The Everyday Work of Healthcare Professionals: An Ethnography of Screening for Down's Syndrome in UK Antenatal Care

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Dedication

This thesis is dedicated to Alison and Martin, the most generous and caring parents anyone could have. Completing this thesis would not have been possible without your kindness, understanding, and willingness to waiver a few debts.

Abstract

This thesis reports on a UK-based ethnography of prenatal screening for Down's syndrome across two hospitals. By studying the mundane and routine practices of the clinic, I initially capture how Down's syndrome screening is organised and how its sedimentation as a taken-for-granted aspect of pregnancy contributes to the procedure being 'downgraded'. This downgrading accomplishes hierarchies of valued/valueless work and professional specialities and also, therefore, of certain professional identities. In what follows, I explore the conduct of care and how professionals detach from Down's syndrome screening by assigning responsibility for decision-making to parents-to-be. Professionals' devotion to the rhetoric of 'informed choice' and 'non-directive care' also naturalises screening as a 'normal' part of pregnancy, this routinisation being extended by parents-to-be (often with professionals) privileging the 'social' rather than 'medical' dimension of ultrasound scanning. I continue by analysing how Down's syndrome itself is constituted both inside and outside screening encounters. During consultations, the condition is rarely discussed and is substituted with dominant discourses of 'risk', 'problem', and 'abnormality'. The condition is subsequently constructed as a negative pregnancy outcome. This intersects with the production and reproduction of ideas around perfection in the social practices and cultural materials of the clinic and how, if a diagnosis is established, the unborn 'baby' is recast as a 'foetus'. By making this move, the unborn baby is denied personhood and a termination of pregnancy is made possible. To conclude, I highlight how the routine practice of prenatal screening for Down's syndrome has transformed antenatal medicine, invigorated parental expectations, shaped issues around reproductive politics, and cultivated certain body-society relations.

Contents

Abbreviations

CVS	Chorionic villus sampling
FAD	Freymarsh antenatal department
FMD	Freymarsh foetal medicine department
NT	Nuchal translucency
REC	Research ethics committee
SAD	Springtown antenatal department

Tables

Chapter One
Introduction

It is almost one-hundred-and-fifty years since John Langdon Down, an English physician, described a group of people with a condition now generally known as Down's syndrome (or Trisomy 21). Down's syndrome is one of the most common chromosomal conditions in the world, affecting approximately one to two of every 1000 live births in England and Wales alone (Morris and Springett 2013). People with Down's syndrome are likely to have a range of symptoms including learning difficulties, shortened limbs, reduced muscle tone, restricted physical growth, a flat profile of the face, and a large protruding tongue (NHS FASP 2012). The condition is often identified as compatible with life, that is, as 'not lethal' (Ivry 2009: 192). This translates to people with Down's syndrome being likely to survive childbirth and enjoying a good quality of life, although symptoms and prognosis vary significantly in each respective case.

In the past fifty years, Down's syndrome has occupied a central position in UK reproductive politics. Prenatal[1] screening for the condition is now a universal programme which has come into 'routine use, becoming embedded in, we might say, a social matrix' (Cowan 1994: 36). Whilst predicted advances of genetic screening generally may be more modest than initially expected, the range of available screening techniques for Down's syndrome (and other conditions) in the UK has steadily expanded with parents-to-be[2] increasingly making use of techniques to assemble knowledge about the health status of unborn babies[3]. In 2011, roughly 74% (N=542,312) of all parents-to-be accessing NHS services in

[1] The terms 'prenatal' and 'antenatal' are used interchangeably throughout the thesis.
[2] The term 'parents-to-be' is my own. Professionals in my research frequently use 'lady', 'woman', 'parent', or 'mum' instead. I considered using the term 'patient' but avoided this since screening commonly involves only one short visit to the clinic and professionals rarely describe parents-to-be this way.
[3] Other conditions including Edward's syndrome (Trisomy 18) and Patau's syndrome (Trisomy 13) may be suspected via prenatal screening for Down's syndrome.

England and Wales opted to be screened for Down's syndrome (NHS FASP 2012)[4]. The uptake in prenatal screening has dramatically increased annually in England and Wales since 2007 (53%). Whilst 2008 and 2009 saw uptake rates of 57% and 62% respectively, an uptake rate of 70% was recorded in 2010 (NHS FASP 2012). This differs from other countries such as the Netherlands where uptake rates vary from 38% to 86% (van den Berg et al. 2005a) and Japan where uptake rates are less than 2% (Nishiyama et al. 2013). The increase in UK uptake rates may be attributable to the recent increase in maternal age (an increase in maternal age is the only known attribute increasing the chance of an unborn baby being diagnosed with Down's syndrome), the risk of miscarriage decreasing on account of increasingly proficient screening technologies, and service supply factors since all mothers-to-be (rather than just mothers-to-be aged thirty-five and above as in earlier years) are now offered screening for the condition (NHS FASP 2012; ONS 2011). The lower uptake rates in Japan, in contrast, are perhaps attributable to a lack of information on prenatal diagnosis and to abortion not being legally permitted for 'foetal abnormalities' (Nishiyama et al. 2013). Nonetheless, the increase in UK uptake rates has coincided with a birth rate increase in England and Wales from 690,013 in 2007 to 723,913 in 2011 (ONS 2011).

In addition, a report conducted by the National Down's Syndrome Cytogenetic Register (NDSCR) claims that in 2011, there were 1,873 diagnoses of the condition in England and Wales, 65% (N=1,211) of which were made prenatally (Morris and Springett 2013)[5]. According to the report, of the 1,211 prenatal diagnoses, 89% (N=931) were terminated, 8% (N=87) were live births, and 3% (N=33) were natural miscarriages or stillbirths (the outcome of 160 prenatal diagnoses is

[4] Screening uptake statistics for Down's syndrome screening in Scotland or Northern Ireland could not be identified. However, the National Services Division (2011) claims 34,768 mothers-to-be in Scotland were screened for Down's syndrome in 2010-2011. However, these statistics do not represent all procedures in Scotland as it is limited to those collected by nationally designated laboratories. In addition, interviews conducted with 666 mothers-to-be across two hospitals in Northern Ireland suggests a lower acceptance rate (26% and 28% respectively) for mothers-to-be than reported in England and Wales (McNeill et al. 2009). I suspect this corresponds to termination of a pregnancy for Down's syndrome being illegal in Northern Ireland.

[5] Positive diagnosis or termination statistics for Down's syndrome in Scotland could not be identified. However, according to the latest statistics, thirty terminations for Down's syndrome were carried out in 2012 (ISD Scotland 2013).

unknown)[6]. The proportion of terminations following a diagnosis of the condition in England and Wales has remained steady for over twenty years. From the first report in 1989 until 2011, the annual rates for termination after a diagnosis of Down's syndrome have ranged from 88% to 94% (the mean rate is 91%). Buckley and Buckley (2008) claim, however, there has been an increase of 25% over fifteen years of babies with Down syndrome being born. They suggest this is because parents-to-be are having children later in life when the chance of having a baby with Down's syndrome increases. Thus, despite this heavy investment in screening/diagnosis, the birth-rate has not fallen but what has been avoided is an increase in the number of children with the condition which may have otherwise resulted (Shakespeare 2011), with nine out of ten prenatal diagnoses of Down's syndrome ending in a pregnancy termination.

However, there are some major disparities in termination statistics once a prenatal diagnosis of Down's syndrome has been established. According to the Department of Health (DoH 2012), there were 511 legal terminations following a diagnosis of Down's syndrome in England and Wales in 2011 (22% of all terminations on medical grounds). The DoH report widely differs to that provided by the NDSCR, suggesting the Department of Health may be underreporting how many unborn babies with Down's syndrome are terminated following a diagnosis. Nonetheless, it is clear how Down's syndrome screening is centrally located in UK reproductive politics. My thesis is dedicated to ethnographically exploring Down's syndrome screening and the conduct of professionals in antenatal care. Whilst studies have examined the social significance of *diagnostic* testing for Down's syndrome (Browner and Preloran 1999; Bryant et al. 2006; Crang-Svalenius et al. 1998; Rapp 2000) or used screening/diagnostic testing interchangeably (Jaques et al. 2004; Kaiser et al. 2004; Marteau 1995; Remennick 2006), I focus exclusively on

[6] It is probable that miscarriages of unborn babies with Down's syndrome are often underreported in comparison to terminations or live births since they may occur early in the pregnancy prior to diagnostic testing (Buckley and Buckley 2008). It is also worth noting there can be some confusion when quoting statistics based on the amount of diagnoses of Down's syndrome ending in a termination of pregnancy. The 89% of 'affected pregnancies' ending in a termination of pregnancy does not represent *all* diagnoses of Down's syndrome but rather *prenatal* diagnoses of the condition. Of all diagnoses of Down's syndrome (N=1,873), 50% end in a termination of pregnancy (so this latter statistic includes postnatal diagnoses of the condition).

screening. This is because screening is important enough to be lifted out of broad debates around universal screening/testing programmes.

Previous research

Screening for Down's syndrome has previously been the subject of academic attention, each drawing on different frameworks and methods, in sociology, medicine (nursing, genetics, and midwifery), psychology, public health, and bioethics. However, the majority of studies can be categorised as examining two core and interrelated aspects of screening for Down's syndrome. First, a proliferation of studies explore decision-making process of parents-to-be and why they do or do not participate in Down's syndrome screening (Aune and Möller 2012; Chiang et al. 2006; Dormandy et al. 2005; García et al. 2008, 2011; Jaques et al. 2004; Kaiser et al. 2004; Liamputtong et al. 2003; McNeill et al. 2009; Pilnick et al. 2004; Pilnick and Zayts 2012; Remennick 2006; Santalahti et al. 1998; Skirton and Barr 2007; Spencer 2002; van den Berg et al. 2005a, 2008). Whilst many of these accounts understand consenting to Down's syndrome screening as a result of rational decision-making processes, others identify how screening is an instance of conformity rather than an expression of choice (Gottfreðsdóttir et al. 2009a, 2009b; Heyman et al. 2006; Marteau 1995; Markens et al. 1999; Pilnick 2004; Press and Browner 1997; Sooben 2010; Tsouroufli 2011; Williams et al. 2005). This corresponds to parents-to-be interpreting screening as a recommended part of pregnancy surveillance (Hunt et al. 2005; Vassy 2006), how they view professionals' offer of screening as endorsing its acceptance (Heyman et al. 2006; McNeill et al. 2009;), and how ultrasound scans can be viewed, first and foremost, as offering a chance for meeting the baby, and to make a pregnancy seem more real, rather than for prenatally detecting conditions (Draper 2002; Gammeltoft and Nyugen 2007; Heyman et al. 2006; Lupton 2013; Williams et al. 2005).

Second, a cluster of studies report on the interactions between parents-to-be and professionals, particularly concerning discrepancies of knowledge directed at the level of the intertwining rhetoric of 'informed choice' and 'non-directive care'. These concepts translate to tendering medically-accurate information to parents-to-be detached from any personal biases (Schwennesen and Koch 2012; Sooben

2010; van den Berg et al. 2005b). Several studies claim parents-to-be do not perceive their care as non-directive since the provision of information is interpreted as an explicit instruction (Browner et al. 1996; Hunt et al. 2005; Lippman 1991; Marteau et al. 1993; Pilnick 2008; Tsouroufli 2011; Williams et al. 2002b). Others simultaneously explore how professionals encounter difficulty in remaining non-directive and ensuring informed choice when communicating information on Down's syndrome screening (García et al. 2008; Heyman et al. 2006; Pilnick et al. 2004). This stems from needing to balance both professional and private values (Anderson 1999; Farsides et al. 2004; Williams et al. 2002a), a conflict between the time professionals have available to explain screening and the time required for discussing the procedure (Sooben 2010; Vassy 2006; Williams et al. 2002a), the trouble of conveying (risk) information and the practical/ethical aspects of screening (Ekelin and Crang-Svalenius 2004; Hey and Hurst 2003; Heyman et al. 2006; Williams et al. 2002a), how parents-to-be may not fully understand screening (Burton-Jeangros et al. 2013; Gammons et al. 2010; van den Berg et al. 2005b), and the different definitions between parents-to-be and professionals of what constitutes a 'normal result' and/or 'normal child' (Hunt et al. 2005; Vassy 2006; Williams 2006).

