factors can have very different experiences of maltreatment (67). It is very difficult to synthesise different research studies which may use different definitions and methodology in researching risk factors (67). Maltreatment can occur without any of these risk factors being present; with only one risk factor; or with multiple risk factors (68). Guidance has suggested that risk factors should act as prompts to practitioners to consider how the particular risk factor or set of indicators is impacting on a child (69). Offering increased support and prevention efforts rather than screening and monitoring families where risk factors are present has been suggested (70). Some risk factors have been the subject of research studies that attempt to explain *why* that particular factor contributes to risk, such as impacting on neurobiological development. Other risk factors have simply been identified, such as certain minority ethnic children being over and under-represented in the care system (67).

#### **4.1.3.1 Caregiver-or family-related risk factors**

##### **Caregiver who was a victim of maltreatment**

Research has found that having a parent with a personal history of maltreatment is a risk factor for child maltreatment (62; 71; 72; 73; 74; 75; 76; 77; 78; 79; 80). Witnessing parental interpersonal violence during childhood has been found to lead to the perpetration of child maltreatment (81). Although literature reviews have consistently found this relationship (82; 83; 84), there has been wide discrepancy in rates, most likely due to methodological differences in studies (63; 82).

Explanations for these findings include that the impact of childhood maltreatment on a parent may have affected their own neurobiological development, particularly if the maltreatment occurred early in life. This may lead to psychological, behavioural and learning problems (85; 86). Lamela and Figueiredo (2013) proposed that depression (88), dissociation (89), mental health problems (90), trauma symptoms (91), and social information processing bias (92) can also occur after maltreatment and these things may put a parent at risk of maltreating their own child. Childhood maltreatment could also lead a parent to alcohol or drug abuse (93). In a meta-analysis Norman et al (2012) found associations between child maltreatment, adult drug abuse, and negative mental health outcomes. Mapp (2006) suggest that mothers who have been sexually abused may be less comfortable with the intimate aspects of parenting, such as changing a nappy. This can lead to increased neglect as well as greater stress than comparison mothers (95). Mothers who experienced childhood maltreatment may also be uncertain of normative child development and possibly having unrealistic expectations of their children which has also been found to be a risk factor for maltreatment (96).

### **Caregiver mental health issues**

Parental mental health issues have also been found to be risk factors for child maltreatment (63; 76; 97; 98; 99; 100; 101; 102; 103), independently of their own experiences of maltreatment as a child. This has been found specifically in relation to depression (59; 63; 77; 80; 104; 105; 106; 107; 108; 109) as a risk factor for physical abuse specifically (110; 111). It has been suggested that depressed mothers have a family environment that is more hostile and rejecting, they may have difficulty communicating with their children and experience more negative interactions with them (112). Lyons-Ruth et al (2002) found that mothers who were depressed were more likely to smack, shout at, and feel aggravated towards their child. Parental anxiety (77; 114), and poor parental self-esteem (97; 99; 115) have also been related to the perpetration of child maltreatment.

Dawson et al (2000) found in a review of the literature that parental mental illness is likely to reduce attachment with a child. Jutte et al (2014) suggested that parents with mental health issues may exhibit suicidal or self-harming behaviour which may also be risk factors for maltreatment. Jutte et al (2014) reviewed cases where a child had died or was seriously injured and found that parental mental illness, often in combination with other problems, was present in more than 50% of cases in England and Northern Ireland, and 43% of cases in Scotland (117; 118; 119).

### **Caregiver substance abuse**

Studies have found that caregiver substance abuse is a risk factor for child maltreatment (63; 66; 77; 100; 102; 104; 111; 120; 121; 122; 123; 124; 125; 126). Sedlak et al (2010) found that out of all documented child maltreatment reports, 11% of cases involved alcohol abuse by a perpetrator and 11% involved drug abuse. Parental abuse of drugs or alcohol, or both, has been found in more than half of parents who neglect their children (127). A survey of social work departments in the UK in 2002 showed that parental substance misuse was found to be a concern among 25% of children who were subject to a CPP (128), and StatsWales (129) reported that parental substance misuse was a concern in 26% of cases for children on the Child Protection Register in Wales. Reviews of cases where a child has died or was seriously injured identified parental substance misuse in 42% of such families in England (130), in 64% of such families in Scotland (119), and 58% of such families in Northern Ireland (118). Vogeltanz et al (1999) interviewed US adult women about their experiences of sexual abuse and also collected data on family and background variables. Women who grew up with both biological parents were more likely to report sexual abuse if their mothers drank but their fathers did not, and women with drinking fathers and abstaining mothers were more likely to report sexual abuse if by age 16 their biological family was no longer intact (131). A discrepancy in parents' drinking patterns may indicate conflict and tensions in the marriage (132). This is likely to reduce parental emotional resources and attention which may leave children less supervised and make children more vulnerable (133). Sebre et al (2004) found in a multi-country study that parental overuse of alcohol was significantly correlated with emotional and physical abuse in Latvia, Lithuania, and Macedonia, and emotional abuse only in Moldova. Some researchers have also found that smoking during pregnancy (135; 136), and mother being a heavy smoker (114) were risk factors for child maltreatment.

There is a direct link between mothers who abuse drugs and alcohol whilst pregnant and child maltreatment, as this is both a risk factor and is directly abusive (67). This can lead to impaired brain development in the foetus (137), congenital malformations, low birth weight, poor growth and premature delivery (138). Maternal substance misuse during pregnancy can also lead to a baby experiencing withdrawal after birth which can lead to irritability, inability to sleep, poor feeding and weight gain, and regurgitation (139). Alcohol misuse can lead to parents being unable to care for their children adequately or provide practical and emotional support to a child (139) and may affect the family's functioning (140).

Substance abuse is unlikely to be an isolated risk factor, and research has found that parents who misuse substances often suffer other adversities such as domestic violence or poor mental health (141).

### **Young parenthood**

Young parenthood has been found to be a risk factor for child maltreatment (63; 74; 76; 77; 97; 99; 110; 135; 136; 143; 144; 145; 146; 147; 148). Sidebotham et al (2001) found that 27% of mothers of children placed on a child protection register were aged less than 20 at the birth of the child, compared to 5% of all mothers of children. Sidebotham et al (2001) found similar results for the father, with nine percent being less than 20 years compared to one percent overall.

Age may reflect on parenting abilities, experience, and knowledge. Stier et al (1993) found that parental age was mostly associated with neglect and younger parents may be especially at risk for neglect because of socio economic determinants. The family may not have the physical resources to meet the child's needs, or through a lack of awareness or appreciation of the child's needs. Social isolation may be one explanation of why young parental age is a risk factor. Young parents may have less contact with peers or have poorer support networks (63).

### **Family composition**

Certain family composition characteristics have been found to be risk factors for child maltreatment, including having more children in the family (102; 104; 105; 135; 136; 150; 151), having large families and crowded households (97; 99; 102; 107; 143; 147; 148; 152; 153; 154; 155; 156; 157), single parent families (76; 77; 99; 110; 147; 148; 153; 154; 158; 159), or unmarried mothers or one-parent female headed households (114; 135; 136; 160). Some research has found that having children in close succession is a risk factor for child maltreatment. Wu et al (2004) found that shorter pregnancy interval was a risk factor, and Zuravin and DiBlasio (1996) found this association was stronger for neglect than abuse. Smith and Alder (1991) found however that maltreated children had fewer siblings. Brown et al (1998) found that the presence of a stepfather, and parental death were also risk factors. Early separation from mother has also been found to be a risk factor for child maltreatment (74; 99).



van IJzendoorn et al (2009) collected data from all 17 Dutch child protective services agencies on 13,538 cases of certified child maltreatment in 2005 and compared the family composition of the maltreated children to a large national representative sample of the Netherlands Kinship Panel Study (NKPS). They found that larger families, one-parent families, and families with a step-parent were more at risk of child maltreatment. The opposite trend however was found for adoptive families, with children from these families being less at risk for maltreatment post-adoption (161). Having more children in a family increases the stresses for the parents, there are likely to be more quarrels and fights between siblings, and more externalising behaviours in need of discipline (162). For single parents, the combination of multiple caretaking tasks and struggling for an income may lead to stress which can increase risk for harsh discipline and child maltreatment (163). For families with a step parent, van IJzendoorn et al (2009) suggested that a lack of a genetic tie to the offspring may decrease parental care efforts, as in the parental investment theory (164). It has been found that on average, step relationships are more distant, discordant, and less satisfying to both parent and child than genetic relationships (165). Sariola & Uutela (1992) similarly found that families with a stepfather was a risk factor for child maltreatment, and Coohey (2000) found families with one non-biological parent to be a risk factor.

A child being in the care system has also been found to be a risk factor for subsequent maltreatment, these children have been found to be specifically vulnerable to sexual exploitation and abusive partner relationships when older (167; 168). Epstein (2002) reported that having a previous child removed from the home was a risk factor for maltreatment. Biehal et al (2014) found that a significant minority of children in care will experience maltreatment by those who are responsible for them. Children in care can experience maltreatment by carers, other adults or peers, poor standards of care, maltreatment disguised as treatment or behaviour modification techniques, and emotional damage caused by placement instability (67; 169).

Although not strictly under the heading of 'family composition', Epstein (2002) found that parental history of incarceration was a risk factor for child maltreatment.

### **Parent education level**

Another parent related risk factor for child maltreatment is lower level of education (62; 76; 77; 99; 104; 135; 151; 170; 171). Many studies have found mothers who did not complete high

school to be more at risk of maltreating their child (105; 114; 135; 150). Euser et al (2010) found in a prevalence study of child maltreatment in the Netherlands that used data gathered from child maltreatment cases, reported by professionals, and cases registered by the Dutch CPS that very low parental education was a risk factor for child maltreatment. Using data from The National Longitudinal Study of Adolescent Health, a prospective cohort study in the US that used interviews with adolescents about prevalence of self-reported maltreatment during childhood Hussey et al (2006) found that there was an association between parental education and physical neglect. Adolescents with a parent with less than a high school education, was a high school graduate, or completed some college were more likely to report physical neglect than children of college graduates. Sidebotham et al (2001) found that parents with lower educational attainment were more at risk of having a child on the child protection register, and that this was especially true for neglect. They suggested that this may be due to a lack of knowledge and awareness of a child's needs. Parent educational level may also be a proxy for SES (62). Other researchers have found that both low parental Intelligence Quotient (IQ) (98) and learning disabilities (102) also to be risk factors for maltreatment.

### **Parenting and family functioning**

Factors relating to parenting and family functioning have been shown to be risk factors for child maltreatment. These include parenting factors such as using harsh or physical discipline and less use of verbal reasoning (77; 99; 174; 175). Other researchers have found that a lack of experience or competence as a caregiver (75; 136; 150; 176), providing less than adequate prenatal care (135), and less knowledge of child development leading to unrealistic expectations from young infants and children are risk factors for child maltreatment (176; 177).

Some aspects of parent personality can also be risk factors for child maltreatment including poor anger expression and management skills and poor frustration tolerance (99; 115), and lack of impulse control (174).

Poor parent-child relations have also been found to be risk factors for maltreatment (77; 110; 148; 178; 179). Including a tendency to attribute negative intent to a child's behaviour (177), and being critical of a child (77). Stith et al (2009) found in a literature review that out of a variety of risk factors investigated that the strongest for neglect was a problematic parent child relationship and a parent viewing a child as a problem. Parents who maltreat have also been

found to have less empathy; (176; 180) and to express less positive affection and warmth toward their children (76; 175).

Some researchers have found that factors related specifically to fathers as perpetrators to be risk factors for maltreatment. These included fathers who felt they were ineffective as parents, a shorter duration of father involvement in child's life, a father having less involvement with household tasks (181), and low father warmth (99). Vogeltanz et al (1999) interviewed US adult women about their experiences of sexual abuse and also collected data on family and background variables. Respondents who felt they had rejecting, unloving fathers were more likely to report sexual abuse (131). Alexander (1992) suggests that insecure interpersonal attachment in a family, such as between a daughter and the father who seems to reject her, may increase the risk of sexual abuse in that family.

Parental stress, poor stress management, and negative perceptions of life events have also been found to be risk factors for child maltreatment (74; 77; 80; 97; 99; 107; 109; 110; 179; 183). Economic stress has been linked to hostile parenting practices (184).

Sidebotham et al (2001) found that parents of maltreated children perceived their *own* childhoods as being unhappy and had poor relationships with their own parents (77; 185). This may be because they were more likely to have divorced or separated parents, were separated at some point from their mother, or (in the case of mothers) their father had not been present throughout their childhood (62). Fathers who maltreated their children were more likely to have been in care themselves. Of those fathers who had been in care, four percent had a child placed on the child protection register, compared to a baseline rate of one percent (62). Bowlby's attachment theory has been used to explain these findings. Parents who did not have the benefit of a secure attachment with their parents are unable to form a secure relationship with their own children (62; 186).

Certain family dynamics have also been found to be risk factors, including if there is conflict in a family or a lack of family cohesion (97; 187). Poor family functioning is also a risk factor, family functioning is the degree to which a family runs smoothly as a unit (61). Mian et al (1994) found that the families of abused girls had less harmony and stability in the marital unit and were headed by less competent parents. Paavilainen et al (2001) found that family functioning in maltreating families is lower on many family dynamics including individuation,

mutuality, flexibility, stability, communication and roles. Communication in families that maltreat tends to be less open (188), and maltreating families have poor stability and less security (151). Stith et al (2009) found in a literature review that of the many risk factors investigated the strongest predictor of physical abuse was high family conflict and low family cohesion.

#### **Intimate partner violence and/or poor parental relationship**

Intimate partner violence (IPV) has been consistently found to be a risk factor for child maltreatment (73; 102; 176; 189; 190; 191; 192). In addition, among welfare recipients (193) and child welfare cases (194), experience of IPV has been shown to approximately double a parent's likelihood of maltreatment perpetration (195). Appel and Holden (1998) found in a literature review a range of co-occurrence of IPV and child abuse from 20% to 100%, with a median of 59%. Annerbäck et al (2010) conducted a population-based survey in 2008 amongst all the pupils in three different grades (n = 8494) in schools in Södermanland County, Sweden. Pupils were surveyed about their exposure to violence and their experiences of parental IPV. They found that of the pupils who reported that violence had occurred between the adults in their families, 58% reported that they themselves had been hit once or more (64). Jutte et al (2014) reported on research that reviewed cases where a child had died or was seriously injured in England; Northern Ireland and Scotland and found that IPV was present in more than 50% of cases (117; 118; 119). Radford et al (2011) found that more than 34% of children who lived in a family where IPV was present had been maltreated.

It should be noted that as well as being a risk factor for maltreatment, IPV between adults in the home is considered to be psychological or emotional child abuse in its own right (67).

As well as IPV, other research has found a poor relationship between parents or other family members (74; 152), parental conflict, maternal dissatisfaction, and poor marital quality (99; 77; 107) to also be risk factors for maltreatment.

#### **4.1.3.2 Child-related risk factors**

##### **Ethnicity or race**

There has been some research showing that children from black and mixed ethnic backgrounds (where these are minority groups, for example in the US) are disproportionately over-represented on child protection registers, in the care system and in the children in need

statistics, and when self-reporting child maltreatment experiences (173). Children from Asian ethnic backgrounds however are disproportionately under-represented in the same categories (67; 122). Some researchers in the US found that Hispanic children were less likely to be maltreated compared with white and black children (102). Other researchers have found no race differences (when in a minority group) in maltreatment rates at all (153)

These findings may be due to social inequalities rather than ethnicity or race. Some researchers have found that in the US there is a significant interaction between race and dependence on public assistance and that non-whites tend to be in lower SES groups (198; 199). These findings may also be due to racial discrimination, language barriers, community and cultural norms and practices, and inadequate or inappropriate services, for example services not taking action for fear of upsetting cultural norms, specifically for minority groups (200). It has been suggested that the complexity and subjectivity involved in assessing child maltreatment cases has raised concerns that the overrepresentation of black children among substantiated victims may be attributable to bias in reporting and in the handling of reported cases (201; 202). Drake et al (2011) and Laskey et al (2012) however did not find this to be the case when tested. Drake et al (2011) used data from national child welfare and public health sources to compare the race of children who have experienced maltreatment from substantiated sources (official child welfare organisations) with those from key public health outcomes not subject to the same potential biases (e.g. general infant mortality). They found that racial differences in victimisation rate data from the official child welfare system were consistent with known differences for other child outcomes. Laskey et al (2012) asked paediatricians from the American Medical Association's Masterfile to rank the degree to which the hypothetical injury was accidental versus abuse and if they would report the injury to CPS. They presented the paediatricians with one of four randomly assigned versions of a fictional clinical presentation of a child that described an event in an 18-month-old child resulting in a fracture where the child was either black/white and had a high SES/low SES. They found that victim's race did not have an effect on a diagnosis of abuse, however, abuse was more likely to be diagnosed in patients with low SES (204).

Some other studies have found that parents born abroad are also a risk group for child maltreatment (171; 205). It has been suggested however this is likely due to poor integration and lower SES rather than land of origin (64). Annerbäck et al (2010) however found in a Swedish study that there was an association between foreign born parents and physical abuse,

and this association remained after adjusting for other variables including socio-economic variables such as parental employment and housing (64). Other explanations for this finding include social isolation or lack of extended family support (206), or a different view of child rearing (207).

### **Health service use by child**

Some researchers have found that children with higher health service use are at higher risk for maltreatment. Guenther et al (2009) examined if maltreatment was associated with A&E visits in children under 13 who had been abused matched with controls and found that children who had been abused were almost twice as likely as controls to have had an A&E visit previous to this. Outcome measures included number of outpatient visits, number of A&E visits, the frequency of injury related diagnoses, the frequency of nonspecific diagnoses that have been previously linked to abuse, and the number of changes in a child's primary care provider (208). Friedlaender et al (2005) did a case-control study among US children in receipt of Medicaid (a public health insurance program for low-income families) to compare patterns of health service use among maltreated children in the year before a first maltreatment report versus children not maltreated. They found that the health service use of 157 children with substantiated maltreatment differed from controls. 16% of maltreated children had a change in primary care provider, compared with 10% of controls. Maltreated children were 2.62 times more likely to have had one previous change in primary care provider and 6.87 times more likely to have changed providers twice or more in the year before their first maltreatment report.

Some researchers have found however no association between use of some health services and maltreatment. Friedlaender et al (2005) found in their study that there were no differences in number of outpatient visits, number of A&E visits, the frequency of injury related diagnoses, and the frequency of nonspecific diagnoses that have been previously linked to abuse in maltreated children and controls. Leaman et al (2010) identified a sample of 220 children aged zero to 12 years from two child protection registers in the Shropshire area and examined whether they were more likely to have attended A&E in the two years before registration compared to a control group, and found no differences between the groups in A&E attendance.

### **Age of child**

Another child related risk factor for maltreatment has been found to be younger age (27; 28; 40; 143; 152; 211; 212; 213; 214; 215), specifically being under 3 years old (160). González-Izquierdo et al (2010) found that the proportion of acute injury admissions with codes for maltreatment was higher in infants than for older children. Leventhal et al (2012) collected data on hospitalisations due to serious physical abuse of children 0-18 in the US and found that the incidence of serious physical abuse was highest in children under one. Vaithianathan et al (2013) used a data set of integrated public benefit and child protection records for children born in New Zealand between 2003 and 2006 to develop a risk algorithm of child maltreatment. The final model included 132 variables and found that of all the children who were substantiated for maltreatment by age five years, 83% had been enrolled in the public benefit system before age two years (217). Other researchers have found however that older children were more likely to be at risk for emotional abuse (160).

Windham et al (2004) suggest that younger children are at more risk for maltreatment because they are more difficult to care for, for example they cry a lot. An alternative approach is to consider that maltreatment represents a continuation of assault that begins in utero, for example with maternal smoking, drinking or drug taking.

### **Child disability, illness, or development**

Disability has been found to be a risk factor for child maltreatment (99; 218; 219; 220). Jones et al (2012) found in a meta-analysis of cross-sectional, case-control and/or cohort studies that disabled children were more likely to be victims of maltreatment. This has been found to be especially true in boys (222). Children with poor health and chronic or long-term illness (219), developmental delay, and prematurity or low birth weight have also been found to be at risk of maltreatment (76; 125; 135; 150; 219). Sullivan and Knutson (2000) used data from a Nebraska schools database that included educationally relevant disabilities, Social Services records, foster care review boards records, and police records and found an association between disabilities and maltreatment. There was a 31% maltreatment rate among children with disabilities in contrast to nine percent for nondisabled children, disabled children were 3.4 times more likely to be victims (219). They also found that children with disabilities tend to be maltreated at younger ages and were more likely to be male (219). Neglect was found to be the predominant form of maltreatment, followed by physical abuse, emotional abuse, and sexual abuse (219). Svensson et al (2011) found that children ages 10, 12 and 15 in Sweden

with self-reported chronic conditions also self-reported more physical abuse. Sylvestre and Mérette (2010) included 68 severely neglected children between 24 and 36 months of age and their mothers in a cross-sectional study and found that the prevalence of language delay was significantly higher in this subgroup of children than in the population as a whole.

Reasons that disabled children are more at risk may include a lack of awareness of risk by service providers, indicators of abuse being mistakenly attributed to a child's impairment, a lack of effective communication with the child and the family, a reluctance to believe that disabled children are maltreated (67). Factors related to the child's needs including dependency on a carer, impaired capacity to resist or avoid abuse, and impaired ability to communicate that abuse has occurred have also been suggested (67). Other suggested reasons include that a child with disabilities may put a strain on parenting or the household, psychological or economic (225). It must be kept in mind however that some of these factors could be about failure to intervene or support children being maltreated rather than solely being reasons for maltreatment in the first place.

Some researchers have found that difficult child temperament or behaviour may elicit abusive behaviour from caretakers (97; 99; 147; 150; 152; 179; 215; 219; 226; 227; 228; 229; 230; 231; 232; 233; 235). Others have found that a parent *perceiving* the child to be a problem is a risk factor for maltreatment (74; 77; 97; 110; 115; 147; 231; 232). Crying patterns have also been found to be associated with child maltreatment (125), as have childhood anxiety or withdrawal (99), low verbal IQ (99), and poorer mental developmental scores (150).

Jaudes and Mackey-Bilaver (2008) examined specific health conditions that placed young children at risk for maltreatment. They included children from Illinois in the US enrolled in Medicaid, with one or more of three chronic conditions; chronic physical illness, developmental delay, and behaviour or mental health conditions (225). They found that for children under the age of six, children with behaviour or mental health conditions were 1.95 times more likely to be maltreated than those without this condition. Children with chronic physical health conditions were 1.1 times more likely to be maltreated, whereas children with developmental delay were not more likely to be maltreated. Furthermore, if the child had a prior history of maltreatment before age three and was also diagnosed with a behavioural health condition, that child was 10 times more likely to be maltreated again (225). Therefore,



children with behavioural or mental health conditions from low-income families were most likely to be maltreated (225).

### **Child gender**

Child gender is a risk factor for child maltreatment (236). Females are more at risk for sexual or emotional/psychological abuse and males are more at risk for physical abuse (114; 126; 153; 218; 222; 237; 238), with gender difference being more apparent at younger ages (211). May-Chahal and Cawson (2005) interviewed UK young adults about maltreatment experiences and found that boys were more likely to experience physical abuse, girls were more likely to experience emotional abuse, and girls were also much more likely to experience sexual abuse (239). Radford et al (2011) reported that victims of physical violence by non-resident adults were more likely to be male, whereas females were disproportionately likely to be sexually abused by non-resident adults. They also found that female adult respondents reported that they had experienced significantly higher rates of severe maltreatment by a parent or guardian in childhood (18%) compared to reports by males (12%). Scher et al (2004) conducted a telephone survey that consisted of a questionnaire addressing childhood maltreatment and demographic questions. They found that more men had experienced a form of childhood maltreatment (41%) than women (30%). However, women who did report maltreatment were more likely than men to report multiple forms of maltreatment, and women were more likely to report sexual abuse and emotional abuse, and men were more likely to report physical neglect (240). Other researchers have found that boys are at greater risk of neglect (211; 222).

Child gender and age have a complex relationship with rates of maltreatment. McKenzie and Scott (2011) used maltreatment codes and looked at one year of Australian hospitalisation data for children under 18 years of age. They found that while males comprised the larger proportion of hospital admission overall (55%), females comprised the larger proportion of hospital admissions where a maltreatment code was assigned (58%) (5). Physical abuse was most common for males and sexual abuse was most common for females. In females younger than one year of age however, the largest proportion of cases with a maltreatment code were assigned an 'other abuse' code (the authors do not provide examples of what this may be). In females aged one to five and six to nine, the largest proportion of cases were assigned a 'physical abuse' code (5). For males the age group with the highest proportion of cases with a maltreatment code assigned was the 10-14 year olds, compared to females where the 15-17 year old age group had the highest proportion of maltreatment codes assigned (5).

Results remain mixed however as Sedlak and Broadhurst (1996) found that boys in the US were more likely to be emotionally abused. Raiha and Soma (1997) found that teenage girls (from a sample of participants who later joined the US Army) were more at risk for physical abuse, emotional abuse, and sexual abuse. Both Timmer et al (2002) and Whipple and Webster-Stratton (1991) have found that overall that boys more likely to be abused than girls.

#### **4.1.3.3 Social or extra-familial risk factors**

##### **Social support**

Families that are more socially isolated and receive less social support are more likely to maltreat their children (73; 74; 76; 77; 97; 107; 109; 150; 154; 176; 241). Connell-Carrick and Scannapieco (2006) found in a random sample of 148 child protective services cases that families who were substantiated for neglect had poorer social climates, including both isolation and negative relationships within the family. The perception of social support seems to play an important role. Hashima and Amato (1994) found that, for low-income parents, perceived social support was negatively associated with parent's reports of punitive behaviour. The positive impact of social support can be protective and that may help parents address other factors that may be impacting on their ability to parent their child safely (83).

##### **Neighbourhood and community**

Factors such as neighbourhood poverty, instability and economic disadvantage have been found to be risk factors for child maltreatment (243; 244; 245; 246; 247). Klebanov, et al (1994) and Ernst (2001) found that poorer neighbourhoods are associated with less maternal warmth and a poorer quality physical home environment. Coulton et al (2007) completed a literature review on the relationships between neighbourhoods and child maltreatment and found that child maltreatment cases are concentrated in disadvantaged areas and a number of socio economic characteristics of neighbourhoods correlate with child maltreatment (247). Risk factors that have been found to be correlated with child maltreatment include child-care burden. For example the ratio of children to adults in the household (243), residential instability (246), overcrowding (249; 250), and per capita density of liquor stores and bars (251; 252). Ben-Arieh (2010) conducted a study that focused on the relationship between community characteristics and maltreatment in Israel and found an association between unemployment, population change and rate of new immigrants in a town, number of single-parent families, and child maltreatment. Much of this research indicates that socio economic

aspects of a neighbourhood and poverty may be responsible for the higher risk of child maltreatment.

Ben-Arieh (2010) says that notwithstanding the growing acceptance of the ecological model, research on the relationships between maltreatment and communities and neighbourhoods lags behind research on individual and family correlates. Research of neighbourhood effects is complicated by the difficulty of defining a neighbourhood and the corresponding reliance on census block groups in research. It is also the case that most of the research has been in western societies and in urban settings (253). There are two research frameworks that can be used to relate neighbourhood to maltreatment, the first concerns social disorganisation and second focuses on the ecological perspective discussed above (253). The social disorganisation theory examines the relationship between geographic concentrations of social problems and social processes within neighbourhoods thought to contribute to social control, such as network ties, shared norms, collective efficacy, institutional resources, and routines (254). Other work has focused on the consequences of concentrated poverty in central city neighbourhoods and the accompanying social isolation from the mainstream as a risk factor in many poor outcomes including maltreatment (255). This has led to interest in how these neighbourhoods can be strengthened (256). Social disorganisation theory however does not specify how neighbourhood characteristics influence behaviours of children and families (247).

### **Socio-economic status**

Many researchers have found a correlation between family low SES, sometimes measured by looking at who is in receipt of benefits, and child maltreatment (59; 77; 99; 102; 136; 143; 144; 146; 152; 153; 154; 160; 176; 215; 257; 258; 259; 260). Others have found a correlation between unemployment and child maltreatment (134; 147; 148; 151; 158; 172; 232; 257; 261), with employment being found to be a protective factor (76; 262). Connell et al (2007) examined child, family, and case characteristics that impact rates of re-referral to CPS. They used data on all closed CPS investigations for the State of Rhode Island in the US between 2001-2004 and found that low family SES was the strongest predictor of re-referral. Approximately 40% of families were identified as receiving public assistance or having financial problems, which were associated with a 325% increase in risk of re-referral to CPS compared to families without low SES (263). In the UK the number of lower-income families who have had contacts with social care are disproportionate to those who are not on low incomes (67). This may of course also be for reasons other than child maltreatment. González-Izquierdo et al

(2010) found that the proportion of all acute injury admissions with any codes for maltreatment or markers of maltreatment were strongly associated with deprivation and were recorded more than twice as often for children living in the most deprived quintile compared with the least deprived.

The association between socio-economic status and child maltreatment may be explained by stress factors associated with unemployment and low income or unemployment (264) including stressors such as overcrowding (176).

Many researchers have found that low SES or income to be specifically linked to neglect. Shook Slack et al (2005) used data from the Illinois Families Study (IFS), a 6-year longitudinal panel study of families who were receiving welfare in late 1998 to assess parent characteristics, and CPS reports to measure neglect. Data to construct a measure of income and poverty were taken from the Illinois Department of Employment Security and the Illinois Department of Human Services. They found that perceived material hardship and infrequent employment were predictive of child neglect (175). Hussey et al (2006) used data from The National Longitudinal Study of Adolescent Health to investigate the relationship between socio demographic characteristics and maltreatment. Adolescents from low-income families faced an increased risk of supervision neglect, physical neglect, and contact sexual abuse. Supervision neglect was significantly associated with immigrant generation, which may be a proxy for SES. First-generation youth were 1.55 times as likely as third-generation-plus respondents to report being left home alone as a child when an adult should have been with them (173). It is important to note however that an inverse relationship has been found between income level and virtually every form maltreatment, regardless of whether this was reported to agencies (153).

The relationship between poverty and maltreatment is not linear, but has been described as 'circular and interdependent' (265).

#### **4.1.4 Critical appraisal**

This review examined and brought together the literature on risk factors and markers for maltreatment. Research has been more extensive on some markers and risk factors than others, for example, parental substance abuse has been more extensively studied than parent or carer-child interactions. It is also interesting to keep in mind that although there has been

extensive research on some markers and risk factors, there is still no agreement on how useful these are for flagging or predicting child maltreatment. Regardless of how extensive the current research base, all *possible* markers and risk factors of maltreatment, collected in the Building Blocks Trial (266; 267) and Building Blocks: 2-6 Study (268) will be included in the analyses. It is also important to note that quality criteria have not been applied to included studies, and that some of these are markers and risk factors of maltreatment that are suggested rather than proven. Critical appraisal of the literature in this review is explored further below.

The research evidence in this review originated from studies utilising various methodologies. A hierarchy of evidence can be used to rank the relative strength of results obtained from studies (e.g. 269). The highest-ranking evidence tends to come from systematic reviews, particularly those containing a meta-analysis. Systematic reviews with meta-analysis of RCTs are particularly high ranking. In the current review, three systematic reviews with meta-analysis were included (83; 94; 221). A review by Stith et al (2009) contained various types of studies including RCTs, Jones et al (2012) and Norman et al (2012) reviewed observational studies (cohort, cross-sectional and case-control) only. Even though Stith et al (2009) included studies with lower quality as well as higher quality evidence, they coded each study on quality. The vast majority included were of 'average' or 'above average' (almost 80%) quality. Removal of the poor studies from their analysis did not significantly alter effect sizes and so they were retained for the final analysis by the authors. A criticism of the Stith et al (2009) review however is that they only searched one online database whereas the other authors reviewed multiple sources of literature. Some publication bias is likely to be present in all systematic and literature reviews, including the current review. Including more than one literature source is a method that can be used to minimise this.

Other authors conducted systematic reviews but did not perform meta-analyses (e.g. Piteau et al, 2012). Others completed literature reviews that were not conducted systematically. Both Coulton et al (2007) and Lopes et al (2012) conducted literature reviews but included very little detail of the search strategy and made no mention of more than one author reviewing the literature. Policy and practice literature were also included in this review. Most of these are evidence-based guidelines, some of which are based on systematic reviews, rather than clinical suspicions.

Few RCTs were included in this review, with some exceptions, including Laskey et al (2012). It should be noted that evidence-based, minimum sets of recommendations for reporting are used in RCTs (CONSORT statement) and systematic reviews and meta-analyses (PRISMA statement). The inclusion of these statements was variable. Laskey et al (2012) did not include a CONSORT statement in the publication of their RCT. Norman et al (2012) however did include a PRISMA statement in their publication.

Cohort studies are considered to be lower ranking in the hierarchy of evidence when compared to systematic reviews or RCTs. Some cohort studies were included in the current review (e.g. Mersky et al, 2009). Although considered lower in evidence quality these studies sometimes benefit from very large sample sizes, for example, Sidebotham et al (2006) included over 14,000 participants in their study. Observational studies were also included in the current review. Smith and Alder (1991) for example conducted a case control study including 45 hospitalised abused children to assess risk factors for maltreatment. Observational studies may be considered a weaker form of evidence, although they can however offer real-world insights.

It may be interesting to note where some variables were only really identified in studies from the lower hierarchy of evidence base. Sidebotham et al (2006) and Shook Slack et al (2005) found that parents who maltreat express less positive affection and warmth toward their children (76; 175). These are the only two studies found demonstrating this association, both of which are cohort studies. This may be a weaker form of evidence for this association compared to, for example an RCT, finding something similar. In a similar vein it is may also be useful to draw attention to variables that have only really been identified in one or a small number of studies. This is because the association between these variables and maltreatment may be more speculative than one(s) that has been repeatedly demonstrated in several studies, including in a systematic review. As an example, there are a wealth of studies that have found an association between parent education level and maltreatment, but very few to have found low parental Intelligence Quotient (IQ) (98) and learning disabilities (102) to be risk factors for maltreatment.

As well as the size of the sample included, whether the sample is representative should be considered. Not all studies in this review included representative samples, e.g. Raiha and Soma (1997) used a sample of US army family member children. Some however did use samples

drawn from the general population including Sullivan and Knutston (2000) who included 50,278 children enrolled in public schools in Nebraska. Some studies utilised clinical samples which tended to be very small indeed. Boscardini et al (2013) included just 10 cases in their study, and Bowket and Kolbe (1998) studied just seven case reports. Small samples in studies may limit the ability to precisely show whether a variable is related to a particular maltreatment outcome.

In addition to using observation there was considerable variation in the literature in how data were collected. Some collected data via self-report (e.g. Chaffin et al, 1996), and some via formally collected data (e.g. Coohy et al, 2000). Data collection from self-report has been extensively covered in chapter two, and data collection from formal sources will be explored in the next literature review in this chapter. There was also some variation in the tools used to collect the data. Many of the studies included in this review utilised validated tools to capture data, which may produce higher quality evidence. Many for example used the Child Behaviour Checklist (e.g. Kinard, 1995, Whipple and Webster-Stratton, 1991). Others used less well validated measures, for example, Appleyard et al (2005) measured physical violence towards mother by partner using a scale derived from interviewer notes taken from interviews with mothers.

Finally, some consideration should also be given to whether the data were analysed appropriately. On the whole suitable tests were used to analyse the data, for example non-parametric tests were used when data were not normally distributed (e.g. Mian et al, 1994). Some studies however suffered from a lack of information which made coming to such conclusion difficult. Laskey et al (2012) for example did not include confidence intervals when providing results, therefore information about direction and strength of effect was missing.

The purpose of this review was to produce a comprehensive list of markers and risk factors of maltreatment which will serve as the beginnings of the quantitative portion of this study. This will ultimately address the third objective of the study, that is to investigate how a variety of data sources can be combined to build a clear picture of confirmed maltreatment, markers of maltreatment, and risk factors of maltreatment for children in the Building Blocks cohort. It will also address the fourth and fifth objectives i.e. investigating which risk factors and markers predict different maltreatment outcomes, varying in severity, and exploring how markers and risk factors predict maltreatment outcomes using case studies. The next literature review will

focus on the collection, linkage, and governance issues related to routinely collected data for research purposes in the UK.

## **4.2 What are the collection, linkage, and governance issues related to routinely collected data for research purposes in the UK?**

### **4.2.1 Summary**

This literature review will introduce the reader to the collection, linkage and governance issues for routinely collected data in the UK. As illustrated in previous literature reviews data on risk factors and markers of maltreatment as well as formally collected data on maltreatment events can be collected from routine records. This review was conducted systematically and will educate the researcher as well as the reader by reviewing current concerns and considerations that affect the use of routine data. This is also to set this work in its broader methodological and governance context. This is in preparation for the next phase of this research study, i.e. the quantitative phase where data from routine records will be utilised. See appendix 1 for a detailed plan of how this literature review was conducted.

### **4.2.2 Using routinely collected medical electronic data for research**

Over recent years there has been greater use of electronic systems that capture individual records in health and social care service delivery (270). Electronic data collected routinely are now being used for secondary purposes, including for research (271). This is a topic that is growing in interest in the UK (272; 273). This literature review will focus on clinical data routinely collected from medical records in the UK NHS as most of the literature is based around medical routinely collected data (as opposed to, for example, data collected from social care records). Routine data can also be collected from a variety of other sources including from Department of Education datasets. Data from both the NHS and Department of Education datasets will be utilised in the analyses in the remainder of the chapter.

In a literature review focused on the use of routinely collected patient data for research, Foster and Young (2011) found that there was a general assumption amongst the public that the use of routine data collected from medical records for research was beneficial to society.

Large public bodies such as the NHS collect and store data electronically on a very wide range of the UK population (274), and this has opened up many possibilities for research. A report by the UKCRC (2007) indicated that the use of routinely collected electronic data can provide



benefits for all types of clinical, public health, and health services research. The data also allows for data linkage and data sharing on a national basis (273). Electronic records are particularly useful for research as they are searchable, *can* allow remote access, and can be interrogated (273).

This methodology can be a faster and less expensive way of obtaining data compared to more traditional data collection methods such as prospective experimental research (273; 275). Datasets include records from patients with diverse demographic characteristics (276). Data may be far more abundant than data generated in traditional clinical trials (274; 275), which typically involve smaller patient numbers (277). Often this sort of data collection is the only method possible when controlled trials are not possible for ethical or other reasons (6). When these data are collected by the NHS, they are likely to reflect the entire population, or at least those with that particular clinical condition of interest. This will likely enhance the precision of any statistical analyses (54; 274). Data can be collected on patients over their entire lifetime (274; 276).

Although routinely collected data are very useful for research, the ability to *link* to this data at an individual level is imperative (278). This is probably more true however for some research questions than others. Aggregate unlinked data can still be of value. Data or record linkage has been defined as ‘a process of pairing records from two files and trying to select the pairs that belong to the same entity’ (279). Data linkage allows researchers to link within and between a variety of data sources, to assess the completeness of datasets, to validate research findings, and to enhance participant follow up rates (278; 280). Health data linkage research centres have been established worldwide, including in Australia (281), North America (282; 283) and the UK (284; 285). Current attempts in the UK to link routinely collected datasets include The SAIL databank (Secure Anonymised Information Linkage) which was established in Wales using a variety of datasets from health and social care service providers (Lyons et al, 2009). The SAIL databank has aimed to develop an accurate matching process between various datasets to create a unique Anonymous Linking Field (ALF) to person-based records to make the databank ready for record linkage research studies (278). The use of data linkage in research studies has increased vastly in recent years (286). Bohenski et al reported in 2010 that there had been an almost six fold increase in data linkage studies in the preceding two decades.

Researchers have identified a variety of research areas that could benefit from routinely collected data including the natural history and development of diseases (271; 275; 287) and the opportunity for disease surveillance (275; 276; 285). The causes of diseases can be studied; as well as the value of health care interventions; the equity of health care; and trends in the use of health care (275; 276; 287), and even the study of child maltreatment (289) as is the case in this current research study. Putman-Hornstein et al (2013) state that in the context of studying child maltreatment, routine data have the potential to provide relatively low-cost, longitudinal information that show interactions between risk (and protective) factors. Using clinical data for research can optimise the reach, success and efficacy of disease prevention, disease management, and public health strategies and programmes (290). These data could also be used for Clinical Decision Support Systems (291) and can be used to study the role of patient education (271). Findings of research using routinely collected data can help make public health decisions, and these sorts of data are especially valuable during public health emergencies (276). Using routinely collected data for research contains real experience and therefore the research conducted using this data can answer questions to improve real experience (275). Research using routine data can also detect unexpected phenomena and patterns or uncover differences amongst subpopulations that may not be included in a prospective experimental study (275). The data collected can also be used to refine research questions, generate hypotheses, and identify potential participants for research (275). Another benefit of using routinely collected clinical data for research is that it is often possible to conduct the research without participants' explicit consent or involvement (275). This can reduce participant burden and anxiety, and can reduce costs.

#### **4.2.3 The governance of collecting and linking routinely collected data in the UK for research**

Data collection about individuals is a particularly sensitive issue. The collection, storage, use and sharing of data about individuals are governed by laws and regulations (292). The laws and regulations are there in order to protect information that can be linked to individuals from being seen and used in ways that could be perceived by the individual as intrusive or damaging (292). The governance regarding the secondary use of data is variable across and within countries (271). This section will therefore focus on governance related to the UK. The section will describe some current legislation as well as include some reflections from researchers about the challenges around legislation and interpretation, and the challenges of accessing data. The reader should keep in mind that the information contained here is time-sensitive as

legislation is being constantly updated. This section is not intended to provide a comprehensive picture of all UK legislation regarding collecting and linking routinely collected data for research, but rather focuses on the most pertinent themes.

There has been some literature published regarding ethical and governance issues related to using routinely collected data for research purposes. Much of the literature however is not empirical but derives from policy and practice (293). Foster and Young (2011) note that the majority of the literature is written by clinicians, health researchers and government advisers, and the language used is often strong and forceful with regards to legislation complicating the research process and therefore putting the benefits to be gained from this research at risk. On the whole this pattern is repeated in the media e.g. Brown et al (2008) searched the content of UK national newspapers over an 18-month period and found that most articles mentioned using patient data for research did so without controversy. They reported new scientific research and when they *did* report 'controversies', these focused on the issue of legislation hampering research.

Some researchers have suggested that that governance models in the UK are preventing the optimal use of data for research. Some have suggested that the restrictive nature of governance models employed by data controllers is a consequence of an ambiguous legislative framework in the UK (295). This is because each routinely collected dataset has its own set of governance regulations and these vary depending on the type of data in the dataset, who the data guardian is, and the parameters of the data collection (271; 295). There is a difference in governance regulation between patient identifiable data, where a variable exists that can be used to identify a participant, and sensitive data. In practice however the definition of the two types of data are variable, even with the same data controller (296).

Some routinely collected NHS data can be used without consent for audit purposes or process evaluation, but not for research (295). From a governance perspective however, Curcin et al (2012) suggest that most of the observational or prospective research that needs consent to be carried out is not very different from service evaluation which does not require consent. They also suggest that governance does not distinguish between observational research and other kinds of experimental research (295). Clark and Findlay (2005) argue however that a distinction can be drawn between personal data that patients should reasonably expect to be accessed by other health professionals for a direct health-related purpose, and data accessed

for non-care related reasons. The actual difference therefore is the purpose to which the data are being put rather than the forms of data being used. While audit can therefore be considered to be an element of usual care, health services research remains supplementary to usual care (298).

In the UK there is no consistent guidance on when during the process of analysis that data can be moved from a secure database to a researcher's computer (295). Some only allow this when the data has been stripped of identifiable data, and some when it has been stripped of sensitive data, or both (295). These sorts of issues mean that researchers may find it difficult to navigate the various governance procedures associated with each routinely collected dataset and may end up inadvertently breaching data protection policies (295). This also means that data sharing between research institutions can become problematic as the governance varies for different datasets (299).

Until the mid-1990s, patient data in routinely collected datasets were freely available for research, this changed when the Data Protection Act was introduced in 1998 (295). The Data Protection Act strengthened previous legislation and gives provisions for the secure processing of identifiable data for medical research (295; 297). The Data Protection Act applies to all use of data in which the patients remain identifiable even by *indirect* means, and the Act also counts all data that are linkable to any identifying information as 'personal data' (300). Some blame the Act for increasing the bureaucratic barriers to research (301), others dispute this (302). Iversen et al (2006) concur that the impact on research of the Data Protection Act is less to do with the legislation per se than the way that data controllers have interpreted the Act. As an example of this, the Data Protection Act did not include definitions for 'secure' and 'medical research', and therefore data controllers adopted an interpretation of the rules that Curcin et al (2012) refer to as 'consent or anonymise'. This is where a participant is either fully consented to take part in a research study, or the data of that patient used in a research study is fully anonymised (295). To complicate matters further statutory regulations and professional guidance can sometimes contradict each other (303).

May 2018 saw the implementation of The General Data Protection Regulation (GDPR). This is a regulation in European Union (EU) law on data protection and privacy for all individuals within the EU and the European Economic Area. This also addresses the export of personal data outside the EU and EEA areas. These regulations need to be followed by UK based researchers

as long as the UK is part of the EU, and will still need to be followed when dealing with personal data of EU citizens even after the UK leaves the EU in 2020. A major component of the GDPR relates to being transparent and providing accessible information to individuals about the collection and use of their personal data. The introduction of the GDPR illustrates the constant shifting and updating of laws related to data protection.

There are some circumstances however in which routinely collected clinical data may be accessed and used for medical research without explicit consent or full anonymisation that is permissible under the Data Protection Act (302). Since the Human Rights Act 1998 became law, data use of this kind are permissible if the research investigates an important question, the research is in the public interest, is of a public nature, and the degree of interference is proportionate to this goal (and no more than necessary). It must be kept in mind however that the courts have not given an authoritative statement related to medical research (302). Some researchers have suggested that data controllers are ignoring the fact that prospective research, specifically public health research very often satisfies the Data Protection Act. Notably Section 33 which allows further processing of previously collected personal data for research purposes (302; 304). In Section 251 of the NHS Act of 2006 provisions were made to allow patient identifiable data to be used in research without patient consent where disclosure of patient identifiable information is necessary and consent is not practical (295; 305; 306). Even after the introduction of the changes brought in by Section 251, the process of obtaining the necessary permissions for research studies to obtain data collected routinely by the NHS is still complex and time consuming (295). In 2012 the UK Government announced that regulations regarding using patient data for research would be relaxed (295; 307) and in 2018 the national data opt-out was introduced in the NHS in England. This enables patients to opt-out from the use of their data for research by NHS Digital and Public Health England. By 2020 all health and care organisations in England will be using this system.

#### **4.2.4 Obtaining informed consent**

Informed consent is the 'ethical touchstone' of medical research (298). As described previously, in UK research it is usual that informed consent, that is permission, must be sought from individuals for any use of their *identifiable* data, including for secondary use of routinely collected data (275; 305). Although approval can be sought to waive informed consent, in practice, as described above, this can be difficult to obtain (302; 308; 309). Some researchers

however have suggested that informed consent is not always possible or even desirable when collecting data from routine records (273). The next paragraphs will further address this.

There can be many issues with obtaining consent to collect data from routine records (275). Tracking participants in order to request their consent may be difficult, since some people change their names or other identifiers, change doctors, or move (275). The practicality of obtaining consent needs to be balanced against the research design including the number of participants that will be in the study (275). It may be very difficult to contact thousands of people to take part in a study, especially if many have moved or died since the records were last updated (275; 310). The risk of consent bias must also be taken into account as particular groups are more likely to opt-out (see section 3.1 for a detailed discussion of consent bias) (273; 275). Some groups of people, due to their individual or personal circumstances, are more difficult to contact, for example students change addresses fairly often (311). Seeking informed consent could create harm as this may upset some people, particularly those recently diagnosed with a serious disease (275; 312). Such experiences are likely to impact on parents' reactions to the request for consent to use their babies' data for research (273). The financial cost and resources needed to contact participants also needs to be taken into account (275). The difficulty in contacting participants directly also needs to be weighed up if there is no existing relationship between the organisation from which the data will be collected and the individual, and the difficulty of contacting them indirectly through advertising and notices (275).

Consenting participants can be costly, time consuming and ineffective in ensuring sufficient numbers of participants are involved in the research. Some researchers have said that the low quality research that could result from these methods could itself be seen as unethical (288; 313; 314; 315). Hansson (2010) said that the requirement to consent participants even in prospective research lowers the scientific value of studies and limits their capacity to provide new knowledge that would benefit society. Iversen et al (2006) reported how the requirement of informed consent for linkage to a cancer registry seriously hampered epidemiological research. Ward et al (2004) had a similar experience with a UK nested case-control study of Creutzfeldt-Jakob disease. Al-Shahi and Warlow (2000) suggested that having to seek informed consent to use identifiable data 'would jeopardise the methodological integrity of research and audit'. This, they point out, 'would not just hinder the progress of medical knowledge but might lead to completely incorrect conclusions'. Chalmers and Muir (2003) agree that data

linked following a process of informed consent are 'skewed by unquantifiable biases' and 'often not worth the cost of collection'. If data are stripped of all identifiers there is the potential for research conclusions to be flawed should such variables as age not be included in data analysis (287; 311). In addition, Iversen et al (2006) notes that it may be useful to be able to re-contact participants, perhaps years after a study, should new, important information about their conditions arise. Some believe that having to gain informed consent is damaging to population based research (310), and that this is particularly concerning as having a national system of health records gives unequalled opportunities for research to improve health (310). Some researchers have suggested that informed consent should not need to be collected for the use of routinely collected data as this research has little or no risk to participants, neither does it directly benefit the participant (309). It is very important to keep in mind however that there are moral arguments for consent and some public concerns around not gaining informed consent which were addressed in the literature review on attitudes towards the collection and linkage of sensitive data (section 3.1).

#### **4.2.5 Consent models**

Models of consent that could be utilised in research using routinely collected data have been explored (275). These include the participant giving informed consent for the current research only, the participant giving informed consent for current research and future research that is clearly specified, and the participant giving consent for broad research use, this is consent for unspecified future research using their data (273; 316). There are problems with the broad consent model as consent must be *informed*, and this cannot always be guaranteed if participants cannot be fully informed about the future studies if they are as of yet unspecified (275; 316; 319; 320). It may also be the case that if research questions and methods change over time this may invalidate the consent (271). A broad consent model may not be very useful in the longer term as when consenting participants for research no one can imagine what future studies may want to use the data (320). Some researchers have suggested that allowing participants to give broad consent for future research is a dilution of ethics (321; 322; 323).

Retrospective consent can also be gained, as can dynamic consent. This is where participants are continuously informed about the study progress and asked to reaffirm their consent if there are any changes to the research (271). Both the retrospective consent model and the dynamic consent model however have some of the same problems as those outlined above for

‘traditional’ informed consent models (271). In some consent models, participants can also consent for aggregated data only to be used (273).

There are also indirect means of using previously collected data without consent, and this is of particular interest for observational and epidemiological research. There are several established medical registries that use this model for example, national cancer registries (316). These do not require consent, however the individual has the right to know what type of information is in the registry (316). As previously mentioned, researchers can collect data without consent under Section 251 of the NHS Act 2006 (295; 309).

Instead of providing informed consent to be part of a study participants can be contacted and given the option to opt-out of participating in the study, researchers exclude only those people who actively object to the research (325). This consent model may have similar problems to the traditional informed consent model as participants need to be contacted to be given the option to opt-out. This can be difficult if they have moved address or changed names, and consent bias is still an issue (275). A criticism of the opt-out model is that a choice is being made for those who choose not to choose (324). Opt-out may be useful when we know what participants’ choices are likely to be, if the majority of people would probably be happy to take part in a study, then using opt-out can be very efficient and does not undermine the principle of providing choice (324).

Different consent models are likely to have different costs (324). If each participant is to be consented into a study, then the cost per case would be constant, however, if an opt-out model was used then a public information campaign would need to be funded or potential participants would all need to be contacted (324). Singleton and Wandworth (2006) suggest that a ‘traditional’ informed consent model is probably only viable therefore for a smaller study, although the authors do not specify what size study they are referring to.

Some research has been conducted on gauging public opinions on various models of consent (273). Levitt and Weldon (2005) used focus groups to explore public perceptions of privacy and trust, and data collection and storage, in the context of genetic research and UK Biobank. Some researchers view that informed consent is the same as ‘consumer choice’, that is, it is entirely a participants choice whether to consent or not. Levitt and Weldon (2005) however found in their public sample that wider social and ethical issues still needed to be taken into



account and that the 'choice' to give informed consent was limited by issues such as information about the consent and trust. Research carried out by NHS Information Authority (326) found through a large-scale survey that the forms of consent that the public would choose were evenly split. 35% wanted to be asked for consent each time; 29% thought one-off consent was appropriate for all uses of their data; and 30% wanted to be asked for consent each time information is used for purposes other than treatment. Interestingly, 45% of survey participants said that they would like a published sharing agreement as a safeguard (326). The authors suggest that this inconsistency is due to a lack of understanding of either the implications of the published agreement; or the implications of collecting consent each time information would be shared (326). Foster and Young (2011) suggest that it is debatable whether participants fully understand the choices that they are asked to make about use of their routinely collected data for research. The literature review on attitudes towards the collection and linkage of sensitive data in section 3.1 explored public consent preferences further.

#### **4.2.6 De-identifying data**

If a waiver of consent is not possible, Kho et al (2009) suggest that researchers need to outline the procedures that will be taken to protect the privacy and confidentiality of each participant and weigh up the risk of a privacy breach (327; 328). Solutions that make it harder for a person to be identified from a dataset include anonymisation or pseudonymisation, encryption, the creation of derived fields, or removing small numbers (327). These techniques make it harder to connect unique characteristics to an individual by generalising and blurring some of the data to make it apply to more people (329). Anonymisation or de-identification of data is a solution to the problem of consent (275), this is where individuals in the dataset can no longer be identified (271). These methods are useful when the seeking of explicit informed consent would be too onerous, costly, slow, or bias the analysis (275). If data aren't identifiable they aren't 'personal', and a variety of rights, obligations, and sanctions that apply to personal data are not relevant (275). Data would become personal however if the data can be associated with an individual, even if the identification is only indirect, deductive, or dependent on matching with other data (275). Using de-identified data for research gives the false impression that it is 'safe' (330). It is difficult to ensure that a dataset is fully anonymised, as a combination of variables *can* deem data identifiable (271; 300; 330).

The researcher themselves may also become aware of personal details and will be able to identify an individual that they know from the data (300). It must be kept in mind that even if a researcher does not recognise personal characteristics as being identifiable this does not prevent someone else from doing so (327). It is difficult to tell whether this ever causes any harm as this depends on how such 'harm' is defined (300). Researchers need to consider also whether data pertaining to discernible individuals are required for research (271). This is especially important when considering if the data will need to be linked to other datasets, as once identifiers are removed from a dataset that data can't then be linked (287; 295). Some researchers therefore use pseudonymisation (275). Participant identifiers are replaced with pseudonyms and then discarded from that dataset, however they are retained in another place, for example in a secure part of a computer system, or in another organisation altogether. This would allow the original identifiers to be linked back to the data in the future if required (275). The main objective of anonymising data for use in research is to maximise the information content level whilst minimising the re-identification risk with respect to the participants involved (271). Some have argued that many of the techniques used to anonymise data can unfortunately excessively reduce the amount of information left in the dataset (271).

In all de-identification techniques either too much information is lost or all individual characteristics are not entirely hidden thus exposing a breach risk (327). The risks and solutions needs to be addressed on a case by case study basis and some studies can cope with blurred or removed demographic data (327).

#### **4.2.7 Balancing between research benefits and confidentiality**

Balancing individuals' right to data protection or confidentiality against the need of research for the 'public good' has been widely debated in the literature (271; 275; 305; 316; 320; 331; 332). Some researchers have purported that it is essential to use patients' data for secondary purposes, beyond the initial care of the individual concerned, for the high quality of healthcare delivery and the effectiveness of scientific research (333). Geissbuhler et al (2013) state that even though there are some privacy concerns regarding accessing routinely collected data, the sharing of these data is essential for clinical research and benefits increase with the scale of the data sharing. Others disagree, Dierks (1993) argued that using routinely collected data for research purposes interferes with the individual's right to informational self-determination. Strobl et al (2000) emphasised that there is a need to find a balance between facilitating

*important* research and protecting confidentiality. Lowrance (2002) argued that the challenge is to ensure privacy and the benefits of research at the same time, and this is possible as both are in the interest of most people.

Foster and Young (2011) say that much of the literature they reviewed presupposed that patients have a responsibility towards 'helping' others. So as well as depending on 'altruistic participation', that health research actually assumes this (336). If the objective of research is to produce knowledge that can be generalised, for example to improve health (320), it is difficult to judge whether confidentiality risks taken in secondary use of this data are reasonable in relation to the potential increase in knowledge. This is since those who participate in research are not always the same ones who benefit from it (337). When most members of the public participate, value builds, and therefore participation is critical (332). Prior research suggests that people will provide consent only if they expect others to act in a similar way and if they believe they will be treated fairly with respect to the give-and-take relationship to the public good (338). People find themselves in these types of social dilemmas when they are presented with an option that provides them with greater benefit when acting selfishly, irrespective of what other decision-makers do, than when acting in a cooperative manner with the others (339; 340). In addition, if everyone acts selfishly, the affected population as a whole will receive less benefit than if a cooperative choice was made (339; 341; 342). 'Public good' is when any group member consumes it, the good cannot be withheld from other group members (343). When the goods are provided no one can be excluded from using them, therefore, there can be a temptation to enjoy the benefit of the research without making a contribution. If however all do this then the research is not conducted and everyone is worse off (332). People evaluate how important their private data are against the return associated with benefiting the public good (332). This evaluation can be based on many factors including what rewards or incentives are offered (344), a belief that the data will be used in a way that does not negatively impact them in the future (332; 345), which can depend on the sensitivity of the data (332). It seems that most patients are willing to allow for their data to be used in research (273). McKinney et al (2005) found in a study into the feasibility of obtaining parental consent for patient identifiable data from a paediatric intensive care units across England to be submitted to a national database that the refusal rate was less than 1%.

#### **4.2.8 Methodological issues when using routinely collected data for research**

There are some methodological issues with using routinely collected data for research, and these are intertwined with technical issues. This is because the quality of the evidence is strictly related to the quality of data (334). These issues are mainly focused on the accuracy of the record itself and accuracy of linkage, and the security of transferring the record (273). The validity of the data obtained from routinely collected records can be problematic (273), there can be data entry errors, and therefore inaccurate clinical data in routine health records will become inaccurate research data (274). Busy clinicians sometimes type quickly and invert numbers, input information in the wrong patient's record, click on incorrect menu items, or copy and paste narrative from prior visits without updating it (347).

Systematic biases can arise from both the nature of the data and the preconceptions of researchers, which are serious threats to the validity of research results, especially in answering causal questions (274). Routinely collected data can be incomplete or fragmented, and may not include all the data necessary for particular research projects (348). Professionals who record data in routine records do not generally do this with research studies in mind (275; 276; 349). This means that researchers must filter and reformat the data they receive for quality and relevance (275). Data that is likely to be missing from routine health records includes data about treatment outcomes, this makes it hard to track whether a treatment is effective over a longer term (274). Patients who receive medication from their doctors often do not report whether the therapy was effective (276). The absence of return visits may mean that the patients were cured, but it could also indicate that they failed to improve or deteriorated and decided to visit different doctors or specialists (348). Data fragmentation can occur because different facilities have different data capture systems that are not interoperable (274; 350). Other problems that may make routinely collected electronic data unsuitable for use in research studies include that like any complex software system, these may contain software defects (274). These defects can cause the data held in the system to be incorrect, and a value that is incorrect but still plausible may not be discovered and still used in a research study (274). This issue is not unique to routine data however.

In routinely collected health records inaccurate diagnostic codes can cause errors (299). Botsis et al (2010) found after analysing 10 years of data on pancreatic cancer from routinely collected health records that between six percent and 46% of the data were incomplete for some variables. Köpcke et al. (2013) found similar findings regarding the completeness of

routinely collected data for research. Coding can be inconsistent, incorrect, or misleading (84), or too general to indicate the specifics of patients' conditions (353). Routinely collected data may contain more coded data and less text detail about patients' medical histories and diagnostic findings (354). Healthcare data are coded using ICD-10, developed by the WHO (274). Before 2014, ICD-9 codes were used, which had approximately 17,000 codes whereas ICD-10 has approximately 155,000 (274). There have been several studies that identified coding inadequacies as problematic for using this data in research studies (353). ICD-9 codes are not specific enough for cancer to enable researchers to distinguish primary tumours from metastatic ones (347), and even though ICD-10 is now used, existing patient records still contain ICD-9 codes (352). de Lusignan et al (2006) examined the separate codes offered by a GP electronic health records system. They found that the coding did not clarify which designation was appropriate for acute rather than more moderate disease and which range of codes indicate the presence of chronic obstructive pulmonary disease. They also found that different physicians used different codes for patients with similar diagnoses, for example, some patients receiving medication to combat osteoporosis were not coded as having osteoporosis (355). Free text fields can also be problematic in electronic health records, there can be information in the free text that is not captured in codes and this information may be difficult to extract for research (352). There is however now a considerable interest in using text-mining approaches to search through electronic health records. Some researchers have argued that most routinely collected records do not provide a very good basis for research. This is because most are lacking in some features such as functions to ensure that the data are correct, complete, and accurate (274; 356; 357).

Linking datasets can be problematic, when two or more datasets are linked on an individual level there will be a proportion of matched and unmatched records (285). Errors happen when records that correspond to the same participant do not link due to missing or inaccurate data, these are false negatives. There are also false positives, this is when records that are unrelated are mistakenly matched (285). Linking is especially difficult where there is not a one-to-one relationship for the linking fields (285), in the UK there is not one unique national identity for an individual across sectors (e.g. health and education), and this can make data linkage problematic (278). A literature review of the accuracy of probabilistic record linkage applied to health databases by Silveira and Artmann (2009) identified just six articles that included complete data on summary measures of linkage quality (in this case, sensitivity and specificity, described below). They found that the accuracy of databases ranged from 74% to 98% on

sensitivity (i.e. the proportion of individuals who have an outcome of interest who are in fact in the database), and from 99% to 100% on specificity (i.e. the proportion of individuals that do not have an outcome of interest and are not in the database). Bohenski et al (2010) conducted a systematic review of linkage accuracy including 33 data linkage studies (12 from the US, eight from Australia, five from the UK, four from Canada and one each from the Netherlands, New Zealand, Switzerland and Taiwan). They examined the characteristics of matched versus unmatched records and found that there were a number of reasons for the variety in rates of data linkage, including aspects relating to the methods of linkage, governance issues, and the accuracy and completeness of the data within each data source (285).

#### **4.2.9 Conclusions and next steps**

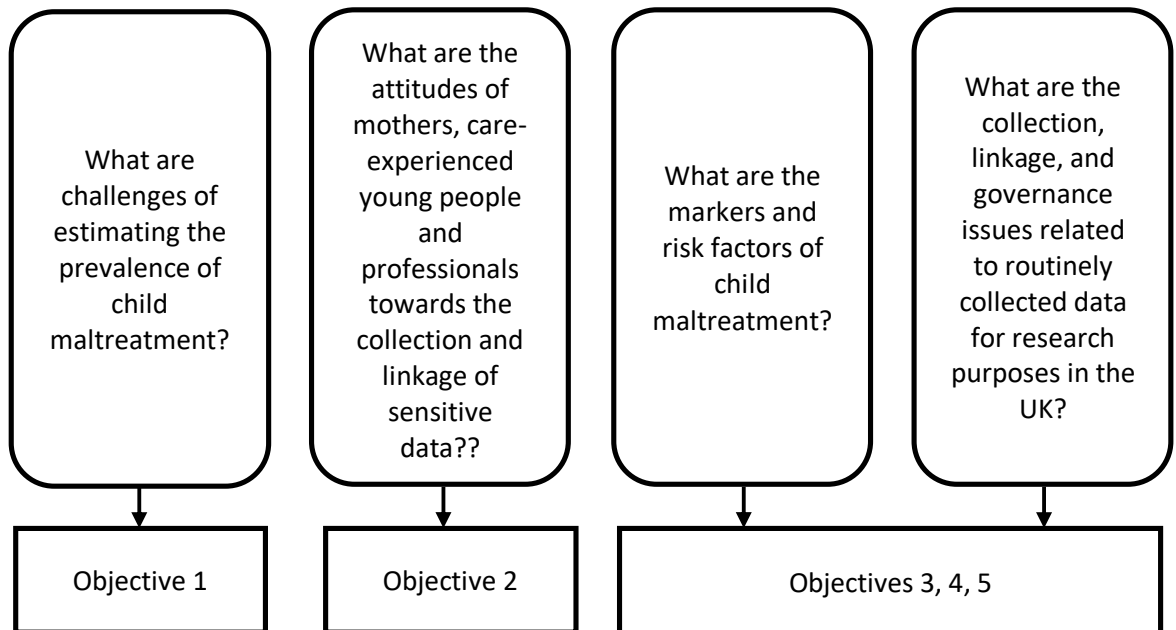
Utilising routine data in research, including in research on child maltreatment, can be very useful for a variety of reasons outlined above. The governance issues surrounding the collection of routine data for research purposes, and some of the practicalities of analysing these data however should not be overlooked. Routine data are by no means 'the easy option'. The overall aim of this review was to stand as an introduction to the issues of the collection, linkage and governance of routinely collected in the UK and to educate the researcher and the reader about the background of routine data collection to prepare for the quantitative phase of the current research study. This review was useful in preparing for the next phase in a variety of ways. Firstly, it was important for the researcher in particular to have a good understanding of the legislation around routine data collection as this will have a bearing on the research ethics that will need to be obtained to complete the quantitative phase of the study. Secondly, the review informed the researcher about the process of anonymisation, this is important for the researcher to understand as pseudonymised data will be used in the quantitative chapter of the research study, with access to and security of the data another important consideration. Thirdly, and finally, the review informs about some methodological issues such missing data which will need to be kept in mind during analysis and will need to be addressed in the discussion of the results.

### **4.3 Methods**

#### **4.3.1 Introduction and objectives**

This section focuses on the quantitative methods used in this study which address the third, fourth, and fifth research questions (Figure 1).

Figure 1. How the study objectives relate to each research question



#### Third objective

To investigate how markers and risk factors of maltreatment, identified from a variety of data sources, predict an outcome that may indicate maltreatment (CIN status) for children in the Building Blocks cohort.

#### Fourth objective

To investigate how risk factors and markers of maltreatment predict *different* outcomes that may indicate maltreatment. These will vary in severity, from referral to Social Services through to a CPP being put in place for children recruited to Building Blocks cohort.

#### Fifth objective

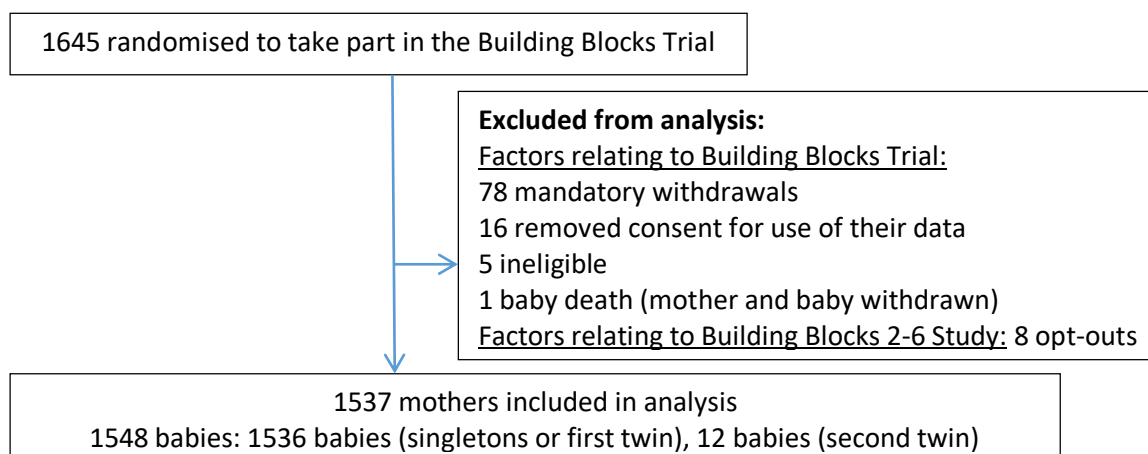
To illustrate how risk factors and markers of maltreatment predict outcomes that may indicate maltreatment using examples from the Building Blocks cohort and the analysis undertaken in this project (case studies).

The data used to address these three objectives have already been collected in the Building Blocks Trial and the Building Blocks: 2-6 Study. See section 1.1 for details of these studies.

### 4.3.2 Participants

Participants were women and their children recruited to the Building Blocks Trial who continued into the Building Blocks 2-6: Study, see figure 8 for numbers included.

**Figure 8.** Numbers of mothers and babies recruited to the Building Blocks Trial who continued to the Building Blocks: 2-6 Study



To be eligible to take part in the Building Blocks Trial participants had to be pregnant, nulliparous, aged 19 or under, and recruited no later than 24 weeks gestation. Participants who were recruited to the Building Blocks Trial continued into the Building Blocks: 2-6 Study along with their children if they were not withdrawn for mandatory reasons (267), or did not opt-out of the Building Blocks: 2-6 Study when given the opportunity.

### 4.3.3 General design and Procedure

Data collected during the Building Blocks Trial and Building Blocks: 2-6 Study was used. As the data have already been collected no further piloting work will be completed. Self-report data were collected in the Building Blocks Trial using face-to-face interviews at baseline and 24 months post-partum by local researchers, usually a midwife or nurse. They were also collected via telephone interview at 34-36 weeks gestation, and 6, 12, and 18 months post-partum by qualified and specially trained telephone interviewers. Routine data were collected via direct data download by the trial team from HES data, by local researchers from maternity units, local researchers or practice staff at primary care centres, from the Abortions Statistics Manager at the Department of Health for abortion statistics, and finally from COVER (Coverage Of Vaccination Evaluated Rapidly) contacts from primary health-care authorities.



In the Building Blocks: 2-6 Study data were collected via data linkage. An anonymised database containing pseudonymised data was created and hosted by the SAIL databank, an independent Trusted Third Party (TTP) based at Swansea University. Participants and their children were followed up until the child was six years old. Routine data were collected from NHS Digital, Office for National Statistics (ONS), and the Department for Education. NHS Digital provided HES data (similar to that collected in the Building Blocks Trial), the ONS provided death data, and the Department for Education provided data from the National Pupil Database (NPD) including social care in two datasets, the CIN and CLA datasets. These datasets were linked to the Building Blocks Trial data in the SAIL databank.

In the Building Blocks: 2-6 Study data were requested from NHS Digital and NPD at two time points. The first data extract was completed for piloting purposes. This was to assess data quality and the suitability of data for answering key study analyses the dataset contained children up to the ages of four (no children in the dataset had turned five). The second data request was made once all children in the study had reached key stage 1 and age six (when they will all have started school) and on which the Building Blocks: 2-6 study findings were based. Mostly the same variables were collected at both time points, with some additional variables collected at the second time point. Data from the first time point was used in this current analyses as these analyses were conducted before the data from the second time point was available in spring 2018.

#### **4.3.3.1 Research ethics and governance**

Existing ethical approval obtained in the Building Blocks Trial and Building Blocks: 2-6 Study covers the work completed in this study. Multi-centre approval was granted by the Research Ethics Committee for Wales (ref. no. 09/MRE09/8) and site-specific approval was granted at all participating Primary Care and Acute Trusts for the Building Blocks Trial. The Building Blocks: 2-6 Study required identifiers to be passed to the Department of Health (NHS Digital) and Department for Education to establish linkage with routine data sets. Approval for this transfer process was provided through Section 251 approval from the Health Research Authority's Confidentiality Advisory Group (CAG). Section 251 approval allowed the researchers to obtain non-consented (opt-out model) access to medical records. This was required in order to obtain an unbiased estimate of the long-term effect of FNP on objective and associated measures of maltreatment. Approval to access Department of Education data were provided by the Data Management Advisory Panel (DMAP) in the Department's Education Data Division (EDD).

Approval for access to NHS Digital data were provided by the Data Access Advisory Group (DAAG). All approvals were granted preceding the work completed in this research study, and no additional approval was required.

#### **4.3.3.2 Data Storage and access**

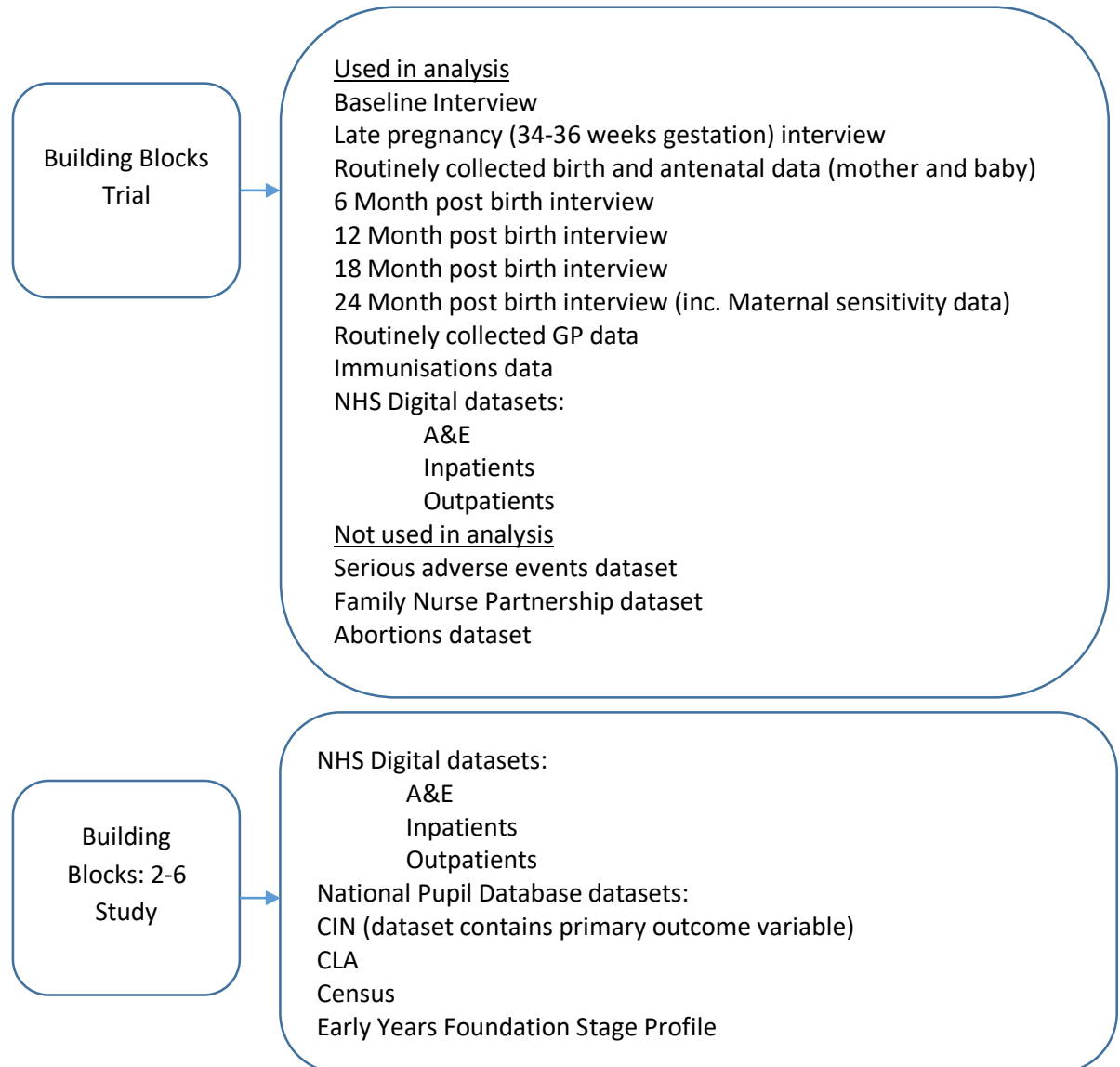
Data are stored in the SAIL databank, the datasets were pseudonymised and could only be accessed via a password protected remote portal. SAIL controls the portal, and processed the pseudonymised data for secure use by Building Blocks: 2-6 Study team and for the current study.

#### **4.3.4 Child in Need (CIN) Status (Third objective)**

##### **4.3.4.1 CIN Status background**

The third objective is to investigate how markers and risk factors of maltreatment, from a variety of data sources, predict CIN status for children recruited to Building Blocks cohort. Figure 9 illustrates the data sources that will be used.

**Figure 9.** Data sources in the quantitative chapter



### **Rationale for collecting multi-source and multi-method data on child maltreatment**

With advances in researchers' ability to link various sources of data using identifying information on children and their families, a combination of different data sources can be used to capture maltreatment data (175). For some research on child maltreatment, it is likely that using multi-source and multi-methods may give a more complete picture than using a single-source and single-method of data collection. There are some methodological issues with the various ways in which child maltreatment data can be collected. These are outlined in the first literature review on the challenges of estimating the prevalence of child maltreatment (section 2.1). By utilising a multi-source and multi-methods approach some of these issues may be addressed.

Single-source and single-method collection of child maltreatment may lead to a missed opportunity to examine discrepancies between various data sources and thus form new hypotheses (359). Using multiple sources of data provides a more complex view of child maltreatment and can include reports from sources that are traditionally less studied or newer emerging sources (359), for example collecting routinely linked data such as from hospital records. Reliance on one source or method will make it difficult to measure some constructs. Collecting self-report data on the times a child has attended A&E with an injury for example may be less reliable than collecting this data from hospital records on account of reliance on recall, and possible social desirability bias.

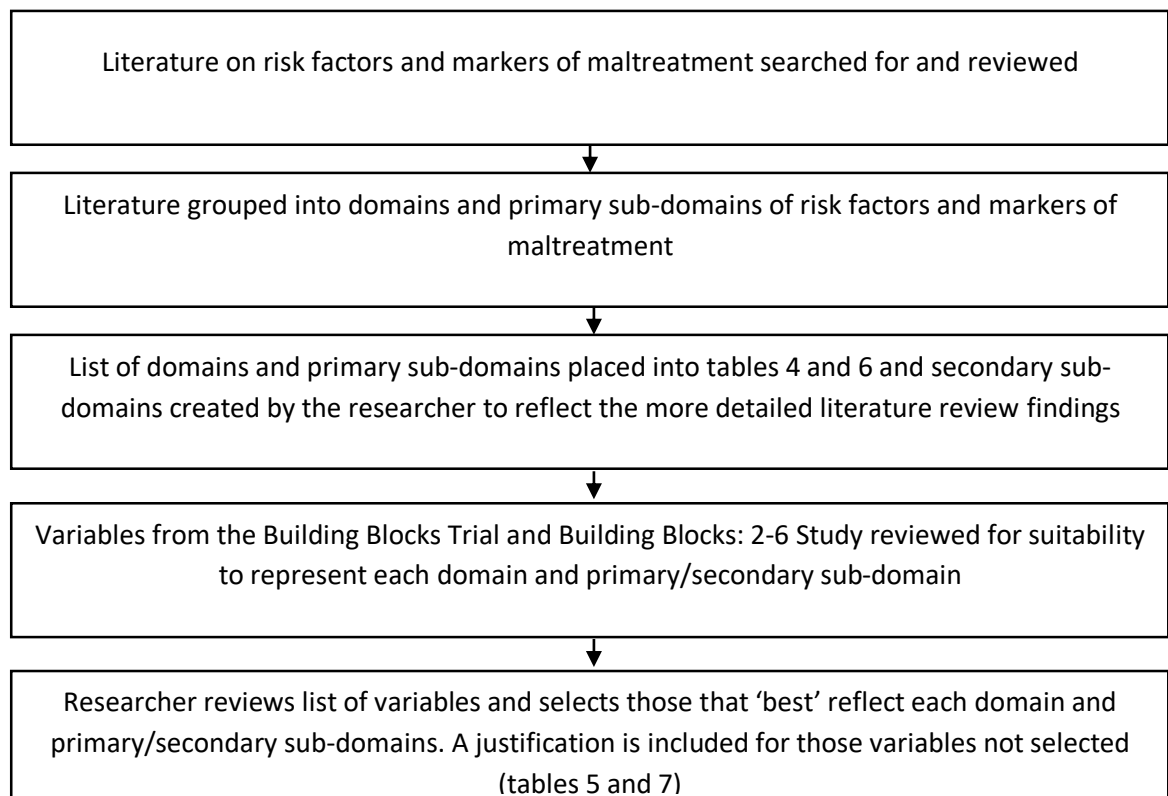
When deciding to use multi-source and multi method data collection it is important to think about which sources and methods are the most appropriate to use in the collection of each variable or construct. Some data sources can be used to 'top up' others when there is missing data. Discrepancies, or low agreement between sources do not necessarily point to errors in one or more sources, or to issues with a method of data collection. Holmbeck et al (2002) believe each source and method provides a unique perspective. A participant for example may self-report mental health problems but there may be nothing to indicate this in their GP records, as it is possible that participants have not visited their GP about their concerns. A note of caution however, utilising multi-source and multi-method data collection can complicate matters and make analysis and interpretation of results more difficult (360; 361). Different types of methods for example have different types of biases that need to be considered (359).

