

## Attitudes towards the collection and linkage of maltreatment data for research: A qualitative study

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### Abstract

#### Introduction

Factors that affect public and professionals' attitudes towards the collection and linkage of health and other data have been explored in the literature. Thus far there has been no study exploring attitudes towards the collection of child maltreatment data.

#### Objectives

Our aim is to explore attitudes regarding the collection and linkage of maltreatment data for research.

#### Methods

Participants included younger mothers, older mothers, care-experienced young people, and professionals who were responsible for recording child maltreatment data. Four face-to-face focus groups were conducted, one with younger mothers ( $n = 6$ ), one with older mothers ( $n = 10$ ), and two with care-experienced young people ( $n = 6$  and  $n = 5$ ). An online focus group was conducted with professionals ( $n = 10$ ), two of whom additionally participated in telephone interviews. Transcribed audio-recorded data were inductively coded, a portion were double-coded by a second researcher, and thematically analysed.

#### Results

Three major themes were identified. The first concerned issues of consent, specifically the conditions for providing consent and factors influencing this. The second concerned trust in data security and validity, the organisations and individuals providing and using the data, and how the information provided shapes attitudes. The third theme explored the benefits of research and the researchers' role in child protection. Participants wanted the choice of providing consent for data collection, especially when consenting on behalf of another, but there were concerns that maltreated children were unidentifiable in anonymised datasets. Care-experienced young people were concerned about data collection from Social Services records due to their sensitivity. There was a general lack of understanding about how research data is viewed and the accuracy of records.

#### Conclusions

Novel findings in the study were strongly related to the sensitive nature of the topic. The findings may be particularly useful when designing research studies and participant materials and a co-productive approach to this should be taken.

#### Keywords

child maltreatment; attitudes; focus group; data collection; data linkage

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## Introduction

In the UK researchers must seek informed consent to look at *identifiable* routinely collected data [1]. Excluding potential participants due to lack of consent can introduce consent bias [1, 2] i.e. those who consent may be in some way different to those who do not [1]. This may threaten the validity of research results [2]. Explicit consent can be difficult to seek, and costs associated with contacting and consenting a large number of potential participants can be high [3].

The use of opt-out consent models are becoming more widespread [4], partly as a response to difficulties in seeking consent. These models have some drawbacks including mass-refusal to participate if there is lack of trust [5]. Researchers cannot be certain if individuals have actually received the communication informing them of the option to opt out [6].

Data can be anonymised or pseudonymised, but it may still be possible to identify individuals from a combination of characteristics in one dataset [7], or by linking many datasets. This is a particular risk where data relate to individuals with rare conditions or they belong to small populations [5, 8].

The literature explores factors that affect the consent preferences of individuals. This literature is based on research exploring data collection and linkage issues for sensitive, mostly medical, data items. These factors include whether data is anonymised [5], the topic of the research or the data items collected [10] (e.g. relating to sexual health [5] or sociodemographic data items [10] such as postcode [11]), and with which records the data will be linked [12]. Perceptions of the security of the data affect consent preferences [11, 13], a concern especially pertinent for electronic data [14, 15]. Consent preferences can also be affected by knowledge of which professionals will access the data [14]. There is a general preference for health professionals accessing data over Universities, which may be related to the purpose of the access (i.e. health vs. research), and an unwillingness to give access to the private sector, for example to pharmaceutical companies [1, 11, 16, 17]. Consent preferences for data collection and linkage can also be affected by knowledge of the research process and public engagement [14, 18]. There is a clear need for increased public education and awareness about research processes and safeguards [19, 20], and that this may increase public acceptability of research without explicit consent [1]. Characteristics of potential participants that affect consent preferences include age [21], current state of health [22], employment or Socio Economic Status [13], gender [23], and ethnicity [24]. Others have found that those who consent and those who do not are similar in characteristics [2].