Taken together, this research shows how the development and diffusion of prenatal screening techniques has triggered critical debates around the seemingly contradictory aspects of offering reproductive choice to, and prompting social, legal, and ethical dilemmas for, parents-to-be. This means parents-to-be, in receipt of information about an unborn baby, must make serious life decisions frequently on the basis of partial knowledge (Ettorre 2002; Franklin and Roberts 2006; Glover 2006; Parens and Asch 2000; Rapp 2000; Rothman 1986; Rothschild 2005; Schwennesen et al. 2010; Thompson 2005). Nonetheless, whilst the substance and contribution of the existing insights cited above is irrefutable, they can be subjected to some criticisms. First, important voices are missing, or at least relatively silent, in the literature such as fathers-to-be and parents-to-be choosing to continue or terminate a pregnancy. Additionally, and most importantly for the current study, research on professionals generates a fairly undersized literature (McCourt 2002; Tsouroufli 2011; Williams et al. 2002a, 2002c). It is surprising that

professionals, playing such a key role in the provision of information, have not been a main priority for researchers.

Second, research is regularly based on retrospective accounts of parents-to-be and professionals (Aune and Möller 2012; Bryant et al. 2010; Burton-Jeangros et al. 2013; García et al. 2008; Gottfreðsdóttir et al. 2009a; Heyman 2010; McNeill et al. 2009; Press and Browner 1998; Santalahti et al. 1998; Williams et al. 2005). Focusing solely on professionals, data have been gathered using questionnaires (Jaques et al. 2004; Samwill 2002; Smith et al. 1994), interviews (Burton-Jeangros et al. 2013; Farsides et al. 2004; Williams et al. 2002b), or more problematically, interviews with parents-to-be speaking for professionals (Gammons et al. 2010; Skotko 2005; Sooben 2010). These techniques, by de-contextualising context-specific encounters and relying on romantic ideas of an experiencing individual (Silverman 1989), make invisible the mundane aspects of, and meaning-making practices in, medical encounters. Ethnographic exceptions are evident (Hunt et al. 2005; Ivry 2006; McCourt 2002; Pilnick 2004, 2008). However, they are far from abundant and, more critically, too frequently focus on the simple patient-professional dyad. This focus on 'where the action is' (Goffman 1967) is a grave sampling error since it mistakes a part for the whole. Interactions between professionals and parents-to-be, in turn, are only one part of medical work around prenatal screening for Down's syndrome.

Third, several studies on Down's syndrome screening often fail to fully discuss the condition and subscribe to medical definitions of Down's syndrome or disability more generally. Although exceptions are identified (Bryant et al. 2001; Gammons et al. 2010; Murray et al. 2006; Sooben 2010), few have conducted extensive empirical research, particularly via in-depth ethnographic observations of clinical settings. They have seldom attended to how Down's syndrome is discussed within screening consultations and how claims that screening fosters a belief that Down's syndrome should be prevented (Alderson 2001; Sooben 2010; Vassy 2006) play out in the clinic. This criticism extends to analyses on reproductive practices more generally (i.e. not limited to Down's syndrome screening) and how values around disability are enacted within medicine (Ettorre 2002; Latimer 2007; Rapp 2000;

Shakespeare 2006). Studies have suggested how medical and scientific advances, despite being widely celebrated and embraced, promote a clear definition of which people should and should not live (Lippman 1994; Parens and Asch 2000; Rothman 1998). Many accounts, however, frame disability as a universal category[7]. Davis (1995: xv) argues that the totalising tag of 'disability' is an extraordinarily unstable category which denies the variability of bodies; 'the category "disability" begins to break down when one scrutinises who make up the disabled'. By utilising a universal term unfairly and inappropriately creating rigid categories of existence, such accounts obscure the complexity of different and distinctive conditions.

The current study

My research – an ethnography of prenatal screening for Down's syndrome across two healthcare institutions – bridges many of the gaps cited above. Specifically, I explore the everyday practices of antenatal medicine and how Down's syndrome screening is 'done' (Garfinkel 1967) in the mundane and taken-for-granted encounters of the clinic, a site in which particular social, cultural, and political affects are accomplished (Atkinson 1995; Latimer 2000; Mol 2002; Silverman 1987). A close ethnographic reading of everyday clinical life unmasks the ongoing, complex, and different ways in which knowledge, meanings, and positions are (re)produced in medical encounters. The study took place in two UK healthcare institutions: 1) Freymarsh, a large NHS teaching hospital in a metropolitan area, and; 2) Springtown, a privately-funded fertility clinic located in an affluent area. My triangulated approach meant I spent over two-hundred hours observing the hospital settings, completed sixteen interviews with healthcare professionals, and analysed secondary documents including hospital/governmental policies and antenatal leaflets distributed to parents-to-be. Two clarifications are provided

[7] I recognise that the term 'disability' is widely contested (Davis 1995; Oliver 1990; Shakespeare 2006). In an analysis of chronic illness, Locker (2008: 86) unpacks the disputed categories of impairment, disability, and handicap. According to Locker, impairment constitutes any loss or abnormality of physiological, psychological, or anatomical structure or function; disability involves a restriction resulting from an impairment of ability to perform certain 'normal' activities; handicap is a social disadvantage because of an impairment or disability which limits or prevents fulfilling a 'normal' role. Whilst I do not necessarily dispute Locker's distinctions, I use the terms interchangeably (though more often than not 'disability') for reflecting how the relation between embodied limits and social discrimination is complex and durable and because 'disability' is used most commonly by Freymarsh and Springtown professionals when referring to a loss of physiological or psychological function. I am fully aware this may reflect the medical – rather than the social – model of disability (Oliver 1990) but I ask for some forbearance here.

here. First, I will not draw on data exclusively concerning parents-to-be. Their experiences, perceptions, and concerns are well-rehearsed in the literature and although I explore their interactions with professionals, I resist regurgitating previous arguments. I choose to primarily focus on professionals since, as stated earlier, they are rarely, if ever, subjected to critical ethnographic attention in the context of Down's syndrome screening. Second, whilst I draw on my observations of two hospitals, this is not a comparative study. There are two reasons for this. First, whilst the sites differed in some respects, the issues raised here were evident in both settings. Indeed, both institutions adopted different screening methods to attain the same result and so my arguments are mostly translatable. Second, many professionals at Springtown also worked at Freymarsh. Whilst comparisons did emerge, these would not hold ground as a thesis. Rather, I draw on fieldwork in each setting to make wider claims about Down's syndrome screening and how it intersects with 'the politics of reproduction' (Ginsburg and Rapp 1991).

My primary focus for this research was on the conduct of professionals when screening for Down's syndrome. I follow professionals, as creatures of habit and bearers of culture, through their worlds. I reveal how their schedules, practices, discourses, and interactions with parents-to-be, colleagues, and materials which 'make up' (Latimer 2008b) the clinic accomplish, intensify, and disturb orders and routines. By recognising the hospital as a privileged environment for studying the dramatisation of routines (Berg 1992), I am interested in how professionals construct and preserve order, how they structure their interactions and working practices, and how they perform their roles (Garfinkel 1967; Goffman 1959). Believing one must unmask unspectacular patterns of everyday life to distinguish spectacular events (Whyte 1955), I describe who does what, where, how, to whom, to what ends, and its consequences for participating people. This means I illuminate how ideas around screening for Down's syndrome in the world of healthcare, as a political and contested site, are produced and made sense of from within social, cultural and medical repertoires. Thus, I place an emphasis not on people specifically and their interiority but rather the multiple forms of clinical life and how people are located in situations with their own properties, rhythms, and

gestures (Silverman 1987), a dynamic often missing in current analyses on Down's syndrome screening.

This involves resisting a subscription to the notion that certain frameworks or categories are *givens* defying cultural interpretation (Atkinson 1995). Rather than affording Down's syndrome screening and the condition itself some unquestioned ontological status and limiting descriptions to biological imperatives as invoked in the medical literature, I view Down's syndrome and screening for the condition as 'things' continually constructed and negotiated in the everyday talk, conduct, and practices of professionals and their interactions with colleagues, parents-to-be, materials, and space (Kerr 2005). This contributes to the literature on how screening is both a social and medical intervention (Armstrong 2012; Gillespie 2012; Lock et al. 2007; Scott et al. 2005; Timmermans and Buchbinder 2013) but extends it by considering how identities, hierarchies, responsibilities, and values are produced and reproduced in antenatal care. Through taking the mundane and taken-for-granted seriously since it is through these that meanings are circulated, I therefore uncover issues (in the interpretive mould) around how Down's syndrome screening is organised and valued, how professionals perform their roles, and how the condition itself is constituted within medical encounters.

Thesis outline

This thesis is separated into nine chapters. Following this introduction, chapter two is dedicated to outlining the theoretical foundations informing my intellectual thinking. I draw largely on ethnomethodological sensibilities (Garfinkel 1967) but recognise the value of theoretical synthesis by drawing on concepts and ideas from other perspectives for making sense of data. Chapter three is a socio-historical narrative of Down's syndrome screening and how the condition has intersected with scientific and medical worlds since the nineteenth century. This socio-history continues with an outline of Down's syndrome screening in recent years and its current use in Freymarsh and Springtown. This socio-history is not a review of the literature as conventionally conceived. Rather than presenting a separate review outlining previous research, I have cited literature and integrated this work throughout the thesis to maintain cohesion and to remain loyal to the ethnographic

tradition. By assimilating other arguments into my chapters, I am able to identify the similarities and discrepancies between my claims and those preceding them. Chapter four situates the study by outlining the process of gaining NHS ethical approval, collecting field data, making fieldnotes, my relations in the field, data analysis, and both the ethics and struggles of ethnography.

Chapter five begins with the presentation of field data. I explore how screening is organised in the everyday practices of Freymarsh and Springtown and how the task of conducting Down's syndrome screening, at least initially, is relegated from consultants to midwives (Freymarsh) and sonographers (Springtown). Midwives and sonographers (mainly midwives), as an unwitting 'mop-up service' (Bosk 1992), classify Down's syndrome screening consultations as a repetitive, ritualised and valueless task. Other duties such as counselling miscarriages are prioritised and preferred for producing and reproducing their identity-work. The organisation of Down's syndrome screening, thus, accomplishes its downgrading since this professional assignment is not aligned with and is not invested with value. Chapter six explores the conduct of care and how the naturalisation of Down's syndrome screening as a 'normal' part of pregnancy is accomplished in mundane affairs. This is achieved in two ways. First, professionals 'dispose' (Latimer 1999) of screening by employing the entwining rhetoric of 'informed choice' and 'non-directive care' to allocate full responsibility to parents-to-be. Second, the 'social' dimensions of ultrasound scans (offering opportunities to 'meet the baby', receive pictures, and reproduce kinship) are promoted over its 'medical' dimensions (to detect potential concerns with the unborn baby). Such moves accomplish Down's syndrome screening, thus, as normal and expected conduct for parents-to-be.