The process outlined below seeks to evaluate the advantages and disadvantages of variables derived from various data sources for collecting data that may point to maltreatment. This is the method for selecting the variables for inclusion in both the third and fourth objective analyses.

Risk factors for child maltreatment that were identified from the literature review addressing the markers and risk factors of child maltreatment (section 4.1) are listed in table 4 (appendix 13). Each risk factor is located in an overall domain (and primary/secondary sub-domain), devised by the researcher and guided partly by the way the risk factors were grouped in the aforementioned literature review. Each domain and first sub-domain is a heading that originated in the literature review and each secondary sub-domain reflects the more detailed

literature review findings. Each sub-domain is numbered for ease of reference. The researcher reviewed each of these domains and primary/secondary sub-domains and listed each variable or group of variables collected in the Building Blocks Trial or Building Blocks: 2-6 Study that may be used to represent each of these. A process of further review for each domain and primary/secondary sub-domain was undertaken, and the variable(s) thought to ‘best’ reflect these domains or primary/secondary sub-domains was chosen to be included in the analysis (table 5, appendix 14). This process and the variables selected for use/not used in the analysis was reviewed and agreed by a second reviewer, a PhD supervisor, to validate it. Table 5 also contains the data source of the variables (see figure 9 for full list), variable descriptions, whether these are chosen for inclusion in the analysis, and a justification for non-selected variables. The numbers used as reference in table 4 are repeated in table 5 to show the relationship between the two tables and for ease of reference. The same process was repeated for markers of child maltreatment (tables 6 and 7, appendices 15 and 16 respectively). The process is illustrated in figure 10.

**Figure 10.** Process of selecting variables for inclusion in first analysis



For any scales, a summary score was used unless there was a justification to use only part of a scale. See appendix 17 for cases where a part of a scale only has been used.

This process was completed to evaluate the advantages and disadvantages of variables derived from various data sources for collecting data that may point to maltreatment. A justification was entered for each variable that was not included (tables 5 and 7).

There are a number of criteria that were applied to assess the eligibility of all variables (risk factors and markers) being considered in tables 5 and 7, for example the coverage of the dataset containing the variable. In order to avoid long justifications being included in these tables each time a series of inclusion rules listed below were applied. Variables that relate to these rules specifically will therefore not appear in the tables.

- Variables from the FNP dataset, GP dataset, and Serious Adverse Event dataset were not included unless these were considered to be the only variables available for that particular domain or sub-domain. These variables were not included as these datasets include a subset of participants only. The FNP dataset contains intervention participants only, and does not include participants from both study arms. There was an attempt to collect GP data, however this was not achieved for all participants in the Building Blocks Trial. The data in the Serious Adverse Event dataset are likely to be non-representative.
- Variables contained in the Early Years Foundation Stage Profile (EYSFP) dataset from the National Pupil Database dataset related to variables on 'Emotional, behavioural, interpersonal and social functioning' were not included. This is because the dataset related to the first time point (pilot data) contained no data, as no children were old enough to be assessed at the pilot stage. Data contained in this dataset were originally intended to be included as markers for developmental delay.

Variables related to school attendance from the NPD dataset were not be included in the list of markers for child maltreatment although this variable was present in the dataset used. A variable related to under/normal attendance cannot be created as no children in the dataset under attended.

#### **4.3.4.2 CIN Status method**

##### **Data preparation**

Firstly, all of the required datasets were prepared. Preparation work included renaming variables used to link the datasets (identification variable) to be the same in each dataset,

changing the structure of some datasets to ensure that each dataset is one row per mother-baby dyad or triad. Any additional scoring of variables not already completed was also performed. Any creation of new variables or flags showing presence of a variable were also completed. Some mothers had maltreatment events (as many mothers will be under the age of 18 at recruitment this is quite possible), these events were not included in the final analysis, only maltreatment events related to children were included.

The next step was to merge all these datasets to create one large dataset which contained all the risk factor and marker variables of interest.

Once this large dataset had been created, the next step was to ensure that each risk factor occurs only *before* a child has an event that may point to a maltreatment outcome. This is because a risk factor is a predictor, or is thought to have a causal link to child maltreatment. A marker however does not need to occur before a maltreatment event and can occur at any time, because a marker is a maltreatment-related feature and does not predict or have a causal link to child maltreatment. As this is the case, for each risk factor, a date was assigned showing when that particular risk factor variable was collected, and a flag was created to show if this date occurred before a maltreatment event occurred.

In the case of the primary analysis an event that may be indicative of maltreatment will be any child with a CIN status. This variable was located in the NPD dataset (CIN Dataset). The NPD dataset however did not contain a date indicating when a CIN Status was given, therefore the first referral date to Social Services together with a positive CIN status was used as a proxy. Table 8 (appendix 18) lists the date variables used to calculate whether the risk factor occurred before the maltreatment event.

The above paragraph describes how each child with a maltreatment event had a date indicating when the maltreatment occurred. This group will be called the maltreated group, and will be included in this group if they have at least one maltreatment event, as indicated by a CIN status. Any risk factors had to occur before this date to be included in the analysis. A similar date was needed for those children who did not have a maltreatment event, the comparison group, in order to be able to calculate if a risk factor occurred before a certain date. This was done by counting the number of children in the maltreatment group and the comparison group and assigning a randomly selected equal number of children from the

comparison group for each one child in the maltreatment group. Those children in the comparison group were then given the same 'date of maltreatment event' as their maltreatment group counterpart before which any risk factors would need to occur to be included in the analysis. Each case (maltreated child) therefore had a control (non-maltreated child) who was then assigned an equivalent event date.

### **Data analysis**

Participant baseline characteristics were collected during the Building Blocks Trial and a full list can be found in the Building Blocks Trial report (362).

Descriptive statistics performed included number of children in the maltreatment and comparison groups, and count of CIN status(es) for the maltreatment group.

Differences in risk factors and markers between those with a child who had a CIN status or not were assessed descriptively and then compared using chi square or t-tests. Each risk factor variable was analysed (univariable analysis) to determine whether it was significantly associated to the presence of a maltreatment event to the  $P < 0.10$  level. The analysis for the univariable associations treated missing values as valid for some variables missingness could be important i.e. it may be that it's the rate of missingness that is driving the association. Following this initial screening stage, each of these significant variables were included in a multivariable logistic regression to determine those independently associated with a maltreatment event ( $P < 0.05$ ). Datasets were included into the logistic regression in temporal order. The above process was repeated for the analysis of the marker variables.

### **Review of independent variables selected for use in the analyses**

Independent variables were selected by the researcher and reviewed and verified by a second reviewer (MR, PhD supervisor). The variables that were queried by the second reviewer are included in table 9 (appendix 19). The right hand column of the table describes the original decision as to whether to include this variable by the researcher, and any decisions made in light of the reviewer's comments.



### **4.3.5 Other maltreatment Outcomes (fourth objective)**

#### **4.3.5.1 Other maltreatment Outcomes background**

The fourth objective investigates which risk factors and markers of maltreatment predict different outcomes that may indicate maltreatment. These will vary in severity, from referral to Social Services through to a CPP being put in place for children recruited to Building Blocks cohort.

In the case of the third objective analysis an event indicative of maltreatment is any child with a CIN status. The same analysis was therefore performed for the fourth objective using other outcomes that may be indicative of maltreatment. These outcomes that may indicate maltreatment vary in severity in the following way from least severe to most severe:

Case referred to Social Services – CIN status given – CPP in place

Of course, any child with a CPP in place will have been initially referred to Social Services. For more details on the severity of child maltreatment outcomes see the flowcharts depicting the Child Protection Proceedings for England and Wales and for Northern Ireland and Scotland (appendices 3 and 4).

#### **4.3.5.2 Other maltreatment outcomes method**

The method for the fourth objective analysis was the same as for the third objective analysis, see section 4.3.4 for details.

### **4.3.6 Case Studies (Fifth objective)**

#### **4.3.6.1 Case Studies background**

The fifth objective is to explore how risk factors and markers of maltreatment predict outcomes that may indicate maltreatment using case studies.

Case studies were used to illustrate a model of risk factors and markers of maltreatment associated with child maltreatment (CIN status event up until age four).

The model, created from the results of the third objective, listed the risk factors and markers associated with child maltreatment. These risk factors and markers were independently significantly associated to child maltreatment.

The case studies also demonstrated the pathways or timelines in which risk factors and markers can occur in a real-life setting.

Using a case study can be useful when a researcher needs to obtain an in-depth appreciation of an issue in its real-life context (363; 364).

Yin (2009) said that case studies can be used to explain, describe, or explore phenomena, and can be used to help understand and explain causal links or pathways (364). For the current study case studies will be used partly to describe a model of risk factors and markers associated with child maltreatment. This will be done by providing examples of cases which may or may not involve some of these risk factors and markers, as well as demonstrate pathways or timelines in which risk factors and markers can occur.

Research using case studies can also offer additional insights into any gaps that exist (8). In the current research this could mean an insight into a gap in the model of risk factors and markers associated with child maltreatment.

Stake (1995) characterised three main types of case study; 'intrinsic', 'instrumental' and 'collective'. An intrinsic case study is undertaken to learn about a phenomena normally unique to that case or a very small number of cases. Instrumental case studies use a particular case to gain a broader appreciation of a phenomenon. The collective case study involves studying multiple cases either simultaneously or sequentially. This study used an instrumental case study type. Instrumental and collective case studies can allow for generalisation of findings to a larger population (365).

Yin (2009) characterised three different types of case study; 'exploratory', 'explanatory' and 'descriptive'. An exploratory case study is used to explore a phenomena in the data which is interesting to the researcher. An explanatory case study examines that data both at surface and at a deep level. A descriptive case study describes the natural phenomena which occur within the data. The current case study method is most similar to a descriptive case study type. The case studies will be used partly to describe a model of risk factors and markers associated with child maltreatment by providing examples of cases which may or may not involve some of these risk factors and markers.

The epistemological standpoint of the researcher may also have a bearing on how case study research is approached (364). A positivist approach is taken in the current instance. This involves establishing which variables will be studied in advance and seeing whether they fit into the findings in the case study, the focus is on testing a theory or model (365). The model lists the risk factors and markers independently significantly associated with child maltreatment, and the case studies reviewed to see if they contain the same risk factors and markers, or different ones, thereby 'testing' the model. It is not however expected that any one case will contain all significant markers and risk factors of maltreatment. Some aspects of other epistemological standpoints may also be applicable to the current research. A critical approach for example involves questioning one's own assumptions taking into account the wider social environment. In the current research the results from the primary analysis are questioned i.e. which risk factors and markers are associated with child maltreatment and if these are prevalent in the case studies reviewed.

#### **4.3.6.2 Case Studies method**

Crowe et al (2011) outlined the main stages of conducting case study research. Outlining the theory or model, defining the cases, selecting the cases, collecting the data, and finally, analysing the data.

##### **Outline the theory or model**

It is important that theory underpins the method and interpretation of the case study (364). In the case of the current research, the theory underpinning the work is a model of risk factors and markers of maltreatment associated with child maltreatment. This was completed using the results of the third objective that will be illustrated using case studies. The model lists the risk factors and markers independently significantly associated with child maltreatment, and the case studies reviewed to see if they contain the same risk factors and markers, or different ones. The case studies also demonstrate the pathways or timelines in which risk factors and markers can occur in a real-life setting.

##### **Define the cases**

The case studies should have pre-defined boundaries clarifying the nature and time period covered, the type of participant or organisation, and the type of evidence collected (364). For the current objective the pool of case studies to choose from has already been defined, data

from the Building Blocks cohort will be used. The boundaries are therefore already pre-defined in terms of nature and time-period, who takes part, and the type of evidence available.

### **Select the cases**

#### *Which cases?*

Case studies can be pre-selected for the researcher (364). The pool from which to select the case studies in the current piece of research is pre-defined. It is very important to consider any risks associated to participants such as breaching anonymity (364). The danger of identification is of course possible in the current piece of research, and pseudonymised data has been used to minimise this.

Rowley (2002) suggested selecting cases based on producing similar results (literal replication) or contrasting results (theoretical replication). For the current objective the researcher believes that selecting cases randomly from two pools of participants is the best design. This reduces the danger of selecting only cases that produce similar results to the model, as Yin (2009) reminds that researchers can allow their biased views to influence the directions of findings and conclusions. The researcher selected cases from two pools, those who have had, and those who have not had a CIN status. Cases were selected from two pools as the number of children with a CIN status is small, and selecting from the overall study sample only would run the risk of not including any case studies of children who had a CIN status. Two datasets were created, one containing all mothers who had a child(ren) with at least one CIN status, and one for mothers whose child(ren) did not have a CIN status. For each of the two datasets, a random number generator was used to assign a number to each mother, these numbers were then sorted in ascending order, and the mother with the lowest number was selected to be the case.

#### *How many?*

Multiple case studies are preferred (367). There is a pool of 1537 cases that could be selected for the current piece of research, 26 of those have a CIN status, 1511 without a CIN status. One case from each of the two pools was randomly selected.

### **Collect the data**

In case study research multiple sources of evidence are usually collected (364; 367). Although case studies often involve both quantitative and qualitative data sources, Yin (2009) cautions

researchers not to think of case studies as qualitative research, and can indeed be based entirely on quantitative evidence. Indeed the data sources in the current research were entirely quantitative. The use of multiple sources is sometimes called data triangulation and has been said to increase the internal validity of the research (365; 368). Variables for inclusion in the case study will be drawn from those used in the multivariable regression analyses, which reflect a range of original data sources. Each source of evidence has its strength and weakness (364) (previously explored in section 4.3.4.1). Rowley (2002) also mentioned the importance of keeping a case study database. For the current research all of the evidence from each source was kept in one database in the SPSS statistical package stored with the rest of the objectives data in the SAIL databank. The importance of keeping a chain of evidence has also been emphasised (364), the sources of each piece of evidence can be seen in figure 9.

### **Analyse, interpret, and report the data**

To analyse the data, evidence from the case study database must be examined and categorised to assess whether it supports or otherwise the research question (364). In the current case studies, the model of risk factors and markers of maltreatment were created from the results of the third objective. The researcher must review the evidence seeking confirmation or otherwise of the model and then record evidence and make a judgement as to whether the model has been substantiated (364). Crowe et al (2011) suggests that when conducting collective case studies that it may be helpful to analyse and report the data for each case study firstly, before making comparisons between each. For the current research, each case study was reviewed and any evidence (risk factor or marker) that was present for a mother child dyad (or triad) was listed. This means that each case study contained a list of risk factors and markers of maltreatment taken from the pool previously listed in tables 5 and 7. The pathway or timeline for each case study was set-out. Each risk factor and marker was listed in the order they appeared by data collection stage. The list of risk factors and markers for each case was next reviewed and a note was made of whether any of these were found to be independently significantly associated with child maltreatment as found in the results. Each case study was then compared with one another and any common risk factors and markers were listed (whether these were independently significantly associated with child maltreatment in the third objective or not). These were reviewed and commented upon i.e. if they are supportive or otherwise of the model that was made from the results of the third objective.

## **4.4 Analysis and results**

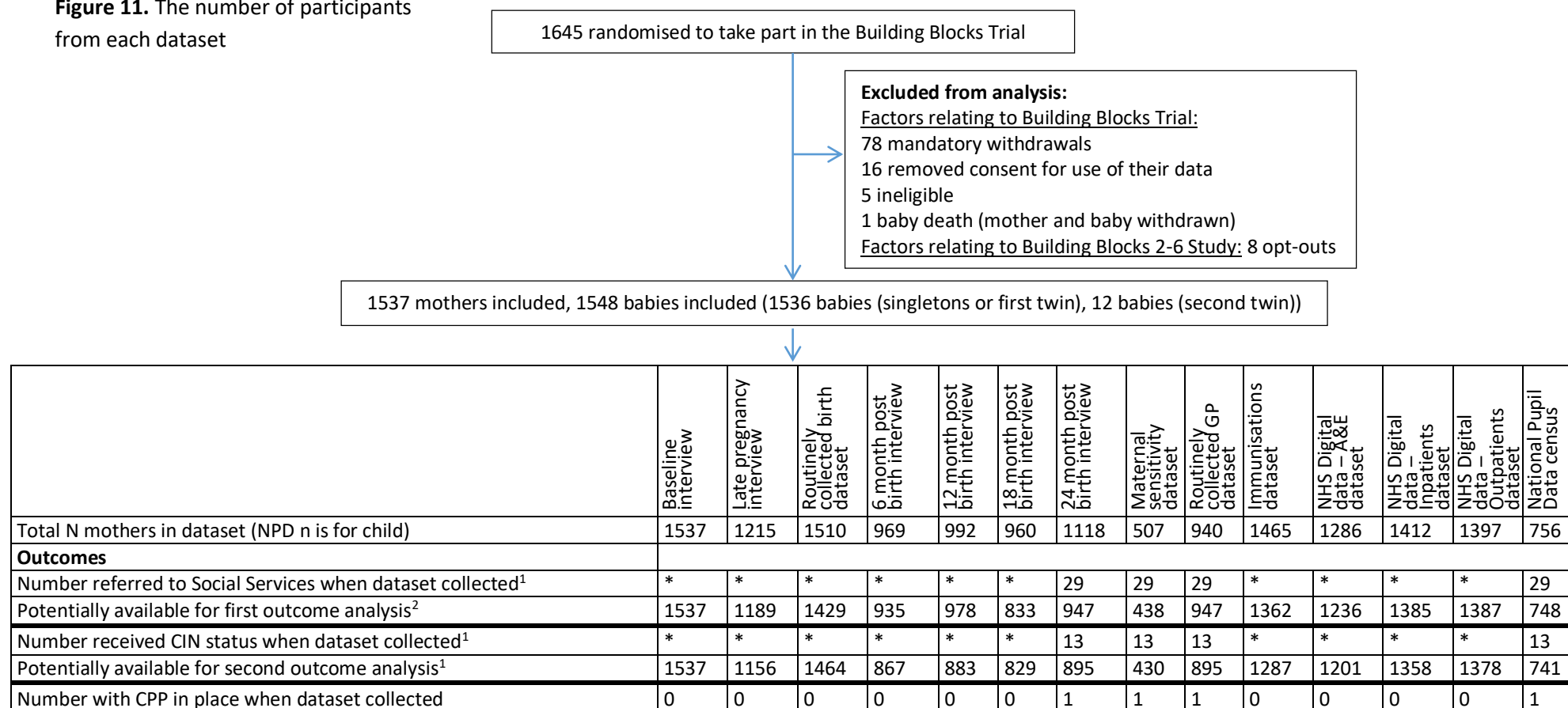
### **4.4.1 CIN status and referral to Social Services**

The third objective was to investigate how markers and risk factors of maltreatment, from a variety of data sources, predict CIN status for children recruited to the Building Blocks cohort. The fourth objective was to investigate how risk factors and markers of maltreatment predict different outcomes that may indicate maltreatment, varying in severity, for children recruited to Building Blocks Trial and Building Blocks: 2-6 Study.

Differences in risk factors and markers between those with a child who had a CIN status or not, and a Social Services referral or not, were assessed descriptively and then compared using chi square or t-tests. The decision was taken not to perform these analyses on those with a child who had a CPP in place (or not) because only nine participants (mothers) had a child with a CPP. These numbers were considered too small to perform any analysis. For both remaining sets of univariable analyses all risk factors and markers associated with CIN status and a Social Services referral ( $p < 0.10$ ) were separately entered into binary logistic regressions to detect all independently significant risk factors and markers at  $< 0.05$  level.

The number of participants from each dataset is shown in figure 11.

**Figure 11.** The number of participants from each dataset



<sup>1</sup> \* denotes the presence of small numbers ( $\leq 5$ ) (cannot be published)

<sup>2</sup> The numbers potentially available take into account both dataset size and the numbers of participants (mothers) who could be included in the analysis taking into account that only those who had risk factors that occurred before the date indicating when maltreatment occurred (referral to Social Services), or the matched date provided to the control group.

1537 mothers were retained in the Building Blocks 2-6 study and included in this study. Not all of these cases were however available for each analysis, due to there being missing response in some follow-up time points and datasets as seen in figure 11.

For this study, an approach to analysis based on all available data was used. A complete case analysis can sometimes be employed when cases are missing from datasets. This approach restricts the analysis to participants with complete data for all variables in the final model. The potential issue with analysing only the complete case dataset is that it may lead to biased or different estimates to those found if we had analysed the whole sample. This is especially true if the complete cases are systematically different from the study sample as a whole and it cannot be said that the data are missing completely at random. Using a complete case analysis in this study would have been inefficient as it would reduce the sample size and analytic power. Once a multivariable regression model is run with variables that have a smaller N, the model will restrict all the variables to that N. Doing this would have thrown away all the information in the incomplete cases since values of a particular variable are discarded when they belong to cases that are missing other variables. It is also very likely that discarding cases would have resulted in a dataset with dependant variable (CIN status or Referral to Social Services) numbers too small to run the analysis. It is important to note that the size of the sample was maximised as much as possible by carefully considering the ordering of the variables included so as to minimise a reduction in sample due to missing data.

If we were to have taken this approach, only 507 participants would have been included in both the risk factor and marker multivariable analyses, a third of the original sample. The reduction in sample is mainly driven by the maternal sensitivity dataset which contained the smallest number of cases and variables from this dataset were used in both the risk factor (e.g. maternal intrusiveness) and markers (e.g. developmentally inappropriate expectations) analyses. The maternal sensitivity data were collected during the 24 month follow-up interview via a videoed interaction between mother and child. It is reasonable to assume that mothers who agreed to the video interaction might be different from the rest of the mothers in the sample. For example, some may be missing at random e.g. because the child was asleep at the time of interview. Some may be missing due to other reasons, e.g. the Building Blocks Trial found that non-completers were more likely to be coded as not in education, employment or training and to report problems with difficulties in life skills (267).



Multiple imputation is an approach that can be used where there are cases of missing data. This is not always an appropriate strategy to use however, especially when large proportions of data are missing, for example imputing two thirds of the maternal sensitivity dataset. If we can be confident that the sample under analysis is not biased in any way, even in the presence of missing data, then it can be argued that the data are representative of the whole sample and estimates will be accurate. If multiple imputations are used to handle missing data it might indicate that the results of the analyses are confirmative, which would be an overestimation of the importance of some variables. This would be problematic if the missingness is considerable. Ideally multiple imputation should be performed when cases are missing at random, which is unlikely to be the case for many of the variables utilised in the current study. It is possible to account for this by developing models where estimates are created for data that are not missing at random. This however can make interpretation difficult.

#### **4.4.1.1 CIN status: Descriptive results**

Of the 1537 children available for analysis, a total of 26 (1.7%) had a CIN status, all of whom were singletons. Age at first CIN status ranged from -1 months old (pre-birth – children can be assigned a CIN status before birth) to 51 months old (4.25 years old), with a mean of 33.8 months old (standard deviation 13.6), and a median of 35.0 months old. As previously mentioned not all children given a CIN Status have been maltreated. There are eight primary need categories for CIN status: abuse or neglect; child illness or disability; parental illness or disability; family in acute stress; family dysfunction; socially unacceptable behaviour; low income; and absent parenting. In the current sample most (58%) had a primary need code of abuse or neglect, and the majority of the remainder had a primary need code of family dysfunction.

Risk factors and markers were compared between those with a child with a CIN status or not (table 10 and table 11 respectively (appendices 20 and 21)).

The risk factors (table 12) and markers (table 13) significant ( $<0.10$ ) at univariable level for those with and without a CIN status are listed.

**Table 12.** Risk factors found to be significant in univariable analyses for mothers with and without a child with a CIN status.

<b>Domain or sub-domain if applicable: risk factor variable</b>	<b>Data Source*</b>	<b>n</b>	<b>X<sup>2</sup> or t-test</b>	<b>p-value</b>
Caregiver mental health issues: EQ5D (caregiver or family-related)	6 month post-birth interview	862	X <sup>2</sup> (2)=5.66	p=0.059
Caregiver mental health issues: EQ5D (caregiver or family-related)	18 month post-birth interview	823	X <sup>2</sup> (2)=50.60	p=0.000
Caregiver mental health issues: EQ5D (caregiver or family-related)	24 month post-birth interview	839	X <sup>2</sup> (2)=9.79	p=0.007
Family composition: large family: number living with (caregiver or family-related)	Baseline interview	1504	t(24.51)=1.97	p=0.057
Family composition: children in close succession (caregiver or family-related)	6 month post-birth interview	856	X <sup>2</sup> (1)=3.46	p=0.063
Parenting and family functioning: lack of experience as a caregiver: baby diet (caregiver or family-related)	24 month post-birth interview	874	X <sup>2</sup> (1)=4.83	p=0.028
Parenting and family functioning: lack of experience as a caregiver: anticipatory parenting (caregiver or family-related)	Late pregnancy interview	1144	t(105.47)=-4.88	p=0.000
Parenting and family functioning: less than adequate maternal care: number antenatal check-ups (caregiver or family-related)	Routinely collected birth data	1349	t(22.98)=-2.17	p=0.041
Parenting and family functioning: poor anger expression and management: annoyance at baby (caregiver or family-related)	12 month post-birth interview	867	X <sup>2</sup> (6)=32.13	p=0.000
Parenting and family functioning: parental stress: difficulty life skills (caregiver or family-related)	Baseline interview	1523	X <sup>2</sup> (1)=5.36	p=0.021

<b>Domain or sub-domain if applicable: risk factor variable</b>	<b>Data Source*</b>	<b>n</b>	<b>X<sup>2</sup> or t-test</b>	<b>p-value</b>
Parenting and family functioning: parents perceived own childhoods as unhappy: mother lived away from parents / Parenting and family functioning: poor stability and less security: mother lived away from parents (caregiver or family-related)	Baseline interview	1522	X <sup>2</sup> (1)=3.90	p=0.048
Parenting and family functioning: parents perceived own childhoods as unhappy: mother's parents separated (caregiver or family-related)	Baseline interview	1525	X <sup>2</sup> (3)=8.57	p=0.036
Parenting and family functioning: parents perceived own childhoods as unhappy: mother's parents separated BINARY (caregiver or family-related)	Baseline interview	1519	X <sup>2</sup> (2)=2.53	p=0.112
Parenting and family functioning: parents perceived own childhoods as unhappy: mother been homeless (caregiver or family-related)	Baseline interview	1528	X <sup>2</sup> (1)=6.41	p=0.011
Parenting and family functioning: parents perceived own childhoods as unhappy: mother been homeless / Parenting and family functioning: poor stability and less security: mother been homeless (caregiver or family- related)	18 month post- birth interview	266	X <sup>2</sup> (1)=2.86	p=0.091
Child disability, illness, development: First congenital abnormality (child- related)	Routinely collected birth data	1381	X <sup>2</sup> (1)=2.82	p=0.093
Child disability, illness, development: developmental delay: language development (child-related)	ELM	894	t(15.89)=2.38	p=0.030

Domain or sub-domain if applicable: risk factor variable	Data Source*	n	X <sup>2</sup> or t-test	p-value
Child gender (child-related)	Routinely collected birth data	1464	X <sup>2</sup> (1)=3.02	p=0.082
Socio-economic status: Low SES: family resources (social or extra-familial)	Baseline interview	1454	t(24.18)=2.55	p=0.017
Socio-economic status: unemployment (social or extra-familial)	Baseline	1528	X <sup>2</sup> (1)=4.46	p=0.034

\*all risk factors precede CIN outcome

**Table 13.** Markers found to be significant in univariable analyses for mothers with and without a child with a CIN status.

Domain or sub-domain if applicable: marker variable	Data Source*	n	X <sup>2</sup> or t-test	p-value
Physical signs of abuse and injuries: bites and bruises: contusion	NHS Digital A&E data	1237	X <sup>2</sup> (1)=4.10	p=0.043
Physical signs of abuse: other physical injuries: nerve injury	NHS Digital A&E data	1237	X <sup>2</sup> (1)=12.69	p=0.000
Physical signs of abuse: other physical injuries: electric shock	NHS Digital A&E data	1237	X <sup>2</sup> (1)=11.22	p=0.001
Clinical presentations other than injuries: failure to attend follow-up appointments	NHS Digital Outpatients data	1537	X <sup>2</sup> (1)=3.95	p=0.047
Clinical presentations other than injuries: immunisations number since last interview	12 month post-birth interview	969	t(11.61)=1.81	p=0.097
Parent/carer-child interactions: carer showing negativity	24 month post-birth interview	1067	t(15.62)=2.10	p=0.053

#### **4.4.1.2 CIN status: Logistic regression**

##### **Risk factors**

A logistic regression was run in the first instance containing all variables significant at univariable level (see table 12 for list) and just 135 participants were included in the analysis (1402 missing). No variables were found to be independently significant. The fact that only 135 participants were included in the analysis could possibly be the cause of there being no independently significant variables as this is a small dataset. Another logistic regression was therefore run with the variables found to be significant at univariable level from the baseline interview being firstly included as this was the most complete dataset, with the next datasets added in temporal order. As well as being a conceptual approach, including datasets into the logistic regression models in this way could also be seen as data driven i.e. many of the datasets utilised in this study had some missing data. When a dataset is added with smaller numbers it automatically restricts the whole analysis to that sample.

Variables converted to binary:

Variable: Parenting and family functioning: parents perceived own childhoods as unhappy: mother's parents separated (baseline)

Mothers whose parents were separated or divorced have been found to be at greater risk of having a maltreated child (62). This variable was collected in the baseline interview where mothers were asked if their parents had separated. As can be seen in table 10 (appendix 20) the item originally had four response categories (yes, no, never lived together, don't know) and was found to be significant in the univariable analyses for CIN status. This was converted into a binary variable for inclusion into the logistic regression, and can be seen in table 14. The first of the four response categories represented 'parents separated', the second and third response categories represented 'no change in status', and the fourth category represented missing data. The response categories were split in this way in order for the new (binary) variable to represent 'changed' or 'stable' status, which could represent both positive and negative states. There is also a relatively even split in distribution between these two new categories. The two original categories that formed 'no change in status' ('no' and 'never lived together') did show fairly similar associations with outcome of CIN status (23.0% and 19.2% respectively), with the category of parents separated being dissimilar to this at 46.2%. The univariable analyses (chi-square) were re-run with the new variable. This however was not found to be significant, and was therefore not included in the logistic regressions.

**Table 14.** Univariable results of variable ‘Mother’s parents separated (baseline) BINARY’ converted into binary for those with and without a CIN status.

	At least one CIN status  N=26		Without a CIN status  N=1511		Overall  N=1537	Univariable assoc. (Chi- squared, p- value)
	n	Median (IQR) or %	n	Median (IQR) or %	Median (IQR) or N (%)	
<b>Risk Factors for Child Maltreatment</b>						
Parenting and family functioning: parents perceived own childhoods as unhappy: mother’s parents separated (baseline) BINARY						N=1519  $\chi^2(2)=2.53$ , p=0.112
Parents separated	12	(46.2)	918	(60.8)	60.5	
No change to status	14	(53.8)	575	(38.0)	38.3	
Missing	0	(0.0)	18	(1.2)	1.2	

#### Model 1

A multivariable logistic regression was run containing variables found to be significant at univariable level for the baseline interview, 1445 participants were included in the analysis (92 missing). One independently significant variable was left in the model. Participants with a child who had been given a CIN status were *more* likely to have difficulties in life skills (table 16).

Variables from other datasets were included to the logistic regression in blocks by dataset in temporal order. Table 15 lists the variables found to be significant at univariable level in all datasets (excluding the baseline interview) and includes information on the order in which each dataset was included into the logistic regression model. The blocks of variables were

added to the regression until adding more variable blocks would not improve the model, i.e. that no variables were found to be independently significant in the model.

**Table 15.** Risk factor variables found to be significant at univariable level from all datasets (excluding the baseline interview) for CIN status and numbers of participants included

Domain or sub-domain if applicable: variable	Data source	Numbers of participants included
Parenting and family functioning: lack of experience as a caregiver: anticipatory parenting (caregiver or family-related)	Late pregnancy interview	1144
Child gender (child-related)	Routinely collected birth data	1464
Parenting and family functioning: less than adequate maternal care: number antenatal check-ups (caregiver or family-related)	Routinely collected birth data	1419
Child disability, illness, development: First congenital abnormality (child-related)	Routinely collected birth data	1381
Caregiver mental health issues: EQ5D (caregiver or family related)	6 month post-birth interview	862
Family composition: children in close succession (caregiver or family-related)	6 month post-birth interview	856
Parenting and family functioning: poor anger expression and management: annoyance at baby (caregiver or family-related)	12 month post-birth interview	867
Caregiver mental health issues: EQ5D (caregiver or family-related)	18 month post-birth interview	826
Parenting and family functioning: parents perceived own childhoods as unhappy: mother been homeless / Parenting and family functioning: poor stability and less security: mother been homeless (caregiver or family-related)	18 month post-birth interview	266

Child disability, illness, development: developmental delay: language development (child-related)	24 month post-birth interview	894
Parenting and family functioning: lack of experience as a caregiver: baby diet (caregiver or family-related)	24 month post-birth interview	874
Caregiver mental health issues: EQ5D (caregiver or family-related)	24 month post-birth interview	839

The method described above to include variables from datasets to the logistic regression in blocks in temporal order was further reviewed. After reviewing the numbers of participants included in each variable, it became apparent that including variables from the late pregnancy interview before variables collected from birth data would be problematic. This was due to the number of participants that could potentially be included from this dataset would be much smaller than those that could be included from the birth data. Including this dataset may also introduce bias as the late pregnancy interview was completed through self-report, therefore there may be some differences between those who chose to complete and not to complete the interview (this is in fact true for all self-report datasets). The routinely collected birth data were not collected through self-report and was instead collected through maternity records. It was therefore decided that variables from the late pregnancy interview would be included after routine birth data. As a note it should be kept in mind that although the baseline interview was also completed through self-report, all participants in the Building Blocks Trial were required to complete this before randomisation.

## Model 2

A logistic regression was run containing variables found to be significant at univariable level for the baseline interview plus the routinely collected birth data. 1340 participants were included in the analysis (197 missing). Three independently significant variables were left in the model (table 16).

Participants with a child who had been given a CIN status were *more* likely to have difficulties in life skills and a child with a congenital abnormality, and to have a higher number of antenatal check-ups.



### Model 3

A logistic regression was run containing variables found to be significant at univariable level for the baseline interview plus the routinely collected birth data plus the late pregnancy interview. 1099 participants were included in the analysis (438 missing). No independently significant variables were left in the model.

The final logistic regression (model 3) did not add any independently significant variables, and therefore model 2 is the final model in this analysis. It is possible that no variables were found to be independently significant in the third model as the 'anticipatory parenting' variables included from the late pregnancy interview reduced the size of the model. These questions were only asked of mothers who had not yet given birth to their baby when this interview was completed, therefore this excluded those who had already had their baby. The size of the dataset reduced by 241 participants from model two to model three. The routinely collected birth data were included in the final model as this was a mostly complete dataset. It was collected from maternity units, and was therefore not dependent on participant availability to self-report. The low missing numbers in this dataset meant that together with the baseline interview dataset three variables were found to be independently significant (table 16). Later time points could not be included in the model as doing this overly reduced the sample size.

**Table 16.** Independent predictors of CIN Status from variables found to be significant at univariable level.

	<b>Model 1: Baseline only N=1145</b>		<b>Model 2 (FINAL): baseline + birth data N=1340</b>	
	Unadjusted OR (95%CI)	Fully adjusted* OR (95%CI)	Unadjusted OR (95%CI)	Fully adjusted** OR (95%CI)
Parenting and family functioning: parental stress: difficulty life skills (Baseline)	2.44, CI 1.12 to 5.33	2.71, CI 1.17 to 6.28, p=0.02	2.44, CI 1.12 to 5.33	3.02, CI 1.23 to 7.44, p=0.02
Parenting and family functioning: less than adequate maternal care: number antenatal check-ups (Routinely collected birth data)			1.12, CI 1.01 to 1.24	1.14, CI 1.02 to 1.28. p=0.02
Child disability, illness, development: First congenital abnormality (Routinely collected birth data)			0.39, CI 0.12 to 0.34	0.19, CI 0.05 to 0.70, P=0.01

\*adjusted for all other risk factors in model 1

\*\*adjusted for all other risk factors in model 2

Although model two contained data from two mostly complete datasets, socio-demographic variables from the baseline interview describing the participants included and not included in the model were compared descriptively (chi square or t-tests). This was done to assess bias by investigating if there were any differences in terms of demographics (such as age), and various self-reported measures such as relationship quality or social support, between the two groups (table 17, appendix 22). Of the 1340 included in the final model, 21 of these had a CIN status, and of the 197 not included, 5 had a CIN status.

Those included in the final model were more likely to be older at recruitment, white, had higher levels of family subjective social status, self-efficacy, adaptive functioning, and social support. They had lower levels of antisocial behaviour, and were less likely to have been married or separated.

### Markers

A logistic regression was run containing all significant variables at univariable level (see table 11, appendix 21), and 828 participants were included in the analysis (709 missing). Three variables were found to be independently significant (table 18).

**Table 18.** Independent markers of CIN Status from variables found to be significant at univariable level.

	Unadjusted OR (95%CI) or Univariable assoc. (Chi- squared, p- value)	Fully adjusted* OR (95%CI)
Physical signs of abuse: other physical injuries: nerve injury (NHS Digital A&E data)	$\chi^2(1)=12.69$ , p=0.00	10.30, CI 2.10 to 50.30, p=0.00
Physical signs of abuse and injuries: bites and bruises: contusion injury (NHS Digital A&E data)	$\chi^2(1)=4.10$ , p=0.04	5.37, CI 1.30 to 22.14, p=0.02
Parent/carer-child interactions: carer showing negativity (24 month post-birth interview)	0.54, CI 0.28 to 1.05	0.34, CI 0.12 to 0.94, p=0.04

\*adjusted for all other risk factors in model

Participants with a child who had been given a CIN status were *more* likely to show their child negativity and were also more likely have a child who to at some point attended A&E with a nerve injury or a contusion injury. Two of these variables originated from the NHS Digital A&E

dataset, and the other was from the 24 month post-birth interview. Note the very large confidence intervals in the data from the A&E dataset, due to small numbers.

#### 4.4.1.3 Referral to Social Services: Descriptive results

A total of 71 (4.6%) children were referred to Social Services (irrespective of CIN status), 69 of these referrals were for singletons; with one twin pair being referred. Therefore 70 mothers had a child who was referred to Social Services. Age of child at first referral to Social Services ranged from -1 months old to 51 months old (4.25 years old), with a mean of 34.2 months old (standard deviation 10.7), and a median of 35.0 months old.

Risk factors and markers were compared between those with a child referred to Social Services or not (table 19 and table 20 respectively, appendices 23 and 24).

The risk factors and markers significant ( $<0.10$ ) at univariable level for those with and without a referral to Social Services are listed below (table 21 and table 22).

**Table 21.** Risk factors found to be significant in univariable analyses for mothers with and without a child referred to Social Services.

Domain or sub-domain if applicable: risk factor variable	Data Source*	n	X <sup>2</sup> or t-test	p-value
Caregiver mental health issues: Maternal anxiety (caregiver or family-related)	6 month post-birth interview	882	t(36.21)=-1.95	p=0.059
Caregiver mental health issues: EQ5D (caregiver or family-related)	18 month post-birth interview	879	X <sup>2</sup> (1)=4.88	p=0.027
Family composition: large family: number living with (caregiver or family-related)	6 month post-birth interview	945	t(42.66)=2.38	p=0.022
Family composition: large family: number living with (caregiver or family-related)	18 month post-birth interview	908	t(42.66)=1.86	p=0.071
Family composition: large family: number living with (caregiver or family-related)	24 month post-birth interview	876	t(39.81)=1.80	p=0.079

<b>Domain or sub-domain if applicable: risk factor variable</b>	<b>Data Source*</b>	<b>n</b>	<b>X<sup>2</sup> or t-test</b>	<b>p-value</b>
Family composition: large family: number of bedrooms (caregiver or family-related)	24 month post-birth interview	473	t(22.73)=-1.84	p=0.079
Family composition: children in close succession (caregiver or family-related)	24 month post-birth interview	947	X <sup>2</sup> (2)=10.62	p=0.005
Family composition: presence of a stepparent since last interview (caregiver or family-related)	6 month post-birth interview	888	X <sup>2</sup> (1)=3.01	p=0.080
Parenting and family functioning: less than adequate maternal care: number antenatal check-ups (caregiver or family-related)	Routinely collected birth data	1394	t(75.77)=-2.40	p=0.019
Parenting and family functioning: less than adequate maternal care: number unplanned attendances (caregiver or family-related)	Routinely collected birth data	1394	t(68.91)=-1.71	p=0.092
Parenting and family functioning: poor anger expression and management: annoyance at baby (caregiver or family-related)	12 month post-birth interview	912	X <sup>2</sup> (6)=15.18	p=0.019
Parenting and family functioning: poor anger expression and management: annoyance at baby (caregiver or family-related)	18 month post-birth interview	860	X <sup>2</sup> (5)=14.78	p=0.011
Parenting and family functioning: less positive affection: when leaving baby (caregiver or family-related)	18 month post-birth interview	856	X <sup>2</sup> (4)=12.76	p=0.013
Parenting and family functioning: parental stress: difficulty life skills (caregiver or family-related)	Baseline interview	1525	X <sup>2</sup> (1)=6.95	p=0.008

<b>Domain or sub-domain if applicable: risk factor variable</b>	<b>Data Source*</b>	<b>n</b>	<b>X<sup>2</sup> or t-test</b>	<b>p-value</b>
Parenting and family functioning: parents perceived own childhoods as unhappy: mother's parents separated (caregiver or family-related)	Baseline interview	1527	X <sup>2</sup> (3)=10.95	p=0.012
Parenting and family functioning: parents perceived own childhoods as unhappy: mother's parents separated BINARY (caregiver or family-related)	Baseline interview	1521	X <sup>2</sup> (2)=0.29	p=0.588
Parenting and family functioning: parents of maltreated children perceived their own childhoods as being unhappy, poor relationships with their own parents, conflict in a family or a lack of family cohesion, Poor family functioning: Mother been homeless (caregiver or family-related)	24 month post- birth interview	476	X <sup>2</sup> (1)=3.24	p=0.072
Child disability, illness, development: developmental delay: language development (child-related)	ELM	894	t(43.39)=2.25	p=0.030
Social support (social or extra-familial)	12 month post- birth interview	871	t(44.92)=2.36	p=0.023
Neighbourhood and community: poverty, instability and economic disadvantage: postcode (Index of Multiple Deprivation) / Socio- economic status: Low SES: postcode (Index of Multiple Deprivation) (social or extra-familial)	Baseline interview	1518	t(75.27)=-4.00	p=0.000
Socio-economic status: Low SES: family resources (social or extra- familial)	18 month post- birth interview	1518	t(35.37)=2.01	p=0.052

<b>Domain or sub-domain if applicable: risk factor variable</b>	<b>Data Source*</b>	<b>n</b>	<b>X<sup>2</sup> or t-test</b>	<b>p-value</b>
Socio-economic status: receiving benefits currently (social or extra-familial)	24 month post-birth interview	946	X <sup>2</sup> (1)=3.74	p=0.053
Socio-economic status: unemployment (social or extra-familial)	Baseline interview	1530	X <sup>2</sup> (1)=8.23	p=0.004
Socio-economic status: unemployment (social or extra-familial)	24 month post-birth interview	332	X <sup>2</sup> (1)=7.15	p=0.007

\*all risk factors precede referral to Social Services

**Table 22.** Markers found to be significant in univariable analyses for mothers with and without a child referred to Social Services.

<b>Domain or sub-domain if applicable: marker variable</b>	<b>Data Source*</b>	<b>n</b>	<b>X<sup>2</sup> or t-test</b>	<b>p-value</b>
Physical signs of abuse: head injuries	NHS Digital A&E data	1237	X <sup>2</sup> (1)=7.12	p=0.007
Physical signs of abuse: ano-genital	NHS Digital A&E data	1237	X <sup>2</sup> (1)=6.53	p=0.011
Physical signs of abuse: other physical injuries: poisoning	NHS Digital A&E data	1237	X <sup>2</sup> (1)=4.74	p=0.029
Physical signs of abuse: other physical injuries: any	NHS Digital Inpatients data	1537	X <sup>2</sup> (1)=9.26	p=0.002
Physical signs of abuse: other physical injuries: nerve injury	NHS Digital A&E data	1237	X <sup>2</sup> (1)=3.64	p=0.057
Physical signs of abuse: other physical injuries: electric shock	NHS Digital A&E data	1237	X <sup>2</sup> (1)=3.14	p=0.076
Clinical presentations other than injuries: failure to attend follow-up appointments	NHS Digital Outpatients data	1537	X <sup>2</sup> (1)=6.11	p=0.013

#### **4.4.1.4 Referral to Social Services: Logistic regression**

##### **Risk factors**

A logistic regression was run in the first instance containing all significant variables at univariable level. Just 77 participants were included in the analysis (1460 missing), and no variables were found to be independently significant. The same approach as in the primary outcome was therefore taken, firstly converting variables to binary where required, and then adding datasets in temporal order into a logistic regression model.

Variables converted to binary:

Variable: Parenting and family functioning: parents perceived own childhoods as unhappy: mother's parents separated (baseline)

See justification for splitting into binary in results for the third objective: CIN Status. The univariable analyses (chi-square) were re-run with the new variable (table 23). This however was not found to be significant, and was therefore not included in the logistic regressions. The two original categories that formed 'no change in status' ('no' and 'never lived together') did show fairly similar associations with outcome of CIN status (20.0% and 14.3% respectively), with the category of parents separated being dissimilar to this at 57.2%.



**Table 23.** Univariable results of variable ‘mother’s parents separated (baseline) BINARY’ converted into binary for referral to Social Services.

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi-squared, p-value)
	n	Median (IQR) or %	n	Median (IQR) or %	Median (IQR) or N (%)	
<b>Risk Factors for Child Maltreatment</b>						
Parenting and family functioning: parents perceived own childhoods as unhappy: mother’s parents separated (baseline) BINARY						N=1521 $\chi^2(2)=0.29$ , p=0.588
Parents separated	40	(57.2)	889	(60.6)	60.4	
No change to status	29	(41.4)	563	(38.4)	38.5	
Missing	1	(1.4)	15	(1.0)	1.1	

#### Model 1

A logistic regression was run containing variables found to be significant at univariable level for the baseline interview, 1520 participants were included in the analysis (17 missing). All three baseline variables included were found to be independently significant. Participants with a child who had a referral to Social Services were *more* likely to have difficulties in life skills, were more deprived, and were more likely to be unemployed (table 25).

Variables from other datasets were included to the logistic regression in blocks by dataset in temporal order. Table 24 lists the variables found to be significant at univariable level in all datasets (excluding the baseline interview) and includes information on the order in which each dataset was included into the logistic regression model. The blocks of variables were added to the regression until adding more variable blocks will not improve the model, i.e. that no variables were found to be independently significant in the model.

**Table 24.** Variables found to be significant at univariable level in all datasets (excluding the baseline interview) for referral to Social Services and numbers of participants included

<b>Variables significant at univariable level (not including those from the baseline interview)</b>	<b>Data Source</b>	<b>Numbers of participants included</b>
Parenting and family functioning: less than adequate maternal care: number antenatal check-ups (caregiver or family-related)	Routinely collected birth data	1394
Parenting and family functioning: less than adequate maternal care: number unplanned attendances (caregiver or family-related)	Routinely collected birth data	1394
Family composition: large family: number living with (caregiver or family-related)	6 month post-birth interview	945
Family composition: presence of a stepparent since last interview (caregiver or family-related)	6 month post-birth interview	888
Caregiver mental health issues: Maternal anxiety (caregiver or family-related)	6 month post-birth interview	882
Social support (social or extra-familial)	12 month post-birth interview	974
Parenting and family functioning: poor anger expression and management: annoyance at baby (caregiver or family-related)	12 month post-birth interview	912
Family composition: large family: number living with (caregiver or family-related)	18 month post-birth interview	908
Caregiver mental health issues: EQ5D (caregiver or family-related)	18 month post-birth interview	879
Parenting and family functioning: poor anger expression and management: annoyance at baby (caregiver or family-related)	18 month post-birth interview	860
Socio-economic status: Low SES: family resources (social or extra-familial)	18 month post-birth interview	859
Parenting and family functioning: less positive affection: when leaving baby (caregiver or family-related)	18 month post-birth interview	856

<b>Variables significant at univariable level (not including those from the baseline interview)</b>	<b>Data Source</b>	<b>Numbers of participants included</b>
Family composition: children in close succession (caregiver or family-related)	24 month post-birth interview	947
Socio-economic status: receiving benefits currently (social or extra-familial)	24 month post-birth interview	946
Child disability, illness, development: developmental delay: language development (child-related)	24 month post-birth interview	894
Family composition: large family: number living with (caregiver or family-related)	24 month post-birth interview	876
Parenting and family functioning: parents of maltreated children perceived their own childhoods as being unhappy, poor relationships with their own parents, conflict in a family or a lack of family cohesion, Poor family functioning: Mother been homeless (caregiver or family-related)	24 month post-birth interview	476
Family composition: large family: number of bedrooms (caregiver or family-related)	24 month post-birth interview	473
Socio-economic status: unemployment (social or extra-familial)	24 month post-birth interview	332

## Model 2

A logistic regression was run containing variables found to be significant at univariable level for the baseline interview plus the routinely collected birth data. 1450 participants were included in the analysis (87 missing). Three independently significant variables were left in the model. Mothers with a child who had a referral to Social Services were *more* likely to have difficulties in life skills, were more deprived, and more likely to have a higher number of antenatal check-ups (table 25).

### Model 3

A logistic regression was run containing variables found to be significant at univariable level for the baseline interview plus the routinely collected birth data plus the 6 month post-birth interview. 913 participants were included in the analysis (624 missing). One independently significant variable was left in the model (table 25).

Participants with a child who had a referral to Social Services were *more* likely to be deprived. This model added nothing new, and adding the variables collected at 6 month post-birth meant that two variables found significant in an earlier model (model 2) were no longer independently significant. This may be because adding the variable from the 6 month post-birth interview reduced the size of the dataset by 537 participants, therefore model 2 will be the final model. Later time points could not be included in the model as doing this overly reduced the sample size.

**Table 25.** Independent predictors of referral to Social Services from variables found to be significant at univariable level.

	<b>Model 1: Baseline only N=1520</b>		<b>Model 2 (FINAL): baseline + birth data N=1450</b>		<b>Model 3: baseline + birth data + 6 month N=913</b>	
	Unadjusted OR (95%CI)	Fully adjusted* OR (95%CI)	Unadjusted OR (95%CI)	Fully adjusted** OR (95%CI)	Unadjusted OR (95%CI)	Fully adjusted*** OR (95%CI)
Parenting and family functioning: parental stress: difficulty life skills (Baseline)	1.93, CI 0.12 to 0.71	1.73, CI 10.5 to 2.84, p=0.03	1.93, CI 0.12 to 0.71	1.74, CI 1.05 to 2.91, p=0.03		
Neighbourhood and community: poverty, instability and	1.03, CI 0.01 to 0.04	1.03, CI 1.01 to 1.04, p=0.00	1.03, CI 0.01 to 0.04	1.03, CI 1.01 to 1.04, 0.00	1.03, CI 0.01 to 0.04	1.03, CI 1.01 to 1.05, p=0.01

economic disadvantage: postcode (Index of Multiple Deprivation) (Baseline)						
Socio-economic status: unemployment (Baseline)	0.29, CI 0.12 to 0.71	0.37, CI 0.15 to 0.93, p=0.03				
Parenting and family functioning: less than adequate maternal care: number antenatal check-ups (Routinely collected birth data)			1.08, CI 1.01 to 1.15	1.08, CI 1.01 to 1.16, p=0.03		

\*adjusted for all other risk factors in model 1

\*\*adjusted for all other risk factors in model 2

\*\*\*adjusted for all other risk factors in model 3

Even though model 2 contained data from two mostly complete datasets, socio-demographic variables from the baseline interview describing the participants included and not included in the model were compared descriptively (chi square or t-tests). This was to investigate if there were any differences between the two groups (table 26, appendix 25). Of the 1439 included in the final model, 21 of these had a referral to Social Services, and of the 98 not included, 2 had a referral.

Those included in the final model were more likely to be white and to have higher levels of family resources.

## Markers

A logistic regression was run containing all significant variables at univariable level (see table 20, appendix 24), and 1537 participants were included in the analysis (0 missing). Two variables were found to be independently significant (table 27).

**Table 27.** Independent markers of referral to Social Services from variables found to be significant at univariable level.

	Unadjusted OR (95%CI) or Univariable assoc. (Chi- squared, p- value)	Fully adjusted* OR (95%CI)
Physical signs of abuse: head injury (NHS Digital A&E data)	$\chi^2(1)=7.12$ , p=0.01	1.91, CI 1.14 to 3.19, p=0.01
Physical signs of abuse: ano-genital injury (NHS Digital A&E data)	$\chi^2(1)=6.53$ , p=0.01	1.77, CI 1.06 to 2.79, p=0.03

\*adjusted for all other risk factors in model

Participants with a child who had been referred to Social Services were *more* likely have a child who to at some point attended A&E with a head injury or an ano-genital injury. Both these variables originated from the NHS Digital A&E dataset.

To recap, table 28 below depicts all independent risk factors and markers of both CIN status and referral to Social Services.

**Table 28.** Independent risk factors and markers of CIN status and referral to Social Services from variables found to be significant at univariable level.

	<b>CIN status</b>	<b>Referral to Social Services</b>
<b>Domain or sub-domain if applicable: risk factor final model (data source)</b>	<p>-Parenting and family functioning: parental stress: difficulty life skills (Baseline interview)</p> <p>-Parenting and family functioning: less than adequate maternal care: number antenatal check-ups (Routinely collected birth data)</p> <p>-Child disability, illness, development: First congenital abnormality (Routinely collected birth data)</p>	<p>-Parenting and family functioning: parental stress: difficulty life skills (Baseline interview)</p> <p>-Neighbourhood and community: poverty, instability and economic disadvantage: postcode (Index of Multiple Deprivation) (Baseline interview)</p> <p>-Parenting and family functioning: less than adequate maternal care: number antenatal check-ups (Routinely collected birth data)</p>
<b>Domain or sub-domain if applicable: marker (data source)</b>	<p>-Physical signs of abuse: other physical injuries: nerve injury (NHS Digital A&amp;E data)</p> <p>-Physical signs of abuse and injuries: bites and bruises: contusion injury (NHS Digital A&amp;E data)</p> <p>-Parent/carer-child interactions: carer showing negativity (24 month post-birth interview)</p>	<p>-Physical signs of abuse: head injury (NHS Digital A&amp;E data)</p> <p>-Physical signs of abuse: ano-genital injury (NHS Digital A&amp;E data)</p>

#### 4.4.2 Case Studies

The risk factors and markers found to be independently significant predictors of a CIN status are listed below:

- More likely for parent to report difficulty with life skills (collected during baseline interview).
- Likely to have more antenatal check-ups (collected from routinely collected birth data).
- More likely to have child with a congenital abnormality (collected from the routinely collected birth data).
- More likely to have signs of nerve injury to child (collected from the NHS Digital A&E data).
- More likely to have signs of contusion injury (collected from the NHS Digital A&E data).
- More likely for parent to report showing some negativity towards child (collected during the 24 month post-birth interview).

A pool of 1537 cases could be selected, there were 26 mothers who had a child(ren) with at least one CIN status, and 1511 mothers whose child(ren) did not have a CIN status. One case from each of the two pools was randomly selected.

Each case study was reviewed and the evidence (risk factor or marker) present for a mother child dyad (or triad) is described below.

Any risk factors and markers (from the literature review) found in a case study are included in the figures, even ones that were not significant at univariable level or independently significant. These were included to illustrate the variety of risk factors and markers that may appear in real life cases that do not significantly predict CIN status but are nonetheless important to include to provide a complete picture of the case study. Both women in the case studies were part of the Building Blocks cohort, and so some of the content of these case reports will utilise information about the cohort as a whole for context. As previously described some risk factors and markers were associated, sometimes significantly, with CIN status. When risk factors or markers associated with CIN status are present in the case studies this will be highlighted. Some details that may identify an individual have been removed.

#### **Case study 1 – mother had a child(ren) with at least one CIN status**

This was an XX year old woman enrolled onto the Building Blocks Trial in early pregnancy when she was interviewed about her background, her current circumstances, and her pregnancy. Her personal circumstances during early pregnancy were difficult. She lived away from her



parents in a small home with one bedroom, a smaller number than most women in the Building Blocks cohort. She was unemployed and was in receipt of benefits. Living away from parents and unemployment are both predictive of CIN status. Her baby's father was XX years old, younger than most of the other fathers of the children in the Building Blocks cohort. She reported at the time that she had some difficulties with life skills. Difficulty in life skills is a composite scale measure derived from five items. This measures the ability to organise one's life e.g. having a bank account. Difficulties in life skills was a risk factor *independently* predictive of CIN status.

At late pregnancy she was interviewed further. During which she was asked about her thoughts on child rearing practices. This was the anticipatory parenting measure, and included such items as asking for agreement if babies should be picked up whenever they cry. She scored lower on this measure than most women in the Building Blocks cohort. She anticipated she would use a less structured rearing environment when her baby was born, a predictor of CIN status. The numbers of contacts with her midwife were less than those for most women in the Building Blocks cohort. She gave birth to a daughter. A female gender of baby is also predictive of CIN status.

She was unable to be followed-up by the interviewer again until her daughter was 18 months old, when she was interviewed for a final time. She had moved home since her last interview. In her current home she had a large number of people living with her, more than most women in the Building Blocks cohort. There were some concerns raised in the interview about child safety in the home. Scores on a child safety measure, including questions such as asking if stair gates had been installed, were lower than the that for most other women in the Building Blocks cohort. During this interview she also reported that she was pregnant again. She was unemployed, and she had been homeless since her last interview in late pregnancy, a predictor of CIN status. She reported being extremely anxious and depressed, another predictor of CIN status. She also scored higher than most other women in the Building Blocks cohort on a measure of parental role strain, this measure is about the different sorts of feelings parents might have when caring for young children. Finally, during the interview she was asked some questions about her daughter, including about her development. It became apparent that her daughter had some language delay compared to what may be expected for a child of her age.

Her GP records were also reviewed. She had visited her GP with concerns regarding her mental health more times than most other women in the Building Blocks cohort. Records from the Department of Education relating to Social Services contacts were also reviewed, her daughter was given a CIN status at age XX.

### **Case study 2, where the mother did not have a child(ren) with a CIN status**

This woman was XX years old when she enrolled onto the Building Blocks Trial, younger than most other women in the Building Blocks cohort. She was interviewed in early pregnancy about her background, her current circumstances, and her pregnancy. During this period she did not live with the father of her baby or her parents, and was homeless. Her parents had previously separated. Living away from parents, being homeless and having parents who have separated are all predictive of CIN status. She reported that she felt some burden due to her living circumstances, for example from lack of privacy and scored higher on a measure of burden compared to most other women in the Building Blocks cohort. She was in receipt of benefits and reported that she did not enough money to pay monthly bills, dependable transportation, money to buy things for herself and money to save. This was identified via the family resources scale on which she scored lower than most women in the Building Blocks cohort. She was a current user of alcohol and/or drugs, scoring higher than the majority of the women in the Building Blocks cohort on a measure of this. Finally, during this interview she reported that she did not receive much social support, and had low self-efficacy compared to other women in the Building Blocks cohort.

She was interviewed for a second time during late pregnancy, during which she scored lower than most other women in the Building Blocks cohort on an anticipatory parenting measure. She anticipated she would use a less structured rearing environment when her baby was born, a predictor of CIN status.

Her hospital records were reviewed. During her pregnancy she had received a higher number of antenatal check-ups than most women in the Building Blocks cohort. Receiving a higher number of antenatal check-ups was a risk factor *independently* predictive of CIN status. During her pregnancy she also made a number of unplanned attendances at hospital, more than most women in the Building Blocks cohort. She gave birth to a boy with a lower birthweight than most babies born in the Building Blocks cohort.

When her son was six months old she was interviewed. She had been homeless again since the last interview a late pregnancy. In findings similar to her previous interviews she reported that she lacked social support, had low self-efficacy and that she still did not have enough money to pay monthly bills, arrange dependable transportation, and to buy things for herself or save. At this interview she also reported that she was having problems in her relationship. She scored lower than on a relationship quality score compared to most women in the Building Blocks cohort. She also showed some indication of possible postnatal depression as she scored higher on a scale measuring this than most women in the Building Blocks cohort. She was asked some questions about her son, specifically about whether he had received his immunisations to date. The number he had received was lower than that for most women in the Building Blocks cohort.

She was unable to be followed-up by the interviewer again until her son was 24 months old, when she was interviewed for a final time. She reported that she had been homeless again since the last interview and that she was currently unemployed and on benefits. She scored higher than most other women in the Building Blocks cohort on a scale measuring domestic abuse. She was still lacking social support, had low self-efficacy and little money. She reported being depressed and anxious and having little interest in doing things. Finally, during the interview she was asked some questions about her son, when she mentioned that she had had some contacts with a XXXX service. She was asked questions about her son's diet and revealed that he did not have healthy food daily. Her son scored lower than most other children in the Building Blocks cohort on a measure of language development. A lack of healthy food daily and language delay are predictors of CIN status.

Her GP records were reviewed. She has visited her GP with concerns regarding her mental health more times than most other women in the Building Blocks cohort. Her GP record also showed that she had been pregnant since the birth of her son. Her hospital records were also reviewed; she had visited A&E when her son sustained XXXX injuries. Records from the Department of Education relating to Social Services contacts were also reviewed, her son had not been given a CIN status at any point.

Some of the findings of the case studies were consistent with the model constructed from the results of the third objective (CIN status). Case one, who had a child with a CIN status did report difficulty in life skills at baseline, this risk factor was an independently significant

predictor of CIN status in the model. There were however other aspects of the case studies that were less consistent with the model. Case two, who did not have a child with a CIN status also had one risk factor that was found to be an independently significant predictor of CIN status, the number antenatal check-ups was greater than the median. This risk factor originated from the routinely collected birth data. As CIN status is the focus for these case studies, too much weight shouldn't be given to the presence of a referral to Social Services. It was interesting to note however that case two also had a marker that was independently predictive of a referral to Social Services, the child was admitted to A&E with an ano-genital injury. Most of the risk factors and markers in the model were not represented in the case studies, including the birth of a child with a congenital abnormality, mother reporting to showing some negativity towards their child, and a child who at some point attended A&E with a nerve injury or a contusion injury. Interestingly, both case studies one and two had some risk factors in common, these included one that was significant at univariable level, the anticipatory parenting score at late pregnancy was lower than the median in both cases. Unexpectedly, case two, where the mother did not have a child with a CIN status, had a greater number of risk factors and markers than case one. However, although there were a greater number, there were no more risk factors and markers that were significant at univariable level or independent predictors of a CIN status. Regardless of these results it should be kept in mind that it is unlikely is it that any one randomly selected case would ever really show support the model. The case studies are helpful in understanding the pattern of variables that could be related to outcome, and how that picture may look for an individual family. The final regression model will have only explained a portion of all variance in outcome and there will be a limit in how predictive the combination of these variables will actually be for a population, and then an even smaller level of apparent association at an individual level.

## **4.5 Discussion**

### **4.5.1 Key findings**

#### **4.5.1.1 CIN status and referral to Social Services**

Mothers with a child who had been given a CIN status had risk factors that included being more likely to report having higher levels of parental stress, a higher number of antenatal check-ups, and more likely to have a child with a congenital abnormality. They had markers that included being more likely to show their child negativity, or having a child who at some point prior to being a CIN attended A&E with a nerve or contusion injury. Mothers with a child who had been referred to Social Services had risk factors that included being more likely to

report having higher parental stress, to be more deprived, and have a higher number of antenatal check-ups. They had markers that included having a child who to at some point prior to being a CIN attended A&E with a head or ano-genital injury.

The third objective the study addressed the advantages and disadvantages of variables derived from various data sources for collecting data that may point to maltreatment. This was completed by detailing the process of selecting variables via a literature review (for inclusion in the analysis) which included evaluating the advantages and disadvantages of each variable from each data source included in the Building Blocks Trial and Building Blocks: 2-6 Study that may point to maltreatment. A clear approach was taken to variable identification via literature review, and a systematic assessment of each variable against a structured framework was undertaken. Some recommendations can be made, focusing on data quality, availability and completeness. Firstly, if at all possible, researchers should not utilise a dataset that contains a subset of participants, particularly if members of the subset have characteristics that a researcher would expect to be somehow different from the overall participant pool. As an example, the FNP dataset was not utilised in the current study as it contained a subset of participants from the Building Blocks Trial, due to the data being only available for those in the intervention arm of the trial. Secondly, researchers are advised to use caution when utilising a dataset or variables contained within a dataset if it is less complete than another comparable and accessible dataset that contains similar data. For example, variables from routinely collected GP data were avoided if there were similar variables collected in other datasets, because the GP data were collected for only a subset of mothers. This is *similar* to the first point of advice given above, however, the participants contained in the GP dataset were not characteristically different from those not in the dataset. Thirdly, researchers must keep in mind that, it is possible that *some* data items collected via self-report, for example through interviews, may be less reliable than routinely collected data. For example, in the Building Blocks Trial, the number of A&E attendances for injuries and ingestions was collected through both participants' self-report and through routinely collected hospital data. The data collected from hospital data were deemed to be the most reliable for two reasons, firstly, because mothers may not accurately recall how many times they had attended A&E with their child, and secondly, because social desirability bias may play a part. Mothers may feel uncomfortable reporting A&E attendance information to a researcher. Self-report may be more useful for other types of data items, and indeed will be the only way to measure subjective items such as how a participant is feeling or what they are thinking. Self-report may also be used when a

researcher wants to use a particular measure not available through routine data. Even though in the future increasing use of self-report data may also be recorded in routine data (such as for Patient Reported Outcome Measures), some consideration still needs to be given to data validity. This is because the way data are collected may influence outcomes, for example, if well-being is reported to a GP or to a researcher.

#### **4.5.1.2 Case Studies**

The findings of the fifth objective are somewhat mixed. Some of the findings of the case studies were consistent with the model constructed from the results of the third objective (CIN status). One case did report difficulty in life skills at baseline, and this risk factor was an independently significant predictor of CIN status in the model. There were however other aspects of the case studies that were less consistent with this model, and most of the risk factors and markers in the model were not represented in the case studies. As mentioned previously, it should be kept in mind that it is unlikely is it that any one randomly selected case would ever really support the model and that the case studies are merely helpful in understanding the pattern of variables that could be related to outcome. It should also be kept in mind that there will be other risk factors and markers not collected and therefore not used in the current study that are influential in driving the outcomes. If that is the case, then the case studies will be to some extent limited in their ability to showcase a model. Interestingly, both case studies had some risk factors in common, these included one that was significant at univariable level, the anticipatory parenting score at late pregnancy which was lower than the median in both cases. This is interesting because for this variable a quarter of the data were missing, this begs the question if the dataset would have been more complete would this have been an independently significant predictor? The loss of power due to attrition and/or potential bias may have affected this association.

### **4.5.2 Methodological considerations, data quality and limitations**

#### **4.5.2.1 Reliability**

##### **Outcome variables**

It is important to keep in mind that the outcome variables utilised for the first and second outcomes (CIN status and referral to Social Services) are merely *indicators* of child maltreatment. These variables only relate to child maltreatment that has been referred to Social Services. As described in the literature review on the challenges of estimating the prevalence of child maltreatment (section 2.1), cases of maltreatment that come to the

attention of Social Services or the police are only a portion of the true numbers (369; 370). There are many more that go undetected, unreported or unrecorded (197). Fallon et al (2010) likens this to the tip of the iceberg analogy. Using these outcomes may therefore be an underestimate of the true number of cases of child maltreatment.

It is also possible (though unlikely) that using these outcomes represent an overestimation of the true cases of child maltreatment. Not all cases referred to Social Services progress through the system and result in confirmed as cases of child maltreatment (see figures 2 and 3, appendices 3 and 4), and indeed not every child given an 'in need' status is due to a child protection issue (but in this case most were). Children can be given a CIN status for various reasons including if they have a disability.

Although definitions of the outcomes of referral to Social Services and CIN status can be provided, these concepts are not static. For example, whether a child is referred to Social Services is dependent on a maltreatment concern being identified by a particular person at a particular time. Whether a child is given a CIN status may be largely dependent on decisions made in the Social Services team and a host of other variables. These factors are largely based on the decision making of individuals, for example a teacher, and this can be dependent on many factors. They may make a decision for example based on previous experiences, or compare the child to other children. It may also be the case that individual differences are greater at the stage of referral than after referral (and when deciding about CIN status). It should be kept in mind however that individual decision-making to refer and then to proceed with a case will of course be guided by policy.

#### **Do the independently significant variables reflect the domains well?**

Risk factors and markers for child maltreatment identified in the literature (section 4.1) were put into an overall domain (and primary/secondary sub-domain). These domains were devised by the researcher and guided by the way the risk factors were grouped in the aforementioned literature review. The researcher reviewed each of these domains and primary/secondary sub-domains and listed each variable or group of variables collected in the Building Blocks Trial or Building Blocks: 2-6 Study that were used to represent each of these. Each of the independently significant risk factors and markers (variables) are reviewed below. This is to assess their validity i.e. consider whether they can truly be regarded as falling within one or other of the domains and primary/secondary sub-domains from which they were located.

## Risk factors

### *Parenting and family functioning: parental stress*

One of the variables used to reflect this domain and primary/secondary sub-domain was a 'difficulty with life skills' sub-scale of a measurement of 'adaptive functioning' collected in the baseline interview in the Building Blocks Trial. This was found to be an independently significant predictor of both CIN status and referral to Social Services. The measure was a composite scale measure derived from five items. These items asked mothers if they ate at least one a meal a day with family or friends, had a diary or a calendar for keeping track of appointments, had a phone, had a bank account, and whether they planned their spending money and had a budget.

Other researchers cited in the aforementioned literature review utilised various ways of measuring parental stress, ranging from using a checklist of stressful life events (109), to creating a stressful environment by using a situational stressor (a videotape of a crying infant) (372). Most researchers (77; 80; 107; 110; 179) measured stress using various editions of the Parenting Stress Index (PSI), created by Abidin. The PSI is based on a three-factor model of parental stress (179). The first factor labelled 'parental distress' does contain some items that are comparable to the parental stress measure in the current research, including the PSI's measurement of social isolation, which may be tapping into a similar construct to the item asking mothers if they ate at least one a meal a day with family or friends. Smith and Alder (1991) included a stress score in their assessments, which was a modification of Beautrais and Fergusson's stress score (373). One of the factors of the measurement used by Smith and Adler (1991), stability of living conditions of families, is likely to be a similar construct to the items in the current research where mothers were asked about whether they have a diary, a phone, a bank account, and if they budget.

On balance, it seems reasonable that the 'difficulty life skills' sub-scale could be associated with parental stress, although may not be a direct measure of it.

### *Parenting and family functioning: less than adequate prenatal care*

One of the variables used to reflect this domain and primary/secondary sub-domain were the number of antenatal check-ups collected in the routinely collected birth data in the Building Blocks Trial. This was found to be an independently significant predictor of both CIN status and referral to Social Services. This variable is thought to be a suitable measure of less than



adequate maternal care as women are expected to attend a certain number of check-ups before birth. Failing to reach this number would be indicative of receiving less than adequate care. It can be speculated that this may be more likely to be associated with women not accessing available care rather than not being offered it. This may be due to a number of factors, for example lack of interest, motivation, capacity, or availability to attend. Wu et al (2004) found that inadequate prenatal care, as measured in the same way as in the present research i.e. by counting expected visits, was significantly related to child maltreatment. It should be kept in mind however that the Wu et al (2004) study was run in the US and differences in usual care provided may also play a part. In the current study it was hypothesised that a woman with a lower number of antenatal check-ups would be more likely to have a child with a CIN status or a referral to Social Services, however, the direction of the effect was the opposite to what was anticipated. A possible explanation for this direction of effect is that the Community Midwife, who is responsible for arranging the antenatal check-ups, may have had a concern for the woman or family early on and thus arranged a greater number of visits with the woman. It is also possible that for the same reasons the Community Midwife went to great effort to ensure that the woman was present for all her antenatal check-ups.

#### *Child disability, illness, development: disability*

The variable used to reflect this domain and primary/secondary sub-domain was whether a child had a congenital abnormality, which was collected in the routinely collected birth data in the Building Blocks Trial. This was found to be an independently significant predictor of CIN status. Congenital abnormalities can contribute to long-term disability (374), this variable is therefore thought to be a suitable marker of disability. It should also be kept in mind however that not all congenital abnormalities result in a disability. In some ways it's unsurprising that this variable was found to be an independently significant predictor as children are often given a CIN status if they have a disability (whether child maltreatment is present or not). In England in year ending March 2017 the children given 'in need' status due to abuse and neglect comprised 52% of the total children in need (375), and 51% in the year ending in March 2016 (376). Some of the other children have been given the status for example due to a disability (13%) (375). Sullivan and Knutson (2000) state that more research is needed to assess maltreatment risk in both congenital and acquired disabilities.

### *Neighbourhood and community: poverty, instability and economic disadvantage*

The variable used to reflect this domain and primary/secondary sub-domain was the mothers' postcode collected in the baseline interview in the Building Blocks Trial. This was found to be an independently significant predictor of referral to Social Services. The postcode was used to calculate an Index of Multiple Deprivation (IMD) score. This variable is a good measure of poverty or economic disadvantage. The IMD is described as the official measure of relative deprivation for small areas (or neighbourhoods) in England, and ranks every small area in England from most deprived area to least deprived (377). IMD score is likely to be a good indication of relative deprivation for the family, although as it's an area-based measure, it's also possible that some individuals may experience less or more actual poverty than the index score would suggest. Nevertheless, this measure provides a useful picture of the family's immediate social context.

### Markers

#### *Physical signs of abuse: other physical injuries*

One of the variables used to reflect this domain and primary/secondary sub-domain was a nerve injury diagnosis in a child who attended A&E. This was collected in the A&E NHS Digital Dataset in the Building Blocks: 2-6 Study. This was found to be an independently significant predictor of CIN status. No other studies have looked specifically at whether 'nerve injuries' are predictors of child maltreatment, and therefore for the purposes of the current research this was listed under the domain of 'other physical injuries'. It is reasonable to describe a nerve injury as a physical injury. NICE Guidelines (2017) advises clinicians to be aware of any physical injuries that are present in the absence of major confirmed accidental trauma or a known medical explanation. Even though some caution should be taken when interpreting this result due to small numbers, this was a statistically significant relationship and likely to be a good predictor of CIN status.

#### *Physical signs of abuse: bites and bruises*

One of the variables used to reflect this domain and primary/secondary sub-domain was a contusion diagnosis in a child who attended A&E, this was collected in the A&E NHS Digital Dataset in the Building Blocks: 2-6 Study. This was found to be an independently significant predictor of CIN status. This variable is a very suitable measure of bites and bruises as it described exactly that. Although caution should be taken when interpreting this result as the numbers of children admitted with bites and bruises were very small, this was a statistically

significant relationship therefore this is likely to be a good predictor of CIN status. This was an interesting finding as bruises have been found to be the most common injury caused by child physical abuse (19).

*Parent/carer-child interactions: carer showing negativity*

One of the variables used to reflect this domain and primary/secondary sub-domain were a subset of items from the 'Parental Role Strain' measurement collected in the 24 month post-birth interview in the Building Blocks Trial. This was found to be an independently significant predictor of CIN status. The measurement was developed by Condon and Dunn (1988) and Condon & Corkindale (1998), and named 'Parental Role Strain' in the Building Blocks Trial (this scale was not given a name by the original authors). Six out of the original 19 items were collected in the Building Blocks Trial. The items asked mothers about the frequency of annoyance or irritation they had when caring for their child, if they resented personal sacrifices they made for their child, the frequency of thoughts they had about their child when separated from them, feelings of separation from their child (sadness or relief), the degree to which they felt competent to care for their child, and the degree of patience they had when interacting with their child. These items were taken from all four constellations described in the original measure: pleasure in proximity; acceptance; tolerance; and competence. These items seem to be a reasonable measure of carer negativity. Indeed the construct of 'indifferent or negative first impression' was something that Condon and Dunn (1988) believed could have an effect on parent-to-infant bonding and this was something they ultimately sought to measure through the questionnaire.

*Physical signs of abuse: head injury*

The variable used to reflect this domain and primary/secondary sub-domain was a head injury diagnosis in a child who attended A&E. This was collected in the A&E NHS Digital Dataset in the Building Blocks: 2-6 Study. This was found to be an independently significant predictor of referral to Social Services. Even though some caution should be taken when interpreting this result due to small numbers, this was a statistically significant relationship this is likely to be a good predictor of referral to Social Services.

*Physical signs of abuse: ano-genital signs or symptoms*

The variable used to reflect this domain and primary/secondary sub-domain was an ano-genital injury diagnosis in a child who attended A&E, this was collected in the A&E NHS Digital

Dataset in the Building Blocks: 2-6 Study. This was found to be an independently significant predictor of referral to Social Services. This variable is a suitable measure of ano-genital signs and symptoms as it describes an ano-genital injury in a child. Although caution should be taken when interpreting this result as the numbers of children admitted with an ano-genital injury were very small, this was a statistically significant relationship therefore this is likely to be a good predictor of referral to Social Services.

### **Missing data**

Some consideration needs to be given to missingness with regards to the variables that were found to be significant predictors (risk factors and markers) of child maltreatment. There was some discussion of missingness in terms of datasets in the results section of the current chapter, here the focus will be on missing cases in variables (not datasets i.e. non-response to some variables) and why this may be. The method of data collection can artificially influence participant response. If the data for example were collected via interview or from existing records, such as hospital records, which do not require participant involvement. It may also be the case that interviewer presence may hamper disclosure if participants are reluctant to reveal sensitive information directly, this may also cause participants to be more vulnerable to the effect of social desirability (362; 380). This may be especially relevant to two of the variables, 'parental stress' and 'carer showing negativity'. These were collected via interview during baseline and 24 month post birth respectively. The variable 'carer showing negativity' had approximately a third of the data missing. A minority of these missing data were due to mothers not completing the 24 month post birth interview in its entirety, i.e. non-completion of the dataset. Non-completion of the dataset was mainly due to mothers refusing to complete the 24 month data collection at all. However a very small subset of mothers were not asked these items as these mothers completed a short postal version of the interview (this was offered to mothers who failed to complete firstly the face-to-face interview with a researcher, and secondly a telephone version of the interview). The majority of missing data were therefore due to the mother choosing not to answer these questions, and may have been affected by social desirability bias. Under one per cent of the data were missing for 'parental stress', therefore it is harder to make similar inferences in terms of social desirability bias. Other variables collected via interview were less likely to be affected by social desirability, for example the variable used to collect data on poverty, instability and economic disadvantage, namely postcode. It's very unlikely that mothers would know that they were being asked their postcode in order to calculate deprivation scores. All of the other variables that were

significant predictors were collected from medical records, therefore any missing data were likely due to factors outside the mother's control. For example, variables collected from the routinely collected birth and antenatal data were likely to be missing either due to these items being missing from the medical notes, or the capacity of the researcher to collect this data.

Missingness between those with and without an *outcome* variable, i.e. CIN status or referral to Social Services, for an outcome (not with or without an outcome variable) is a separate issue and should be explored. Missing rates for the variable 'head injuries' between those who did and did not have a child referred to Social Services was 7.1% and 20.1% respectively. This is difficult to explain as this variable originated from the A&E NHS Digital dataset which was routinely collected data. This was collected via direct data download by the trial team from hospital records (HES data), and was not reliant on mother completing an interview. This difference is interesting, but unexplained. It must be kept in mind however that the numbers of missing variables overall for children referred was very small overall at 5% and therefore the rate of missing data could easily be quite different due to chance. It is possible that some variables found to be significant at univariable levels were not independently significant on account of missing data, an interesting example of this would be family resources at baseline (domain name: Socio-economic status). Eighty-three mothers refused to answer these questions in the baseline interview and the difference by arm was quite large, 5% who did not have a child with a CIN status refused to answer, whereas 46% of those who did have a child with a CIN status refused to answer. Is it possible that this would have been an independently significant predictor if all mothers would have answered the question? Non-willingness to complete the question could indeed have been an indicator in its own right of likelihood of CIN status. Exploring this further may be an interesting future study.