Factors that affect medical professionals' (e.g. GPs) attitudes towards the collection and linkage of health data are similar to those of the public, including with whom they would be happy to share data [25]. Data governance concerns are common, related to data security, legal restrictions, and data quality [25, 26]. Professionals have also expressed concerns about future repercussions if patients believe their data has been used without their explicit consent [17], and about interference with patient-physician relationship [26]. Attitudes amongst professionals has been found to be positive about data sharing for a public health purpose [27], with identifiability of records affecting attitudes [26].

Thus far there has been no study exploring the attitudes of the public and professionals towards the collection of child maltreatment data (that is data that might indicate child maltreatment collected from medical or social care records) which might be viewed as particularly sensitive. The attitudes towards the data collection and linkage of health data of (mostly only medical) professionals has been explored to a lesser extent than those of the general public.

Service records capture processes and outcomes for children rereferred to local departments of children's Social Services. Similarly, data present in health records may also capture information about abuse and neglect experienced by children. Maltreatment data is currently used by researchers for a variety of purposes including estimating prevalence of maltreatment [e.g. 28], research into what may be the causes of child maltreatment [e.g. 29], and research into features of maltreatment [e.g. 30].

## Aim

The aim of this study is to explore attitudes towards the collection and linkage of child maltreatment data for research.

## Methods

### Participants

Face-to-face focus groups were conducted with three groups, a younger mothers group, an older mothers group, and a group of care-experienced young people. An asynchronous online focus group was conducted with professionals. An asynchronous online focus group is a focus group 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. Following this, semi-structured telephone interviews were conducted with two participants from the professionals group.

Participants in the younger mothers group were from the Our Place group – funded by Children in Need and the Big Lottery, which is a network of parents (mainly mothers) aged 16-24 who have children aged under two. Our Place is based in South Wales and provides a programme of support for young parents where they can build their emotional resilience to establish healthy, independent and happy lives. They were recruited via an existing relationship between the researchers and the Centre for Trials Research (CTR), Cardiff University. The Centre had been involved in public and patient involvement activities for previous research [31–33]. Participants in the older mothers group had children who attended a local primary school in Cardiff, and formed an existing informal friendship group. Each mother had at least one child of primary school age, but some also had children of varying ages. This group was recruited through a personal connection of one of the researchers with the school (RC-J).

A group of young people with experience of the social care system called CASCADE Voices [34], a collaboration between Voices from Care Cymru and CASCADE, Cardiff University formed two focus groups. This group was recruited through an existing relationship between CASCADE Voices and the

researchers [31–33]. Due to the personal circumstances of many of the young people who attend the group, numbers of attendees at the first group were low, therefore the first focus group consisted of a mixture of both care-experienced young people and staff members from CASCADE Voices. A second focus group was run that consisted of care-experienced young people only.

Mothers were invited to take part in the study as they (rather than fathers) are more likely to be asked to provide consent on behalf of their child to take part in research in the UK (e.g. in the Millennium Cohort Study, permission was asked of the mother to link her hospital episode of delivery records and birth registration records to the MCS study data), and fathers have been less involved in family research on the whole compared to mothers when asked to consent on their own behalf or that of their child [35, 36]. Where either parent is asked to consent, mothers are more likely to do so which may be due to the greater likelihood of the mother being the primary carer in a family, and for legal reasons (as defined in the Children's Act 1989) [37] which are now historical, but continued culturally.

The group of care-experienced young people were invited to take part in the research as they had direct experience of the care system and consequently are more likely to have maltreatment data in electronic records about them.

These groups were purposefully sampled. They were identified and approached as part of a sampling framework designed to explore populations that had some direct or indirect similarities with young mothers of young children with greater risks of adversity or maltreatment (participants who were included in the Building Blocks Trial and Building Blocks 2-6 Study [31, 32], data from which were used in the first author's PhD from which this qualitative study is based). The online focus group consisted of UK professionals responsible for recording maltreatment data in records as part of their job role, for example GPs, Teachers. They were recruited through the researchers' professional contacts. A 'snowballing' technique was used; every participant who agreed to take part was asked if they knew of anyone else who could be approached. An asynchronous online group methodology [38] was chosen as it was felt that it would be difficult for time pressed and geographically dispersed participants to be in the same place at the same time (as would be the case with a face-to-face group). 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. These were conducted 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.