Chapter seven explores how Down's syndrome itself is constituted in screening consultations and antenatal care more generally. Professionals are often critical of Down's syndrome screening and are positive about the condition specifically yet in consultations, such beliefs and interpretations become absent. Down's syndrome is talked *around* and as opposed to being talked *about* or *through*. As such, it becomes subsumed by the broader, universalising, and more negative discourse of 'risk', 'problem', or 'abnormality', ensuring that a negative portrayal of the condition and

familiar scripts of reproductive misfortune remain intact. Chapter eight shows how screening brings cultural ideals around perfection close to hand. This positions mothers-to-be and especially mothers-to-be at an 'advanced maternal age', the discourse used by professionals and in the antenatal literature, as accountable for their reproductive choices. The notion that unborn babies are 'perfectible' (Ivry 2006: 459) also relates to the constitution of those with the condition. Whilst the effects of Down's syndrome can vary significantly from one individual to another, the unborn baby with or suspected as having Down's syndrome is frequently classified as a 'foetus' in the ordering work of professionals. As such, the nonhuman and technical classification of the 'foetus' with Down's syndrome contributes to its disposal, both figuratively and physically, in the clinic.

Chapter nine concludes the thesis by reiterating the previous findings and their importance for the sociology of medicine and beyond. I also reflect on how Down's syndrome screening plays a central role in reproductive politics, transforming reproductive medicine whilst simultaneously invigorating parental expectations and providing a commentary on what lives are valued (or not). Thus, I show how prenatal technologies, rather than being solely perceived as a positive knowledge practice remaining beneficial to medical and social advancement, produces and reproduces the idealised (unborn) body to collude in a form of social exclusion. I also offer some recommendations for future antenatal practice, namely how we need a more critical reflection on how Down's syndrome is constituted in antenatal encounters. However, whilst suggestions are proposed, I do not offer political or moral disclaimers about Down's syndrome screening. Drawing on Goffman (1974: 74), my main intention, thus, is not 'to present a lullaby but merely to sneak in and watch the way the people snore'.

Taken together, the chapters tell a story of both extraordinary drama and ordinary routine. By providing 'thick descriptions' (Geertz 1973) of often slim encounters and answering Han's (2013) call for analysing the humdrum and banal aspects of pregnancy, I document a select crosscut of professionals' worlds with important implications for our conceptions of pregnancy, parenthood, the family, and ideas surrounding the 'normal'. I consider Down's syndrome screening, thus, not as a

patient-centred and individual transaction between professionals and parents-to-be but rather as a complicated and collective social and cultural concern extending well beyond the clinic and powerfully shaping the constitution of contemporary society.

Chapter Two
Theoretical Foundations

Before delving deep into the worlds of Freymarsh and Springtown, I dedicate this chapter to introducing the theoretical foundations on which the thesis is grounded. Ethnography, as Bosk (1979: 19) presses, is both a 'theoretic and a theoretically motivated activity'. However, as will be made clear throughout the thesis, I stress I do not entirely buy into the worldview of one tradition. Whilst the study could be loosely defined as a cultural and interpretive analysis, my arguments draw on concepts borrowed from other paradigms, meaning my theoretical allegiance is partial, fluid, and subject to change. Undoubtedly, my research has been influenced by ethnomethodological concerns, that is, 'the study of folk or members' methods for producing recognisable and reasonable social orders' (Laurier 2009: 633). However, in the thesis, I combine ethnomethodological sensibilities together with ideas and concepts from several perspectives to engage with a particular way of analysing the social. The complexity of the theoretical framework reflects, in turn, how the complexity of prenatal screening for Down's syndrome cannot be handled by a single discipline or framework. Restricting analysis to one perspective would not do justice to the multiple, mundane, and messy character of everyday life in the clinic which does not always cleave at neat points. This chapter, therefore, is my attempt to condense the disorderliness into a coherent account with reference to a collection of theoretical tropes. Specifically, I describe my position here for making arguments throughout the remainder of the thesis.

In sum, to draw on Foucault's analogy of a toolbox, I procure tools offered by different theoretical foundations to make sense of Down's syndrome screening in two hospital settings. Despite synthesising several concepts and ideas, my main aim is to analyse the mundane, familiar, and taken-for-granted 'micro' practices, routines, rhythms, and rituals of everyday life which produce and reproduce order and values. To do this, I focus on interactions, identity-work, accounts, materials, power relations, discourse, typifications, 'motility' (Latimer 2013; Latimer and Munro 2006; Munro 2001) and 'disposal' (Latimer 1997; Munro 2001). These

ideas will be briefly explained in this chapter and elaborated on more extensively as the thesis progresses. Following Scott (2009: 10), then, I will use material which involves 'theorising the mundane' and reveals how the micro and banal help us understand the wider processes and complexities of everyday life and specifically the everyday life of the antenatal clinic in relation to Down's syndrome screening.

Interactions, identity-work, accounts

As stated, my intention is to examine the mundane practices of the antenatal clinic. Rather than simply interviewing professionals about work practices, I observe the interactions between them and parents-to-be, colleagues, and others. As such, a key feature of this research concerns attending to the micro-study of face-to-face interaction. The work of Goffman (1959, 1963, 1983) is valuable here. Goffman illuminates the strategic choices underpinning knowledge, meanings, and accounts and its effects on the self (Scott 2009). His 'dramaturgical' (Goffman 1959) insights are united by a recurring concern with the quirks of human conduct and the strategic ways people behave in situations. During such collective recitals, people manage impressions, maintain performances, and negotiate identities to uphold normal appearances. Such co-presence, for Goffman, corresponds to the regulation of a public order. In sum, Goffman claims one cannot dismiss the minute as trivial, highlighting how the intricate politics of small rules and transgressions add up to ordinary yet very powerful and symbolic rituals (in a dramaturgical sense) and ceremonies in everyday life.

In relation to my own study, I explore the extraordinariness of ordinariness, that is, I analyse the subtle scaffolding of human interaction, the character of institutions, and, more generally, how professionals make sense of their world (Goffman 1959, 1983). I examine how professionals, as 'members' (Garfinkel 1967), produce a local order as well as make shared sense of their circumstances and act on this. By treating 'practical activities, practical circumstances, and practical sociological reasoning as topics of empirical study', I capture the nuance of ordinary (and often hidden) knowledge and the 'most commonplace activities of daily life' in the clinic (Garfinkel 1967: 1). Thus, I identify the role background expectancies play in constructing and controlling a local order, as a 'socially managed production', and

in accomplishing ordinary routines in Freymarsh and Springtown (Garfinkel 1967: 75). This order is a moral one (Garfinkel 1967); it produces particular moral forms, that is, how people organise the world and the local order. This is important for considering the moral order of Freymarsh and Springtown. Indeed, professionals 'encounter and know the moral order as perceivedly normal courses of action-familiar scenes of everyday affairs' (1967: 35). It is the taken-for-granted, in turn, which becomes 'natural' and 'moral' facts of life (1967: 35). Thus, I explore how professionals, in their everyday conduct, produce and reproduce particular moral values not only around their daily duties but also around certain bodies/future bodies.

Attending to how people as 'members' accomplish a (moral) order shows how my study answers Schütz's (1970) call for a sociology of the mundane, of questioning unquestionable assumptions about the constancy of our structure of the world, of the validity of our experience, and our ability to act upon the world and within the world. This means treating the obvious as a phenomenon ('topic') as opposed to an 'unexplicated resource' by examining how people 'assemble particular scenes so as to provide for one another evidence of a social order as-ordinarily-conceived' (Zimmerman and Pollner 1970: 81-83). Such arguments replicate that of Douglas (1966) who describes 'dirt' as too mundane to be explicit, a 'thing' too true to warrant contemplation. Douglas recognises how the mundane must be unpacked in order to make sense of the world. Similarly, I recognise the value of analysing the taken-for-granted and for embracing multiplicity rather than attributing social life – contextual, historical, local, and specific – to universal laws. By analysing how meanings, orders, and routines are produced and reproduced in a clinical setting, I identify how expectations and values at the micro-level are consolidated into wider normative codes of conduct which appear as 'natural' and 'real' (Scott et al. 2013).

Additionally, I capture how professionals, primarily though their interactions with parents-to-be, engage in identity-work (Goffman 1959). The social audience is important for identity construction since the self and any adjustments thereof is not a property of the individual but arises through interactions with other people

(Thomas 2014). People share a world with others in which there is an ongoing correspondence between each person's meanings and interpretations. I agree with Goffman that these meanings and interpretations are located in historical time and space and circulate in social and cultural meanings. As such, I explore how professionals accomplish order by managing, performing, and directing interaction (Scott et al. 2013), that is, how they take account of others and reaffirm their identity in relation to the conventions of the clinic. Within such situated occasions, identity is relational, amorphous, and routinely created in the reflexive actions of people. Against the notion of the self-as-consumer, the collective rather than the individual is the primary site for identity-work and for making the world together. As such, I examine how professionals create their identity and how parents-to-be, as patients, are used for this construction (Latimer 2000).

Related to professionals' identity-work is their 'accounting' practices (Garfinkel 1967). Accountability refers to the ways people, as 'members', signify, describe, or explain the properties of conduct in a social situation (Garfinkel 1967). They make what they do and who they are appear grounded, reasonable, and rational to others. People work to maintain consistency, order, and meaning in their lives, that is, to accomplish identity and membership within given groups. It is principally via language, as 'situated practices of looking-and-telling', that this is accomplished and members subsequently create a sense of reality (1967: 1). Accounts, therefore, are essential to maintain stable grounds 'in the social structures of everyday activities' (1967: 185). This is important for this study since I examine how professionals account for the conduct of both themselves and others, that is, how they describe interactions with parents-to-be, validate their actions within such occasions, and use this to construct and reconstruct their identity.

Power relations, discourse, materials

Another intention for this study is to explore how the micro-physics of power are enacted in Freymarsh and Springtown. The arguments of Foucault (1967, 1972, 1983) are a valuable asset here. Foucault argues that power is not concentrated in one space or possessed by one person but rather is localised and fragmented, with people becoming conduits through which power is exercised. Modern power, for

Foucault, is more efficient and productive than its predecessor. Invisible yet potent in its effects, power is realised in its reach 'into the very grain of processes and everyday life' (Foucault 1980: 39). As a productive network, power is a practical accomplishment which 'produces and traverses things, it induces pleasure, forms of knowledge, produces discourses' (1980: 119). Agreeing with Foucault power is not repressive but productive, not coercive but legitimate, I explore how power works in Freymarsh and Springtown, namely by examining how it facilitates, mobilises, and elicits the actions of those subjected to it. This focus on disciplinary power – working consciousness through, and controlling the operations and positions of, the body (Foucault 1973) – means I can analyse how professionals formulate, disperse, and use power and knowledge within and across settings to organise activities and assign meanings to the conduct of themselves and others.

More specifically, I capture how power is expressed and meanings are distributed in the clinic via 'discourse' (Foucault 1972), that is, in the language and practices of embodied individuals (Scott 2010). Lessa (2006: 285) defines Foucault's notion of discourse as 'composed of ideas, attitudes, courses of action, beliefs and practices that systematically construct the subjects and the worlds of which they speak'. Following Foucault, I capture the role discourse plays in power relations and the production of current truths, suggesting discourse is a culturally constructed representation as opposed to an exact replica of reality. In the antenatal clinic, discourse constructs knowledge and disciplines via the production of categories and assemblages of text (Foucault 1967, 1983). As such, I identify how discourse constitutes categories in Freymarsh and Springtown, particularly around – putting it simply – the 'normal' and 'abnormal' body. People are constituted via 'dividing practices' (Foucault 1983: 208) which, as forces of 'normalising judgement' (Foucault 1973: 177), produce classifications. People can be divided, for instance, into 'the mad and the sane, the sick and the healthy, the criminals and the "good boys"' (Foucault 1983: 208). Thus, I attend to how in Freymarsh and Springtown, professionals' knowledge finds consistency and stability in categories of certain people – or future people – to help construct 'the order of things' (Foucault 1970).