With regards to the results of the case studies, as already mentioned, it was interesting to note that both case studies included a risk factor for CIN status that was significant at univariable level, the 'anticipatory parenting' score at late pregnancy. It may be possible that if the dataset would have been more complete that this may have been an independently significant predictor.

The general analytical approach used for the third and fourth objectives for the study was to screen variables at univariable stage and then to model at multivariable regression stage. This standard approach was taken to uncover which variables were independently significant, i.e.

significantly associated with outcome whilst taking into account other significant variables. Some variables that were expected to be independently significant (for example fractures, as they have been found to be the second most common injury caused by child physical abuse (19)) were not included in the final model. This may have been due to collinearity (high correlation with another variable in the model). This is likely to be the case for the variable related to fractures in the analysis for CIN status, as it's unlikely that non-inclusion was due to missingness as fractures had the same rate of missingness as other variables that were included in the final model (i.e. nerve injury and contusion injury).

### **Differences in baseline characteristics of mothers in the final models**

There were some differences in the baseline characteristics of mothers who were and were not included in the final model for CIN status. Those included in the final model were more likely to be older at recruitment, white, and to have higher levels of family subjective social status, self-efficacy, adaptive functioning, and social support. They also had lower levels of antisocial behaviour, and were less likely to have been married or separated. These differences are indicative of a difference in psycho-social status between the two groups as well as some difference in demographics. There were just two variables found to be significantly different for mothers included and not included in the final model for referral to Social Services. Those included in the final model were more likely to be white and to have higher levels of family resources. These variables are also arguably indicative of a difference in psycho-social status between the two groups. These findings may also have a bearing on generalisability, and may not be applicable to other populations, for example non-white or those with lower levels of family resources.

These differences in psycho-social status between those included and not included in the final models are unlikely to have occurred due to mothers 'choosing' to/not to respond to certain questions. Although the baseline interview was collected through self-report, all mothers were required to complete this before being randomised into the Building Blocks Trial. The birth dataset was completed by a researcher accessing hospital records and completion was therefore outside of mothers' control. One reason for mothers not being included in the final model may be due to some non-completion of the birth dataset, most of the data were missing either due to these items being missing from the medical notes, or the capacity of the researcher to collect this data. However, given that both sets of regression analyses are associated with a similar pattern of inclusion / non-inclusion, which are reflective of family

psycho-social circumstances, perhaps some aspects of the mothers' family situation may also be responsible for these differences.

Some of the variables that were found to be significantly different for mothers who were and were not included in the final model for CIN status may have been due to chance. This is because the differences in percentages between the two groups were relatively small. There are some variables however with very large differences between the two groups that were less likely due to chance, including ethnicity (both for mothers included in the final models for CIN status and referral to Social Services), relationship status, and adaptive functioning: life skills. It could be speculated that a mechanism related to psycho-social circumstances could have driven this, for example, if more disadvantaged families are less engaged with healthcare then the availability of data may be caused by lack of follow-up and also greater pressures on health services working in certain more deprived localities.

#### **4.5.2.2 Generalisability**

The population of participants included in the current research were women who were, when recruited, pregnant, nulliparous, aged 19 or under, and recruited no later than 24 weeks gestation. The risk factors and markers found to be significant predictors of a CIN status or a referral to Social Services are likely to be generalisable to other younger pregnant women in the UK. It should be kept in mind however that these participants are not representative of the whole population, as they were more likely to have faced challenging circumstances and to have been deprived (362). The risk factors and markers may be very different for other populations, for example, older, more affluent parents. More work should be done therefore to investigate what risk factors and markers predict child maltreatment for other populations.

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## **Chapter 5- Bringing it all Together**

### **5.1.1 Summary and integration of findings**

This final chapter will firstly review the key findings from the qualitative and quantitative portions of this research study and how these can be integrated. Any methodological considerations will next be discussed as well as strengths and limitations of the research study. Directions for future research and the implications of the research will be outlined, before finally reviewing the conclusions and recommendations from this piece of research.

#### **Key findings from chapter 2, setting the scene**

This chapter sought to review of the prevalence of self-reported child maltreatment in the UK and worldwide. Data on child maltreatment can be collected from a variety of sources including from formally collected sources such as Social Services records as well as being self-reported by research participants. A literature review addressed the worldwide prevalence of lifetime reported maltreatment with 343 prevalence rates identified. North American studies were most numerous across each category of abuse, whereas South American studies were least numerous. In approximately two-thirds of studies prevalence rates were available for either or both genders. Where differentiated, studies of girls were more common than for boys across all maltreatment categories. Prevalence rates were most commonly available for sexual abuse, then for physical abuse and least commonly for neglect. Few studies of emotional abuse were found for Africa, Australia and South America. There are methodological differences in the research that may give rise to these variations, including the participants' age, gender, and type of population, the method of data collection and the definitions used.

#### **Key findings from chapter 3, exploring attitudes on the collection and linkage of maltreatment data for research**

This chapter explored mothers, care-experienced young people and professionals' attitudes towards collecting and linking routinely collected sensitive data, particularly child maltreatment data, for research purposes. Utilising focus groups and interviews to collect data three major themes were identified, consent, trust, and understanding. An additional-sub-theme, concerning data linkage, stood apart from the major themes.

### **Key findings from chapter 4, building a clearer picture of the relationships between markers and risk factors of maltreatment and later maltreatment outcomes in first time teenage mothers**

This chapter sought to address potential risk factors and markers of outcomes that may indicate maltreatment through secondary regression analyses and case studies. The advantages and disadvantages of using various sources for collecting data that may point to maltreatment were also evaluated. The results indicated that mothers with a child who had been given a CIN status had risk factors that included being more likely to report having higher levels of parental stress, were more likely to have had a higher number of antenatal check-ups, and more likely to have a child with a congenital abnormality. They had markers that included being more likely to show their child negativity, or having a child who to at some point attended A&E with a nerve or contusion injury. Mothers with a child who had been referred to Social Services had risk factors that included being more likely to report having higher parental stress, to be more deprived, and have a higher number of antenatal check-ups. They had markers that included having a child who to at some point attended A&E with a head or ano-genital injury.

Researchers should not utilise a dataset that contains a subset of participants, particularly if these have characteristics that are somehow different from the overall participant pool. A dataset or variables contained within a dataset should not be utilised if it is less complete than another comparable dataset. Finally, it should be kept in mind that that *some* data items collected via self-report may be less reliable than routinely collected data.

Case studies were helpful in understanding the pattern of variables that could be related to outcomes that may indicate maltreatment, and how that picture may look for an individual family.

### **Integration of findings**

This theses took a mixed-methods approach, with both quantitative and qualitative data being obtained for analysis. Chapter one described aspects that influence the design of a mixed-methods study. When and how to mix the quantitative and qualitative components should be considered. In the current study the mixing of the quantitative and qualitative aspects is completed below during interpretation. The current study uses a 'concurrent embedded design'. Quantitative and qualitative data are collected simultaneously, and the secondary



method (qualitative) is embedded in the quantitative method. This embedding means that the secondary method addresses a different question than the primary method. Qualitative and quantitative data sources will not be compared as they are used to answer different research questions, but are brought together to address the overall problem. The qualitative and quantitative aspects of the study are brought together in three ways during interpretation, when discussing the source of the data, when discussing the model of data collection utilised, and when discussing the baseline characteristics of various participants in this study. These are described in detail below.

As mentioned previously, one of the objectives set out in the quantitative chapter was to evaluate the advantages and disadvantages of various data *sources* for collecting data that may point to maltreatment. It is interesting to view this alongside mothers, care-experienced young people and professionals' views in the qualitative chapter. The *source* of maltreatment data was a sub-theme that emerged, under the major theme of consent. The group of care-experienced young people showed less support for the idea of researchers accessing Social Services data compared to the other groups of participants. Many participants from all the groups did consider Social Services data to be more sensitive than medical data. Most of the professional participants viewed the collection of data with a focus on data quality, availability and completeness. The professionals viewed the sources of data in terms of practicality, which source has the most reliable or valid data, and not in terms of their feelings about how sensitive the data items were. These things reflect the recommendations arising from the qualitative chapter outlined above. Acceptability of collecting data from various sources therefore had very different meanings to different groups of participants. This, as well as the advantages and disadvantages from a researchers' point of view, should be considered when designing a multi-source and multi-method approach.

Issues of consent were also discussed in the qualitative chapter. Many factors affected possible participants' consent preferences, for example the information provided about the research. This is interesting to keep in mind alongside how data were obtained for the quantitative chapter of the study, i.e. using an opt-out model. It may be that other models of consent are preferable, with this very much depending on context and detail of the specific study.

In the quantitative chapter it was also discovered that there were some difference in the baseline characteristics of mothers who were and were not included in the final model for the

outcomes of CIN status and referral to Social Services. Much of these differences were indicative of a difference in psycho-social status between the two groups as well as some difference in demographics. For example, those included in the final model for the outcome of CIN status were more likely to have higher levels of family subjective social status. Differences in participant characteristics are also likely to be partly responsible for variation in the prevalence of child maltreatment found in different studies. Given these differences found, it is interesting to note some of the differences in attitudes between the participants in the focus groups in the qualitative chapter and how these may also be related to demographics. Three face-to-face focus groups were run, one with younger mothers, one with older mothers, and one with young people who had some experience of the social care system. The older mother group was expected to be less deprived than the younger mothers group, mainly on account of their age. Some differences in attitudes were observed between these groups. For example in the young mothers group, there was a general feeling that they were much more likely to consent to their own data being collected than to that of their child. They were also very concerned about researchers' intentions and why researchers would want to collect data on their child. As mentioned previously, in the group of care-experienced young people there was less support for researchers accessing Social Services data compared to the other groups. Such differences in attitudes may be related to differences in demographics and indeed possibly even in psycho-social status. It is therefore important to keep demographics as well as psycho-social status of participants in mind when designing a study. These things may not only have a bearing on attitudes and willingness to consent to certain aspects of a study, but also on data completeness. Willingness to respond to some data items will vary across different data sources. For example, willingness to self-report (as in the interview data utilised from the Building Blocks Trial) will be driven by many factors including social factors, and socio-demographic differences could also lead to systematic differences in the capture and availability of routine data, for example mobility may affect the attendance of hospital appointments.

### **5.1.2 Critical review of the findings**

#### **Setting the scene**

In the literature review exploring the prevalence of child maltreatment differences were found by gender and geography consistent with previous reviews of child sexual abuse. In the current review median rates of sexual abuse were higher for girls than boys in the three continents with the highest number of studies (North America, Europe, Asia). Pereda et al's (1) data

suggested a ratio of 2.5 girls for every one male sexual abuse victim. Stoltenborgh et al (2) found gender made a substantial difference in difference in rates of self-reported abuse worldwide, and that girls were more likely to report sex abuse than boys. The pattern of lower rates of sexual abuse Stoltenborgh found in Asia is also consistent with the current findings, as was the highest rate of sexual abuse overall for Australian girls.

In the current review prevalence rates were most commonly available for sexual abuse, then for physical abuse and least commonly for neglect. This is reflective of the relative scarcity of literature reviews on any other type of maltreatment other than sexual abuse. Considerable variation in lifetime prevalence rates of self-reported child maltreatment was found between studies. While some of this variation may reflect actual different experiences that children have, there are methodological differences that exist in the research that are likely to give rise to these variations. These include the age at time of reporting, gender and population of study participants, the data collection mode, and the way child maltreatment is defined in the study. The current review therefore expanded on the works of others such as Pereda and Stoltenberg by reviewing more contemporary studies, and presenting studies on prevalence of the four different types of maltreatment in one review.

### **Exploring attitudes on the collection and linkage of maltreatment data for research**

#### **Consent**

Some findings under the major theme of Consent reflect those found by other researchers. In findings similar to other researchers (3; 4; 5; 6; 7; 8; 9), the current study found that information provided about a potential study, for example, information on what happens to the data after the study is finished, made participants more likely to provide consent. The current study also found that collecting anonymised data was not necessarily preferred to collecting identifiable data. This confirms *some* of the findings in the literature (7; 9), however some authors have found consent rates to be higher when data are anonymised (10; 11; 12; 13). In findings similarly to Davidson et al (2013) and Haddow et al (2011), some participants in the current study were concerned about data linking rendering participants identifiable, and some were unhappy to learn that researchers can collect anonymised data without explicit consent. In findings reflective of some previous studies, the current research found that providing information to aid understanding of consent bias could alter individual opinions, but aggregated opinion showed little change (5; 6).

Some findings in the current study are in contrast however to what others have found previously. Other researchers have found that some data items and data sources are more sensitive than others and that this affects consent (16). Previous research has mainly focused on sensitive data items in relation to medical data, whereas this is the first study to focus on the collection of child maltreatment data and so makes an original contribution to the literature. Most findings in relation to professional participants were newly emerging and unanticipated as other researchers had not explored similar themes. Professionals in the current study, for example, were concerned with the *perceived* acceptability of the collection of various types of data to the public.

### **Trust**

Some of the findings in the Trust major theme reflect those in previous studies. For example, familiarity with an organisation and being a non-profit making organisation meant that participants were more likely to consent (3; 5; 13; 15; 17; 18; 19). In findings similar to those of Clerkin et al (2013) and Davidson et al (2013), some participants had concerns about the security of data transfer partly arising from hearing negative news stories (14; 21). Some professionals in the current and previous studies were concerned about patients being unhappy that their data were used without specific consent and that this would affect the patient–physician relationship (19; 22).

Some of the findings of the current study were novel. This study found that participants preferred data to be transferred online rather than through paper based records. This differs from findings of other researchers who found participants to be especially concerned about electronic data (8; 12; 23). This contrast may be due to the fact that the current study contained some participant groups that were younger than those in previous reports. They may, on account of their age be more familiar and comfortable with electronic data sharing. Professional participants did not believe that there should be a difference between the security level of child maltreatment data compared to any other kind of personal data. This is contrast to others' findings that professionals' concerns about data security were common (22; 24; 25). Some findings in relation to professional participants were newly emerging and unexplored by previous research. Most professionals for example were unconcerned that their child maltreatment record entries would be 'judged' by researchers, but believed that this may not be true for all professionals.

Findings that were especially novel were those related to the fact that this study included discussions about collecting and linking *child maltreatment* data specifically. The care-experienced young people interviewed, for example, viewed child maltreatment data as more sensitive than other data. They believed that therefore it should be subject to a higher level of security.

### **Understanding**

Some findings of the current study that fitted under the third major theme of Understanding were similar to those found by other researchers. This study found for example that some participants did not have a full understanding of the focus group discussions. Berry et al (2012) found that most parents had a poor understanding of the information sent to them regarding the purpose of a data linkage study.

Some findings in the current study are novel and are an original contribution to the research evidence. Many for example believed that it was the duty of researchers to inform authorities if they noticed cases of maltreatment in the data, and there were concerns that this would not be possible if the data were anonymised. Participants wanted anonymisation and yet wanted to be able to take action if abuse is detected, which is unlikely to be possible. There was much discussion in the current study about the benefits of collecting and linking child maltreatment data and whether these were clear. Others have found clearer support in their studies for the collection and linking of medical data (4; 5; 6; 8; 9). The discrepancy may be due to the different sources of data being discussed. The benefits of collecting and linking medical data are clearer to participants than those concerning social care data.

### **Participant characteristics**

The current study differs from others in many ways including the participants who took part. Many others utilised less specific groups of participants and instead included participants from the general population or primary care patients (7; 9; 11; 13; 14; 15). There are some examples however of findings that are similar to previous research concerning the characteristics of participants. Care-experienced young people and younger mothers had greater concerns about researchers accessing Social Services data, possibly, in the case of the former group because of an existing Social Services record. Similarly, others have found that those with *medical* records that contain more stigmatising information are less likely to consent to data collection (20; 27). No other research has been done on similar themes concerning child

maltreatment data. Younger participants (care-experienced young people and young mothers' groups) were not more accepting of the collection of child maltreatment data than older participants. This adds to the currently mixed picture in the literature. Some have found that that younger people were more likely to consent to data from records being used in research (28; 29), others have found that those who consented were more likely to be older (4; 8). This is however likely to be confounded by the fact that one of the younger groups consisted of care-experienced young people.

### **Building a clearer picture of the relationships between markers and risk factors of maltreatment and later maltreatment outcomes in first time teenage mothers**

A nerve injury diagnosis in a child who attended A&E was found to be an independently significant marker of CIN status. This is the first study to look specifically at whether 'nerve injuries' are predictors of child maltreatment, and so provides an original contribution to the field.

Another variable that was an independently significant marker of CIN status was a bruise in a child who attended A&E. Caution should however be taken as the numbers of children admitted with a bruise were small. Other studies have found an association between bruises and maltreatment. Indeed, bruises have been found to be the most common injury caused by child physical abuse (30). Other researchers have found that specific bruising patterns, bruising on some locations on the body, and bruising in younger babies without an explanation are indicative of abuse (31; 32; 33; 34; 35). Details such as location of bruise could not be collected in the current study. The fact however that bruising was independently significant confirms what has been found in existing literature regarding its importance as a marker of maltreatment.

A child presenting at A&E was found to be an independently significant predictor of referral to Social Services. Other researchers have found that head injury is indicative of maltreatment (36; 37; 38), although there is a lack of consensus about the definition and ICD codes used for its characterisation (39; 40; 41; 42; 43; 44). The findings in this study are similar to those of other researchers in some ways. Younger children, under the age of five were included in the current study similar to Brown and Malone (2003), Lee et al (2012) and González-Izquierdo et al (2010). González-Izquierdo et al (2010) and Lee et al (2012) also utilised the same data-capture method for collecting child maltreatment data as the current study (maltreatment

data identified in health records - HES data). The current study however suffers again from a lack of details about the injury compared to previous studies which show that specific types of head injury were indicative of maltreatment (31; 36; 44; 45; 46; 47). Although the current study indicated that head injuries shows an important association with maltreatment, more work needs to be done on the strength of the association with other researchers finding the strength of the association to be vastly different (37; 38). Some caution should also be exercised with the results of this study however as the numbers of children with head injuries in the dataset was small.

In a finding reflective of NICE Guidelines (2017) the current study also found that ano-genital injuries were a significantly independent predictor of maltreatment. Similar to other physical signs of maltreatment, there are small numbers of cases in the current dataset. It is also the case, as with the other physical markers, that no details of the ano-genital injuries were collected in the current study and therefore the additional contribution that this study can make to the literature is limited.

The final independently significant marker for CIN status was 'carer showing negativity'. Much of the literature describing this association comes from NICE Guidelines (2017) (which are based on a summary of existing literature) and so the current study is useful in contributing more evidence to demonstrate its strength.

In a similar finding to other researchers (48; 49; 50; 51; 52; 53) a marker of parental stress was found to be an independently significant risk factor of both CIN status and referral to Social Services. Existing studies utilised a different measure of parental stress than the current study, with most using various editions of the Parenting Stress Index. There are other differences between the previously conducted research and the current study. Most other studies were conducted outside the UK (the vast majority in the US), and have mostly utilised a case-control study methodology with clinical populations. One notable exception was Brown et al (1998) who utilised a population sample, and unlike most of the other studies used routinely collected child maltreatment data for their dependant variable. The current piece of work therefore contributes to the evidence. Because it was conducted in the UK, used formally collected child maltreatment data, and a composite measure of parental stress not used previously. Some previous studies found a particular association between parental stress and neglect.

Unfortunately, the type of maltreatment was not measured in the current study and so no further evidence of this can be provided.

Number of antenatal check-ups was found to be an independently significant predictor of both CIN status and referral to Social Services. The direction of effect however was opposite to what was anticipated. Women with a higher number check-ups more likely to have a maltreated child. Wu et al (2004) have found a similar association, but with women who had a *lower* number of antenatal check-ups more likely to have a maltreated child (54). It should be kept in mind however that the Wu study was run in the US and differences in usual care provided may also play a part. A possible explanation for this direction of effect is that a Community Midwife may have had a concern for the family early on and thus arranged a greater number of visits with the woman, or go to great effort to ensure that the woman was present for all her check-ups.

Other researchers have found disability (51; 55; 56; 57) and chronic conditions (58; 59) in children to be risk factors for maltreatment. In a similar finding, a congenital abnormality in a child was found to be an independently significant predictor of CIN status. It should be kept in mind however that, as previously stated, not all congenital abnormalities result in a disability. Other researchers have found the association between disabilities and maltreatment to be especially true in boys (55; 60) with a stronger association between disabilities and neglect in particular. The current study did not analyse associations based on gender or type of maltreatment and so cannot contribute any further to this. The outcomes of most other studies showing this association have been based on self-reported maltreatment, and so the current study adds to the knowledge base by demonstrating the association utilising formally collected maltreatment data. Finding this association in formally collected data however may be unsurprising as children are often given a CIN status if they have a disability (whether child maltreatment is present or not). Sullivan and Knutson (2000) have stated that more research is needed to assess maltreatment risk in both congenital and acquired disabilities and so this study contributes further to the evidence base.

Deprivation was found to be an independently significant risk factor of referral to Social Services. Other research has also indicated that socio economic aspects of a neighbourhood and poverty may be responsible for the higher risk of child maltreatment (61; 62; 63). It should be kept in mind however that although the measure of deprivation utilised in the current study



(IMD) is likely a good indicator, it's an area-based measure therefore some individuals may experience less or more actual poverty than the index score would suggest. Other researchers have stated that the relationships between maltreatment and communities and neighbourhoods lags behind research on individual and family correlates (63) and so the current study adds useful additional evidence to this field.

Many risk factors and markers for maltreatment have been reported in the literature, however, the literature has mostly focused on a single risk factor or marker, or a small group of these. The current study adds to the evidence base analysing which, from a large number of risk factors and markers of maltreatment, are most predictive.

### **5.1.3 Overall methodological considerations, strengths and limitations**

#### **Methodological considerations**

The source of data on outcomes that may indicate maltreatment obtained in this study warrants further discussion. The reader may have questioned why these data were collected from the Department of Education (National Pupil Database (NPD)) rather than directly from Social Services records. Data that relate to CIN and CLA are submitted by local authorities to NPD on an annual basis, and the Building Blocks: 2-6 study utilised these data. The data submitted contained all the information required to answer the research question of the current research study. The reader may be interested to note however that Social Services records would contain more detailed and in depth information about each episode of maltreatment. Further work could be done to obtain these data if required in future, that however was outside the scope of this study. For the current cohort, based around England, obtaining Social Services records would have been a huge undertaking. Approaching local Social Services departments would have been logistically challenging, and unlikely to have resulted in as comprehensively matched sample. Even if this had been done, it would not be possible to identify mothers who lived outside of the local authority area (for all or part of the relevant time-period).

All children who were referred to Social Services were included in the analysis, regardless of the reason for referral and some children were referred to Social Services for reasons other than for maltreatment. The same is true of CIN Status, as previously discussed some children were given a CIN status for reasons other than maltreatment. The outcome of CIN status (rather than using the primary need code of 'abuse or neglect') was utilised in the third

objective to maximise the numbers available for the analysis. CIN status was thought to be a reasonable proxy for maltreatment as half the children were indeed given the primary need code of abuse or neglect, with the majority of the remainder having being given the primary need code of family dysfunction which itself may point to maltreatment.

This study used data collected in two previous studies, the Building Blocks Trial and the Building Blocks: 2-6 Study. It could therefore be argued that the current researcher had less control over the outcome variables utilised. The discussion section of the quantitative chapter (section 4.5) explores this issue further and whether the outcome variables (CIN status and referral to Social Services) were good measures of child maltreatment. Although this focuses on the outcome variables used, the same is in fact true for all the variables used in the current study, and is the case for much secondary and routine data research.

As mentioned in the methods section of the quantitative chapter (section 4.3), the first data extract collected in the Building Blocks: 2-6 Study from NHS Digital and NPD was used, a second data request was made once all children in the study had reached age six. The second data extract however was not utilised in the current study as the analyses needed to be completed before the data from the second time point was available in spring 2018. This piece of work therefore utilised a reduced dataset in terms of all data ultimately gathered from NPD and NHS Digital for the Building Blocks cohort. This may mean that the outcome data (CIN status and referral to Social Services) did not reflect children for whom these outcomes emerged only after age four. As previously mentioned, some additional variables were also collected at the second time point that were not collected for the first, these were reviewed and one relating to emotional, behavioural, interpersonal and social functioning could have been an useful marker for developmental delay.

### **Strengths and limitations**

A particular strength of the study was the rigorously completed systematic search for studies reporting the prevalence of child maltreatment, which was published in a peer review journal (64). A number of databases were searched that were thought to likely contain relevant literature, and a large amount of papers were yielded. It is recognised however that other databases not utilised could have yielded additional papers. Some limitations of the work arose due to budgetary or resource restrictions. Literature that were not in the English language were excluded, and an assumption on the upper age limit in some studies was made. The

authors had originally planned to conduct a meta-analysis on the prevalence rates. It was found however that studies varied considerably in the data they collected, the tools they used to collect the data, and the populations included, it was therefore not possible to form sufficiently large groups to warrant a meta-analysis. It was decided that a narrative review was more suitable.

A rigorous screening exercise was conducted for each literature review. For each literature review a random selection of 100 titles and abstracts were either triple- or double-screened against the inclusion and exclusion criteria by two or three additional reviewers, along with any useful definitions. The additional reviewers decided if they would deem the title and abstract to be worthy of further review. The results of this exercise were then compared to those titles and abstracts selected by the first reviewer. Agreement, using either Fleiss' or Cohen's Kappa, was very high with the lowest being 0.86. Agreement levels however deemed to be acceptable were not agreed a priori to completing the exercise. Perhaps therefore a prior agreement levels should have been considered before starting this work.

The qualitative chapter, 'exploring attitudes on the collection and linkage of maltreatment data for research' was based around focus groups and interviews with mothers, care-experienced young people and professionals. There is no other study found in the literature which explores the attitudes of mothers, care-experienced young people and professionals towards the use of child maltreatment data for research specifically. This thesis therefore offers an original contribution to knowledge, therein lies the strength of this piece of work. Another strength of this piece of work was the thorough piloting work completed beforehand. Three face-to-face focus groups were run, one with younger mothers, one with older mothers, and one with young people who had some experience of the social care system. One asynchronous online focus group was completed that consisted of UK professionals who were responsible for recording maltreatment data in records. A criticism of this work was the omission of the views of fathers and social workers. There was an attempt to recruit social workers to take part in the professional group, however the researcher failed to obtain any who were willing to take part. It should also be kept in mind that these were self-selective small groups from specific populations and so views may not be generalisable. However, the aim of the study was to explore views rather than produce generalisable results. Another limitation was that it was clear that some participants did not fully understand the focus group discussions. This has implications for the validity of the interpretation of the results.

The results of the quantitative analyses completed in chapter four indicated which risk factors and markers (listed above) were more likely to be associated with mothers who had a child with a CIN status or referral to Social Services. Despite the small number of cases that may point to maltreatment, the sample size was nevertheless sufficient to detect statistically significant differences, a strength of this piece of work. An even larger sample again (with more cases and more data on independent variables) may have led to some more associations being shown to be significant. It is important to keep in mind that the outcome variables of CIN status and referral to Social Services are merely *indicators* of child maltreatment. These may be an underestimate of the true number of cases of child maltreatment. The use of the outcome of CIN status (rather than using the primary need code of 'abuse or neglect') may also be a limitation as this is a proxy variable. Half of children with a CIN status were given the primary need code of abuse or neglect. The use of CIN status as the main outcome of this study should also be considered in light of other outcomes collected from Social Services that could have been used in its place. Chapter two discusses the hierarchy of formally collected outcomes and the strength of the evidence pointing to maltreatment being stronger in some rather than others. The strength of the evidence is likely to be superior for a child being subject to a CPP, for example compared to being recorded as in need. There may therefore be some limitations in using an outcome such as CIN as a proxy for maltreatment. The specificity of the evidence however needs to be weighed against the sensitivity of the variable. Some variables are more likely to be specific. For example, a child being subject to a CPP may be more likely to have been truly the victim of maltreatment. However, this variable may not be as sensitive as CIN status. Keeping the above in mind, it is important to note that the analysis would not have been viable using the primary need code of 'abuse and neglect' or using the outcome of CPP due to small numbers.

Consideration should also be given to the validity of the independently significant variables and if they can be truly regarded as falling within one or other of the domains from which they were located. Some of the variables better reflected the domains than others, a limitation of the study. The 'head injuries' variable for example was a very suitable measure of head injuries as it described exactly that. Whereas 'congenital abnormalities' was selected to reflect child disability, this was perhaps less suitable as not all congenital abnormalities result in a disability, just as all disabilities are not the result of a congenital abnormality. A strength of this piece of

work however is the systematic process by which variables were selected from the Building Blocks cohort datasets.

Biases are present in all research and it is important to consider which are present in this current study and whether they can be mitigated. The four literature reviews completed are likely to have contained some selection bias. This was minimised by ensuring the double or triple-screening of titles abstracts. Other methods were also used to minimise bias including noting concerns about the quality of some of the literature included in reviews that might have a bearing on results, and always keeping the inclusion and exclusion criteria in mind when selecting literature to include.

The researchers' own biases and credentials were explored in the qualitative chapter and how these might affect participants during focus groups and interviews. The criteria of 'peer debriefing' was utilised. This is the process of discussing the research with peers or superiors with the aim to hear other experiences and perceptions and discuss alternate approaches. This technique can be used to allow researchers to recognise their own biases through peer review. This technique was utilised in the current research both during and after data collection, with co-facilitators following each focus group, with supervisors and at conferences. The technique of 'confirmability' was also used. This refers to the extent that the researcher maintains a degree of neutrality to ensure that the findings of the research are shaped by the participants and not researcher bias. The risk of the results being shaped by the researchers' personal bias has been mitigated to some extent by techniques including a qualitative researcher performing double-coding 15% of the data. Some of the themes in the qualitative component were unanticipated and novel. This evidences the fact that the findings of the researcher were shaped by participants and not the researcher.

Multi-source and multi-method data were utilised in the quantitative chapter to minimise bias. Every source and method comes with its own bias, for example, self-reported data collected through interview might be subject to social desirability bias. Datasets were introduced into the logistic regression models in temporal as well as a data driven method to reduce bias. The late pregnancy dataset was omitted from the models because participants had a choice of whether they wanted complete it which may have been partly driven by social desirability bias. Bias was also assessed by describing participants included and not included in the final models of the first and second objective analyses.

#### **5.1.4 Directions for future research**

Future research would very much involve making some changes to the aspects of this study listed in the above 'methodological considerations, strengths and limitations' section (section 5.1.3).

For the current study a narrative review was thought to be more fitting when reporting on studies of the prevalence of child maltreatment. Future work could however include a series of mini meta-analyses for different groups of study participants, for example, a meta-analysis could be completed that only included a specific population such as younger reporters of maltreatment. Further work would need to be done to ascertain whether this would be possible with a smaller number of studies in each group. This may be a way to arrive at more useful rates of child maltreatment which will allow better comparisons between studies.

Obtaining data directly from Social Services would enable researchers to view maltreatment records in more detail. Although detail contained in these records were not required to answer the research questions for this study, future research with different research questions may benefit from accessing these data. For example, Social Services records include detail of support offered to families and future research could investigate if this would be a protective factor against any future maltreatment events.

Including fathers and social workers, as well as other populations, in future qualitative work would enable researchers to gather data on their views and attitudes on the collection and linkage of maltreatment data for research. Gathering these views, which may be similar or very different to those gathered for the current study, would be an important piece of research. It may for example be the case that social workers might have different views to other professionals, as they have a markedly different professional relationship with families than healthcare professionals.

The quantitative discussion (section 4.5) introduced the idea that non-willingness of mothers to answer some items during interview could be an indicator in its own right of likelihood of CIN status. Future work could further explore this, and if other elective non-response to data items (and also missingness due to lack of routine data) is itself associated with outcomes that may indicate maltreatment.

The first data extract collected in the Building Blocks: 2-6 Study from NHS Digital and NPD was used, and using the second data extract was not possible due to time contracts in the current study. A future project could determine if a more complete dataset with more cases, longer follow-up and more complete data results in the same conclusions as the current study, or whether additional associations are identified.

The risk factors and markers utilised in the quantitative chapter were not included in the same models during logistic regression analysis. They were arrived at from a comprehensive review of the extant literature and theories of maltreatment. The current study sought to distinguish between factors that might indicate current maltreatment (markers) from those that might predict future maltreatment (risk factors). Future work could look at combining some or all of these markers and risk factors in the same models.

Future research could also investigate whether including a different participant population (for example older mothers, or a less deprived population) would yield similar results in terms of independently significant risk factors and markers of child maltreatment.

### **5.1.5 Implications**

There are a variety of implications to the work presented in this thesis. Knowledge of the risk factors and markers of child maltreatment that are most likely to lead to a referral to Social Services or for a child to be given an 'in need' status may allow those areas to be targeted in future interventions. For example, the current study found that those with a higher number of antenatal check-ups were more likely to have outcomes that may indicate maltreatment; this knowledge may allow resources to be targeted at specific risk factors for some populations. Knowledge of these may also assist future research to focus on the more likely causes of child maltreatment and build theories about maltreatment. It should be kept in mind however that the current study was conducted with a very specific and high risk population of young mothers, and so this may limit the generalisability of the results. The current study included risk factors and markers of maltreatment, future studies could also include protective factors. The results of this study may also contribute to developing theory on the causes of maltreatment, expanding on the work concerning an ecological model of maltreatment. Knowledge of markers of maltreatment, particularly those found to be independently significant, may also be useful to professionals when coming into contact with families.

Some of the work completed in this study on various participants' consent preferences could be very useful for researchers interested in gaining consent to collect child maltreatment data. It may be useful to understand potential participants' concerns when designing information sheets and considering how to relay information to potential participants when asking them to consent. It would also be useful for researchers when considering study design and the population they would like to involve in the research. Some populations may have particular concerns, for example, young care-experienced people were not happy about researchers viewing child maltreatment data. A co-productive approach to research design could be taken by involving members of the public in the design of research studies from the beginning. An example of this might be a facilitated lay advisory group that provides input across all stages of a study. It is interesting to note that although time was taken at the start of each focus group to explain and discuss unfamiliar concepts such as data linkage to participants, it became clear during the running of the groups that there was still a lack of understanding of these concepts by many participants. With this in mind, perhaps using the traditional format of a paper-based information sheet to convey such information is even less likely to promote sufficient understanding of such concepts. Introducing or improving education in schools on complex concepts such as the use of routine data for research, data linkage, anonymisation, and consent may serve as a starting point to improve the public's general understanding of such concepts. This may in time improve consent rates into studies. Using different ways, perhaps with the use of video, to present these complex concepts may also be a valuable avenue to explore further in future research.

#### **5.1.6 Generalisability of results**

The findings of the qualitative chapter may not be generalisable to all populations and was quite narrowly focused. It may be the case that those who agreed to take part were somehow different from the eligible population, and given the absolute numbers of participants concerned and the numbers of groups this is to be expected. The results of this chapter however were not intended to be generalisable, the work was exploratory in nature. As previously mentioned future work may focus on gathering the views of fathers and social workers. These are groups who may have had differing views to those included but were not represented in the current research. Social workers may be a group that would have been particularly different from other professionals included in this study. Social workers on the whole are not approached by families when in need (such as a GP might be) but rather provide a response identified from potential harm. Social workers may therefore have a unique



relationship with families in their care as the families that they come into contact with may not be under their care on a voluntary basis. Quotes by participants have been provided in the results section of the qualitative chapter to allow other researchers to be able to decide for themselves how far the results may be transferrable to other settings. The technique utilised is 'thick description'. This is describing a phenomenon in enough detail as to enable a researcher to adequately evaluate the extent the results are transferrable to other times, setting and people. Some of the results of this chapter may indeed be transferrable. Consideration, for example, needs to be given to the participant population when collecting sensitive data items. It should be kept in mind that although these were groups from specific populations and so views may not be generalisable, the aim of the study was to explore views rather than produce generalisable results.

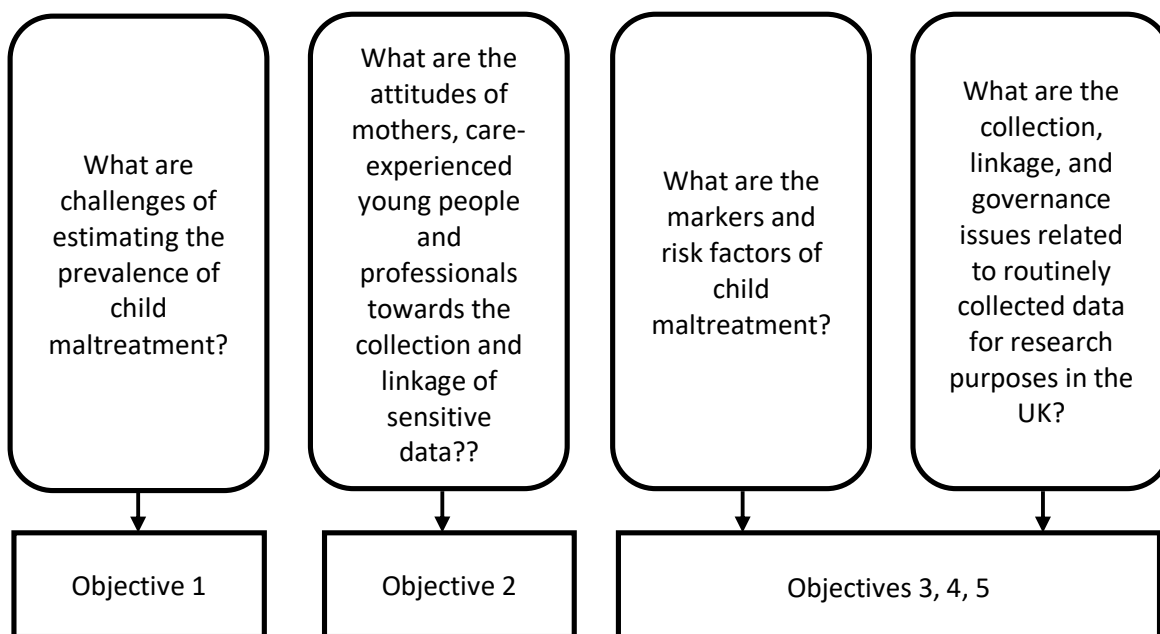
The sample of participants from the Building Blocks cohort used to complete the quantitative analysis were when recruited, pregnant, nulliparous, aged 19 or under, and no further than 24 weeks gestation. The Building Blocks Trial reported that the participants included in the Building Blocks cohort were representative of women entering the FNP programme as a whole, but faced more challenging circumstances than many other pregnant women in the UK (65). They were more deprived, more likely to be homeless, and less likely to be in education or employment than the UK average for women of the same age group (65). The risk factors and markers found to be significant predictors of a CIN status or a referral to Social Services are likely to be generalisable to other younger, more deprived, pregnant women in the UK. Indeed, one of the independent risk factors for CIN status found in the current study was higher level of deprivation. These participants were not however representative of the whole population of parents, the average age of pregnancy in the UK is 30 years old. Older, more affluent parents may have different risk factors and markers for child maltreatment. There were some differences in the baseline characteristics of mothers who were and were not included in the final model for CIN status which were indicative of a difference in psycho-social status between the two groups as well as some difference in demographics. These differences may also have a bearing on generalisability of results.

### **5.1.7 Conclusions**

This study had five objectives, firstly to review of the prevalence of self-reported child maltreatment in the UK and worldwide. Secondly, to explore mothers, care-experienced young people and professional attitudes regarding the collection and linkage of maltreatment data

for research. Thirdly, to investigate how markers and risk factors of maltreatment predicted CIN status for children in the Building Blocks cohort. Fourth, to investigate how risk factors and markers of maltreatment predict *different* outcomes that may indicate maltreatment for children recruited to Building Blocks cohort. Finally, to explore how markers and risk factors of maltreatment predict outcomes that may indicate maltreatment through using case studies. Four separate research questions were addressed (figure 1), which involved firstly formally reviewing the background to each by literature review. A mixed-methods approach was taken, using quantitative and qualitative methods to collect and analyse data.

Figure 1. How the study objectives relate to each research question



The presence of outcomes that may indicate maltreatment was assessed using both self-report and routine data, and the methods used to do this including ethical, legal, practical and public & professional perspectives reviewed. The current study used a specific study cohort to examine what may provide an indication of maltreatment and its cause, basing the methods on an in-depth review of literature about what risk factors and markers may lead to maltreatment outcomes.

When exploring mothers, care-experienced young people and professionals attitudes towards collecting and linking maltreatment data for research purposes three major themes were identified, consent, trust, and understanding. Mothers with a child who had been given a CIN status were more likely to have higher parental stress, to have a child with a congenital

abnormality, to show their child negativity, to have a child who at some point attended A&E with a nerve or contusion injury, and were more likely to have had a higher number of antenatal check-ups. Mothers with a child who had been referred to Social Services were more likely to have higher parental stress, be more deprived, to have a child who attended A&E with a head or ano-genital injury, and have had a higher number of antenatal check-ups. When collecting data on child maltreatment from various sources it was recommended that researchers should not utilise a dataset that contains a subset of participants, a dataset or variables contained within a dataset if less complete than another dataset, and should keep in mind that that *some* data items collected via self-report may be less reliable than routinely collected data. Case studies were useful in gaining a deeper understanding the pattern of variables that could be related to outcome, and how that picture may look for an individual family.

These results have implications for future research and interventions, knowledge of the risk factors and markers of child maltreatment that lead to a referral to Social Services or to a CIN status will allow targeted interventions and further research. Knowledge of participants' consent preferences and concerns regarding child maltreatment data collection will have implications for researchers seeking to collect this data and may prove very useful when designing participant materials.

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## **Appendix 1.** Literature review details and documentation

The literature reviews were designed to address each of the four research questions:

- Research question 1: *What are the challenges of estimating the prevalence of child maltreatment?*
- Research question 2: *What are the attitudes of mothers, care-experienced young people and professionals towards the collection and linkage of sensitive data?*
- Research question 3: *What are the markers and risk factors of child maltreatment?*
- Research question 4: *What are the collection, linkage, and governance issues related to routinely collected data for research purposes in the UK?*

### **Piloting and reviewing**

For each literature search, the first 300 results were reviewed (title and abstract or executive summary), and if the reviewer was confident that these results were relevant to the research question, then the remaining results were reviewed. If the first 300 results were not relevant to the research question, then the search terms used were revised.

### **Definitions**

- Maltreatment

Abuse and neglect are forms of the maltreatment of a child (Radford et al, 2011). This includes Physical abuse (PA), Neglect, Emotional abuse (EA) and Child sexual abuse (CSA) (HM Government, 2013). ‘Somebody may abuse or neglect a child by inflicting harm, or by failing to act to prevent harm’ (HM Government, 2013).

Physical abuse: 'A form of abuse which may involve hitting, shaking, throwing, poisoning, burning or scalding, drowning, suffocating or otherwise causing physical harm to a child. Physical harm may also be caused when a parent or carer fabricates the symptoms of, or deliberately induces, illness in a child' (HM Government, 2013).

Emotional abuse: 'The persistent emotional maltreatment of a child such as to cause severe and persistent adverse effects on the child's emotional development' (HM Government, 2013).

Sexual abuse: 'Involves forcing or enticing a child or young person to take part in sexual activities, not necessarily involving a high level of violence, whether or not the child is aware of what is happening' (HM Government, 2013).

Neglect: 'The persistent failure to meet a child's basic physical and/or psychological needs' (HM Government, 2013).

- Confirmed cases of maltreatment

Confirmed cases are substantiated cases of child maltreatment and include when a child is put under 'immediate protection', and/or the 'child is in need' (and assessed under section 17 of the Children Act 1989)(Department of Health, 1989), and/or there is reasonable cause to suspect that the 'child is suffering, or likely to suffer, significant harm' and there is initial child protection conference (assessed under section 47 of the Children Act 1989) (Department of Health, 1989).

- Markers of maltreatment

There are many markers for maltreatment including maltreatment-related features, such as physical signs of abuse or injuries, clinical presentations other than injuries, and markers of maltreatment visible in the emotional, behavioral, interpersonal or social functioning of a child or parent.

- Risk factors of maltreatment

Factors that may be associated with causing child maltreatment.

- Child

Children and young people aged under 18 years old. The UN Convention on the Rights of the Child, ratified by the UK government in 1991, states that a child 'means every human being below the age of eighteen years unless, under the law applicable to the child, majority is attained earlier' (Article 1, United Nations, 1989).

- Data linkage

Linking data across multiple datasets that relate (for the purposes of this topic) to the same individual. Record linkage is when multiple records are linked.

- Governance

Research governance 'sets out principles, requirements, and standards, defines mechanisms to deliver them, and describes monitoring and assessment arrangements. It improves research and safeguards the public by enhancing ethical awareness and scientific quality, promoting good practice, reducing adverse incidence and ensuring lessons are learned forestalling poor performance and misconduct' (Department of Health, 2005).

### **Literature sources**

- published research literature from the following databases:

<http://www.ncbi.nlm.nih.gov/pubmed>

[www.thecochranelibrary.com](http://www.thecochranelibrary.com)

[wok.mimas.ac.uk](http://wok.mimas.ac.uk) (Web of Science)

OvidSP (PsychInfo from 2002 only and Medline)

- policy and practice literature – UK Government specifically:

<https://www.gov.uk/government/publications>

- Charity publications – NSPCC, Action for Children:  
<http://www.nspcc.org.uk/Inform/publications/>  
[www.actionforchildren.org.uk/policy-research/publications-and-briefings](http://www.actionforchildren.org.uk/policy-research/publications-and-briefings)
- *Use Web of Science or Google scholar to search for citations of articles and by authors important in the field:*  
[scholar.google.co.uk](http://scholar.google.co.uk)
- *Cardiff Child Protection Systematic Reviews:*  
<http://www.core-info.cardiff.ac.uk/>

## **Inclusion and exclusion criteria**

### Research questions 1 and 3

- Setting and population
  - Included are literature related to the maltreatment of children and young people (humans) under the ages of 18.
  - Countries: Worldwide.
- Date of research
 

Included will be literature from 1989 onwards, the UK The Children Act 1989 gave every child the right to protection from abuse and exploitation and the right to inquiries to safeguard their welfare (Department of Health, 1989).
- Research methods
 

Primarily systematic reviews and Observational Studies, Randomised Control Trials, Cohort Studies, Case Control Studies, and Qualitative studies. Policy and practice literature and literature from Charities will be of equal importance as published research literature.
- Language of report

English only, literature will not be translated on account of budget restrictions.

- Topic

Child maltreatment literature unrelated to the research questions will be excluded.

### Research question 2

- Setting and population

- Included are as above for maltreatment literature. Mothers, care-experienced young people and professionals' attitudes towards the collection and linkage of sensitive data will also be included for any age group.

- Countries: worldwide.

- Date of research

As electronic data collection and linkage has only been commonly used since the early 1990, literature will be included from 1990 onwards.

- Research methods

Primarily systematic reviews and Observational Studies, Randomised Control Trials, Cohort Studies, Case Control Studies, and Qualitative studies, Qualitative studies will be especially relevant to Research question 2.

Policy and practice literature and literature from Charities will be of equal importance as published research literature.

- Language of report

English only, literature will not be translated on account of budget restrictions.

- Topic

Literature on public and professionals attitudes towards data collection and data linkage issues possibly, but not exclusively, related to child maltreatment.

#### Research question 4

- Setting and population
  - Included are as above for maltreatment literature. Governance and data linkage issues not related to maltreatment will also be included for any age group.
  - Countries: worldwide.
- Date of research

As electronic data collection and linkage has only been commonly used since the early 1990, literature will be included from 1990 onwards.
- Research methods

Primarily systematic reviews and Observational Studies, Randomised Control Trials, Cohort Studies, Case Control Studies, and Qualitative studies. Policy and practice literature and literature from Charities will be of equal importance as published research literature.
- Language of report

English only, literature will not be translated on account of budget restrictions.
- Topic

Literature on data collection, data linkage, and governance issues possibly, but not exclusively related to child maltreatment.

#### **Search strategy**

A 'snowballing' methodology was used to locate relevant references, firstly, relevant papers were found using search strategy then the reference lists of these papers were reviewed for other relevant literature. An EndNote database was utilised to ensure that references were kept in order and remove duplicates.



### Assessing relevant literature

- review the title and abstract or executive summary, this should give a first impression as to whether the literature will be relevant to the research question, if the title and abstract appear to be relevant, read the rest of the literature.
- Keep inclusion and exclusion criteria in mind when searching.
- Classify literature into 'clearly relevant', 'possibly relevant', and 'irrelevant' to the research question.
- Read through references of chosen papers to search for more relevant literature.
- A random selection of 100 titles and abstracts will be either double-or triple-screened against the inclusion/exclusion criteria by two/three additional reviewers, along with inclusion and exclusion criteria and any useful definitions. The additional reviewers will decide if they would deem the title and abstract to be worthy of further review (article/chapter etc.). The results of this exercise will be compared to those titles and abstracts selected by the first reviewer (as in the first bullet point).

To ensure that the research is kept up-to-date, citation and keyword alerts will be set-up in the databases. Email updates will be sent to the researcher when a keyword is used. A journal table of contents alert in ZETOC (<http://zetoc.mimas.ac.uk/>) will also be set-up every time a new journal issue is published, from a pre-determined list of the most relevant journals, an email alert is sent to the researcher. Key pieces of research published after completion of the original and update searches will be reviewed, these pieces of research may not be included in the literature reviews but will be noted in the final discussion.

### Research questions

Research question 1: *What are the challenges of estimating the prevalence of child maltreatment?*

Amendments were made to the research question and search strategy after the first 300 results were reviewed:

- The title of this literature review was amended from 'How is child maltreatment formally assessed and confirmed in a UK setting'. Changes were made to as the researcher was interested in additional themes such as informal assessments of child maltreatment and prevalence rates.
- The word 'report' was removed from the search terms.
- The following words were removed from the search terms as they did not appear in the literature without the associated words 'abuse' or 'maltreatment'.

physical\*

sexual\*

emotion\*

safeguard\*

looked after

child protect\*

in-need / in need

harm\*

injury\*

violen\* (violence/violent)

non-accident\*

- The following words were removed from the search as these words did not appear in the literature in relation to abuse and maltreatment (whereas 'child' always appeared in the literature in relation to abuse or maltreatment).

paediatric\*

pediatric\*

infant\*

adverse childhood experiences\*

The final search strategy included the following:

Search terms list – keywords:

measur\*

quantify\*

comput\*

estimat\*

evaluat\*

assess\*

confirm\*

child\*

young pe\* (people/person)

maltreat\*

abuse\*

neglect\*

Medical Subject heading (MeSH) Terms:

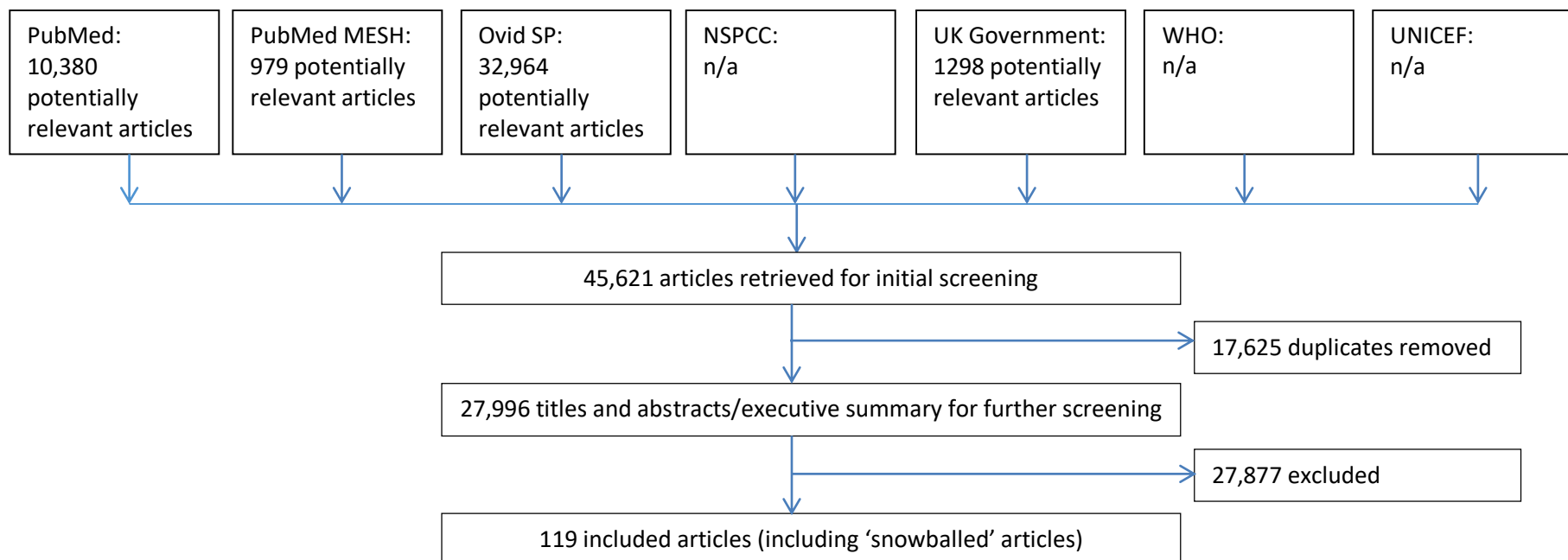
abuse, child (MeSH)

Grouped search terms:

(measur\* OR quantify\* OR comput\* OR estimat\* OR evaluat\* OR assess\* OR confirm\*) AND (maltreat\* OR abuse\* OR neglect\*) AND (child\* OR young pe\*)

A literature search between May and June 2014 was conducted for the purposes of informing both the first research question and the journal article entitled 'Establishing the international prevalence of self-reported child maltreatment: a systematic review by maltreatment type and gender', and therefore the search terms above relate to this original search. The literature review was updated in March 2017 for the purposes of the journal article. Figure 1 provides details of the searches for both the original and updated searches. See table1 for details of the searches, this details of databases searched and search terms and key words used.

**Appendix 1 Figure 1.** Flowchart of literature included in research question 1 literature review



Results of screening exercise for research question 1:

100 titles and abstracts were triple-screened and agreement and results were calculated using Fleiss' Kappa (Fleiss, 1971), agreement was very high at 0.97.

Further details of the search strategy utilised in 'The challenges of estimating the prevalence of child maltreatment journal article' are included in the piece of work.

Research question 2: *What are the attitudes of mothers, care-experienced young people and professionals towards the collection and linkage of sensitive data??*

Amendments were made to the research question and search strategy after the first 300 results were reviewed:

- The word 'identify' was removed from the search terms as this was not deemed to be specific enough.

The final search strategy included the following:

Search terms list – keywords:

public\*

professional\*

patient\*

participa\* (participant/participate)

subject\*

attitude\*

perspective\*

feeling\*

opinion\*

view\*

data\* (database)

link\*

confidential\*

anonymous\*

accept\*

consent\*

privacy\*

electronic\*

routine\*

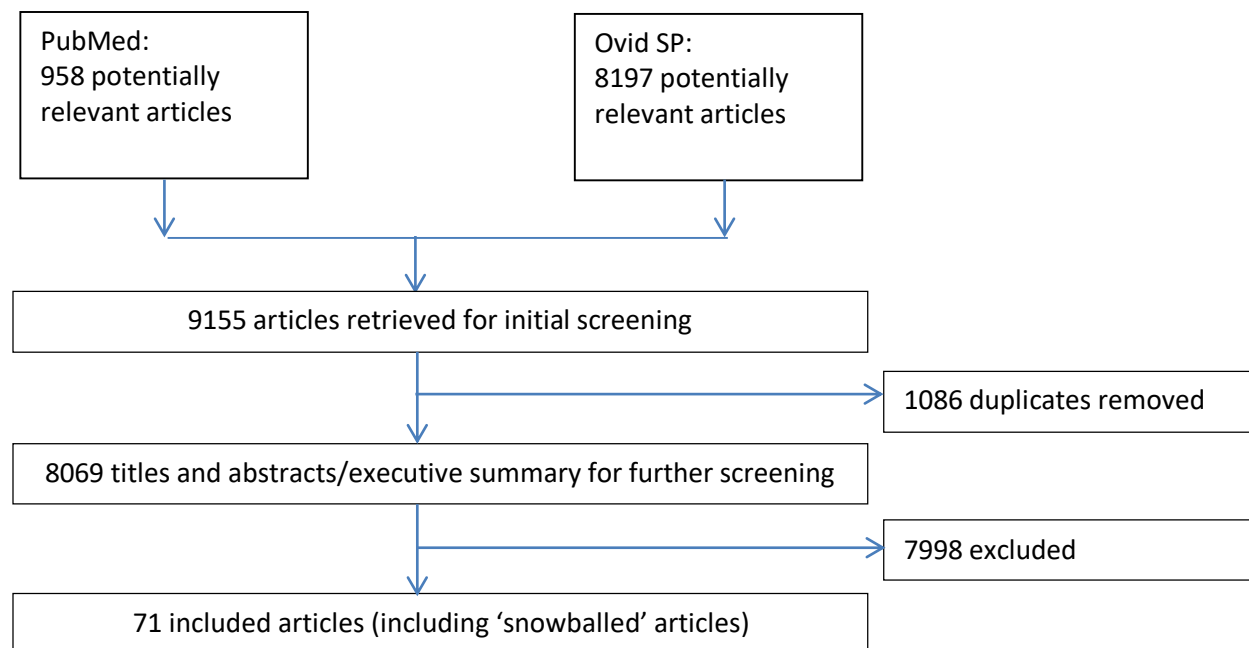
record\*

Grouped search terms:

((data\*) AND (link\* OR electronic\* OR routine\* OR record\*) AND (public\* OR professional\* OR patient\* OR participa\* OR subject\*) AND (attitude\* OR perspective\* OR feeling\* OR opinion\* OR view\* OR accept\*) AND (confidential\* OR anonymous\* OR consent\* OR privacy\* OR sensitive\*))

See table 1 for details of the searches, this details of databases searched and search terms and key words used.

**Appendix 1 Figure 2.** Flowchart of literature included in research question 2 literature review



Results of screening exercise for research question 2:

100 titles and abstracts were double-screened and agreement and results were calculated using Cohen's Kappa (Cohen, 1960), agreement was very high at 0.96.

Research question 3: What are the markers and predictors of unconfirmed maltreatment?

Amendments were made to the research question and search strategy after the first 300 results were reviewed:



- The title of this literature review was amended from ‘What are the markers and predictors of unconfirmed maltreatment? What data on markers and risk factors of maltreatment may be available from a variety of routine and other sources?’\_this was amended as the second half of the question was already addressed in research question 4 and research question 1 respectively. Research question 4 addressed routine data collection and research question 1 addressed other modes of data collection for example self-report.

The final search strategy included the following:

Search terms list – keywords:

Risk factor\*

predict\*

influence\*

correlate\*

marker\*

cause\*

maltreat\*

abuse\*

neglect\*

child\*

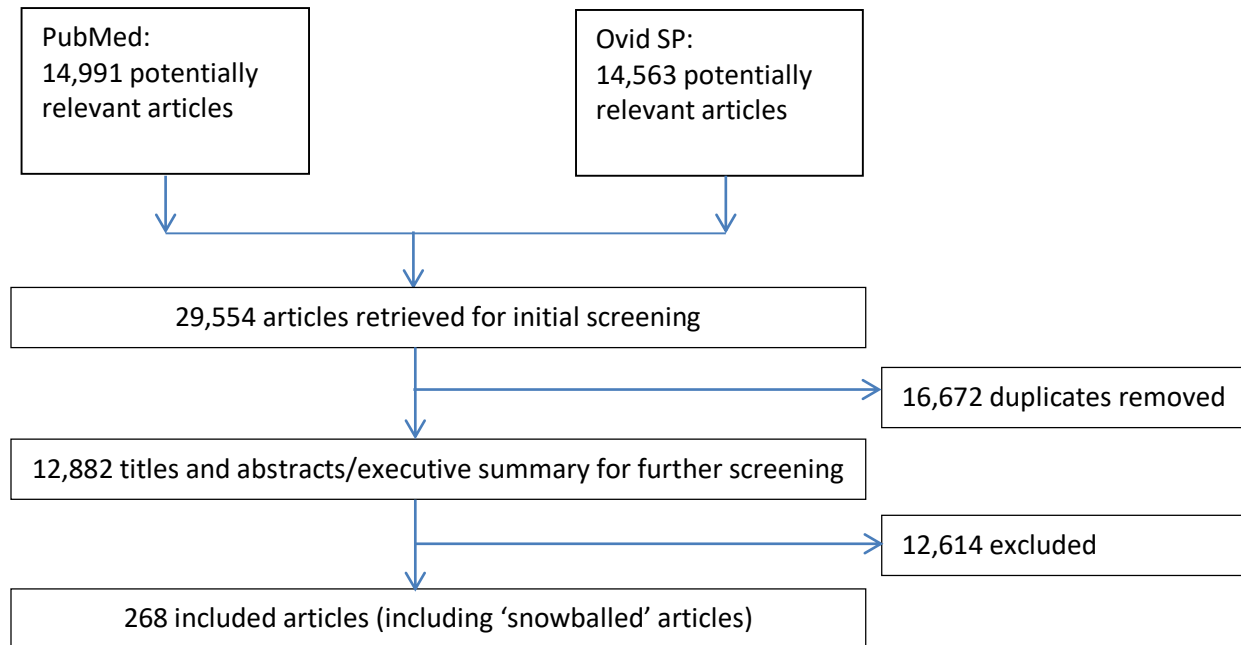
young pe\* (people/person)

Grouped search terms:

(maltreat\* OR abuse\* OR neglect\*) AND (child\* OR young pe\*) AND (correlate\* OR risk factor\* OR influence\* OR predict\* OR marker\*)

See table1 for details of the searches, this details of databases searched and search terms and key words used.

**Appendix 1 Figure 3.** Flowchart of literature included in research question 3 literature review



Results of screening exercise for research question 3:

100 titles and abstracts were double-screened and agreement and results were calculated using Cohen's' Kappa (Cohen, 1960), agreement was very high at 0.86.

Research question 4: *What are the collection, linkage, and governance issues related to routinely collected data for research purposes in the UK?*

The final search strategy included the following:

Search terms list – keywords:

data\* (database)

link\*

match\*

source\*

routine\*

record\*

electronic\*

governance\*

access\*

ethic\*

regulat\* (regulation/regulatory/regulate)

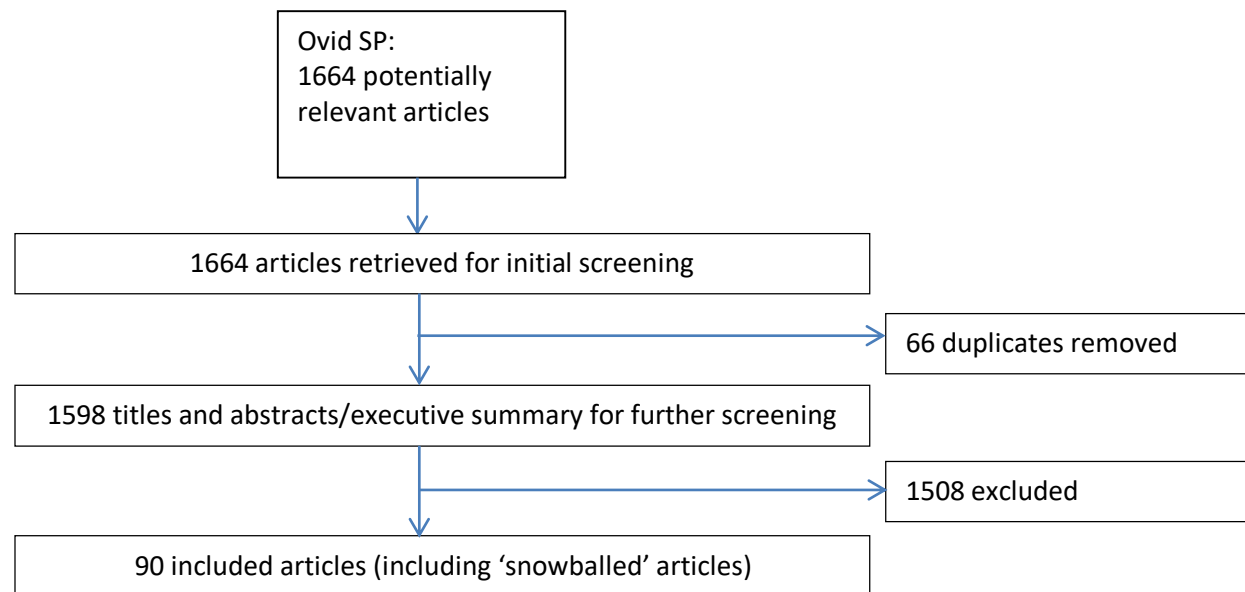
legal\*

Grouped search terms (used the 'adj' in OvidSP, cannot search in PubMed using one of these connectors):

(data\* adj15 link\*) OR (access\* OR match\* OR source\* OR routine\* OR record\*) AND (electronic\*) AND (governance\* OR regulat\* OR legal\* OR ethic\*)

See table 1 for details of the searches, this details of databases searched and search terms and key words used.

**Appendix 1 Figure 4.** Flowchart of literature included in research question 4 literature review



\* PubMed not used for research question 3 hits as I can't do the 'adj' command

Results of screening exercise for research question 4:

100 titles and abstracts were double-screened and agreement and results were calculated using Cohen's' Kappa (Cohen, 1960), agreement was very high at 0.89.

**Appendix 1 Table 1.** Details of the searches, including databases searched and dates, and search terms and key words used

Search database/website	Research question number	Search terms used	Date search performed	Number of returns ('hits')	Notes	Citation or keyword alert
PubMed	1	((measur*[Title/Abstract] OR quantify*[Title/Abstract] OR comput*[Title/Abstract] OR estimat*[Title/Abstract] OR evaluat*[Title/Abstract] OR assess*[Title/Abstract] OR confirm*[Title/Abstract]) AND (maltreat*[Title/Abstract] OR abuse*[Title/Abstract] OR neglect*[Title/Abstract]) AND (child*[Title/Abstract] OR young pe*[Title/Abstract]))	28/05/2014	8532	Saved as .txt file and then imported into EndNote	Search saved on 30/05/2014 and alert set-up to email monthly of any new articles relating to this search

Search database/website	Research question number	Search terms used	Date search performed	Number of returns ('hits')	Notes	Citation or keyword alert
PubMed	3	((correlate*[Title/Abstract] OR risk factor*[Title/Abstract] OR influence*[Title/Abstract] OR predict*[Title/Abstract] OR marker*[Title/Abstract] OR cause*[Title/Abstract]) AND (maltreat*[Title/Abstract] OR abuse*[Title/Abstract] OR neglect*[Title/Abstract]) AND (child*[Title/Abstract] OR young pe*[Title/Abstract]))	29/05/2014	6576	Saved as .txt file and then imported into EndNote	Search saved on 30/05/2014 and alert set-up to email monthly of any new articles relating to this search

Search database/website	Research question number	Search terms used	Date search performed	Number of returns ('hits')	Notes	Citation or keyword alert
OvidSP	4	((data* adj15 link*) or (access* match* or source* or routine* or record*) and electronic* and (governance* or regulat* or legal* or ethic*)).tw.	29/05/2014	1664	Imported directly into EndNote. PubMed not used for research question 3 hits as I can't do the 'adj' command	Search saved on 30/05/2014 and alert set-up to email monthly of any new articles relating to this search



PubMed	2	((data*[Title/Abstract]) AND (link*[Title/Abstract] OR electronic*[Title/Abstract] OR routine*[Title/Abstract] OR record*[Title/Abstract]) AND (public*[Title/Abstract] OR professional*[Title/Abstract] OR patient*[Title/Abstract] OR participa*[Title/Abstract] OR subject*[Title/Abstract]) AND (attitude*[Title/Abstract] OR perspective*[Title/Abstract] OR feeling*[Title/Abstract] OR opinion*[Title/Abstract] OR view*[Title/Abstract] OR accept*[Title/Abstract]) AND (confidential*[Title/Abstract] OR anonymous*[Title/Abstract] OR consent*[Title/Abstract] OR	28/05/2014	958	Saved as .txt file and then imported into EndNote	Search saved on 30/05/2014 and alert set-up to email monthly of any new articles relating to this search
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Search database/website	Research question number	Search terms used	Date search performed	Number of returns ('hits')	Notes	Citation or keyword alert
		privacy*[Title/Abstract] OR sensitive*[Title/Abstract]))				
Zetoc			30/05/2014			Journal alert se-up to alert when new copies of 'Child abuse & neglect' journal published

Search database/website	Research question number	Search terms used	Date search performed	Number of returns ('hits')	Notes	Citation or keyword alert
PubMed MeSH terms	1	Child abuse/epidemiology [mh]	30/05/2014	979	MeSH terms for child abuse and epidemiology was searched as an add-on to research question 1. Saved as .txt file and then imported into EndNote	

Search database/website	Research question number	Search terms used	Date search performed	Number of returns ('hits')	Notes	Citation or keyword alert
Ovid SP	2	(data* and (link* or electronic* or routine* or record*) and (public* or professional* or patient* or participa* or subject*) and (attitude* or perspective* or feeling* or opinion* or view* or accept*) and (confidential* or anonymous* or consent* or privacy* or sensitive*)).tw.	04/06/2014	8197	Imported directly into EndNote	Search saved on 04/06/2014 and alert set-up to email monthly of any new articles relating to this search
Ovid SP	3	((correlate* OR risk factor* OR influence* OR predict* OR marker* OR cause*) AND (maltreat* OR abuse* OR neglect*) AND (child* OR young pe*)).tw.	04/06/2014	14991	Imported directly into EndNote	Search saved on 04/06/2014 and alert set-up to email monthly of any new articles relating to this search

Search database/website	Research question number	Search terms used	Date search performed	Number of returns ('hits')	Notes	Citation or keyword alert
Ovid SP	1	((measur* or quantify* or comput* or estimat* or evaluat* or assess* or confirm*) and (maltreat* or abuse* or neglect*) and (child* or young pe*)).tw.	05/06/2014	18401	Imported directly into EndNote	Search saved on 04/06/2014 and alert set-up to email monthly of any new articles relating to this search
NSPCC	1	Searched through all literature on website <a href="http://www.nspcc.org.uk/Inform/publications/">http://www.nspcc.org.uk/Inform/publications/</a>	18/06/2014	N/A	Saved relevant publications in folder	N/A
UK Government	1	Searched through all literature on website <a href="https://www.gov.uk/government/publications">https://www.gov.uk/government/publications</a> using search terms 'child abuse'	18/06/2014	1298 for 'Child abuse'	Saved relevant publications in folder	N/A

Search database/website	Research question number	Search terms used	Date search performed	Number of returns ('hits')	Notes	Citation or keyword alert
WHO	1	Searched through all literature on website <a href="http://www.who.int/publications/en/">http://www.who.int/publications/en/</a>	24/06/2014	N/A	Saved relevant publications in folder	N/A
UNICEF	1	Searched through all literature on website <a href="http://www.unicef.org/publications/">http://www.unicef.org/publications/</a>	24/06/2014	N/A	Saved relevant publications in folder	N/A
UPDATED SEARCHES						

Search database/website	Research question number	Search terms used	Date search performed	Number of returns ('hits')	Notes	Citation or keyword alert
PubMed	1 (for lit review paper-searching only for studies reporting lifetime prev self-reported maltreatment – updated search from 28/05/2014 – 15/03/2017)	((measur*[Title/Abstract] OR quantify*[Title/Abstract] OR comput*[Title/Abstract] OR estimat*[Title/Abstract] OR evaluat*[Title/Abstract] OR assess*[Title/Abstract] OR confirm*[Title/Abstract]) AND (maltreat*[Title/Abstract] OR abuse*[Title/Abstract] OR neglect*[Title/Abstract]) AND (child*[Title/Abstract] OR young pe*[Title/Abstract]))	15/3/2017 (searched from 28/05/2014 – 15/03/2017)	1848	Saved as csv file (not imported into endnote). These just reviewed by GM to select those for lit review 1 paper	No saved alerts

Search database/website	Research question number	Search terms used	Date search performed	Number of returns ('hits')	Notes	Citation or keyword alert
Ovid SP	1 (for lit review paper-searching only for studies reporting lifetime prev self-reported – updated search from 28/05/2014 – 15/03/2017)	((measur* or quantify* or comput* or estimat* or evaluat* or assess* or confirm*) and (maltreat* or abuse* or neglect*) and (child* or young pe*)).tw.	15/3/2017 (searched from 05/06/2014 – 15/03/2017)	14563	Saved as csv file (not imported into endnote). These just reviewed by GM to select those for lit review 1 paper	No saved alerts



Search database/website	Research question number	Search terms used	Date search performed	Number of returns ('hits')	Notes	Citation or keyword alert
NSPCC	1 (for lit review paper-searching only for studies reporting lifetime prev self-reported – updated search from 28/05/2014 – 15/03/2017)	Searched through all literature on website <a href="http://www.nspcc.org.uk/Inform/publications/">http://www.nspcc.org.uk/Inform/publications/</a>		N/A	Saved relevant publications in folder	N/A

Search database/website	Research question number	Search terms used	Date search performed	Number of returns ('hits')	Notes	Citation or keyword alert
UK Government	1 (for lit review paper-searching only for studies reporting lifetime prev self-reported – updated search from 28/05/2014 – 15/03/2017)	Searched through all literature on website <a href="https://www.gov.uk/government/publications">https://www.gov.uk/government/publications</a> using search terms 'child abuse'		1298 for 'Child abuse' (reviewed any since 2014)	Saved relevant publications in folder	N/A

Search database/website	Research question number	Search terms used	Date search performed	Number of returns ('hits')	Notes	Citation or keyword alert
WHO	1 (for lit review paper-searching only for studies reporting lifetime prev self-reported – updated search from 28/05/2014 – 15/03/2017)	Searched through all literature on website <a href="http://www.who.int/publications/en/">http://www.who.int/publications/en/</a>		N/A	Saved relevant publications in folder	N/A

Search database/website	Research question number	Search terms used	Date search performed	Number of returns ('hits')	Notes	Citation or keyword alert
UNICEF	1 (for lit review paper-searching only for studies reporting lifetime prev self-reported – updated search from 28/05/2014 – 15/03/2017)	Searched through all literature on website <a href="http://www.unicef.org/publications/">http://www.unicef.org/publications/</a>		N/A	Saved relevant publications in folder	N/A

### **Appraising and synthesising findings in literature**

A narrative review was written for each of the four research questions. The narrative review will identify the themes that become apparent in each literature review; these themes are listed in the contents table and will provide the headings in each review.

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## **Appendix 2. Maltreatment definitions in England, Wales, Scotland, and Northern Ireland**

### **England (1)**

#### **Physical abuse**

A form of abuse which may involve hitting, shaking, throwing, poisoning, burning or scalding, drowning, suffocating or otherwise causing physical harm to a child. Physical harm may also be caused when a parent or carer fabricates the symptoms of, or deliberately induces, illness in a child.

#### **Emotional abuse**

The persistent emotional maltreatment of a child such as to cause severe and persistent adverse effects on the child's emotional development. It may involve conveying to a child that they are worthless or unloved, inadequate, or valued only insofar as they meet the needs of another person. It may include not giving the child opportunities to express their views, deliberately silencing them or 'making fun' of what they say or how they communicate. It may feature age or developmentally inappropriate expectations being imposed on children. These may include interactions that are beyond a child's developmental capability, as well as overprotection and limitation of exploration and learning, or preventing the child participating in normal social interaction. It may involve seeing or hearing the ill-treatment of another. It may involve serious bullying (including cyber bullying), causing children frequently to feel frightened or in danger, or the exploitation or corruption of children. Some level of emotional abuse is involved in all types of maltreatment of a child, though it may occur alone.

#### **Sexual abuse**

Involves forcing or enticing a child or young person to take part in sexual activities, not necessarily involving a high level of violence, whether or not the child is aware of what is happening. The activities may involve physical contact, including assault by penetration (for example, rape or oral sex) or non-penetrative acts such as masturbation, kissing, rubbing and touching outside of clothing. They may also include non-contact activities, such as involving children in looking at, or in the production of, sexual images, watching sexual activities, encouraging children to behave in sexually inappropriate ways, or grooming a child in preparation for abuse (including via the internet). Sexual abuse is not solely perpetrated by adult males. Women can also commit acts of sexual abuse, as can other children.

**Neglect**

The persistent failure to meet a child's basic physical and/or psychological needs, likely to result in the serious impairment of the child's health or development. Neglect may occur during pregnancy as a result of maternal substance abuse. Once a child is born, neglect may involve a parent or carer failing to:

- provide adequate food, clothing and shelter (including exclusion from home or abandonment);
- protect a child from physical and emotional harm or danger;
- ensure adequate supervision (including the use of inadequate care-givers); or

ensure access to appropriate medical care or treatment. It may also include neglect of, or unresponsiveness to, a child's basic emotional needs.

Wales (2)

**Physical abuse**

The hitting, shaking, throwing, poisoning, burning or scalding, drowning, suffocating, or otherwise causing physical harm to a child. Physical harm may also be caused when a parent or carer fabricates or induces illness in a child whom they are looking after.

**Emotional abuse**

The persistent emotional ill-treatment of a child such as to cause severe and persistent adverse effects on the child's emotional and behavioural development.

**Sexual abuse**

Forcing or enticing a child or young person to take part in sexual activities, whether or not the child is aware of what is happening, including:

- physical contact, including penetrative or non-penetrative acts;
- non-contact activities, such as involving children in looking at, or in the production of, pornographic material or watching sexual activities; or
- encouraging children to behave in sexually inappropriate ways.

**Neglect**

The persistent or severe neglect of a child, or the failure to protect a child from exposure to any kind of danger, including cold, starvation or extreme failure to carry out important aspects

of care, resulting in the significant impairment of the child's health or development, including non-organic failure to thrive.

### Scotland (3)

#### **Physical abuse**

Physical abuse is the causing of physical harm to a child or young person. Physical abuse may involve hitting, shaking, throwing, poisoning, burning or scalding, drowning or suffocating.

Physical harm may also be caused when a parent or carer feigns the symptoms of, or deliberately causes, ill health to a child they are looking after.

#### **Emotional abuse**

Emotional abuse is persistent emotional neglect or ill treatment that has severe and persistent adverse effects on a child's emotional development. It may involve conveying to a child that they are worthless or unloved, inadequate or valued only insofar as they meet the needs of another person. It may involve the imposition of age- or developmentally-inappropriate expectations on a child. It may involve causing children to feel frightened or in danger, or exploiting or corrupting children. Some level of emotional abuse is present in all types of ill treatment of a child; it can also occur independently of other forms of abuse.

#### **Sexual abuse**

Sexual abuse is any act that involves the child in any activity for the sexual gratification of another person, whether or not it is claimed that the child either consented or assented.

Sexual abuse involves forcing or enticing a child to take part in sexual activities, whether or not the child is aware of what is happening. The activities may involve physical contact, including penetrative or non-penetrative acts. They may include non-contact activities, such as involving children in looking at, or in the production of, pornographic material or in watching sexual activities, using sexual language towards a child or encouraging children to behave in sexually inappropriate ways.

#### **Neglect**

Neglect is the persistent failure to meet a child's basic physical and/or psychological needs, likely to result in the serious impairment of the child's health or development. It may involve a parent or carer failing to provide adequate food, shelter and clothing, to protect a child from physical harm or danger, or to ensure access to appropriate medical care or treatment. It may



also include neglect of, or failure to respond to, a child's basic emotional needs. Neglect may also result in the child being diagnosed as suffering from 'non-organic failure to thrive', where they have significantly failed to reach normal weight and growth or development milestones and where physical and genetic reasons have been medically eliminated. In its extreme form children can be at serious risk from the effects of malnutrition, lack of nurturing and stimulation. This can lead to serious long-term effects such as greater susceptibility to serious childhood illnesses and reduction in potential stature. With young children in particular, the consequences may be life-threatening within a relatively short period of time.

#### Northern Ireland (4)

##### **Physical Abuse**

Physical abuse is the deliberate physical injury to a child, or the wilful or neglectful failure to prevent physical injury or suffering. This may include hitting, shaking, throwing, poisoning, burning or scalding, drowning, suffocating, confinement to a room or cot, or inappropriately giving drugs to control behaviour.