## Consent

Participants from the mothers and young people groups were asked to read an information sheet and sign a consent form before taking part. The professional group completed the consent process online. Professionals who completed a telephone interview provided audio-recorded verbal consent. All participants were screened for eligibility by one of the researchers (GM) and some demographic data were also collected. To be eligible participants had to be able to provide

informed consent and did not need a translator to be part of the focus groups. Participants in the younger and mothers groups were offered a children's book to thank them for their time and the group of care-experienced young people were paid for their time by CASCADE Voices (Cardiff University).

## Procedure

The mothers and young people groups were conducted face-to-face and involved discussions that took place around various scenarios designed to embed the discussion in a concrete 'story' [39, 40]. This was because many of the concepts discussed, for example data linkage, were complex and could be abstract. The scenarios presented were designed to be increasingly complex and introduced the idea of collecting data on child maltreatment gradually by firstly discussing the collection of data from hospital records before moving on to discuss the collection of data from Local Authority records. Other researchers have had success utilising a similar method in terms of both participants' understanding of the concepts discussed and to facilitate lively discussion [9]. All face-to-face focus-groups were facilitated by the main author (GM) and co-facilitated by one of the other authors (MR, RC-J) or a qualitative-experienced staff member from the CTR. Group discussions were audio recorded and the scenarios were presented visually on a projector. The online focus group was an asynchronous group run over five weeks with one topic discussed per week, and was facilitated by GM. The weekly topic question was posted to the group and they responded by discussing this with each other (asynchronously i.e. not in real time). All focus groups were guided by a topic guide written in light of some of issues identified through a literature review. The topic guides allowed some flexibility to address newly arising issues.

The following areas of interest were chosen to be included in the topic guides:

- Attitudes towards various models of consent and preference for consent (face-to-face groups).
- Attitudes towards data security and transfer (face-to-face groups, online group and telephone interviews).
- Attitudes towards and preference for anonymisation (face-to-face groups, online group and telephone interviews).
- Acceptability of the collection of child maltreatment data from various sources (face-to-face groups) and whom receives the data (online group and telephone interviews).
- Acceptability of collecting data on: confirmed cases of child maltreatment, markers of maltreatment and risk factors for maltreatment (face-to-face groups).
- The importance of research and any risks or benefit of conducting research on child maltreatment (face-to-face groups, online group and telephone interviews).
- Attitudes towards recording maltreatment data (online group and telephone interviews).

Detailed topic guides and scenarios presented can be found in Appendix 1.

## Data analysis

An inductive methodology, thematic analysis [41] was used to analyse the data. A transcript based analysis was used; and coded in Nvivo10 software. A transcript based analysis is where an audio recording (or video recording) is transcribed. These transcribed data are then analysed. The coding framework was validated by an experienced qualitative researcher from the CTR by reviewing 15% of the data. The qualitative researcher was asked to review transcripts along with the coding framework and the detailed definitions (Figure 1) and to note their agreement next to each code on the transcript. Any differences in coding were discussed.

## Ethical approval

The study was approved by the Cardiff University School of Medicine Research Ethics Committee (SMREC REF: 15/36).

## Results

A total of 37 participants took part, 10 of these were male. Age was collected for the mothers and care-experienced young people groups and these ranged from 16–45 years old.

Fifteen percent of the data collected during the focus groups and interviews were reviewed by a CTR qualitative researcher. The qualitative researcher agreed with 98.7% of codes (i.e. disagreed with 1.3% of codes). Table 1 provides the details and composition of the focus groups and interviews.

Figure 1 depicts the coding framework devised by the researchers, illustrating the major themes and sub-themes developed. The major themes were Consent, Trust, and Role of Research. The themes that emerged from the interviews are illustrated with quotes. Illustrative quotes presented identify participant by group (YM: Young Mothers, OM: Older mothers, CE1: Care-experienced young people group 1, CE2: Care-experienced young people group 2, P: Professionals) and participant number (e.g. 1).