Through a Foucauldian lens, we see how people internalise discourses and impose such discourses on themselves (Scott 2009). Discourse can be used to produce and reproduce dominance or resistance and make explicit taken-for-granted rules facilitating both inclusive and exclusive practices (Foucault 1967, 1979). However, agreeing with Foucault that discourse is never limited to 'words' or people alone, a key feature of this research is how materials are invoked, 'aligned with' (Latimer 2004), and resisted in different moments (White 2007). That is, I recognise how power is transmitted via materials and the spatial organisation of Freymarsh and Springtown. Drawing on her work in a hospital setting, a site of multiple discourses (Silverman 1987), Latimer (2004) argues discourse extends to materials involved in producing and reproducing dominant relations. She claims that doctors make 'moves', sometimes figurative and sometimes literal, which 'align' social practices and cultural materials to re-accomplish asymmetrical power relations (2004: 757). One example provided by Latimer involves a doctor overruling a physiotherapist by placing a zimmerframe in front of a patient. On such occasions, the doctor can 'move' the patient and colleague around by using materials as well as accounts.

During this study, I take heed of Latimer's contentions by paying attention to the use of and 'extension' (Munro 1996) with cultural materials, alongside whether professionals 'attach' or 'detach' (Latimer 2004) themselves or others to/from such materials, in constituting power relations. By recognising the importance of materials when analysing the social, my arguments are not unlike actor-network theory. However, this is not an actor-network theory study. Unlike Callon (1987) and Latour (1987), I suggest meanings are not given but are constructed *post hoc* in relation to other people and materials (Garfinkel 1967; Geertz 1973; Latimer 2004). This is not to say, however, I have not found actor-network theory useful. Indeed, I cite Latour on several occasions to think *with* and *through* my data, particularly when I treat materials and space seriously rather than as 'second class citizens' (Law 1991: 6). By thinking socio-technically (Law 1991), I view the antenatal clinic as a site of 'simultaneous and imbricated material and discursive construction' (Rapp 2000: 194). The materials of the clinic – ultrasound machines, medical records, furniture, and so forth – are drawn upon and aligned with by professionals which brings into play a whole set of relations. Thus, I show how

alongside interactions and accounts, materials make the clinic 'durable' (Latour 1991).

Motility, typifications, disposal

As stated, I explore professionals' 'accounts' with regards to Down's syndrome screening. Crosschecking accounts with observations of professionals' everyday practices means I am able to reveal the discrepancies between what they *do* and what they *say*. I do not treat such inconsistencies as 'infractions' (Garfinkel 1971) or as 'breaches' (Garfinkel 1967) or, at worst, as untruths. Rather, I view them as instances of 'motility', referring to how people or things are moved in different spaces of discourse (Latimer 2013; Latimer and Munro 2006; Munro 2001). What is made important or unimportant, present or absent, changes from moment to moment, helping 're-accomplish socio-cultural relations of power' (Latimer 2008a: 2). Thus, I capture what professionals make present and absent, what they view as important and unimportant, and who or what they categorise as normal and abnormal, at different moments, in Freymarsh and Springtown.

In the thesis, the notion of motility is explored – particularly in chapter seven – through an analysis of how professionals produce and reproduce 'typifications'. Typifications refer to how people establish schemes of meaning (typify) by categorising and classifying things which, in turn, seem 'natural'. This subsequently allows people to find and make meaning and order (Douglas 1966; Garfinkel 1967; Schütz 1962). For Latimer (1997: 160), processes of typification also entail 'systems of distinction' which can be used to 'bring things together and hold things apart'. In Freymarsh and Springtown, I capture how certain clinical duties and unborn babies are, in certain situated occasions, classified and categorised in particular ways. This is particularly true in the constitution of both 'normal' and 'abnormal' babies and the enactment of exclusion, though this claim is built on more extensively later in the thesis.

The typification/classification of certain persons/future persons and things relates to the concept of 'disposal' (Latimer 1997, 2000). I understand disposal as the means through which professionals engage in ordering work to help maintain

order in the clinic, that is, how they place, displace, and replace certain persons, ideas, or things (Munro 2001). I relate the concept of disposal to how professionals classify certain tasks (i.e. Down's syndrome screening) in everyday practice, in relation to identity-work and membership, and how they erect an understanding of certain persons/future persons (Goffman 1963). Berg (1992) claims that within medicine, physicians construct medical disposals, that is, they dissemble patients into traits so they can be classified and subsequently disposed of. He claims medical criteria and disposal options are not 'givens' which lead a physician towards a certain decision (1992: 168). Rather, the physician actively moulds and reconstructs the patient so their problems are solvable. In this study, I explore how professionals – with reference to certain classificatory systems – 'detach from' (Latimer 2004) and transform problem bodies into the other. Specifically, I show how they *make* problems solvable, that is, how certain persons or future persons are made disposable in the clinic.

Summary of the study

In this chapter, I have identified the key theoretical undercurrents which inform my approach and implicitly highlighted how ethnographic fieldwork is a detailed search in which deductive orientations, with loyalties to theory, and indicative orientations, with loyalties to the field, 'join in a dialectical fashion' (Desmond 2007: 296). Nonetheless, I underline the virtues found in practicing theoretical pluralism in opposition to developing a 'grand narrative' (Law 1991). Pinch (2010) suggests researchers need to combine more conventional sociological approaches like Goffman's (1959, 1963, 1983) with an analysis of materials and space. I argue my work – taking the ordinary seriously as a category of analysis and showing how social relations, practices, and materials are equally mundane and dynamic – offers this possibility. Whilst specific theories are not explicitly cited or deployed as a framework for interpreting the data, they are deeply embedded in the fabric of my arguments. Martin (2010: 24) claims attending to the interplay of practice, discourse, and materials 'provides a window into the coming-into-being of novel scientific facts and entities'. Whilst I detract focus from the *novel* by analysing the old frontier of Down's syndrome screening, Martin's focus on the relations between practices, discourses, and materials becomes essential in contemplating

the everyday politics of antenatal care and particularly of prenatal screening practices.

In sum, with reference to the theoretical tropes above, I explore the ways in which order and realities are accomplished and how matters are decided locally. Replicating Garfinkel's (1967) charge for studying everyday affairs, my research fleshes out the specific socially-embedded concreteness of situated occasions, that is, the taken-for-granted and mundane rhythms of hospital life which 'combine to create and sustain a sense of order, stability, and predictability' (Scott 2009: 5). Interested in the 'content' of medical action (Berg 1992: 151), my study is a story of how Down's syndrome screening is 'done' (Garfinkel 1967) and how the clinic is a site in which 'people do (perform, reproduce, and occasionally challenge) social life, day to day' (Scott 2009: 1).

More specifically, guided by an interest in professionals' conduct in the context of Down's syndrome screening, I capture the significance of interactions, accounts, discourses, identity-work, power relations, materials, typifications, motility, and disposal practices – all of which produce social, moral, and cultural contexts – in the clinic (Latimer 1997; Silverman 1993). In so doing, I identify who or what is privileged/trivialised and made absent/present, how resources are distributed, what or who is 'normal', how professionals 'do member' (Garfinkel 1967) and learn technical knowledge, and how hierarchies, as cultural forms, are erected, legitimated, and mutated in antenatal care (Latimer 1997; Silverman 1993; White et al. 2012). This involves a focus on how cultural assumptions are embedded in the metaphors and discourse of biology (Martin 1991; Martin 2010) and how reproductive technologies have dominant pictures of norms surrounding bodies, families, and desires built into them. By carrying out my very own 'breaching experiment' (Garfinkel 1967)[8], I show how reproductive politics, in the context of

[8] This corresponds to Stengers' (2005: 994) discussion of Deleuze's 'idiot', he or she 'who always slows the others down, who resists the consensual way in which the situation is presented and in which emergencies mobilize thought or action'. The idiot, for Stengers (2005: 996), demands 'we slow down, that we don't consider ourselves authorized to believe we possess the meaning of what we know'. As an ethnographer, I conduct a breaching experiment by similarly not asserting my own knowledge about proceedings and by my interests contravening, and making visible, the ordering, underpinnings, and conditions of possibility of the clinic.

screening for Down's syndrome, are worked through in the familiar scenes of everyday affairs and practical accomplishments of professionals in antenatal care. This involves pressing how situated encounters are both social and technical accomplishments (Law 1991; Mol 2002). Making the materiality of peoples' worlds explicit and central, rather than implicit and marginal, is of paramount importance for grasping everyday life in the hospital (Sandelowski 2003).

This chapter has set up my grounds for the following two chapters, namely, for describing how Down's syndrome screening has become a site of critical attention (chapter three) and how my theoretical thinking has influenced how I carried out fieldwork (chapter four).

Chapter Three
The Critical Site of Down's Syndrome Screening

A SHORT SOCIO-HISTORY

This chapter begins by outlining a short socio-history of Down's syndrome in the UK and beyond. It follows previous socio-historical analyses of medical conditions including cystic fibrosis (Kerr 2005), diabetes (Hedgecoe 2002), cancer (Fujirama 1996), and atherosclerosis (Mol 2002). Starting from the position that one must have a firm comprehension of the past in order to understand the present and ponder the future, I piece together key developments, inside and outside the UK, within the last two-hundred years which have contributed to Down's syndrome being subjected to the reproductive gaze. A range of technological, scientific, legal, economic, political, and cultural developments over many years have stimulated new research and clinical tools around Down's syndrome and prenatally detecting the condition, from the contested to the mundane. Far from the dramatic discoveries attributable to medical progress, Down's syndrome and its intersection with antenatal care evolves in a gradual and often ordinary fashion 'as new techniques and social mores are incorporated within existing epistemological and technological frames' (Kerr 2005: 874).

Casper and Clarke (1998: 255) show how the pap smear became the 'right tool for the job' for cervical cancer screening; technical manipulation, the automation of record-keeping, the proliferation of health activists, public pressure following high rates of incorrect readings, and the creation of the American Cancer Society, among other trends, created an environment necessary for supporting its development and subsequent diffusion. Similar to Casper and Clarke, I identify how Down's syndrome screening has become a routine procedure, that is, the 'right tool for the job' in antenatal care. This socio-history is loosely chronological but often messy and convoluted, reflecting the immense complexity of how the diagnostic category of Down's syndrome and screening for the condition has come into being. In this chapter, I draw on ideas from medical historians (Cowan 1994; Wright 2011), healthcare practitioners (Nancollas 2012; Reynolds 2010), anthropologists (Rapp

2000), and disability activists (Logan 2011). This small but comprehensive collection of material – which I am indebted to for formulating this short history – is a product of failing to unearth similar sociological accounts. As such, one can recognise this chapter not only as reflecting the interdisciplinary nature of my work but also as rectifying an inadequacy in the sociological literature.

The making of mongolism

The inception of the category 'mongolism' or 'idiocy'[9] (or what is now referred to as Down's syndrome) seemingly began in 1838 with the publication of Jean-Étienne Dominique Esquirol's *Des Maladies Mentales Considérées Sous les Rapports Médical, Hygiènique et Médico-Légal, Volume 1* (1838). A psychiatrist by trade, Esquirol described a collection of certain people as 'idiots', roughly translating as those with intellectual and developmental disabilities. This work was developed by Édouard Séguin, a physician and educationist working with children who had cognitive impairments. His book *Traitment Moral, Hygi*ène *et Éducation des Idiots et des Autres Enfants Arri*érés (1846) was dedicated to the diagnosis and treatment of such children. However, the notion of mongolism specifically was more famously developed by English physician John Langdon Down in 1866. Working at the Royal Earlswood Asylum for Idiots, Down ([1866] 1997) was the first person to extensively describe a group of people sharing anatomical and behavioural characteristics, a group he described as 'mongoloids' since their facial features paralleled people of Mongolian descent (Starbuck 2011).