##### **Emotional Abuse**

Emotional abuse is the persistent emotional ill-treatment of a child such as to cause severe and persistent adverse effects on the child's emotional development. It may involve conveying to children that they are worthless or unloved, inadequate, or valued only insofar as they meet the needs of another person. It may involve causing children frequently to feel frightened or in danger, or the exploitation or corruption of children. Some level of emotional abuse is involved in all types of ill-treatment of a child, though it may occur alone. Domestic violence, adult mental health problems and parental substance misuse may expose children to emotional abuse.

##### **Sexual Abuse**

Sexual abuse involves forcing or enticing a child to take part in sexual activities. The activities may involve physical contact, including penetrative or non-penetrative acts. They may include non-contact activities, such as involving children in looking at, or the production of, pornographic material or watching sexual activities, or encouraging children to behave in sexually inappropriate ways.

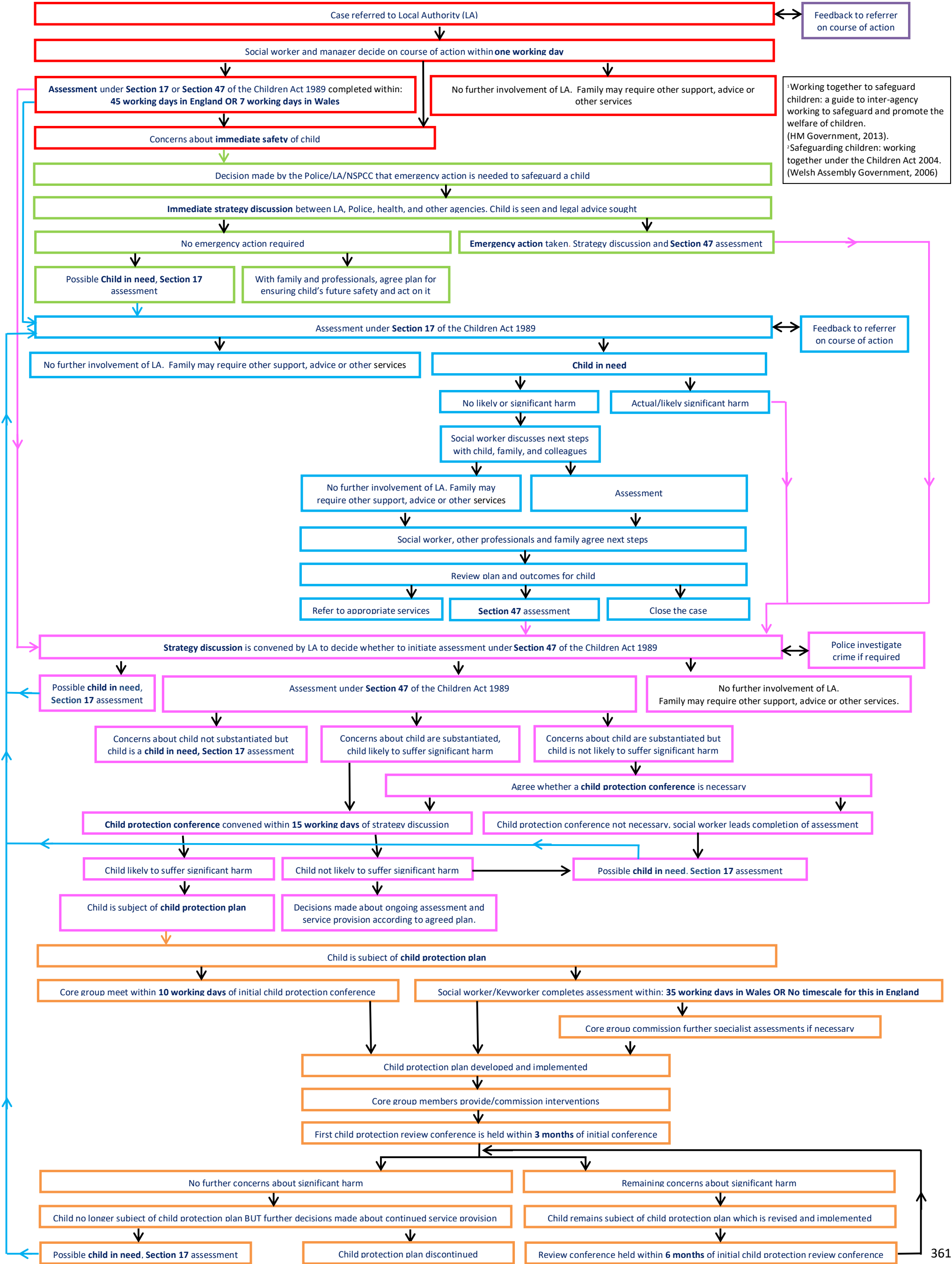
## **Neglect**

Neglect is the persistent failure to meet a child's physical, emotional and/or psychological needs, likely to result in significant harm. It may involve a parent or carer failing to provide adequate foods, shelter and clothing, failing to protect a child from physical harm or danger, failing to ensure access to appropriate medical care or treatment, lack of stimulation or lack of supervision. It may also include non-organic failure to thrive.

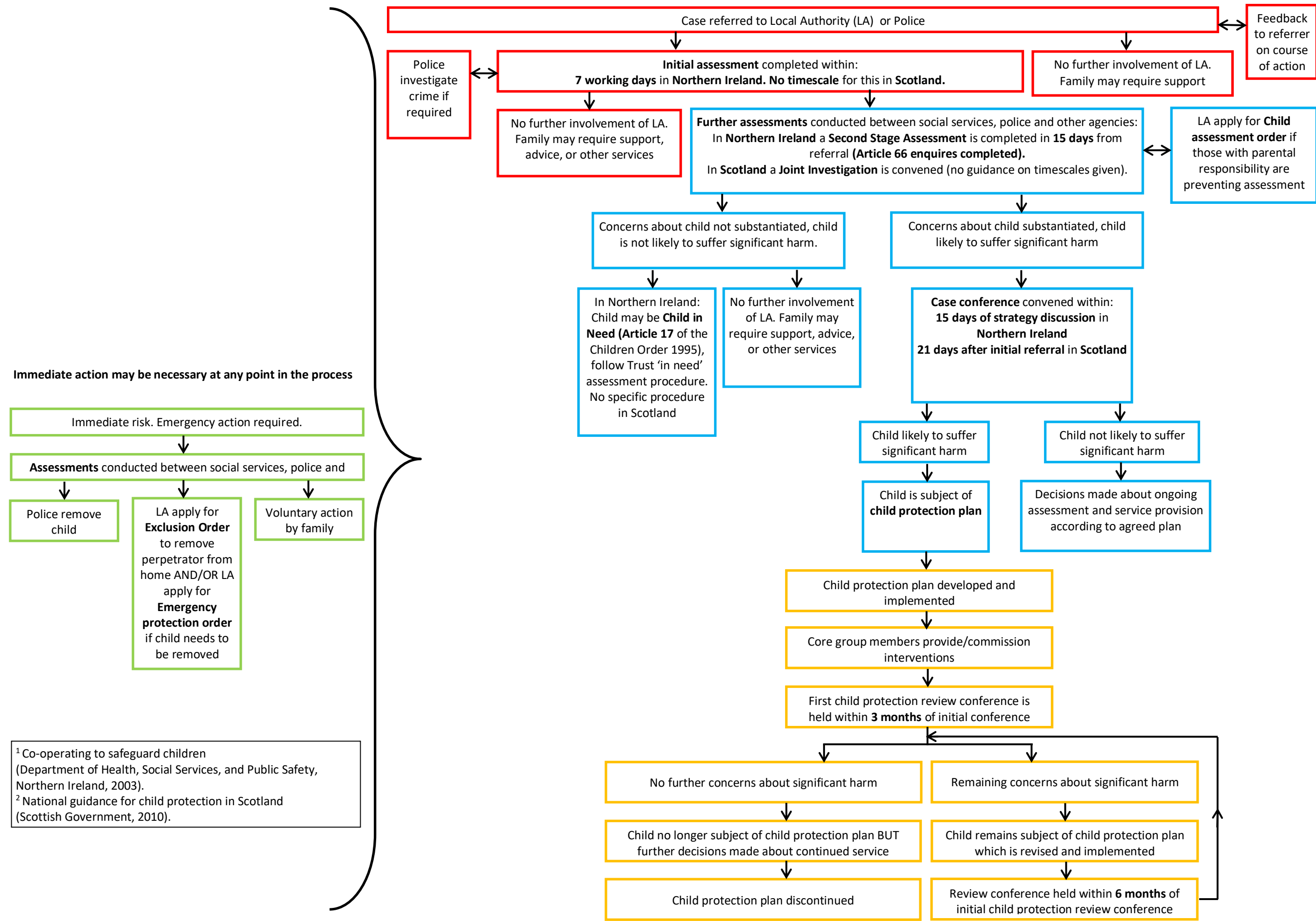
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Appendix 3. Figure 1. Child protection processes from referral in England<sup>1</sup> and Wales<sup>2</sup>



**Appendix 4.** Figure 1. Child protection processes from referral in Northern Ireland<sup>1</sup> and Scotland<sup>2</sup>



RESEARCH ARTICLE

Open Access



# Establishing the international prevalence of self-reported child maltreatment: a systematic review by maltreatment type and gender

Gwenllian Moody<sup>1\*</sup> , Rebecca Cannings-John<sup>1</sup>, Kerenza Hood<sup>1</sup>, Alison Kemp<sup>2</sup> and Michael Robling<sup>1</sup>

## Abstract

**Background:** Estimating the prevalence of child maltreatment is challenging due to the absence of a clear 'gold standard' as to what constitutes maltreatment. This systematic review aims to review studies using self-report maltreatment to capture prevalence rates worldwide.

**Methods:** PubMed, Ovid SP and grey literature from the NSPCC, UNICEF, The UK Government, and WHO from 2000 to 2017 were searched. The literature review focused on the variation found in self-reported lifetime prevalence for each type of maltreatment between studies by continent and gender, and how methodological differences may explain differences found.

**Results:** Sexual abuse is the most commonly studied form of maltreatment across the world with median (25th to 75th centile) prevalence of 20.4% (13.2% to 33.6%) and 28.8% (17.0% to 40.2%) in North American and Australian girls respectively, with lower rates generally for boys. Rates of physical abuse were more similar across genders apart from in Europe, which were 12.0% (6.9% to 23.0%) and 27.0% (7.0% to 43.0%) for girls and boys respectively, and often very high in some continents, for example, 50.8% (36.0% to 73.8%) and 60.2% (43.0% to 84.9%) for girls and boys respectively in Africa. Median rates of emotional abuse were nearly double for girls than boys in North America (28.4% vs 13.8% respectively) and Europe (12.9% vs 6.2% respectively) but more similar across genders groups elsewhere. Median rates of neglect were highest in Africa (girls: 41.8%, boys: 39.1%) and South America (girls: 54.8%, boys: 56.7%) but were based on few studies in total, whereas in the two continents with the highest number of studies, median rates differed between girls (40.5%) and boys (16.6%) in North America but were similar in Asia (girls: 26.3%, boys: 23.8%).

**Conclusions:** Median prevalence rates differ substantially by maltreatment category, gender and by continent. The number of studies and available data also varies and relatively little is known about prevalence for some forms of maltreatment, particularly outside of the North American context. Prevalence rates require caution in interpretation as some variation will reflect methodological differences, including the data collection methods, and how the maltreatment is defined.

**Keywords:** Child maltreatment, Prevalence, Self-report, Systematic review

\* Correspondence: [MoodyG@cardiff.ac.uk](mailto:MoodyG@cardiff.ac.uk)

<sup>1</sup>Centre for Trials Research, Cardiff University, Neuadd Meirionnydd, Heath Park, Cardiff, Wales, UK

Full list of author information is available at the end of the article



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## Background

Nationally and internationally, there has been a growing recognition of the importance of identifying, documenting and reporting suspected and confirmed child maltreatment [1], with the World Health Organisation (WHO) in collaboration with the United Nations Children's Fund (UNICEF) calling for maltreatment to be recognised as a global public health concern [2].

Having a clear definition of child maltreatment is recognised as fundamental [3]. WHO has defined child maltreatment as 'All forms of physical and/or emotional ill-treatment, sexual abuse, neglect or negligent treatment or commercial or other exploitation, resulting in actual or potential harm to the child's health, survival, development or dignity in the context of a relationship of responsibility, trust or power', with the clear realisation that the four categories may coexist in the same child [4]. There is some variation in the definitions of the different categories in the four countries in the United Kingdom (UK), and these differences can make comparisons difficult, however, all can nevertheless be classified as 'maltreatment' for the purposes of this review.

### Public sector collected data

Data routinely collected within the public sector which could shed light on the extent of child maltreatment in the UK and can be found from records of contacts with child protection services i.e. social services, and in offences against children [5]. Data related to contacts with social services include the number of referrals accepted by social services, when a child is recorded as a 'child in need', (assessed under section 17 of the Children Act 1989, article 17 of the Children Order 1995, Section 12 of the Children (Scotland) Act 1995), and/or has suffered or is likely to suffer 'significant harm' (section 47 of the Children Act 1989, articles 2(2) and 50(3) of the Children Order 1995, Children (Scotland) Act 1995), and/or the child is the subject of a 'child protection plan' or on the 'child protection register', and when a child is being 'looked after'. Data relating to the reasons a child is subject to a protection plan or on the child protection register are also collected, with neglect being the most common reason for this in each of the four UK countries [6]. The rate of children who are subject to a child protection plan has increased in all UK countries over recent years [6]. Statistics on offences against children recorded by the police include data on homicides and child deaths [6], as well as sexual, cruelty and neglect offences.

Cases of maltreatment that come to the attention of social services or the police are only a portion of the true numbers [7, 8]. There are many more that go undetected, unreported or unrecorded [9]. Fallon et al. (2010) likened this to the tip of the iceberg [10].

### Other sources of maltreatment data: Self-report

Gathering data on maltreatment using formally collected data only can be problematic because of the sole reliance on system indicators, created for bureaucratic and tracking purposes as opposed to research purposes [11], although formally reported cases are likely to represent more serious episodes. Even when data are collected from several different organisations and combined, this is likely to be an underrepresentation [12], due to underreporting. Fallon et al. (2010) note that how a child maltreatment event is measured will affect counts of maltreatment cases by agencies. The number of children investigated for maltreatment may be hard to detect as this will depend on data collection and aggregation methods. For some agencies children investigated several times in a year may be counted each time as a separate investigation [10]. The area covered by the agency could also affect count; cases where children or families move between areas could be double-counted or missed altogether [10].

Formally collected data are especially likely to under represent child maltreatment in middle-and-upper-income families [13], this may be due to agencies being less likely to intervene in these groups. Less is known about the prevalence of maltreatment that is not reported to social services or the police [5], however, many have conducted studies to attempt to capture the prevalence of maltreatment using self-reporting methods.

Formal estimations of the prevalence of child maltreatment based mostly on self-report have been conducted by other researchers. Barth et al. (2013) conducted a systematic review with a meta-analysis of the prevalence of child sexual abuse worldwide in studies published between 2002 and 2009. Fifty-five studies from 24 countries were included and prevalence estimates ranged from 3 to 31% [14]. Pereda et al. (2009b) conducted a meta-analysis of self-reported child sexual abuse in community and student samples worldwide. They included sixty-five articles covering 22 countries, and found that the mean prevalence was 7.9% for men and 19.7% for women [15]. Both of these studies included meta-analyses of data from studies of child sexual abuse only; the current review seeks to expand on this by including prevalence rates of physical, emotional/psychological abuse, and neglect. Stoltenborgh and colleagues have conducted meta-analyses of data from studies of that addressed the four types of maltreatment [17–19, 26], all of these included studies published up to 2008, the current systematic review expands on these works by reviewing more contemporary studies, and presenting studies on prevalence of the four different types of maltreatment in one review.

The aim of this current study is to establish prevalence rates for each category of self-reported maltreatment and how they may vary by gender and geography. How

methodological differences may explain differences found in prevalence figures will be explored.

## Methods

### Literature review

A literature search took place between May and June 2014, and was updated in March 2017. Electronic literature databases (PubMed, OvidSP) as well as literature from other organisations (NSPCC, UK Government, WHO, UNICEF) were searched for potentially eligible studies and grey literature. The combined search strategy included terms for the population (children and young people), the incident (maltreatment) and various terms to convey 'measurement'. Duplicate literature was removed using a standard de-duplication function in EndNote, titles and abstracts were reviewed. The detailed search strategy is included in Appendix 1.

### Study selection

The original search between May and June 2014 was conducted for a wider literature review, and included searching for all studies reporting the prevalence of ever experienced child maltreatment (under 18 years old) worldwide published from 2000 onwards, and therefore the search terms in Appendix 1 relate to this original search. Studies before 2000 were not included as the authors were interested in relatively contemporary data. The studies included in this review are more focused in that we have included only those that relate to *lifetime* prevalence of child maltreatment by *self-report*. Prevalence can be either the lifetime or period prevalence of child maltreatment. Lifetime prevalence is the number of individuals having experienced maltreatment at some point during childhood, with 'childhood' being defined in various ways depending on the paper or the country in question. Period prevalence is the number of individuals having experienced maltreatment at some point during a specified period of time, for example, the past year [10, 16]. It should be kept in mind that lifetime prevalence of childhood maltreatment would be contracted in some studies that include child self-report due to the children not having completed childhood which may be reduced due to lower time of exposure. For the purposes of this review therefore, 'lifetime' prevalence refers to true lifetime prevalence of child maltreatment as well as studies that include children and their lifetime prevalence to the point of self-report.

A reference list checking technique was used when ascertaining potential studies, i.e. where relevant studies were found using the search strategy, the reference lists of these studies were searched for other relevant publications.

Table 1 in additional file 1 details the inclusion and exclusion criteria applied to the literature.

Included in the search was any study where a participant (adult (18+) or a child (<18)) self-reported lifetime child maltreatment before the age of 18 years. Study designs were methodologically restricted to the primary data collection (i.e. no routinely collected or secondary data sources). Excluded were any study restricting child maltreatment to a specific time reference period (e.g. in the past year) compared to entire 18 years of childhood and any study where a secondary person reports childhood maltreatment on behalf of the participant (e.g. parent).

Initial stage of review for inclusion: All titles and abstracts found were reviewed by a single reviewer. A random selection of 100 titles and abstracts were triple-screened against the inclusion/exclusion criteria by two additional reviewers.

Agreement for inclusion/exclusion between the three reviewers was ascertained using Fleiss' Kappa [20], and agreement was very high at 0.97. Fleiss' Kappa, as opposed to Cohen's Kappa was used to as Fleiss' Kappa should be used when there are more than two raters.

Final stage of review for inclusion: As reviewer agreement was high, full papers were retrieved for all selected abstracts and then screened again with more detailed inclusion criteria. Confirmation of inclusion was performed at this stage as this related to criteria that could usually only be ascertained with the whole paper.

### Data extraction

The following data were extracted from the included studies: Authors and year of publication, country, age and gender of participants, population, total number of participants in study, mode of self-reporting completion (self-completed, interview), type of maltreatment, description of maltreatment, and prevalence rates. Prevalence rates were recorded by type of maltreatment and split by gender where possible. Additional file 2 presents these data for each study included, and additional file 3 contains the references for these studies. An additional reviewer verified the data extraction for a random selection of 10 studies, the data extraction process was found to be satisfactory.

### Presentation of data

Box and whisker plots are presented to show the median (alongside 25th to 75th centiles and outliers) of lifetime prevalence of maltreatment by gender and geographical region (continent) for each of type of maltreatment (emotional/psychological abuse, neglect, sexual, physical) (Figs. 2, 3, 4, and 5). Where a study reported results from more than one country we have represented prevalence rates from these countries separately where possible to do so. In two studies which involved countries politically within two continents (Turkey, Russia) we have categorised by



continent based on the location of the majority of the study population (i.e. to Asia and Europe respectively). We have also generated separate prevalence rates for studies that involved separately self-reported maltreatment by adults and by children. Ranges of rates are presented rather than pooled prevalence due to the high level of heterogeneity variation observed. As this study was conducted as part of a larger body of work assessing maltreatment assessment and reporting in the UK, we have also presented data for UK studies only (Additional file 4).

Prevalence rates were apparently higher in some clinical samples compared to samples drawn from a general population. Therefore, for presentation purposes we have further presented the same figures showing rates for each type of maltreatment by gender and continent for general population samples only (Additional file 5). This excludes those sampled either due to specific socio-demographic or clinical characteristic (including specific professional groups) but has included those recruited from natural sampling frames such as schools, universities, broadly-based health-care or primary care organisations and epidemiological cohorts (e.g. population-based pregnancy cohort).

The authors made the following assumptions and changes in order for data to be depicted in Figs. 2, 3, 4, and 5 in an orderly manner. Where prevalence figures were available for more than one country within a single study, we reported a prevalence rate for each separate country, the same was done for studies presenting separate self-reported prevalence rates for adult and child participants, these assumptions lead to there being a total of 343 'prevalence rates' (within studies) relating to 337 studies. For studies that reported on witnessing family violence, this was grouped under emotional/psychological abuse. As gender split for prevalence rates were unspecified in many of the studies, 'male', 'female' and 'unspecified' genders were included in the results. We defined the age of the victim of maltreatment to be 18 and under, however, it is important to note here that some studies included in this review specified a lower upper age limit.

## Results

Of the 44359 records identified through database searching and 1325 through additional sources, 15967 duplicates were removed and a further 29253 excluded at title and abstract stage (Fig. 1). A further 175 articles were identified through citation checking and 639 articles were assessed as full texts, of which 302 were excluded as not meeting eligibility criteria. A total of 337 articles were retained for inclusion.

There were more studies including retrospective reports from adults only ( $n = 216$ , 64.1%) (adults being defined as 18 or over), rather than children only ( $n = 28$ , 8.3%), and the remaining studies included self-reports of both adults and children ( $n = 93$ , 27.6%). The vast majority of studies used self-completed data collection ( $n = 213$ , 63.2%), the

rest included data collected via interview ( $n = 120$ , 35.6%), and a very small number collected data via both interview and self-completion ( $n = 3$ , 0.9%), or interview or self-completion ( $n = 1$ , 0.3%).

Figures 2, 3, 4, and 5 show prevalence rates for each type of maltreatment. In addition, there were studies where form of maltreatment was not distinguished and these have been excluded from presentation. Approximately a third of all studies did not report the gender of participants (108, 32.0%), some studies included only female participants ( $n = 109$ , 32.3%), some had a mixture of males and females ( $n = 101$ , 30.8%), and a minority included males only ( $n = 17$ , 5.0%).

### Prevalence of sexual abuse

When assessing study samples, a single study may comprise separate combinations of continent and gender (i.e. one study may report data for four samples, boys and girls in two different countries). In this context the most commonly studied form of maltreatment was sexual abuse and half of all such study samples (171 of 337) were found in North America. The second largest set of study samples was found for Asia and in contrast the least in South America. Where gender was distinguished, prevalence rates were generally higher for female samples apart from South America (but which had only a small number of studies) and Asia. In the three continents with much higher numbers of studies (North America, Asia and Europe), median (25th to 75th centile) prevalence rates still varied considerably for girls: 20.4% (13.2% to 33.6%), 9.0% (5.7% to 16.7%) and 14.3% (7.8% to 28.0%) respectively and for boys: 14.1% (4.3% to 21.0%), 6.7% (4.3% to 14.9%) and 6.2% (4.8% to 15.2%) respectively. When excluding studies focusing on clinical / sub-group samples (additional file 5), median prevalence rates were generally similar apart from that for North American boys (median 6.5%, 25th to 75th centile, 4.0% to 16.0%).

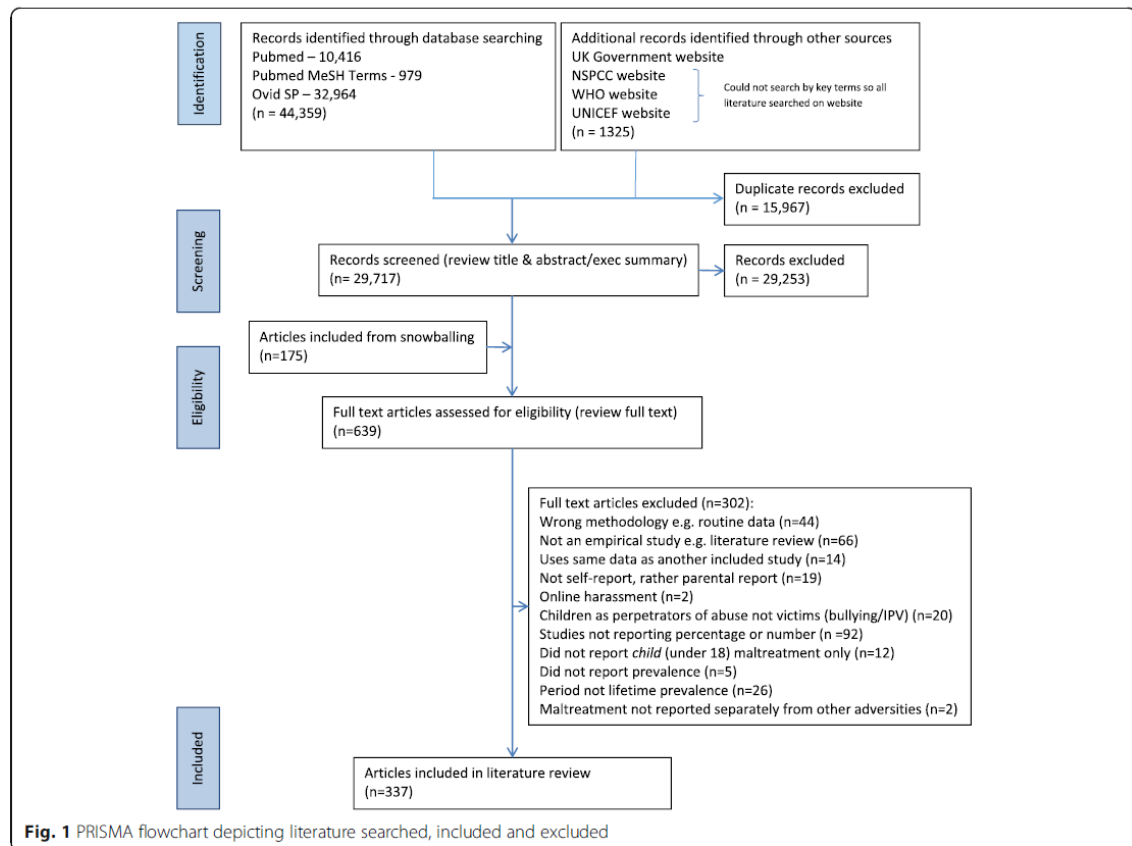
### Prevalence of physical abuse

Median rates of physical abuse similarly varied across continent, especially in Africa, Australia and South America but these were based on a very small number of studies in each case. In North America, where most studies had been undertaken, median prevalence rates (25th to 75th centile) were similar for boys and girls at 24.3% (14.1% to 32.1%) and 21.7% (14.2% to 33.3%) respectively. Rates were similar (and for both genders) in Asia, which had the second highest number of studies. In European studies, physical abuse was much higher for boys (27.0%) than for girls (12.0%).

### Prevalence of emotional abuse

Studies of emotional abuse were less commonly found and only in North America and Asia were there more than ten studies for each gender category reported separately.





Prevalence rates amongst girls (28.4%) in North America were twice that for boys (13.7%) although there were twice as many study samples for girls found. Prevalence rates in Europe were approximately half those reported in North America for both genders (boys: 6.2%, girls: 12.9%) and based on a smaller number of studies (boys  $n = 5$ , girls  $n = 8$ ). In Asia, where there were more study samples involved median prevalence rates were higher for boys (33.2%) than for girls (26.9%). Prevalence rates elsewhere were high for both boys and girls but were based on a much smaller number of studies in each case. When reviewing non-clinical samples only, the rates of emotional abuse in North American girls was much lower (15.9%) but little different for boys (12.3%).

#### Prevalence of neglect

There were fewer studies of neglect than for any other category of maltreatment, with North America providing the largest number for both boys ( $n = 8$ ) and girls ( $n = 15$ ). Prevalence rates were much higher for North American girls (40.5%) than for boys (16.6%). Prevalence rates in Asia were similar for boys (23.8%) and girls (26.3%), which was

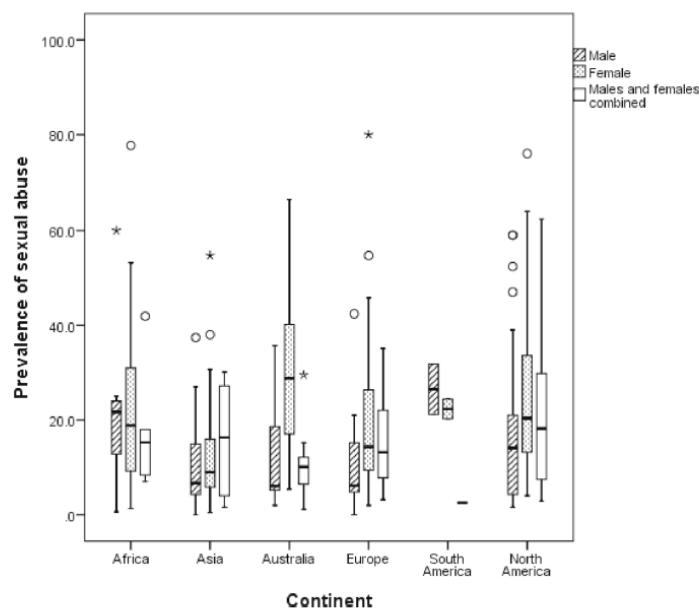
also the case in Europe but at a lower rate overall (boys: 14.8%, girls: 13.9%). There were only a very small number of studies across the remaining continents (Africa, Australia and South America) and prevalence rates were very high for each gender group.

#### UK

There were 18 UK studies. Lifetime prevalence rates of self-reported maltreatment in childhood in UK literature varied considerably, prevalence of physical abuse ranged from 3.6% [21] to 32.6% [22]. Prevalence of sexual abuse ranged from 0.7% [9] to 27.8% [283]. Prevalence of emotional or psychological abuse ranged from 4% [5] to 66.7% [23], and prevalence of neglect ranged from 5.6% [9] to 77.8% [23]. Finally, the prevalence of unspecified maltreatment ranged from 9.5% [24] to 48.4% [24].

#### Discussion

We reviewed 337 study reports, which provided 343 prevalence rates, based on self-report from either adults or children. North American studies were most numerous across



o = Outliers. Between 1.5 and 3 times the height of the boxes (25<sup>th</sup> to 75<sup>th</sup> centile)  
 \* = Extreme outliers. Values more than 3 times the height of the boxes (25<sup>th</sup> to 75<sup>th</sup> centile)

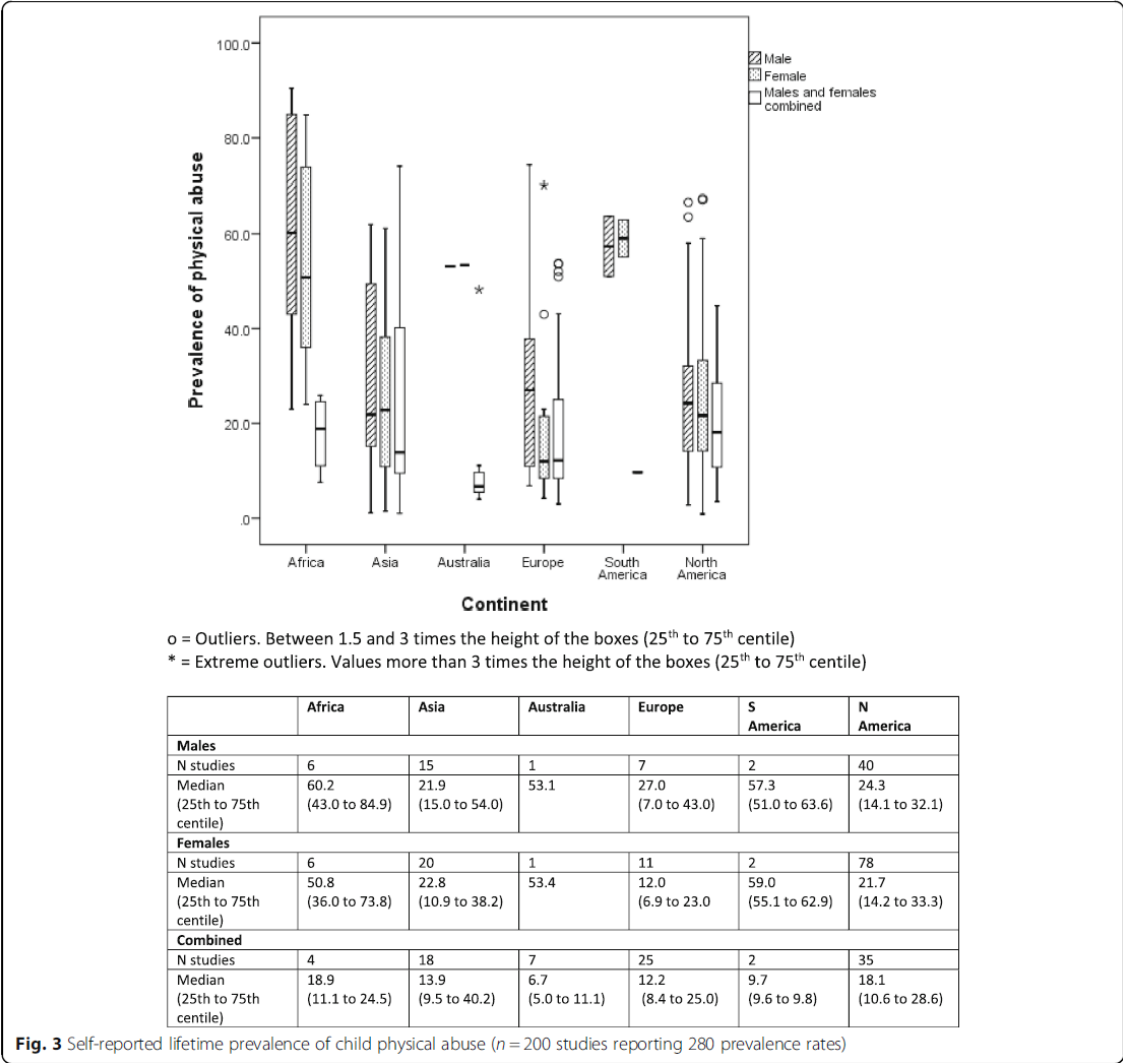
	Africa	Asia	Australia	Europe	S America	N America
<b>Males</b>						
N studies	9	21	8	18	2	56
Median (25th to 75th centile)	21.7 (12.8 to 24.0)	6.7 (4.3 to 14.9)	6.1 (5.3 to 18.6)	6.2 (4.8 to 15.2)	26.5 (21.2 to 31.8)	14.1 (4.3 to 21.0)
<b>Females</b>						
N studies	14	43	12	27	2	106
Median (25th to 75th centile)	18.9 (9.2 to 31.0)	9.0 (5.7 to 16.7)	28.8 (17.0 to 40.2)	14.3 (7.8 to 28.0)	22.4 (20.3 to 24.4)	20.4 (13.2 to 33.6)
<b>Combined</b>						
N studies	6	8	11	21	2	36
Median (25th to 75th centile)	15.3 (8.4 to 18.0)	16.3 (4.0 to 27.2)	10.1 (6.4 to 12.3)	13.2 (7.8 to 22.0)	2.6 (2.5 to 2.6)	18.2 (7.5 to 29.8)

**Fig. 2** Self-reported lifetime prevalence of child sexual abuse ( $n = 287$  studies reporting 402 prevalence rates)

each category of abuse, whereas South American studies were least numerous. In approximately two-thirds of studies prevalence rates were available for either or both genders. Where differentiated, studies of girls were more common than for boys across all maltreatment categories. Prevalence rates were most commonly available for sexual abuse, then for physical abuse and least commonly for neglect. Median rates of sexual abuse were higher for girls than boys in the three continents with the highest number of studies (North America, Europe, Asia) and there were big differences between continents in actual rates (for example 20.4% and 14.3% for girls in North America and Europe respectively). Median rates of physical abuse were similar for boys and girls in all continents (for

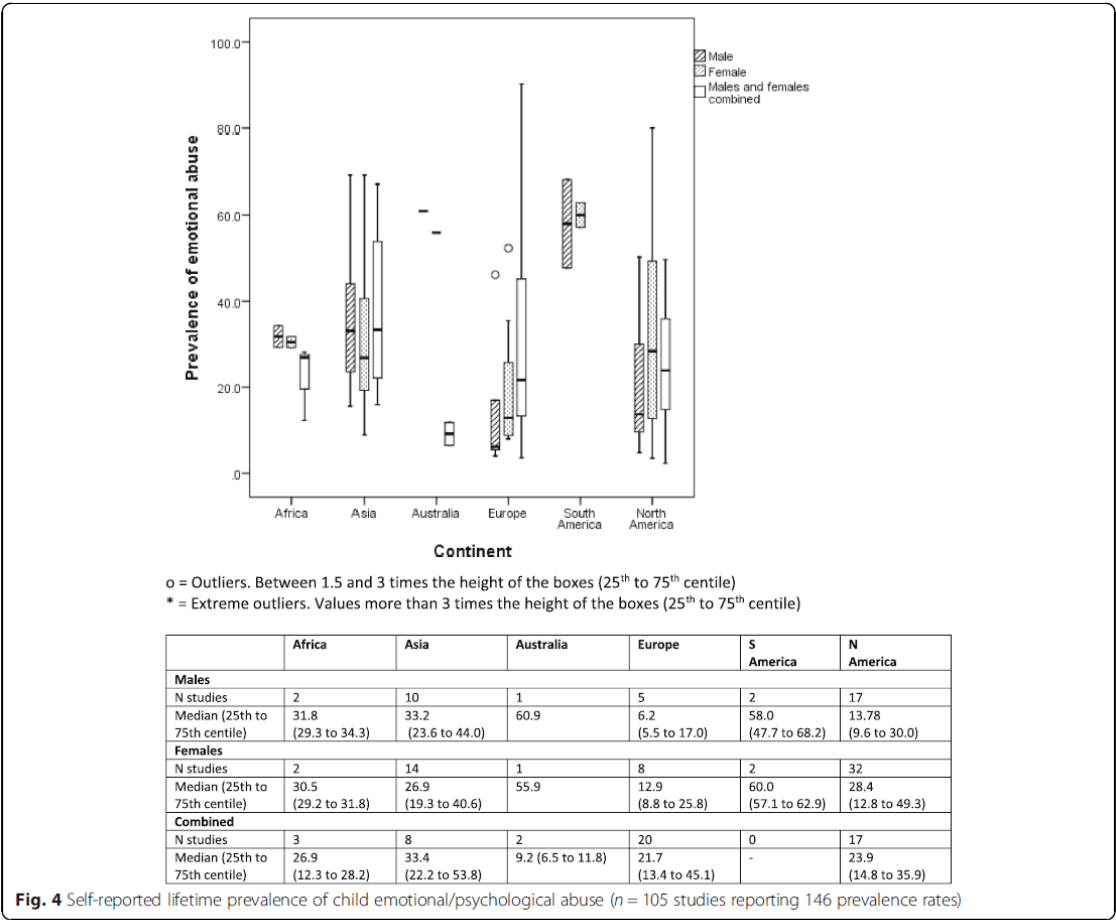
example 24.3% and 21.7% respectively in North America) apart from Europe and Africa where it was higher for boys (for example, 60.2 and 50.8 respectively for Africa, while rates varied considerably between continents for both girls and boys. Few studies of emotional abuse were found for Africa, Australia and South America and rates were much higher for girls than boys in North America and Europe but more similar in Asia (33.2% for boys, 26.9% for girls). Finally, a similar picture of study frequency was found for neglect and rates were much higher in North American girls (40.5%) compared to boys (16.6%) but similar across gender in both Europe and in Asia.

Pereda and colleagues [15] found substantial differences in prevalence of self-reported sexual abuse in their 2009



review of 65 studies. Their data suggested a ratio of 2.5 females for every one male victim. More recently, Stoltenborgh and colleagues [16] reported estimated prevalence for self-report studies of child sexual abuse in 2011 similarly across continents and by gender. They found gender made a substantial difference in difference in rates of self-reported abuse worldwide. While we did not statistically assess differences by gender, our findings bear that finding out. The paucity of studies in some geographical regions makes it more difficult to affirm such gender differences. The number of studies we retrieved where gender was not specified also confounds any potential differential effect of gender. The pattern of lower rates of sexual abuse Stoltenborgh found in Asia is also consistent

with our findings, as was the highest rate of sexual abuse overall for Australian girls. Considerable variation in lifetime prevalence rates of self-reported child maltreatment was found between studies, particularly between worldwide studies (between 0.0 and 100.0%), however, the variation in rates reported in UK based studies was still very large (between 0.7 and 77.8%). It is perhaps important to provide some context to the studies that reported the rather surprising extreme rates of 0.0% and 100.0%. Harkness and Monroe (2002) [25] found that all the females in their study reported that they had suffered neglect at some point, this was a clinical (depressed) sample, and so that may have had a bearing on the results. Khamis et al. (2000) [26] found that no males in



**Fig. 4** Self-reported lifetime prevalence of child emotional/psychological abuse ( $n = 105$  studies reporting 146 prevalence rates)

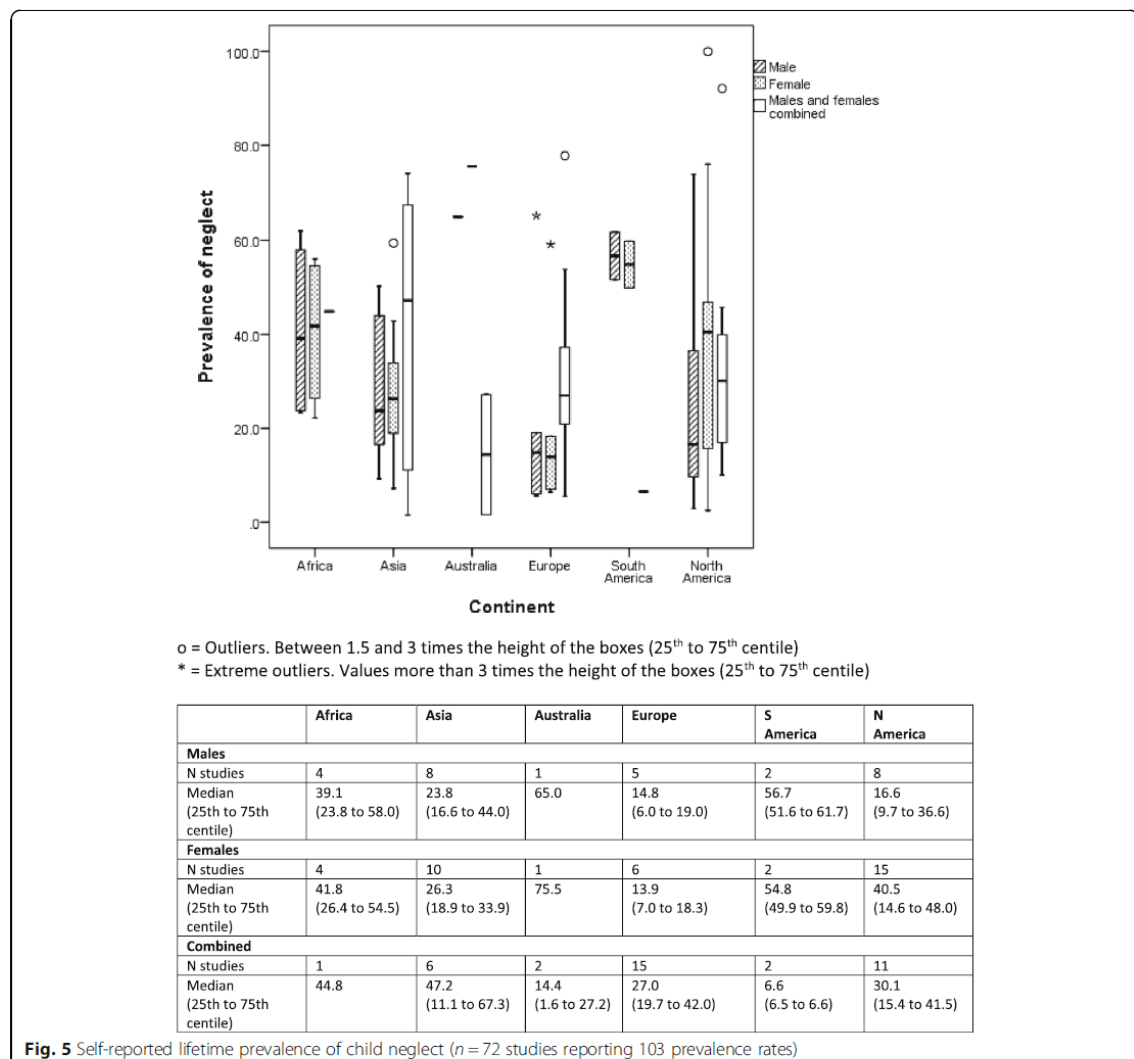
their study had reported sex abuse, the respondents were boys aged 12–16 who were interviewed by school counselors, it is possible that they therefore may have been reluctant to disclose a history of sex abuse due to discomfort or embarrassment. In both UK and worldwide studies the greatest difference in prevalence rates reported was for neglect. While some of this variation may reflect actual different experiences that children have, there are methodological differences that exist in the research that are likely to give rise to these variations [7, 9, 27]. We adopted a broad approach to inclusion for the review resulting in a heterogeneous sample of studies and prevalence rates.

#### Study participants

The age of the participant at time of reporting may have an effect on prevalence rates. One of the most common methodological approaches for collecting maltreatment data involved the use of retrospective adult self-reports of childhood experiences [28]. Some researchers have raised

concerns about the reliability and validity of retrospective recall in adult respondents, especially about childhood events and about events that are emotionally charged [29], what is known as recall bias [12, 30, 31]. Concerns include forgetting an experience that happened many years ago [32], while length of time since the abuse occurred may impact reliability [33], and adults maltreated as children may experience memory impairment related to the event [34]. Characteristics of the abuse may influence recall, including the type of abuse, the kinds of acts committed, or severity or chronicity of abuse [35]. It may be the case however that maltreatment is much more likely to be under-acknowledged rather than forgotten [36], and respondents may actively choose not to think about or disclose maltreatment experiences to avoid being reminded of them [37, 38].

Children are also asked to self-report maltreatment, and studies sometimes included both adults and children, and many of the methodological issues related to retrospective



recall by adults can be problematic for children. Some researchers have been reluctant to question children directly about their experiences on account of ethical and procedural complications related to reporting requirements [39].

Comparison of prevalence rates from studies that collected self-reports from adults with those that involved children is problematic [11], for example, a study conducted in 2017 may include self-reported maltreatment as far back as the 1930s or 1940s for adults, but only as far back as the 1990s for children, the time lapse may have an effect, as well as social and legal changes in the definition and recognition of child maltreatment [36]. What individuals consider to be abusive behaviour may change between generations, for example, smacking a child was socially acceptable in the UK as recently as the 1980s [40], and still

may be today. In principle however it may be possible to compare adult and child reports for time periods that coincide.

Gender of the participant may influence reporting, some evidence suggests that men may be less likely to reveal a history of maltreatment [33, 41]. The results of the current study seem to support this notion, particularly in relation to sexual abuse, however, the number of studies found concerning sexual abuse in men was relative low at 33% (115/345) compared to those concerning sexual abuse in women (56%, 195/345), it may be the case that there are true differences in prevalence rates between males and females [42]. It has been suggested that definitions of maltreatment do not capture the experiences of males adequately, specifically sexual abuse [15], or that fear of being labelled as weak or



being flagged as homosexual might underestimate prevalence in males [43].

The population of study participants may affect prevalence rates [16], studies variously derived their samples from large samples of participants from the general population [9], clinical or service user samples, convenience samples such as university or college students, school pupils, or self-selecting volunteers. Prevalence estimates tended to be lower for samples drawn at random from general populations and convenience samples than those based on research with volunteers or service user samples [9, 43], for example Cawson et al. (2000) [44] found lower prevalence rates in all four types of maltreatment when using a population sample as compared to Fisher et al. (2011) who used individuals presenting to mental health services with psychosis [45]. University students may also be more aware of the study's aims and thus more liable to response biases [16], while Goldman & Padayachi (2000) somewhat controversially suggested that university students may be a psychologically healthier group which may be associated with lower sexual abuse prevalence [43]. Drawing inferences from clinical samples can be problematic if the clinical setting from which the respondents are sampled is related to child protection intervention; it may be difficult to sort out causal order among the variables [11]. To demonstrate the impact that such variation can have on prevalence rates our additional figures showed results based on 'non-clinical' study samples. This did not always reduce the prevalence rates, although this was the general direction of effect. The study design, sampling framework adopted (for example, the application of staged and sub-group over-sampling) and the eligibility criteria applied could still exert a substantial effect of apparent prevalence rates even in non-clinical samples.

#### Data collection mode

The measures used to collect data in self-report studies can be broadly divided into those that require the presence of a researcher presenting questions to a participant, and those that are self-administered. Method of data collection can artificially influence participant response, and some studies have shown that face-to-face interviews result in higher reporting rates compared to self-completed questionnaires [27]. Amodeo et al. (2006) found that the prevalence of sexual abuse in their sample was higher based on a combined questionnaire and interview rather than a questionnaire alone [46]. Face-to-face methods can also give opportunities for clarification and probe ambiguous responses, and remind participants of expectations for honesty [47, 48]. Face-to-face interviews have the advantage of allowing for greater rapport, participants may prefer this method [47], disclosure may be promoted [48] through understanding and support on the part of the interviewer while others have not reported such a difference [27]. It may also be the

case however that interviewer presence may hamper disclosure if participants are reluctant to reveal sensitive information directly, may also cause participants to be more vulnerable to the effect of social desirability [11, 12]. Not everyone however, is equally prone to discomfort relating to sensitive questions, even at a young age [36].

#### Definitions of child maltreatment

Participants' ideas of what constitutes maltreatment can vary [5], and this may affect self-reported prevalence rates. Participants make a personal judgment about whether what took place was abusive if the questions asked are not specific [36, 49, 50]. Answers provided will therefore be influenced by participants' subjective perceptions of abuse [16], which may be influenced by intergenerational changes in attitudes and cross-cultural differences, amongst other things. Previous studies have found that many people do not perceive childhood experiences such as 'being whipped or beaten to the point of laceration' as maltreatment, and there is a tendency to believe that discipline experienced as a child was normal [51, 52]. This however, should not affect responses to descriptive questions [5]; direct and specific questions tend to be used in validated measures, and are tested for internal consistency and pre-test reliability [9]. Age-appropriate questions that give behavioural descriptions of events help respondents to think about specific incidents and are preferred over questions that use legal terminology or ask respondents to label themselves as maltreated [53], and some have found that using broad questions are associated with lower prevalence rates of sexual abuse than more specific questions [54]. Furthermore, both the context and the number of questions asked can affect number of reports [27].

Some researchers specified an age range when asking participants about their maltreatment experiences, Bebbington et al. (2011) defined child sexual abuse as occurring before the age of 16 [36], and some did not. Diaz-Olavarrieta et al. (2001) asked participants if as a 'child' they experienced physical or sexual abuse [55], this may affect reported prevalence rates as one person's idea of a 'child' may vary from another's. When researchers defined child maltreatment as something that happens before the age of 16, those who were maltreated at ages 17 and 18 are missed. The definition of the perpetrator of the maltreatment may also affect prevalence rates, most studies do not specify details about the perpetrator, however, some focused narrowly on perpetrators as caregivers and family members, for example Annerbäck et al. (2010) [56]. It should also be noted that studies will under estimate infant and toddler abuse as the reporters may not be recall these events.

Some studies focused on one form of abuse, 34% (114/339) of the studies reviewed in this paper focused on sexual abuse only, with 56% (189/339) including more than one form of maltreatment. Although Bentley et al. (2017)

reported that neglect was the most common reason for a child being subject to a protection plan or on the child protection register in the four UK countries [6], a disproportionate amount of studies have been conducted on the prevalence of sexual and physical abuse. Perhaps this is a reflection of perceived or actual seriousness of the various types of abuse, or possibly the understanding of what emotional abuse is or thresholds for neglect and whether neglect is always physical neglect or emotional neglect. The definitions used to assess the prevalence of abuse and neglect vary greatly between studies, and this may affect prevalence rates [30]. Radford et al. (2011) asked participants a series of very specific questions about experiences they may have had as a child [9], whereas Diaz-Olavarrieta et al. (2001) simply asked participants if they had experienced persistent physical/sexual abuse as a child [55], allowing participants to impose their own definition of abuse. Most studies, such as that by Diaz-Olavarrieta et al. (2001) [55] do not present their maltreatment definitions in enough detail in published papers [10].

Pereda et al. (2009) noted differences in definitions of what constitutes sexual abuse, including the age difference between the perpetrator and the victim, the age used to define childhood, and the type of sexual abuse [27]. Edgardh and Ormstad (2000) [57] and McCrann et al. (2006) [58] defined sexual abuse as when the perpetrator was at least five years older than the victim, this is often done to rule out sexual activity among peers [16]. There are also cultural and legal differences between countries in the age of consent to sexual intercourse which affects definitions [44]. The acts that constitute sexual abuse are a crucial part of a definition and would almost certainly affect prevalence rates, for example non-contact abuse such as exhibitionism can be more commonplace and may yield higher prevalence rates than contact abuse only [16].

Definitions of physical abuse may suffer from cultural preconceptions. As previously mentioned smacking is still legal in the UK but outlawed in some parts of Europe [40]. In spite of this, often too much is made of cultural differences, and there is a general consensus in many cultures about what constitutes maltreatment [40], cultural differences may therefore only play a small role in differences in reported rates of maltreatment.

Definitions of neglect vary greatly because recognition of neglect can be difficult; children who are victims of neglect experience multiple types of neglect and it is mostly persistent and rarely traceable to a single incident [59]. Definitions of neglect have been criticised for imposing middle-class values on lower-class families [60], and that they do not take cultural differences into account [59]. There has been debate on whether the focus of the definition should be around either caregiver behaviours, or of the experiences of the child, regardless of who is to blame [11]. Risk and protective factors can change with age and developmental

ability; this can affect definitions [11]. Some researchers have purported that definitions of neglect should consider the frequency, duration, and severity of the neglect, the age of the child, and potential consequences to the child's development [59, 61, 62]. Tonmyr et al. (2011) noted that emotional or psychological abuse can also have particularly ambiguous definitions [63].

Some forms of maltreatment overlap, for example, sexual abuse often also involves physical abuse, and all forms of maltreatment include an element of emotional or psychological abuse, this can complicate definitions [44].

Some of the reasons for differing prevalence rates described above are expected, for example, it's unsurprising that there are variations in self-reports of different types of abuse and neglect, these expected reasons are less likely to represent error. Some of the differences in prevalence rates found however are more likely to represent error; for example, whether data collection is self-administered or requires the presence of an interviewer.

### Strengths and limitations

We have reviewed the literature and collated data on the lifetime prevalence of self-reported child maltreatment worldwide. PubMed, Ovid SP and grey literature from the NSPCC, UNICEF, The UK Government, and WHO from 2000 to 2017 were searched. These databases were selected as they were thought to likely contain literature on the prevalence of child maltreatment, and indeed yielded a large amount of articles on the subject. The authors recognise however that it is possible that other databases not utilised could have yielded additional papers. Literature that were not in the English language were excluded, this was due to budget restriction on translation work as this review was part of a PhD. All four types of child maltreatment were included in this review, and studies which did not specify the type were also included. Including all types of child maltreatment in the same review has not been done for some time and this is a strength of the current piece of work. For some studies no upper age limit was provided, contacting the authors of these papers was not justifiable given the current resources and so the authors assumed the upper age limit of 100 for those studies. The authors planned to conduct a meta-analysis on the prevalence reported rates however, studies varied considerably in the data they collected, the tools to collect the data, and the populations included. It was therefore not possible to form sufficiently large groups to warrant a meta-analysis.

Although a portion of all titles and abstracts were triple-screened against the inclusion/exclusion criteria by three additional reviewers, just a single reviewer was responsible for reviewing all the other abstracts, however, reviewer agreement was very high and so we believe that the review process was completed systematically.

## Conclusions

This review focused on the lifetime prevalence rates of maltreatment observed through respondent self-report. We found differences by gender and geography which are broadly consistent with previous reviews of child sexual abuse. In addition, we have expanded the focus to include other categories of maltreatment. The different number of studies across categories of maltreatment and across settings makes it harder to have similar levels of confidence about summary rates of prevalence, especially in Africa and South America. The lack of distinction by gender in many studies is concerning given the sizeable differences observed here and in previous reviews between boys and girls. Methodological differences between the studies may go some way towards explaining the differences found in prevalence rates. Methods and techniques for collecting data about experiences of maltreatment have advanced in recent years [9], and further research is required to optimise use of data from a variety of sources.

Recommendations for future work include, given the range of methodological differences in studies observed, that researchers may need to be more precise when selecting studies to include in a review such as this one, for example, by excluding studies that have used broad, non-specific labels of maltreatment which require a high degree of interpretation by the respondent. This may be a way to arrive at more useful rates of child maltreatment which will allow better comparisons between studies.

## Appendix 1: Search strategy

### Search terms defined

Maltreatment to include (HM Gov, 2013):

Physical abuse: 'A form of abuse which may involve hitting, shaking, throwing, poisoning, burning or scalding, drowning, suffocating or otherwise causing physical harm to a child. Physical harm may also be caused when a parent or carer fabricates the symptoms of, or deliberately induces, illness in a child'.

Emotional abuse: 'The persistent emotional maltreatment of a child such as to cause severe and persistent adverse effects on the child's emotional development'.

Sexual abuse: 'Involves forcing or enticing a child or young person to take part in sexual activities, not necessarily involving a high level of violence, whether or not the child is aware of what is happening'.

Neglect: 'The persistent failure to meet a child's basic physical and/or psychological needs'.

*Lifetime prevalence and period prevalence* (Fallon et al, 2010; Stoltenborgh et al 2011):

Lifetime prevalence of maltreatment: the number of individuals having experienced maltreatment at some point during childhood.

Period prevalence of child maltreatment: the number of individuals having experienced maltreatment at some

point during a specified period of time, for example, the past year.

### Search terms list – keywords

measur\*  
quantify\*  
comput\*  
estimat\*  
evaluat\*  
assess\*  
confirm\*  
child\*  
young pe\* (people/person)  
maltreat\*  
abuse\*  
neglect\*

### Medical Subject heading (MeSH) Terms

abuse, child (MeSH)

#### grouped search terms

(measur\* OR quantify\* OR comput\* OR estimat\* OR evaluat\* OR assess\* OR confirm\*) AND (maltreat\* OR abuse\* OR neglect\*) AND (child\* OR young pe\*)

### Literature sources

- published research literature from the following databases:

<http://www.ncbi.nlm.nih.gov/pubmed>  
[www.thecochranelibrary.com](http://www.thecochranelibrary.com)  
[wok.mimas.ac.uk](http://wok.mimas.ac.uk) (Web of Science)  
OvidSP (PsychInfo from 2002 only and Medline)

- policy and practice literature – UK Government specifically:

<https://www.gov.uk/government/publications>

- Charity publications – NSPCC, Action for Children:  
<http://www.nspcc.org.uk/Inform/publications/>  
[www.actionforchildren.org.uk/policy-research/publications-and-briefings](http://www.actionforchildren.org.uk/policy-research/publications-and-briefings)
- Use Web of Science or Google scholar to search for citations of articles and by authors important in the field:

[scholar.google.co.uk](http://scholar.google.co.uk)

- Cardiff Child Protection Systematic Reviews:

<http://www.core-info.cardiff.ac.uk/>



**Inclusion and exclusion criteria:**

Inclusion	Exclusion
Initial stage	
Child maltreatment (sexual, physical, emotional/psychological abuse and neglect)	
Lifetime prevalence	Period prevalence
Self-report	Data collected through routine sources or proxy report only (e.g. parents report)
English language	Not English language (literature was not translated as this was part of a PhD an included budget restrictions)
Systematic reviews as well as individual studies	Anything that is not a study or does not direct the reader to other studies
Maltreatment occurred when victim was under 18	Maltreatment occurred when victim was over 18
Published from 01/01/2000 onwards	Before 01/01/2000
Final stage	
As above in initial stage	As above in initial stage
	Between-peer maltreatment such as bullying and teen partner abuse
	Studies that did not report either a percentage or a number (where percentage could be derived) of the prevalence of child maltreatment

**Search strategy**

Search database/ website	Search terms used	Date search performed	Number of returns
PubMed	((measur*[Title/Abstract] OR quantify*[Title/Abstract] OR comput*[Title/Abstract] OR estimat*[Title/Abstract] OR evaluat*[Title/Abstract] OR assess*[Title/Abstract] OR confirm*[Title/Abstract]) AND (maltreat*[Title/Abstract] OR abuse*[Title/Abstract] OR neglect*[Title/Abstract]) AND (child*[Title/Abstract] OR young pe*[Title/Abstract]))	1 <sup>st</sup> search: 01/01/2000 - 28/05/2014 2 <sup>nd</sup> search: 28/05/2014 - 15/03/2017	1 <sup>st</sup> search: 8532 2 <sup>nd</sup> search: 1884
PubMed MeSH terms	Child abuse/epidemiology [mh]	30/05/2014	979
Ovid SP	((measur* or quantify* or comput* or estimat* or evaluat* or assess* or confirm*) and (maltreat* or abuse* or neglect*) and (child* or young pe*)).tw.	1 <sup>st</sup> search: 01/01/2000 - 05/06/2014 2 <sup>nd</sup> search: 05/06/2014 - 15/03/2017	1 <sup>st</sup> search: 18401 2 <sup>nd</sup> search: 14563
NSPCC	Searched through all literature on website <a href="http://www.nspcc.org.uk/Inform/publications/">http://www.nspcc.org.uk/Inform/publications/</a>	1 <sup>st</sup> search: 18/06/2014 2 <sup>nd</sup> search: 15/03/2017	N/A
UK Government	Searched through all literature on website <a href="https://www.gov.uk/government/publications">https://www.gov.uk/government/publications</a> using search terms 'child abuse'	1 <sup>st</sup> search: 18/06/2014 2 <sup>nd</sup> search: 15/03/2017	N/A
WHO	Searched through all literature on website <a href="http://www.who.int/publications/en/">http://www.who.int/publications/en/</a>	1 <sup>st</sup> search: 24/06/2014 2 <sup>nd</sup> search: 15/03/2017	N/A
UNICEF	Searched through all literature on website <a href="http://www.unicef.org/publications/">http://www.unicef.org/publications/</a>	1 <sup>st</sup> search: 24/06/2014 2 <sup>nd</sup> search: 15/03/2017	N/A

## Additional files

**Additional file 1:** Inclusion and exclusion criteria applied to the literature. (DOCX 12 kb)

**Additional file 2:** Table containing data for each of the studies included in review. (DOCX 73 kb)

**Additional file 3:** References for table (additional file 2) containing data for each of the studies included in review. (DOCX 47 kb)

**Additional file 4:** Prevalence of abuse by type and population. (DOCX 28 kb)

**Additional file 5:** Prevalence of maltreatment by continent and gender - non-clinical samples only. (DOCX 81 kb)

## Availability of data and material

Data sharing is not applicable to this article as no datasets were generated or analysed during the current study.

## Authors' contributions

Study conception: GM, MR, RCJ, KH, AK, drafting manuscript: GM. All authors critically reviewed and approved the final version of the submitted manuscript

## Ethics approval and consent to participate

Not applicable.

## Consent for publication

Not Applicable.

## Competing interests

The authors declare that they have no competing interests.

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## Author details

<sup>1</sup>Centre for Trials Research, Cardiff University, Neuadd Meirionnydd, Heath Park, Cardiff, Wales, UK. <sup>2</sup>School of Medicine, Department of Population Medicine, Cardiff University, Neuadd Meirionnydd, Heath Park, Cardiff, Wales, UK.

Received: 25 January 2018 Accepted: 18 September 2018

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**Table 1. Inclusion and exclusion criteria applied to the literature**

Inclusion	Exclusion
<b>Initial stage</b>	
Child maltreatment (sexual, physical, emotional/psychological abuse and neglect)	
Lifetime prevalence	Period prevalence
Self-report	Data collected through routine sources or proxy report only (e.g. parents report)
English language	Not English language
Systematic reviews as well as individual studies	Any publication that is not a study or does not direct the reader to other studies
Maltreatment occurred when victim was less than 18 years of age	Maltreatment occurred when victim was older than 18 years of age
Published from 01/01/2000 onwards	Before 01/01/2000
<b>Final stage</b>	
As above in initial stage	As above in initial stage
	Peer to -peer maltreatment such as bullying and teen partner abuse
	Studies that did not report either a percentage or the frequency (where percentage could be derived) of child maltreatment

**Additional file 2. Table containing data for each of the studies included in review**

Number	Author	Country	age as seen in paper	Age range inferred	Population	Total N	mode of completion	Type of maltreatment, gender, %	Maltreatment descriptions and calculations
1	Aaron & Hughes (2007)	US	18-83	18-83	women who identified as lesbian	416	interview	sexual,female,31.0%	child sexual abuse
2	Aberle et al (2007)	Croatia	14-18	14-18	school pupils	2140	self-completed	sexual,male,6.0% sexual,female,3.3% physical,nogender,12.5% emo/psych,nogender,90.3%	Physical and emotional abuse and possible sexual molestation. Calculated for this review as: for physical abuse: frequency of physical punishment = anything over 'never', for emotional abuse: the highest % taken in a list of 'types of punishment' (harassment)
3	Afifi et al (2003)	Egypt	12-18	12-18	school pupils	555	self-completed	sexual,nogender,7.0% physical,nogender,7.6% emo/psych,nogender,12.3%	sexual, physical, emotional abuse
4	Afifi et al (2006)	US	15-54	15-54	population sample	5877	self-completed	unspecified,nogender,16.5%	Physical and sexual child abuse, BUT results do not separate types so coded as type of abuse 'unsure'
5	Afifi et al (2012)	US	20 and above	20-100	population sample	34653	interview	physical,nogender,5.9%	physical punishment
6	Akyuz et al (2005)	Turkey	18-65	18-65	population sample	628	self-completed	sexual,female,2.5% physical,female,24.5% emo/psych,female,21.5% neglect,female,33.9%	sexual, physical, emotional abuse, neglect

7	Alami and Kadri (2004)	Morocco	20 and over	20-100	Women randomly selected by using systematic sampling from eight jurisdictions in Casablanca	728	interview	sexual,female,9.2%	Child sexual abuse
8	Alikasifoglu et al (2006)	Turkey	mean age 16.3, school pupils 9th to 11th grade	15-17	school pupils	1871	self-completed	sexual,female,13.4%	sexual abuse in female adolescents
9	Allard (2009)	Japan and US	18-28	18-28	university/college students	79	self-completed	sexual,nogender,20.5% physical,nogender,9.5% emo/psych,nogender,41.9% neglect,nogender,11.1%	sexual, physical, emotional abuse and neglect
10	Almeida et al (2011)	Australia	60-101	60-101	patients who had been in contact with GP in last 12 months	20677	self-completed	sexual,nogender,9.5% physical,nogender,11.1%	Early sexual and physical abuse
11	Ammerman et al (2012)	US	16 and over	16-100	mothers participating in home visitation programs	90	self-completed	sexual,female,51.1% physical,female,57.8% emo/psych,female,80.0% neglect,female,73.3%	sexual, physical, emotional, emotional and physical neglect. Highest % taken for emotional and physical neglect
12	Amodeo et al (2006)	US	21-65	21-65	population sample	290	self-completed and interview	sexual,female,27.9%	child sexual abuse
13	Angst et al (2011)	Switzerland	27-30	27-30	population sample	591	self-completed	sexual,male,4.8% sexual,female,18.7%	childhood sexual trauma

14	Annerbäck et al (2010)	Sweden	pupils in grades 7 (ca. 13 years old) and 9 (ca. 15 years old) in compulsory school and grade 2 (ca. 17 years old) in upper secondary school	13-18	School pupils	8494	self-completed	physical,nogender,15.2%	child physical abuse
15	Ansara et al (2005)	Canada	19-42	19-42	women post-childbirth	253	interview	sexual,female,14.1% physical,female,6.5% emo/psych,female,3.5%	childhood sexual, physical, emotional abuse
16	Appel et al (2011)	Germany	29-89	29-89	population sample	2157	self-completed	sexual,nogender,3.6% physical,nogender,4.5% emo/psych,nogender,3.6% neglect,nogender,16.2%	sexual, physical, emotional, emotional and physical neglect. Highest % taken for emotional and physical neglect
17	Arata et al (2005)	US	17-61	17-61	university/college students	384	self-completed	sexual,nogender,4.4% physical,nogender,4.4% emo/psych,nogender,2.3% neglect,nogender,15.4%	sexual, physical, emotional abuse and neglect.
18	Ariga et al (2008)	Japan	16-19	16-19	female juvenile offenders	64	interview	sexual,female,54.7% unspecified,female,32.8%	sexual, physical, psychological abuse, does not split physical and psychological abuse so listed as unsure
19	Arreola et al (2008)	US	18 and over	18-100	gay and bisexual men	2506	interview	sexual,male,21.0%	forced sex before the age of 18
20	Arreola et al (2009)	US	mean age 31.2	31.2	Latino gay and bisexual men	912	interview	sexual,male,15.8%	childhood sexual abuse

21	Arreola et al (2005)	US	over 18	18-100	Adult men who have sex with men	2692	interview	sexual,male,13.0%	childhood sexual abuse
22	Aslund et al (2007)	Sweden	15-18	15-18	school pupils	5048	self-completed	sexual,male,11.9% sexual,female,29.0%	sexual abuse
23	Aspelmeier et al (2007)	US	18-21	18-21	university/college students	324	self-completed	sexual,female,37.7%	childhood sexual abuse
24	Audu et al (2009)	Nigeria	under 18	7-18	Girls engaged in economic activity	316	interview	sexual,female,77.7%	child sexual assault
25	Baccini et al (2003)	Italy	17-72	17-72	gastrointestinal out-patients	260	self-completed	sexual,nogender,17.0% physical,nogender,25.0%	childhood sexual and physical abuse
26	Back et al (2003) US	US	17-47	17-24	university/college students	65	self-completed	sexual,female,15.4% physical,nogender,38.5%	child sexual and physical abuse
27	Back et al (2003) Singapore	Singapore	18-21	18-21	university/college students	88	self-completed	sexual,female,4.5% physical,nogender,62.5%	child sexual and physical abuse
28	Bailey et al (2012)	Australia	20-73	20-73	adults with current depression and alcohol use problems	221	self-completed	sexual,male,21.3% sexual,female,46.8%	sexual assault. Various questions used to measure, highest % taken
29	Balsam et al (2010)	US	18-74	18-74	Lesbian, gay and bisexual adults	669	self-completed	sexual,male,32.0% sexual,female,42.4% physical,male,35.3% physical,female,37.5% emo/psych,male,50.2% emo/psych,female,60.8%	sexual, physical, emotional abuse
30	Bandelow et al (2005)	Germany	mean ages 30.2 for patients and 32.3 for controls	31.3	Patients with borderline personality disorder and healthy controls	175	self-completed	sexual,nogender,30.9% physical,nogender,50.9% emo/psych,nogender,11.4%	sexual abuse, father/mother beats child, father beats mother. Numerous questions asked and so highest % taken.



31	Banerjee et al (2008)	India	8-14	8-14	Children employed as whole time workers	330	interview	sexual,nogender,3.4% physical,nogender,18.8% emo/psych,nogender,19.9%	sexual abuse, beating, and rebukes or mental assaults
32	Banou et al (2009)	US	26-77	26-77	cancer patients	64	interview	unspecified,female,59.4%	sexual and physical abuse, and witness to violence. BUT results do not separate types so coded as type of abuse 'unsure'
33	Barney (2004)	US	12-19	12-19	gay and heterosexual American Indian or Alaska Native males	5602	self-completed	sexual,male,2.5% physical,male,7.6%	sexual and physical abuse
34	Bebbington et al (2011)	England	16 and over	16-100	population sample	7353	self-completed	sexual,male,5.3% sexual,female,11.1%	child sexual abuse
35	Bensley et al (2000)	US	18 and older	18-100	population sample	3473	interview	sexual,male,11.4% sexual,female,13.8% physical,male,9.4% physical,female,4.4%	sexual and physical abuse
36	Bensley et al (2003)	US	18 and over	18-100	population sample	3527	interview	sexual,female,9.6% physical,female,2.0% emo/psych,female,6.1%	physically or sexually assaulted or witnessed interparental violence in childhood
37	Berliner et al (2001)	US	18 - 96	18-96	population sample	1325	interview	sexual,female,18.0%	sexual assault experiences - child rape or molestation. Highest % was taken as measure
38	Bifulco et al (2000)	UK	20-45	20-45	sister pairs	198	interview	unspecified,female,40.4%	sexual and physical abuse and neglect. BUT results do not separate types so coded as type of abuse 'unsure'
39	Birdthistle et al (2008)	Zimbabwe	15-19	15-19	population sample	863	interview	sexual,female,52.2%	participant answered yes to 'ever forced to have sex'

40	Blain et al (2012)	US	19-63	19-63	gay and bisexual men reporting compulsive sexual behaviour symptoms	182	self-completed	sexual,male,39.0%	child sexual abuse
41	Bohn et al (2013)	Germany	23-69	23-69	patients diagnosed with fibromyalgia syndrome	117	self-completed	sexual,nogender,28.2% physical,nogender,24.0% emo/psych,nogender,47.9% neglect,nogender,53.8%	sexual, physical, emotional, emotional and physical neglect. Highest % taken for emotional and physical neglect
42	Bonomi et al (2008)	US	18-64	18-64	insured women	3568	interview	sexual,female,19.4% physical,female,6.4%	sexual and physical abuse
43	Boynton-Jarrett et al (2012)	US	21-69	21-69	self-identified black women	33298	self-completed	unspecified,female,26.9%	sexual and physical abuse. BUT results do not separate types so coded as type of abuse 'unsure'. Highest % taken for various types and severity of abuse
44	Bradley et al(2008)	US	18-81	18-81	patients with and without major depressive disorder	200	interview	unspecified,nogender,34.0%	moderate to severe child abuse
45	Brand et al (2010)	US	mean age 34	34	postpartum women with history of major depressive disorder	126	self-completed	sexual,female,22.2% physical,female,7.1%	sexual and physical abuse
46	Brennan et al (2007)	US	at least 18 years of age	18-100	gay and bisexual men	862	self-completed	sexual,male,15.5%	childhood sexual abuse
47	Brezo et al (2008)	Canada	19-24	19-24	school pupils	1684	interview	sexual,male,2.7% sexual,female,18.0% physical,male,26.3% physical,female,14.3%	contacts sexual abuse and physical abuse

48	Briere and Elliott (2003)	US	18-90	18-90	population sample	935	self-completed	sexual,male,14.2% sexual,female,32.3% physical,male,22.2% physical,female,19.5%	childhood physical and sexual abuse
49	Brodsky et al (2001)	US	mean age 35.4 for abused and 37.2 for non-abused	36.3	depressed adult inpatients	136	self-completed	unspecified,nogender,38.0%	sexual and physical abuse. BUT results do not separate types so coded as type of abuse 'unsure'.
50	Brooker et al (2001)	UK	18-24	18-24	random probability sampling throughout UK	2869	interview	sexual,male,2.5% sexual,female,4.0% physical,male,27.0% physical,female,23.0% emo/psych,male,17.0% emo/psych,female,16.0% neglect,male,19.0% neglect,female,16.0%	Physical maltreatment, physical neglect, emotional and psychological maltreatment and sexual abuse
51	Brown et al (2005)	US	at least 18, young adults	18-100	population sample	642	self-completed	sexual,nogender,48.2% physical,nogender,11.6%	sexual and physical abuse
52	Brown et al (2013)	UK	19-51	19-51	systematically enriched for risk factors for depressive disorders	273	interview	physical,female,11.0% emo/psych,female,35.5%	mother's lack of affection or rejection, and father's physical abuse
53	Cawson et al (2000)	UK	18-24	18-24	population sample	2869	self-completed	sexual,nogender,11.0% physical,nogender,14.0% emo/psych,nogender,6.0% neglect,nogender,6.0%	sexual, physical, emotional/psychological, neglect
54	Champion et al (2004)	Mexico	14-19	14-19	women attending a rural health clinic	106	self-completed	sexual,female,24.0% physical,female,29.0% emo/psych,female,63.0%	Psychological abuse, physical abuse, sexual abuse

55	Chapman et al (2004)	US	mean age 56.6	56.6	health maintenance organisation members in a primary care clinic	9460	self-completed	sexual,male,6.9% sexual,female,13.2% physical,male,14.7% physical,female,15.4% emo/psych,male,5.1% emo/psych,female,7.5%	sexual, physical, emotional abuse, battered mother. Took the highest % out of emotional abuse and battered mother
56	Chartier et al (2007)	US	15-98	15-98	population sample	9953	interview	sexual,male,4.3% sexual,female,12.8% physical,male,31.2% physical,female,21.1%	sexual and physical abuse
57	Chartier et al (2009)	Canada	15-64	15-64	population sample	8116	self-completed	sexual,nogender,9.0% physical,nogender,26.0%	sexual and physical abuse
58	Chen et al (2004)	China	11-12	16-18	school pupils	2300	self-completed	sexual,male,10.5% sexual,female,16.7%	child sexual abuse
59	Chen et al (2006)	China	16-23	16-23	school pupils	351	self-completed	sexual,female,21.9%	child sexual abuse
60	Cheng-Fang et al (2008)	Taiwan	Junior high school pupils	12-15	school pupils	1684	self-completed	sexual,male,3.0% sexual,female,2.0% physical,male,21.9% physical,female,22.5%	child physical and sexual abuse
61	Clemmons et al (2003)	US	18-49	18-49	Latina university students	112	self-completed	sexual,female,38.4% physical,female,10.7% emo/psych,female,33.9%	sexual, physical emotional abuse and witness violence between parents. Took the highest % for emotional abuse or witnessing violence
62	Cohen et al (2001)	US	mean age 22	22	population sample	664	self-completed	sexual,nogender,2.9% physical,nogender,3.5%	sexual and physical abuse
63	Cohen et al (2006) US	US	18-70	18-70	healthy volunteers	1659	self-completed	sexual,nogender,5.3% physical,nogender,4.7% emo/psych,nogender,14.8%	sexual, physical, emotional abuse, domestic violence in the home. Highest % taken from domestic violence and emotional abuse
64	Cohen et al (2006) UK & Amsterdam	UK & Amsterdam	18-70	18-70	healthy volunteers	1659	self-completed	sexual,nogender,7.7% physical,nogender,7.7% emo/psych,nogender,16.5%	sexual, physical, emotional abuse, domestic violence in the home. Highest % taken from domestic violence and emotional abuse

65	Cohen et al (2006) Australia	Australia	18-70	18-70	healthy volunteers	1659	self-completed	sexual,nogender,4.2% physical,nogender,5.0% emo/psych,nogender,11.8%	sexual, physical, emotional abuse, domestic violence in the home. Highest % taken from domestic violence and emotional abuse
66	Coid et al (2003)	UK	16-85	16-85	patients in a primary care clinic	1207	self-completed	sexual,female,11.0% physical,female,12.0%	childhood sexual and physical abuse
67	Collishaw et al (2007)	UK	42-46	42-46	adults recruited when they were school pupils	378	interview	sexual,nogender,7.8% physical,nogender,4.7%	repeated or very severe sexual abuse, physical abuse
68	Collin-Vezina et al (2005)	Canada	23-51	23-51	mothers referred to or delegated responsibility to Youth Protection Services	93	self-completed	sexual,female,56.8%	child sexual abuse
69	Comijs et al (2013)	Netherlands	60-93	60-93	depressed and non-depressed persons	510	interview	sexual,nogender,18.0% physical,nogender,12.2% emo/psych,nogender,21.0% neglect,nogender,32.4%	sexual, physical, psychological abuse and emotional neglect
70	Cong et al (2012)	China	30-60	30-60	women with and without recurrent major depression	4508	interview	sexual,female,5.7%	child sexual abuse
71	Conroy et al (2009)	Australia	mean 36.5 and 34.7	35.6	participants with and without a history of opioid pharmacotherapy	1313	interview	sexual,male,35.7% sexual,female,66.5% physical,male,53.1% physical,female,53.4% emo/psych,male,60.9% emo/psych,female,55.9% neglect,male,65.0% neglect,female,75.5%	sexual, physical, emotional abuse and neglect. % reported participants with and without a history of opioid pharmacotherapy, calculated the numbers these should be, added together and divided by total to give %

72	Corliss et al (2002)	US	25-74	25-74	population sample	3032	self-completed	physical,male,37.4% physical,female,31.1% emo/psych,male,37.0% emo/psych,female,37.4%	Emotional maltreatment, any physical maltreatment
73	Cyr et al (2013)	Canada	12-17	12-17	population sample	2801	interview	sexual,nogender,47.7% physical,nogender,41.6% emo/psych,nogender,35.9% neglect,nogender,30.1%	any sexual victimisation or any sexual assault (highest % taken). Physical, psychological/emotional abuse and neglect. For all these, n for two age groups calculated and then added together and divided by 2.
74	Dalenberg & Palesh (2004)	Russia	15-55	15-55	university/college students	301	self-completed	sexual,nogender,5.7% physical,nogender,11.9%	Child physical trauma, child sexual abuse
75	Danese et al (2008)	New Zealand	26 years	26	population sample	1000	self-completed	sexual,nogender,12.0% physical,nogender,4.0%	sexual and physical abuse
76	De Von Figueroa-Moseley (2004)	US	18-74	18-74	university/college students	296	self-completed	sexual,female,29.4%	sexual abuse in childhood
77	Decker et al (2007)	US	14-17	14-17	school pupils	5919	self-completed	sexual,female,15.0%	Sexual Violence Against Adolescent Girls
78	Decker et al (2010)	Thailand	14-17	14-17	female sex workers	815	interview	unspecified,female,25.0%	physical or sexual violence victimisation, does not split physical and sexual abuse so listed as unsure
79	Dennis et al (2009)	US	mean age 40	40	women with and without PTDS and major depression	148	self-completed	sexual,female,45.3% physical,female,45.9%	childhood sexual trauma, childhood violence
80	Deyessa et al (2009)	Ethiopia	15-49	15-49	married women living in the Butajira Rural Health Programme area	1943	self-completed	sexual,female,8.5%	childhood sexual abuse
81	Diaz et al (2002)	US	10-18	10-18	school pupils	3575	self-completed	sexual,female,5.0% physical,female,8.0%	physical and sexual abuse
82	Diaz-Olavarrieta et al (2001)	Mexico	17-85	17-85	Nurses and nurses aids	1150	self-completed	sexual,female,5.0% physical,female,10.7%	sexual and physical abuse during childhood

83	Dibble et al (2007)	US	40-77	40-77	women who identified as lesbian and were Asian, Native Hawaiian, or other Pacific Islander	29	self-completed	sexual,female,34.7% physical,female,28.6%	sexual and physical abuse
84	Dietz (2009)	US	50 years and older	50-100	homeless adults	862	interview	sexual,nogender,4.0% physical,nogender,10.0% nogender,6.0%	sexual and physical abuse and neglect
85	Dolezal & Carballo-Diequez (2002)	US	18-54	18-54	Latino men who have sex with men	307	interview	sexual,male,59.0%	participant considers a childhood sexual experience as sexual abuse
86	Dong et al (2004)	US	mean age 55 for women and 57 for men	18-100	adult members of a health plan	8629	self-completed	sexual,nogender,21.0% physical,nogender,26.4% emo/psych,nogender,24.1% neglect,nogender,14.8%	sexual abuse, physical abuse, emotional abuse, physical and emotional neglect, witnesses domestic violence. Highest % taken for physical and emotional neglect, and emotional abuse and witnessed domestic violence.
87	Draper et al (2008)	Australia	60 and older	60-100	older patients recruited through their GP	22251	self-completed	sexual,nogender,6.5% physical,nogender,6.7%	sexual and physical abuse
88	Dube et al (2001)	US	mean age 56	56	health maintenance organisation members	17337	self-completed	sexual,male,16.0% sexual,female,24.7% physical,male,27.0% physical,female,29.9% emo/psych,male,13.7% emo/psych,female,11.5%	sexual, physical, emotional abuse and battered mother. Highest % taken for emotional abuse of battered mother

89	Dube et al (2003)	US	mean age 55 and 57	56	health maintenance organisation members	8613	self-completed	sexual,male,17.1% sexual,female,24.3% physical,male,27.9% physical,female,25.1% emo/psych,male,7.8% emo/psych,female,12.2% neglect,male,12.4% neglect,female,16.7%	sexual, physical, emotional abuse and emotional and physical neglect. Highest % taken for emotional and physical neglect
90	Duke et al (2010)	US	10-19	10-19	school pupils	136549	self-completed	sexual,male,2.7% sexual,female,7.4% physical,male,9.1% physical,female,11.6% emo/psych,male,9.9% emo/psych,female,13.3%	sexual and physical abuse and witnessing physical abuse by family member on another family member. Two sexual abuse questions, highest number taken
91	Duncan (2000)	US	17-20	17-20	university/college students	210	self-completed	sexual,nogender,20.0% physical,nogender,11.0% emo/psych,nogender,18.0%	sexual, physical, psychological abuse
92	Dunkle et al (2004)	South Africa	16-44	16-44	women attending antenatal clinics	1395	self-completed	sexual,female,8.0%	child sexual assault
93	Dunne et al (2003)	Australia	18-59	18-59	population sample	1784	interview	sexual,male,15.9% sexual,female,33.6%	sexual abuse in childhood. Took highest % in list of experiences.
94	Duran et al (2004)	US	18-45	18-45	women attended outpatient ambulatory services at a hospital	234	self-completed	sexual,female,23.1% physical,female,17.5% emo/psych,female,26.1% neglect,female,22.6%	sexual, physical, emotional abuse, neglect. Took highest % out of 3 categories of maltreatment severity.