### Major theme: Consent

This theme centred around issues of consent, specifically the conditions for providing consent and which factors may influence this. A number of sub-themes were developed under this theme, some of which were also related to other major themes, for example, how information provided to participants about the research shapes attitudes was a sub-theme which appeared under all three major themes.

#### Sub-theme: Information provided about the research

The information provided by researchers to participants was important to the mothers and care-experienced young people both in how they viewed the research and whether they would be happy to provide consent to collect their own or their child's data. These participants wanted justification for data collection, as illustrated by the below quote. They were also interested in what would happen to the data after the project

finished, if participants would be provided with the findings of the research, and who would have access to the data.

CE2-1: '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.'

#### Sub-theme: Professional and ethical standards

Professional participants often quoted the professional and ethical standards they would take into account during discussions about the collection of, and their provision of access to, child maltreatment data to researchers.

P-5: '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?'

Some felt that allowing researchers to access data was the right or proper thing to do from an ethical perspective. There were some concerns surrounding ensuring that patients were aware that their data could be accessed by researchers and litigation issues that could arise from this.

P-4: '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.'

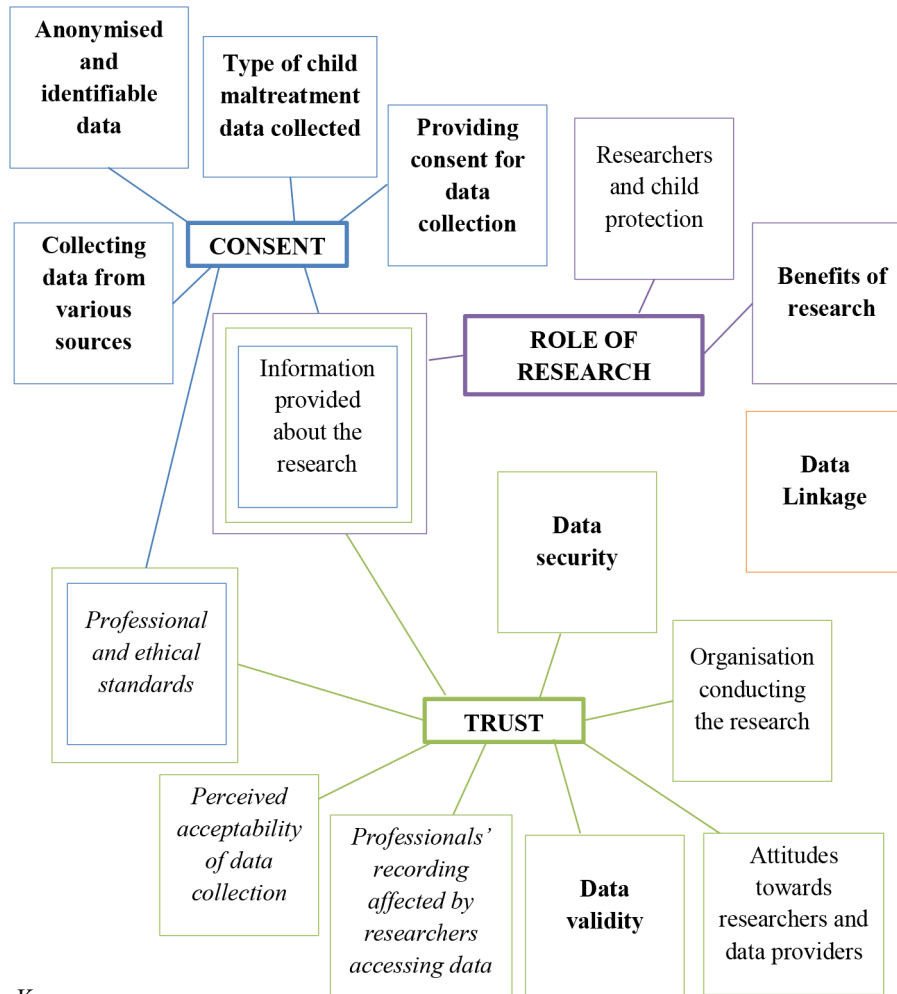
#### Sub-theme: Type of child maltreatment data collected

The *type* of data collected, for example whether researchers were collecting confirmed or unconfirmed cases of maltreatment was important to mothers and care-experienced young people. Some participants felt that collecting data related to physical signs of maltreatment and factors that may be associated with causing maltreatment, as well as confirmed cases, could be beneficial to the researcher. Others felt that collecting any data unrelated to confirmed cases could be problematic because they believed that unconfirmed cases were more open to diverging views from health professionals.