Pueschel (2000) offers three reasons for why mongolism was not recognised as a clinical entity prior to 1866. First, few physicians before the nineteenth century were interested in children with developmental conditions. Second, the prevalence of many diseases and conditions would have overshadowed mongolism. Third, only half of women aged above thirty-five survived during this period, arguably resulting in lower amounts of late-aged pregnancies in which women were likely to have a child with mongolism. Regardless of this, it is within this time period that

[9] I am fully aware the terms *mongolism* and *idiocy* are likely to cause great offence to UK (and perhaps other international) advocacy organisations and parents of children with the condition. However, their use here is integral to fully outline the history and *making* of Down's syndrome. I return to the importance of the discourse surrounding Down's syndrome later in the thesis.

mongolism as a diagnostic category was *made*, namely, that it was constituted by social and medical/scientific discourse[10].

Eugenics and institutionalisation

So how were people with 'mongolism', recognised by Down, Esquirol, and Séguin as a clinical entity deserving its own status (Starbuck 2011), treated by society when their work was published? According to Logan (2011), 'training schools' in the nineteenth century in Germany, Switzerland, England, and the US were opened for those with learning disabilities (mongolism included). Whilst not offering a cure and abuse being reported, improvements in the behaviour, physicality, and social competence of people with 'mongolism' were described. However, a sudden economic downturn offered no opportunity for employment for those housed in training schools. As such, schools expanded but quickly became asylums providing basic levels of care for its inhabitants. Such institutions were also soon colonised by medicine with doctors and custodians working inside the premises. Rather than being educated and returned to the community, inhabitants were identified as sick and needing treatment/cure. The medicalisation of training schools subsequently produced systemised prejudices of people with disabilities, including those with mongolism, as sick and in need of medical management. This reflected a shift in public consciousness from compassion and care to burden and segregation, that is, from education to protecting society from social undesirables (Wright 2011).

Whilst originally designed under idealistic aspirations of providing asylum (Giddens 1991), schools became 'total institutions' (Goffman 1961) built on the premise of maintaining order among disorder with simple custody becoming a dominant feature. Bauman (1993: 163) claims social space is controlled through both 'phagic' ('inclusivist') and 'emetic' ('exclusivist') strategies. Schools quickly became emetic institutions for nonconformists. Giddens (1991: 165) describes this process as 'sequestration', a contrived consequence of a culture in which 'moral and aesthetic domains are held to be dissolved by the expansion of technical

[10] Although the diagnostic category of Down's syndrome/mongolism was first described in the nineteenth century, Starbuck (2011) identifies skeletal remains and different forms of material culture (paintings, figurines, and pottery) that may depict Down's syndrome well before this time period.

knowledge', in which the sick and dying are separated from 'normal' members of society. The sequestration of people with mongolism or other conditions meant their fate became a 'technical matter', handled by medical experts with inhabitants 'routinely hidden from view' (1991: 161).

I return to the institutional confinement of those with the condition later in this chapter. Nonetheless, by the early twentieth century, mongolism became the most commonly recognised learning disability and many people with the condition lived their (short) lives in institutions (Wright 2011). The forced institutionalisation of people with mongolism was closely linked to racial and eugenic theory in the early twentieth century. Eugenics, a term developed by Galton (1883), represents a theory and practice of improving the genetic quality of humans through pursuing the reproduction of people with desired attributes and reducing the reproduction of those with undesirable attributes. The eugenics movement gained popularity in the early twentieth century in the UK and US scientific and medical community (Cunningham-Burley and Kerr 1999). This is reflected most profoundly not only by institutionalisation but also by enforced sterilisation programmes being performed worldwide – the UK included – for people with mongolism and other learning disabilities (Selikowitz 2008).

Although eugenics eventually lost scientific credibility, this was not before many had been sterilised in the name of social purity and before Nazi Germany embraced the strategy. The relationship between mongolism and the eugenic movement was most profoundly represented in the rise of Nazi Germany and the implementation of *Aktion T4*, a euthanasia programme officially running from 1939 to 1941 – though said to continue unofficially thereafter – whereby physicians murdered individuals 'judged incurably sick by critical medical examination' (Proctor 1988: 177). People with mongolism, along with other conditions or diseases (e.g. hydrocephaly, cerebral palsy) and physical malformations (e.g. missing limbs), were characterised in a highly medicalised system as incurably sick (Lifton 1986) and categorised as 'untermensch', a term integral to Nazi racial ideology referring to those deemed to be life unworthy of life. Even after the war and rebuffing of

eugenic policies, people with conditions like mongolism were still encouraged to be incarcerated within institutions well into the 1960s and 1970s.

The French connection: clinical genetics

The rise of eugenics and institutionalisation of people with mongolism coincided with great strides being made in medical genetics. Despite invaluable contributions from mid-to-late-nineteenth century scientists and medical practitioners, it was not until 1932 where significant progress in medicine and genetics concerning mongolism was made. At the *International Congress of Genetics*, Davenport (1932) suggested non-disjunction, an error in cell division in which an embryo has three copies of a chromosome instead of the usual two, as a cause of mongolism. A year later, Penrose (1933), an English geneticist and psychiatrist, identified a partial correlation between mongolism and maternal age.

However, it took another sixteen years for the next major landmark in the genetic legacy of mongolism to be established. In 1949, Barr and his colleagues discovered cells of male and female mammals could be distinguished by the presence or absence of a small, cellular body known as the sex chromatin. Present in females and absent in males, it could be used to determine sex in humans and animals when sex chromosomes were unclear under the microscope (Cowan 1994). One year later, medical specialists and geneticists became interested in ascertaining the sex of unborn babies in cases of sex-related conditions such as haemophilia. This was possible using a new technology called amniocentesis, a diagnostic test carried out during a pregnancy to assess whether an unborn baby developed a condition or any adverse health outcome. Diagnoses of haemophilia, for example, were little more than tentative probability statements but Barr and his colleagues' discovery – and the use of amniocentesis – held promise for geneticists predicting with greater certainty whether unborn babies had the disorder (Macintyre 1973). Sure enough, in 1955, a number of different researchers in the USA, Denmark, and Israel were credited with discovering that the sex of unborn babies could be predicted through analysing cells in the amniotic fluid (Cowan 1994).

Four years or so later, Dr Jerome Lejeune (1959), a French physician and disability advocate, and colleagues discovered mongolism was a chromosomal abnormality caused by the presence of three copies of chromosome 21, that is, those with the condition have forty-seven chromosomes rather than forty-six chromosomes. This discovery, giving rise to the name 'Trisomy 21' rather than mongolism or idiocy, was important in 'dramatising the medical value of human genetics' since doctors learned many disorders had a genetic/chromosomal origin (Kevles 1995: 254). Although the culturing of foetal cells following an amniocentesis was initially difficult since cells in amniotic fluid are neither abundant nor in active division (so mitotic figures became few and far between), this was resolved in 1966. As well as the development of amniocentesis, researchers in the early 1960s (Clarke et al. 1961; Polani et al. 1960) identified two rarer types of Down's syndrome other than the common form discovered by Lejeune et al. (1959): Translocation Trisomy 21 and Mosaic Trisomy 21 (both conditions are discussed in more detail later in this chapter).

Giving birth to Down's syndrome and amniocentesis

The capacity to test in utero for chromosomal conditions, according to Kevles (1995) and Rapp (2000), legitimised amniocentesis and conferred on it the necessary value for scientific recognition as an integral tool for genetic diagnosis. Indeed, in 1960, the first amniocentesis was used in Copenhagen to determine the sex of an unborn baby and subsequently offer a termination of pregnancy since the mother was identified as a carrier of haemophilia (Cowan 1994). The amniotic tap itself, what Cowan (1994: 36) refers to as the 'low-tech part of the procedure', had become a routine part of obstetric medicine by the mid-1950s since it was used to relieve patients with hydramnios[11] and test the incompatibility between mothers with Rh-negative blood types and their unborn babies (Fuchs and Cederqvist 1970). However, it is at this point in the 1960s that amniocentesis was recognised as a possible mechanism for prenatal diagnosis. It remained in its developmental stages for around fifteen years since techniques and safety needed improving and because Scandinavia – where the first amniocentesis was used to terminate a pregnancy – was the only place, for much of that time, where 'eugenic therapeutic

[11] Hydramnios is a build-up of too much amniotic fluid.

abortions' could be legally accessed (Callahan 1970; Cowan 1994). Still, similar abortions were reported in 1968 and a cooperative registry established to ensure the safety of the procedure began in the USA in 1971 (Cowan 1994).

In conjunction with the development of amniocentesis for prenatal detection, the Abortion Act was implemented in the UK in 1967. Additionally, abortion laws were liberalised throughout several Western democracies in the 1960s and 1970s (Rapp 2000). Under section 1(1)(d) of the 1967 Abortion Act, a pregnancy could be terminated 'up to term' where there is a risk that the child, if born, would be severely disabled and would endanger the mental and physical health of the mother. The Human Fertilisation and Embryology Act 1990 amended the Abortion Act 1967 by creating a general upper-limit of twenty-four weeks for lawful terminations except in circumstances where there was a serious risk to the pregnant woman's life or health or there was a substantial risk of 'serious foetal abnormality'.

Regardless of the amendment, terminating an unborn baby who would 'suffer from physical or mental abnormalities as to be seriously handicapped', using the discourse of the 1967 Act, was (and still is) considered to be appropriate grounds for legal abortion in the UK, although what constitutes a 'serious handicap' is debated and challenged (McGuinness 2013; Savulescu 2001). Such reflections on discourse were also evident when an illustrious group of biomedical researchers (Allen et al. 1961: 426) signed a letter in 1961 objecting to the 'embarrassing term' mongolism, proposing the use of 'Trisomy 21', 'congenital acromicria', or 'Down syndrome or anomaly' after John Langdon Down. Similarly, in 1965, a Mongolian delegation approached the World Health Organisation to stop using the term 'mongolism'. Whilst this change was accepted and the term was removed from all references to the condition, it was evident in scientific literature during the 1970s (Global Down Syndrome Foundation 2012)[12]. Nonetheless, it is at this point where one can claim 'Down's syndrome' was born.

Deinstitutionalisation and community care

[12] Notably, the term 'mongolism' has been used in recent leading medical texts (Underwood 2004).

This birth of Down's syndrome and onset of genetic testing coincided not only with abortion laws but also with the continued institutionalisation of people with the condition (Nancollas 2012). Prior to the 1970 Education Act, people with Down's syndrome mostly lived in state institutions (Lewis 2008). According to Buckley and Buckley (2008), it was between 1920s and 1960s that healthcare professionals widely encouraged institutionalising children with the condition. Despite such institutions being nationalised and transformed after the foundation of the NHS in 1948, the experimental treatments, sterilisation, lobotomies, and physical abuse persisted (Logan 2011). Although institutions were originally designed for moral treatment, they were crowded, overstretched, non-therapeutic, devoid of extensive funding, and isolated in location (Wright 2011). The moral therapy promised by the institutions was supplanted by the custodial treatment of those detained. Their mission moved from curing to mitigating and maintaining, therapeutic considerations receding into the background with institutions becoming dumping grounds for 'social undesirables'; the 'once-grand asylums deteriorated into snake pits and hellholes worthy of exposés', warehouses for the discarded isolating them physically and symbolically from the larger society (Geller and Morrissey 2004: 1128).