95	Dussich & Maekoya (2007)	Japan, South Africa, US	mean ages 18.5 for Japan, 19.3 For South Africa, 20.6 for US	19.5	university/college students	852	self-completed	physical, male, Japan 56.6% phys, male, S Africa 72.3% phys, male, US 63.5% phys, female, Japan 58.0% phys, female, S Africa 65.5% phys, female, US 54.7%	physical child abuse
96	Edgardh and Ormstad (2000)	Sweden	17	17	School pupils and non-attenders	2153	self-completed	sexual,male,4.0% sexual,female,28.0%	sexual abuse
97	Edwards et al (2003)	US	19-97	19-97	adults in a health maintenance organization (HMO)	8667	self-completed	sexual,male,17.5% sexual,female,25.0% physical,male,21.0% physical,female,19.7% emo/psych,male,12.3% emo/psych,female,15.9%	Sexual abuse, physical abuse, witness to maternal battery,
98	Eisenberg et al (2007)	US	11-12, 14-15, 17-18	11-18	school pupils	124881	self-completed	sexual,male,4.0% sexual,female,9.7%	sexual abuse
99	Enns et al (2006)	Netherlands	18-64	18-64	population sample	7076	interview	sexual,nogender,6.9% physical,nogender,8.9% emo/psych,nogender,12.9% neglect,nogender,24.8%	sexual, physical, psychological abuse and neglect. % taken for measures taken at baseline
100	Eskin et al (2005)	Turkey	17-43	17-43	university/college students	1262	self-completed	sexual,nogender,28.1%	childhood sexual abuse
101	Evans-Campbell et al (2006)	US	18-77	18-77	population sample of American Indian/Alaska Natives	112	interview	physical,female,28.2%	physical abuse

102	Evren & Evren (2005)	Turkey	mean age 28.5 for patients with substance-dependence and 40.6 for patients without substance dependence	34.6	males with substance dependence with and without self-mutilation	136	interview	sexual,male,7.3% physical,male,31.6% emo/psych,male,23.6% neglect,male,43.4%	sexual, physical, emotional abuse and neglect. Numbers reported for with and without suicide ideation, added these together
103	Evren et al (2006)	Turkey	over 18	18-100	adults with substance dependence	132	self-completed	sexual,nogender,12.1% physical,nogender,40.2% emo/psych,nogender,32.6% neglect,nogender,36.4%	sexual, physical, emotional abuse, physical or emotional neglect
104	Everson et al (2008)	US	12-13	12-13	At-risk children involved in LONGSCAN (longitudinal study of child maltreatment [Runyan et al, 1998])	350	self-completed	sexual,nogender,9.0% physical,nogender,21.0% emo/psych,nogender,39.0%	Physical, Sexual, and Psychological childhood Abuse

105	Fakhari et al (2012)	Iran	mean age 14.9	14.9	school pupils	399	self-completed	sexual,female,10.7% physical,female,22.5% emo/psych,female,24.5% neglect,female,25.4%	sexual and physical abuse, abusive language, humiliation, discrimination, unkindness, neglect. Abusive language, humiliation, discrimination, unkindness taken as emotional/psychological abuse, highest % taken. Sexual abuse reported as inside and outside the home, highest % taken. Various frequencies provided, highest % taken when over 'seldom' (no 'never' option)
106	Fanslow et al (2007)	New Zealand	18-64	18-64	population sample	2855	interview	sexual,female,28.2%	child sexual abuse
107	Feldman & Meyer (2007)	US	mean age 33	33	gay and biexual men	193	interview	sexual,male,34.0% physical,male,33.0%	sexual and physical abuse
108	Feng et al (2015)	Taiwan	12-18	12-18	school pupils	5236	self-completed	sexual,male,21.8% sexual,female,17.7% physical,male,61.9% physical,female,61.1% emo/psych,male,69.3% emo/psych,female,69.3% neglect,male,50.2% neglect,female,59.4%	sexual, physical, emotional abuse and neglect.
109	Fergusson et al (2000)	New Zealand	18 and 21	18-21	Participants form a birth cohort study	980	interview	sexual,male,6.1% sexual,female,30.4%	child sexual abuse
110	Fergusson et al (2008)	New Zealand	18-25	18-25	young adults in birth cohort	1265	self-completed	sexual,nogender,6.4%	child sexual abuse. Contact and non-contact CSA, highest % taken
111	Figueiredo et al (2004)	Portugal	22-84	22-84	Parents and grandparents of school pupils	932	self-completed	sexual,male,2.6% sexual,female,2.7% physical,male,74.3% physical,female,70.1%	physical abuse and sexual abuse
112	Fillingim & Edwards (2005)	US	mean age 22.1 for females and 23 for males	22.6	university/college students	110	self-completed	sexual,male,7.3% sexual,female,19.1% physical,male,4.5% physical,female,0.9%	sexual and physical childhood abuse.

114	Finkelhor et al (2014)	US	15-17	15-17	population sample	2293	interview	sexual,male,5.1% sexual,female,26.6%	child sexual abuse
114	Finkelhor et al (2015)	US	14-17	14-17	population sample	4000	interview	physical,nogender,18.1% emo/psych,nogender,23.9% neglect,nogender,18.4%	physical and emotional abuse by a caregiver, and neglect.
115	Fisher et al (2011)	UK	16-64	16-64	individuals presenting to mental health services with psychosis	157	self-completed	sexual,nogender,19.2% physical,nogender,25.5% emo/psych,nogender,23.6% neglect,nogender,19.7%	sexual and physical abuse, paternal antipathy (taken as emotional abuse), and paternal neglect
116	Fisher et al (2013)	UK	20-82	20-82	individuals with and without recurrent unipolar depression	455	self-completed	sexual,nogender,12.7% physical,nogender,8.4% emo/psych,nogender,21.1% neglect,nogender,25.1%	sexual, physical, emotional abuse, physical or emotional neglect. Moderate and severe maltreatment measured so highest % taken, and highest % for physical and emotional neglect
117	Flynn O'Brien et al (2016)	Haiti	13-24	13-24	population sample	2916	interview	physical,male,66.6% physical,female,67.4%	childhood physical violence
118	Fogarty et al (2008)	US	18 and over	18-100	population sample	7918	self-completed	unspecified,female,16.0%	sexual and physical abuse. BUT results do not separate types so coded as type of abuse 'unsure'.
119	Fricker et al (2003)	US	18-47	18-47	university/college students	236	self-completed	sexual,male,39.0% sexual,female,29.0%	Sexual abuse.
120	Friedman et al (2002)	US	mean age 39	39	Patients recruited through a general psychiatry outpatients clinic	201	interview	sexual,nogender,27.5% physical,nogender,31.0%	sexual and physical abuse
121	Friedman et al (2008)	US	18-40	18-40	gay and bisexual men	1383	interview	physical,male,27.8%	Parental physical abuse. Various gay-related development stages reported, highest % taken.

122	Fuemmeler et al (2009)	US	mean age 22	22	population sample	15197	self-completed	sexual,male,4.8% sexual,female,4.1% physical,male,13.6% physical,female,15.6% male,4.8% female,5.3%	sexual and physical abuse and neglect.
123	Fujiwara et al (2010) (b)	Japan	19-56	19-56	mothers who are experiencing family problems and are in mother-child home facilities	421	self-completed	unspecified,female,45.6%	childhood abuse, does not specify type.
124	Fujiwara et al (2011)	Japan	20 and above	20-100	population sample	1722	self-completed	sexual,nogender,0.5% physical,nogender,7.5% neglect,nogender,1.5%	sexual and physical abuse and neglect
125	Fuller-Thompson et al (2010)	Canada	12 and over	12-100	population sample	13089	self-completed	physical,nogender,7.4%	physical abuse
126	Gagne et al (2005)	Canada	14-20	14-20	school pupils	622	self-completed	sexual,female,29.0%	sexual abuse. Took highest % out of 2 categories
127	Gallagher et al (2002)	UK	9-16	9-16	school pupils	2420	self-completed	sexual,nogender,22.0%	child sexual abuse
128	Gamble et al (2007)	US	50-84	50-84	patients with depression	187	self-completed	sexual,nogender,46.6%	childhood sexual abuse
129	Garcia et al (2002)	US	18-30	18-30	University students, gay/bisexual/lesbian and heterosexual	138	self-completed	sexual,male,16.4% sexual,female,45.8% physical,male,18.2% physical,female,32.5% emo/psych,male,45.5% emo/psych,female,63.9%	sexual, physical, emotional abuse. Highest % taken from a range of questions on each of these. Added together n for lesbian/bisexual/gay and homosexual to give total

130	Garcia-Moreno et al (2005)	Bangladesh, Brazil, Ethiopia, Japan, Namibia, Peru, Samoa, Serbia and Montenegro, Thailand, United Republic of Tanzania	15-49	15-49	population sample	24097	self-completed	sexual, female. Bangladesh 7.0%, Peru 19.0%, Brazil 12.0%, Ethiopia 7.0%, Japan 14.0%, Namibia 21.0%, Samoa 2.0%, Serbia and Montenegro 4.0%, Thailand 9.0%, Tanzania 11.0%	asked directly whether anyone had ever touched them sexually, or made them do something sexual that they did not want to before the age of 15 years.
131	Gaudiano & Zimmerman (2010)	US	18-79	18-79	adult outpatients diagnosed with Major Depressive Disorder	623	interview	sexual,nogender,36.0% physical,nogender,38.5% emo/psych,nogender,40.0% neglect,nogender,38.4%	sexual, physical, emotional abuse, physical neglect
132	Gault-Sherman et al (2009)	Iceland	16-29	16-20	school pupils	8618	self-completed	sexual,male,6.3% sexual,female,17.6%	sexual abuse.
133	Gerke et al (2006)	US	16-53	16-53	university/college students	417	self-completed	sexual,female,19.0% physical,female,53.0% emo/psych,female,78.0% neglect,female,76.0%	sexual, physical, emotional abuse, physical or emotional neglect. Highest % taken for physical or emotional neglect
134	Gibb et al (2003)	US	mean 40.59	40.6	psychiatric outpatients	552	interview	sexual,nogender,6.9% physical,nogender,11.2% emo/psych,nogender,34.8%	sexual, physical, emotional abuse
135	Gladstone et al (2004)	Australia	17-68	17-68	women with depressive disorders	126	self-completed	sexual,female,29.4%	childhood sexual abuse

136	Goodwin & Stein (2004)	US	15-54	15-54	population sample	5877	self-completed	sexual,male,3.5% sexual,female,17.2% physical,male,11.8% physical,female,9.6% neglect,male,2.9% neglect,female,2.5%	sexual and physical abuse and neglect
137	Goodwin et al (2003)	US	25-74	25-74	population sample	3032	self-completed	unspecified,nogender,15.8%	childhood abuse, does not specify type.
138	Goodwin et al (2005)	New Zealand	18-21	18-21	birth cohort sample	983	self-completed	sexual,nogender,11.4% physical,nogender,6.0%	childhood sexual and physical abuse
139	Gratz et al (2002)	US	18-49	18-49	university/college students	133	self-completed	sexual,male,14.0% sexual,female,30.0% physical,male,21.0% physical,female,29.0% neglect,male,7.0% neglect,female,3.0%	sexual and physical abuse and physical neglect
140	Grayson et al (2005)	US	25-75	25-75	population sample	1327	interview	sexual,nogender,24.0%	childhood sexual abuse
141	Green et al (2010)	US	18 and over	18-100	population sample	5692	interview	sexual,nogender,6.0% physical,nogender,8.4% nogender,5.6%	sexual and physical abuse and neglect
142	Groleau et al (2012)	Canada	mean age 24.95 for bulimic women and 23.91 for normal eaters	25.4	women with and without a bulimic eating disorder	315	interview	sexual,female,17.1% physical,female,33.3% emo/psych,female,68.3%	sexual, physical and emotional abuse
143	Grote et al (2012)	US	18 years or older	18-100	pregnant, depressed, nontreatment seeking women on low incomes	53	self-completed	sexual,female,17.3% physical,female,38.5% emo/psych,female,40.5% neglect,female,40.5%	sexual, physical, emotional abuse, physical or emotional neglect. Highest % taken for physical or emotional neglect

144	Gunn et al (2008)	Australia	18-76	18-76	Adult patients with depressive symptoms	789	self-completed	sexual,nogender,29.5% physical,nogender,48.2%	sexual and physical abuse
145	Gunnlaugsson et al (2011)	Iceland	14-15	14-15	school pupils	3515	self-completed	emo/psych,nogender,51.2%	Witnessed adult physical violence in the home
146	Gwadz et al (2007)	US	16-23	16-23	youth who are homeless or at risk for homelessness	85	interview	sexual,male,15.0% sexual,female,44.0% physical,male,29.0% physical,female,43.0% emo/psych,male,15.0% emo/psych,female,35.0% neglect,male,51.0% neglect,female,45.0%	sexual, physical, emotional abuse, emotional and physical neglect. Highest number taken from emotional and physical neglect.
147	Hamburger et al (2008)	US	pupils in grades 7, 9, and 11/12	12-18	school pupils	3559	self-completed	sexual,male,6.1% sexual,female,11.5% physical,male,21.2% physical,female,23.4% emo/psych,male,26.3% emo/psych,female,38.1%	sexual and physical abuse and witnessing domestic violence between parents/guardians. Witnessing domestic violence between parents/guardians taken as emotional/psychological abuse
148	Hamelin et al (2009)	New Caledonia	18-54	18-54	population sample	1099	interview	sexual,female,11.6%	childhood sexual abuse
149	Handa et al (2008)	Japan	29-56	29-56	outpatients at the Department of Psychosomatic Medicine in a hospital with a psychiatric disorder	518	self-completed	physical,nogender,13.7%	childhood physical abuse
150	Hanson et al (2001)	US	18 and over	18-100	population sample	4008	interview	sexual,female,7.5% physical,female,1.7%	child rape and child aggravated assault



151	Harkness & Monroe (2002)	US	18-70	18-70	Women with major depression	76	interview	sexual,female,52.6% physical,female,67.1% emo/psych,female,30.3% neglect,female,100.0%	sexual, physical, psychological abuse and neglect. Non-severe and severe reported, total taken.
152	Harkness et al (2012)	Canada	18-60	18-60	outpatients with major depressive disorder	203	interview	unspecified,nogender,44.8%	severe child maltreatment
153	Harrison & Narayan (2003)	US	14-15	14-15	school pupils	50168	self-completed	sexual,male,9.6% sexual,female,13.2% physical,male,9.6% physical,female,13.2%	victim of physical abuse at home, victim of sexual abuse
154	Hasnain & Kumar (2006)	India	adult women	18-100	University/college students	150	self-completed	sexual,female,38.0%	child sexual abuse
155	Hegarty et al (2004)	Australia	16-50	16-50	Women who presented at GP clinics who had ever been in an intimate relationship as an adult	1210	self-completed	unspecified,female,27.2%	Abused as child, does not specify type of abuse.
156	Heidt et al (2005)	US	18-77	18-77	people who attended gay, lesbian, bisexual, and transgendered community organisations and events	342	self-completed	sexual,nogender,30.7%	child sexual abuse
157	Helweg-Larsen and Bøving Larsen (2006)	Denmark	15-16	15-16	school pupils	5829	self-completed	sexual,male,6.7% sexual,female,15.8%	unlawful early sexual experiences
158	Henny et al (2007)	US	19-63	19-63	HIV-seropositive homeless or unstably housed adults	644	interview	sexual,male,32.8% sexual,female,52.4% physical,male,50.5% physical,female,57.0%	sexual and physical abuse

159	Hester et al (2009)	China and UK	no definitive age range, University students	18-100	university/college students	979	self-completed	physical, male, China 60.0% physical, male, UK 43.0% physical, fem, China 50.0% physical, female, UK 43.3%	physical punishment.
160	Hetzel et al (2005)	US	18-221	18-21	university/college students	467	self-completed	sexual,female,8.4% physical,female,15.8%	sexual, physical abuse
161	Hill et al (2000)	UK	25-36	25-36	socio-economically representative sample of women from GP surgeries	862	self-completed	sexual,female,17.5%	child sexual abuse. Took highest% from a range of questions.
162	Hillis et al (2000)	US	19 to over 65	19-65	health maintenance organisation members	5032	self-completed	sexual,nogender,24.5% physical,nogender,28.6% emo/psych,nogender,13.9%	sexual, physical, emotional abuse and battered mother. Highest % taken for emotional abuse of battered mother
163	Hovens et al (2010)	Netherlands	18-65	18-65	participants with and without anxiety and depression	1931	interview	sexual,nogender,11.1% physical,nogender,8.5% emo/psych,nogender,13.8% neglect,nogender,22.1%	sexual, physical, psychological abuse and emotional neglect. Highest number taken for frequency
164	Hovens et al (2012)	Netherlands	18-65	18-65	individuals with and without a depressive or anxiety disorder	1209	interview	sexual,nogender,13.2% physical,nogender,10.5% emo/psych,nogender,18.2% neglect,nogender,27.3%	sexual, physical, psychological abuse and emotional neglect. Highest number taken for frequency
165	Howard et al (2005)	US	9th - 12th grade	14-18	school pupils	13601	self-completed	sexual,male,5.1% sexual,female,10.2%	forced sex

166	Huang et al (2011)	US	mean age 21.8	21.8	population sample	4882	interview	sexual,male,4.4% sexual,female,4.3% physical,male,15.2% physical,female,13.4% male,21.3% female,20.2%	sexual and physical abuse and neglect
167	Hughes et al (2000)	US	10-86	20-86	lesbian and heterosexual women	829	self-completed	sexual,female,13.6%	childhood sexual abuse
168	Hughes et al (2001)	US	18 and over	18-100	Lesbian and heterosexual women	120	interview	sexual,female,57.5%	child sexual abuse. Reported both Wyatt measure and self-perception, taken highest %
169	Hussey et al (2006)	US	pupils in grades 7-12	12-18	school pupils	15197	interview	sexual,nogender,4.5% physical,nogender,28.4% nogender,41.5%	Supervision neglect, physical assault, physical neglect, and contact sexual abuse
170	Jewkes et al (2002)	South Africa	15-49	15-49	population sample	11735	interview	sexual,female,1.3%	rape before the age of 15
171	Jewkes et al (2010)	South Africa	15-26	15-26	population sample	2782	interview	sexual,male,12.8% sexual,female,23.9% physical,male,84.9% physical,female,73.8% emo/psych,male,34.3% emo/psych,female,31.8% neglect,male,24.2% neglect,female,22.2%	sexual, physical, emotional abuse, emotional neglect. Various frequency taken so highest reported
172	Jirapramukpitak et al (2005)	Thailand	16-25	16-25	population sample	202	interview	sexual,male,4.9% sexual,female,6.5% physical,male,15.3% physical,female,9.0% emo/psych,male,34.0% emo/psych,female,32.2%	sexual, physical, emotional abuse and witness of maternal battering. Took highest % of emotional abuse or witness of maternal battering.
173	Jirapramukpitak et al (2011)	Thailand	16-25	16-25	population sample	1052	self-completed	nogender,16.7% physical,nogender,11.6%	physical abuse and exposure to domestic violence
174	Johnson et al (2006)	US	18-66	18-66	incarcerated men	100	self-completed	sexual,male,59.0%	sexual abuse
175	Johnstone et al (2009)	New Zealand	mean age 35.5	35.5	depressed patients	195	interview	sexual,nogender,12.3%	childhood sexual abuse. Highest % taken for severity of abuse

176	Johnstone et al (2013)	New Zealand	mean age 32	32	outpatients with depression	159	interview	sexual,nogender,10.1%	sexual abuse. Highest % taken for severity of abuse
177	Joyce et al (2003)	New Zealand	18 and over	18-100	depressed outpatients	180	interview	neglect,nogender,27.2% unspecified,nogender,25.0%	childhood neglect and childhood abuse (abuse therefore recorded as unsure as it does not specify type). Highest % taken for severity of abuse and neglect
178	Ju & Lee (2010)	Republic of Korea	9-12	9-12	children who had been removed from their families	357	interview	physical,nogender,34.7% emo/psych,nogender,24.4%	physical and emotional abuse
179	Jumaian (2001)	Jordan	18-20	18-20	University/college students	100	self-completed	sexual,male,27.0%	child sexual abuse
180	Jun et al (2008)	US	25-42	25-42	Nurses	68505	self-completed	sexual,female,14.9% physical,female,25.7%	sexual and physical abuse. Various numbers of severity reported, highest taken
181	Karayianni et al (2017)	Cyprus	15-25	15-25	school pupils and university and college students	1852	self-completed	sexual,male,21.0% sexual,female,80.0%	sexual abuse in childhood
182	Keeshin & Campbell (2011)	US	18-23	18-23	homeless adults	64	interview	sexual,male,3.0% sexual,female,4.0% physical,male,20.0% physical,female,31.0%	sexual and physical abuse. Sexual and physical abuse only and combined reported, % for the sexual and physical abuse only taken
183	Kendler et al (2000)	US	17-55	17-55	female adult twins	1411	self-completed	sexual,male,21.0%	sexual abuse. Took highest % from a range of questions
184	Kenny & McEachern (2000)	US	19-57	19-57	university/college students	164	self-completed	sexual,female,18.0%	childhood sexual abuse
185	Kerr et al (2009)	Canada	14-26	14-26	high-risk youth	560	interview	sexual,nogender,26.8% physical,nogender,40.7% emo/psych,nogender,49.6% neglect,nogender,45.7%	sexual, physical, emotional abuse and emotional and physical neglect. Highest % taken for emotional and physical neglect
186	Khamis (2000)	Palestine	12-16	12-16	school pupils	1000	interview	sexual,male,0.0% sexual,female,0.9% physical,nogender,14.1%	sexual abuse, physical abuse

187	Kilpatrick et al (2000)	US	12-17	17-17	population sample	4023	interview	sexual,nogender,8.0% physical,nogender,22.0%	sexual and physical assault
188	Kim and Kim (2005)	Korea	12-18	12-18	school pupils	1672	self-completed	sexual,male,0.5% sexual,female,10.2%	Sexual abuse and incest. Incest was defined as a clear and conscious memory by the victim of at least one incident of unwanted sexual penetration of a bodily orifice by an older blood relative occurring either by threat or force.
189	Kim et al (2009)	Republic of Korea	average age 42.39	42.4	population sample	1079	interview	physical,female,23.1% emo/psych,female,31.3%	verbal and physical violence by parents
190	King et al (2004)	South Africa	12 - 18 and over	12-18	school pupils	939	self-completed	sexual,nogender,8.4%	attempted and actual rape. Took the highest %
191	Kitamura et al (2000)	Japan	18-91	18-91	population sample	220	interview	physical,male,14.6% physical,female,9.7% emo/psych,male,20.8% emo/psych,female,14.5%	Scolding, slapping, punching, hitting, burning. Scolding taken as psychological abuse, rest of items taken as physical abuse. Many items, took highest number.
192	Kong & Bernstein (2009)	Korea	14-36	14-36	patients with eating disorders	74	self-completed	sexual,nogender,30.1% physical,nogender,53.4% emo/psych,nogender,65.8% neglect,nogender,74.0%	sexual, physical, emotional abuse, physical or emotional neglect. Highest % taken for physical or emotional neglect
193	Kounou et al (2013)	Togo	18-65	18-65	individuals with and without major depressive disorder	181	interview	sexual,nogender,41.9% physical,nogender,25.9% emo/psych,nogender,28.2% neglect,nogender,44.8%	sexual, physical, emotional abuse, physical or emotional neglect. Highest % taken for physical or emotional neglect. n reported for with and without MD separately, added these together.
194	Kraaij & de Wilde (2001)	Netherlands	65 and over	65-100	population sample	194	self-completed	sexual,nogender,3.2% physical,nogender,5.3% emo/psych,nogender,22.3%	sexual and physical abuse and emotional abuse or neglect. Emotional abuse or neglect therefore recorded as emotional/psychological abuse.
195	Kvam (2004)	Norway	18-65	18-65	Adult deaf Norwegians	302	self-completed	sexual,male,42.4% sexual,female,45.8%	sexual abuse

196	Leeners et al (2006)	Germany	mean age 31.6 for those who experienced CSA and 32 for those who did not	31.8	Women who had recently given birth	226	self-completed	sexual,female,11.5%	child sexual abuse
197	Lehavot et al (2009)	US	18 years or older	18-100	Lesbian, bisexual, and two-spirit women	152	self-completed	sexual,female,76.0%	child sexual contact
198	Lepisto et al (2011)	Finland	14-17	14-17	school pupils	1393	self-completed	physical,nogender,43.1% emo/psych,nogender,42.3%	Witnessing domestic violence, parental expressions of symbolic aggression, parental mild violence, parental severe violence. Witnessing domestic violence and parental expressions of symbolic aggression taken to be emotional/psychological abuse, highest %taken. Parental mild and severe violence taken to be physical abuse, highest % taken.
199	Lewis et al (2003)	US	mean 21.53	21.5	university/college students	255	self-completed	sexual,female,64.0%	sexual abuse
200	Li et al (2012)	Taiwan	15-24	15-24	school pupils and university and college students	4084	self-completed	sexual,male,4.3% sexual,female,6.2%	child sexual abuse
201	Libby et al (2005)	US	15-54	15-54	Participants from American Indian Tribes	3084	self-completed	sexual,male,1.6% sexual,female,7.3% physical,male,6.7% physical,female,8.1%	sexual and physical abuse. n provided for two tribes, added and divided by 2
202	Logan et al (2009)	US	7th grade	12-13	high-risk youth	1484	self-completed	physical,nogender,18.9%	early physical abuse

203	Lu et al (2008)	US	mean age 42.87	42.9	adults with major mood disorders	254	interview	sexual,male,28.0% sexual,female,58.0% physical,male,58.0% physical,female,54.0%	sexual and physical abuse
204	Lutenbacher et al (2000)	US	16-41	16-41	low-income single mothers with a young child	59	interview	sexual,female,15.0% physical,female,31.0%	sexual and physical abuse
205	MacMillan et al (2001)	US	15-64	15-64	population sample	7016	self-completed	sexual,male,4.3% sexual,female,12.4% physical,male,29.9% physical,female,21.2%	sexual and physical abuse
206	Madu & Peltzer (2001)	South Africa	14-30	14-30	school pupils	414	self-completed	sexual,male,60.0% sexual,female,53.2%	child sexual abuse
207	Madu (2003)	South Africa	15-47	15-47	university/college students	722	self-completed	sexual,male,21.7% sexual,female,23.7% physical,nogender,14.5% emo/psych,nogender,26.9%	sexual, physical, emotional abuse. Highest % taken from a range of questions on each of these
208	Mahram et al (2013)	Iran	9 to 13 and over	9-13	school pupils	1028	self-completed	physical,male,19.9% physical,female,15.8% emo/psych,male,32.3% emo/psych,female,29.2% neglect,male,20.2% neglect,female,18.4%	physical and emotional abuse and neglect
209	Mamun et al (2007)	Australia	21	21	singletons whose mothers were enrolled the first antenatal visit	2571	self-completed	sexual,nogender,15.2%	child sexual abuse. Took highest % from a range of questions.

210	Mann et al (2005)	US	17 or older	17-100	First-degree relatives of persons with mood disorder who attempt suicide	457	interview	sexual,nogender,9.6% physical,nogender,17.8%	sexual and physical abuse
211	Martin et al (2004)	Australia	year 8,9,10high school	12-15	school pupils	2475	self-completed	sexual,male,2.0% sexual,female,5.4%	sexual abuse
212	Martsolf (2004)	Haiti	18 or older	18-100	individuals seated in a waiting area in a hospital	258	interview	sexual,male,52.4% sexual,female,20.6% physical,male,52.4% physical,female,21.8% emo/psych,male,31.0% emo/psych,female,14.1% neglect,male,73.8% neglect,female,42.4%	sexual, physical, emotional abuse, physical or emotional neglect. Highest % taken for physical or emotional neglect
213	Masho & Amhed (2007)	US	18 and over	18-100	population sample	1769	self-completed	sexual,female,20.8%	sexual assault under 18
214	Matsumoto et al (2004)	Japan	15-34	15-34	outpatients with habitual self-mutilation or general psychiatric outpatients or controls with no clinical issues	65	self-completed	physical,female,41.5%	child physical abuse
215	Matsumoto et al (2009)	Japan	15-17	15-17	juvenile adolescents and school pupils	632	self-completed	sexual,nogender,4.6%	sexual abuse. % presented for juvenile and non-juvenile adolescents and these added together and divided by two



216	Matsuura et al (2009)	Japan	15-19	15-19	juvenile females	91	self-completed	sexual,female,8.6% physical,female,27.2% emo/psych,female,23.8%	sexual, physical, psychological abuse
217	Matthews et al (2002)	US	average age 43	43	lesbian and heterosexual women	829	self-completed	sexual,female,25.3%	childhood sexual abuse.
218	May-Chahal and Cawson (2005)	UK	18-24	18-24	population sample	2869	self-completed and interview	sexual,male,6.0% sexual,female,15.0% physical,male,15.0% physical,female,12.0% emo/psych,male,4.0% emo/psych,female,8.0% neglect,male,6.0% neglect,female,7.0%	physical abuse to an intermediate degree, emotional abuse, absence of care, absence of supervision, and sexual abuse involving contact
219	Mazzeo et al (2008)	US	mean age 20.15 for African-Americans and 19.59 for Europeans	19.9	university/college students	604	self-completed	sexual,female,16.1% physical,female,54.9% emo/psych,female,74.2% neglect,female,45.6%	sexual, physical, emotional abuse, physical or emotional neglect. % reported for European-American and African-American participants separately, added these together and divided by 2. Highest % taken for physical or emotional neglect
220	Mbagaya et al (2013)	Kenya, Zambia, Netherlands	18-40	18-40	university/college students	862	self-completed	physical, male, Kenya 48.0% phys, male, Zambia 43.0% phys, no gend, N'lands 3.0% phys, female, Kenya 36.0% phys, female, Zambia 36.0% neglect, male, Kenya 62.0% neg, male, Zambia 54.0% neg, no gend, N'lands 42.0% neg, female, Kenya 56.0% neg, female, Zambia 53.0%	physical abuse and neglect.
221	McCann et al (2006)	Tanzania	20-53	20-53	university/college students	486	self-completed	sexual,male,25.0% sexual,female,31.0%	child sexual abuse

222	McNutt et al (2002)	US	18-44	18-44	women who attended primary care centres	557	interview	sexual,female,25.3% physical,female,21.5%	childhood physical and sexual abuse
223	Melander & Tyler (2010)	US	mean 21.45	21.5	homeless youth or youth with a history of homelessness	172	interview	sexual,nogender,47.1%	sexual abuse
224	Menard et al (2004)	US	18-24	18-24	young adults, recruited to the study when they were school pupils	1715	self-completed	sexual,male,15.3% sexual,female,18.4% physical,male,26.3% physical,female,21.5% emo/psych,male,27.4% emo/psych,female,26.5%	sexual, physical, emotional abuse
225	Messman-Moore & Brown (2004)	US	18-22	18-22	university/college students	944	self-completed	sexual,female,8.9% physical,female,4.2% emo/psych,female,8.6%	sexual, physical, emotional abuse
226	Messman-Moore (2000)	US	mean age 19.74	19.7	university/college students	648	self-completed	sexual,female,20.1%	child sexual abuse
227	Mimiaga et al (2009)	US	16 years or older	16-100	men who sleep with men	4295	self-completed	sexual,nogender,39.7%	child sexual abuse
228	Molnar et al (2001)	US	15-54	15-54	population sample	5877	interview	sexual,male,2.5% sexual,female,13.5%	child sexual abuse
229	Moran et al (2004)	US	15-18	15-18	School pupils	2164	self-completed	sexual,nogender,5.5% physical,nogender,10.6% emo/psych,nogender,9.5%	emotional, sexual and physical abuse
230	Morris & Balsam (2003)	US	15-83	15-83	lesbian and bisexual women	2431	self-completed	sexual,female,39.3% physical,female,30.8%	sexual assault and physical abuse

231	Moskvina et al (2007)	UK	20-82	20-82	adults with unipolar depression	324	self-completed	sexual,male,15.7% sexual,female,24.7% physical,male,32.6% physical,female,20.0% emo/psych,male,46.1% emo/psych,female,52.3% neglect,male,65.2% neglect,female,59.1%	sexual, physical, emotional abuse, physical or emotional neglect. Highest % taken for physical or emotional neglect
232	Mowlds et al (2010)	UK	22-74	22-74	patients with bipolar disorder	52	interview	unspecified,male,9.5% unspecified,female,48.4%	sexual and physical abuse. BUT results do not separate types so coded as type of abuse 'unsure'.
233	Mullings et al (2000)	US	average age 32	32	female prisoners	500	interview	sexual,female,26.0%	sexually mistreated, abused, or raped while growing up
234	Ndeti et al (2007)	Kenya	12-26	12-26	school pupils	1110	self-completed	sexual,nogender,16.5% physical,nogender,23.2%	physical abuse, sexual abuse
235	Nduna et al (2013)	South Africa	15-26	15-26	population sample	2783	interview	sexual,male,22.4% sexual,female,24.9% physical,male,90.5% physical, female,84.8% emo/psych,male,29.3% emo/psych,female,29.2% neglect,male,23.3% neglect,female,30.5%	Sexual, physical, emotional abuse, emotional neglect. Paper reports % for each item in scale, highest % taken for each type of abuse. n shown for depressed and not depressed, added together and divided by 2.
236	Nelson et al (2002)	Australia	mean age 29.9	29.9	twins	1991	interview	sexual,male,5.4% sexual,female,16.7%	sexual abuse
237	Nelson et al (2006)	Australia	mean age 29.9	29.9	twins	6050	interview	sexual,male,6.0% sexual,female,17.4%	child sexual abuse
238	Nemeroff et al (2003)	US	18-75	18-75	participants with chronic major depressive disorder	681	self-completed	sexual,nogender,16.4% physical,nogender,43.5% neglect,nogender,10.0%	sexual and physical abuse and neglect. n provided for participants in various drug and psychotherapy groups, added and divided by 3.

239	Nguyen et al (2009)	Vietnam	12-18	12-18	school pupils	2591	self-completed	sexual,male,21.0% sexual,female,18.5% physical,male,54.0% physical,female,41.6% emo/psych,male,36.3% emo/psych,female,42.5% neglect,male,24.9% neglect,female,33.4%	sexual, physical, emotional abuse and neglect
240	Nichols & Harlow (2004)	US	36-45	36-45	depressed and non-depressed women	722	self-completed	sexual,female,6.0% physical,female,17.0%	sexual and physical abuse
241	Nickel et al (2004)	Germany	mean age 41	41	inpatients at a clinic for psychosomatic medicine and psychotherapy	936	self-completed	sexual,nogender,26.7%	child sexual abuse
242	Nicolaidis et al (2004)	US	25-60	25-60	women presenting at medical clinics	174	interview	sexual,female,39.0% physical,female,44.0%	sexual and physical abuse. Various sexual abuse types reported, highest % taken
243	Nicolaidis et al (2009)	US	18-92	18-92	women presenting at medical clinics	380	self-completed	sexual,female,29.0% physical,female,23.0%	sexual and physical childhood abuse
244	Niederberger (2002)	Switzerland	20-40	20-40	population sample	890	self-completed	sexual,female,39.8%	sexual abuse
245	Oaksford and Frude (2001)	Wales	18-41	18-41	university/college students	213	self-completed	sexual,female,13.0%	child sexual abuse
246	O'Leary et al (2003)	US	18 or older	18-100	HIV positive men who have sex with men	456	self-completed	sexual,male,14.9%	child sexual abuse
247	Olsson et al (2000)	Nicaragua	25-44	25-44	population sample	367	self-completed	sexual,male,20.0% sexual,female,26.0%	sexual abuse in childhood

248	Oquendo et al (2005)	US	25-79	25-79	patients with and without PTSD	221	interview	sexual,nogender,30.5% physical,nogender,38.7%	sexual and physical abuse. Highest % taken for severity of abuse. n for patients with and without PTSD added and divided by 2
249	Orozco et al (2008)	Mexico	12-17	12-17	non-institutionalised children resident in the Mexico City Metropolitan Area	3005	interview	sexual,male,2.3% sexual,female,9.7% physical,male,12.2% physical,female,14.2%	sexual abuse, Beaten up as a child by caregiver
250	Parillo et al (2001)	US	mean age 32	32	Non-injecting female sex partners of male heterosexual intravenous drug users	1490	self-completed	sexual,female,33.6%	sexual abuse in childhood and adolescence involving penetration
251	Paul et al (2001)	US	18 or older	18-100	men who sleep with men	2881	interview	sexual,male,20.6%	child sexual assault
252	Pavio and Cramer (2004)	US	mean age of 19	19	university/college students	470	self-completed	sexual,male,11.8% sexual,female,19.0% physical,male,22.2% physical,female,15.7% emo/psych,male,30.0% emo/psych,female,37.5% neglect,male,16.0% neglect,female,14.6%	emotional, sexual and physical abuse, and emotional and physical neglect
253	Pereda et al (2015)	Spain	12-17	12-17	school pupils	1105	self-completed	sexual,nogender,8.8%	sexual victimisation
254	Pérez-Fuentes et al (2013)	US	18 and over	18-100	population sample	34653	interview	sexual,nogender,10.1%	child sexual abuse

255	Peschers et al (2003)	Germany	14-87	14-87	women attending an outpatients gynaecological clinic	1075	self-completed	sexual,female,33.8%	sexual abuse in childhood
256	Pluck et al (2011)	UK	18-53	18-53	homeless adults	55	interview	sexual,nogender,27.8% physical,nogender,53.7% emo/psych,nogender,66.7% neglect,nogender,77.8%	sexual, physical, emotional abuse, emotional and physical neglect. Highest number taken from emotional and physical neglect. Various severity reported, highest % taken.
257	Priebe & Svedin (2009)	Sweden	mean age 18.15	18.2	school pupils	4339	self-completed	sexual,male,15.2% sexual,female,54.7%	child sexual abuse. Various types reported, highest % taken
258	Rada (2014)	Romainia	18-75	18-75	population sample	869	interview	physical,nogender,53.7% emo/psych,nogender,35.0%	victims of family violence and witnessed violence between their parents
259	Radford et al (2011) Child	UK	11-17	11-17	population sample	2275	self-completed	sexual,male,0.7% sexual,female,2.2% physical,male,6.8% physical,female,6.9% emo/psych,male,5.5% emo/psych,female,8.0% neglect,male,14.8% neglect,female,11.8% ma	emotional abuse, physical violence, sexual abuse, neglect (split by 2 tables by within and outside the family, highest % taken from each table)
260	Radford et al (2011) Adult	UK	18-24	18-24	population sample	1761	self-completed	sexual,male,11.4% sexual,female,14.3% physical,male,7.0% physical,female,9.9% emo/psych,male,6.2% emo/psych,female,9.6% neglect,male,5.6% neglect,female,6.4% ma	emotional abuse, physical violence, sexual abuse, neglect (split by 2 tables by within and outside the family, highest % taken from each table)

261	Ramiro et al (2010)	Philippines	mean 46.7	46.7	population sample	1068	self-completed	sexual,male,4.5% sexual,female,6.0% physical,male,1.1% physical,female,1.5% emo/psych,male,26.4% emo/psych,female,19.3% neglect,male,44.5% neglect,female,42.8%	sexual, physical, emotional abuse and emotional and physical neglect. Highest % taken for emotional and physical neglect
262	Ramos et al (2004)	US	18-44	18-44	women from a primary health care setting	491	interview	sexual,female,11.6% physical,female,10.8%	sexual and physical abuse.n reported for White and African-American participants separately, added these together and divided by 2. Highest n taken for severity of abuse.
263	Rayburn et al (2005)	US	18-55	18-55	women who lived in shelters and low-income housing	810	interview	sexual,female,29.8% physical,female,31.0%	sexual and physical abuse
264	Rich-Edwards et al (2010)	US	25-42	25-42	adult nurses with diabetes	7843	self-completed	physical,female,54.0%	physical abuse in childhood or adolescence
265	Riley et al (2010)	US	25-44	25-44	Nurses	68505	self-completed	sexual,female,33.0% physical,female,53.0%	sexual and physical abuse
266	Ritchie et al (2009)	France	65-92	65-92	population sample	942	interview	emo/psych,nogender,5.6% neglect,nogender,5.5% unspecified,nogender,1.9%	sexual and physical abuse. BUT results do not separate types so coded as type of abuse 'unsure'. Neglect. Verbal abuse and Humiliation, harassment or mental cruelty taken as emotional abuse, highest % taken.
267	Roberts et al (2013)	US	from age 20	20-100	population sample	34296	self-completed	sexual,male,2.2% sexual,female,7.0% unspecified,male,38.4% unspecified,female,34.4%	sexual abuse and non-sexual maltreatment. Various severity reported, highest % taken, and people who have ever and not ever had same sex partners n added together and divided by 2
268	Robohm et al (2003)	US	18-23	18-23	lesbian and bisexual women	227	self-completed	sexual,female,37.9%	child sexual abuse

269	Rohde et al (2008)	US	mean age 52	52	women enrolled in a large health plan	4641	interview	sexual,female,15.4% physical,female,12.3%	child sexual and physical abuse.
270	Romans et al (2002)	New Zealand	26-70	26-70	population sample	354	interview	sexual,female,48.9%	child sexual abuse
271	Rosenberg et al (2005)	US	13-18	13-18	population sample	16644	self-completed	sexual,nogender,7.0% physical,nogender,11.0%	sexual and physical assault
272	Rosenman and Rogers (2004)	Australia	20-64	20-64	population sample	7485	self-completed	sexual,nogender,1.1% physical,nogender,8.2% emo/psych,nogender,6.5% neglect,nogender,1.6%	sexual abuse, physical abuse and punishment (took the highest %of the two), verbal abuse and humiliation/mental cruelty (emotional abuse) (took the highest %of the two), neglect
273	Ross et al (2005)	China	average age 39.5	39.5	inpatients and outpatients at a Mental Health Centre, and a non-clinical sample of workers at a clothing manufacturing factory	1345	interview	sexual,nogender,1.6% physical,nogender,4.8%	child physical and sexual abuse
274	Runtz (2002)	Canada	17-56	17-56	university/college students	775	self-completed	sexual,female,18.5% physical,female,19.7%	child sexual abuse, child physical maltreatment
275	Sar et al (2004)	Turkey	16-56	16-56	patients with conversion disorder	38	interview	sexual,nogender,26.3% physical,nogender,44.7% emo/psych,nogender,34.2% neglect,nogender,57.9%	sexual, physical, emotional abuse, emotional and physical and overall neglect. Highest number taken from emotional, physical and overall neglect.
276	Sar et al (2013)	Turkey	mean 34.8	34.8	depressive women in the general population	619	interview	sexual,female,2.4% physical,female,9.0% emo/psych,female,8.9% neglect,female,20.7%	child sexual, physical and emotional abuse. Medical, emotional, and economic neglect, and deficiency of security and deficiency of nutrition (all taken to be neglect). Highest % taken for medical, emotional, and economic neglect and deficiency of security and deficiency of nutrition. Numbers reported with and without early cessation of education separately, added these together



277	Schein et al (2000)	Israel	18-55	18-55	adults presenting for routine health care at family practice clinics	1005	self-completed	sexual,male,15.7% sexual,female,30.7%	child sexual abuse
278	Scher et al (2004)	US	18-65	18-65	population sample	967	interview	sexual,male,2.2% sexual,female,7.5% physical,male,21.0% physical,female,17.1% emo/psych,male,9.6% emo/psych,female,14.3% neglect,male,22.1% neglect,female,14.2%	emotional abuse, emotional neglect, physical abuse, physical neglect, and sexual abuse
279	Schoemaker et al (2002)	Netherlands	18-45	18-45	participants with bulimia nervosa, psychiatric problems, substance misuse, dual diagnoses, and none of these issues	1987	interview	sexual,female,7.8% physical,female,4.2% emo/psych,female,11.8% neglect,female,18.3%	sexual, physical, psychological abuse and neglect. % reported for participants with various conditions reported separately, calculated the numbers these should be, added together and divided by total to give %
280	Schultz et al (2006)	US	18-88	18-88	women veterans and civilian community members	223	self-completed	sexual,female,46.6%	child sexual abuse

281	Scott et al (2008)	Colombia, Belgium, France, Germany, Italy, Netherlands, Spain, Japan, Mexico, US	21-98	21-98	adults with and without asthma	18952	interview	sexual,nogender,2.6% physical,nogender,9.8% neglect,nogender,6.6%	sexual and physical abuse and neglect. % reported participants with and without asthma, calculated the numbers these should be, added together and divided by total to give %
282	Seedat et al (2004) South Africa	South Africa	14-22	14-22	school pupils	1140	self-completed	sexual,male,15.0% sexual,female,12.0% sexual,nogender,14.0%	sexual assault
283	Seedat et al (2004) Kenya	Kenya	14-22	14-22	school pupils	901	self-completed	sexual,male,24.0% sexual,female,14.0% sexual,nogender,18.0%	sexual assault
284	Sesar et al (2008)	Croatia	15-20	15-20	School pupils	458	self-completed	sexual,male,21.0% sexual,female,13.0% physical,nogender,52.0% emo/psych,nogender,77.0% neglect,nogender,30.0%	emotional abuse, physical abuse, neglect, witnessing family violence, sexual abuse
285	Shen (2008)	Taiwan	16-40	16-40	University/college students	1924	self-completed	physical,nogender,6.0%	child physical maltreatment
286	Shen et al (2009)	Taiwan	16-40	16-40	university/college students	1924	self-completed	physical,nogender,11.8% emo/psych,nogender,15.9%	child physical maltreatment and interparental violence (taken to be emotional/psychological abuse).Many items reported, highest % taken.
287	Silvern et al (2000)	US	no age provided, college students	18-100	university/college students	542	self-completed	sexual,male,4.4% sexual,female,16.5% physical,male,26.5% physical,female,19.6%	child sexual and physical abuse both researcher and self-defined, took the highest %
288	Slonim-Nevo & Mukuka (2007)	Zambia	10-19	10-19	population sample of adolescents	3360	self-completed	sexual,male,7.0% sexual,female,10.0% physical,male,23.0% physical,female,24.0%	sexual and physical abuse. Took highest % from a series of questions.
289	So-kum Tang (2002)	China	18-25	18-25	university/college students	2147	self-completed	sexual,male,4.3% sexual,female,7.4%	child sexual abuse

290	Sørbo et al (2013)	Norway	14 to over 35	14-35	population sample based on a pregnancy cohort	65393	self-completed	sexual,female,7.0% physical,female,6.0% emo/psych,female,14.0%	sexual, physical, emotional child abuse
291	Spertus et al (2003)	US	19-82	19-82	women who presented in a hospital based primary care practice	205	self-completed	sexual,female,8.9% physical,female,5.4% emo/psych,female,19.5% neglect,female,22.4%	sexual, physical, emotional abuse and emotional neglect. Highest % taken for varying severity presented.
292	Springer (2009)	US	mean age 53	53	population sample	3317	self-completed	physical,nogender,11.9%	physical abuse
293	Springer et al (2007)	US	mean age 55	55	siblings of men and women who graduated in 1957 from Wisconsin high schools	2051	self-completed	physical,nogender,11.4%	child physical abuse
294	Steel & Herlitz (2005)	Sweden	23-79	23-79	population sample	2810	self-completed and interview	sexual,male,5.6% sexual,female,13.9%	childhood or adolescent sexual abuse
295	Stein et al (2002)	US	16-50	16-50	homeless adults	581	interview	sexual,female,36.0% physical,female,31.0% emo/psych,female,49.0%	sexual and physical abuse and verbal abuse. Verbal abuse taken to be emotional/psychological abuse
296	Stenson et al (2003)	Sweden	16-43	16-43	women registered at antenatal clinics	1038	self-completed	sexual,female,2.0%	child sexual abuse before 13
297	Stephenson et al (2006)	Iran	11-18	11-18	school pupils	1370	self-completed	physical,nogender,74.0% emo/psych,nogender,67.2% neglect,nogender,67.3%	Physical and mental maltreatment and neglect. Average of % of abuse taken in home and school used
298	Stoddard et al (2009)	US	40 and older	40-100	lesbians and their heterosexual sisters	648	self-completed	sexual,female,20.8% physical,female,15.0%	childhood sexual and physical abuse

299	Strine et al (2012)	US	18-over 75	18-75	managed care population	7279	self-completed	sexual,male,16.7% sexual,female,24.1% physical,male,28.3% physical,female,24.4% emo/psych,male,8.2% emo/psych,female,11.7%	sexual, physical, emotional abuse
300	Subica (2013)	US	18-84	18-84	participants with schizophrenia-spectrum, bipolar, or recurrent major depressive disorders	172	interview	sexual,nogender,29.1% physical,nogender,44.8%	child sexual and physical abuse
301	Suija et al (2011)	Estonia	18-75	18-75	patients with depression	123	self-completed	unspecified,nogender,68.0%	childhood abuse, does not specify type.
302	Sun et al (2008)	China	18-25	18-25	University/college students	1307	self-completed	sexual,male,14.7% sexual,female,22.1%	child sexual abuse
303	Sun et al (2012)	China	30-60	30-60	melancholic versus nonmelancholic patients with major depression	1970	interview	sexual,female,9.6%	childhood sexual abuse. Numbers reported for women with and without melancholia separately, added these together
304	Sung et al (2013)	US	mean 37.6 for early-onset MDD patients and 46.8 for adult-onset MDD patients	42.2	outpatients non-psychotic chronic major depressive episode or recurrent major depressive disorder	663	self-completed	sexual,nogender,21.7% physical,nogender,19.6% emo/psych,nogender,39.1% neglect,nogender,35.9%	sexual, physical, emotional abuse and neglect. Numbers reported for early and adult onset separately, added these together

305	Swahn & Bossarte (2007)	US	14-18	14-18	School pupils	13,639	self-completed	sexual,male,3.8% sexual,female,10.7%	sexual assault
306	Tang (2002)	China	18-30	18-30	University/college students	2147	self-completed	sexual,male,4.3% sexual,female,7.4%	child sexual abuse
307	Thakkar et al (2000)	US	mean age 18.74	18.7	university/college students	707	self-completed	sexual,female,13.4% physical,female,14.7%	childhood contact sexual abuse and physical abuse
308	The NIMH Multisite HIV Prevention Trial Group (2001)	US	18-65	18-65	population sample	3336	interview	sexual,female,38.5%	Unwanted sexual activity during childhood
309	Thompson et al (2000)	US	18-64	18-64	women who presented at a hospital for non-fatal suicide attempts and controls who presented for non-emergency medical problems	335	interview	sexual,female,44.5% physical,female,59.0% emo/psych,female,49.5% neglect,female,48.0%	sexual, physical, emotional, emotional and physical neglect. Highest % taken for emotional and physical neglect
310	Thompson et al (2002)	US	18 and over	18-100	population sample	8000	interview	unspecified,female,86.0%	child sexual and physical victimisation. BUT results do not separate types so coded as type of abuse 'unsure'
311	Thompson et al (2004)	US	18 and over	18-100	population sample	16000	interview	physical,male,53.8% physical,female,40.0%	physical abuse. % reported for many items, chose 'experienced any violence'
312	Thurman et al (2006)	South Africa	14-18	14-18	population sample	1694	interview	sexual,male,0.6% sexual,female,7.4%	forced to have sex/raped
313	Tietjen et al (2010)	US and Canada	mean age 41	41	patients seeking treatment in headache centres	1348	self-completed	sexual,nogender,8.1% physical,nogender,9.0% emo/psych,nogender,17.7% neglect,nogender,19.1%	sexual, physical, emotional abuse, physical or emotional neglect. Highest % taken for physical or emotional neglect. Highest % taken for severity
314	Timko et al (2008)	US	18 and older	18-100	population sample	6942	self-completed	sexual,female,11.2% physical,female,19.1% emo/psych,female,18.4%	emotional abuse and physical and sexual assault

315	Tomeo et al (2001)	US	18-68	18-68	gay and heterosexual men and women	942	self-completed	sexual,male,33.7% sexual,female,29.0%	sexual molestation
316	Tourigny et al (2008)	Canada	18 and over	18-100	population sample	1002	interview	sexual,nogender,16.0% physical,nogender,19.0% emo/psych,nogender,22.0%	physical, sexual and psychological violence against children
317	Tran et al (2015)	Vietnam	18-30	18-30	university/college students	2099	self-completed	sexual,male,14.9% sexual,female,15.2% physical,male,44.9% physical,female,34.9% emo/psych,male,44.0% emo/psych,female,40.6% neglect,male,9.3% neglect,female,7.2%	sexual, physical, emotional abuse and physical neglect
318	Tran et al (2016)	Vietnam	12-17	12-17	school pupils	1851	self-completed	sexual,male,8.9% sexual,female,5.3% physical,male,42.8% physical,female,34.6% emo/psych,male,57.5% emo/psych,female,62.6% neglect,male,22.6% neglect,female,27.2%	both emotional abuse and Witnessed parental conflict measured and so highest % was taken as a measure of emotional/psychological abuse
319	Trent et al (2007)	US	mean age 19.9	19.9	US Navy recruits	5697	self-completed	sexual,male,22.5% sexual,female,48.5% physical,male,43.7% physical,female,51.7%	sexual and physical abuse
320	van der Kooij et al (2015) adult	Suriname	18-22	18-22	school pupils and those on vocational courses	239	self-completed	sexual,male,31.8% sexual,female,24.4% physical,male,63.6% physical,female,62.9% emo/psych,male,68.2% emo/psych,female,62.9% neglect,male,61.7% neglect,female,59.8%	sexual abuse, physical abuse, neglect, for psychological/emotional abuse authors used 2 measures 'Psychological aggression of parents & Experienced conflicts between parents' - took highest %

321	van der Kooij et al (2015) child	Suriname	12-17	12-17	school pupils and those on vocational courses	1072	self-completed	sexual,male,21.2% sexual,female,20.3% physical,male,51.0% physical,female,55.1% emo/psych,male,47.7% emo/psych,female,57.1% neglect,male,51.6% neglect,female,49.9%	sexual abuse, physical abuse, neglect, for psychological/emotional abuse authors used 2 measures 'Psychological aggression of parents & Experienced conflicts between parents' - took highest %
322	Vander Weg (2011)	US	18 to over 65	18-65	population sample	10227	interview	sexual,nogender,9.3% physical,nogender,12.2% emo/psych,nogender,28.8%	Touched sexually, forced to touch adult sexually, forced to have sex, victim of physical assault, victim of verbal abuse, household physical assault. 3 items for sexual abuse, taken highest. Household physical assault and victim of verbal abuse taken to be emotional/psychological abuse, highest taken
323	Von Korff et al (2009)	Colombia, Belgium, France, Germany, Italy, Netherlands, Spain, Japan, Mexico, US	adults, no age data	18-100	adults with and without arthritis	18309	interview	sexual,nogender,2.5% physical,nogender,9.6% neglect,nogender,6.5%	sexual and physical abuse and neglect
324	Wainwright & Surtees (2002)	UK	17-77	17-77	population sample	3353	self-completed	physical,nogender,3.6%	physical abuse
325	Wan & Leung (2010)	China	11-18	11-18	school pupils	2754	self-completed	physical,nogender,9.8%	history of physical abuse
326	Welles et al (2009)	US	18 years or older	18-100	HIV positive men who have sex with men	593	self-completed	sexual,male,47.0%	childhood sexual abuse

327	Wiersma et al (2009)	Netherlands	mean 40.7	40.7	participants with and without anxiety or depressive disorders	1204	interview	sexual,nogender,16.7% physical,nogender,11.0% emo/psych,nogender,28.5% neglect,nogender,44.5%	sexual, physical, emotional abuse, emotional neglect. Highest % taken for frequency. % reported for non-chronic and chronic MDD separately, added these together
328	Wilhelm et al (2002)	Australia	mean 44.1 for men and 42.9 for women	43.5	patients with major depression	270	interview	sexual,male,5.1% sexual,female,20.5%	sexual abuse. Split by parent and by other, highest % taken
329	Wilsnack et al (2008)	US	21-40	21-40	lesbian and heterosexual women	953	interview	sexual,female,34.8%	childhood sexual abuse. % presented for many groups indicating sexual orientation, numbers calculated from % and these added together and divided by number of groups
330	Wilsnack et al (2012)	US	18 and older	18-100	Lesbian and heterosexual women	1328	self-completed	sexual,female,33.5%	childhood sexual abuse.
331	Wise et al (2001)	US	36-45	36-45	population sample	732	self-completed	sexual,female,9.0% physical,female,30.0%	sexual and physical abuse
332	Wise et al (2011)	US	21-69	21-69	convenience sample of African American women	35728	self-completed	sexual,female,18.0% physical,female,42.0%	sexual and physical abuse
333	Yen et al (2008) (a)	Taiwan	13-8	13-18	school pupils	2079	self-completed	sexual,male,3.0% sexual,female,2.0% physical,male,21.9% physical,female,22.5%	sexual and physical abuse
334	Yen et al (2008) (b)	Taiwan	13-18	13-18	school pupils	1684	self-completed	physical,nogender,22.3%	physical abuse
335	Yoshihama & Horrocks (2010)	Japan	18-49	18-49	population sample	1371	interview	sexual,female,10.4%	child sexual abuse



336	Yoshinaga et al (2004)	Japan	14-19	14-19	incarcerated juvenile delinquents	251	self-completed	sexual,male,2.9% sexual,female,6.7% physical,male,15.0% physical,female,8.9%	sexual and physical assault
337	Young et al (2006)	US	18-20	18-20	men starting military training	41482	self-completed	sexual,male,1.7% physical,male,2.8% emo/psych,male,13.2% neglect,male,17.1%	sexual abuse, physical abuse, emotional abuse, physical and emotional neglect, witnesses domestic violence. Highest % taken for physical and emotional neglect, and emotional abuse and witnessed domestic violence.
338	Young et al (2008)	US	12-18	12-18	School pupils	1086	self-completed	sexual,male,26.6% sexual,female,48.4%	sexual assault victimization experiences
339	Ystgaard et al (2004)	Norway	16-82	16-82	Patients who had taken an overdose or deliberately injured themselves	74	interview	sexual,nogender,35.1% physical,nogender,17.6% neglect,nogender,27.0%	sexual and physical abuse and neglect
340	Zanarini et al (2002)	US	18-35	18-35	borderline inpatients	290	interview	sexual,nogender,62.4% neglect,nogender,92.1% unspecified,nogender,86.2%	sexual abuse and neglect. 'Other' forms of abuse (not sexual) also reported so listed as unsure
341	Zhao et al (2010)	China	6-18	6-18	children who had lost one or both parents to HIV, other vulnerable children, and comparison children	1019	self-completed OR interview	sexual,male,37.4% sexual,female,24.1%	child sexual abuse
342	Zlotnick et al (2001)	US	18-65	18-65	patients with major depression	235	interview	sexual,nogender,24.7%	sexual abuse

343	Zoroglu et al (2003)	Turkey	12-17	12-17	school pupils	839	self-completed	sexual,male,6.7% sexual,female,13.3% physical,male,14.6% physical,female,12.1% emo/psych,male,15.6% emo/psych,female,16.1% neglect,male,12.9% neglect,female,18.9%	childhood physical, sexual and emotional abuse, and neglect
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**Additional file 3. References for table (additional file 2) containing data for each of the studies included in review**

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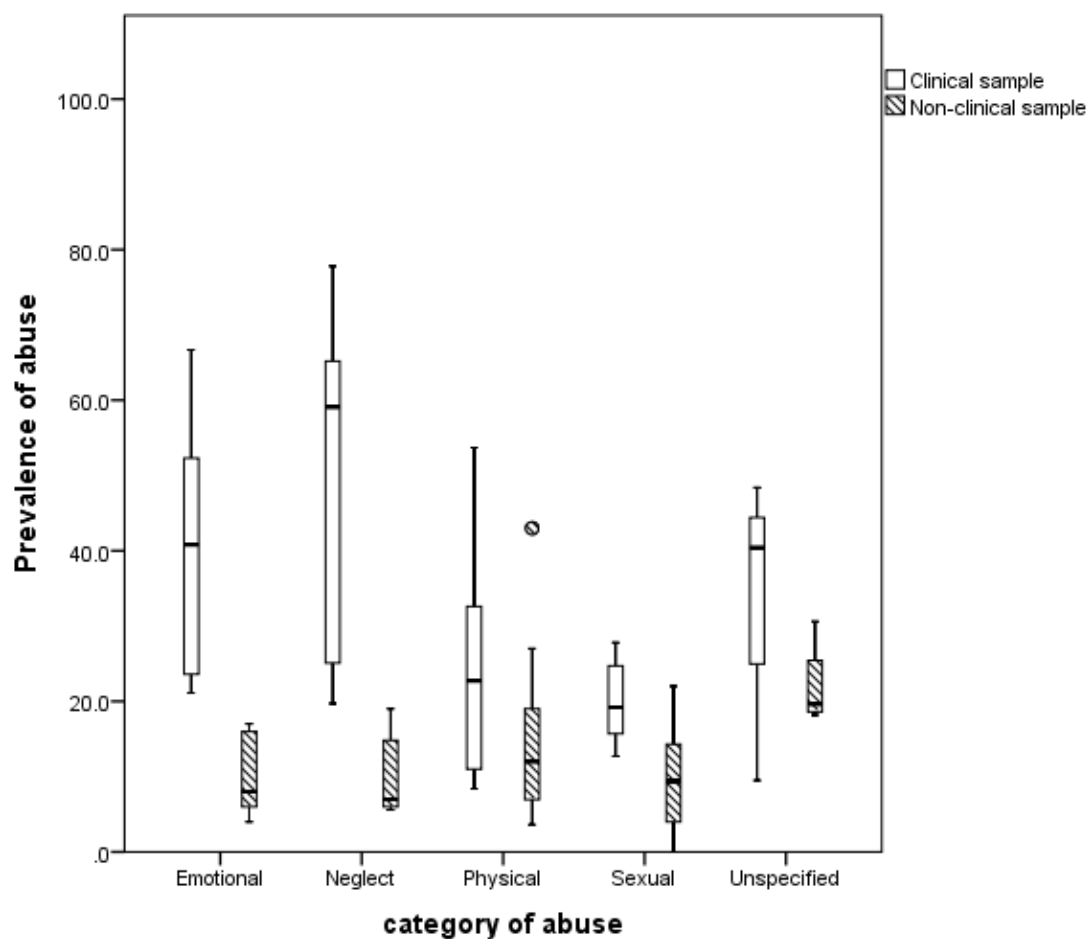
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#### Additional file 4

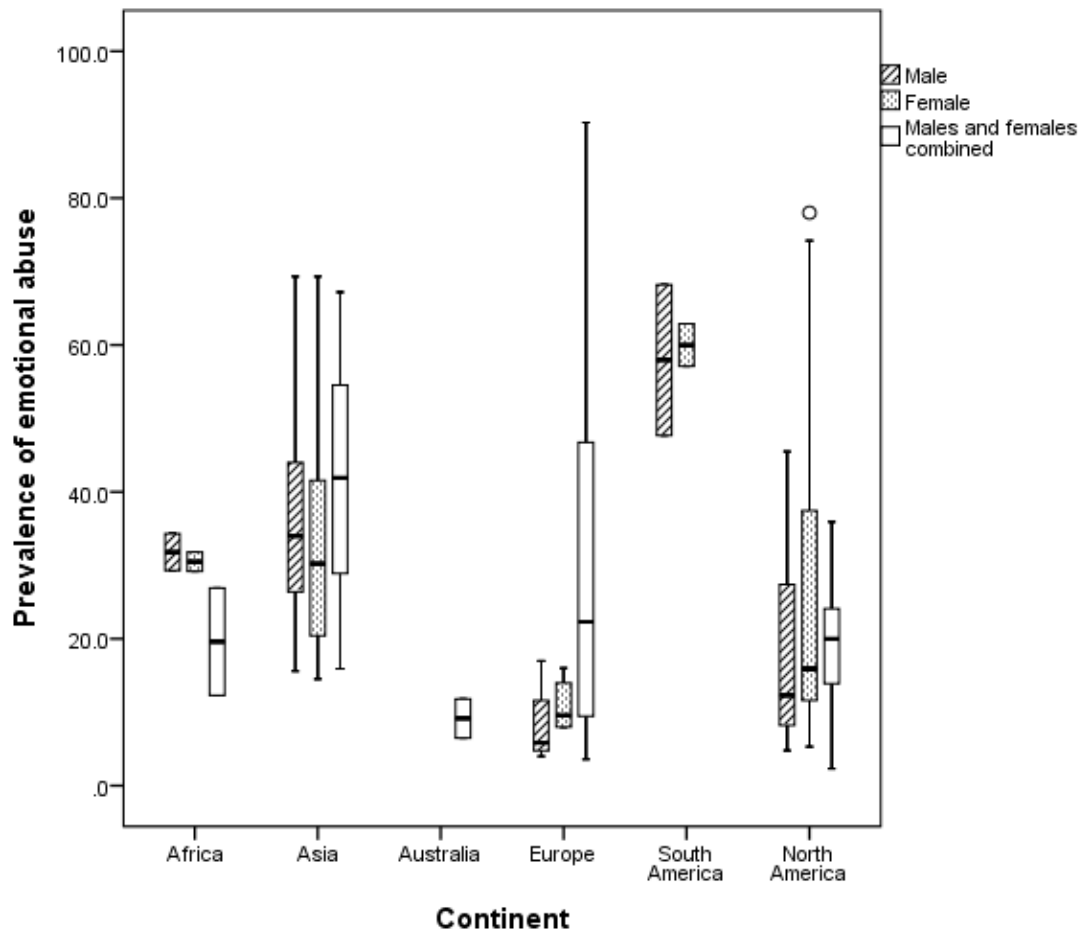
#### Prevalence of abuse by type and population



	Emotional	Neglect	Physical	Sexual	Unspecified
<b>Clinical sample</b>					
N studies	6	5	6	5	3
Median (25th to 75th centile)	40.8 (23.6 to 52.3)	59.1 (25.1 to 65.2)	22.8 (11.0 to 32.6)	19.2 (15.7 to 24.7)	40.4 (9.5 to 48.4)
<b>Non-clinical sample</b>					
N studies	10	9	15	14	4
Median (25th to 75th centile)	8.0 (6.0 to 16.0)	7.0 (6.0 to 14.8)	12.0 (6.9 to 23.0)	9.4 (4.0 to 14.3)	19.7 (18.6 to 25.5)

**Additional file 5**

**Prevalence of emotional abuse by continent and gender - non-clinical sample only**

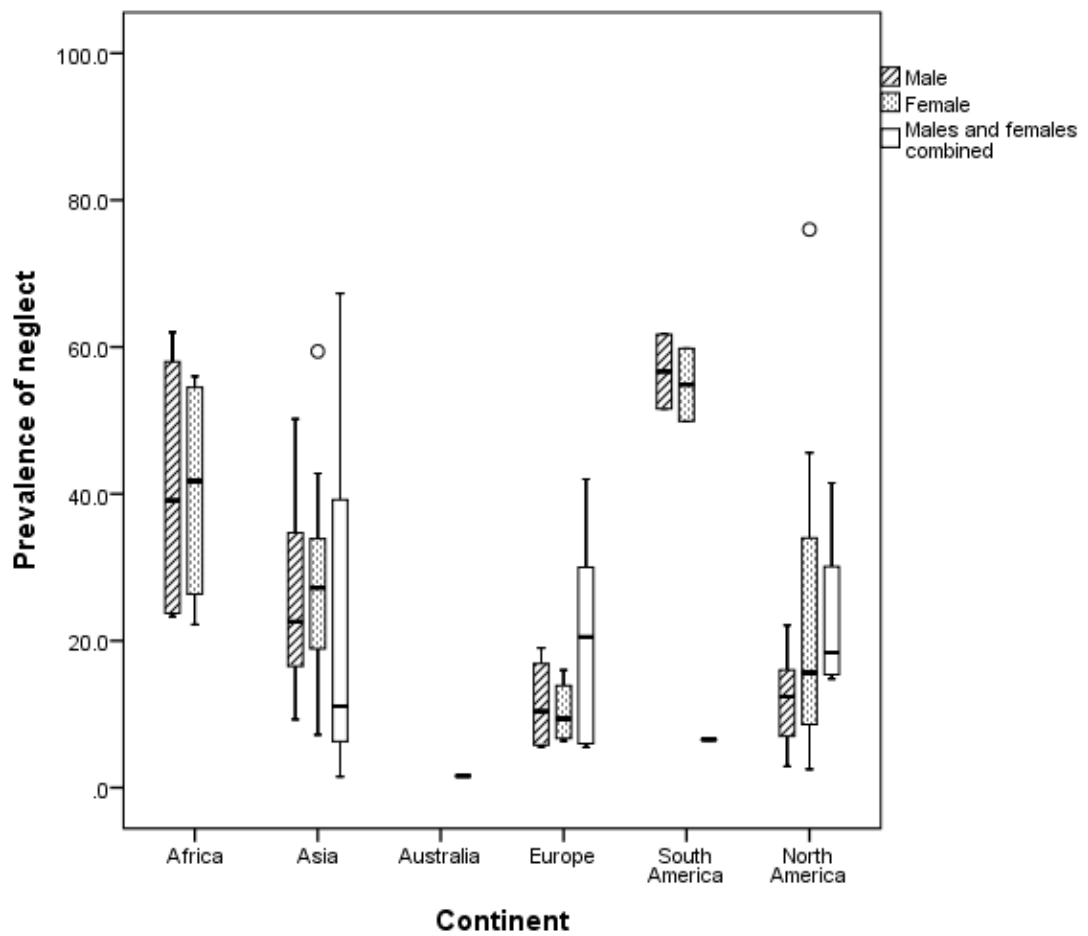


o = Outliers. Between 1.5 and 3 times the height of the boxes (25<sup>th</sup> to 75<sup>th</sup> centile)

\* = Extreme outliers. Values more than 3 times the height of the boxes (25<sup>th</sup> to 75<sup>th</sup> centile)

	Africa	Asia	Australia	Europe	S America	N America
<b>Males</b>						
N studies	2	9	0	4	2	13
Median (25th to 75th centile)	31.8 (29.3 to 34.3)	34.0 (26.4 to 44.0)	-	5.9 (4.8 to 11.6)	58.0 (47.7 to 68.2)	12.3 (8.2 to 27.4)
<b>Females</b>						
N studies	2	12	0	5	2	19
Median (25th to 75th centile)	30.5 (29.2 to 31.8)	30.3 (20.4 to 41.6)	-	9.6 (8.0 to 14.0)	60.0 (57.1 to 62.9)	15.9 (11.5 to 37.5)
N studies	2	3	2	11	0	10
Median (25th to 75th centile)	19.6 (12.3 to 26.9)	41.9 (15.9 to 67.2)	9.2 (6.5 to 11.8)	22.3 (6.0 to 51.2)	-	20.0 (13.9 to 24.1)

# Prevalence of neglect by continent and gender - non-clinical sample only

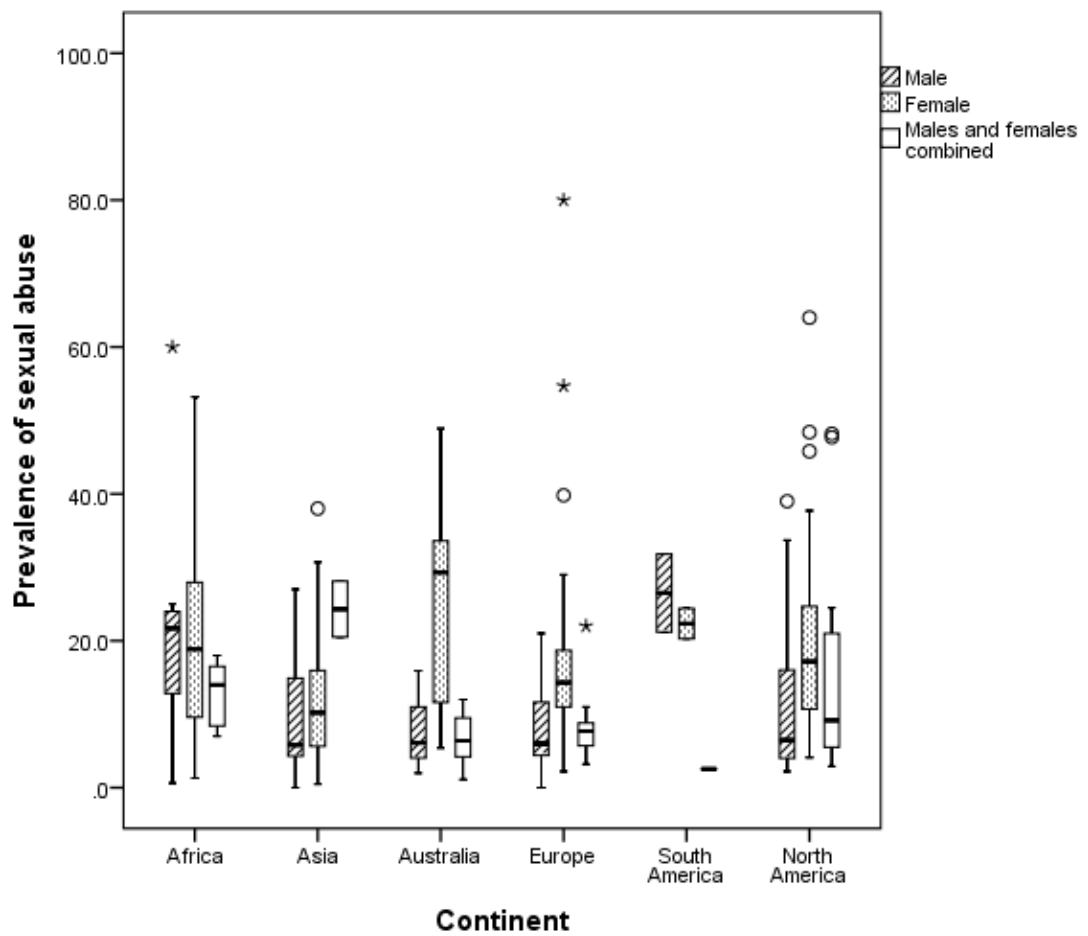


o = Outliers. Between 1.5 and 3 times the height of the boxes (25<sup>th</sup> to 75<sup>th</sup> centile)

\* = Extreme outliers. Values more than 3 times the height of the boxes (25<sup>th</sup> to 75<sup>th</sup> centile)

	Africa	Asia	Australia	Europe	S America	N America
<b>Males</b>						
N studies	4	7	0	4	2	5
Median (25th to 75th centile)	39.1 (23.8 to 58.0)	22.6 (12.9 to 44.5)	-	10.4 (5.8 to 16.9)	56.7 (51.6 to 61.7)	12.4 (7.0 to 16.0)
<b>Females</b>						
N studies	4	9	0	4	2	8
Median (25th to 75th centile)	41.8 (26.4 to 54.5)	27.2 (18.9 to 33.9)	-	9.4 (6.7 to 13.9)	54.8 (49.9 to 59.8)	15.6 (8.6 to 34.0)
<b>Combined</b>						
N studies	0	3	1	6	2	151
Median (25th to 75th centile)	-	11.1 (31.5 to 67.3)	1.6	20.5 (6.0 to 30.0)	6.6 (6.5 to 6.6)	18.4 (15.4 to 30.1)

# Prevalence of sexual abuse by continent and gender - non-clinical sample only



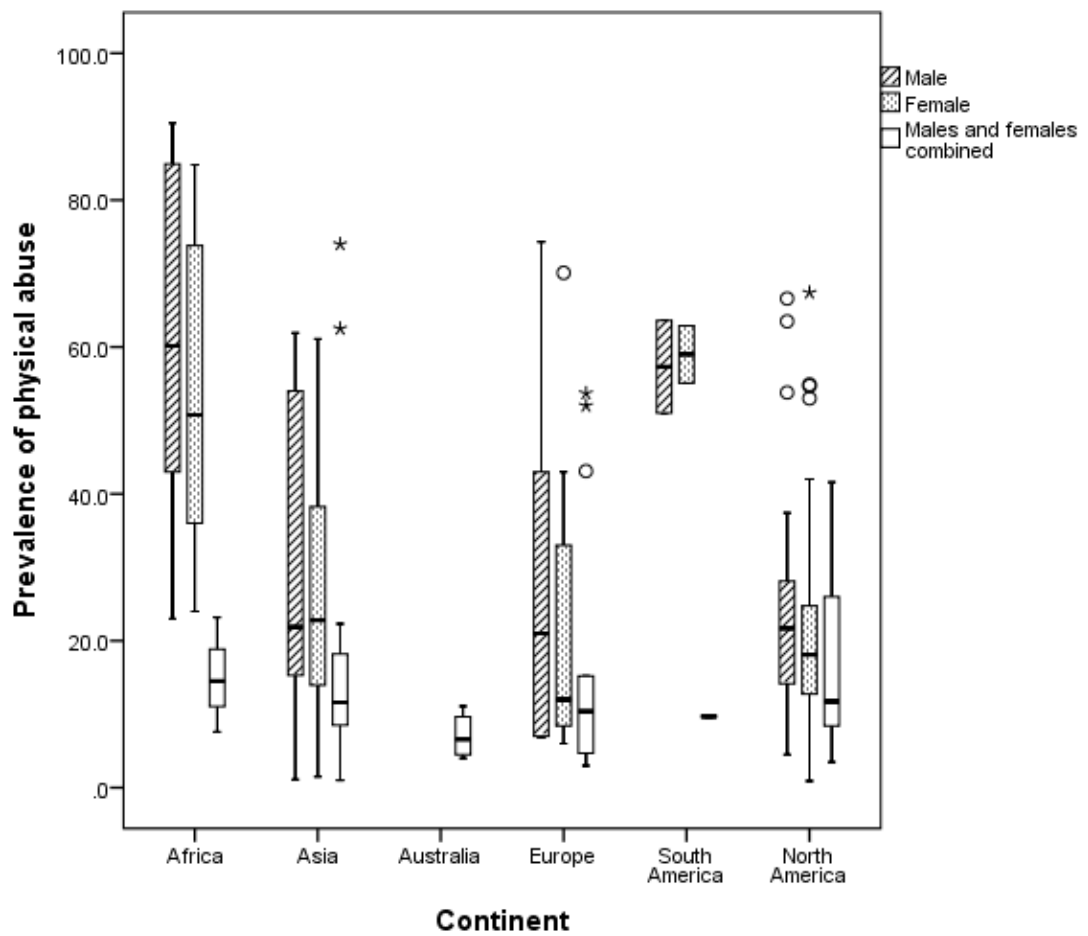
o = Outliers. Between 1.5 and 3 times the height of the boxes (25<sup>th</sup> to 75<sup>th</sup> centile)

\* = Extreme outliers. Values more than 3 times the height of the boxes (25<sup>th</sup> to 75<sup>th</sup> centile)

	Africa	Asia	Australia	Europe	S America	N America
<b>Males</b>						
N studies	9	18	3	16	2	34
Median (25th to 75th centile)	21.7 (12.8 to 24.0)	5.8 (4.3 to 14.9)	6.1 (2.0 to 15.9)	6.0 (4.4 to 11.7)	26.5 (21.2 to 31.8)	6.5 (4.0 to 16.0)
<b>Females</b>						
N studies	12	35	6	21	2	61
Median (25th to 75th centile)	18.9 (9.6 to 28.0)	10.2 (5.3 to 16.7)	29.3 (11.6 to 33.6)	14.3 (11.0 to 18.7)	22.4 (20.3 to 24.4)	17.2 (10.7 to 24.7)
<b>Combined</b>						
N studies	5	2	5	9	2	18
Median (25th to 75th centile)	13.0 (8.4 to 16.5)	24.3 (20.5 to 28.1)	6.4 (4.2 to 9.5)	7.7 (5.7 to 8.8)	2.6 (2.5 to 2.6)	9.2 (5.5 to 21.0)



# Prevalence of physical abuse by continent and gender – non-clinical sample only



o = Outliers. Between 1.5 and 3 times the height of the boxes (25<sup>th</sup> to 75<sup>th</sup> centile)

\* = Extreme outliers. Values more than 3 times the height of the boxes (25<sup>th</sup> to 75<sup>th</sup> centile)

	Africa	Asia	Australia	Europe	S America	N America
<b>Males</b>						
N studies	6	13	0	6	2	28
Median (25th to 75th centile)	60.2 (43.0 to 84.9)	21.9 (15.3 to 54.0)	-	21.0 (7.0 to 43.0)	57.3 (51.0 to 63.6)	21.7 (14.1 to 28.1)
<b>Females</b>						
N studies	6	16	0	8	2	44
Median (25th to 75th centile)	50.8 (36.0 to 73.8)	22.8 (14.0 to 38.3)	-	12.0 (8.4 to 33.0)	59.0 (55.1 to 62.9)	18.1 (12.8 to 24.8)
<b>Combined</b>						
N studies	3	11	4	14	2	22
Median (25th to 75th centile)	14.5 (7.6 to 23.2)	11.6 (7.5 to 22.3)	6.6 (4.5 to 9.6)	10.4 (4.7 to 15.2)	9.7 (9.6 to 9.8)	11.8 (8.4 to 26.0)

## Appendix 6. Focus groups young people invitation leaflet

**We are looking for Young people  
to take part in group discussions!**

MINIMAL  
Measuring child MALTreatment  
in community-based trials

What is the group discussion about?