YM-4: 'That poor boy (Baby P) had so many bruises and doctors didn't pick it up, I think maybe, I think maybe if like, like researchers 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.'

CE1-2: '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

Figure 1: 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**

Definitions

**Theme 1: Consent**

The conditions for providing consent and which factors may influence this

- **Information provided about the research** (under all 3 major themes)

How the information provided, to participants about the research shapes attitudes towards the collection and linkage of child maltreatment data

- **Professional and ethical standards** (under Consent and Trust themes)

Discussion of professional standards and ethics that are taken into account when collecting and giving access to child maltreatment data

- **Type of child maltreatment data collected**

Markers, risk factors, confirmed and unconfirmed maltreatment

- **Anonymised and identifiable data**

Discussion about the collection of anonymised and identifiable data and attitudes towards the conditions in which anonymised or identifiable data should be collected

- **Providing consent for data collection**

Attitudes towards asking for and providing consent for data collection and other consent issues



Figure 1: Continued

- **Collecting data from various sources**

The acceptability of researchers collecting data from various sources such as from medical or social care records

**Theme 2: Trust**

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

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

How professionals recording child maltreatment data may be affected by the knowledge that it will be accessed by researchers and their feelings about this

- **Perceived acceptability of data collection**

The perceived acceptability of the public as judged by professionals of researchers collecting child maltreatment data

- **Attitudes towards researchers and data providers**

Attitudes towards the researchers collecting the data and the individuals and organisations who provide the data

- **Organisation conducting the research**

Attitudes about various organisations e.g. Government, University Researchers, Pharmaceutical Companies collecting data

- **Data security**

Discussion about the security of electronic data transfer, data linkage, data storage and access to the data.

- **Data validity**

Discussions surrounding the validity of data in records and how validity may affect research findings and conclusions

**Theme 3: Role of Research**

Focus group 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.

- **Researchers and child protection**

Discussion about whether researchers are responsible for flagging child protection concerns

- **Benefits of research**

Discussion about the benefits of research in this field

- **Data linkage sub-theme (Does not fit under any of the major themes)**

Discussion about issues surrounding data linkage

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.'

A professional participant was concerned about *perceived* acceptability of collecting unconfirmed (rather than confirmed) cases of maltreatment to the public.

P-6: '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.'

**Sub-theme: Anonymised and identifiable data**

Participants did not have a preference overall of whether researchers should collect identifiable or anonymised data, this was dependent on context. There were concerns from some participants that if enough anonymised data was linked then this could render a participant identifiable.

CE2-1: '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.'

Table 1: Focus groups and interviews composition details

	Group size	Age (years) (median or range)	Number of children and average age (years)	Gender split	Number in education	Meeting duration	Area
Young mothers focus group	6	16–25	<ul style="list-style-type: none"> <li>• 4 with 1 child</li> <li>• 1 with 2 children</li> <li>• 1 with 3 children</li> </ul> Average age of children was five.	All female	n/a	37 mins 58 secs	South Wales
Older mothers focus group	10	Between 26–35 and 36–45	<ul style="list-style-type: none"> <li>• 2 with 1 child</li> <li>• 3 with 2 children</li> <li>• 4 with 3 children</li> <li>• 1 with 4 children</li> </ul> Average age of children was five.	All female	n/a	30 mins, 11 secs	Cardiff
Care-experienced young people focus group (some young people, some CASCADE Voices staff)	6 (3 young people, 3 staff)	25	n/a	3 male, 3 female	2	1 hr, 17 mins, 25 secs	Cardiff
Care-experienced young people focus group (young people only)	5	23	n/a	4 males, 1 female	0	55 mins, 28 secs	Cardiff
Online professional focus group	10	Not collected	n/a	3 male, 7 female	n/a	5 weeks	7 in Wales 2 in Northern Ireland 1 in England
Telephone interviews with professionals	2	Not collected	n/a	All female	n/a	19 mins, 32 secs 28 mins, 38 secs	Wales

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

OM-4: '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.'