Over the course of the 1960s, people with disabilities – Down's syndrome included – were liberated from asylums in a process of 'deinstitutionalisation', essentially 'a policy designed to reorganise mental health resources away from the institutions and into the community' (Wilson 1999: 252). The motives for this move are multiple and contested though Durham (1989) offers three reasons: humanitarian concern for people with disabilities, the emergence of drug therapy, and economic factors. Arguably, deinstitutionalisation was further influenced by backlashes against abuse, growing anti-psychiatry and pro-disability movements, evidence of cognitive improvement of people with access to a steady caregiver and consistent stimulation, and the rise of the popular premise that communities hold the capacity to de-stigmatise and advance the lives of those previously detained (Goffman 1961; Stedman and Eichorn 1964; Szasz 1961; Wilson 1999). In the UK alone, the number of asylum residents dropped from 154,000 in 1954 to 100,000 in 1982 (Pilgrim and Rogers 1993). By the 1980s, people with conditions such as

Down's syndrome were moved into the community under post-war policies of inclusion and community provision (Nancollas 2012).

Down's syndrome and diagnostic testing

The inception of deinstitutionalisation overlapped with developments in prenatal genetic testing. In 1968, Down's syndrome was detected via amniocentesis for the first time, although the use of this diagnostic technology was still sporadic owing to its 'experimental' status (Nadler 1968). In the same year, researchers in Copenhagen experimented with chorionic villus sampling (CVS) to identify genetic conditions – Down's syndrome included – in the first trimester of a pregnancy (Global Down Syndrome Foundation 2012). Like amniocentesis, CVS is a diagnostic test carried out during a pregnancy to assess whether an unborn baby has developed a condition or any adverse health outcome. Widespread diagnostic testing via CVS and amniocentesis was adjourned at this stage but scientific research on Down's syndrome continued. In 1974, Down's syndrome was identified as possibly pathogenetic (Neibuhr 1974) and the first mouse model of Down's syndrome, Ts16, was created (Gropp et al. 1974). Gropp et al. (1975) developed a new systematic model for studying chromosomal trisomies in mice one year later, although it was discovered in 1980 that this proposed mouse model failed since mice frequently died at/near birth (Polani and Adinolfi 1980). The development of mouse models, as with much of other medical research, was to determine whether specific treatment options were effective in animal models and if they could translate to the human race.

Eight years after Down's syndrome was first detected using amniocentesis in 1968, the procedure came into common use in the USA and the first abortions following mid-trimester procedures were reported (Global Down Syndrome Foundation 2012). According to Cowan (1994), it is in 1975 and 1976 that amniocentesis could be said to be extending beyond the developmental and into the diffusion stages. Rapp (2000: 33) highlights how the widespread deployment of prenatal diagnosis 'only became conceivable and possible when enrolled by and through legal access to abortion'. Since laws were reformed and therapeutic abortion, following the Abortion Act 1967, had become legal in the UK (and other countries), diffusion of

amniocentesis was rife. With it established as an acceptable part of reproductive practice, larger amounts of potential patients were anticipated after a presenting symptom of 'advanced maternal age', identified years earlier by Penrose (1933), was recognised more extensively in comparison to the previous indicator of a family history of sex-linked hereditary conditions (Cowan 1994). With the risk of miscarriage akin to the chance of having an unborn baby with Down's syndrome, offering diagnostic testing to mothers-to-be at an advanced maternal age was seen as 'worthwhile' (Buckley and Buckley 2008: 80).

Notably, the widespread inception of amniocentesis was implicated in a number of legal cases during the late 1970s. In 1978 in the USA, a couple sued a hospital for malpractice because the mother – aged over thirty-five – was not referred for amniocentesis and had a child with Down's syndrome (Global Down Syndrome Foundation 1982). In 1983, the American Congress of Obstetrics and Gynaecologists and the American Academy of Paediatrics advised members that women over thirty-five years old should be mandatorily offered prenatal testing for genetic conditions including Down's syndrome (Global Down Syndrome Foundation 2012). Additionally, Hook et al. (1983) published a paper suggesting at a maternal age of thirty-five, the risk of having a baby with a chromosome problem and the risk of having a miscarriage from an amniocentesis were both around 1 in 200. As such, the age of thirty-five was designated as the 'cut-off' for diagnostic testing, that is, of being offered an amniocentesis since the risk of discovering a condition (0.5%) matched that of causing a miscarriage. Amniocentesis was subsequently offered exclusively to mothers-to-be aged thirty-five or above as opposed to all pregnant women (Wald et al. 1988).

It was not until the early-to-mid 1990s that CVS came into common use (Cowan 1994). The first efforts to biopsy the chorion were made in the late 1960s and early 1970s by Mohr (1968) and Hahnemann (1974) in Copenhagen. Their reason for exploring a diagnostic technique carried out in the first rather than second trimester corresponded to carrying out this procedure – given potential legal, physical, and mental implications – as early as possible. Their trials were largely unsuccessful as were other efforts using the technique. Only in the early 1980s was

CVS recognised as a possibly effective procedure for prenatal diagnosis, with a flurry of researchers enjoying success with diagnosing sex and genetic conditions (e.g. sickle-cell disease), obtaining tissue, and not causing miscarriages (Cowan 1994). However, development of the technology stalled for many years owing to the technique of chorion biopsy being difficult to learn (meaning amniocentesis was preferred) and the obstruction of research with prohibitions against the use of federal funds, in light of the anti-abortion politics of the 1980s, to finance research in this area (Cowan 1994). In recent years, the technology has been improved and is currently used in obstetric practice.

Prenatal screening for Down's syndrome

Whilst diagnostic testing for Down's syndrome was developed and diffused from the late-1950s and early 1960s onwards, prenatal screening for the condition entered medical and scientific worlds in the latter stages of the twentieth century. Such procedures were largely introduced as an extension of earlier screening programmes for neural tube defects. Screening for Down's syndrome, one of the first instances of mass population testing to detect and possibly prevent a genetic condition, began in the late 1980s following the discovery that low maternal serum alpha-fetoprotein in the second trimester is associated with the condition (Cuckle et al. 1984) and the publication of Wald et al. (1988) on the possibility of serum screening for Down's syndrome. From this point onwards, Down's syndrome screening was subsequently introduced as a clinical service with research carried out on data collected by patients following a screening procedure (Reynolds 2010). As such, according to Reynolds, research was often implemented without approval from research ethics committees and with little governmental pronouncement on the issue of screening for Down's syndrome. Nonetheless, the first routine screening programme for Down's syndrome in the NHS began in February 1990 in Newport and Cardiff (Wales) during a one-year trial reported on three years later (Reynolds 2000). Reynolds (2010) notes how, then, it took just two years of research indicating the effectiveness of serum screening before the technique was introduced as an accessible test.

By 1998, many health authorities in the UK offered prenatal screening for Down's syndrome via serum screening for all parents-to-be regardless of age, although some only offered age-restricted screening, that is, only for mothers-to-be aged thirty-five and above (Reynolds 2000). Most authorities offering screening used a double screen which, rather than relying on maternal age or a history of a previously afflicted born or unborn baby (Shaw et al. 2008), involved measuring two biochemical markers in the second trimester: alpha-fetoprotein (AFP)[13] and total or free-beta human chorionic gonadotrophin (hCG)[14]. Regardless of the screening method, parents-to-be were categorised as 'screen-positive' (higher-risk) or 'screen-negative' (lower-risk) which guided decisions around diagnostic testing (Buckley and Buckley 2008). The performance of Down's syndrome screening was established by measuring a detection rate and false-positive rate. The false-positive rate was crucial since it indicates the number of unaffected pregnancies subjected to potentially dangerous diagnostic tests (Harrison and Goldie 2006)[15]. However, due to the low detection rate and poor cost-effectiveness of the double screen (Shaw et al. 2008), the triple screen was developed to identify mothers-to-be who should be offered diagnostic testing to detect Down's syndrome or another chromosomal condition (Reynolds 2010)[16]. The triple screen, first described in the UK in 1988 but implemented years later (Canick et al. 1988), improved the double screen by measuring ue3 (unconjugated estriol)[17], alongside AFG and hCG, and offered an improved detection rate and reduced false-positive rate (Wald et al. 1988).

The double screen was initially opted for over the triple screen since the slight increment in detection, without increasing the false-positive rate, was viewed as unworthy of additional costs (Reynolds 2010). However, the triple screen was more widely used between 2000 and 2010, becoming the most commonly offered

[13] Alpha-fetoprotein (AFP) is a protein in humans encoded by the AFP gene produced during foetal development.
[14] Total or free-beta human chorionic gonadotrophin (hCG) is a hormone produced following pregnancy conception.
[15] The selection of a cut-off is decided by a choice between affected live births prevented and unaffected unborn babies lost (Buckley and Buckley 2008).
[16] A large body of literature reports many discrepancies in the performance of different screening programmes, with a range of projects using distinct cut-off rates and often analysing a small amount of data (Harrison and Goldie 2006; Malone et al. 2005).
[17] Estriol is one of the main three oestrogens produced by the human body.

prenatal screening for Down's syndrome technique in the UK (NHS FASP 2012). This emerged despite developing the quadruple screen which involves measuring the same biochemical markers as the triple screen plus inhibin-A[18] around 15-18 weeks into a pregnancy. This was reported to have an improved detection rate and false-positive rate in comparison with the triple screen (Malone et al. 2005). In 2006, the UK National Screening Committee (NSC) – implementing a national screening policy – recommended using quadruple screening for achieving a 75% detection rate and 3% false-positive rate for Down's syndrome at a cut-off rate of 1 in 250 (Harrison and Goldie 2006; Wald et al. 2003). Quadruple screening did not initially surpass triple screening since the only assay commercially available for inhibin-A was not suitable for use in a laboratory owing to it being inefficiently stable and the intra-batch assay variation being excessive (Reynolds 2010). The reluctance to embrace quadruple screening fully in the UK, according to Reynolds, could also be attributed to diminishing returns in relation to economic cost, an incremental improvement of detection being less with each extra analyte being added, and the wishes of parents-to-be to undertake an earlier test (in the first trimester). Nonetheless, in more recent years, the inhibin assay has been being automated and so quadruple screening has subsequently been used ahead of triple screening in clinical practice (Harrison and Goldie 2006; Reynolds 2010). Indeed, triple screening has not been offered anywhere in the UK since 2012 (NHS FASP 2012).

Despite improvements in biochemical serum screening, there were calls for first trimester screening for Down's syndrome to be offered in the UK, primarily because it was predicted it could help fulfil the NSC's desire to develop a screening programme offering a 75% detection rate and 3% false-positive rate (Harrison and Goldie 2006). The initial development of first trimester screening for Down's syndrome followed research by Nicolaides et al. (1992) and Snijders et al. (1998) who suggested a nuchal translucency[19] measurement via an ultrasound scan could be used as a possible marker for the condition and other chromosomal conditions.

[18] Inhibin-A is a hormone made by the placenta during a pregnancy.
[19] A nuchal translucency is the fluid thickness in the nape of an unborn baby's neck. Enlarged fluid is associated with chromosomal conditions including Down's syndrome.

The first screening programme developed for the first trimester of pregnancy was combined screening which involved combining the results from an ultrasound scan and biochemical serum screening – hCG and pregnancy associated protein A (PAPP-A)[20] – around eleven to fourteen weeks into a pregnancy. The association between Down's syndrome and low levels of PAPP-A and high levels of hCG during the first trimester was reported during the early 1990s (Wald et al. 1992). The ultrasound scan involved measuring the crown rump length (CRL)[21] and depth of the nuchal translucency. Combined screening, in sum, offered improved detection and false-positive rates in comparison to all methods of second trimester screening (Malone et al. 2005) and made early results possible since CVS could be carried out in the first trimester (Shaw et al. 2008).