---

We want to know your opinions about researchers collecting data on child maltreatment from medical and other records e.g. Local Authority records.

More details

***Where and when?***

We don't have a specific time or date for this yet: it will depend on when you, and the other members, will be available. It will take no longer than 2 hours and will be held in a convenient location in Cardiff. Your travel costs can be covered by us.

***Who else will be in the group?***

Between 6 to 10 young people including yourself. We would like all the young people taking part to be fluent English speakers as we want everyone to be able to understand each other.

## Who we are

---

The information collected in the group discussions will be used as part of a PhD project which is run by the South East Wales Trials Unit, a part of Cardiff University. All of the information collected will be confidential and the study will be conducted under ethical approval from Cardiff University.

## How do I take part?

---

If you think you would be interested in taking part, or would just like to know more about this, please contact me:

### **CONTACT DETAILS** Gwenllian Moody

#### Address

South East Wales Trials Unit  
Cardiff University  
7th Floor  
Neuadd Meirionnydd  
Heath Park, Cardiff  
CF14 4YS

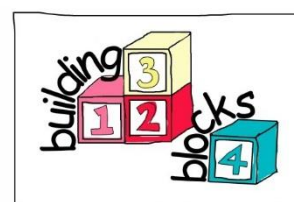
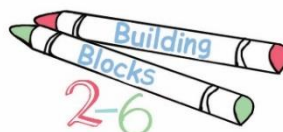
#### Email

moodyG@cardiff.ac.uk

#### Phone

02920 687257

## Appendix 7. Information sheet young people



### Information sheet for face-to-face focus groups participants

#### **Study title: MINIMAL - Measuring child maltreatment in community-based trials.**

You are being invited to take part in a focus group for a research study. Before you decide to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you want. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you would like to take part.

#### **What is this about?**

As part of the MINIMAL study we want to hear the opinions of people about collecting data on child maltreatment from medical and other records e.g. Local Authority records.

To achieve this we are planning a focus group discussion with members of the public. We are asking you to consider whether you would be willing to take part in this focus group.

#### **Why have I been chosen?**

You are being asked to take part because you are a member of the public. We would like all the members taking part to be fluent English speakers as it will be a group discussion and we want everyone to be able to understand each other.

#### **Do I have to take part?**

No. It is up to you to decide whether you feel happy to take part in the focus group. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide you would like to take part, but you change your mind later then you don't have to take part and you don't have to give us a reason why you have changed your mind.

#### **What will I have to do if I am happy to take part?**

If, after reading all the information on this leaflet, you are still happy to take part, you can ask us any further questions. You will then be asked to sign a consent form for audio recording (voice recording) the focus group discussion. The focus group will be a small group discussion where you will be able to give your opinion on the topic and to hear the opinion of other members of the group.

#### **What will happen to the recording?**

Researchers at Cardiff University will listen to the recording and create a written version (called a transcript) of what was said in the focus group discussion. Any names will be removed from these transcripts so that all of the information will be anonymised (this means when we are reading the transcripts we will not be able to identify you, we will not use your name or personal details at all). All your information will be kept on a password protected computer and all the transcripts will be kept in a locked file cabinet at Cardiff University.

We will keep all the information you give us during the focus group confidential. Any information you provide that is published will be anonymised, that is your name and personal details will not be used in results we publish from the focus group discussion.

**What will happen at the focus group?**

You will come along to a group discussion of between 6 and 10 people, which will last between one and two hours. Two researchers will run the focus group.

**Are there any risks to taking part?**

The topic discussed at the focus group will be about collecting data on child maltreatment, so you might find this a bit upsetting.

**Are there any benefits to taking part?**

Although we do not think that you will benefit personally by taking part in the focus groups, they do provide an opportunity for you to have your say, you will also be helping with the research.

**What will happen to the results of the study?**

The focus group findings will help us understand your opinions about collecting data about child maltreatment from medical and other records. This information will be used as part of a PhD project and may be published in professional journals over the next few years (with all personal or identifiable details removed). If you wish, we can let you know about any publications we make from this study.

**Who is organising and paying for the research?**

The project is being paid for, organised and run by Cardiff University.

**Thank you for reading this information leaflet. Please keep it and feel free to contact the research team for further information.**

**Please do not hesitate to contact the researcher for further information:**

Mrs Gwenllian Moody  
South East Wales Trials Unit (SEWTU)  
School of Medicine  
Cardiff University  
7th Floor  
Neuadd Meirionnydd  
Heath Park  
Cardiff  
CF14 4YS

email: MoodyG@cardiff.ac.uk

phone: 02920 687257

## Appendix 8. Consent form young people



### Consent form for face-to-face focus groups participants

**Study title: MINIMAL - Measuring child maltreatment in community-based trials.**

Researcher name: Gwenllian Moody

**Please initial box**

1. I confirm that I have read and understand the Focus Groups Information Sheet (version 1.0 15 January 2016) for the above study and have had the opportunity to ask questions.

☐

2. I understand that these focus groups will be audio recorded and transcribed. Any information I or other focus group participants provide will be kept confidential; all published quotes will be anonymised and comments will not be attributed to any locality.

☐

3. I understand that my decision to take part is voluntary and that I am free to stop participating at any time.

☐

4. I agree to take part in the above study.

☐

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Person taking consent  
(if different from researcher)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

## Appendix 9. Rationale for an online focus groups method to collect data

### Contents

- Can online groups be considered ‘focus groups’?
- Free from the limitations of the ‘real world’
- Increased anonymity
- Recruitment and participants
- Non-verbal cues are missed
- Technology
- References

### Can online groups be considered ‘focus groups’?

There has been some discussion in the literature about whether online focus groups can really be considered ‘focus groups’. Five characteristics of focus groups identified by Krueger and Casey (2014) will be reviewed and discussed in turn in relation to the online focus group that was conducted in the current study. Firstly, **focus groups should involve people**. The focus groups in the current study indeed involved people, UK professionals responsible for recording maltreatment data in records. Second, the **participants are reasonably homogenous and unfamiliar with each other**. In the current online groups the participants were *mostly* unfamiliar with each other, it may be the case however that *some* participants knew each other if they were recruited after being identified by others in the group (snowballing technique). As they were posting entries using pseudonyms however, each participant did not know the identity of the individual behind each comment posted. Third, focus groups **are methods of data collection**, that are fourth, **qualitative in nature**. In the current research text-based data were collected to reflect the discussions that happened in the group, and these data were analysed. Fifth, **they constitute a focused discussion**. The current online focus groups work fulfilled these criterion as the data provided insight into the attitudes, perceptions, and opinions of the participants and these were gathered by recording participant responses to a series of predetermined, open-ended questions based on a topic guide (2). Some researchers have also stated that focus groups should be conducted in a series. Krueger (1994) insisted that multiple groups with similar participants should be run, and that at least 3 groups need to be run because single focus groups can result in the collection of extraordinary results due to a variety of factors, such as a dominant personality in the group or the reluctance of a group to participate. Turney and Pocknee (2005) examined whether an online



focus group would measure up to the aforementioned five criteria and this one final criteria. They concluded that online groups share the first five criteria, but not the final one. In the current piece of research there was only one online focus group. This was felt to be justified, the point also argued by Turney and Pocknee (2005) that the purpose was substantially different from that of evaluation research and therefore a single group is sufficient. Single focus groups can be used to give insight into a particular issue from the viewpoint of those with an interest or stake in the topic and so do not provide generalisability but depth of understanding. Stewart and Williams (2005) added that online focus groups follow the tradition of face-to-face groups as they are characterised by a group discussion about a topic facilitated by a researcher, and the group interaction produces data. They reasoned that if we can accept that telephone interviews are truly interviews, then we can accept that online focus groups are truly focus groups (4).

Other researchers have found that online focus groups are mostly on par with face-to-face focus groups in terms of data quantity and quality. Underhill and Olmsted (2003) compared the quantity and quality of information collected in three types of focus group; traditional face-to-face groups, communication using laptop computers, and a private internet chat room. They found that discussions in the two types of computer-based focus groups produced the same quantity and quality of information obtained from face-to-face focus groups (5). The rates of participation did not vary significantly between the groups and although the participants in the face-to face groups produced more words than the other groups, the amount of unique ideas produced by each was not significantly different (5). The computer-mediated and internet-simulated groups occasionally became more 'off topic' than the face-to-face groups; however they still produced similar numbers of unique ideas (5). The Internet-simulated groups had fewer disagreements and insults than the other groups (5), a positive outcome in that fewer insults were recorded. This could also however be seen as a negative outcome as on occasion disagreements produce good data. Finally, regardless of the focus group mode, participants indicated that they enjoyed the experience of taking part (5).

If online groups can indeed be viewed as true 'focus groups', what about the unique advantages and disadvantages of this method of data collection?

#### **Free from the limitations of the 'real world'**

One of the main advantages of running focus groups online is that these groups are not constrained by the limitations of the 'real world' (6). Use of the internet in general has provided the opportunity for research that overcomes some of the barriers imposed by conventional research approaches (7; 8; 9).

Physical barriers that could affect whether participants could meet face-to-face are reduced; these include geographic boundaries (2; 4; 6; 9; 10; 11; 12). Holmes (1997) reasoned that these lack of limitations could leave participants 'free to create'. The choice of location to participate in the group is the participants' own, participants can choose a location that they feel comfortable and secure in, this is more likely to facilitate the exploration of personal issues and increase motivation to participate (9; 10; 14). Although the choice of location is somewhat restricted by the need for internet access (9). For online focus groups it is not necessary to arrange transport or allow for travel time, this is particularly important for participants who are geographically dispersed or spatially restricted (9). This can lead to online focus groups being less costly as there are no travel costs or venue hire (4; 10; 12; 14). There are less organisational demands on the researcher who no longer needs to seek out a venue which meets the needs of each participant (1; 11; 15). One disadvantage of not being in the same physical location as participants is that the moderator cannot respond to factors that are invisible, such as a respondent not paying full attention to what is happening (9). Moderating online groups requires slightly different skills than those for a face-to-face group (2; 6; 10). Moderators need to be able to type quickly and efficiently, be competent in the technology being used, and be able to moderate and re-direct conversations with a keyboard as well as establish rapport between participants who only interact through the online group (6). The moderator needs to be less interventionist and less directive than in face-to-face focus groups (2). Asynchronous online focus groups may however be easier to moderate as there is less speed in the discussions (4). As well as having less geographical constraints, there are also no time restrictions in asynchronous online focus groups, the group can go on for days or weeks if needed (2; 6; 10). These groups can be as long or short as required and can be assembled and disassembled quickly (10), but will certainly last much longer than a face-to-face focus group (16). Asynchronous groups can provide access to hard to reach participants including those who may find it difficult to commit to certain times and dates to participate (14). More time is required to allow participants to post comments in their own time and around their other commitments (16). Murray (1997) ran an online focus group for four weeks, this was considered long enough not to conflict with participants' other commitments and not so long

as participants would lose interest in the discussions. If there are multiple topics of discussion, or research questions, flexibility on how long the discussion topics run is important. They can be closed down early if discussion ends or prolonged if discussion is ongoing (16). Murray (1997) found that when all topics were opened at the same time there was little discussion and participants merely provided short responses to each topic, however when introduced one at a time there was more interaction. In the current study the online focus group ran for five weeks, one week for every topic of discussion, and only one topic was open at a time. The topics of discussion were available to view from the time the online focus group was opened, however, participants were only able to post comments in the 'open' topic. There are some disadvantages of having no time restrictions, the main being as there are no strict timelines from the beginning to the end of the focus group discussion, this may lead to sporadic participation, loss of participation, and variable interaction among the participants (12). It has also been argued participants may be less motivated to take part and there is a higher 'no-show' rate in online focus groups compared to face-to-face groups (9; 11). In a similar vein to the method used by Yu et al (2011), the participants in the current study had the capability to log in and out of the website at any time. This was to avoid any coercion or pressure to remain in that particular discussion and indeed the group, which may be felt by participants in face-to-face focus groups. Closing an asynchronous online group may be difficult for the moderator as discussions could continue (6). A disadvantage of an *asynchronous* online focus group (as compared to a *synchronous* group) is that the level of group interaction may be reduced as the sense of immediacy of responding is removed and spontaneity may be removed (9; 10). Benefits to asynchronous groups include allowing participants to consider responses in their own time leading to more measured and lengthier responses (2; 4; 10). It is also the case that in many asynchronous groups such as the one in the current study, participants will still also have the ability to discuss in real-time if more than one is logged on at once.

### **Increased anonymity**

Online focus groups can allow a participant increased anonymity as compared to a face-to-face group, this could be especially beneficial if the topic is sensitive or emotive (2; 6). Participants can be asked to create their own pseudonyms to protect their identity, this will make them anonymous to each other. The researcher however will be able to identify them from looking at which pseudonyms are associated with which log-in details, this gives security to the researcher who can ensure that all participants are eligible and cannot be deceptive regarding their identities (2; 4). Oringderff (2008) notes that participants are doubly protected by both

the anonymity of their online identity, and a second time by the researcher's call for confidentiality. Some researchers have argued that increased anonymity could lead to participants behaving differently online than they would in a face-to-face group, the rules of discourse can be changed (9). There is more freedom of expression, and communication styles are less hierarchical and less formal (18). Interactions through the internet, on account of the interpersonal distance, may lead participants to reveal more about themselves. They can be more open, this can increase rapport, and there may be less fear of reprisals (4; 19; 20). Some participants who would be reluctant to reveal their 'true' identity may be more willing to take part in online focus groups (10), however, there has been some evidence that the differences between self-presentation in real life and online is far less divergent than might have been thought (21). Some researchers have argued that the online settings can offer social equalisation and reduce bias. This is because demographic factors including socio-economic status, ethnicity, and gender which can be potential issues of contention in a face-to-face setting, are hidden (6; 10; 11). This can make online groups more egalitarian method of data collection (10), although this may not be entirely the case in the current study as it is likely that participants reveal their professional roles in the discussions, and therefore hierarchies in professionals may come into play. It could be said that online focus groups could also be beneficial in reducing bias towards the researcher as well as they can also be 'hidden' (6). This will not be the case in the current study as the identity of the researcher was made available to participants when approached to take part.

### **Recruitment and participants**

As well as running focus groups online the internet can provide an effective means of identifying potential participants (6). They can be recruited from existing discussion groups (6), or from social media websites e.g. twitter. Stewart and Williams (2005) argued that as focus groups, including those run online, do not strive to collect data that is generalisable to whole populations but seek a greater depth of understanding about a topic so systematic random sampling should not be required, and suggested tapping into pre-existing social groups and snowball sampling (4).

Online focus groups, much like the face-to-face focus groups, will capture both group similarities and differences in opinions (16). Murray (1997) suggested choosing six to eight participants for an online focus group as to mirror how many would be in a face-to-face group. Stewart and Williams (2005) suggested that an online focus group should contain more

participants than a face-to-face group as participants would be dipping in and out of the discussion, this is especially true of an asynchronous methodology. Murray (1997) concedes that in some circumstances a larger group may be needed for online groups to promote the level of discussion and interaction the researcher seeks, however he also believed that group size is not necessarily a predictor to the level of contribution and interaction. Oringderff (2008) argues that more respondents can be included in online groups because the online environment is not affected by size of the group.

Salmon (2003) noted that online information communication tools (ICTs) favour articulate, script-based, opinionated participants who have high levels computer literacy. The online focus groups therefore should be a suitable medium for participants with professional backgrounds. Although this sentiment is not referring to online focus groups, it is nonetheless very applicable and relevant to the online focus groups conducted in this current study. Although less relevant to the current study it may also be the case that an online group could attract a different type of participant who may be self-conscious or embarrassed in a face-to-face setting (6; 23).

### **Non-verbal cues are missed**

The main criticism of online focus groups is that any non-verbal cues that could be seen in face-to-face communication are lost, including visual or physical cues such as facial expressions and vocal cues such as inflection (6; 9; 10; 12). Neither the researcher, nor other participants can 'see' a smile or a sigh online, only written communication (6). Meanings may be misconstrued when participants are in discussion without these cues (10). This could lead to the loss of important observational elements and cues that some say are vital to the validation of researcher-respondent exchange (6). Some researchers have argued that online focus groups contain less media richness and social presence compared to face-to-face focus groups (11). Media richness is the ability of a communication medium to foster immediate interaction and feedback and to permit people to communicate with many kinds of cues using multiple senses such as nonverbal cues (24). Social presence is the degree to which a medium conveys the immediacy of face-to-face conversation (25; 26), and the richest media tend to convey social presence.

Non-verbal cues can also be used by researchers to build rapport and gain the trust of participants in the group (9), such as a friendly smile from the researcher to put participants at

ease. Visual cues that reveal differences or similarities in participants, such as gender, can also affect rapport, with shared characteristics likely to contribute to a greater feeling of rapport (27). Researchers such as Oakley (1981) and Finch (1993) have explored the impact that shared characteristics can have, concluding that when women interview women rapport will often happen naturally. Researchers conducting online focus groups will therefore need to build rapport in other ways. O'Connor and Madge (2003) did this through self-disclosure at an early stage by providing photographs and brief biographies of the researchers. Email communication with participants before the focus groups is also a good way to build rapport (9). These approaches were utilised in the current study. The researcher included a brief biography on the home page of the focus groups website and also contacted participants via email before and during the focus groups to help build rapport.

Turney and Pocknee (2005) noted that some theorists have argued however that computer-mediated communication can be hyperpersonal and characterised by more openness. It is also the case that there are some cues that can be analysed in online focus groups which are comparable to non-verbal cues seen in face-to-face groups, for example emoticons, line width, use of capitals, colour and font (4). Markham (1998) purports that 'just as the text cannot capture the nuance of the voice, the voice cannot capture the nuance of the text'.

There are other communication differences between online and face-to-face focus groups. Online participants can't interrupt each other (11), this means that often online groups can last longer than face-to-face focus groups (32). Online participants may contribute more comments as they cannot be interrupted and can't sense disapproval from others about what they are saying or how much they are contributing (11). Participants may communicate differently, and as some have argued that they are less likely to be self-conscious or embarrassed (6; 23). Online participants can have more freedom of expression and also be less tactful when expressing their views, this can lead to conflict, especially when the topic is sensitive (10). In a long running online group there is a tendency for participants to develop 'pair friendships' where they engage in their own exclusive dialogue and alienate the rest of the group (10). The comments provided online are shorter, less elaborate, and participants are less likely to explain their opinions or provide detailed explanations (11), this may be because participants have to type make their points point before the conversation moves on. Online participants are more likely to interject brief statements to substitute nonverbal cues to show approval or just to show they are still online (11). Schneider et al (2002) noted that these types of

comments are not very useful to researchers as they don't provide any information about participants' reasons for their opinions and online moderators should ask participants to elaborate on these sorts of posts. This may also be problematic however as participants may not want to type lengthy explanations. Online participants may contribute fewer off topic comments, there is also less small talk as there tend to be fewer distractions (11).

### **Technology**

Turney and Pocknee (2005) suggest that before deciding exactly on how an online focus group will be run, the researcher must review all the technical options available to them. Those without access to the internet cannot take part in online focus groups (2; 6; 16). Most participants were likely to have access to internet in 2016 when the groups for the current study were conducted, this was likely especially true of the groups of professional participants taking part. The risk remains of participants losing internet connection during a discussion (11), this is however a lesser issue for those taking part in an asynchronous online focus group as opposed to a synchronous focus group. Out of date or incompatible software could also be a problem for conducting this sort of research online (6), the website designed for the current research did not require any specialist software.

Online security and identification of participant identity should also be considered (10; 16). The website designed for the current study was only accessible via registration and the use of a username and password for log-in, and users were therefore only able to register if the moderator allowed this.

One obvious advantage of online focus groups is that the moderator does not need to get a voice or video recording manually transcribed (9), the transcript is available instantly (6; 9; 10; 11). This avoids transcription costs (16) and any mistakes that could be made during transcription (2; 10). This may put the participant at a slight disadvantage however, those with slower typing speeds and participants who prefer more time to reply to posts may fall behind in the discussion as they could still be preparing a post while the discussion has moved on, at worst this could result in loss of data as the participant may delete their half-written post (9). This could also affect motivation because as well as taking part in the discussion, participants have to read text on the screen and type (9).

This rationale has discussed whether online groups can be considered 'focus groups', as well as discussing the various advantages and disadvantages of this method of data collection. When

considering whether to collect data using online focus groups, it is important to keep in mind Illingworth's (2001) notion that researchers should avoid that notion that the use of the internet is an 'easy option'. Researchers should be encouraged to view a more developed focus on the justification, applicability and benefits of using online methods to the particular research project.

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## **Appendix 10.** Topic guide face-to-face focus groups

### **Face-to-face focus group topic guide**

The face-to-face focus groups are based on Research Question two '*What are the attitudes of mothers, care-experienced young people and professionals towards the collection and linkage of sensitive data??*' and will specifically investigate **young peoples'/parents'** attitudes regarding collecting child maltreatment data from records.

The questions are based on the literature review findings.

#### **Focus groups start**

- Thank respondents for attending.
- Introduce facilitator and moderator.
- Facilitator to take consent (provide Information Sheet and complete Consent Form).
- Participants to complete Demographic Data Collection Form.
- Emphasise confidentiality, no right or wrong answers, your views are important.
- Provide etiquette guidance: There are a few guidelines I would like to ask you to follow during the focus group interview. First, you do not need to speak in any particular order. When you have something to say, please do so. Second, please do not speak while someone else is talking. Sometimes the exchanges get emotional and it is tempting to jump in when someone is talking, but we ask you to refrain from doing so. Third, remember that there are many people in the group and that it is important that we obtain the point of view of each of you. Fourth, you do not need to agree with what everyone of anyone in the groups says, but you do need to state your point of view without making any negative comments or put downs. Finally, because we have limited time together, I may need to stop you and redirect our discussion. Do you have any questions about this?
- Housekeeping: toilets, fire exits, refreshments, mobile phones on silent.
- Please complete name stickers.

\*start PowerPoint presentation 'PowerPoint presentation for face-to-face focus groups'

*Slide 1*

### **Introductory presentation on topic for discussion**

- Ask participants to introduce themselves (name, job, who live with, any hobbies/interests [don't have to answer all of these, these are just examples to give participants])
- **Purpose of today's focus group meeting:** For my PhD I want to know more about what **young people/parents** think about researchers collecting information on child maltreatment.
  - Information on child maltreatment is captured by organisations as part of routine care in records such as medical and social care records. This information can then be used by researchers. Today we will be talking about this sort of information and NOT about researchers collecting new information.
  - All sorts of information can be used in research, today we will be talking about data related to child maltreatment.
- Remind participants about confidentiality and that there are no right or wrong answers, and to give everyone opportunity to speak even if you don't agree with what they are saying.

### **Discuss key terms**

*Slide 2*

*Slide 3*

*Slide 4*

*Slide 5*

*Slide 6*

**How data are collected currently in the UK:** At the moment in the UK research using personal but anonymised data about people can be conducted by organisations without asking for the person's consent. If researchers want to use data that is identifiable then they have to obtain consent.

### **Who might use this data for research:**

- **Public sector** e.g. University researchers, NHS, Government
- **Private Sector** e.g. pharmaceutical companies, insurance companies
- **Third sector** e.g. charities and voluntary organisations

*Slide 7* – this is an example of dataset that can be seen by researchers when doing this sort of work

**Scenario 1 discussion** (Collecting identifiable non-sensitive data with consent from hospital records)

*Slide 8*

**Does anyone have any thoughts about this?**

**I'm now going to ask you some questions so that we can discuss this scenario.**

**Attitudes towards various models of consent and preference for consent**

'Would you decide to give consent depending on what *sort* of data are going to be collected?'

(Prompt: 'Do you feel that data related to some things are easier to give consent to than others?')

**Attitudes towards data security and transfer**

'When data are being sent to researchers from hospital records, do you think that there are more or less security risks when the data are electronic, that is on a computer, or if it's on paper?'

'Sometimes we hear stories in the news about people's data being lost or stolen. Do you think these stories would affect how you felt about researchers collecting and transferring your data even if you were told that the data would be secure?'

**Consent yes/no for scenario 1**

'What would be your answer if the researchers were asking your consent for your data to be collected in this way?'

**Scenario 2 discussion** (Collecting anonymised non-sensitive data without consent from hospital records)

*Slide 9*

**Does anyone have any thoughts about this?**

**I'm now going to ask you some questions so that we can discuss this scenario.**

**Attitudes towards and preference for anonymisation**

'We have discussed how data can be anonymised. How do you feel about the idea of data being collected without permission needing to be given?' (Prompt: 'Do you think that researchers should ask before obtaining anonymised data, even though they don't have to?')

**Scenario 3 discussion** (Collecting anonymised child maltreatment data without consent from hospital and Local Authority records)

*Slide 10*

*Slide 11*

**Does anyone have any thoughts about this?**

**I'm now going to ask you some questions so that we can discuss this scenario.**

**Acceptability of collection of child maltreatment data from various sources**

'How do you feel about child maltreatment data being collected from different organisations such as from medical records or Local Authority records? Do you feel that it is more acceptable to collect this data from some of these records rather than others?'

**Attitudes towards data security and transfer**

'When data that might be considered more sensitive such as data on child maltreatment is being sent to researchers from hospital and Local Authority records, do you think that security is more important when transferring the data or just the same as any other data?'

**Acceptability of collecting data on:**

- **confirmed cases of child maltreatment**
- **markers of maltreatment**

- **risk factors for maltreatment**

‘How do you feel about researchers collecting data from records about cases of child maltreatment that have been confirmed?’

‘How do you feel about researchers collecting data that is we would call ‘markers’ of child maltreatment?’

‘How do you feel about researchers collecting data on things that may predict that child maltreatment might happen in the future?’

### **Discussing the importance of research and risk/benefit**

‘What do you think the benefits of this research is?’

‘Do you think researchers having access to child maltreatment data without asking the persons’ permission is a good thing or not?’

### **Consent yes/no for scenario 3**

‘If the researchers were asking your consent for your data to be collected in this way, would you say yes or no (or undecided)?’

### **Before we finish, would anyone like to add anything to the discussion?**

### **Co-facilitator to summarise points and ask group if they agree.**

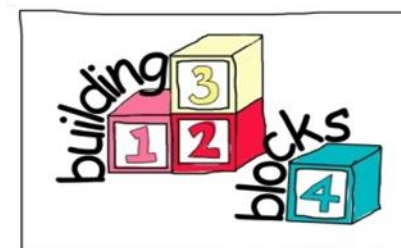
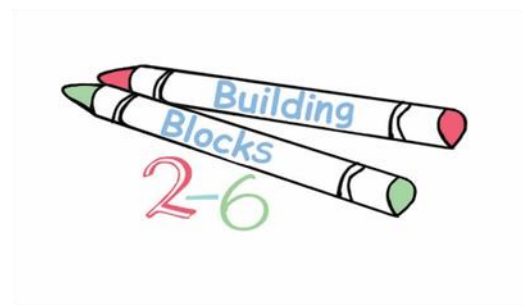
### **Close focus group**

*Side 12*

- ‘Thank you’.
- Advise participants that they can obtain more information about the PhD from myself (details are on the information sheet provided).
- If they would like to be given results of the focus groups research please provide contact details.
- Please complete expenses form before leaving/post to me.



**Appendix 11.** Presentation with topic guide for face-to-face focus groups



# Welcome!

## My name: Gwenllian Moody (Gwen)

# Key terms

- **Data:** information which is collected about individuals.

First name	Surname	Age	Gender
Gwenllian	Moody	32	Female
Jon	Jones	45	Male
Alex	Griffiths	82	Female

- **Data linkage:** data collected in different places (e.g. in medical records, education records) that can be joined together.

First name	Surname	Age	Gender
Gwenllian	Moody	32	Female
Jon	Jones	45	Male
Alex	Griffiths	82	Female

First name	Surname	Job	Hobby
Gwenllian	Moody	Researcher	PhD!
Jon	Jones	Postman	Art
Alex	Griffiths	Retired	Cycling

First name	Surname	Age	Gender	Job	Hobby
Gwenllian	Moody	32	Female	Researcher	PhD!
Jon	Jones	45	Male	Postman	Art
Alex	Griffiths	82	Female	Retired	Cycling

- **Identifiable data:** This is where we could identify a person in a dataset e.g. the dataset may contain their name.

First name	Surname	Age	Gender	Job	Hobby
Gwenllian	Moody	32	Female	Researcher	PhD!
Jon	Jones	45	Male	Postman	Art
Alex	Griffiths	82	Female	Retired	Cycling

- **Anonymised data:** This is where a person can't be identified in a dataset, so the dataset does not contain any information that we could use to identify that person.

Identifier	Age	Gender	Job	Hobby
001	32	Female	Researcher	PhD!
002	45	Male	Postman	Art
003	82	Female	Retired	Cycling

BUT a person could become 'identifiable' if enough anonymised datasets are linked together.

Identifier	Age	Gender	Job	Hobby
001	32	Female	Researcher	PhD!
002	45	Male	Postman	Art
003	82	Female	Retired	Cycling

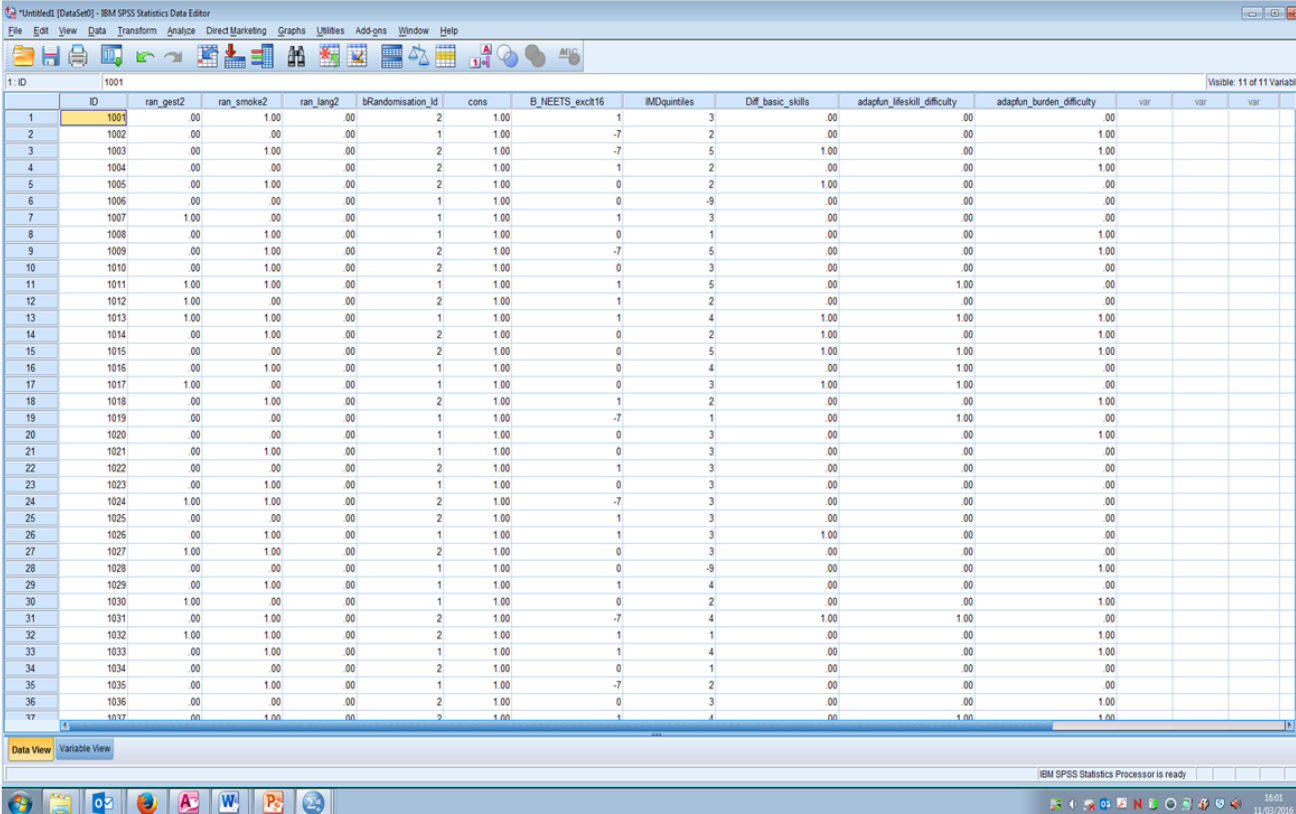
Identifier	Postcode
001	CF14 3QR
002	SA31 4YS
003	CF24 8BI

- **Consent:** Asking a person's permission about something. In this case this is about asking a person's permission to use their data.

Do you agree? Please tick

<input checked="" type="checkbox"/>	yes
<input type="checkbox"/>	no

# Dataset example



Visible: 11 of 11 Variables

	ID	ran_gest2	ran_smoke2	ran_lang2	bRandomisation_id	cons	B_NEETS_excit16	IMDQuintiles	Diff_basic_skills	adapfun_lifeskill_difficulty	adapfun_burden_difficulty	var	var	var
1	1001	.00	1.00	.00	2	1.00	1	3	.00	.00	.00			
2	1002	.00	.00	.00	1	1.00	-7	2	.00	.00	1.00			
3	1003	.00	1.00	.00	2	1.00	-7	5	1.00	.00	1.00			
4	1004	.00	.00	.00	2	1.00	1	2	.00	.00	1.00			
5	1005	.00	1.00	.00	2	1.00	0	2	1.00	.00	.00			
6	1006	.00	.00	.00	1	1.00	0	-9	.00	.00	.00			
7	1007	1.00	.00	.00	1	1.00	1	3	.00	.00	.00			
8	1008	.00	1.00	.00	1	1.00	0	1	.00	.00	1.00			
9	1009	.00	1.00	.00	2	1.00	-7	5	.00	.00	1.00			
10	1010	.00	1.00	.00	2	1.00	0	3	.00	.00	.00			
11	1011	1.00	1.00	.00	1	1.00	1	5	.00	1.00	.00			
12	1012	1.00	.00	.00	2	1.00	1	2	.00	.00	.00			
13	1013	1.00	1.00	.00	1	1.00	1	4	1.00	1.00	1.00			
14	1014	.00	1.00	.00	2	1.00	0	2	1.00	.00	1.00			
15	1015	.00	.00	.00	2	1.00	0	5	1.00	1.00	1.00			
16	1016	.00	1.00	.00	1	1.00	0	4	.00	1.00	.00			
17	1017	1.00	.00	.00	1	1.00	0	3	1.00	1.00	.00			
18	1018	.00	1.00	.00	2	1.00	1	2	.00	.00	1.00			
19	1019	.00	.00	.00	1	1.00	-7	1	.00	1.00	.00			
20	1020	.00	.00	.00	1	1.00	0	3	.00	.00	1.00			
21	1021	.00	1.00	.00	1	1.00	0	3	.00	.00	.00			
22	1022	.00	.00	.00	2	1.00	1	3	.00	.00	.00			
23	1023	.00	1.00	.00	1	1.00	0	3	.00	.00	.00			
24	1024	1.00	1.00	.00	2	1.00	-7	3	.00	.00	.00			
25	1025	.00	.00	.00	2	1.00	1	3	.00	.00	.00			
26	1026	.00	1.00	.00	1	1.00	1	3	1.00	.00	.00			
27	1027	1.00	1.00	.00	2	1.00	0	3	.00	.00	.00			
28	1028	.00	.00	.00	1	1.00	0	-9	.00	.00	1.00			
29	1029	.00	1.00	.00	1	1.00	1	4	.00	.00	.00			
30	1030	1.00	.00	.00	1	1.00	0	2	.00	.00	1.00			
31	1031	.00	1.00	.00	2	1.00	-7	4	1.00	1.00	.00			
32	1032	1.00	1.00	.00	2	1.00	1	1	.00	.00	1.00			
33	1033	.00	1.00	.00	1	1.00	1	4	.00	.00	1.00			
34	1034	.00	.00	.00	2	1.00	0	1	.00	.00	.00			
35	1035	.00	1.00	.00	1	1.00	-7	2	.00	.00	.00			
36	1036	.00	.00	.00	2	1.00	0	3	.00	.00	1.00			
37	1037	.00	1.00	.00	2	1.00	1	4	.00	1.00	1.00			

IBM SPSS Statistics Processor is ready

16:01 11/03/2015

# **Scenario 1:**

## **now I want you to imagine a scenario.....**

Researchers from a University want to collect identifiable data on all children in Wales from their hospital records.

As this data is identifiable the researchers must therefore ask each child's parents for consent to get this data.

This data will be used in a research project that will develop and improve hospital services for children in Wales, this data is not data on child maltreatment.

This data will be transferred from the various records to the researchers by electronic record transfer, that is by sending a file via the internet containing the data.



## **Scenario 2:**

### **data will need to be anonymous.....**

While the researchers were asking all of the parents in Wales for consent they hit a problem.....some of the parents said 'no'.

The researchers would very much like to include all of the children in Wales in the dataset.

So they decide that they would prefer to collect anonymous data, none of the children in the dataset would be identifiable and therefore the researchers would not need to ask the parents' permission to collect this data.

## **Scenario 3: collecting more sensitive data.....**

After collecting the anonymous data and doing the research, the researchers now think that they would like to link the data from the hospital records to data in the children's Local Authority records.

Remember that because the data is anonymised the researchers do not need to ask the parents' permission to collect and link this data.

This time however the data will be collected to investigate child maltreatment and how data from the children's hospital records and Local Authority records can be used to improve services for children who are at risk of maltreatment in Wales.

## Scenario 3: continued.....

The researchers want to look at different types of data:

- data about cases of child maltreatment that have been confirmed, that is cases where the maltreatment has been investigated by Social Services or the Police and they are sure that it has happened.
- data on 'markers' of child maltreatment, that is things that could make us suspect that there *may* have been maltreatment but this has not been confirmed e.g. physical signs or injuries that are recorded in hospital records.
- data that may help us predict that child maltreatment might happen in the future e.g. data on domestic violence in the family could be collected because it has been found in the past that violence in a family raises the risk of maltreatment for the child.

# Thank you for your time!

## **Appendix 12.** Topic guide online focus group

### **Online focus group topic guide**

The online focus group is based on Research Question two '*What are the attitudes of mothers, care-experienced young people and professionals towards the collection and linkage of sensitive data??*' and will specifically investigate professionals' attitudes regarding collecting child maltreatment data from records.

The questions are based on the literature review findings.

Participant logs on to website

- Participants read information sheet and confirm this (first-time log-on only)
- Participants complete consent form (first-time log-on only)
- Participants complete Demographic Data Collection Form.
- Participant reads the etiquette guidelines before joining discussion.
- Participants read the list of Key Terms before joining discussion.

Questions for the focus group (in order of presentation)

Acceptability of collection of child maltreatment data from various sources and whom receives the data

1. 'How do you feel about child maltreatment data being collected for research from various sources such as from medical records or Local Authority records? Do you feel that it is more acceptable to collect this data from some of these records rather than others?'

Attitudes towards recording maltreatment data

2. 'If you know that child maltreatment data may be accessed by researchers; does this affect what data you choose to record?'

Attitudes towards data security and transfer

3. 'When data that might be considered more sensitive such as data on child maltreatment is being sent to researchers from hospital and Local Authority records, do you think that security is more important when transferring the data or just the same as any other data?'

#### Attitudes towards and preference for anonymisation

4. 'Data are often anonymised before being sent to researchers, anonymised data can be sent to researchers without obtaining participant consent. How do you feel about the idea of data being collected without permission needing to be given? Do you think that researchers should ask before obtaining anonymised data, even though they don't have to?'

#### Discussing the importance of research and risk/benefit

5. 'Do you think researchers having access to child maltreatment data without asking parents' permission is a good thing or not? Do you think the benefits of research outweigh concerns surrounding security and confidentiality?'

After all of the topics have been closed:

- Put a 'thank you' message on the website and email a personal letter to each participant thanking them. The letter will also contain:
  - Advise participants that they can obtain more information about the PhD from myself (details are on the information sheet provided).
  - If they would like to be given results of the focus groups research please provide contact details.

## Appendix 13.

**Table 4.** Risk factors for child maltreatment from the literature search

Domain	Primary Sub-domain	Secondary Sub-domain	Reference number
<u>Caregiver-or family-related risk factors</u>	<u>Caregiver who was a victim of abuse</u>		1.00
	<u>Caregiver mental health issues</u>		2.00
	<u>Caregiver substance abuse</u>		3.00
	<u>Young parenthood</u>		4.00
	<u>Family composition</u>	having more children in the family	5.01
		having large families and crowded households	5.02
		single parent families	5.03
		unmarried mothers	5.04
		female headed households	5.05
		having children in close succession	5.06
		shorter pregnancy interval	5.07
		parental history of incarceration	5.08
		presence of a stepparent	5.09

Domain	Primary Sub-domain	Secondary Sub-domain	Reference number
		parental death	5.10
		early separation from mother	5.11
		a child being in the care system	5.12
		having a previous child not living in the house	5.13
	<u>Parent education level</u>	low education level	6.01
		low IQ and/or learning disabilities	6.02
	<u>Parenting and family functioning</u>	using harsh or physical discipline	7.01
		less use of verbal reasoning	7.02
		lack of experience or competence as a caregiver	7.03
		providing less than adequate prenatal care	7.04
		less knowledge of child development	7.05
		poor anger expression and management skills	7.06
		poor frustration tolerance	7.07
		lack of impulse control	7.08
		poor parent-child relations including a tendency to attribute negative intent to a child's behaviour	7.09
		poor parent-child relations including being critical of a child	7.10



Domain	Primary Sub-domain	Secondary Sub-domain	Reference number
		poor parent-child relations including less empathy	7.11
		poor parent-child relations including less positive affection and warmth toward their children	7.12
		father related factors (including fathers who felt they were ineffective as parents, a shorter duration of father involvement in child's life, a father having less involvement with household tasks, and low father warmth)	7.13
		parental stress	7.14
		poor stress management	7.15
		negative perceptions of life events	7.16
		economic stress	7.17
		parents of maltreated children perceived their <b>own</b> childhoods as being unhappy	7.18
		poor relationships with their own parents	7.19
		fathers who maltreated their children were more likely to have been in care	7.20
		conflict in a family or a lack of family cohesion	7.21

Domain	Primary Sub-domain	Secondary Sub-domain	Reference number
		poor family functioning (family functioning is the degree to which a family runs smoothly as a unit)	7.22
		poor family communication	7.23
		poor stability and less security in family	7.24
	<u>Intimate partner violence and/or poor parental relationship</u>	intimate partner violence	8.01
		poor relationship between parents or other family members	8.02
		parental conflict	8.03
		maternal dissatisfaction	8.04
		poor marital quality	8.05
<b><u>Child-related risk factor</u></b>	<u>Ethnicity or race</u>	ethnicity or race	9.01
		foreign-born parents	9.02
	<u>Health service use by child</u>		10.00
	<u>Age of child</u>		11.00
	<u>Child disability, illness, or development</u>	disability	12.01
		poor health and chronic or long term illness	12.02

Domain	Primary Sub-domain	Secondary Sub-domain	Reference number
		developmental delay	12.03
		prematurity or low birth weight	12.04
		difficult child temperament or behaviour	12.05
	<u>Child gender</u>		13.00
<b><u>Social or extra-familial risk factors</u></b>	<u>Social support</u>		14.00
	<u>Neighbourhood and community</u>	neighbourhood poverty, instability and economic disadvantage	15.00
	<u>Socio-economic status</u>	low SES	16.01
		benefits	16.02
		unemployment	16.03
		deprivation scores related to area	16.04

## Appendix 14.

**Table 5.** Risk factors for child maltreatment and how variables collected on the Building Blocks cohort may be used to measure them.

Reference number	Secondary Sub-domain	Source	Brief description of variable(s)	Selected	Justification
1.00	Caregiver who was a victim of abuse	6 - 24 month post birth interviews	Contact services – fostering services, leaving care services, social worker contact	No	Dataset is self-report and reliability could be an issue. These data would only provide very indirect and not specific indication of abuse.
1.00	Caregiver who was a victim of abuse	6 - 24 month post birth interviews	Mother fostered	No	Dataset is self-report and reliability could be an issue, participants may also contact these services for any number of reasons including but also excluding own past abuse. These data would only provide very indirect and not specific indication of abuse.
1.00	Caregiver who was a victim of abuse	Baseline interview	Time living away from parents – in care	No	Dataset is self-report and reliability could be an issue, participants may also contact these services for any number of reasons including or excluding own past abuse. These data would only provide very indirect and not specific indication of abuse.

Reference number	Secondary Sub-domain	Source	Brief description of variable(s)	Selected	Justification
1.00	Caregiver who was a victim of abuse	Routinely collected GP data	Mother under 18 record of abuse	Yes	
2.00	Caregiver mental health issues	Late pregnancy interview	Seeing counsellor	No	Participants could be seeing counsellor for any number of reasons including but also excluding mental health issues
2.00	Caregiver mental health issues	NHS Digital datasets - A&E	Diagnosis – mental health outcome	No	This dataset contains only participants admitted to A&E with mental health issues and so this measure was not thought to be sensitive enough and the sample would be tiny
2.00	Caregiver mental health issues	24 month post birth interview	2 questions on depression	Yes	
2.00	Caregiver mental health issues	6 month post birth interview	Edinburgh postnatal depression scale	Yes	
2.00	Caregiver mental health issues	Baseline – 24 month post birth interviews	EQ5D qu.5 (see justification for using item in appendix 17)	Yes	

Reference number	Secondary Sub-domain	Source	Brief description of variable(s)	Selected	Justification
2.00	Caregiver mental health issues	Baseline interview, 24 month post birth interview	Kessler psych distress scale	Yes	
2.00	Caregiver mental health issues	Routinely collected GP data	Reason for seeing GP coded as mental health	Yes	
3.00	Caregiver substance abuse	6 - 18 month post birth interviews	Smoke in house questions	No	Smoking not considered to be substance abuse.
3.00	Caregiver substance abuse	Baseline – 24 month post birth interviews	All smoking questions	No	Smoking not considered to be substance abuse.
3.00	Caregiver substance abuse	Routinely collected birth data	Participant drugs history	Yes	

Reference number	Secondary Sub-domain	Source	Brief description of variable(s)	Selected	Justification
3.00	Caregiver substance abuse	6 - 24 month post birth interviews	Contact services – drug and alcohol support	Yes	
3.00	Caregiver substance abuse	Baseline interview, 24 month post birth interview	CRAFTT	Yes	
4.00	Young parenthood	Baseline interview	Participant and baby father age	Yes	
5.01 – 5.02	Family composition - having more children in the family, having large families and crowded households	Baseline – 24 month post birth interviews	Home/Accommodation type	No	Using home/accommodation type was not thought to be a good reflection of family composition and size
5.01 – 5.02	Family composition - having more children in the family, having large families and crowded households	Baseline – 24 month post birth interviews	Alternate housing	No	Using alternate housing was not thought to be a good reflection of family composition and size

Reference number	Secondary Sub-domain	Source	Brief description of variable(s)	Selected	Justification
5.01 – 5.02	Family composition - having more children in the family, having large families and crowded households	Baseline – 24 month post birth interviews	Number of people living with participant	Yes	
5.01 – 5.02	Family composition - having more children in the family, having large families and crowded households	Baseline interview, 24 month post birth interview	Number of bedrooms	Yes	
5.01 – 5.02	Family composition - having more children in the family, having large families and crowded households	NHS Digital datasets - Inpatients	Birth records	No	Additional births cannot be calculated as in the dataset there is a 'date of admission' variable but as the dataset is pseudonymised there is no DOB therefore we do not know which admissions relate to childbirth
5.03 – 5.05	Family composition - single parent families, unmarried mothers, female headed households	Baseline interview	Live with father of baby	Yes	



Reference number	Secondary Sub-domain	Source	Brief description of variable(s)	Selected	Justification
5.03 – 5.05	Family composition - single parent families, unmarried mothers, female headed households	Baseline – 24 month post birth interviews	Relationship status	Yes	
5.06 – 5.07	Family composition - having children in close succession, shorter pregnancy interval	6 - 24 month post birth interviews	Pregnancy status	Yes	
5.06 – 5.07	Family composition - having children in close succession, shorter pregnancy interval	Abortions dataset	Number of pregnancies – abortions	No	This dataset will also not tell us about the number of <i>livebirths</i> just pregnancies that ended in abortion
5.06 – 5.07	Family composition - having children in close succession, shorter pregnancy interval	Routinely collected birth data	Number of previous pregnancies	No	Dataset will only tell about pregnancies previous to index child rather than second or third pregnancies
5.06 – 5.07	Family composition - having children in close succession, shorter pregnancy interval	NHS Digital datasets - Inpatients	Birth records	No	Births cannot be calculated as in the dataset there is a 'date of admission' variable but as the dataset is pseudonymised there is no DOB therefore we do not know which admissions relate to childbirth

Reference number	Secondary Sub-domain	Source	Brief description of variable(s)	Selected	Justification
5.08	Family composition - parental history of incarceration	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	
5.09	Family composition - presence of a stepparent	Baseline – 24 month post birth interviews	Relationship status with someone other than baby's father	Yes	
5.10	Family composition - parental death	Baseline interview	Mother and father alive	No	These variables related to Building Blocks Trial participant's (mother's) parent's own deaths, whereas the literature shows that a child is more likely to have a maltreatment event when their own parent dies.
5.11	Family composition - Early separation from mother	Baseline interview	Time living away from parents	No	This variable related to Building Blocks Trial participant's (mother's) early separation from her own parents, whereas the literature shows that a child is more likely to have a maltreatment event when separated from their mother.

Reference number	Secondary Sub-domain	Source	Brief description of variable(s)	Selected	Justification
5.11	Family composition - Early separation from mother	National Pupil Database dataset - CLA	Safeguarding been living away	Yes	
5.12	Family composition - A child being in the care system, having a previous child not living in the house	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	
6.01 – 6.02	Parent education level - low education level, low IQ and learning disabilities	Baseline – 24 month post birth interviews	NEET	No	Being out of education may not be a good reflection of low education level and low IQ
6.01 – 6.02	Parent education level - low education level, low IQ and learning disabilities	Baseline interview	Education & qualifications	Yes	
6.01 – 6.02	Parent education level - low education level, low IQ and learning disabilities	Baseline interview, 24 month post birth interview	Adaptive functioning – reading & maths skills	Yes	
7.01	Parenting and family functioning - using harsh or physical discipline	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	

Reference number	Secondary Sub-domain	Source	Brief description of variable(s)	Selected	Justification
7.02	Parenting and family functioning - less use of verbal reasoning	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	
7.03, 7.05	Parenting and family functioning - lack of experience or competence as a caregiver, less knowledge of child development	24 month post birth interview	Child safety – mother asked about child burns admissions	No	Child burns are not a good reflection of knowledge of child development or experience
7.03, 7.05	Parenting and family functioning - lack of experience or competence as a caregiver , less knowledge of child development	Late pregnancy - 24 month post birth interviews	Baby feeding	No	A participants choice of how to feed their baby is not a good reflection of knowledge of child development or experience
7.03, 7.05	Parenting and family functioning - lack of experience or competence as a caregiver , less knowledge of child development	12 - 24 month post birth interviews	Child safety	Yes	
7.03, 7.05	Parenting and family functioning - lack of experience or competence as a caregiver , less knowledge of child development	18 - 24 month post birth interviews	Baby diet – mother interviewed about baby diet	Yes	
7.03, 7.05	Parenting and family functioning - lack of experience or competence as a caregiver , less knowledge of child development	Late pregnancy interview	Anticipatory parenting	Yes	

Reference number	Secondary Sub-domain	Source	Brief description of variable(s)	Selected	Justification
7.03, 7.05	Parenting and family functioning - lack of experience or competence as a caregiver , less knowledge of child development	Maternal sensitivity data	Maternal intrusiveness	Yes	
7.04	Parenting and family functioning - providing less than adequate prenatal care	Routinely collected birth data	Planned & unplanned attendances	No	Number of planned and unplanned attendances are not a good measure of providing adequate prenatal care
7.04	Parenting and family functioning - providing less than adequate prenatal care	Late pregnancy interview	Number of times seen midwife, antenatal etc.	Yes	
7.04	Parenting and family functioning - providing less than adequate prenatal care	Routinely collected Birth data	Antenatal check-ups & admissions	Yes	
7.06 – 7.07	Parenting and family functioning - poor anger expression and management skills, poor frustration tolerance	6 - 24 month post birth interviews	Parental role strain qu.1 (see justification for using item in appendix 17)	Yes	
7.08	Parenting and family functioning - lack of impulse control	Baseline – 24 month post birth interviews	Contraception	No	Use of contraception may not be a good reflection of impulse control

Reference number	Secondary Sub-domain	Source	Brief description of variable(s)	Selected	Justification
7.09	Parenting and family functioning - tendency to attribute negative intent to a child's behaviour	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	
7.10	Parenting and family functioning - being critical of a child	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	
7.11	Parenting and family functioning - less empathy	Maternal sensitivity data	Maternal sensitivity	Yes	
7.12	Parenting and family functioning - less positive affection and warmth toward their children	Late pregnancy interview	Anticipatory parenting	Yes	
7.12	Parenting and family functioning - less positive affection and warmth toward their children	6 - 24 month post birth interviews	Parental role strain qu.2,3 (see justification for using item in appendix 17)	Yes	
7.12	Parenting and family functioning - less positive affection and warmth toward their children	Maternal sensitivity data	Maternal sensitivity	Yes	

Reference number	Secondary Sub-domain	Source	Brief description of variable(s)	Selected	Justification
7.13	Parenting and family functioning - Father related factors including fathers who felt they were ineffective as parents, a shorter duration of father involvement in child's life, a father having less involvement with household tasks, and low father warmth.	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	
7.14 – 7.15, 7.17	Parenting and family functioning - Parental stress, poor stress management, economic stress	Baseline interview, 24 month post birth interview	Adaptive functioning	Yes	
7.14 – 7.15, 7.17	Parenting and family functioning - Parental stress, poor stress management, economic stress	Baseline interview, 6 - 24 month post birth interviews	Generalised Self-efficacy scale	Yes	
7.16	Parenting and family functioning - negative perceptions of life events	Baseline interview, 6 - 24 month post birth interviews	Generalised Self-efficacy scale	Yes	

Reference number	Secondary Sub-domain	Source	Brief description of variable(s)	Selected	Justification
7.18 – 7.19, 7.21 – 7.22	Parenting and family functioning - parents of maltreated children perceived their own childhoods as being unhappy, poor relationships with their own parents, conflict in a family or a lack of family cohesion, Poor family functioning	6 - 24 month post birth interviews	Contacts with fostering services, leaving care services, social worker	Yes	
7.18 – 7.19, 7.21 – 7.22	Parenting and family functioning - parents of maltreated children perceived their own childhoods as being unhappy, poor relationships with their own parents, conflict in a family or a lack of family cohesion, Poor family functioning	6 - 24 month post birth interviews	Participant fostered	No	These data would only provide very indirect and not specific indication of abuse.
7.18 – 7.19, 7.21 – 7.22	Parenting and family functioning - parents of maltreated children perceived their own childhoods as being unhappy, poor relationships with their own parents, conflict in a family or a lack of family cohesion, Poor family functioning	Baseline interview	Time living away from parents	Yes	



Reference number	Secondary Sub-domain	Source	Brief description of variable(s)	Selected	Justification
7.18 – 7.19, 7.21 – 7.22	Parenting and family functioning - parents of maltreated children perceived their own childhoods as being unhappy, poor relationships with their own parents, conflict in a family or a lack of family cohesion, Poor family functioning	Baseline interview	Participant contact with mother and father	Yes	
7.18 – 7.19, 7.21 – 7.22	Parenting and family functioning - parents of maltreated children perceived their own childhoods as being unhappy, poor relationships with their own parents, conflict in a family or a lack of family cohesion, Poor family functioning	Baseline interview	Participants' parents separated	Yes	
7.18 – 7.19, 7.21 – 7.22	Parenting and family functioning - parents of maltreated children perceived their own childhoods as being unhappy, poor relationships with their own parents, conflict in a family or a lack of family cohesion, Poor family functioning	Baseline interview, 6 - 24 month post birth interviews	Homeless	Yes	

Reference number	Secondary Sub-domain	Source	Brief description of variable(s)	Selected	Justification
7.20	Parenting and family functioning - fathers who maltreated their children were more likely to have been in care themselves	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	
7.23	Parenting and family functioning - Poor family communication	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	
7.24	Parenting and family functioning - poor stability and less security in family	6 - 24 month post birth interviews	Not living with baby – reason not baby death	Yes	
7.24	Parenting and family functioning - poor stability and less security in family	6 - 24 month post birth interviews	Moved homes	Yes	
7.24	Parenting and family functioning - poor stability and less security in family	6 - 24 month post birth interviews	Participant fostered	Yes	
7.24	Parenting and family functioning - poor stability and less security in family	Baseline interview	Time living away from parents	Yes	

Reference number	Secondary Sub-domain	Source	Brief description of variable(s)	Selected	Justification
7.24	Parenting and family functioning - poor stability and less security in family	Baseline – 24 month post birth interviews	Relationship status changes	Yes	
7.24	Parenting and family functioning - poor stability and less security in family	Baseline interview, 24 month post birth interview	Adaptive functioning	Yes	
7.24	Parenting and family functioning - poor stability and less security in family	Baseline interview, 6 - 24 month post birth interviews	Homeless	Yes	
7.24	Parenting and family functioning - poor stability and less security in family	National Pupil Database dataset - CLA	Safeguarding – been away from parents	Yes	
8.01	Intimate partner violence - intimate partner violence	6 - 24 month post birth interviews	Used women's refuge	No	A woman could use refuge for reasons not relating to intimate partner violence e.g. could be there because of violence of own parents etc.

Reference number	Secondary Sub-domain	Source	Brief description of variable(s)	Selected	Justification
8.01	Intimate partner violence - intimate partner violence	Routinely collected birth data	Assault	No	This is admitted to maternity unit after assault, but this could have been for any reason not just intimate partner violence
8.01	Intimate partner violence - intimate partner violence	NHS Digital datasets - A&E	Assault mother	No	This is admitted to A&E after assault, but this could have been for any reason not just intimate partner violence
8.01	Intimate partner violence - intimate partner violence	24 month post birth interview	Composite abuse scale	Yes	
8.2 – 8.5	Intimate partner violence - poor relationship between parents or other family members , parental conflict, maternal dissatisfaction, poor marital quality	Baseline – 24 month post birth interviews	Relationship quality scale	Yes	
9.1 – 9.02	Ethnicity or race - ethnicity or race, Foreign-born parents	Baseline interview	Mother and father ethnicity	No	The ethnicity of participants' parents does not provide us with participants ethnicity and does also not tell us if they were born abroad. Child ethnicity was not recorded.

Reference number	Secondary Sub-domain	Source	Brief description of variable(s)	Selected	Justification
9.1 – 9.02	Ethnicity or race - ethnicity or race, Foreign-born parents	National Pupil Database dataset - CIN	CIN ethnicity	No	This will only provide information on those who has a CIN status and so this dataset is less completed than the Building Blocks Trial self-report one
9.1 – 9.02	Ethnicity or race - ethnicity or race, Foreign-born parents	Baseline interview	Mother born outside UK	Yes	
10.00	Health service use by child	Routinely collected GP data	Number of visits to GP	Yes	
10.00	Health service use by child	NHS Digital datasets - A&E	Number of visits to A&E	Yes	
10.00	Health service use by child	NHS Digital datasets - Inpatients	Number of visits to inpatients & duration	Yes	
10.00	Health service use by child	NHS Digital datasets - Outpatients	Number of visits to outpatients	Yes	

Reference number	Secondary Sub-domain	Source	Brief description of variable(s)	Selected	Justification
11.00	Age of child	Routinely collected Birth data	Child DOB	No	This variable is not going to be possible to analyse as most of the children in the dataset don't have a date at which they had a maltreatment event (as they had no event).
12.01	Child disability, illness, or development - Disability	Routinely collected Birth data	Congenital abnormalities	Yes	
12.02	Child disability, illness, or development - poor health and chronic or long term illness,	Routinely collected birth data	Poor health at birth variables	No	The measures used to indicate poor health at birth (e.g. Apgar score, time spent on neonatal unit) may not be a good reflection of disability or a long-term condition
12.03	Child disability, illness, or development - developmental delay	6 - 24 month post birth interviews	Contact with child development centre	Yes	
12.03	Child disability, illness, or development - developmental delay	12 - 24 month post birth interviews	Cognitive development	Yes	

Reference number	Secondary Sub-domain	Source	Brief description of variable(s)	Selected	Justification
12.03	Child disability, illness, or development - developmental delay	12 - 18 month post birth interviews	Language development	Yes	
12.03	Child disability, illness, or development - developmental delay	24 month post birth interview	Language development (Early language milestone scale)	Yes	
12.04	Child disability, illness, or development - prematurity or low birth weight	NHS Digital datasets - Inpatients	Birth weight	No	The Building Blocks Trial routinely collected birth dataset contains more complete data regarding birth weight than this dataset
12.04	Child disability, illness, or development - prematurity or low birth weight	Routinely collected Birth data	Birth weight	Yes	
12.05	Child disability, illness, or development - Difficult child temperament or behaviour	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	
13.00	Child gender	Routinely collected Birth data	Gender	Yes	

Reference number	Secondary Sub-domain	Source	Brief description of variable(s)	Selected	Justification
14.00	Social support	Baseline interview, 6 - 24 month post birth interviews	Social support and networks	Yes	
15.00, 16.04	Neighbourhood and community - neighbourhood poverty, instability and economic disadvantage	Baseline interview	Index of multiple deprivation based on postcode	Yes	
16.01	Socio-economic status - low SES	Baseline interview	Index of multiple deprivation based on postcode	Yes	
16.01	Socio-economic status - low SES	Baseline interview, 6 - 24 month post birth interviews	Family resources scale	Yes	
16.01	Socio-economic status - low SES	National Pupil Database dataset - Census	Free school meals	Yes	



Reference number	Secondary Sub-domain	Source	Brief description of variable(s)	Selected	Justification
16.02	Socio-economic status – benefits	Baseline interview, 24 month post birth interview	Benefits variables, receive regular payments variables	Yes	
16.03	Socio-economic status - unemployment	Baseline interview, 6 - 24 month post birth interviews	Unemployed	Yes	

## Appendix 15.

**Table 6.** Markers for child maltreatment from the literature search

Domain	Primary Sub-domain	Secondary Sub-domain	Reference number
<b><u>Physical signs of abuse and injuries</u></b>	Head injuries		1.01
	Fractures		1.02
	Thermal injuries (burns, scalds)		1.03
	Bites and Bruises		1.04
	Lacerations abrasions and scars		1.05
	Ano-Genital signs symptoms or injuries		1.06
	Other physical injuries		1.07
<b><u>Clinical presentations other than injuries</u></b>		seemingly fabricated or induced illness	2.01
		inappropriately explained poor school attendance	2.02
		signs of neglect such as dental decay or poor oral health	2.03
		Poisoning	2.04
		evidence of submersion	2.05

Domain	Primary Sub-domain	Secondary Sub-domain	Reference number
		gastrointestinal complaints	2.06
		persistent infestations	2.07
		child's clothing or footwear is consistently inappropriate	2.08
		child is persistently smelly and dirty	2.09
		malnourished including 'failure to thrive'	2.10
		failure to attend essential follow-up appointments	2.11
		failure to engage with immunisation health and development reviews and screening	2.12
<b><u>Emotional, behavioural, interpersonal and social Functioning</u></b>		recurrent nightmares	3.01
		extreme distress	3.02
		oppositional behaviour	3.03
		becoming withdrawn or withdrawing communication	3.04
		being fearful or aggressive	3.05
		having low self-esteem	3.06
		habitual body rocking	3.07

Domain	Primary Sub-domain	Secondary Sub-domain	Reference number
		indiscriminate contact or affection seeking	3.08
		over-friendliness to strangers	3.09
		excessive clinginess	3.10
		persistently resorting to gaining attention	3.11
		demonstrating excessively 'good' behaviour to prevent parental or carer disapproval	3.12
		failing to seek or accept comfort when significantly distressed	3.12
		coercive controlling behaviour	3.14
		very young children showing excessive comforting behaviours when witnessing parental or carer distress	3.15
		emotional responses not in proportion to a situation or developmental stage	3.16
		response to a health examination or assessment in an unusual way	3.17
		self-harm	3.18

Domain	Primary Sub-domain	Secondary Sub-domain	Reference number
		disturbances in eating and feeding behaviour	3.19
		secondary or deliberately wetting	3.20
		encopresis or smearing of faeces	3.21
		running away from home or care	3.22
		sexualised	3.23
<b><u>parent or carer–child interactions</u></b>		carer showing negativity or hostility	4.01
		rejecting or scapegoating	4.02
		developmentally inappropriate expectations	4.03
		exposure to frightening or traumatic experiences e.g. domestic violence	4.04
		using the child for the fulfilment of the adult's needs such as in marital disputes	4.05
		failure to promote the child's appropriate socialisation	4.06
		punishing a child for involuntarily wetting	4.07
		being emotionally unavailable or unresponsive	4.08

Domain	Primary Sub-domain	Secondary Sub-domain	Reference number
		refusing to allow a child or young person to speak to a healthcare professional on their own	4.09

## Appendix 16.

**Table 7.** Markers for child maltreatment and how variables collected on the Building Blocks cohort may be used to measure them.

Reference number	Secondary Sub-domain	Source	Brief description of variable(s)	Selected	Justification
1.01	Physical signs of abuse and injuries - Head injuries	NHS Digital datasets - A&E	Variables related to head injury	Yes	
1.02	Physical signs of abuse and injuries – Fractures	NHS Digital datasets - A&E	Variables related to fractures	Yes	
1.03	Physical signs of abuse and injuries - Thermal injuries (burns, scalds)	24 month post birth interview	Child safety – burns	Yes	
1.03	Physical signs of abuse and injuries - Thermal injuries (burns, scalds)	NHS Digital datasets - A&E	Variables related to burns	Yes	
1.04	Physical signs of abuse and injuries - Bites and Bruises	NHS Digital datasets - A&E	Variables related to bites and bruises	Yes	
1.05	Physical signs of abuse and injuries - Lacerations abrasions and scars	NHS Digital datasets - A&E	Variables related to lacerations and scars	Yes	
1.06	Physical signs of abuse and injuries - Ano-Genital signs symptoms or injuries	NHS Digital datasets - A&E	Variables related to ano-genital signs	Yes	

Reference number	Secondary Sub-domain	Source	Brief description of variable(s)	Selected	Justification
1.07	Physical signs of abuse and injuries - Other physical injuries	6 - 18 month post birth interviews	A&E baby injuries or ingestions	No	Dataset is less complete than comparable one from NHS Digital dataset (inpatients and A&E), dataset is self-report and so could be argued to be less reliable than the data collected in NHS Digital datasets
1.07	Physical signs of abuse and injuries - Other physical injuries	6 - 18 month post birth interviews	Outpatients baby injuries or ingestions	No	Dataset is less complete than comparable one from NHS Digital dataset (inpatients and A&E), dataset is self-report and so could be argued to be less reliable than the data collected in NHS Digital datasets
1.07	Physical signs of abuse and injuries - Other physical injuries	6 - 18 month post birth interviews	Other health care injuries or ingestions	No	Dataset is less complete than comparable one from NHS Digital dataset (inpatients and A&E), dataset is self-report and so could be argued to be less reliable than the data collected in NHS Digital datasets
1.07	Physical signs of abuse and injuries - Other physical injuries	6 - 18 month post birth interviews	GP visits	No	Dataset is less complete than comparable one from NHS Digital dataset (inpatients and A&E), dataset is self-report and so could be argued to be less reliable than the data collected in NHS Digital datasets



Reference number	Secondary Sub-domain	Source	Brief description of variable(s)	Selected	Justification
1.07	Physical signs of abuse and injuries - Other physical injuries	NHS Digital datasets - A&E	Any injuries or ingestions etc	Yes	
1.07	Physical signs of abuse and injuries - Other physical injuries	NHS Digital datasets - Inpatients	Any injuries or ingestions etc	Yes	
2.01	Clinical presentations other than injuries - seemingly fabricated or induced illness	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	
2.02	Clinical presentations other than injuries - inappropriately explained poor school attendance	National Pupil Database dataset - Census	School attendance	No	No children under attended in dataset
2.03	Clinical presentations other than injuries - signs of neglect such as dental decay or poor oral health	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	
2.04	Clinical presentations other than injuries – poisoning	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	
2.05	Clinical presentations other than injuries - evidence of submersion	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	

Reference number	Secondary Sub-domain	Source	Brief description of variable(s)	Selected	Justification
2.06	Clinical presentations other than injuries - gastrointestinal complaints	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	
2.07	Clinical presentations other than injuries - persistent infestations	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	
2.08	Clinical presentations other than injuries - child's clothing or footwear is consistently inappropriate	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	
2.09	Clinical presentations other than injuries - child is persistently smelly and dirty	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	
2.10	Clinical presentations other than injuries - malnourished including 'failure to thrive'	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	
2.11	Clinical presentations other than injuries - failure to attend essential follow-up appointments	Routinely collected GP data	Did Not Attend	Yes	
2.11	Clinical presentations other than injuries - failure to attend essential follow-up appointments	NHS Digital datasets - Outpatients	Did Not Attend	Yes	

Reference number	Secondary Sub-domain	Source	Brief description of variable(s)	Selected	Justification
2.12	Clinical presentations other than injuries - failure to engage with immunisation health and development reviews and screening	6 - 18 month post birth interviews	Baby jabs	Yes	
2.12	Clinical presentations other than injuries - failure to engage with immunisation health and development reviews and screening	Immunisations data	Immunisations	Yes	
3.01	Emotional, behavioural, interpersonal and social functioning - recurrent nightmares	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	
3.02	Emotional, behavioural, interpersonal and social functioning - extreme distress	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	
3.05	Emotional, behavioural, interpersonal and social functioning - being fearful or aggressive	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	
3.07	Emotional, behavioural, interpersonal and social functioning - habitual body rocking	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	

Reference number	Secondary Sub-domain	Source	Brief description of variable(s)	Selected	Justification
3.08	Emotional, behavioural, interpersonal and social functioning - indiscriminate contact or affection seeking	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	
3.09	Emotional, behavioural, interpersonal and social functioning - over-friendliness to strangers	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	
3.11	Emotional, behavioural, interpersonal and social functioning - persistently resorting to gaining attention	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	
3.12	Emotional, behavioural, interpersonal and social functioning - demonstrating excessively 'good' behaviour to prevent parental or carer disapproval	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	
3.13	Emotional, behavioural, interpersonal and social functioning - failing to seek or accept comfort when significantly distressed	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	

Reference number	Secondary Sub-domain	Source	Brief description of variable(s)	Selected	Justification
3.14	Emotional, behavioural, interpersonal and social functioning - coercive controlling behaviour	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	
3.15	Emotional, behavioural, interpersonal and social functioning - very young children showing excessive comforting behaviours when witnessing parental or carer distress	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	
3.17	Emotional, behavioural, interpersonal and social functioning - response to a health examination or assessment in an unusual way	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	
3.18	Emotional, behavioural, interpersonal and social functioning - self-harm	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	
3.19	Emotional, behavioural, interpersonal and social functioning - Disturbances in eating and feeding behaviour	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	

Reference number	Secondary Sub-domain	Source	Brief description of variable(s)	Selected	Justification
3.20	Emotional, behavioural, interpersonal and social functioning - secondary or deliberately wetting	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	
3.21	Emotional, behavioural, interpersonal and social functioning - encopresis or smearing of faeces	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	
3.22	Emotional, behavioural, interpersonal and social functioning - running away from home or care	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	
3.23	Emotional, behavioural, interpersonal and social functioning - sexualised behaviour	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	
4.01 – 4.02	Parent or carer-child interactions - carer showing negativity or hostility, rejecting or scapegoating	6 - 24 month post birth interviews	Parental role strain	Yes	
4.03	Parent or carer-child interactions - developmentally inappropriate expectations	Maternal sensitivity data	Maternal intrusiveness	Yes	

Reference number	Secondary Sub-domain	Source	Brief description of variable(s)	Selected	Justification
4.04	Parent or carer-child interactions - exposure to frightening or traumatic experiences e.g. domestic violence	Routinely collected birth data	Assault	No	This variable will reflect assaults on the mother and does not reflect well the parent-child interactions, this may have happened before child's birth
4.04	Parent or carer-child interactions - exposure to frightening or traumatic experiences e.g. domestic violence	24 month post birth interview	Composite abuse scale	Yes	
4.05	Parent or carer-child interactions - using the child for the fulfilment of the adult's needs such as in marital disputes	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	
4.06	Parent or carer-child interactions - failure to promote the child's appropriate socialisation	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	
4.07	Parent or carer-child interactions - punishing a child for involuntarily wetting	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	
4.08	Parent or carer-child interactions - being emotionally unavailable or unresponsive	Maternal sensitivity data	Maternal sensitivity	Yes	

Reference number	Secondary Sub-domain	Source	Brief description of variable(s)	Selected	Justification
4.09	Parent or carer-child interactions - refusing to allow a child or young person to speak to a healthcare professional on their own	<i>n/a</i>	<i>none suitable</i>	<i>n/a</i>	



## **Appendix 17.** Justifications for using some items only from scales as risk factor variables

### **Domain: 2. Caregiver mental health issues**

One of the items selected to reflect this domain was taken from the European Quality of Life - 5 Dimensions (EQ5D) questionnaire. The EQ5D (1) is a five item questionnaire which is used to measure general health status.

One of the five items measures anxiety or depression and is highlighted in BOLD below, this was the item selected to reflect this domain:

#### *Mobility*

- [1] I have no problems in walking about*
- [2] I have some problems in walking about*
- [3] I am confined to bed*

#### *Self-Care*

- [1] I have no problems with self-care*
- [2] I have some problems washing or dressing myself*
- [3] I am unable to wash or dress myself*

#### *Usual Activities (e.g. work, study, housework, family or leisure activities)*

- [1] I have no problems with performing my usual activities*
- [2] I have some problems with performing my usual activities*
- [3] I am unable to perform my usual activities*

#### *Pain/Discomfort*

- [1] I have no pain or discomfort*
- [2] I have moderate pain or discomfort*
- [3] I have extreme pain or discomfort*

#### **Anxiety/Depression**

- [1] I am not anxious or depressed**
- [2] I am moderately anxious or depressed**
- [3] I am extremely anxious or depressed**

This item was selected as it was thought to best reflect the domain, the others items in the EQ5D poorly reflect caregiver mental health issues.

**Domain: 7.06 – 7.07. Parenting and family functioning - poor anger expression and management skills, poor frustration tolerance**

The items selected to reflect this domain were taken from the Parental Role Strain questionnaire. The Parental Role Strain questionnaire is a 19 item questionnaire (2), however, the Building Blocks Trial used a shorter 6 item version used in the Millennium Cohort Study (3).