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

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

CE1-3: '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.'

#### Sub-theme: Providing consent for data collection

Issues around providing consent were discussed widely including consent bias.

P-5: '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.'

Discussions regarding the option to 'opt out' of providing consent also took place. The professional participants discussed the practical difficulties of obtaining consent for large samples. Some participants also believed that people should be informed that their data were being used even if they were not consented.

OM-2: '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.'

P-9: '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.'

In the young mothers' group, there was some discussion about the differences between providing consent on their own behalf, or on behalf of their child. 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-2: '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".'

#### **Sub-theme: Collecting data from various sources**

The acceptability of researchers collecting data from various sources such as from medical or social care records was discussed in each group. There was less support for 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, and many other participants viewed Social Services data as being more sensitive than medical data.

CA2-1: '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.'

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

Most of the professional participants discussed this issue in terms of practicality, e.g. which source has the most reliable or valid data, and less in terms of their feelings about how sensitive the data items were.

P-5: '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.'

#### **Major theme: Trust**

This theme 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.

#### **Sub-theme: Professionals' recording affected by researchers accessing data**

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

P-2: '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.'

#### **Sub-theme: Perceived acceptability of data collection**

Professional participants discussed the *perceived* acceptability by the public of researchers collecting child maltreatment data, and the type of data that may be more or less acceptable.

P-1: '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 that the relationship between the public and professionals could be damaged if members of the public realised that data being collected by the professionals were accessed by researchers.

P-3: '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?'



**Sub-theme: Attitudes towards researchers and data providers**

There was some suspicion by the mothers and care-experienced young people about whether researchers were going to look at data items that participants were not aware of. There was a general lack of understanding about the type of data that 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.

CE2-1: '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 Social Services were breaking the law by providing those data. Many had been explicitly told by their social workers that their data would be completely confidential, and to them this meant that their data would not be shared.

CE1-4: '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.'

CE1-6: 'You can get a social worker done for it.'

CE1-2: '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?'

CE1-2: '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.'

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.

CE1-5: '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.'

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

YM-3: '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?'

**Sub-theme: Organisation conducting the research**

Most mothers and care-experienced young people 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.

CE1-2: '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.'

**Sub-theme: Data security**

Some mothers and care-experienced young people had concerns about the security of data transfer from the data providers to the researchers, which partly arose from hearing negative stories in the news about personal data being lost or stolen. The vast majority of mothers and care-experienced young people did not however have many security concerns and trusted the procedures that researchers would put in place to ensure data security.

OM-1: '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 was transferred between data provider and researchers via the internet rather than paper-based files, and generally had a good understanding of data security.

CE2-4: '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.'

Following data protection procedures was seen as very important to all groups.

P-9: '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, however the care-experienced young people group viewed child maltreatment data as more sensitive than other data and so believed that there should be a higher level of security.

CE1-2: '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'

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

P-4: '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 were related to the accuracy of the data and a belief that there was some inaccurate data in medical and Social Services records.

CE1-6: 'Some of it, the data, will be good, and sometimes it's just bullshit.'

There were also some concerns that what appears in the records does not reflect fully a family's circumstances and that this would lead to unfair judgements made by researchers.

YM-6: '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...'

### Major theme: role of research

This theme concerned the benefits of research, and the researchers' role in child protection.

#### Sub-theme: 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 unconfirmed possible maltreatment cases in datasets. There were concerns that researchers could not identify a maltreated child if data were anonymised.

CE1-2: '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.'

#### Sub-theme: Benefits of research

Many participants were happy for research of this sort to be conducted as they could appreciate the benefits.

P-9: '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.'

YM-7: '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-2: '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?'