In the 2000s, whilst other screening methods were developed (serum integrated screening, integrated screening, contingent screening), these were not widely used in the UK (Shaw et al. 2008). Despite often promising higher detection rates and lower false-positive rates, such techniques were overlooked since they were costly, could delay results since it requires collecting data in both trimesters, required parents-to-be to attend the clinic on at least two occasions (risking dropouts), and could involve withholding information about a first-trimester result, a move often described as unethical practice (Reynolds 2010). In the UK, Down's syndrome screening standards imposed by the NHS Foetal Anomaly Screening Programme (NHS FASP 2012), an organisation dedicated to ensuring access to a uniform screening programme, claims screening should currently be carried out using the combined screen, serum integrated screen, or integrated screen in the first trimester or the quadruple screen in the second semester (Reynolds 2010). An annual report produced by NHS FASP (2012) suggests in 2011 and 2012, the primary screening method offered by hospitals in England alone was combined screening (86% and 96% respectively), with parents-to-be booking too late for combined screening (first trimester) alternatively being offered a quadruple screen (second trimester).

[20] Pregnancy associated protein A (PAPP-A) is the largest pregnancy associated protein produced by the embryo and placenta.
[21] Crown rump length (CRL) is the measurement of the length of unborn babies from the top of the head to the bottom of the buttocks.

Summary

In this chapter, I have outlined a short socio-history of Down's syndrome and screening/testing for the condition. I show how Down's syndrome has become a critical site in antenatal care and how it has been drawn into reproductive politics through entwining social (institutionalisation and deinstitutionalisation, eugenics), medical (the growth of genetics, amniocentesis, screening), and legal (abortion law reforms, legal cases) developments. By studying Down's syndrome historically, I highlight the practices and values we now take-for-granted. The likes of Lejeune and Penrose were unlikely to be aware in the first instance of the potential their findings had for detecting and terminating unborn babies with Down's syndrome. However, this is the situation antenatal medicine now finds itself in, with prenatal screening and testing for Down's syndrome being established as an accepted and routine component of antenatal care.

DOWN'S SYNDROME SCREENING/TESTING: FREYMARSH AND SPRINGTOWN

Following a short socio-history of Down's syndrome and screening/testing for the condition, I begin this section by describing the origins and possible symptoms of the condition itself. I subsequently outline current screening and testing practices in Freymarsh and Springtown and how maternal age is implicated in an increased chance of having a baby with Down's syndrome. To conclude, I contextualise my study and draw attention to current practices establishing Down's syndrome as a critical site of sociological attention.

Down's syndrome: the condition

The human body is made up of cells containing genes. Genes are enclosed within thread-like structures referred to as chromosomes, that is, the packages of genetic material or deoxyribonucleic acid (DNA) stored within the nucleus of each cell. These contain instructions of how the body's cells develop, eye colour, and the sex of the unborn baby (NHS 2013). A human usually has forty-six chromosomes organised into twenty-three pairs (twenty-two autosomal pairs and one pair of sex chromosomes) inherited from the mother-to-be and father-to-be. Genetic diversity

among different people is generated via the exchange of genetic material between homologous chromosomes (meiosis I) and the separation of chromosome pairs (meiosis II). When an egg becomes fertilised to create a new cell called a zygote, new pairs of chromosomes are created in which each parent-to-be contributes one chromosome to each pair. On occasions, an error in meiosis (non-disjunction) occurs in which there is a failure of the chromosomal pairs to separate. This causes an imbalance of chromosomes in the gamete ('aneuploidy'). A cell *losing* a chromosome ('monosomy') is likely to be lethal. This may not always be the case when a cell *gains* a chromosome ('trisomy'), causing three copies of a chromosome instead of a usual pair (CARIS 2012).

According to CARIS (2012), trisomies are the most common anomaly in which there are more or less than forty-six chromosomes. One such trisomy is Down's syndrome (or Trisomy 21) caused by the presence of an extra chromosome on the twenty-first pairing. It is the most common aneuploidy detected during pregnancy followed by Edward's syndrome (Trisomy 18)[22] and Patau's syndrome (Trisomy 13)[23]. Down's syndrome is an incurable chromosomal condition which occurs in one to two of every 1,000 live births in the UK (NHS 2013). It is one of the most common genetic causes of learning disability and the National Down Syndrome Cytogenetic Register (NDSCR) reports most people with the condition (94% of all cases) have Full Trisomy 21 Down's syndrome, whilst 4% of cases have Translocation Down's syndrome and 2% of cases have Mosaic Down's syndrome. Children with Translocation Trisomy 21 have extra chromosome 21 material attached to another chromosome (Buckley and Bird 2002). Only Translocation Down's syndrome can be hereditary. Some people do not have symptoms of Translocation Down's syndrome but they can be a 'carrier', meaning they have

[22] Edward's syndrome (Trisomy 18) is a chromosomal condition affecting three of every 10,000 live births. It is caused by an extra copy of chromosome 18 in each cell. There are three forms of Edward's syndrome: complete trisomy, mosaic trisomy, and partial trisomy. According to NHS FASP (2012), complete trisomy 18 is fatal. Babies with partial and mosaic trisomy 18 may survive to adulthood but this is rare. The condition is associated with intellectual disability and physiological impairment, although the prognosis of a partial or mosaic trisomy 18 is less clear.

[23] Patau's syndrome (Trisomy 13) is a chromosomal condition affecting two of every 10,000 live births. It is caused by an extra copy of chromosome 13 in each cell. There are three forms of Patau's syndrome: complete trisomy, mosaic trisomy, and partial trisomy. According to NHS FASP (2012), complete trisomy 13 is fatal. Babies with partial and mosaic trisomy 13 may survive to adulthood but this is rare. The condition is associated with intellectual disability and physiological impairment, although the prognosis of a partial or mosaic trisomy 13 is less clear.

altered genes triggering the condition in their unborn children (NHS 2013). The risk of 'passing on' the condition depends on the sex of the carrier (with mothers-to-be more likely to 'pass' the condition onto a child). Mosaic Down's syndrome is caused by the mis-division of chromosomes *after* fertilisation during early cell division. Whilst children with Full Trisomy 21 have an extra copy of chromosome 21 in every cell, children with Mosaic Trisomy 21 have forty-six chromosomes and some cell lines with an extra chromosome and some cells lines which are not similarly affected (Buckley and Bird 2002).

Whilst symptoms of the condition vary between each case, common symptoms of Down's syndrome include an upward eye slant, large tongue, clinodactyly of the fifth finger, single or transverse palm crease, sandal gap toe, excess skin on the back of the neck, a flat profile of the face, brushfield spots, hypotonia, and umbilical hernia (CARIS 2012). People with condition may also have impaired cognitive abilities, a reduced IQ, learning difficulties, shortened limbs, poor muscle tone, and restricted physical growth. They may also be susceptible to colds, ear infections, bronchitis, and pneumonia. Females with Down's syndrome can have fertility problems and males with the condition are frequently infertile (CARIS 2012). The outlook of life for a person with Down's syndrome can vary widely depending on if a child develops other serious health conditions such as sight and hearing loss, intestinal problems, hearing and vision problems, thyroid complications, dementia, Alzheimer's disease, and leukaemia (Buckley and Buckley 2008; NHS 2013). Around 50% of children with Down's syndrome have a congenital heart defect and around 60% of this group require treatment in hospital. By contrast, the condition appears to offer protection against some cancers and cardiovascular disease (Buckley and Buckley 2008). Importantly, people with Down's syndrome may experience few or several of these complications (NHS 2013).

There is no 'cure' for the condition but Down's syndrome is frequently demarcated as 'not lethal' (Ivry 2009), meaning individuals with the condition are likely to survive childbirth and can enjoy a good 'quality of life' (Buckley and Buckley 2008; CARIS 2012; NHS FASP 2012). NHS (2013) reports there are a number of ways in which children with the condition can develop into 'healthy and fulfilled

individuals' who can achieve independence and enjoy access to healthcare and early intervention programmes. Similarly, Buckley and Buckley (2008) suggest support for people with the condition is much better than in earlier years and their current medical needs are largely understood; several healthcare professionals may monitor and treat people with Down's syndrome including physiotherapists, speech and language therapists, ophthalmologists, occupational therapists, general practitioners, audiologists, dieticians, paediatricians, and cardiologists (NHS 2013). Adults with Down's syndrome can pursue further education, gain employment, and live independently (Buckley and Buckley 2008). Additionally, according to Buckley and Buckley (2008: 84), people with the condition are rarely anti-social or violent and whilst they can experience challenges, they can 'make positive contributions to family and community life and often form loving and caring relationships'.

However, whilst the progress of people with the condition has been remarkable in the past fifty years, the prognosis of the condition is uncertain and it is impossible to predict how a child will be affected (NHS 2013). Nonetheless, due to medical advancements and better knowledge regarding treatment and care, children born with Down's syndrome – most of which are diagnosed postnatally – are likely to survive beyond sixty years today (CARIS 2012). This has significantly increased from nine years old in 1929, twelve years old in 1946, twenty-five years old in 1983, and forty-nine years old in 1997 (Penrose 1949; Yang et al. 2002).

The object of screening at Freymarsh and Springtown

In the UK, all parents-to-be are offered prenatal screening for Down's syndrome which cannot establish a diagnosis but can assist reproductive decision-making regarding diagnostic testing (NHS 2013). Screening should take place in a window of ten to twenty weeks during a pregnancy although the preferred period of time is by the end of the first trimester (thirteen weeks and six days gestation). During my fieldwork at two institutions – Freymarsh (NHS hospital) and Springtown (privately-funded clinic) – two screening methods were used: quadruple screening (Freymarsh) and combined screening (Springtown). The quadruple screen, using a risk threshold of 1 in 150, can detect approximately 75% of affected pregnancies with a 3% false-positive rate. In contrast, combined screening, also using a risk

threshold of 1 in 150, can detect around 85% of affected pregnancies with a lower false-positive rate (CARIS 2012).

Irrespective of the screening method, parents-to-be receive a 'risk factor', namely a numerical ratio establishing the odds of an unborn baby having the condition. Both screening methods are based on the same mathematical principle and work by combining a prior probability – maternal age at expected date of delivery – with a likelihood ratio based on a range of factors such as blood proteins, hormones, and a nuchal translucency measurement (Reynolds 2010). Taken together, these create an estimate of whether the unborn baby has Down's syndrome. At Freymarsh and Springtown, this is calculated using computer software combining a risk factor with other characteristics including maternal age, weight, gestation, ethnicity, pregnancy history, smoking habits, the number of unborn babies, and whether it is an assisted conception. At Springtown, these factors are combined with the size of a nuchal translucency[24]. Parents-to-be receive three risk factors at Freymarsh: a background risk (based on age, ethnicity, previous history, etc.), a biochemistry risk (based on measurements of four biochemical markers), and an adjusted risk (based on combining a background risk and biochemistry risk). At Springtown, parents-to-be receive these three risk factors alongside an ultrasound risk (based on the nuchal translucency size alone). In Freymarsh and Springtown, only the adjusted risk factor is referred to when delivering a result. In addition, whilst only a risk factor for Down's syndrome is given to parents-to-be in Freymarsh, parents-to-be in Springtown also receive risk factors for Edward's syndrome and Patau's syndrome. This reflects a shift in modern biomedical practice from the actual to the potential, redefining the idea of 'the patient' to include those 'at risk' alongside those who are 'sick' (Gross and Shuval 2008; Scott et al. 2005).

In Freymarsh and Springtown, the cut-off point for this categorisation is 1:150 (a 1 in 150 risk of having a baby with Down's syndrome). If parents-to-be receive a risk factor numerically higher than 1:150 (e.g. 1:250), they are categorized as 'lower-risk' and receive a letter notifying them of this information (at Springtown, they

[24] Some institutions will also take account of the presence/absence of a nasal bone, another marker of Down's syndrome and other genetic conditions (Cicero et al. 2001). However, Springtown do not usually offer this service owing to a lack of training among sonographers.

receive a telephone call). At this point, parents-to-be are not offered or advised to have further treatment other than an ultrasound scan at twenty weeks to check for potential problems (an 'anomaly scan'). In contrast, if parents-to-be receive a risk factor numerically lower than 1:150 (e.g. 1:100), they are categorised as 'higher-risk' and diagnostic testing (amniocentesis/CVS) is offered to prove or refute a suspected diagnosis. Around three to five percent of pregnant women in England and Wales consenting to screening receive a higher-risk result (NHS FASP 2012) and according to Buckley and Buckley (2008), between 1 in 20 and 1 in 30 higher-risk (screen-positive) results detect an unborn baby with Down's syndrome. For a timeline and flowchart of Down's syndrome screening in Freymarsh/Springtown and the UK more generally, see Appendices 1-3[25].