The items selected to reflect the domain 'Parenting and family functioning - poor anger expression and management skills, poor frustration tolerance' are highlighted in BOLD below:

**First, when you are caring for your baby(ies), do you get feelings of annoyance or irritation?**

- [1] almost all the time**
- [2] very frequently**
- [3] frequently**
- [4] occasionally**
- [5] very rarely**
- [6] or never**

*When you are not with your baby(ies), do you find yourself thinking about him/her?*

- [1] almost all the time*
- [2] very frequently*
- [3] frequently*
- [4] occasionally*
- [5] very rarely*
- [6] or never*

*When you have to leave your baby(ies)...*

- [1] do you always feel rather sad?*
- [2] often feel rather sad?*
- [3] have mixed feelings of both sadness and relief?*
- [4] often feel rather relieved?*

*[5] always feel rather relieved?*

*When you are caring for your baby(ies), do you feel...*

*[1] very incompetent and lacking in confidence?*

*[2] fairly incompetent and lacking in confidence?*

*[3] fairly competent and confident?*

*[4] very competent and confident?*

*Usually when you are with your baby(ies)...*

*[1] are you very impatient?*

*[2] a bit impatient?*

*[3] fairly patient?*

*[4] extremely patient?*

*Regarding the things that you have had to give up because of your baby(ies)...*

*[1] do you find that you resent it quite a lot?*

*[2] find that you resent it a fair amount?*

*[3] find that you resent it a bit?*

*[4] you don't resent it at all?*

In the paper describing the original 19 item scale items were grouped into 'constellations', the first item was from the 'Tolerance' constellation. The tolerance constellation is described as whether a mother has feelings of anger and hostility towards the baby. This item seems to fit quite well with the domain as the concept of anger management is explored. The other five items in the scale (italicised) were not thought to reflect this domain as well as the chosen one. Therefore, only the first item in this scale was used for this domain.

**Domain: 7.12. Parenting and family functioning - less positive affection and warmth toward their children**

The items selected to reflect this domain were taken from the Parental Role Strain questionnaire. The Parental Role Strain questionnaire is a 19 item questionnaire (Condon & Corkindale, 1998), however, the Building Blocks Trial used a shorter 6 item version used in the Millennium Cohort Study (National Centre for Social Research, 2003).

The items selected to reflect the domain 'Parenting and family functioning - less positive affection and warmth toward their children' are highlighted in BOLD below.

*First, when you are caring for your baby(ies), do you get feelings of annoyance or irritation?*

*[1] almost all the time*

*[2] very frequently*

*[3] frequently*

*[4] occasionally*

*[5] very rarely*

*[6] or never*

**When you are not with your baby(ies), do you find yourself thinking about him/her?**

**[1] almost all the time**

**[2] very frequently**

**[3] frequently**

**[4] occasionally**

**[5] very rarely**

**[6] or never**

**When you have to leave your baby(ies)...**

**[1] do you always feel rather sad?**

**[2] often feel rather sad?**

**[3] have mixed feelings of both sadness and relief?**

**[4] often feel rather relieved?**

**[5] always feel rather relieved?**

*When you are caring for your baby(ies), do you feel...*

*[1] very incompetent and lacking in confidence?*

*[2] fairly incompetent and lacking in confidence?*

*[3] fairly competent and confident?*

*[4] very competent and confident?*

*Usually when you are with your baby(ies)...*

*[1] are you very impatient?*

*[2] a bit impatient?*

*[3] fairly patient?*

*[4] extremely patient?*

*Regarding the things that you have had to give up because of your baby(ies)...*

*[1] do you find that you resent it quite a lot?*

*[2] find that you resent it a fair amount?*

*[3] find that you resent it a bit?*

*[4] you don't resent it at all?*

In the paper describing the original 19 item scale items were grouped into 'constellations', both these items were from the same constellation, the 'pleasure in proximity' constellation. This is described as representing the amount of desire for proximity, enjoyment of interaction, and affection and pride during times with the baby. This description seemed to fit fairly well with the domain concept of positive affection and warmth towards the baby. The other four items in the scale (italicised) were not thought to reflect this domain as well as the chosen two items. Therefore, only the two above items in this scale was used for this domain.

## **References**

1. The EuroQol Group (1990). EuroQol-a new facility for the measurement of health-related quality of life. *Health Policy* 16, 3, 199-208.
2. Condon, J.T. & Corkindale, C.J. (1998). The assessment of parent-to-infant attachment: Development of a self-report questionnaire instrument. *Journal of Reproductive and Infant Psychology*, 16, 57-76.
3. National Centre for Social Research. Millennium Cohort Study First Survey: CAPI Questionnaire Documentation. London: Institute of Education, University of London, 2003.

## Appendix 18.

**Table 8.** Date variables in each dataset used to indicate when risk factors were collected.

<b>Trial/Study in which dataset was collected</b>	<b>Dataset name</b>	<b>Date used to indicate when the <i>risk factor</i> was collected</b>	<b>Notes</b>
Building Blocks Trial	Baseline interview dataset	Interview conducted date	
	Late pregnancy interview (34-36 weeks gestation) dataset	Interview conducted date	
	Routinely collected birth dataset – baby dataset	Baby date of birth	Month and year of birth only used as this variable was anonymised before the dataset was sent to SAIL
	Routinely collected birth dataset – mothers dataset	Baby date of birth	Month and year of birth only used as this variable was anonymised before the dataset was sent to SAIL
	6 month post birth interview dataset	Interview conducted date	
	12 month post birth interview dataset	Interview conducted date	
	18 month post birth interview dataset	Interview conducted date	
	24 month post birth interview dataset	Interview conducted date	

<b>Trial/Study in which dataset was collected</b>	<b>Dataset name</b>	<b>Date used to indicate when the <i>risk factor</i> was collected</b>	<b>Notes</b>
	Maternal sensitivity dataset (collected at the 24 month post birth interview)	24 month interview conducted date	Dataset was collected at the same time as part of the 24 month interview
	Routinely collected GP dataset	24 month interview conducted date	Date of GP visit was not collected, therefore the 24 month interview conducted date was chosen as it marked the end of the Building Blocks Trial, i.e. any GP related data could have occurred as late as the 24 month interview.
	Immunisation dataset	Baby date of birth plus 14 months	All babies should have received the scheduled immunisation collected in this dataset by 12 months, a grace period of two months was added to allow any late to be immunised to be included
Building Blocks: 2-6 Study	NPD data - CIN dataset	First referral date to Social Services that lead to a CIN status	No CIN date available in dataset
	NPD data – CLA dataset	Date of first period of care	Period of care (yes/no) is the only risk factor variable of interest in this dataset
	NPD data - Census dataset	Census date	

Trial/Study in which dataset was collected	Dataset name	Date used to indicate when the <i>risk factor</i> was collected	Notes
	NHS Digital data – A&E dataset	Arrival at A&E date	
	NHS Digital data – Inpatients dataset	Inpatients admissions date	
	NHS Digital data – Outpatients dataset	Outpatients appointment date	



## Appendix 19.

**Table 9.** Queried variables and justification of change

Variable Number	Secondary Sub-domain	Data source	Brief description of variable(s)	Justification of inclusion after second review
3.00	Caregiver substance abuse	Routinely collected birth data	Participant drugs history	<p><u>Original decision (by researcher):</u> Do not include.</p> <p><u>Changes made (in light of reviewer comments):</u> Could be seen as an event that is sufficiently serious to appear in routine records. Do include.</p>
7.18 – 7.19, 7.21 – 7.22	Parenting and family functioning - parents of maltreated children perceived their own childhoods as being unhappy, poor relationships with their own parents, conflict in a	6 - 24 month post birth interviews	Contacts with fostering services, leaving care services, social worker	<p><u>Original decision:</u> Do not include.</p> <p><u>Changes made:</u> Include, because the variable 'participant fostered' was included and so there was no</p>

Variable Number	Secondary Sub-domain	Data source	Brief description of variable(s)	Justification of inclusion after second review
	family or a lack of family cohesion, Poor family functioning			real justification of including 'participant fostered' and not their contact with fostering services. If the participant (mother) had contact with fostering services in childhood it is reasonable to assume that this is likely to have made their childhood more unhappy.
12.03	Child disability, illness, or development - developmental delay	6 - 24 month post birth interviews	Contact with child development centre	<p><u>Original decision:</u> Do not include.</p> <p><u>Changes made:</u> Include, this variable could conceivably be indicative of developmental delay.</p>
All	All	All	All	<p><u>Changes to the structure of the tables 5 and 7.</u></p> <p><u>Changes made:</u></p>

<b>Variable Number</b>	<b>Secondary Sub-domain</b>	<b>Data source</b>	<b>Brief description of variable(s)</b>	<b>Justification of inclusion after second review</b>
				Reviewer advised including a series of 'rules' in order to avoid long justifications being included in these tables.

## Appendix 20.

**Table 10.** Risk factors of participants with and without a child with a CIN status.

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
<b>Risk Factors for Child Maltreatment Domain</b>						
<b>Caregiver was a victim of abuse</b>						
Mother abuse in records (GP data)						$\chi^2(1)=0.37$ , p=0.541
Yes	0	(0.0)	6	(0.4)	0.4	
No	6	(23.0)	369	(24.4)	24.4	
Missing	20	(77.0)	1136	(75.2)	75.2	
<b>Caregiver mental health issues</b>						
Depressed or anxious (24 month)						$\chi^2(1)=0.24$ , p=0.625
Yes	3	(11.5)	258	(17.1)	17.0	
No	10	(38.5)	623	(41.2)	41.2	
Missing	13	(50.0)	630	(41.7)	41.8	
Bothered by being anxious & little interest in doing things (24 month)						$\chi^2(1)=0.55$ , p=0.459
Yes	4	(15.4)	195	(12.9)	12.9	

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi-squared or t-test statistic, p-value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
No	9	(34.6)	685	(45.3)	45.2	
Missing	13	(50.0)	631	(41.8)	41.8	
Maternal anxiety (6 month) (range 0=low - 30=high)	11	8.0 (3.0 to 13.0) 9.18 (6.49)	827	6.0 (3.0 to 10.0) 6.75 (5.24)	6.0 (3.0 to 10.0) 6.78 (5.26)	t(836.00)= -1.53, p=0.243
EQ5D (baseline)						$\chi^2(2)=0.53$ , p=0.767
Not anxious or depressed	20	(76.9)	1201	(79.5)	79.4	
Moderately anxious or depressed	5	(19.2)	269	(17.8)	17.8	
Extremely anxious or depressed	1	(3.9)	29	(1.9)	2.0	
Missing	0	(0.0)	12	(0.8)	0.8	
EQ5D (late pregnancy)						$\chi^2(2)=3.36$ , p=0.186
Not anxious or depressed	19	(73.0)	986	(65.2)	65.4	
Moderately anxious or depressed	1	(3.8)	131	(8.7)	8.6	
Extremely anxious or depressed	1	(3.8)	12	(0.8)	0.8	
Missing	5	(19.2)	382	(25.3)	25.2	
EQ5D (6 month)						$\chi^2(2)=5.66$ , p=0.059
Not anxious or depressed	8	(30.8)	723	(47.8)	47.6	
Moderately anxious or depressed	2	(7.7)	118	(7.8)	7.8	

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Extremely anxious or depressed	1	(3.8)	10	(0.7)	0.7	
Missing	15	(57.7)	660	(43.7)	43.9	
EQ5D (12 month)						$\chi^2(3)=3.72$ , p=0.293
Not anxious or depressed	7	(27.0)	747	(49.5)	49.0	
Moderately anxious or depressed	1	(3.8)	103	(6.8)	6.8	
Extremely anxious or depressed	1	(3.8)	17	(1.1)	1.2	
Missing	17	(65.4)	644	(42.6)	43.0	
EQ5D (18 month)						$\chi^2(2)=50.60$ , p=0.000
Not anxious or depressed	6	(23.1)	717	(47.5)	47.0	
Moderately anxious or depressed	3	(11.5)	85	(5.6)	5.7	
Extremely anxious or depressed	3	(11.5)	9	(0.6)	0.8	
Missing	14	(53.9)	700	(46.3)	46.5	
EQ5D (24 month)						$\chi^2(2)=9.79$ , p=0.007
Not anxious or depressed	9	(34.6)	724	(47.9)	47.7	
Moderately anxious or depressed	2	(7.7)	137	(9.1)	9.0	
Extremely anxious or depressed	2	(7.7)	19	(1.3)	1.4	
Missing	13	(50.0)	631	(41.7)	41.9	

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Mental health score (baseline) (range 10=low level of distress – 50=high level of distress)	26	20.5 (15.8 to 27.3) 22.12 (8.58)	1494	20.0 (16.0 to 26.0) 21.47 (6.59)	20.0 (16.0 to 26.0) 21.48 (6.62)	t(25.52)=-3.84, p=0.704
Mental health score (24 month) (range 10=low level of distress – 50=high level of distress)	13	16.0 (12.0 to 24.5) 18.67 (7.87)	882	14.0 (12.0 to 20.0) 16.77 (7.17)	14.0 (12.0 to 20.0) 16.80 (7.18)	t(12.30)=-0.86, p=0.405
GP consultation mental health (GP data) (number)	6	1.0 (0.0 to 4.5)	560	0.0 (0.0 to 2.0)	0.0 (0.0 to 2.0)	t(5.03)=-0.70, p=0.515
<b>Caregiver substance abuse</b>						
Contact with alcohol & drug support (birth)						$\chi^2(1)=0.93$ , p=0.336
Yes	2	(7.7)	55	(3.6)	3.7	
No	22	(84.6)	1229	(81.3)	81.4	
Missing	2	(7.7)	227	(15.1)	14.9	
Contact with alcohol & drug support (6 month)						$\chi^2(1)=0.04$ , p=0.840
Yes	0	(0.0)	3	(0.2)	0.2	
No	11	(42.3)	812	(53.7)	53.5	
Missing	15	(57.7)	696	(46.1)	46.3	
Contact with alcohol & drug support (12 month)						$\chi^2(2)=0.03$ , p=0.984

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Yes	0	(0.0)	2	(0.1)	0.1	
No	9	(34.6)	857	(56.7)	56.4	
Missing	17	(65.4)	652	(43.2)	43.5	
Contact with alcohol & drug support (18 month)						$\chi^2(2)=0.04$ , p=0.980
Yes	0	(0.0)	2	(0.1)	0.1	
No	11	(42.3)	804	(53.2)	53.0	
Missing	15	(57.7)	705	(46.7)	46.9	
Contact with alcohol & drug support (24 month)						$\chi^2(1)=0.06$ , p=0.808
Yes	0	(0.0)	4	(0.3)	0.3	
No	13	(50.0)	877	(58.0)	57.9	
Missing	13	(50.0)	630	(41.7)	41.8	
CRAFFT substance abuse scale (baseline) (range 0= less problems dugs/alcohol – 6=more problems drugs/alcohol)	25	1.0 (0.0 to 2.5) 1.48 (1.58)	1429	1.0 (0.0 to 2.0) 1.33 (1.53)	1.0 (0.0 to 2.0) 1.33 (1.53)	t(24.79)=-0.48, p=0.637
CRAFFT substance abuse scale (24 month) (range 0= less problems dugs/alcohol – 6=more problems drugs/alcohol)	13	12.0 (10.0 to 12.0) 11.15 (1.41)	880	12.0 (12.0 to 12.0) 11.66 (0.79)	12.0 (12.0 to 12.0) 11.66 (0.80)	t(12.11)=-1.31, p=0.215
<b>Young parenthood</b>						



	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Mother age (baseline)	26	17.0 (16.0 to 18.0) 17.04 (1.40)	1502	17.0 (16.0 to 18.0) 17.36 (1.26)	17.0 (16.0 to 18.0) 17.35 (1.26)	t(25.71)=1.15, p=0.262
Father age (baseline)	19	19.0 (18.0 to 21.0) 20.16 (3.66)	1222	20.0 (18.0 to 22.0) 20.35 (3.60)	20.0 (18.0 to 22.0) 20.35 (3.60)	t(18.55)=0.23, p=0.823
<b>Family composition: having more children in the family, having large families and crowded households</b>						
Number living with mother (adults and children) (baseline)	25	1.0 (0.5 to 1.0) 0.84 (0.55)	1479	1.0 (1.0 to 1.0) 1.06 (0.44)	1.0 (1.0 to 1.0) 1.06 (0.44)	t(24.51)=1.97, p=0.057
Number living with mother (adults and children) (6 month)	11	1.0 (0.0 to 2.0) 1.27 (1.10)	852	1.0 (0.0 to 2.0) 1.52 (1.62)	1.0 (0.0 to 2.0) 1.51 (1.62)	t(10.57)=7.19, p=0.488
Number living with mother (adults and children) (12 month)	9	1.0 (0.0 to 2.0) 1.78 (1.48)	863	1.0 (1.0 to 2.5) 1.24 (1.48)	1.0 (0.0 to 2.0) 1.24 (1.48)	t(8.17)=-1.09, p=0.308
Number living with mother (adults and children) (18 month)	12	1.0 (0.0 to 2.0) 1.08 (1.00)	810	1.0 (0.0 to 1.0) 1.02 (1.27)	1.0 (0.0 to 1.0) 1.02 (1.27)	t(11.54)=-0.21, p=0.834

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi-squared or t-test statistic, p-value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Number living with mother (adults and children) (24 month)	13	1.0 (0.0 to 1.5) 0.92 (0.95)	879	1.0 (0.0 to 1.0) 1.03 (1.33)	1.0 (0.0 to 1.0) 1.03 (1.33)	t(12.70)=0.40, p=0.695
Number of bedrooms (baseline)	24	3.0 (2.0 to 3.0) 2.71 (0.86)	1441	3.0 (2.0 to 3.0) 2.92 (2.12)	3.0 (2.0 to 3.0) 2.92 (2.10)	t(27.88)=1.16, p=0.255
Number of bedrooms (24 month)	8	2.0 (2.0 to 3.0) 2.38 (0.52)	425	2.0 (2.0 to 3.0) 2.40 (0.79)	2.0 (2.0 to 3.0) 2.40 (0.79)	t(7.63)=0.16, p=0.878
<b>Family composition: single parent families, unmarried mothers, female headed households</b>						
Mother live with father (baseline)						X <sup>2</sup> (1)=2.12, p=0.146
Yes	17	(65.4)	346	(22.9)	23.6	
No	2	(7.7)	1035	(68.5)	67.5	
Missing	7	(26.9)	130	(8.6)	8.9	
Mother relationship status (baseline)						X <sup>2</sup> (3)=5.21, p=0.157
Married	0	(0.0)	16	(1.1)	1.0	
Separated	1	(3.9)	149	(9.9)	9.8	
Closely involved/boyfriend	18	(69.2)	194	(12.8)	13.8	

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Just friends	7	(26.9)	1066	(70.5)	69.8	
Missing	0	(0.0)	86	(5.7)	5.6	
Mother relationship status if changed since baseline (late pregnancy)						$\chi^2(4)=4.12$ , p=0.381
Married	0	(0.0)	2	(0.1)	0.1	
Separated	0	(0.0)	9	(0.6)	0.6	
Closely involved/boyfriend	0	(0.0)	62	(4.1)	4.0	
Just friends	0	(0.0)	45	(3.0)	3.0	
Not in any relationship	2	(7.7)	55	(3.6)	3.7	
Missing	24	(92.3)	1338	(88.6)	88.6	
Mother relationship status if changed since last interview (6 month)						$\chi^2(4)=0.99$ , p=0.911
Married	0	(0.0)	19	(1.3)	1.2	
Separated	0	(0.0)	25	(1.7)	1.6	
Closely involved/boyfriend	7	(26.9)	476	(31.5)	31.4	
Just friends	1	(3.8)	128	(8.5)	8.4	
Not in any relationship	3	(11.6)	204	(13.4)	13.5	
Missing	15	(57.7)	659	(43.6)	43.9	
Mother relationship status if changed since last interview (12 month)						$\chi^2(5)=4.29$ , p=0.509
Married	0	(0.0)	21	(1.4)	1.4	

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Separated	0	(0.0)	12	(0.8)	0.8	
Closely involved/boyfriend	3	(34.6)	430	(28.5)	28.2	
Just friends	1	(3.8)	181	(11.9)	11.8	
Not in any relationship	5	(19.2)	223	(14.8)	14.8	
Missing	17	(65.4)	644	(42.6)	43.0	
Mother relationship status if changed since last interview (18 month)						$\chi^2(4)=2.14$ , p=0.710
Married	0	(0.0)	24	(1.6)	1.6	
Separated	0	(0.0)	10	(0.7)	0.7	
Closely involved/boyfriend	6	(23.1)	341	(22.6)	22.6	
Just friends	1	(3.8)	182	(12.0)	11.9	
Not in any relationship	5	(19.2)	254	(16.8)	16.8	
Missing	14	(53.9)	700	(46.3)	46.4	
Mother relationship status if changed since last interview (24 month)						$\chi^2(5)=1.15$ , p=0.950
Married	0	(0.0)	35	(2.3)	2.3	
Separated	1	(3.9)	41	(2.7)	2.7	
Divorced	0	(0.0)	2	(0.1)	0.1	
Closely involved/boyfriend	5	(19.2)	373	(24.7)	24.6	
Just friends	2	(7.7)	159	(10.5)	10.5	
Not in any relationship	5	(19.2)	270	(17.9)	17.9	

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi-squared or t-test statistic, p-value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Missing	13	(50.0)	631	(41.8)	41.9	
<b>Family composition: having children in close succession, shorter pregnancy interval</b>						
Pregnancy status (6 month)						$\chi^2(1)=3.46$ , p=0.063
Been pregnant since birth	2	(7.7)	45	(3.0)	3.1	
Not been pregnant since birth	9	(34.6)	800	(52.9)	52.6	
Missing	15	(57.7)	666	(44.1)	44.3	
Pregnancy status (12 month)						$\chi^2(3)=0.38$ , 0.944
Currently pregnant	2	(7.7)	130	(8.6)	8.6	
Not been pregnant since birth	7	(26.9)	735	(48.6)	48.3	
Not sure	0	(0.0)	1	(0.1)	0.1	
Missing	17	(65.4)	645	(42.7)	43.0	
Pregnancy status (18 month)						$\chi^2(2)=262$ , p=0.269
Currently pregnant	5	(19.2)	179	(11.8)	12.0	
Not been pregnant since birth	7	(26.9)	631	(41.8)	41.5	
Not sure	0	(0.0)	1	(0.1)	0.1	
Missing	14	(53.9)	700	(46.3)	46.4	

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi-squared or t-test statistic, p-value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Pregnancy status (24 month)						$\chi^2(2)=3.10$ , p=0.213
Currently pregnant	6	(23.1)	220	(14.6)	14.7	
Not been pregnant since birth	7	(26.9)	657	(43.5)	43.2	
Not sure	0	(0.0)	5	(0.3)	0.3	
Missing	13	(50.0)	629	(41.6)	41.8	
<b>Family composition: presence of a stepparent</b>						
Relationship with someone other than baby's father (baseline)						$\chi^2(1)=1.59$ , p=0.207
Yes	2	(7.7)	50	(3.3)	3.4	
No	23	(88.5)	1436	(95.0)	94.9	
Missing	1	(3.8)	25	(1.7)	1.7	
Relationship status with someone other than baby's father status (baseline)						$\chi^2(1)=3.01$ , p=0.183
Married	0	(0.0)	0	(0.0)	0.0	
Separated	0	(0.0)	0	(0.0)	0.0	
Closely involved/boyfriend	1	(3.8)	45	(3.0)	3.0	
Just friends	1	(3.8)	5	(0.3)	0.4	
Missing	24	(92.2)	1491	(98.7)	98.6	

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi-squared or t-test statistic, p-value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Relationship with someone other than baby's father since baseline (late pregnancy)						$\chi^2(1)=0.14$ , p=0.711
Yes	0	(0.0)	11	(0.7)	0.7	
No	2	(7.7)	160	(10.6)	10.5	
Missing	24	(92.3)	1340	(88.7)	88.8	
Relationship status with someone other than baby's father since baseline status (late pregnancy)						n/a
Married	0	(0.0)	0	(0.0)	0.0	
Separated	0	(0.0)	0	(0.0)	0.0	
Closely involved/boyfriend	0	(0.0)	10	(0.6)	0.6	
Just friends	0	(0.0)	1	(0.1)	0.1	
Missing	26	(100.0)	1500	(99.3)	99.3	
Relationship with someone other than baby's father since last interview (6 month)						$\chi^2(1)=1.1$ , p=0.301
Yes	0	(0.0)	74	(4.9)	4.8	
No	11	(42.3)	759	(50.2)	50.1	
Missing	15	(57.7)	678	(44.9)	45.1	
Relationship status with someone other than baby's father since last interview status (6 month)						n/a
Married	0	(0.0)	0	(0.0)	0.0	

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Separated	0	(0.0)	0	(0.0)	0.0	
Closely involved/boyfriend	0	(0.0)	72	(4.8)	4.7	
Just friends	0	(0.0)	2	(0.1)	0.1	
Missing	26	(100.0)	1437	(95.1)	95.2	
Relationship with someone other than baby's father since last interview (12 month)						$\chi^2(2)=0.55$ , p=0.973
Yes	1	(3.8)	77	(5.1)	5.1	
No	8	(30.8)	770	(55.0)	50.6	
Missing	17	(65.4)	664	(43.9)	44.3	
Relationship status with someone other than baby's father since last interview status (12 month)						$\chi^2(3)=0.11$ , p=0.996
Married	0	(0.0)	1	(0.1)	0.1	
Separated	0	(0.0)	0	(0.0)	0.0	
Closely involved/boyfriend	1	(3.8)	68	(4.5)	4.5	
Just friends	0	(0.0)	2	(0.1)	0.1	
Missing	25	(96.2)	1440	(95.3)	95.3	
Relationship with someone other than baby's father since last interview (18 month)						$\chi^2(1)=0.24$ , p=0.626
Yes	2	(7.7)	94	(6.2)	6.3	
No	10	(38.5)	687	(45.5)	45.4	



	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Missing	14	(53.8)	729	(48.3)	48.3	
Relationship status with someone other than baby's father since last interview status (18 month)						$\chi^2(1)=1.17$ , p=0.712
Married	0	(0.0)	18	(1.2)	1.2	
Separated	0	(0.0)	138	(9.1)	9.0	
Closely involved/boyfriend	2	(7.7)	88	(5.8)	5.8	
Just friends	0	(0.0)	6	(0.4)	0.4	
Missing	24	(92.3)	1261	(83.5)	83.6	
Relationship with someone other than baby's father since last interview (24 month)						$\chi^2(1)=2.61$ , p=0.106
Yes	5	(19.2)	171	(11.3)	11.4	
No	8	(30.8)	674	(44.6)	44.4	
Missing	13	(50.0)	666	(44.1)	44.2	
Relationship status with someone other than baby's father since last interview status (24 month)						$\chi^2(2)=0.16$ , p0.952
Married	0	(0.0)	0	(0.0)	0.0	
Separated	0	(0.0)	1	(0.1)	0.1	
Closely involved/boyfriend	4	(15.4)	163	(10.8)	10.9	
Just friends	0	(0.0)	3	(0.2)	0.2	
Missing	22	(84.6)	1344	(88.9)	88.8	

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
<b>Family composition: Early separation from mother</b>						
Child had period of care (NPD)						$\chi^2(1)=0.09$ , p=0.762
Yes	0	(0.0)	6	(0.4)	0.4	
No	23	(88.5)	1501	(99.3)	99.1	
Missing	3	(11.5)	4	(0.3)	0.5	
<b>Parent education level - low education level, low IQ and learning disabilities</b>						
Problems with reading, writing, maths (baseline) (range 3=less problems – 9=more problems)	26	3.0 (3.0 to 4.0) 3.42 (0.90)	1500	3.0 (3.0 to 4.0) 3.42 (0.83)	3.0 (3.0 to 4.0) 3.42 (0.83)	t(25.73)=-0.04, p=0.966
Problems with reading, writing, maths (24 month) (range 3=less problems – 9=more problems)	13	3.0 (3.0 to 3.0) 3.46 (0.78)	881	3.0 (3.0 to 4.0) 3.18 (0.51)	3.0 (3.0 to 3.0) 3.18 (0.52)	t(12.15)=-1.31, p=0.214
<b>Parenting and family functioning: lack of experience or competence as a caregiver, less knowledge of child development</b>						
Child safety (12 month) (range 0=safest – 5=less safe)	9	3.0 (2.0 to 4.0) 3.00 (1.23)	709	3.0 (2.0 to 4.0) 2.79 (1.86)	3.0 (1.0 to 4.0) 2.79 (1.85)	t(8.47)=-0.50, p=0.607

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi-squared or t-test statistic, p-value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Child safety (18 month) (range 0=safest – 5=less safe)	11	4.0 (2.0 to 5.0) 2.91 (2.84)	794	3.0 (0.0 to 4.0) 1.65 (4.03)	3.0 (0.5 to 4.0) 1.67 (4.02)	t(17.52)=0.81, p=0.176
Child safety (24 month) (range 0=safest – 5=less safe)	13	3.0 (0.0 to 3.0) 0.69 (4.50)	863	2.0 (0.0 to 4.0) 0.13 (4.87)	2.0 (0.0 to 4.0) 0.14 (4.86)	t(12.43)=-0.44, p=0.665
Baby diet (18 month)						$\chi^2(1)=0.45$ , p=0.503
Had healthy food every day	7	(26.9)	580	(38.4)	38.2	
Did not have healthy food every day	4	(15.4)	281	(18.6)	18.5	
Missing	15	(57.7)	650	(43.0)	43.3	
Baby diet (24 month)						$\chi^2(1)=4.83$ , p=0.028
Had healthy food every day	5	(19.2)	580	(38.4)	38.1	
Did not have healthy food every day	8	(30.7)	281	(18.6)	18.8	
Missing	13	(50.0)	650	(43.0)	43.1	
Anticipatory parenting (late pregnancy) (range 5= structured child rearing practices – 25=less structured environment)	21	9.0 (7.5 to 11.0) 8.81 (4.46)	1123	9.0 (7.0 to 10.0) 5.37 (17.83)	9.0 (7.0 to 10.0) 5.44 (17.67)	t(105.47)= -4.88, p=0.000
Maternal intrusiveness (maternal sensitivity) (range 0=lower intrusiveness – 18=higher intrusiveness)	6	2.0 (1.5 to 2.0)	415	1.0 (0.0 to 3.0)	1.0 (0.0 to 3.0)	t(5.71)=-0.08, p=0.943

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi-squared or t-test statistic, p-value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
		1.67 (0.82)		1.64 (1.77)	1.64 (1.77)	
<b>Parenting and family functioning: providing less than adequate prenatal care</b>						
Times seen midwife (all contacts) (late pregnancy)	19	2.0 (3.0 to 8.0) 6.21 (3.63)	1059	6.0 (5.0 to 9.0) 7.07 (4.01)	6.0 (5.0 to 9.0) 7.06 (4.00)	t(18.80)=1.02, p=0.319
Times been to antenatal clinic (late pregnancy)	21	2.0 (0.0 to 4.0) 2.43 (6.06)	1121	2.0 (0.0 to 4.0) 2.54 (3.38)	2.0 (0.0 to 4.0) 2.54 (3.36)	t(21.44)=0.20, p=0.841
Times maternity clinic (late pregnancy)	21	1.0 (0.0 to 1.5) 0.90 (1.14)	1126	0.0 (0.0 to 1.0) 0.76 (1.55)	0.0 (0.0 to 1.0) 0.77 (1.55)	t(21.42)=-0.56, p=0.580
Number antenatal check-ups (birth)	23	12.0 (9.0 to 14.0) 11.83 (3.34)	1326	10.0 (8.0 to 12.0) 10.30 (3.77)	10.0 (8.0 to 12.0) 10.33 (3.77)	t(22.98)=-2.17, p=0.041
Number planned attendances (birth)	23	1.0 (0.0 to 3.0) 1.70 (1.66)	1326	0.5 (0.0 to 2.0) 1.54 (2.64)	1.0 (0.0 to 2.0) 1.54 (2.63)	t(23.96)=-0.44, p=0.666
Number unplanned attendances (birth)	23	1.0 (0.0 to 4.0) 2.52 (3.09)	1326	1.0 (0.0 to 2.0) 1.67 (1.96)	1.0 (0.0 to 3.0) 1.68 (1.98)	t(22.31)=-1.32, p=0.201

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
<b>Parenting and family functioning: poor anger expression and management skills, poor frustration tolerance</b>						
Annoyance at baby (6 month)						$\chi^2(4)=2.59$ , p=0.628
Almost all of the time	0	(0.0)	0	(0.0)	0.0	
Very frequently	0	(0.0)	5	(0.3)	0.3	
Frequently	0	(0.0)	14	(0.9)	0.9	
Occasionally	1	(3.8)	91	(6.0)	6.0	
Very rarely	6	(23.1)	264	(17.5)	17.6	
Never	4	(15.4)	444	(29.4)	29.1	
Missing	15	(57.7)	693	(45.9)	46.1	
Annoyance at baby (12 month)						$\chi^2(6)=32.13$ , p=0.000
Almost all of the time	0	(0.0)	3	(0.2)	0.2	
Very frequently	1	(3.8)	2	(0.1)	0.2	
Frequently	0	(0.0)	14	(0.9)	0.9	
Occasionally	2	(7.7)	113	(7.5)	7.5	
Very rarely	4	(15.4)	359	(23.8)	23.6	
Never	2	(7.7)	367	(24.3)	24.0	
Missing	17	(65.4)	653	(43.2)	43.6	

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Annoyance at baby (18 month)						$\chi^2(5)=1.69$ , p=0.891
Almost all of the time	0	(0.0)	1	(0.1)	0.1	
Very frequently	0	(0.0)	4	(0.3)	0.3	
Frequently	0	(0.0)	14	(0.9)	0.9	
Occasionally	3	(11.5)	115	(7.6)	7.7	
Very rarely	5	(19.2)	387	(25.6)	25.5	
Never	3	(11.5)	276	(18.2)	18.1	
Missing	15	(57.8)	714	(47.3)	47.4	
Annoyance at baby (24 month)						$\chi^2(4)=3.59$ , p=0.464
Almost all of the time	0	(0.0)	0	(0.0)	0.0	
Very frequently	0	(0.0)	4	(0.3)	0.3	
Frequently	0	(0.0)	13	(0.8)	0.8	
Occasionally	1	(3.9)	66	(4.4)	4.4	
Very rarely	5	(19.2)	204	(13.5)	13.6	
Never	2	(7.7)	336	(22.2)	22.0	
Missing	18	(69.2)	888	(58.8)	58.9	
<b>Parenting and family functioning: less empathy</b>						
Maternal sensitivity (maternal sensitivity) (range 0=less sensitive – 18=more sensitive)	6	10.5 (10.0 to 11.3)	415	12.0 (10.0 to 12.0)	12.0 (10.0 to 12.0)	t(5.62)=1.00, p=0.356

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
		10.67 (0.82)		11.01 (1.66)	11.01 (1.66)	
<b>Parenting and family functioning: less positive affection and warmth toward their children</b>						
Anticipatory parenting (late pregnancy), see domain 'Parenting and family functioning: lack of experience or competence as a caregiver, less knowledge of child development' for results						
Parental role strain: thinking about baby (6 month)						$\chi^2(4)=2.78$ , p=0.596
Almost all the time	11	(42.3)	648	(42.9)	42.9	
Very frequently	0	(0.0)	110	(7.3)	7.2	
Frequently	0	(0.0)	40	(2.6)	2.6	
Occasionally	0	(0.0)	13	(0.9)	0.8	
Very rarely	0	(0.0)	1	(0.1)	0.1	
Never	0	(0.0)	0	(0.0)	0.0	
Missing	15	(57.7)	699	(46.2)	46.4	
Parental role strain: when leaving baby (6 month)						$\chi^2(4)=0.29$ , p=0.990
Always feel sad	3	(11.5)	216	(14.3)	14.2	
Often feel sad	2	(7.7)	134	(8.9)	8.9	
Mixed feelings sadness and relief	6	(23.1)	433	(28.7)	28.6	
Often relieved	0	(0.0)	17	(1.1)	1.1	

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Always relieved	0	(0.0)	3	(0.2)	0.2	
Missing	15	(57.7)	708	(46.8)	47.0	
Parental role strain: thinking about baby (12 month)						$\chi^2(5)=0.40$ , p=0.995
Almost all the time	7	(26.9)	673	(44.5)	44.3	
Very frequently	1	(3.9)	93	(6.2)	6.1	
Frequently	1	(3.8)	67	(4.4)	4.4	
Occasionally	0	(0.0)	22	(1.5)	1.4	
Very rarely	0	(0.0)	3	(0.2)	0.2	
Never	0	(0.0)	0	(0.0)	0.0	
Missing	17	(65.4)	652	(43.2)	43.6	
Parental role strain: when leaving baby (12 month)						$\chi^2(5)=0.66$ , p=0.985
Always feel sad	2	(7.7)	205	(13.6)	13.5	
Often feel sad	1	(3.8)	148	(9.8)	9.7	
Mixed feelings sadness and relief	6	(23.1)	473	(31.3)	31.2	
Often relieved	0	(0.0)	19	(1.3)	1.2	
Always relieved	0	(0.0)	4	(0.3)	0.3	
Missing	17	(65.4)	661	(43.7)	44.1	
Parental role strain: thinking about baby (18 month)						$\chi^2(5)=2.05$ , p=0.842



	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi-squared or t-test statistic, p-value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Almost all the time	8	(30.8)	578	(38.2)	38.1	
Very frequently	1	(3.8)	125	(8.3)	8.2	
Frequently	2	(7.7)	64	(4.2)	4.3	
Occasionally	0	(0.0)	22	(1.5)	1.4	
Very rarely	0	(0.0)	5	(0.3)	0.3	
Never	0	(0.0)	1	(0.1)	0.1	
Missing	15	(57.7)	716	(47.4)	47.6	
Parental role strain: when leaving baby (18 month)						$\chi^2(4)=0.25$ , p=0.993
Always feel sad	3	(11.5)	198	(13.1)	13.1	
Often feel sad	2	(7.7)	146	(9.7)	9.6	
Mixed feelings sadness and relief	6	(23.1)	431	(28.5)	28.4	
Often relieved	0	(0.0)	13	(0.9)	0.9	
Always relieved	0	(0.0)	3	(0.2)	0.2	
Missing	15	(57.7)	720	(47.6)	47.8	
Parental role strain: thinking about baby (24 month)						$\chi^2(5)=2.98$ , p=0.703
Almost all the time	8	(30.8)	535	(35.4)	35.3	
Very frequently	3	(11.5)	158	(10.5)	10.5	
Frequently	0	(0.0)	94	(6.2)	6.1	
Occasionally	2	(7.7)	62	(4.1)	4.2	

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Very rarely	0	(0.0)	10	(0.7)	0.7	
Never	0	(0.0)	5	(0.3)	0.3	
Missing	13	(50)	647	(42.8)	42.9	
Parental role strain: when leaving baby (24 month)						$\chi^2(4)=2.66$ , p=0.616
Always feel sad	0	(0.0)	135	(8.9)	8.8	
Often feel sad	3	(11.5)	162	(10.7)	10.7	
Mixed feelings sadness and relief	8	(30.8)	506	(33.5)	33.4	
Often relieved	1	(3.9)	39	(2.6)	2.6	
Always relieved	0	(0.0)	6	(0.4)	0.4	
Missing	14	(53.8)	663	(43.9)	44.1	
Maternal sensitivity (maternal sensitivity), see domain 'Parenting and family functioning: less empathy' for result						
<b>Parenting and family functioning: Parental stress, poor stress management, economic stress</b>						
Adaptive functioning: difficulty basic skills (baseline)						$\chi^2(1)=0.17$ , p=0.897
Yes	7	(26.9)	387	(25.6)	25.6	
No	19	(73.1)	1113	(73.7)	73.6	
Missing	0	(0.0)	11	(0.7)	0.7	

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Adaptive functioning: difficulty life skills (baseline)						$\chi^2(1)=5.36$ , p=0.021
Yes	12	(46.2)	389	(25.8)	26.1	
No	14	(53.8)	1108	(73.3)	73.0	
Missing	0	(0.0)	14	(0.9)	0.9	
Adaptive functioning: burden (baseline)						$\chi^2(1)=0.02$ , p=0.895
Yes	7	(26.9)	441	(29.2)	29.1	
No	19	(73.1)	1050	(69.5)	69.6	
Missing	0	(0.0)	20	(1.3)	1.3	
Self-efficacy (baseline) (range 10=lower self-efficacy – 40=higher self-efficacy)	26	29.5 (25.5 to 33.0) 29.12 (4.74)	1479	30.0 (28.0 to 33.0) 30.05 (4.42)	30.0 (28.0 to 33.0) 30.03 (4.42)	t(25.77)=0.99, p=0.329
Self-efficacy (6 month) (range 10=lower self-efficacy – 40=higher self-efficacy)	11	31.0 (29.0 to 37.0) 32.00 (6.10)	837	33.0 (30.0 to 37.0) 33.25 (4.14)	33.0 (30.0 to 37.0) 33.23 (4.17)	t(10.12)=0.68, p=0.514
Self-efficacy (12 month) (range 10=lower self-efficacy – 40=higher self-efficacy)	9	33.0 (27.5 to 39.0) 33.00 (6.40)	865	33.0 (30.0 to 37.0) 33.64 (4.42)	33.0 (30.0 to 37.0) 33.63 (4.44)	t(8.08)=0.30, p=0.774
Self-efficacy (18 month) (range 10=lower self-efficacy – 40=higher self-efficacy)	11	32.0 (27.0 to 35.0)	809	33.0 (30.0 to 37.0)	33.0 (30.0 to 37.0)	t(10.16)=1.31, p=0.221

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
		31.45 (5.52)		33.64 (4.24)	33.61 (4.26)	
Self-efficacy (24 month) (range 10=lower self-efficacy – 40=higher self-efficacy)	13	30.0 (28.5 to 33.0) 31.00 (4.64)	882	32.0 (30.0 to 36.0) 32.74 (3.96)	32.0 (30.0 to 36.0) 32.71 (3.98)	t(12.26)=1.35, p=0.203
<b>Parenting and family functioning: negative perceptions of life events</b>						
Self-efficacy baseline – 24 month), see domain ‘Parenting and family functioning: Parental stress, poor stress management, economic stress’ for results						
<b>Parenting and family functioning: parents of maltreated children perceived their own childhoods as being unhappy, poor relationships with their own parents, conflict in a family or a lack of family cohesion, Poor family functioning</b>						
Mother contact with fostering services (6 month)						$\chi^2(1)=0.41$ , p=0.840
Yes	0	(0.0)	3	(0.2)	0.2	
No	11	(42.3)	812	(53.7)	53.5	
Missing	15	(57.7)	696	(46.1)	46.3	
Mother contact with fostering services (12 month)						$\chi^2(2)=0.42$ , p=0.979
Yes	0	(0.0)	3	(0.2)	0.2	

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
No	9	(34.6)	856	(56.6)	56.3	
Missing	17	(65.4)	652	(43.2)	43.5	
Mother contact with fostering services (18 month)						$\chi^2(2)=0.41$ , p=0.980
Yes	0	(0.0)	2	(0.1)	0.1	
No	11	(42.3)	804	(53.2)	53.0	
Missing	15	(57.7)	705	(46.7)	46.9	
Mother contact with fostering services (24 month)						$\chi^2(1)=0.03$ , p=0.863
Yes	0	(0.0)	2	(0.1)	0.1	
No	13	(50.0)	879	(58.2)	58.1	
Missing	13	(50.0)	630	(41.7)	41.8	
Mother fostered (6 month)						$\chi^2(1)=0.03$ , p=0.868
Yes	0	(0.0)	2	(0.1)	0.1	
No	11	(42.3)	802	(53.1)	52.9	
Missing	15	(57.7)	707	(46.8)	47.0	
Mother fostered (12 month)						$\chi^2(2)=0.04$ , p=0.979
Yes	0	(0.0)	3	(0.2)	0.2	
No	9	(34.6)	856	(56.7)	56.3	

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi-squared or t-test statistic, p-value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Missing	17	(65.4)	652	(43.1)	43.5	
Mother fostered (18 month)						$\chi^2(1)=0.05$ , p=0.815
Yes	0	(0.0)	4	(0.3)	0.2	
No	11	(42.3)	803	(53.1)	53.0	
Missing	15	(57.7)	704	(46.6)	46.8	
Mother fostered (24 month)						$\chi^2(1)=0.02$ , p=0.903
Yes	0	(0.0)	1	(0.1)	0.1	
No	13	(50.0)	881	(58.3)	58.2	
Missing	13	(50.0)	629	(41.6)	41.7	
Mother lived away from parents (baseline)						$\chi^2(1)=3.89$ , p=0.048
Yes	17	(65.4)	687	(45.5)	45.8	
No	9	(34.6)	809	(53.5)	53.2	
Missing	0	(0.0)	15	(1.0)	1.0	
Mother contact with own mother (baseline)						$\chi^2(8)=5.72$ , p=0.678
Lives with mother	11	(42.3)	853	(56.5)	56.2	
Every day	2	(7.7)	111	(7.3)	7.4	
3-6 times a week	1	(3.9)	198	(13.1)	12.9	

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
1-2 times a week	3	(11.5)	154	(10.2)	10.2	
At least once a month	4	(15.4)	98	(6.5)	6.6	
Once very few months	1	(3.8)	47	(3.1)	3.1	
Once a year	0	(0.0)	14	(0.9)	0.9	
Less than once a year	0	(0.0)	13	(0.9)	0.8	
Never	2	(7.7)	67	(4.4)	4.5	
Missing	2	(7.7)	46	(3.0)	3.1	
Mother contact with own father (baseline)						$\chi^2(8)=12.21$ , p=0.142
Lives with mother	4	(15.4)	357	(23.6)	23.5	
Every day	3	(11.5)	70	(4.6)	4.7	
3-6 times a week	1	(3.9)	85	(5.6)	5.6	
1-2 times a week	4	(15.4)	163	(10.8)	10.9	
At least once a month	0	(0.0)	143	(9.5)	9.3	
Once very few months	1	(3.8)	163	(10.8)	10.7	
Once a year	0	(0.0)	47	(3.1)	3.1	
Less than once a year	3	(11.5)	70	(4.6)	4.7	
Never	6	(23.1)	243	(16.1)	16.2	
Missing	4	(15.4)	170	(11.3)	11.3	
Mother's parents separated (baseline)						$\chi^2(3)=8.57$ , p=0.036

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Yes	12	(46.2)	918	(60.8)	60.5	
No	6	(23.0)	490	(32.4)	32.3	
Parents never lived together	5	(19.2)	88	(5.8)	6	
Don't know	0	(0.0)	6	(0.4)	0.4	
Missing	0	(0.0)	12	(0.8)	0.8	
Mother's age (years) when parents separated (baseline)	12	6.0 (1.5 to 8.0) 6.08 (4.93)	894	5.0 (2.0 to 10.0) 6.02 (4.95)	5.0 (2.0 to 10.0) 6.02 (4.95)	t(11.30)=-0.04, p=0.967
Mother been homeless (baseline)						$\chi^2(1)=6.41$ , p=0.011
Yes	10	(38.5)	282	(18.7)	19	
No	16	(61.5)	1220	(80.7)	80.4	
Missing	0	(0.0)	9	(0.6)	0.6	
Mother been homeless (6 month)						$\chi^2(1)=0.06$ , p=0.806
Yes	1	(3.8)	77	(5.1)	5.1	
No	6	(23.1)	354	(23.4)	23.4	
Missing	19	(73.1)	1080	(71.5)	71.5	
Mother been homeless (12 month)						$\chi^2(2)=1.44$ , p=0.488
Yes	1	(3.7)	59	(3.9)	3.9	



	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi-squared or t-test statistic, p-value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
No	1	(3.8)	276	(18.3)	18	
Missing	24	(92.3)	1176	(77.8)	78.1	
Mother been homeless (18 month)						$\chi^2(1)=2.86$ , p=0.091
Yes	3	(11.5)	55	(3.6)	3.8	
No	3	(11.5)	205	(13.6)	13.5	
Missing	20	(77.0)	1251	(82.8)	82.7	
Mother been homeless (24 month)						$\chi^2(1)=0.27$ , p=0.604
Yes	1	(3.8)	85	(5.6)	5.6	
No	7	(27.0)	343	(22.7)	22.8	
Missing	18	(69.2)	1083	(71.7)	71.6	
<b>Parenting and family functioning: poor stability and less security in family</b>						
Mother not living with baby (6 month)						n/a
Baby in foster care	0	(0.0)	1	(0.1)	0.1	
Baby living with someone else in informal agreement	0	(0.0)	4	(0.3)	0.3	
Baby in hospital	0	(0.0)	0	(0.0)	0	
Baby adopted	0	(0.0)	0	(0.0)	0	
Missing	26	(100)	1506	(99.6)	99.6	

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Mother not living with baby (12 month)						n/a
Baby in foster care	0	(0.0)	2	(0.1)	0.1	
Baby living with someone else in informal agreement	0	(0.0)	3	(0.2)	0.2	
Baby in hospital	0	(0.0)	1	(0.1)	0.1	
Baby adopted	0	(0.0)	0	(0.0)	0	
Missing	26	(100)	1505	(99.6)	99.5	
Mother not living with baby (18 month)						n/a
Baby in foster care	0	(0.0)	5	(0.3)	0.3	
Baby living with someone else in informal agreement	0	(0.0)	7	(0.5)	0.5	
Baby in hospital	0	(0.0)	0	(0.0)	0	
Baby adopted	0	(0.0)	0	(0.0)	0	
Missing	26	(100)	1499	(99.2)	99.2	
Mother not living with baby (24 month)						n/a
Baby in foster care	0	(0.0)	3	(0.2)	0.2	
Baby living with someone else in informal agreement	0	(0.0)	7	(0.5)	0.5	
Baby in hospital	0	(0.0)	0	(0.0)	0	
Baby adopted	0	(0.0)	0	(0.0)	0	
Missing	26	(100)	1501	(99.3)	99.3	

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Mother moved home (6 month)						$\chi^2(1)=0.77$ , p=0.381
Yes	7	(26.9)	431	(28.5)	28.5	
No	4	(15.4)	425	(28.1)	27.9	
Missing	15	(57.7)	655	(43.4)	43.6	
Mother moved home (12 month)						$\chi^2(2)=1.02$ , p=0.602
Yes	2	(7.7)	335	(22.2)	21.9	
No	7	(26.9)	584	(38.6)	38.5	
Missing	17	(65.4)	592	(39.2)	39.6	
Mother moved home (18 month)						$\chi^2(1)=1.75$ , p=0.186
Yes	6	(23.1)	260	(17.2)	17.3	
No	6	(23.1)	552	(36.5)	36.3	
Missing	14	(53.8)	699	(46.3)	46.4	
Mother moved home (24 month)						$\chi^2(1)=0.86$ , p=0.353
Yes	5	(19.2)	453	(30.0)	29.8	
No	8	(30.8)	428	(28.3)	28.4	
Missing	13	(50.0)	630	(41.7)	41.8	

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Mother fostered (6 – 24 month), see domain 'Parenting and family functioning: parents of maltreated children perceived their own childhoods as being unhappy, poor relationships with their own parents, conflict in a family or a lack of family cohesion, Poor family functioning' for results						
Mother lived away from parents (baseline), see domain 'Parenting and family functioning: parents of maltreated children perceived their own childhoods as being unhappy, poor relationships with their own parents, conflict in a family or a lack of family cohesion, Poor family functioning' for results						
Mother relationship status (late pregnancy – 24 month), see domain 'Family composition: single parent families, unmarried mothers, female headed households' for results						
Adaptive functioning (baseline), see domain 'Parenting and family functioning: Parental stress, poor stress management, economic stress' for results						
Child had period of care (NPD), see domain 'Family composition: Early separation from mother' for results						
<b>Intimate partner violence: intimate partner violence</b>						
Composite abuse scale (24 month) (range 0=lower abuse score – 145=higher abuse score)	7	1.0 (0.0 to 5.0)	528	0.0 (0.0 to 3.0)	0.0 (0.0 to 3.0)	t(6.74)=0.67, p=0.525

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
		3.43 (6.04)		5.06 (13.23)	5.04 (13.16)	
<b>Intimate partner violence: poor relationship between parents or other family members , parental conflict, maternal dissatisfaction, poor marital quality</b>						
Relationship quality (baseline) (range 7=lower quality – 35=higher quality)	18	25.0 (23.8 to 31.0) 25.94 (6.22)	1190	29.0 (26.0 to 32.0) 28.12 (4.76)	29.0 (26.0 to 32.0) 28.08 (4.79)	t(17.30)=1.48, p=0.158
Relationship quality if relationship changed since baseline (late pregnancy) (range 7=lower quality – 35=higher quality)	0	0.0 (0.0 to 0.0) n/a	73	31.0 (27.0 to 32.5) 29.42 (4.12)	31.0 (27.0 to 32.5) 29.42 (4.12)	n/a
Relationship quality if relationship changed since last interview (6 months) (range 7=lower quality – 35=higher quality)	7	29.0 (28.0 to 29.0) 27.86 (4.10)	556	29.0 (26.0 to 32.0) 28.61 (4.67)	29.0 (26.0 to 32.0) 28.60 (4.66)	t(6.20)=0.48, p=0.646
Relationship quality if relationship changed since last interview (12 months) (range 7=lower quality – 35=higher quality)	4	28.5 (27.3 to 29.0) 28.25 (0.96)	518	29.0 (26.0 to 32.0) 28.52 (4.88)	29.0 (26.0 to 32.0) 28.56 (4.86)	t(4.32)=0.51, p=0.633
Relationship quality if relationship changed since last interview (18 months) (range 7=lower quality – 35=higher quality)	7	28.0 (25.0 to 31.0) 28.57 (3.95)	448	29.0 (27.0 to 32.0) 28.90 (4.18)	29.0 (27.0 to 32.0) 28.89 (4.17)	t(6.21)=0.22, p=0.835
Relationship quality if relationship changed since last interview (24 months) (range 7=lower quality – 35=higher quality)	9	27.0 (26.5 to 29.0)	560	29.0 (26.0 to 32.0)	29.0 (26.0 to 32.0)	t(8.62)=0.51, p=0.626

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi-squared or t-test statistic, p-value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
		28.22 (2.82)		28.71 (4.33)	28.70 (4.31)	
<b>Ethnicity or race: ethnicity or race, foreign-born parents</b>						
Mother born outside UK (baseline)						$\chi^2(1)=1.12$ , p=0.290
Yes	0	(0.0)	62	(4.1)	4.0	
No	26	(100.0)	1440	(95.3)	95.4	
Missing	0	(0.0)	9	(0.6)	0.6	
<b>Health service use by child</b>						
Number of visits to GP (GP data)	6	6.0 (3.0 to 9.3) 6.83 (4.79)	560	9.0 (5.0 to 13.0) 9.70 (6.43)	9.0 (5.0 to 13.0) 9.67 (6.42)	t(5.20)=1.45, p=0.204
Baby attended A&E (NHS Digital A&E data)						$\chi^2(1)=0.16$ , p=0.687
Yes	19	(73.1)	1094	(72.4)	72.4	
No	1	(3.8)	87	(5.8)	5.7	
Missing	6	(23.1)	330	(21.8)	21.9	
Baby attended Inpatients at any time (NHS Digital Inpatients data)						$\chi^2(1)=0.07$ , p=0.376
Yes	26	(100)	1293	(85.6)	85.8	

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi-squared or t-test statistic, p-value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
No	0	(0)	39	(2.6)	2.5	
Missing	0	(0)	179	(11.8)	11.7	
Baby attended Outpatients at any time (NHS Digital Outpatients data)						$\chi^2(1)=0.78$ , p=0.793
Yes	18	(69.2)	903	(59.8)	59.9	
No	8	(30.8)	449	(29.7)	29.7	
Missing	0	(0.0)	159	(10.5)	10.4	
<b>Child disability, illness, or development: disability (up to three congenital abnormalities)</b>						
First congenital abnormality (birth)						$\chi^2(1)=2.81$ , p=0.093
Yes	3	(11.5)	64	(4.2)	4.4	
No	22	(84.6)	1292	(85.5)	85.5	
Missing	1	(3.9)	155	(10.3)	10.1	
Second congenital abnormality (birth)						$\chi^2(1)=0.15$ , p=0.700
Yes	0	(0.0)	8	(0.5)	0.5	
No	25	(96.2)	1348	(89.2)	89.4	
Missing	1	(3.8)	155	(10.3)	10.1	
third congenital abnormality (birth)						$\chi^2(1)=0.06$ , p=0.814

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Yes	0	(0.0)	3	(0.2)	0.2	
No	25	(96.2)	1353	(89.5)	89.7	
Missing	1	(3.8)	155	(10.3)	10.1	
<b>Child disability, illness, or development: developmental delay</b>						
Mother contact with child development service (6 month)						$\chi^2(1)=0.07$ , p=0.794
Yes	0	(0.0)	5	(0.3)	0.3	
No	11	(42.3)	810	(53.6)	53.4	
Missing	15	(57.7)	696	(46.1)	46.3	
Mother contact with child development service (12 month)						$\chi^2(2)=0.12$ , p=0.943
Yes	0	(0.0)	9	(0.6)	0.6	
No	9	(34.6)	849	(56.2)	55.8	
Missing	17	(65.4)	653	(43.2)	43.6	
Mother contact with child development service (18 month)						$\chi^2(2)=0.17$ , p=0.920
Yes	0	(0.0)	9	(0.6)	0.6	
No	11	(42.3)	794	(52.5)	52.4	
Missing	15	(57.7)	708	(46.9)	47.0	
Mother contact with child development service (24 month)						$\chi^2(1)=0.24$ , p=0.624



	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi-squared or t-test statistic, p-value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Yes	0	(0.0)	16	(1.1)	1.0	
No	13	(50.0)	866	(57.3)	57.2	
Missing	13	(50.0)	629	(41.6)	41.8	
Cognitive development gross motor delay (development of larger movements e.g. crawling) (12 months)						$\chi^2(2)=0.13$ , p=0.938
Yes	0	(0.0)	11	(0.7)	0.7	
No	9	(34.6)	841	(55.7)	55.3	
Missing	17	(65.4)	659	(43.6)	44.0	
Cognitive development fine motor delay (development of smaller movements e.g. turning pages of book) (12 months)						$\chi^2(2)=0.51$ , p=0.774
Yes	0	(0.0)	45	(3.0)	2.9	
No	9	(34.6)	807	(53.4)	53.1	
Missing	17	(65.4)	659	(43.6)	44.0	
Cognitive development gross motor delay (development of larger movements e.g. crawling) (18 months)						$\chi^2(1)=0.49$ , p=0.483
Yes	0	(0.0)	34	(2.3)	2.2	
No	11	(42.3)	760	(50.3)	50.2	
Missing	15	(57.7)	717	(47.4)	47.6	
Cognitive development fine motor delay (development of smaller movements e.g. turning pages of book) (18 months)						$\chi^2(1)=0.08$ , p=0.772
Yes	0	(0.0)	6	(0.4)	0.4	

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
No	11	(42.3)	788	(52.2)	52.0	
Missing	15	(57.7)	717	(47.4)	47.6	
Cognitive development gross motor delay (development of larger movements e.g. crawling) (24 months)						$\chi^2(1)=0.22$ , p=0.638
Yes	1	(3.8)	42	(2.8)	2.8	
No	12	(46.2)	823	(54.5)	54.3	
Missing	13	(50.0)	646	(42.7)	42.9	
Cognitive development fine motor delay (development of smaller movements e.g. turning pages of book) (24 months)						$\chi^2(1)=0.03$ , p=0.868
Yes	1	(3.8)	56	(3.7)	3.7	
No	12	(46.2)	800	(53.0)	52.8	
Missing	13	(50.0)	655	(43.3)	43.5	
Language development delay (12 months)						$\chi^2(1)=2.40$ , p=0.121
Yes	3	(11.5)	126	(8.3)	8.4	
No	6	(23.1)	726	(48.1)	47.6	
Missing	17	(65.4)	659	(43.6)	44.0	
Language development delay (18 months)						$\chi^2(1)=0.03$ , p=0.854
Yes	2	(7.7)	162	(10.7)	10.7	
No	9	(34.6)	631	(41.8)	41.6	

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Missing	15	(57.7)	718	(47.5)	47.7	
Language development (ELM) (percentiles)	16	40.0 (34.8 to 43.8) 44.5 (5.98)	878	44.0 (39.0 to 50.0) 44.10 (7.58)	44.0 (39.0 to 50.0) 44.04 (7.57)	t(15.89)=2.38, p=0.030
<b>Child disability, illness, or development: prematurity or low birth weight</b>						
Birth weight (birth)	25	3040.0 (2905.0 to 3620.0) 3205.24 (550.37)	1358	3270.0 (2928.8 to 3596.3) 3230.84 (575.46)	3270.0 (2930.0 to 3595.0) 3230.38 (574.83)	t(24.97)=0.23, p=0.820
<b>Child gender</b>						
Gender (birth)						$\chi^2(1)=3.02$ , p=0.082
Female	17	(65.4)	693	(45.9)	46.2	
Male	9	(34.6)	745	(49.3)	49.1	
Missing	0	(0.0)	73	(4.8)	4.7	
<b>Social support</b>						
Social support (baseline) (range 0=lower support – 100=higher support)	26	88.2 (75.7.0 to 92.4) 82.64 (17.50)	1489	90.8 (77.6 to 98.9) 85.08 (16.74)	90.8 (77.6 to 98.9) 85.04 (16.75)	t(25.80)=0.71, p=0.487

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi-squared or t-test statistic, p-value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Social support (6 month) (range 0=lower support – 100=higher support)	11	89.5 (82.9 to 97.4) 87.08 (12.51)	806	90.8 (75.0 to 98.7) 84.93 (16.41)	90.8 (75.0 to 98.7) 84.96 (16.36)	t(10.48)=-0.56, p=0.585
Social support (12 month) (range 0=lower support – 100=higher support)	12	81.6 (69.1 to 96.7) 76.86 (22.00)	962	88.2 (75.0 to 98.7) 83.60 (17.33)	87.5 (75.0 to 98.7) 83.52 (17.40)	t(11.17)=1.06, p=0.311
Social support (18 month) (range 0=lower support – 100=higher support)	11	89.5 (73.4 to 96.1) 84.09 (14.54)	804	89.5 (75.0 to 98.7) 84.39 (17.09)	89.5 (75.0 to 98.7) 84.39 (17.05)	t(10.38)=0.07, p=0.947
Social support (24 month) (range 0=lower support – 10=higher support)	13	4.4 (4.0 to 4.9) 4.28 (0.73)	874	4.6 (4.0 to 5.0) 4.38 (0.72)	4.6 (4.0 to 5.0) 4.38 (0.72)	t(12.35)=0.46, P=0.655
<b>Neighbourhood and community: neighbourhood poverty, instability and economic disadvantage</b>						
Postcode (Index of Multiple Deprivation) (baseline)	26	44.0 (27.9 to 56.7) 43.30 (16.49)	1490	38.1 (25.0 to 51.8) 39.06 (18.19)	38.2 (25.1 to 52.2) 39.13 (18.16)	t(26.07)=-1.30, P=0.206
<b>Socio-economic status: low SES</b>						
Postcode (Index of Multiple Deprivation) (baseline), see domain 'Neighbourhood and community: neighbourhood poverty, instability and economic disadvantage' for results						

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Family resources (baseline) (range 4=less resources – 20=more resources)	14	12.0 (10.0 to 13.8) 11.63 (3.41)	1440	14.0 (11.0 to 17.0) 13.42 (4.21)	14.0 (11.0 to 17.0) 13.39 (42.04)	t(24.18)=2.55, P=0.017
Family resources (6 month) (range 4=less resources – 20=more resources)	10	14.5 (10.0 to 20.0) 14.7 (4.62)	762	15.0 (12.0 to 17.0) 14.28 (3.76)	15.0 (12.0 to 17.0) 14.29 (3.77)	t(9.16)=-0.29, P=0.781
Family resources (12 month) (range 4=less resources – 20=more resources)	9	12.0 (10.0 to 16.0) 12.78 (3.83)	842	14.0 (11.0 to 17.0) 13.79 (4.04)	14.0 (11.0 to 17.0) 13.78 (4.04)	t(8.19)=0.79, P=0.454
Family resources (18 month) (range 4=less resources – 20=more resources)	10	12.5 (10.0 to 14.8) 12.60 (4.60)	795	14 (11.0 to 17.0) 13.96 (3.72)	14.0 (11.0 to 17.0) 13.94 (3.73)	t(9.15)=0.93, P=0.377
Family resources (24 month) (range 4=less resources – 20=more resources)	12	12.0 (7.3 to 17.0) 12.42 (5.38)	860	14.0 (11.0 to 16.0) 13.47 (3.68)	14.0 (11.0 to 16.0) 13.46 (3.71)	t(11.14)=0.68, P=0.512
Free school meal eligible (NPD)						X <sup>2</sup> (1)=0.55, P=0.460
Yes	6	(23.1)	126	(8.3)	8.6	
No	20	(76.9)	596	(39.5)	40.1	
Missing	0	(0.0)	789	(52.2)	51.3	
<b>Socio-economic status: benefits</b>						

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Receiving benefits currently (baseline)						$\chi^2(1)=0.06$ , P=0.806
Yes	10	(38.5)	542	(35.9)	35.9	
No	16	(61.5)	958	(63.4)	63.4	
Missing	0	(0.0)	11	(0.7)	0.7	
Receiving benefits currently (24 month)						$\chi^2(1)=1.63$ , P=0.202
Yes	13	(50)	782	(51.7)	51.7	
No	0	(0.0)	98	(6.5)	6.4	
Missing	13	(50)	631	(41.8)	41.9	
<b>Socio-economic status: unemployment</b>						
Unemployed (baseline)						$\chi^2(1)=4.50$ , P=0.034
No	1	(3.8)	312	(20.6)	20.4	
Yes	25	(96.2)	1190	(78.8)	79.0	
Missing	0	(0.0)	9	(0.6)	0.6	
Unemployed (6 month)						n/a
No	0	(0.0)	39	(2.6)	2.6	
Yes	0	(0.0)	139	(9.2)	9.0	
Missing	26	(100)	1333	(88.2)	88.4	
Unemployed (12 month)						n/a

	At least one CIN status N=26		Participants without a CIN status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
No	0	(0.0)	102	(6.8)	6.6	
Yes	0	(0.0)	162	(10.7)	10.6	
Missing	26	(100)	1247	(82.5)	82.8	
Unemployed (18 month)						$\chi^2(1)=0.05$ , P=0.826
No	1	(3.8)	114	(7.5)	7.5	
Yes	2	(7.7)	174	(11.5)	11.4	
Missing	23	(88.5)	1223	(80.9)	81.1	
Unemployed (24 month)						n/a
No	0	(0.0)	146	(9.7)	9.5	
Yes	0	(0.0)	167	(11.0)	10.9	
Missing	26	(100)	1198	(79.3)	79.6	

## Appendix 21.

**Table 11.** Markers of participants with and without a child with a CIN status.

	At least one CIN Status N=26		Participants without a CIN Status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p-value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Markers for child maltreatment Domain						
Physical signs of abuse and injuries: head injuries						
Head injuries (NHS Digital A&E data)						$\chi^2(1)=1.64$ , p=0.201
Yes	10	(38.5)	359	(23.8)	24.0	
No	14	(53.8)	854	(56.5)	56.5	
Missing	2	(7.7)	298	(19.7)	19.5	
Physical signs of abuse and injuries: fractures						
Fractures (NHS Digital A&E data)						$\chi^2(1)=0.01$ , p=0.929
Yes	4	(15.4)	194	(12.8)	12.9	
No	20	(76.9)	1019	(67.5)	67.6	
Missing	2	(7.7)	298	(19.7)	19.5	
Physical signs of abuse and injuries: thermal injuries						
Thermal injuries (24 month)						$\chi^2(1)=2.24$ , p=0.134
Yes	4	(15.4)	125	(8.3)	8.4	



	At least one CIN Status N=26		Participants without a CIN Status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p-value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
No	11	(42.3)	806	(53.3)	53.2	
Missing	11	(42.3)	580	(38.4)	38.4	
Burns (NHS Digital A&E data)						$\chi^2(1)=1.54$ , p=0.215
Yes	0	(0.0)	73	(4.8)	4.8	
No	24	(92.3)	1140	(75.5)	75.7	
Missing	2	(7.7)	298	(19.7)	19.5	
Physical signs of abuse and injuries: bites and bruises						
Bites and bruises (NHS Digital A&E data)						$\chi^2(1)=0.98$ , p=0.323
Yes	2	(7.7)	51	(3.4)	3.5	
No	22	(84.6)	1162	(76.9)	77.0	
Missing	2	(7.7)	298	(19.7)	19.5	
Contusion (NHS Digital A&E data)						$\chi^2(1)=4.10$ , p=0.043
Yes	8	(30.8)	211	(14.0)	14.3	
No	16	(61.5)	1002	(66.3)	66.2	
Missing	2	(7.7)	298	(19.7)	19.5	
Physical signs of abuse and injuries: lacerations, abrasions and scars						
Lacerations, abrasions, scars (NHS Digital A&E data)						$\chi^2(1)=2.00$ , p=0.158

	At least one CIN Status N=26		Participants without a CIN Status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p-value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Yes	8	(30.8)	259	(17.2)	17.4	
No	16	(61.5)	954	(63.1)	63.1	
Missing	2	(7.7)	298	(19.7)	19.5	
Physical signs of abuse and injuries: ano-genital injuries						
Ano-genital (NHS Digital A&E data)						$\chi^2(1)=0.38$ , p=0.536
Yes	8	(30.8)	335	(22.2)	22.3	
No	16	(61.5)	878	(58.1)	58.2	
Missing	2	(7.7)	298	(19.7)	19.5	
Physical signs of abuse and injuries: other physical injuries						
Soft tissue inflammation (NHS Digital A&E data)						$\chi^2(1)=1.15$ , p=0.285
Yes	2	(7.7)	200	(13.2)	13.1	
No	22	(84.6)	1013	(67.1)	67.4	
Missing	2	(7.7)	298	(19.7)	19.5	
Sprain/ligament injury (NHS Digital A&E data)						$\chi^2(1)=0.59$ , p=0.443
Yes	2	(7.7)	167	(11.1)	11.0	
No	22	(84.6)	1046	(69.2)	69.5	
Missing	2	(7.7)	298	(19.7)	19.5	
Muscle/tendon injury (NHS Digital A&E data)						$\chi^2(1)=1.65$ , p=0.199

	At least one CIN Status N=26		Participants without a CIN Status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p-value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Yes	3	(11.5)	74	(5.0)	5.0	
No	21	(80.8)	1139	(75.3)	75.5	
Missing	2	(7.7)	298	(19.7)	19.5	
Nerve injury (NHS Digital A&E data)						$\chi^2(1)=12.69$ , p=0.000
Yes	4	(15.4)	39	(2.6)	2.8	
No	20	(76.9)	1174	(77.7)	77.7	
Missing	2	(7.7)	298	(19.7)	19.5	
Vascular injury (NHS Digital A&E data)						$\chi^2(1)=0.40$ , p=0.842
Yes	0	(0.0)	2	(0.1)	0.1	
No	24	(92.3)	1211	(80.2)	80.4	
Missing	2	(7.7)	298	(19.7)	19.5	
Electric shock (NHS Digital A&E data)						$\chi^2(1)=11.22$ , p=0.001
Yes	1	(3.8)	3	(0.2)	0.3	
No	23	(88.5)	1210	(80.1)	80.2	
Missing	2	(7.7)	298	(19.7)	19.5	
Foreign body (NHS Digital A&E data)						$\chi^2(1)=1.65$ , p=0.199
Yes	0	(0.0)	78	(5.2)	5.1	
No	24	(92.3)	1135	(75.1)	75.4	

	At least one CIN Status N=26		Participants without a CIN Status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p-value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Missing	2	(7.7)	298	(19.7)	19.5	
Poisoning (NHS Digital A&E data)						$\chi^2(1)=1.02$ , p=0.313
Yes	4	(15.4)	125	(8.3)	8.4	
No	20	(76.9)	1088	(72.0)	72.1	
Missing	2	(7.7)	298	(19.7)	19.5	
Near drowning (NHS Digital A&E data)						n/a
Yes	0	(0.0)	0	(0.0)	0.0	
No	24	(92.3)	1213	(80.3)	80.5	
Missing	2	(7.7)	298	(19.7)	19.5	
Visceral injury (NHS Digital A&E data)						n/a
Yes	0	(0.0)	0	(0.0)	0.0	
No	24	(92.3)	1213	(80.3)	80.5	
Missing	2	(7.7)	298	(19.7)	19.5	
Any injuries or ingestions (NHS Digital Inpatients data)						$\chi^2(1)=5.11$ , p=0.474
Yes	6	(23.1)	267	(17.7)	17.8	
No	20	(76.9)	1244	(82.3)	82.2	
Missing	0	(0.0)	0	(0.0)	0.0	
Clinical presentations other than injuries: failure to attend essential follow-up appointments						
Did not attend (GP data)	12	0.0	844	0.0	0.0	n/a

	At least one CIN Status N=26		Participants without a CIN Status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p-value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
		(0.0 to 0.0)		(0.0 to 0.0)	(0.0 to 0.0) 0.09 (0.45)	
Did not attend (NHS Digital Outpatients data)						$\chi^2(1)=3.95$ , p=0.047
Yes	22	(84.6)	998	(66.0)	66.4	
No	4	(15.4)	513	(34.0)	33.6	
Missing	0	(0.0)	0	(0.0)	0.0	
Clinical presentations other than injuries: failure to engage with immunisation health and development reviews and screening						
Immunisations number (6 month)	12	3.0 (3.0 to 3.0) 3.42 (1.51)	939	3.0 (3.0 to 3.0) 3.22 (1.17)	3.0 (3.0 to 3.0) 3.22 (1.18)	$t(11.17)=-$ 0.45, p=0.661
Immunisations number since last interview (12 month)	12	0.0 (0.0 to 0.0) 0.25 (0.87)	957	0.0 (0.0 to 1.0) 0.71 (1.28)	0.0 (0.0 to 1.0) 0.70 (1.28)	$t(11.61)=1.81$ , p=0.097
Immunisations number since last interview (18 month)	15	1.0 (1.0 to 2.0) 1.40 (0.51)	922	1.0 (1.0 to 2.0) 1.26 (0.44)	1.0 (1.0 to 2.0) 1.26 (0.44)	$t(14.34)=-$ 1.05, p=0.310
Received full schedule of immunisations (immunisations data)						$\chi^2(1)=0.33$ , p=0.565
Yes	16	(61.5)	862	(57.1)	57.1	
No	1	(3.9)	97	(6.4)	6.4	

	At least one CIN Status N=26		Participants without a CIN Status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p-value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Missing	9	(34.6)	552	(36.5)	36.5	
Parent or carer-child interactions: carer showing negativity or hostility, rejecting or scapegoating						
Parental role strain (6 month) (range 0-6)	12	1.5 (1.0 to 2.0) 1.50 (0.52)	898	1.0 (1.0 to 2.0) 1.49 (0.66)	1.0 (1.0 to 2.0) 1.49 (0.65)	t(11.47)= -0.08,p=0.937
Parental role strain (12 month) (range 0-6)	12	1.0 (1.0 to 2.0) 1.42 (0.67)	952	1.0 (1.0 to 2.0) 1.44 (0.95)	1.0 (1.0 to 2.0) 1.44 (0.94)	t(11.56)=0.12, p=0.907
Parental role strain (18 month) (range 0-6)	13	2.0 (1.0 to 2.0) 1.69 (0.95)	913	1.0 (1.0 to 2.0) 1.44 (0.72)	1.0 (1.0 to 2.0) 1.44 (0.73)	t(12.20)= -0.95,p=0.360
Parental role strain (24 month) (range 0-6)	16	1.0 (0.3 to 1.0) 0.94 (0.68)	1051	1.0 (1.0 to 2.0) 1.30 (0.79)	1.0 (1.0 to 2.0) 1.29 (0.79)	t(15.16)=2.10, p=0.053
Parent or carer-child interactions: developmentally inappropriate expectations						
Maternal intrusiveness (maternal sensitivity)	6	2.0 (1.5 to 2.0) 1.67 (0.82)	501	1.0 (0.0 to 0.3) 1.60 (1.74)	1.0 (0.0 to 2.0) 1.60 (1.73)	t(5.56)=-0.20, 0.846
Parent or carer-child interactions: exposure to frightening or traumatic experiences e.g. dv						

	At least one CIN Status N=26		Participants without a CIN Status N=1511		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p-value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Composite abuse scale (24 month) (range 0-145)	8	0.5 (0.0 to 0.4) 3.00 (5.90)	663	0.0 (0.0 to 0.3) 4.91 (13.88)	0.0 (0.0 to 3.0) 4.89 (13.81)	t(7.96)=0.89, p=0.401
Parent or carer-child interactions: being emotionally unavailable or unresponsive						
Parent/carers-child interactions: emotionally unavailable (maternal sensitivity)	6	10.5 (10.0 to 11.3) 10.67 (0.82)	501	12.0 (10.0 to 12.0) 11.06 (1.65)	12.0 (10.0 to 12.0) 11.05 (1.64)	t(5.50)=1.14, p=0.301

## Appendix 22.

**Table 17.** Baseline Interview variables describing the participants of those included and not included in the final model for those with and without a CIN status.