#### Data linkage additional sub-theme

There was a final sub-theme relating to data linkage which did not fit under any of the major themes. Some mothers and care-experienced young people believed that using data linkage was more useful for clinical care and prevention of maltreatment rather than research, and thought it would be helpful if different organisations could access one another's data sets.

CE2-3: '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.'

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

OM-7: 'So how could they link it to Social Services records if it's non-identifiable?'

## Discussion

Three major themes were identified, Consent, Trust, and Role of Research. Under the theme of consent it was found that the *type* of child maltreatment data collected i.e. whether researchers wanted to collect confirmed or unconfirmed cases was important to mothers and care-experienced young people. Other researchers have found that some data items are considered more sensitive than others, which may affect consent [9]. 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.

Participants did not have a clear preference on whether data should be anonymised or identifiable when sharing and linking data for research purposes, and this was very much dependent on context. The literature contains similarly mixed views, some researchers have found that potential participants are more likely to consent when data are anonymised [5], where some have not found this [39]. The findings in the current study were similar to those by 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 anonymised data. This study also shared similar findings to Haddow, Bruce, Sathanandam, & Wyatt (2011) where some participants were surprised and unhappy when the researchers revealed to them that researchers can collect anonymised data without explicit consent. It should be noted that there are some similarities and well as differences in the population samples included in this study compared to others. Participants in the current study were selected to be from specific populations i.e. younger/older mothers, care-experienced young people and professionals, whereas most of the other studies included participants from the general population/primary care patients [11].

Most participants wanted the choice of whether to give permission for data to be collected, and participants in the young mothers groups spent a lot of time reflecting on the differences between providing consent on their own behalf or on behalf of their child and were much more likely to consent to their own data being collected than to that of their child.

Some data items were considered to be more sensitive than others. Individuals may not give consent based on the topic of the research or the possible use of the findings [9]. These things are very important to consider during the design stage of a study, for example it is perhaps understandable for care-experienced young people to be less supportive of data collection from Social Services records as these participants will likely have a personal experience of having such a record. Such concerns should be addressed in study materials such as participant information sheets.

Under the trust theme it was uncovered that there was some suspicion about researchers. Some in the young mothers group were suspicious about why researchers would want to collect data on their child, pointing to a great need to fully explain the purpose of research to potential participants before attempting recruitment. There was a general lack of understanding about the type of data researchers view and suspicion that they would view entire medical records rather than specific data items. There was particular concern among the care-experienced young people around the loss of control

over who would know details of their own care history, having incorrectly believed that data from their records would never be shared. They also viewed child maltreatment data as more sensitive than other data; and so believed that they should be handled with a higher level of security.

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 does not appear in other literature and so was considered a newly emerging theme. 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. There may therefore, be a considerable lack of clarity about how researchers analyse the data in these records.

The third theme concerned the role of research. 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. Participants on the whole wanted anonymisation and yet want to be able to take action if abuse is detected by research, and these things are, in general, incompatible.

There was much discussion about the benefits of collecting and linking child maltreatment data and whether these were clear. Nair, Willison, Holbrook, & Keshavjee (2004) found that potential participants often considered the balance of obtaining consent against the public benefit incurred by unrestricted research [42]. Many other studies have found that members of the public believe that collecting and sharing data for research is important [14]. 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.

Much of the discussions and concerns surrounded the nature of the data collected. 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, Spina, & Sankar (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 [43]. Clerkin, Buckley, Murphy, & MacFarlane (2013) found that some in their study emphasised the risks of anonymised information from their medical records being used in research in relation to social discomfort and embarrassment [13].

In summary, most participants wanted the choice of whether to give permission for data to be collected, this was especially the case when consenting on behalf of another.

However there were also concerns that researchers could not identify a maltreated child if the data were anonymised. Care-experienced young people were less supportive of data collection from Social Services records and these were deemed to be more sensitive than other data items. There was a general lack of understanding about the type of data researchers view and suspicion that they would view entire medical records rather than specific data items. There was also concern about the accuracy of records.