	Included in final model CIN status N=1340		Not included in final model CIN status N=197		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
Baseline characteristic	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Age (years)	1340	17.0 (16.0 to 18.0) 17.38 (1.26)	197	17.0 (16.0 to 18.0) 17.17 (1.28)	17.0 (16.0 to 18.0) 17.35 (1.26)	t(255.180)= -2.16, p=0.032
Ethnicity						X <sup>2</sup> (4)=12.13, p=0.016
White background	1193	(89.0)	162	(82.2)	88.2	
Mixed background	69	(5.1)	13	(6.6)	5.3	
Asian background	17	(1.3)	8	(4.1)	1.6	
Black background	56	(4.2)	13	(6.6)	4.5	
Other background	5	(0.4)	1	(0.5)	0.4	
Missing	0	(0.0)	0	(0.0)	0.0	
Relationship status						X <sup>2</sup> (3)=14.79, p=0.002
Married	10	(0.8)	6	(3.1)	1.0	
Separated	122	(9.1)	28	(14.2)	9.8	



	Included in final model CIN status N=1340		Not included in final model CIN status N=197		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
Baseline characteristic	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Closely involved/boyfriend	1032	(77.0)	136	(69.0)	76.0	
Just friends	176	(13.1)	27	(13.7)	13.2	
Missing	0	(0.0)	0	(0.0)	0.0	
Live with father of baby						$\chi^2(1)=0.02$ , p=0.885
Yes	308	(23.0)	40	(20.3)	22.7	
No	936	(69.8)	125	(63.5)	69.0	
Missing	96	(7.2)	32	(16.2)	8.3	
Family subjective social status	1334	6.0 (5.0 to 7.0) 5.76 (1.66)	195	5.0 (4.0 to 7.0) 5.42 (1.89)	6.0 (5.0 to 7.0) 5.71 (1.69)	t(240.09)= -2.40, p=0.017
Personal subjective social status	1335	7.0 (6.0 to 8.0) 6.91 (1.79)	196	7.0 (5.0 to 8.0) 6.8 (2.12)	7.0 (6.0 to 8.0) 6.89 (1.84)	t(237.89)= -0.70, p=0.482
NEETS <sup>a</sup> :						$\chi^2(1)=1.70$ , p=0.493
Yes	474	(35.4)	74	(37.6)	35.7	
No	679	(50.7)	85	(43.1)	49.7	
Missing	187	(13.9)	38	(19.3)	14.6	
Receive any welfare benefits						$\chi^2(1)=0.09$ , p=0.763

	Included in final model CIN status N=1340		Not included in final model CIN status N=197		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
Baseline characteristic	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Yes	481	(35.9)	73	(37.1)	36.1	
No	857	(64.0)	124	(62.9)	63.8	
Missing	2	(0.1)	0	(0.0)	0.1	
Ever been homeless						$\chi^2(1)=2.09$ , p=0.148
Yes	248	(18.5)	45	(22.8)	19.1	
No	1092	(81.5)	152	(77.2)	80.9	
Missing	0	(0.0)	0	(0.0)	0.0	
Socio-economic status: Index of Multiple Deprivation Score <sup>b</sup>	1330	38.2 (24.9 to 52.0) 39.10 (18.22)	195	38.1 (27.4 to 52.8) 38.92 (17.88)	38.2 (25.0 to 52.1) 39.08 (18.17)	t(256.76)= -0.13, p=0.899
EQ5D-Binary						$\chi^2(1)=2.15$ , p=0.143
Perfect health	862	(64.3)	115	(58.4)	63.6	
Less than perfect health	477	(35.6)	80	(40.6)	36.2	
Missing	1	(0.1)	2	(1.0)	0.2	
Self-rated health						$\chi^2(3)=0.72$ , p=0.869
Excellent	213	(15.9)	35	(17.8)	16.1	
Good	900	(67.2)	127	(64.5)	66.8	
Fair	211	(15.7)	33	(16.7)	15.9	

	Included in final model CIN status N=1340		Not included in final model CIN status N=197		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
Baseline characteristic	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Poor	16	(1.2)	2	(1.0)	1.2	
Missing	0	(0.0)	0	(0.0)	0.0	
Limiting long-term illness:						$\chi^2(1)=0.00$ , p=0.964
Yes	233	(17.4)	34	(17.3)	17.4	
No	1107	(82.6)	163	(82.7)	82.6	
Missing	0	(0.0)	0	(0.0)	0.0	
Generalized self-efficacy scale <sup>c</sup>	1325	30.0 (28.0 to 33.0) 30.13 (4.32)	188	29.0 (26.0 to 33.0) 29.30 (5.20)	30.0 (28.0 to 33.0) 30.03 (4.44)	t(225.10)= -2.08, p=0.039
Adaptive functioning <sup>d</sup> Difficulty in at least one basic skill						$\chi^2(1)=0.50$ , p=0.480
Yes	342	(25.5)	55	(27.9)	25.8	
No	996	(74.3)	142	(72.1)	74.1	
missing	2	(0.2)	0	(0.0)	0.1	
Adaptive functioning <sup>d</sup> Had 3 or less life skills (out of 5)						$\chi^2(1)=5.59$ , p=0.018
Yes	339	(25.3)	64	(32.5)	26.2	
no	1001	(74.7)	128	(65.0)	73.5	
missing	0	(0.0)	5	(2.5)	0.3	

	Included in final model CIN status N=1340		Not included in final model CIN status N=197		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
Baseline characteristic	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Adaptive functioning <sup>d</sup> At least one burden						X <sup>2</sup> (1)=2.13, p=0.144
Yes	385	(28.7)	66	(33.5)	29.4	
No	947	(70.7)	128	(65.0)	69.9	
missing	8	(0.6)	3	(1.5)	0.7	
Substance abuse	1281	1.0 (0.0 to 2.0) 1.31 (1.51)	182	1.0 (0.0 to 3.0) 1.48 (1.63)	1.0 (0.0 to 2.0) 1.33 (1.53)	t(227.15)=1.35, p=0.177
Antisocial behaviour Score	1336	2.0 (1.0 to 4.0) 2.32 (1.74)	194	3.0 (1.0 to 4.0) 2.73 (1.75)	2.0 (1.0 to 4.0) 2.37 (1.75)	t(251.85)=3.09, p=0.002
Social support	1330	91.0 (77.6 to 99.0) 85.50 (16.12)	194	88.2 (75.0 to 97.4) 82.15 (20.16)	90.8 (77.6 to 98.7) 85.07 (16.72)	t(230.41)= -2.21, p=0.028
Relationship quality	1071	29.0 (26.0 to 32.0) 28.11 (4.81)	144	28.5 (25.0 to 31.0) 27.85 (4.62)	29.0 (26.0 to 32.0) 28.08 (4.79)	t(187.19)=-0.63, p=0.530
Family resources	1340	14.0 (11.0 to 17.0) 13.44 (4.18)	133	14.0 (10.5 to 17.0) 13.10 (4.40)	14.0 (11.0 to 17.0) 13.41 (4.20)	t(156.58)=-0.86, p=0.392
Psychological distress/Mental health	1338	20.0 (16.0 to 26.0)	191	20.0 (16.0 to 26.0)	20.0 (16.0 to 26.0)	t(245.58)=-0.06, p=0.951

	Included in final model CIN status N=1340		Not included in final model CIN status N=197		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
Baseline characteristic	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
		21.49 (6.62)		21.46 (6.72)	21.48 (6.63)	
<sup>a</sup> Definition of NEET: Not in education employment or training status (applicable only to those whose academic age is >16 at baseline interview); <sup>b</sup> Higher IMD score indicated more deprivation [12]; <sup>c</sup> Higher score indicates higher level of self-efficacy; <sup>d</sup> Higher score indicates better management of day-to-day lives and routines (for each of the three sub-scales).						

## Appendix 23.

**Table 19.** Risk factors of mothers with and without a child referred to Social Services.

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
<b>Risk Factors for Child Maltreatment Domain</b>						
<b>Caregiver was a victim of abuse</b>						
Mother abuse in records (GP data)						$\chi^2(1)=1.05$ , p=0.307
Yes	0	(0.0)	25	(1.7)	1.6	
No	16	(22.9)	382	(26)	25.9	
Missing	54	(77.1)	1060	(72.3)	72.5	
<b>Caregiver mental health issues</b>						
Depressed or anxious (24 month)						$\chi^2(1)=1.39$ , p=0.238
Yes	9	(12.9)	277	(18.9)	18.6	
No	32	(45.7)	628	(42.8)	42.9	
Missing	29	(41.4)	562	(38.3)	38.5	
Bothered by being anxious & little interest in doing things (24 month)						$\chi^2(1)=1.46$ , p=0.228
Yes	6	(8.6)	205	(14)	13.7	

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
No	35	(50.0)	700	(47.7)	47.8	
Missing	29	(41.4)	562	(38.3)	38.5	
Maternal anxiety (6 month) (range 0=low - 30=high)	35	8.0 (3.0 to 13.0) 8.66 (5.89)	847	6.0 (3.0 to 10.0) 6.69 (5.18)	6.0 (3.0 to 10.0) 6.77 (5.22)	t(36.21)= -1.95, p=0.059
EQ5D (baseline)						X <sup>2</sup> (2)=2.04, p=0.360
Not anxious or depressed	56	(80.0)	1166	(79.5)	79.5	
Moderately anxious or depressed	11	(15.7)	263	(17.9)	17.8	
Extremely anxious or depressed	3	(4.3)	28	(1.9)	2.0	
Missing	0	(0.0)	10	(0.7)	0.7	
EQ5D (late pregnancy)						X <sup>2</sup> (2)=1.70, p=0.428
Not anxious or depressed	49	(70.0)	982	(66.9)	67.1	
Moderately anxious or depressed	10	(14.3)	128	(8.7)	9.0	
Extremely anxious or depressed	1	(1.4)	13	(0.9)	0.9	
Missing	10	(14.3)	344	(23.5)	23.0	
EQ5D (6 month)						X <sup>2</sup> (2)=1.70, p=0.432
Not anxious or depressed	27	(38.6)	739	(50.4)	49.8	

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Moderately anxious or depressed	7	(10.0)	120	(8.2)	8.3	
Extremely anxious or depressed	1	(1.4)	12	(0.8)	0.8	
Missing	35	(50.0)	596	(40.6)	41.1	
EQ5D (12 month)						$\chi^2(3)=2.28$ , p=0.516
Not anxious or depressed	32	(45.7)	766	(52.2)	51.9	
Moderately anxious or depressed	6	(8.6)	99	(6.8)	6.8	
Extremely anxious or depressed	2	(2.9)	18	(1.2)	1.3	
Missing	30	(42.8)	584	(39.8)	40.0	
EQ5D (18 month)						$\chi^2(2)=20.21$ , p=0.000
Not anxious or depressed	26	(37.1)	745	(50.8)	50.2	
Moderately anxious or depressed	6	(8.6)	86	(5.9)	6.0	
Extremely anxious or depressed	4	(5.7)	12	(0.8)	1.0	
Missing	34	(48.6)	624	(42.5)	42.8	
EQ5D (24 month)						$\chi^2(2)=1.31$ , p=0.520
Not anxious or depressed	32	(45.7)	741	(50.5)	50.3	
Moderately anxious or depressed	7	(10.0)	143	(9.7)	9.8	
Extremely anxious or depressed	2	(2.9)	20	(1.4)	1.4	



	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Missing	29	(41.4)	563	(38.4)	38.5	
Mental health score (baseline) (range 10=low level of distress – 50=high level of distress)	70	20.5 (16.8 to 28.0) 22.40 (7.81)	1452	20.0 (16.0 to 26.0) 21.43 (6.58)	20.0 (16.0 to 26.0) 21.48 (6.64)	t(73.79)= -1.02, p=0.312
Mental health score (24 month) (range 10=low level of distress – 50=high level of distress)	41	15.0 (11.0 to 20.5) 16.53 (6.49)	906	14.0 (12.0 to 21.0) 17.07 (7.45)	14.0 (12.0 to 21.0) 17.04 (7.41)	t(44.91)=0.52, p=0.608
GP consultation mental health (GP data) (number)	20	1.0 (0.0 to 3.0) 1.95 (3.03)	573	0.0 (0.0 to 2.0) 1.43 (2.72)	0.0 (0.0 to 2.0) 1.45 (2.73)	t(20.08)= -0.75, p=0.462
<b>Caregiver substance abuse</b>						
Contact with alcohol & drug support (birth)						X <sup>2</sup> (1)=0.13, p=0.464
Yes	4	(5.7)	53	(3.6)	3.7	
No	63	(90.0)	1232	(84.0)	84.3	
Missing	3	(4.3)	182	(12.4)	12.0	
Contact with alcohol & drug support (6 month)						X <sup>2</sup> (1)=0.13, p=0.722
Yes	0	(0.0)	3	(0.2)	0.2	
No	35	(50.0)	831	(56.7)	56.3	
Missing	35	(50.0)	633	(43.1)	43.5	

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Contact with alcohol & drug support (12 month)						$\chi^2(2)=0.13$ , p=0.935
Yes	0	(0.0)	2	(0.1)	0.1	
No	39	(55.7)	874	(59.6)	59.4	
Missing	31	(44.3)	591	(40.3)	40.5	
Contact with alcohol & drug support (18 month)						$\chi^2(2)=0.13$ , p=0.939
Yes	0	(0.0)	2	(0.1)	0.1	
No	35	(50.0)	836	(57.0)	56.7	
Missing	35	(50.0)	629	(42.9)	43.2	
Contact with alcohol & drug support (24 month)						$\chi^2(1)=0.18$ , p=0.670
Yes	0	(0.0)	4	(0.3)	0.3	
No	41	(58.6)	901	(61.4)	61.3	
Missing	29	(41.4)	562	(38.3)	38.4	
CRAFFT substance abuse scale (baseline) (range 0= less problems dugs/alcohol – 6=more problems dugs/alcohol)	66	0.5 (0.0 to 2.0) 1.23 (1.55)	1390	1.0 (0.0 to 2.0) 1.34 (1.53)	1.0 (0.0 to 2.0) 1.33 (1.53)	$t(71.16)=0.58$ , p=0.566
CRAFFT substance abuse scale (24 month) (range 0= less problems dugs/alcohol – 6=more problems dugs/alcohol)	41	12.0 (12.0 to 12.0) 11.61 (0.89)	904	12.0 (12.0 to 12.0) 11.66 (0.80)	12.0 (12.0 to 12.0) 11.66 (0.80)	$t(42.97)=0.35$ , p=0.728

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
<b>Young parenthood</b>						
Mother age (baseline)	70	17.0 (16.0 to 18.0) 17.11 (1.28)	1460	17.0 (16.0 to 18.0) 17.36 (1.26)	17.0 (16.0 to 18.0) 17.35 (1.26)	t(75.57)=1.58, p=0.119
Father age (baseline)	54	20.0 (18.8 to 23.0) 20.93 (3.94)	1191	20.0 (18.0 to 22.0) 20.33 (3.57)	20.0 (18.0 to 22.0) 20.35 (3.59)	t(57.01)= -1.09, p=0.279
<b>Family composition: having more children in the family, having large families and crowded households</b>						
Number living with mother (adults and children) (baseline)	68	1.0 (1.0 to 1.0) 1.04 (0.53)	1438	1.0 (1.0 to 1.0) 1.06 (0.44)	1.0 (1.0 to 1.0) 1.06 (0.44)	t(71.31)=0.24, p=0.811
Number living with mother (adults and children) (6 month)	34	1.0 (0.0 to 2.0) 1.06 (1.51)	874	1.0 (0.0 to 2.0) 1.59 (2.31)	1.0 (0.0 to 2.0) 1.57 (2.28)	t(42.66)=2.38, p=0.022
Number living with mother (adults and children) (12 month)	40	1.0 (0.0 to 2.0) 1.30 (1.67)	879	1.0 (0.0 to 2.0) 1.27 (1.47)	1.0 (0.0 to 2.0) 1.27 (1.47)	t(41.75)= -0.13, p=0.897
Number living with mother (adults and children) (18 month)	36	0.0 (0.0 to 1.0) 0.75 (1.03)	840	1.0 (0.0 to 2.0) 1.08 (1.28)	1.0 (0.0 to 2.0) 1.06 (1.27)	t(39.81)=1.86, p=0.071

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Number living with mother (adults and children) (24 month)	40	1.0 (0.0 to 1.0) 0.80 (0.94)	905	1.0 (0.0 to 1.5) 1.08 (1.33)	1.0 (0.0 to 1.0) 1.07 (1.32)	t(46.19)=1.80, p=0.079
Number of bedrooms (baseline)	66	3.0 (3.0 to 3.0) 2.95 (1.22)	1401	3.0 (2.0 to 3.0) 2.92 (2.94)	3.0 (2.0 to 3.0) 2.92 (2.10)	t(85.02)= -0.20, p=0.844
Number of bedrooms (24 month)	21	3.0 (2.0 to 3.0) 2.67 (0.66)	452	2.0 (2.0 to 3.0) 2.39 (0.79)	2.0 (2.0 to 3.0) 2.41 (0.78)	t(22.73)= -1.84, p=0.079
<b>Family composition: single parent families, unmarried mothers, female headed households</b>						
Mother live with father (baseline)						X <sup>2</sup> (1)=0.07, p=0.787
Yes	14	(20)	334	(22.8)	22.7	
No	46	(65.7)	1009	(68.8)	68.6	
Missing	10	(14.3)	124	(8.4)	8.7	
Mother relationship status (baseline)						X <sup>2</sup> (3)=1.16, p=0.764
Married	0	(0.0)	16	(1.1)	1.0	
Separated	8	(11.4)	141	(9.6)	9.7	
Closely involved/boyfriend	54	(77.2)	1110	(75.7)	75.7	

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Just friends	8	(11.4)	193	(13.1)	13.1	
Missing	0	(0.0)	7	(0.5)	0.5	
Mother relationship status if changed since baseline (late pregnancy)						$\chi^2(4)=1.78$ , p=0.776
Married	0	(0.0)	2	(0.1)	0.1	
Separated	0	(0.0)	9	(0.6)	0.6	
Closely involved/boyfriend	4	(5.7)	57	(3.9)	4.0	
Just friends	1	(1.4)	46	(3.1)	3.1	
Not in any relationship	3	(4.3)	57	(3.9)	3.9	
Missing	62	(88.6)	1296	(88.4)	88.3	
Mother relationship status if changed since last interview (6 month)						$\chi^2(4)=1.03$ , p=0.905
Married	0	(0.0)	19	(1.3)	1.2	
Separated	1	(1.4)	22	(1.5)	1.5	
Closely involved/boyfriend	21	(30.0)	499	(34.0)	33.8	
Just friends	6	(8.6)	132	(9.0)	9.0	
Not in any relationship	7	(10.0)	199	(13.6)	13.4	
Missing	35	(50.0)	596	(40.6)	41.1	
Mother relationship status if changed since last interview (12 month)						$\chi^2(5)=1.79$ , p=0.878

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Married	0	(0.0)	19	(1.3)	1.2	
Separated	1	(1.4)	12	(0.8)	0.8	
Closely involved/boyfriend	18	(25.7)	438	(29.9)	29.7	
Just friends	10	(14.3)	183	(12.5)	12.6	
Not in any relationship	11	(15.7)	231	(15.7)	15.7	
Missing	30	(42.9)	584	(39.8)	40.0	
Mother relationship status if changed since last interview (18 month)						$\chi^2(4)=3.39$ , p=0.710
Married	0	(0.0)	20	(1.4)	1.3	
Separated	0	(0.0)	11	(0.7)	0.7	
Closely involved/boyfriend	19	(27.1)	363	(24.7)	24.9	
Just friends	5	(7.2)	192	(13.1)	12.8	
Not in any relationship	12	(17.1)	295	(20.1)	20.0	
Missing	34	(48.6)	586	(39.9)	40.3	
Mother relationship status if changed since last interview (24 month)						$\chi^2(5)=5.95$ , p=0.312
Married	0	(0.0)	32	(2.2)	2.1	
Separated	2	(2.9)	39	(2.6)	2.7	
Divorced	0	(0.0)	2	(0.1)	0.1	
Closely involved/boyfriend	24	(34.3)	378	(25.8)	26.2	

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Just friends	7	(10.0)	172	(11.7)	11.6	
Not in any relationship	8	(11.4)	281	(19.2)	18.8	
Missing	29	(41.4)	563	(38.4)	38.5	
<b>Family composition: having children in close succession, shorter pregnancy interval</b>						
Pregnancy status (6 month)						$\chi^2(1)=0.04$ , p=0.842
Been pregnant since birth	2	(2.9)	42	(2.9)	2.9	
Not been pregnant since birth	33	(47.1)	823	(56.1)	55.7	
Missing	35	(50.0)	602	(41.0)	41.4	
Pregnancy status (12 month)						$\chi^2(3)=0.32$ , p=0.956
Currently pregnant	7	(10)	130	(8.8)	8.9	
Not been pregnant since birth	33	(47.1)	751	(51.2)	51.0	
Not sure	0	(0.0)	1	(0.1)	0.1	
Missing	30	(42.9)	585	(39.9)	40.0	
Pregnancy status (18 month)						$\chi^2(2)=1.50$ , p=0.472
Currently pregnant	11	(15.7)	185	(12.6)	12.7	
Not been pregnant since birth	25	(35.7)	656	(44.7)	44.3	

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Not sure	0	(0.0)	1	(0.1)	0.1	
Missing	34	(48.6)	625	(42.6)	42.9	
Pregnancy status (24 month)						$\chi^2(2)=10.62$ , p=0.005
Currently pregnant	20	(28.6)	234	(16)	16.5	
Not been pregnant since birth	21	(30.0)	668	(45.5)	44.8	
Not sure	0	(0.0)	4	(0.3)	0.3	
Missing	29	(41.4)	561	(38.2)	38.4	
<b>Family composition: presence of a stepparent</b>						
Relationship with someone other than baby's father (baseline)						$\chi^2(1)=0.06$ , p=0.802
Yes	2	(2.9)	50	(3.4)	3.4	
No	67	(95.7)	1394	(95.0)	95.0	
Missing	1	(1.4)	23	(1.6)	1.6	
Relationship status with someone other than baby's father status (baseline)						$\chi^2(1)=3.01$ , p=0.183
Married	0	(0.0)	0	(0.0)	0.0	
Separated	0	(0.0)	0	(0.0)	0.0	
Closely involved/boyfriend	1	(1.4)	45	(3.1)	3.0	
Just friends	1	(1.4)	5	(0.3)	0.4	



	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Missing	68	(97.2)	1417	(96.6)	96.6	
Relationship with someone other than baby's father since baseline (late pregnancy)						$\chi^2(1)=0.61$ , p=0.435
Yes	0	(0.0)	12	(0.8)	0.8	
No	8	(11.4)	157	(10.7)	10.7	
Missing	62	(88.6)	1298	(88.5)	88.5	
Relationship status with someone other than baby's father since baseline status (late pregnancy)						n/a
Married	0	(0.0)	0	(0.0)	0.0	
Separated	0	(0.0)	0	(0.0)	0.0	
Closely involved/boyfriend	0	(0.0)	11	(0.7)	0.7	
Just friends	0	(0.0)	1	(0.1)	0.1	
Missing	70	(100.0)	1455	(99.2)	99.2	
Relationship with someone other than baby's father since last interview (6 month)						$\chi^2(1)=3.07$ , p=0.080
Yes	0	(0.0)	69	(4.7)	4.5	
No	35	(50.0)	784	(53.4)	53.3	
Missing	35	(50.0)	614	(41.9)	42.2	
Relationship status with someone other than baby's father since last interview status (6 month)						n/a

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Married	0	(0.0)	0	(0.0)	0.0	
Separated	0	(0.0)	0	(0.0)	0.0	
Closely involved/boyfriend	0	(0.0)	75	(5.1)	4.9	
Just friends	0	(0.0)	2	(0.1)	0.1	
Missing	70	(100.0)	1390	(94.8)	95.0	
Relationship with someone other than baby's father since last interview (12 month)						$\chi^2(2)=0.58$ , p=0.749
Yes	2	(2.8)	71	(4.9)	4.8	
No	38	(54.3)	794	(54.1)	54.1	
Missing	30	(42.9)	602	(41.0)	41.1	
Relationship status with someone other than baby's father since last interview status (12 month)						$\chi^2(3)=0.17$ , p=0.982
Married	0	(0.0)	1	(0.1)	0.1	
Separated	0	(0.0)	0	(0.0)	0.0	
Closely involved/boyfriend	3	(4.3)	69	(4.7)	4.7	
Just friends	0	(0.0)	2	(0.1)	0.1	
Missing	67	(95.7)	1395	(95.1)	95.1	
Relationship with someone other than baby's father since last interview (18 month)						$\chi^2(1)=0.45$ , p=0.504
Yes	3	(4.3)	98	(6.7)	6.6	

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
No	33	(47.1)	718	(48.9)	48.8	
Missing	34	(48.6)	651	(44.4)	44.6	
Relationship status with someone other than baby's father since last interview status (18 month)						$\chi^2(1)=0.24$ , p=0.626
Married	0	(0.0)	0	(0.0)	0.0	
Separated	0	(0.0)	0	(0.0)	0.0	
Closely involved/boyfriend	4	(5.7)	101	(6.9)	6.8	
Just friends	0	(0.0)	6	(0.4)	0.4	
Missing	66	(94.3)	1360	(92.7)	92.8	
Relationship with someone other than baby's father since last interview (24 month)						$\chi^2(1)=0.37$ , p=0.543
Yes	7	(10.0)	188	(12.8)	12.7	
No	33	(47.1)	685	(46.7)	46.7	
Missing	30	(42.9)	594	(40.5)	40.6	
Relationship status with someone other than baby's father since last interview status (24 month)						$\chi^2(2)=0.26$ , p=0.877
Married	0	(0.0)	0	(0.0)	0.0	
Separated	0	(0.0)	2	(0.1)	0.1	
Closely involved/boyfriend	11	(15.7)	209	(14.3)	14.3	
Just friends	0	(0.0)	3	(0.2)	0.2	

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Missing	59	(84.3)	1253	(85.4)	85.4	
<b>Family composition: Early separation from mother</b>						
Child had period of care (NPD)						$\chi^2(1)=0.28$ , p=0.599
Yes	0	(0.0)	6	(0.4)	0.4	
No	67	(95.7)	1457	(99.3)	99.1	
Missing	3	(4.3)	4	(0.3)	0.5	
<b>Parent education level - low education level, low IQ and learning disabilities</b>						
Problems with reading, writing, maths (baseline) (range 3=less problems – 9=more problems)	70	3.0 (3.0 to 4.0) 3.43 (0.84)	1458	3.0 (3.0 to 4.0) 3.41 (0.83)	3.0 (3.0 to 4.0) 3.41 (0.83)	$t(75.56)=-0.15$ , p=0.880
Problems with reading, writing, maths (24 month) (range 3=less problems – 9=more problems)	41	3.0 (3.0 to 3.0) 3.29 (0.64)	905	3.0 (3.0 to 3.0) 3.19 (0.53)	3.0 (3.0 to 3.0) 3.20 (0.54)	$t(42.55)=-0.99$ , p=0.324
<b>Parenting and family functioning: lack of experience or competence as a caregiver, less knowledge of child development</b>						
Child safety (12 month) (range 0=safest – 5=less safe)	39	3.0 (2.0 to 4.0) 3.00 (1.64)	709	3.0 (2.0 to 4.0) 2.82 (1.82)	3.0 (2.0 to 4.0) 2.83 (1.81)	$t(43.31)=-0.67$ , p=0.506

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Child safety (18 month) (range 0=safest – 5=less safe)	35	4.0 (1.0 to 5.0) 1.89 (4.26)	822	3.0 (0.0 to 4.0) 1.60 (4.02)	3.0 (0.0 to 4.0) 1.61 (4.03)	t(49.66)=0.72, p=0.475
Child safety (24 month) (range 0=safest – 5=less safe)	40	2.0 (0.0 to 4.0) 0.08 (5.34)	881	2.0 (0.0 to 4.0) 0.18 (4.88)	2.0 (0.0 to 4.0) 0.17 (4.90)	t(42.02)=0.30, p=0.768
Baby diet (18 month)						X <sup>2</sup> (1)=0.02, p=0.885
Had healthy food every day	25	(35.7)	597	(40.7)	40.5	
Did not have healthy food every day	10	(14.3)	226	(15.4)	15.3	
Missing	35	(50.0)	644	(43.9)	44.2	
Baby diet (24 month)						X <sup>2</sup> (1)=0.80, p=0.371
Had healthy food every day	24	(34.3)	586	(40.0)	39.7	
Did not have healthy food every day	16	(22.8)	291	(19.8)	20.0	
Missing	30	(42.9)	590	(40.2)	40.3	
Anticipatory parenting (late pregnancy) (range 5= structured child rearing practices – 25=less structured environment)	60	9.0 (8.0 to 10.0) 7.23 (12.65)	1117	9.0 (7.0 to 10.0) 5.50 (17.43)	9.0 (7.0 to 10.0) 5.59 (17.22)	t(71.62)= -1.01, p=0.314
Maternal intrusiveness (maternal sensitivity) (range 0=lower intrusiveness – 18=higher intrusiveness)	21	1.0 (0.0 to 2.0)	417	1.0 (0.0 to 3.0)	1.0 (0.0 to 3.0)	t(23.30)=1.28, p=0.212

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
		1.24 (1.37)		1.64 (1.73)	1.61 (1.71)	
<b>Parenting and family functioning: providing less than adequate prenatal care</b>						
Times seen midwife (all contacts) (late pregnancy)	56	2.0 (3.3 to 8.0) 6.50 (3.69)	1055	6.0 (5.0 to 9.0) 7.05 (4.00)	6.0 (5.0 to 9.0) 7.02 (4.00)	t(62.08)=1.08, p=0.283
Times been to antenatal clinic (late pregnancy)	60	3.0 (0.3 to 5.0) 3.35 (3.82)	1115	2.0 (0.0 to 4.0) 2.52 (3.36)	2.0 (0.0 to 4.0) 2.57 (3.39)	t(64.02)= -1.65, p=0.105
Times maternity clinic (late pregnancy)	60	1.0 (0.0 to 1.0) 1.00 (1.74)	1120	0.0 (0.0 to 1.0) 0.77 (1.54)	0.0 (0.0 to 1.0) 0.78 (1.55)	t(64.09)= -1.01, p=0.314
Number antenatal check-ups (birth)	67	11.0 (10.0 to 14.0) 11.28 (3.16)	1327	10.0 (9.0 to 12.0) 10.33 (3.76)	10.0 (8.0 to 12.0) 10.37 (3.74)	t(75.79)= -2.40, p=0.019
Number planned attendances (birth)	67	1.0 (0.0 to 2.0) 1.36 (2.70)	1327	0.5 (0.0 to 2.0) 1.55 (2.63)	1.0 (0.0 to 2.0) 1.54 (2.64)	t(72.43)=0.58, p=0.564
Number unplanned attendances (birth)	67	1.0 (0.0 to 3.0) 2.28 (2.91)	1327	1.0 (0.0 to 3.0) 1.67 (1.91)	1.0 (0.0 to 3.0) 1.70 (1.98)	t(69.91)= -1.71, p=0.092

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
<b>Parenting and family functioning: poor anger expression and management skills, poor frustration tolerance</b>						
Annoyance at baby (6 month)						$\chi^2(5)=1.15$ , p=0.950
Almost all of the time	0	(0.0)	1	(0.1)	0.1	
Very frequently	0	(0.0)	4	(0.3)	0.3	
Frequently	0	(0.0)	13	(0.9)	0.8	
Occasionally	3	(4.3)	94	(6.4)	6.3	
Very rarely	13	(18.6)	276	(18.8)	18.8	
Never	19	(27.1)	449	(30.6)	30.4	
Missing	35	(50.0)	630	(42.9)	43.3	
Annoyance at baby (12 month)						$\chi^2(6)=15.18$ , p=0.019
Almost all of the time	1	(1.4)	3	(0.2)	0.3	
Very frequently	1	(1.4)	1	(0.1)	0.1	
Frequently	0	(0.0)	15	(1.0)	1.0	
Occasionally	5	(7.1)	117	(8.0)	7.9	
Very rarely	16	(22.9)	366	(25.0)	24.9	
Never	16	(22.9)	371	(25.3)	25.2	
Missing	31	(44.3)	594	(40.4)	40.6	

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Annoyance at baby (18 month)						$\chi^2(5)=14.78$ , p=0.011
Almost all of the time	1	(1.4)	1	(0.1)	0.1	
Very frequently	0	(0.0)	4	(0.3)	0.3	
Frequently	2	(2.8)	16	(1.1)	1.2	
Occasionally	7	(10.0)	118	(8.0)	8.1	
Very rarely	16	(22.9)	401	(27.3)	27.1	
Never	9	(12.9)	284	(19.4)	19.1	
Missing	35	(50.0)	642	(43.8)	44.1	
Annoyance at baby (24 month)						$\chi^2(5)=1.03$ , p=0.960
Almost all of the time	0	(0.0)	1	(0.1)	0.1	
Very frequently	0	(0.0)	3	(0.2)	0.2	
Frequently	0	(0.0)	12	(0.8)	0.8	
Occasionally	2	(2.9)	66	(4.5)	4.4	
Very rarely	10	(14.3)	209	(14.2)	14.2	
Never	14	(20.0)	337	(23.0)	22.8	
Missing	44	(62.8)	840	(57.2)	57.5	
<b>Parenting and family functioning: less empathy</b>						



	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Maternal sensitivity (maternal sensitivity) (range 0=less sensitive – 18=more sensitive)	21	11.0 (10.0 to 12.0) 10.90 (0.89)	417	12.0 (10.0 to 12.0) 11.04 (1.68)	11.0 (10.0 to 12.0) 11.03 (1.65)	t(27.76)=0.63, p=0.531
<b>Parenting and family functioning: less positive affection and warmth toward their children</b>						
Anticipatory parenting (late pregnancy), see domain 'Parenting and family functioning: lack of experience or competence as a caregiver, less knowledge of child development' for results						
Parental role strain: thinking about baby (6 month)						X <sup>2</sup> (4)=1.31, p=0.860
Almost all the time	30	(42.9)	662	(45.1)	45.0	
Very frequently	4	(5.7)	108	(7.4)	7.3	
Frequently	1	(1.4)	45	(3.1)	3.0	
Occasionally	0	(0.0)	15	(1)	1.0	
Very rarely	0	(0.0)	1	(0.1)	0.1	
Never	0	(0.0)	0	(0.0)	0.0	
Missing	35	(50.0)	636	(43.3)	43.6	
Parental role strain: when leaving baby (6 month)						X <sup>2</sup> (4)=2.71, p=0.607
Always feel sad	13	(18.6)	218	(14.9)	15.0	
Often feel sad	6	(8.5)	142	(9.7)	9.6	

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Mixed feelings sadness and relief	16	(22.9)	442	(30.1)	29.8	
Often relieved	0	(0.0)	18	(1.2)	1.2	
Always relieved	0	(0.0)	3	(0.2)	0.2	
Missing	35	(50.0)	644	(43.9)	44.2	
Parental role strain: thinking about baby (12 month)						$\chi^2(5)=4.14$ , p=0.995
Almost all the time	28	(40)	683	(46.5)	46.3	
Very frequently	8	(11.4)	98	(6.7)	6.9	
Frequently	3	(4.3)	67	(4.6)	4.6	
Occasionally	0	(0.0)	22	(1.5)	1.4	
Very rarely	0	(0.0)	3	(0.2)	0.2	
Never	0	(0.0)	0	(0.0)	0.0	
Missing	31	(44.3)	594	(40.5)	40.6	
Parental role strain: when leaving baby (12 month)						$\chi^2(5)=7.05$ , p=0.217
Always feel sad	10	(14.3)	207	(14.1)	14.1	
Often feel sad	5	(7.2)	163	(11.1)	10.9	
Mixed feelings sadness and relief	22	(31.4)	476	(32.5)	32.4	
Often relieved	1	(1.4)	16	(1.1)	1.1	
Always relieved	1	(1.4)	2	(0.1)	0.2	

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Missing	31	(44.3)	573	(39.1)	39.3	
Parental role strain: thinking about baby (18 month)						$\chi^2(5)=0.35$ , p=0.997
Almost all the time	25	(35.7)	601	(41)	40.7	
Very frequently	6	(8.6)	137	(9.3)	9.3	
Frequently	3	(4.3)	58	(4.0)	4.0	
Occasionally	1	(1.4)	21	(1.4)	1.4	
Very rarely	0	(0.0)	4	(0.3)	0.3	
Never	0	(0.0)	1	(0.1)	0.1	
Missing	35	(50.0)	645	(43.9)	44.2	
Parental role strain: when leaving baby (18 month)						$\chi^2(4)=12.76$ , p=0.013
Always feel sad	9	(12.9)	205	(14.0)	13.9	
Often feel sad	4	(5.7)	162	(11.0)	10.8	
Mixed feelings sadness and relief	21	(30.0)	440	(30.0)	30.0	
Often relieved	0	(0.0)	13	(0.9)	0.9	
Always relieved	1	(1.4)	1	(0.1)	0.1	
Missing	35	(50.0)	646	(44.0)	44.3	
Parental role strain: thinking about baby (24 month)						$\chi^2(5)=1.22$ , p=0.943

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Almost all the time	28	(40.0)	551	(37.6)	37.7	
Very frequently	6	(8.6)	157	(10.7)	10.6	
Frequently	3	(4.3)	99	(6.7)	6.6	
Occasionally	3	(4.3)	62	(4.2)	4.2	
Very rarely	0	(0.0)	10	(0.7)	0.7	
Never	0	(0.0)	3	(0.2)	0.2	
Missing	30	(42.9)	585	(39.9)	40.0	
Parental role strain: when leaving baby (24 month)						$\chi^2(4)=1.63$ , p=0.803
Always feel sad	4	(5.7)	145	(9.9)	9.7	
Often feel sad	8	(11.5)	171	(11.7)	11.7	
Mixed feelings sadness and relief	25	(35.7)	512	(34.9)	34.9	
Often relieved	1	(1.4)	36	(2.4)	2.4	
Always relieved	0	(0.0)	6	(0.4)	0.4	
Missing	32	(45.7)	597	(40.7)	40.9	
Maternal sensitivity (maternal sensitivity), see domain						
'Parenting and family functioning: less empathy' for result						
<b>Parenting and family functioning: Parental stress, poor stress management, economic stress</b>						

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Adaptive functioning: difficulty basic skills (baseline)						$\chi^2(1)=0.34$ , p=0.558
Yes	20	(28.6)	371	(25.3)	25.4	
No	50	(71.4)	1087	(74.1)	74	
Missing	0	(0.0)	9	(0.6)	0.6	
Adaptive functioning: difficulty life skills (baseline)						$\chi^2(1)=6.95$ , p=0.008
Yes	28	(40.0)	375	(25.6)	26.2	
No	42	(60.0)	1080	(73.6)	73	
Missing	0	(0.0)	12	(0.8)	0.8	
Adaptive functioning: burden (baseline)						$\chi^2(1)=0.01$ , p=0.915
Yes	20	(28.6)	429	(29.2)	29.2	
No	49	(70.0)	1021	(69.6)	69.6	
Missing	1	(1.4)	17	(1.2)	1.2	
Self-efficacy (baseline) (range 10=lower self-efficacy – 40=higher self-efficacy)	70	29.0 (26.0 to 32.3) 29.41 (4.68)	1436	30.0 (28.0 to 33.0) 30.05 (4.43)	30.0 (28.0 to 33.0) 30.02 (4.44)	$t(75.15)=1.12$ , p=0.268
Self-efficacy (6 month) (range 10=lower self-efficacy – 40=higher self-efficacy)	35	32.0 (29.0 to 36.0) 32.08 (4.57)	856	33.0 (30.0 to 37.0) 33.23 (4.12)	33.0 (30.0 to 37.0) 33.18 (4.13)	$t(36.29)=1.47$ , p=0.151

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Self-efficacy (12 month) (range 10=lower self-efficacy – 40=higher self-efficacy)	39	33.0 (30.0 to 36.0) 32.87 (4.28)	882	33.0 (30.0 to 38.0) 33.66 (4.47)	33.0 (30.0 to 37.5) 33.62 (4.46)	t(41.75)=1.12, p=0.270
Self-efficacy (18 month) (range 10=lower self-efficacy – 40=higher self-efficacy)	35	32.0 (30.0 to 36.0) 32.54 (4.76)	841	33.0 (30.0 to 37.0) 33.62 (4.23)	33.0 (30.0 to 37.0) 33.58 (4.25)	t(36.26)=1.32, p=0.196
Self-efficacy (24 month) (range 10=lower self-efficacy – 40=higher self-efficacy)	41	33.0 (30.0 to 37.5) 33.10 (5.34)	905	32.0 (30.0 to 36.0) 32.65 (4.10)	32.0 (30.0 to 36.0) 32.67 (4.16)	t(42.17)= -0.53, p=0.596
<b>Parenting and family functioning: negative perceptions of life events</b>						
Self-efficacy baseline – 24 month), see domain ‘Parenting and family functioning: Parental stress, poor stress management, economic stress’ for results						
<b>Parenting and family functioning: parents of maltreated children perceived their own childhoods as being unhappy, poor relationships with their own parents, conflict in a family or a lack of family cohesion, Poor family functioning</b>						
Mother contact with fostering services (6 month)						X <sup>2</sup> (1)=0.17, p=0.681
Yes	0	(0.0)	4	(0.3)	0.3	

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
No	35	(50.0)	830	(56.6)	56.3	
Missing	35	(50.0)	633	(43.1)	43.4	
Mother contact with fostering services (12 month)						$\chi^2(2)=0.18$ , p=0.915
Yes	0	(0.0)	3	(0.2)	0.2	
No	39	(55.7)	856	(58.4)	58.2	
Missing	31	(44.3)	608	(41.4)	41.6	
Mother contact with fostering services (18 month)						$\chi^2(2)=0.13$ , p=0.939
Yes	0	(0.0)	2	(0.1)	0.1	
No	35	(50.0)	836	(57.0)	56.7	
Missing	35	(50.0)	629	(42.9)	43.2	
Mother contact with fostering services (24 month)						$\chi^2(1)=0.14$ , p=0.712
Yes	0	(0.0)	3	(0.2)	0.2	
No	41	(58.6)	902	(61.5)	61.3	
Missing	29	(41.4)	562	(38.3)	38.5	
Mother fostered (6 month)						$\chi^2(1)=0.13$ , p=0.720
Yes	0	(0.0)	3	(0.2)	0.2	

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
No	35	(50.0)	818	(55.8)	55.5	
Missing	35	(50.0)	646	(44.0)	44.3	
Mother fostered (12 month)						$\chi^2(2)=0.18$ , p=0.915
Yes	0	(0.0)	3	(0.2)	0.2	
No	39	(55.7)	873	(59.5)	59.3	
Missing	31	(44.3)	591	(40.3)	40.5	
Mother fostered (18 month)						$\chi^2(1)=0.17$ , p=0.682
Yes	0	(0.0)	4	(0.3)	0.3	
No	35	(50.0)	835	(56.9)	56.6	
Missing	35	(50.0)	628	(42.8)	43.1	
Mother fostered (24 month)						$\chi^2(1)=0.05$ , p=0.831
Yes	0	(0.0)	1	(0.1)	0.1	
No	41	(58.6)	905	(61.7)	61.5	
Missing	29	(41.4)	561	(38.2)	38.4	
Mother lived away from parents (baseline)						$\chi^2(1)=0.24$ , p=0.623
Yes	34	(48.6)	673	(45.9)	46.0	



	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
No	35	(50.0)	782	(53.3)	53.2	
Missing	1	(1.4)	12	(0.8)	0.8	
Mother contact with own mother (baseline)						$\chi^2(8)=10.80$ , p=0.213
Lives with mother	32	(45.7)	834	(56.9)	56.3	
Every day	8	(11.4)	105	(7.2)	7.4	
3-6 times a week	4	(5.7)	105	(7.2)	7.1	
1-2 times a week	9	(12.9)	148	(10.1)	10.2	
At least once a month	6	(8.6)	97	(6.6)	6.7	
Once very few months	1	(1.4)	47	(3.2)	3.1	
Once a year	0	(0.0)	14	(0.9)	0.9	
Less than once a year	1	(1.4)	12	(0.8)	0.9	
Never	7	(10.0)	62	(4.2)	4.5	
Missing	2	(2.9)	43	(2.9)	2.9	
Mother contact with own father (baseline)						$\chi^2(8)=15.41$ , p=0.152
Lives with mother	11	(15.7)	352	(24.0)	23.6	
Every day	6	(8.6)	68	(4.6)	4.8	
3-6 times a week	3	(4.3)	83	(5.7)	5.6	
1-2 times a week	9	(12.9)	157	(10.7)	10.8	

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
At least once a month	3	(4.3)	139	(9.5)	9.2	
Once very few months	4	(5.7)	160	(10.9)	10.7	
Once a year	0	(0.0)	47	(3.2)	3.1	
Less than once a year	4	(5.7)	69	(4.7)	4.7	
Never	18	(25.7)	231	(15.7)	16.2	
Missing	12	(17.1)	161	(11.0)	11.3	
Mother's parents separated (baseline)						$\chi^2(3)=10.95$ , 0.012
Yes	40	(57.2)	889	(60.6)	60.4	
No	14	(20.0)	485	(33.1)	32.5	
Parents never lived together	10	(14.3)	83	(5.7)	6.1	
Don't know	1	(1.4)	5	(0.3)	0.4	
Missing	0	(0.0)	10	(0.7)	0.6	
Mother's age (years) when parents separated (baseline)	37	5.0 (2.0 to 8.0) 5.86 (5.03)	868	5.0 (2.0 to 10.0) 60.4 (4.95)	5.0 (2.0 to 10.0) 6.03 (4.95)	$t(39.03)=0.21$ , $p=0.838$
Mother been homeless (baseline)						$\chi^2(1)=0.68$ , $p=0.411$
Yes	16	(22.9)	276	(18.8)	19.0	
No	54	(77.1)	1184	(80.7)	80.5	

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Missing	0	(0.0)	7	(0.5)	0.5	
Mother been homeless (6 month)						$\chi^2(1)=0.27$ , p=0.602
Yes	3	(4.3)	79	(5.4)	5.3	
No	19	(27.1)	360	(24.5)	24.7	
Missing	48	(68.6)	1028	(70.1)	70.0	
Mother been homeless (12 month)						$\chi^2(2)=0.15$ , p=0.927
Yes	3	(4.3)	61	(4.2)	4.2	
No	11	(15.7)	279	(19.0)	18.9	
Missing	56	(80)	1126	(76.8)	76.9	
Mother been homeless (18 month)						$\chi^2(1)=2.60$ , p=0.107
Yes	6	(8.6)	63	(4.3)	4.5	
No	8	(11.4)	202	(13.8)	13.7	
Missing	56	(80.0)	1201	(81.9)	81.8	
Mother been homeless (24 month)						$\chi^2(1)=3.24$ , p=0.072
Yes	1	(1.4)	95	(6.5)	6.3	
No	20	(28.6)	360	(24.5)	24.7	

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Missing	49	(70.0)	1012	(69.0)	69.0	
<b>Parenting and family functioning: poor stability and less security in family</b>						
Mother not living with baby (6 month)						n/a
Baby in foster care	0	(0.0)	1	(0.1)	0.1	
Baby living with someone else in informal agreement	0	(0.0)	4	(0.3)	0.3	
Baby in hospital	0	(0.0)	0	(0.0)	0.0	
Baby adopted	0	(0.0)	0	(0.0)	0.0	
Missing	70	(100.0)	1462	(99.6)	99.6	
Mother not living with baby (12 month)						n/a
Baby in foster care	0	(0.0)	2	(0.1)	0.1	
Baby living with someone else in informal agreement	0	(0.0)	5	(0.3)	0.3	
Baby in hospital	0	(0.0)	1	(0.1)	0.1	
Baby adopted	0	(0.0)	0	(0.0)	0.0	
Missing	70	(100.0)	1459	(99.5)	99.5	
Mother not living with baby (18 month)						n/a
Baby in foster care	0	(0.0)	5	(0.3)	0.3	
Baby living with someone else in	0	(0.0)	11	(0.8)	0.7	

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
informal agreement						
Baby in hospital	0	(0.0)	0	(0.0)	0.0	
Baby adopted	0	(0.0)	0	(0.0)	0.0	
Missing	70	(100.0)	1451	(98.9)	99.0	
Mother not living with baby (24 month)						$\chi^2(1)=0.41$ , p=0.523
Baby in foster care	0	(0.0)	5	(0.3)	0.3	
Baby living with someone else in informal agreement	1	(1.4)	12	(0.8)	0.8	
Baby in hospital	0	(0.0)	0	(0.0)	0.0	
Baby adopted	0	(0.0)	0	(0.0)	0.0	
Missing	69	(98.6)	1450	(98.9)	98.9	
Mother moved home (6 month)						$\chi^2(1)=2.19$ , p=0.139
Yes	22	(31.4)	439	(29.9)	30.0	
No	12	(17.1)	437	(29.8)	29.2	
Missing	35	(50.0)	591	(40.3)	40.8	
Mother moved home (12 month)						$\chi^2(2)=0.24$ , p=0.889
Yes	14	(20.0)	340	(23.2)	23.0	

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
No	26	(37.1)	545	(37.1)	37.2	
Missing	30	(42.9)	582	(39.7)	39.8	
Mother moved home (18 month)						$\chi^2(1)=0.89$ , p=0.347
Yes	14	(20.0)	265	(18.1)	18.2	
No	22	(31.4)	578	(39.4)	39.0	
Missing	34	(48.6)	624	(42.5)	42.8	
Mother moved home (24 month)						$\chi^2(1)=0.01$ , p=0.906
Yes	21	(30.0)	455	(31.0)	31.0	
No	20	(28.6)	450	(30.7)	30.6	
Missing	29	(41.4)	562	(38.3)	38.4	
Mother fostered (6 – 24 month), see domain 'Parenting and family functioning: parents of maltreated children perceived their own childhoods as being unhappy, poor relationships with their own parents, conflict in a family or a lack of family cohesion, Poor family functioning' for results						
Mother lived away from parents (baseline), see domain 'Parenting and family functioning: parents of maltreated children perceived their own childhoods as being unhappy,						

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
poor relationships with their own parents, conflict in a family or a lack of family cohesion, Poor family functioning' for results						
Mother relationship status (late pregnancy – 24 month), see domain 'Family composition: single parent families, unmarried mothers, female headed households' for results						
Adaptive functioning (baseline), see domain 'Parenting and family functioning: Parental stress, poor stress management, economic stress' for results						
Child had period of care (NPD), see domain 'Family composition: Early separation from mother' for results						
<b>Intimate partner violence: intimate partner violence</b>						
Composite abuse scale (24 month) (range 0=lower abuse score – 145=higher abuse score)	20	0.0 (0.0 to 1.0) 2.50 (8.30)	551	0.0 (0.0 to 3.0) 5.00 (13.45)	0.0 (0.0 to 3.0) 4.91 (13.31)	t(22.79)=1.29, p=0.212
<b>Intimate partner violence: poor relationship between parents or other family members , parental conflict, maternal dissatisfaction, poor marital quality</b>						
Relationship quality (baseline) (range 7=lower quality – 35=higher quality)	54	29.0 (25.0 to 31.3) 28.02 (4.94)	1158	29.0 (26.0 to 32.0) 28.08 (4.80)	29.0 (26.0 to 32.0) 28.08 (4.80)	t(57.76)=0.10, p=0.924

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Relationship quality if relationship changed since baseline (late pregnancy) (range 7=lower quality – 35=higher quality)	4	30.0 (26.5 to 34.3) 30.25 (4.03)	69	31.0 (27.0 to 32.5) 29.36 (4.15)	31.0 (27.0 to 32.5) 29.41 (4.12)	t(3.38)=-0.43, p=0.695
Relationship quality if relationship changed since last interview (6 months) (range 7=lower quality – 35=higher quality)	20	29.0 (25.5 to 31.5) 28.00 (4.66)	576	29.0 (26.0 to 32.0) 28.66 (4.64)	29.0 (26.0 to 32.0) 28.64 (4.64)	t(20.33)=0.63, p=0.538
Relationship quality if relationship changed since last interview (12 months) (range 7=lower quality – 35=higher quality)	19	29.0 (27.0 to 30.0) 27.95 (3.84)	519	29.0 (26.0 to 32.0) 28.60 (4.79)	29.0 (26.0 to 32.0) 28.58 (4.76)	t(20.11)=0.73, p=0.477
Relationship quality if relationship changed since last interview (18 months) (range 7=lower quality – 35=higher quality)	21	28.0 (24.6 to 31.0) 27.38 (5.79)	470	29.0 (27.0 to 32.0) 29.93 (4.11)	29.0 (27.0 to 32.0) 28.87 (4.20)	t(20.91)=1.22, p=0.238
Relationship quality if relationship changed since last interview (24 months) (range 7=lower quality – 35=higher quality)	30	28.0 (26.0 to 32.3) 28.27 (3.89)	580	29.0 (27.0 to 32.0) 28.92 (4.36)	29.0 (27.0 to 32.0) 28.88 (4.33)	t(32.89)=0.87, p=0.382
<b>Ethnicity or race: ethnicity or race, foreign-born parents</b>						
Mother born outside UK (baseline)						$\chi^2(1)=1.30$ , p=0.254
Yes	1	(1.4)	61	(4.2)	4.0	
No	69	(98.6)	1399	(95.4)	95.5	
Missing	0	(0.0)	7	(0.4)	0.5	



	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi-squared or t-test statistic, p-value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
<b>Health service use by child</b>						
Number of visits to GP (GP data)	20	6.5 (3.3 to 11.8) 8.60 (6.38)	571	9.0 (5.0 to 13.0) 9.96 (6.74)	9.0 (5.0 to 13.0) 9.91 (6.73)	t(20.51)=0.93, p=0.362
Baby attended A&E (NHS Digital A&E data)						X <sup>2</sup> (1)=1.78, p=0.182
Yes	60	(85.7)	1082	(73.7)	74.3	
No	2	(2.9)	92	(6.3)	6.1	
Missing	8	(11.4)	293	(20.0)	19.6	
Baby attended Inpatients at any time (NHS Digital Inpatients data)						X <sup>2</sup> (1)=2.31, p=0.129
Yes	70	(100.0)	1273	(86.8)	87.4	
No	0	(0.0)	42	(2.9)	2.7	
Missing	0	(0.0)	152	(10.3)	9.9	
Baby attended Outpatients at any time (NHS Digital Outpatients data)						X <sup>2</sup> (1)=0.13, p=0.722
Yes	48	(68.6)	876	(59.7)	60.1	
No	22	(31.4)	441	(30.1)	30.1	
Missing	0	(0.0)	150	(10.2)	9.8	
<b>Child disability, illness, or development: disability (up to three congenital abnormalities)</b>						

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
First congenital abnormality (birth)						$\chi^2(1)=0.07$ , p=0.786
Yes	3	(4.3)	69	(4.7)	4.7	
No	66	(94.3)	1289	(87.9)	88.1	
Missing	1	(1.4)	109	(7.4)	7.2	
Second congenital abnormality (birth)						$\chi^2(1)=0.41$ , p=0.523
Yes	0	(0.0)	8	(0.6)	0.5	
No	69	(98.6)	1350	(92.0)	92.3	
Missing	1	(1.4)	109	(7.4)	7.2	
third congenital abnormality (birth)						$\chi^2(1)=0.15$ , p=0.696
Yes	0	(0.0)	3	(0.2)	0.2	
No	69	(98.6)	1355	(92.4)	92.6	
Missing	1	(1.4)	109	(7.4)	7.2	
<b>Child disability, illness, or development: developmental delay</b>						
Mother contact with child development service (6 month)						$\chi^2(1)=0.21$ , p=0.646
Yes	0	(0.0)	5	(0.3)	0.3	
No	35	(50.0)	829	(56.5)	56.2	
Missing	35	(50.0)	633	(43.2)	43.5	

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Mother contact with child development service (12 month)						$\chi^2(2)=0.54$ , p=0.763
Yes	0	(0.0)	10	(0.7)	0.7	
No	39	(55.7)	865	(59.0)	58.8	
Missing	31	(44.3)	592	(40.3)	40.5	
Mother contact with child development service (18 month)						$\chi^2(2)=0.64$ , p=0.920
Yes	0	(0.0)	11	(0.8)	0.7	
No	35	(50.0)	823	(56.1)	55.8	
Missing	35	(50.0)	633	(43.1)	43.5	
Mother contact with child development service (24 month)						$\chi^2(1)=0.10$ , p=0.751
Yes	1	(1.4)	16	(1.1)	1.1	
No	41	(58.6)	890	(60.7)	60.6	
Missing	28	(40.0)	561	(38.2)	38.3	
Cognitive development gross motor delay (development of larger movements e.g. crawling) (12 months)						$\chi^2(2)=0.69$ , p=0.710
Yes	0	(0.0)	14	(1.0)	0.9	
No	39	(55.7)	853	(58.1)	58	
Missing	31	(44.3)	600	(40.9)	41.1	

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Cognitive development fine motor delay (development of smaller movements e.g. turning pages of book) (12 months)						$\chi^2(2)=2.28$ , p=0.320
Yes	0	(0.0)	47	(3.2)	3.1	
No	39	(55.7)	819	(55.8)	55.8	
Missing	31	(44.3)	601	(41.0)	41.1	
Cognitive development gross motor delay (development of larger movements e.g. crawling) (18 months)						$\chi^2(1)=0.10$ , p=0.755
Yes	1	(1.4)	32	(2.2)	2.2	
No	34	(48.6)	790	(53.8)	53.6	
Missing	35	(50.0)	645	(44.0)	44.2	
Cognitive development fine motor delay (development of smaller movements e.g. turning pages of book) (18 months)						$\chi^2(1)=0.26$ , p=0.612
Yes	0	(0.0)	8	(0.6)	0.5	
No	35	(50.0)	816	(55.6)	55.4	
Missing	35	(50.0)	643	(43.8)	44.1	
Cognitive development gross motor delay (development of larger movements e.g. crawling) (24 months)						$\chi^2(1)=0.04$ , p=0.834
Yes	2	(2.8)	38	(2.6)	2.6	
No	38	(54.3)	844	(57.5)	57.4	
Missing	30	(42.9)	585	(39.9)	40	

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Cognitive development fine motor delay (development of smaller movements e.g. turning pages of book) (24 months)						$\chi^2(1)=0.74$ , p=0.391
Yes	4	(5.7)	57	(3.9)	4	
No	36	(51.4)	815	(55.5)	55.4	
Missing	30	(42.9)	595	(40.6)	40.6	
Language development delay (12 months)						$\chi^2(1)=0.00$ , p=0.949
Yes	6	(8.6)	130	(8.8)	8.9	
No	33	(47.1)	736	(50.2)	50	
Missing	31	(44.3)	601	(41.0)	41.1	
Language development delay (18 months)						$\chi^2(1)=1.56$ , p=0.212
Yes	4	(5.7)	164	(11.2)	10.9	
No	31	(44.3)	657	(44.8)	44.8	
Missing	35	(50.0)	646	(44.0)	44.3	
Language development (ELM) (percentiles)	41	41.0 (35.5 to 47.0) 41.27 (8.09)	853	44.0 (39.0 to 50.0) 44.17 (7.52)	44.0 (39.0 to 50.0) 44.04 (7.57)	$t(43.39)=2.25$ , p=0.030
<b>Child disability, illness, or development: prematurity or low birth weight</b>						

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Birth weight (birth)	69	3050.0 (2890.0 to 3550.0) 3200.43 (517.79)	1360	3270.0 (2935.0 to 3598.8) 3230.49 (575.46)	3260.0 (2934.5 to 3590.0) 3229.04 (572.68)	t(76.78)=0.47, p=0.641
<b>Child gender</b>						
Gender (birth)						X <sup>2</sup> (1)=1.53, p=0.216
Female	39	(55.7)	671	(45.7)	46.2	
Male	31	(44.3)	723	(49.4)	49.1	
Missing	0	(0.0)	73	(4.9)	4.7	
<b>Social support</b>						
Social support (baseline) (range 0=lower support – 100=higher support)	70	90.8 (79.0 to 99.0) 85.45 (17.08)	1447	90.8 (77.6 to 98.7) 85.04 (16.73)	90.8 (77.6 to 98.7) 85.06 (16.74)	t(75.54)= -0.20, p=0.846
Social support (6 month) (range 0=lower support – 100=higher support)	34	85.5 (68.4 to 96.4) 81.23 (17.68)	827	90.8 (76.3 to 98.7) 85.09 (16.40)	90.8 (75.7 to 98.7) 84.94 (16.46)	t(35.38)=1.25, p=0.219
Social support (12 month) (range 0=lower support – 100=higher support)	43	76.3 (68.4 to 94.8) 76.53 (20.00)	931	88.2 (75.0 to 98.7) 83.84 (17.21)	87.5 (75.0 to 98.7) 83.52 (17.40)	t(44.92)=2.36, p=0.023

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Social support (18 month) (range 0=lower support – 100=higher support)	35	84.2 (60.5 to 96.1) 80.15 (18.03)	836	89.5 (75.0 to 98.7) 84.31 (17.09)	89.5 (75.0 to 98.7) 84.14 (17.14)	t(36.61)=1.34, p=0.188
Social support (24 month) (range 0=lower support – 10=higher support)	41	4.7 (4.0 to 5.0) 4.45 (0.66)	899	4.4 (4.0 to 5.0) 4.36 (0.74)	4.6 (4.0 to 5.0) 4.36 (0.74)	t(44.79)= -0.91, p=0.368
<b>Neighbourhood and community: neighbourhood poverty, instability and economic disadvantage</b>						
Postcode (Index of Multiple Deprivation) (baseline)	70	50.4 (33.8 to 66.0) 47.81 (18.00)	1448	37.9 (24.8 to 51.5) 38.64 (18.04)	38.2 (25.0 to 52.0) 39.06 (18.17)	t(75.27)= -3.99, p=0.000
<b>Socio-economic status: low SES</b>						
Postcode (Index of Multiple Deprivation) (baseline), see domain 'Neighbourhood and community: neighbourhood poverty, instability and economic disadvantage' for results						
Family resources (baseline) (range 4=less resources – 20=more resources)	70	50.4 (33.8 to 66.0) 13.42 (3.95)	1448	37.9 (24.8 to 51.5) 13.41 (4.21)	38.2 (25.0 to 52.0) 13.41 (4.20)	t(69.70)= -0.03, p=0.000
Family resources (6 month) (range 4=less resources – 20=more resources)	64	13.0 (11.0 to 16.8) 13.88 (4.03)	1404	14.0 (11.0 to 17.0) 14.35 (3.73)	14.0 (11.0 to 17.0) 14.33 (3.74)	t(33.21)=0.65, p=0.976

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Family resources (12 month) (range 4=less resources – 20=more resources)	32	14.0 (10.3 to 17.0) 13.05 (4.12)	784	15.0 (12.0 to 17.0) 13.84 (4.04)	15.0 (12.0 to 17.0) 13.81 (4.04)	t(41.38)=1.17, p=0.518
Family resources (18 month) (range 4=less resources – 20=more resources)	39	12.0 (11.0 to 16.0) 12.99 (4.00)	858	14.0 (11.0 to 17.0) 13.99 (3.70)	14.0 (11.0 to 17.0) 13.94 (3.72)	t(35.37)=2.01, p=0.247
Family resources (24 month) (range 4=less resources – 20=more resources)	39	12.2 (12.0 to 17.0) 13.56 (4.12)	886	13.5 (11.0 to 16.0) 13.52 (3.71)	13.5 (11.0 to 16.0) 13.52 (3.72)	t(40.75)= -0.06, p=0.951
Free school meal eligible (NPD)						$\chi^2(1)=1.13$ , p=0.289
Yes	15	(21.4)	114	(7.8)	8.4	
No	53	(75.7)	559	(38.1)	39.8	
Missing	2	(2.9)	794	(54.1)	51.8	
<b>Socio-economic status: benefits</b>						
Receiving benefits currently (baseline)						$\chi^2(1)=0.01$ , p=0.942
Yes	25	(35.7)	527	(35.9)	35.9	
No	45	(64.3)	931	(63.5)	63.5	
Missing	0	(0.0)	9	(0.6)	0.6	



	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Receiving benefits currently (24 month)						$\chi^2(1)=3.74$ , p=0.053
Yes	40	(57.1)	792	(54.0)	54.1	
No	1	(1.5)	113	(7.7)	7.4	
Missing	29	(41.4)	562	(38.3)	38.5	
<b>Socio-economic status: unemployment</b>						
Unemployed (baseline)						$\chi^2(1)=8.23$ , p=0.004
No	5	(7.1)	312	(21.3)	20.6	
Yes	65	(92.9)	1148	(78.2)	78.9	
Missing	0	(0.0)	7	(0.5)	0.5	
Unemployed (6 month)						$\chi^2(1)=1.22$ , p=0.269
No	1	(1.5)	53	(3.6)	3.5	
Yes	8	(11.4)	137	(9.3)	9.4	
Missing	61	(87.1)	1277	(87.1)	87.1	
Unemployed (12 month)						$\chi^2(2)=4.00$ , p=0.135
No	1	(1.4)	113	(7.7)	7.4	
Yes	9	(12.9)	160	(10.9)	11	

	At least one referral to SS N=70		Participants without a referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Missing	60	(85.7)	1194	(81.4)	81.6	
Unemployed (18 month)						$\chi^2(1)=2.50$ , p=0.114
No	2	(2.8)	130	(8.9)	8.6	
Yes	9	(12.9)	179	(12.2)	12.2	
Missing	59	(84.3)	1158	(78.9)	79.2	
Unemployed (24 month)						$\chi^2(1)=7.15$ , p=0.007
No	0	(0.0)	166	(11.3)	10.8	
Yes	7	(10.0)	159	(10.8)	10.8	
Missing	63	(90.0)	1142	(77.9)	78.4	

## Appendix 24.

**Table 20.** Markers of participants with and without a child with a referral to Social Services.

	At least one referral to SS N=70		Participants without referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p-value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
<b>Markers for child maltreatment Domain</b>						
<b>Physical signs of abuse and injuries: head injuries</b>						
Head injuries (NHS Digital A&E data)						$\chi^2(1)=7.17$ , p=0.007
Yes	29	(41.5)	340	(23.2)	24.0	
No	36	(51.4)	832	(56.7)	56.5	
Missing	5	(7.1)	295	(20.1)	19.5	
<b>Physical signs of abuse and injuries: fractures</b>						
Fractures (NHS Digital A&E data)						$\chi^2(1)=0.24$ , p=0.626
Yes	9	(12.9)	189	(12.9)	12.9	
No	56	(80.0)	983	(67.0)	67.6	
Missing	5	(7.1)	295	(20.1)	19.5	
<b>Physical signs of abuse and injuries: thermal injuries</b>						
Thermal injuries (24 month)						$\chi^2(1)=0.37$ , p=0.545
Yes	7	(10.0)	121	(8.3)	8.3	

	At least one referral to SS N=70		Participants without referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p-value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
No	35	(50.0)	782	(53.3)	53.2	
Missing	28	(40.0)	564	(38.4)	38.5	
Burns (NHS Digital A&E data)						$\chi^2(1)=0.20$ , p=0.651
Yes	3	(4.3)	70	(4.8)	4.8	
No	62	(88.6)	1102	(75.1)	75.7	
Missing	5	(7.1)	295	(20.1)	19.5	
<b>Physical signs of abuse and injuries: bites and bruises</b>						
Bites and bruises (NHS Digital A&E data)						$\chi^2(1)=1.94$ , p=0.163
Yes	5	(7.2)	48	(3.3)	3.5	
No	60	(85.7)	1124	(76.6)	77.0	
Missing	5	(7.1)	295	(20.1)	19.5	
Contusion (NHS Digital A&E data)						$\chi^2(1)=0.25$ , p=0.618
Yes	13	(18.6)	206	(14.0)	14.3	
No	52	(74.3)	966	(65.9)	66.2	
Missing	5	(7.1)	295	(20.1)	19.5	
<b>Physical signs of abuse and injuries: lacerations, abrasions and scars</b>						
Lacerations, abrasions, scars (NHS Digital A&E data)						$\chi^2(1)=0.85$ , p=0.358

	At least one referral to SS N=70		Participants without referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p-value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Yes	17	(24.3)	250	(17.0)	17.4	
No	48	(68.6)	922	(62.9)	63.1	
Missing	5	(7.1)	295	(20.1)	19.5	
<b>Physical signs of abuse and injuries: ano-genital injuries</b>						
Ano-genital (NHS Digital A&E data)						$\chi^2(1)=6.53$ , p=0.011
Yes	27	(38.6)	316	(21.5)	22.3	
No	38	(54.3)	856	(58.4)	58.2	
Missing	5	(7.1)	295	(20.1)	19.5	
<b>Physical signs of abuse and injuries: other physical injuries</b>						
Soft tissue inflammation (NHS Digital A&E data)						$\chi^2(1)=1.55$ , p=0.213
Yes	7	(10.0)	195	(13.3)	13.2	
No	58	(82.9)	977	(66.6)	67.3	
Missing	5	(7.1)	295	(20.1)	19.5	
Sprain/ligament injury (NHS Digital A&E data)						$\chi^2(1)=1.14$ , p=0.285
Yes	6	(8.6)	163	(11.1)	11.0	
No	59	(84.3)	1009	(68.8)	69.5	
Missing	5	(7.1)	295	(20.1)	19.5	
Muscle/tendon injury (NHS Digital A&E data)						$\chi^2(1)=0.00$ , p=0.981

	At least one referral to SS N=70		Participants without referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p-value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Yes	4	(5.7)	73	(5.0)	5.0	
No	61	(87.2)	1099	(74.9)	75.5	
Missing	5	(7.1)	295	(20.1)	19.5	
Nerve injury (NHS Digital A&E data)						$\chi^2(1)=3.64$ , p=0.057
Yes	5	(7.2)	38	(2.6)	2.8	
No	60	(85.7)	1134	(77.3)	77.7	
Missing	5	(7.1)	295	(20.1)	19.5	
Vascular injury (NHS Digital A&E data)						$\chi^2(1)=0.11$ , p=0.739
Yes	0	(0.0)	2	(0.1)	0.1	
No	65	(92.9)	1170	(79.8)	80.4	
Missing	5	(7.1)	295	(20.1)	19.5	
Electric shock (NHS Digital A&E data)						$\chi^2(1)=3.14$ , p=0.076
Yes	1	(1.5)	3	(0.2)	0.3	
No	64	(91.4)	1169	(79.7)	80.2	
Missing	5	(7.1)	295	(20.1)	19.5	
Foreign body (NHS Digital A&E data)						$\chi^2(1)=0.99$ , p=0.319
Yes	6	(8.6)	72	(4.9)	5.1	
No	59	(84.3)	1100	(75)	75.4	

	At least one referral to SS N=70		Participants without referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p-value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Missing	5	(7.1)	295	(20.1)	19.5	
Poisoning (NHS Digital A&E data)						$\chi^2(1)=4.74$ , p=0.029
Yes	12	(17.2)	117	(8.0)	8.4	
No	53	(75.7)	1055	(71.9)	72.1	
Missing	5	(7.1)	295	(20.1)	19.5	
Near drowning (NHS Digital A&E data)						n/a
Yes	0	(0.0)	0	(0.0)	0.0	
No	65	(92.3)	1172	(80.3)	85.0	
Missing	5	(7.1)	295	(20.1)	15.0	
Visceral injury (NHS Digital A&E data)						n/a
Yes	0	(0.0)	0	(0.0)	0.0	
No	65	(92.3)	1172	(80.3)	85.0	
Missing	5	(7.1)	295	(20.1)	15.0	
Any injuries or ingestions (NHS Digital Inpatients data)						$\chi^2(1)=9.26$ , p=0.002
Yes	22	(31.4)	252	(17.2)	17.8	
No	48	(68.6)	1215	(82.8)	82.2	
Missing	0	(0.0)	0	(0.0)	0.0	
<b>Clinical presentations other than injuries: failure to attend essential follow-up appointments</b>						

	At least one referral to SS N=70		Participants without referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p-value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Did not attend (GP data)	35	0.0 (0.0 to 0.0) 0.06 (0.34)	821	0.0 (0.0 to 0.0) 0.09 (0.45)	0.0 (0.0 to 0.0) 0.09 (0.45)	t(39.41)=0.50, p=0.624
Did not attend (NHS Digital Outpatients data)						$\chi^2(1)=6.11$ , p=0.013
Yes	56	(80.0)	964	(65.7)	66.4	
No	14	(20.0)	503	(34.3)	33.6	
Missing	0	(0.0)	0	(0.0)	0.0	
<b>Clinical presentations other than injuries: failure to engage with immunisation health and development reviews and screening</b>						
Immunisations number (6 month)	36	3.0 (3.0 to 3.0) 3.25 (0.97)	915	3.0 (3.0 to 3.0) 3.22 (1.19)	3.0 (3.0 to 3.0) 3.22 (1.18)	t(39.26)= -0.17, p=0.866
Immunisations number since last interview (12 month)	44	0.0 (0.0 to 1.0) 0.66 (1.24)	925	0.0 (0.0 to 1.0) 0.70 (1.28)	0.0 (0.0 to 1.0) 0.70 (1.28)	t(47.47)=0.23, p=0.816
Immunisations number since last interview (18 month)	40	1.0 (1.0 to 2.0) 1.33 (0.48)	897	1.0 (1.0 to 2.0) 1.26 (0.44)	1.0 (1.0 to 2.0) 1.26 (0.44)	t(42.04)= -0.84, p=0.406
Received full schedule of immunisations (immunisations data)						$\chi^2(1)=0.10$ , p=0.756
Yes	42	(60.0)	836	(57.0)	57.1	



	At least one referral to SS N=70		Participants without referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p-value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
No	4	(5.7)	94	(6.4)	6.4	
Missing	24	(34.3)	537	(36.6)	36.5	
<b>Parent or carer-child interactions: carer showing negativity or hostility, rejecting or scapegoating</b>						
Parental role strain (6 month) (range 0-6)	36	2.0 (1.0 to 2.0) 1.69 (0.79)	874	1.0 (1.0 to 2.0) 1.48 (0.65)	1.0 (1.0 to 2.0) 1.49 (0.65)	t(36.98)= -1.62, p=0.114
Parental role strain (12 month) (range 0-6)	43	1.0 (1.0 to 2.0) 1.47 (0.68)	921	1.0 (1.0 to 2.0) 1.44 (0.95)	1.0 (1.0 to 2.0) 1.44 (0.94)	t(48.21)= -0.22, p=0.828
Parental role strain (18 month) (range 0-6)	38	2.0 (1.0 to 2.0) 1.55 (0.83)	888	1.0 (1.0 to 2.0) 1.44 (0.72)	1.0 (1.0 to 2.0) 1.44 (0.73)	t(39.43)= -0.82, p=0.416
Parental role strain (24 month) (range 0-6)	45	1.0 (0.3 to 1.0) 1.16 (0.71)	1022	1.0 (1.0 to 2.0) 1.30 (0.79)	1.0 (1.0 to 2.0) 1.29 (0.79)	t(48.97)=1.32, p=0.192
<b>Parent or carer-child interactions: developmentally inappropriate expectations</b>						
Maternal intrusiveness (maternal sensitivity) (range 0-18)	23	1.0 (0.0 to 2.0) 1.39 (1.44)	484	1.0 (0.0 to 0.3) 1.61 (1.74)	1.0 (0.0 to 2.0) 1.60 (1.73)	t(25.17)=0.70, p=0.492

	At least one referral to SS N=70		Participants without referral to SS N=1467		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p-value)
	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
<b>Parent or carer-child interactions: exposure to frightening or traumatic experiences e.g. dv</b>						
Composite abuse scale (24 month) (range 0-145)	22	0.0 (0.0 to 0.2) 5.09 (14.97)	649	0.0 (0.0 to 0.3) 4.88 (13.78)	0.0 (0.0 to 3.0) 4.89 (13.81)	t(22.22)= -0.07, p=0.949
<b>Parent or carer-child interactions: being emotionally unavailable or unresponsive</b>						
Parent/carer-child interactions: emotionally unavailable (maternal sensitivity) (range 0-18)	23	11.0 (10.0 to 12.0) 10.78 (0.95)	484	12.0 (10.0 to 12.0) 11.06 (1.67)	12.0 (10.0 to 12.0) 11.05 (1.64)	t(28.84)=1.33, p=0.195

## Appendix 25.

**Table 26.** Baseline Interview variables describing the participants of those included and not included in the final model for referral to Social Services.

	Included in final model referral to SS N=1439		Not included in final model referral to SS N=98		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
Baseline characteristic	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Age (years)	1439	17.0 (16.0 to 18.0) 17.36 (1.26)	98	17.0 (17.0 to 18.0) 17.19 (1.24)	17.0 (16.0 to 18.0) 17.35 (1.26)	t(111.14)= -1.29, p=0.199
Ethnicity						X <sup>2</sup> (4)=24.02, p=0.000
White background	1277	(88.7)	78	(79.6)	88.2	
Mixed background	77	(5.4)	5	(5.1)	5.3	
Asian background	18	(1.3)	7	(7.1)	1.6	
Black background	61	(4.2)	8	(8.2)	4.5	
Other background	6	(0.4)	0	(0.0)	0.4	
Missing	0	(0.0)	0	(0.0)	0.0	
Relationship status						X <sup>2</sup> (3)=5.05, p=0.168
Married	13	(0.9)	3	(3.1)	1.0	
Separated	138	(9.6)	12	(12.2)	9.8	

	Included in final model referral to SS N=1439		Not included in final model referral to SS N=98		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
Baseline characteristic	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Closely involved/boyfriend	1098	(76.3)	70	(71.4)	76.0	
Just friends	190	(13.2)	13	(13.3)	13.2	
Missing	0	(0.0)	0	(0.0)	0.0	
Live with father of baby						$\chi^2(1)=1.34$ , p=0.247
Yes	322	(22.4)	26	(26.5)	22.7	
No	1000	(69.5)	61	(62.3)	69.0	
Missing	117	(8.1)	11	(11.2)	8.3	
Family subjective social status	1431	6.0 (5.0 to 7.0) 5.73 (1.68)	98	5.0 (4.0 to 7.0) 5.42 (1.83)	6.0 (5.0 to 7.0) 5.71 (1.69)	t(108.59)= -1.66, p=0.100
Personal subjective social status	1434	7.0 (6.0 to 8.0) 6.90 (1.82)	97	7.0 (5.5 to 8.0) 6.87 (2.87)	7.0 (6.0 to 8.0) 6.89 (1.84)	t(106.36)= -0.14, p=0.891
NEETS <sup>a</sup> :						$\chi^2(1)=0.00$ , p=0.984
Yes	513	(35.6)	35	(35.7)	35.7	
No	715	(49.7)	49	(50.0)	49.7	
Missing	211	(14.7)	14	(14.3)	14.6	
Receive any welfare benefits						$\chi^2(1)=1.01$ , p=0.314

	Included in final model referral to SS N=1439		Not included in final model referral to SS N=98		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
Baseline characteristic	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Yes	514	(35.7)	40	(40.8)	36.1	
No	923	(64.2)	58	(59.2)	63.8	
Missing	2	(0.1)	0	(0.0)	0.1	
Ever been homeless						$\chi^2(1)=0.78$ , p=0.378
Yes	271	(18.8)	22	(22.4)	19.1	
No	1168	(81.2)	76	(77.6)	80.9	
Missing	0	(0.0)	0	(0.0)	0.0	
Socio-economic status: Index of Multiple Deprivation Score <sup>b</sup>	1439	38.1 (24.7 to 51.7) 38.88 (18.26)	86	39.7 (30.6 to 54.9) 42.37 (16.44)	38.2 (25.0 to 52.1) 39.08 (18.74)	t(97.96)=1.90, p=0.060
EQ5D-Binary						$\chi^2(1)=2.19$ , p=0.139
Perfect health	922	(64.1)	55	(56.1)	63.6	
Less than perfect health	515	(35.8)	42	(42.9)	36.2	
Missing	2	(0.1)	1	(1.0)	0.2	
Self-rated health						$\chi^2(3)=5.76$ , p=0.124
Excellent	235	(16.3)	13	(13.3)	16.1	
Good	965	(67.1)	62	(63.2)	66.8	
Fair	221	(15.4)	23	(23.5)	15.9	

	Included in final model referral to SS N=1439		Not included in final model referral to SS N=98		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
Baseline characteristic	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Poor	18	(1.2)	0	(0.0)	1.2	
Missing	0	(0.0)	0	(0.0)	0.0	
Limiting long-term illness:						$\chi^2(1)=0.08$ , p=0.778
Yes	251	(17.4)	16	(16.3)	17.4	
No	1188	(82.6)	82	(83.7)	82.6	
Missing	0	(0.0)	0	(0.0)	0.0	
Generalized self-efficacy scale <sup>c</sup>	1423	30.0 (28.0 to 33.0) 30.03 (4.43)	90	29.0 (27.8 to 33.0) 29.99 (4.69)	30.0 (28.0 to 33.0) 30.03 (4.44)	t(99.32)=-0.08, p=0.937
Adaptive functioning <sup>d</sup> Difficulty in at least one basic skill						$\chi^2(1)=1.23$ , p=0.267
Yes	367	(25.5)	30	(30.6)	25.8	
No	1070	(74.4)	68	(69.4)	74.1	
Missing	2	(0.1)	0	(0.0)	0.1	
Adaptive functioning <sup>d</sup> Had 3 or less life skills (out of 5)						$\chi^2(1)=1.22$ , p=0.270
Yes	374	(26.0)	29	(29.6)	26.2	
No	1065	(74.0)	64	(65.3)	73.5	
Missing	0	(0.0)	5	(5.1)	0.3	

	Included in final model referral to SS N=1439		Not included in final model referral to SS N=98		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
Baseline characteristic	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
Adaptive functioning <sup>d</sup> At least one burden						$\chi^2(1)=0.29$ , p=0.592
Yes	420	(29.2)	31	(31.6)	29.3	
No	1009	(70.1)	66	(67.4)	70.0	
Missing	10	(0.7)	1	(1.0)	0.7	
Substance abuse	1375	1.0 (0.0 to 2.0) 1.32 (1.52)	88	1.0 (0.0 to 3.0) 1.51 (1.58)	1.0 (0.0 to 2.0) 1.33 (1.53)	t(97.60)=1.10, p=0.273
Antisocial behaviour Score	1433	2.0 (1.0 to 4.0) 2.36 (1.76)	97	2.0 (1.0 to 4.0) 2.46 (1.69)	2.0 (1.0 to 4.0) 2.37 (1.75)	t(110.49)=0.57, p=0.568
Social support	1439	90.8 (77.6 to 98.8) 85.20 (16.46)	85	89.5 (76.8 to 98.0) 82.93 (20.63)	90.8 (77.6 to 98.9) 85.07 (16.72)	t(90.43)=-0.99, p=0.321
Relationship quality	1141	29.0 (26.0 to 32.0) 28.11 (4.80)	74	28.5 (24.0 to 31.3) 27.72 (4.68)	29.0 (26.0 to 32.0) 28.08 (4.79)	t(83.25)=-0.69, p=0.489
Family resources	1377	14.0 (11.0 to 17.0) 13.48 (4.16)	96	13.0 (9.0 to 15.8) 12.35 (4.60)	14.0 (11.0 to 17.0) 13.41 (4.20)	t(106.12)=-2.34, p=0.021
Psychological distress/Mental health	1435	20.0 (16.0 to 26.0)	94	20.0 (16.0 to 28.0)	20.0 (16.0 to 26.0)	t(102.15)=0.92, p=0.360

	Included in final model referral to SS N=1439		Not included in final model referral to SS N=98		Overall N=1537	Univariable assoc. (Chi- squared or t- test statistic, p- value)
Baseline characteristic	n	%, or Median, Mean (SD)	n	%, or Median, Mean (SD)	%, or Median, Mean (SD)	
		21.44 (6.56)		22.18 (7.66)	21.48 (6.63)	
<sup>a</sup> Definition of NEETS: Not in education employment or training status (applicable only to those whose academic age is >16 at baseline interview); <sup>b</sup> Higher IMD score indicated more deprivation [12]; <sup>c</sup> Higher score indicates higher level of self-efficacy; <sup>d</sup> Higher score indicates better management of day-to-day lives and routines (for each of the three sub-scales.						