## Strengths and limitations

This is the first study to explore data collection and linkage issues for child maltreatment data specifically, with other literature exploring issues around mostly medical data items. The study contains the views of a range of public and professional participants. A criticism of the study however is the omission of the views of fathers and social workers. 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. It should also be kept in mind that the participants included those comfortable and agreeable to take part and that people who are less engaged were not well represented in our sample. We chose to focus upon maternal views on the use of maltreatment data because of the match with our previous work with teenage mothers and the greater likelihood that mothers, rather than fathers, would be approached for consent in research studies. This does place limits on the generalisability of the findings, although the study primarily aimed to explore the nature of opinions on data use rather than seek representative results. The main consequence of only including mothers is that perspectives of particular concern to fathers may not have emerged in our study. Such differences could arise in a number of ways, for example, due to gendered patterns of parenting (i.e. systematic differences in maternal and paternal child-rearing practices), the consequences of family breakdown including absent fathers, and systematic differences between mothers and fathers as perpetrators of different forms of abuse and neglect. Not only will practical opportunities and legal requirements for consent differ between parents, but it is reasonable to speculate that some additional issues may arise for fathers. Whilst the current study is a first attempt to understand maternal views on access to maltreatment data, further work is required to broaden and deepen our understanding to accommodate the potentially differing views of fathers. Some additional data collection was completed to explore topics more fully with certain groups e.g. a second care-experienced group was run as well as some additional telephone interviews with professionals post asynchronous focus group. Exploring some of the issues more deeply was not feasible *during* the asynchronous focus groups as the potential to quickly respond to comments made was lost, and this is a limitation of this methodology. 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. Understanding was not tested

in any way and this could be addressed in the future by use of approaches such as paraphrasing.

## Conclusion

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 was not acceptable in terms of researchers collecting sensitive data. A co-productive approach to research design should therefore be taken by involving members of the public in the design of research studies accessing maltreatment data from the beginning. Researchers should gather participant representatives' views on which data items are acceptable to collect from which sources, whether data should be anonymised, and how data should be transferred. To our knowledge this is the only study to collect attitudes on child maltreatment data specifically from both public (albeit specific groups of the public) and professional participants, with the vast majority of other studies collecting the views of the public rather than those of professionals. Other studies have done similar work on sensitive topics [e.g. 9], however the added dimension of a person consenting on behalf of another i.e. a parent on behalf of a child, adds to the sensitive nature of the topic and study. Some of the findings of this study are also novel, for example, mothers and care-experienced young people were concerned about accuracy of the data in their records related to child maltreatment. This finding is strongly linked to the data type (child maltreatment) due to its sensitive nature.

## Ethics statement

This study was approved by Cardiff University School of Medicine Research Ethics Committee (SMREC ref 15/36). All participants provided written informed consent and were made aware they could withdraw their participation at any time. All methods were performed in accordance with the relevant guidelines and regulations.

## Conflict of interests

All authors declare that they have no competing interests.

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## Abbreviations

CTR:	Centre for Trials Research
CE2:	Care-experienced young people group 2
P:	Professionals
YM:	Young Mothers
CE1:	Care-experienced young people group 1
OM:	Older Mothers



## Appendix 1. Topic guides

### Face-to-face focus groups

#### Scenario 1 discussion

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.

1. Does anyone have any thoughts about this?
2. 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?')

3. 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?
4. 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?
5. What would be your answer if the researchers were asking your consent for your data to be collected in this way?

#### Scenario 2 discussion

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.

6. Does anyone have any thoughts about this?
7. 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

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.

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.

8. Does anyone have any thoughts about this?
9. 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?
10. 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?
11. How do you feel about researchers collecting data from records about cases of child maltreatment that have been confirmed?
12. How do you feel about researchers collecting data that is what we would call 'markers' of child maltreatment?
13. How do you feel about researchers collecting data on things that may predict that child maltreatment might happen in the future?
14. Are there benefits to this researcher? If so what are they?
15. Do you think researchers having access to child maltreatment data without asking the persons' permission is a good thing or not?
16. If the researchers were asking your consent for your data to be collected in this way, would you say yes or no (or undecided)?



## Online focus group

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?
2. If you know that child maltreatment data may be accessed by researchers; does this affect what data you choose to record?
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?
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?
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?