The object of testing at Freymarsh and Springtown

Diagnostic testing for Down's syndrome involves undertaking an amniocentesis or CVS. During CVS, a small sample of placenta is taken either by passing a small needle through the abdomen of a mother-to-be or by passing a small tube through a vagina and the neck of a womb (NHS 2013). During an amniocentesis, a small sample of amniotic fluid is taken by passing a fine needle through the abdomen of a mother-to-be and drawing the fluid out using a syringe. CVS is carried out in the first trimester after ten weeks of a pregnancy and an amniocentesis is commonly carried out in the second trimester between fifteen and twenty weeks gestation (NHS 2013). An amniocentesis can also be carried out late in a pregnancy to check the unborn baby's wellbeing and potentially diagnose a condition (although not for the purpose of termination). Amniocentesis and CVS provide an accurate diagnosis but have a few possible complications including miscarriage, infection, heavy bleeding, premature labour, and postural deformities. The risk of miscarriage following amniocentesis is 1% and is 2% following CVS (Buckley and Buckley 2008). The move toward first trimester screening, together with detecting more unborn babies who may not have naturally survived to term than biochemical serum screening, may trigger an increase in the miscarriage of unborn babies who do not have Down's syndrome since CVS, which has a higher-risk of miscarriage

[25] Suspicions of Down's syndrome can also be established during an 'anomaly scan' performed at twenty weeks gestation. The absence of a nasal bone, an increased nuchal translucency, cardiac defects, or an echogenic bowel can indicate a potential diagnosis of the condition.

than amniocentesis, can also be performed in the first trimester (Buckley and Buckley 2008). Diagnostic testing is offered because of an indication of a condition, previous pregnancy complications, a family history of a particular condition, and an advanced maternal age (although this last option is currently not common in UK medicine).

After diagnostic testing is completed, samples are sent to a cytogenetic laboratory. Cytogenetics is concerned with the function and structure of cells, especially chromosomes. Two results are possible following testing: a QF-PCR (quantitative fluorescence polymerase chain reaction) result and a full karyotype. A QF-PCR result includes amplification, detection, and analysis of chromosome-specific DNA sequences. This provides a conclusive diagnosis for Down's syndrome, Edward's syndrome, Patau's syndrome, and sex chromosome 'aneuploidies' such as Turner syndrome[26] or Klinefelter's syndrome[27]. A diagnosis of cystic hygroma might also be possible via QF-PCR testing. Since QF-PCR misses some chromosomal conditions, it is followed by a full karyotype which involves analysing all chromosomes in detail at the microscopic level including deletions and duplications, translocations, mosaicisms, and inversions and insertions. This reveals chromosomal conditions other than those specified above together with any abnormal genes. Although a QF-PCR result is usually available in less than two days following a procedure, a full karyotype is available approximately two weeks after this period.

After a result is established, this information is returned to professionals who must deliver this news to parents-to-be. If a diagnosis is established, counselling is offered to parents-to-be before a decision is made about whether to continue or terminate a pregnancy. The main objective of screening is to identify women in whom a risk factor is deemed high enough to warrant offering them diagnostic testing.

[26] Turner syndrome is a genetic disorder which only affects females. A female with the condition will have all or part of one X chromosome missing.
[27] Klinefelter's syndrome is the set of symptoms resulting from extra X genetic material in males.

Maternal age and Down's syndrome

While it is not fully understood why some babies are conceived with abnormal copies of chromosomes, maternal age is the only clear factor which increases the chance of having a baby with Down's syndrome (NHS 2013). Whilst the reason for this relationship remains unclear, what is observable is despite higher pregnancy rates among mothers under thirty-five years old (ONS 2011), more babies with Down syndrome are born to mothers aged thirty-five and above (CARIS 2012). This could reflect the increasing numbers of women delaying childbearing for reasons including increased participation in higher education and the labour force, the rising opportunity costs of childbearing, labour market uncertainty, housing factors, and instability of partnerships (ONS 2011). Nevertheless, according to a handbook published for professionals at Freymarsh, a mother-to-be who is sixteen years old has a maternal age risk of 1:1509, that is, there is a 1 in 1509 chance the unborn baby has Down's syndrome. This increases to 1:1476 at the maternal age of twenty, 1:1339 at twenty-five, and 1:937 at thirty. At the age of thirty-five, a maternal age risk prior to any form of screening is 1:352. This increases to 1:266 at thirty-six, 1:199 at thirty-seven, 1:148 at thirty-eight, 1:111 at thirty-nine, and 1:85 at forty. At the age of forty-five, the maternal age risk is 1:35.

A report conducted by the National Down's Syndrome Cytogenetic Register (NDSCR) claims in 2011 in England and Wales, 119 mothers-to-be aged twenty-four and below (6% of all cases) received a prenatal or postnatal diagnosis of Down's syndrome (Morris and Springett 2013). This increased to 183 for mothers-to-be aged twenty-five to twenty-nine (10% of all cases), 331 for mothers-to-be aged thirty to thirty-four (18% of all cases), 622 for mothers-to-be aged thirty-five to thirty-nine (33% of all cases), 450 for mothers-to-be aged forty to forty-four (24% of all cases), and 50 for mothers-to-be aged forty-five and above (3% of all cases)[28]. The mean age of mothers with a prenatal diagnosis was 36.7 compared to 34.4 of mothers with a postnatal diagnosis. According to the NDSCR report, 64% (N=1122) of mothers with a known age and who received a diagnosis of Down's syndrome were thirty-five years old and above (Morris and Springett 2013).

[28] According to Morris and Springett (2013), 118 (6% of all cases) cases are missing.

Summary

In this section of the chapter, I have described Down's syndrome, its (possible) symptoms, how it is screened and testing for at Freymarsh and Springtown, and how maternal age is associated with the condition. Alongside the socio-history provided at the beginning of the chapter, this section has identified how screening for the condition has become a routine practice in NHS medicine. By outlining the history and recent developments regarding Down's syndrome and its intersection with medical and scientific worlds, I have recognised how a mundane procedure has been widely accepted and embraced by the public and medical communities, particularly Freymarsh and Springtown. After identifying how Down's syndrome screening represents a key site for sociological attention, I spend chapter four situating the study by discussing my entry to the field, how data was collected, fieldwork, data analysis, and both ethnographic and my study's limitations.

Chapter Four
Situating the Study (Notes on Method)

This chapter situates my study by discussing my entry to the field, what/how data was collected, the fieldwork process, analysing data, and the limitations of my study and of ethnography more generally. I begin by reflecting on gaining access and NHS ethical approval by drawing on the notion of 'preliminary field-work' (Caine et al. 2009: 491), a supplement to Cohen's (1992) 'post-fieldwork fieldwork' concept. In what follows, I outline my field entry and how data were collected during my stay at Freymarsh, a large NHS teaching hospital in a metropolitan area, and Springtown, a privately-funded fertility clinic in an affluent area. I reflect on how I was positioned by professionals during fieldwork, that is, my identity-work both performed and ascribed. I subsequently describe my data analysis strategy based on Clarke's (2003: 571) 'situational analyses', an approach holding clear links with the theoretical tropes outlined in chapter three. Finally, I flesh out the underlying problems of my research and, in grander terms, the ethnographic craft.

In sum, I sketch out my approach and recognise self-conscious reflexivity – urging us to think critically about roles and relationships, about ethics and responsibilities – as a fundamental feature of ethnography. Reflexivity should not be confused with self-disclosure. Whilst self-disclosure concerns confusions and repentant accounts constructed through acts of contrition, reflexivity refers to objectifying the subject of our attention by analysing the researcher's own thinking and how this is the product of complex social, political, cultural, and moral relations (Desmond 2007). Rather than burying my fieldwork experiences within a methodological epilogue as an apologetic afterthought, I interweave them with a discussion of my methods of choice, recognising this as a valuable statement about the ethnographic craft (Smith and Kornblum 1996).

Constructing a site

Data are drawn from my fieldwork at two settings: Freymarsh and Springtown. Before describing how data was collected, I explain how I gained access to such

privileged environments. To begin, I initially planned to conduct research only in Freymarsh (I explain access to Springtown later) which was selected for two reasons. First, the hospital has a large influx of people from a variety of social and ethnic backgrounds. Second, and most importantly, Down's syndrome screening was offered to parents-to-be here. In order to secure access to Freymarsh, I had to undertake NHS ethical approval. This involves being granted or declined ethical clearance for a study by an independent collection of people from medical and nonmedical backgrounds.

Ethnographic research has a considerable history in medical settings (Atkinson 1995; Bosk 1979; Latimer 2000; Silverman 1987; Strong 1979). However, access to NHS settings to carry out ethnographic work is a difficult, lengthy, and complex exercise (Reed 2007). The ethnographer must know, respect, and comply with the rules of the field prior to official entry, with the success of research depending on outside forces such as other people accepting the project as meaningful. Attaining ethical approval is one instance in which an ethnographer must perfect their 'art' (Wolcott 2005). Extending beyond information sheets, box-ticking, and attending meetings, all fixtures of the ethics landscape, securing access begins well before navigating the treacherous waters of the application process. It is accomplished in interactions with medical and nonmedical professionals, recruiting gatekeepers, and engaging with the necessary literature, all of which precede the juridical review. This spadework reveals how fieldwork begins long before entrée is secured and 'field data' is gathered. One may consider Rabinow's (1977: 11) reflections on his fieldwork in Morocco:

> 'In Morocco only several days and already I was set up in a hotel, an obvious remnant of colonialism, was having my coffee in a garden, and had little to do but start 'my' fieldwork. Actually, it was not exactly clear to me what that meant, except that I supposed I would wander around Sefrou a bit. After all, now that I was in the field, everything was fieldwork'.

Whilst Rabinow's contention that 'everything was fieldwork' certainly holds sway, the essence of fieldwork is revealed by *intent* as opposed to location. For Wolcott (2005: 58), fieldwork constitutes a form of inquiry in which one is 'immersed personally in the ongoing social activities of some individual or group for the purposes of research' in order to acquire a level of understanding to share with outsiders. Accepting this definition, ethnographic fieldwork is not consigned to data collection but begins much before this often prolonged process. One of the most vexing tasks for researchers has been to establish the exact definition of ethnography. It is an ambiguous term, having been simultaneously viewed as a means and an end or both process and product. At times, ethnography has been used interchangeably with 'participant observation' and 'fieldwork' in reference to the empirical observation of people's lives broadly defined as 'ways of life' (Denzin 1997). However, ethnography should not be confined to concerns solely over methodological preferences; it is both a practice and an emergent relation to the domain of study. Whilst the data collection process is certainly one of its key features, ethnography is processual, accomplished in both writing and rewriting our tales from the field (Clifford and Marcus 1986). To interpret ethnography exclusively within methodological confines is to limit understanding by incorrectly focusing entirely on collecting 'field data'. Consider the following definition of ethnography provided by Reeves et al. (2008: 512):

> 'Ethnography is the study of social interactions, behaviours, and perceptions that occur within groups, teams, organisations, and communities […] The central aim of ethnography is to provide rich, holistic insights into people's views and actions, as well as the nature (that is, sights, sounds) of the location they inhabit, through the collection of detailed observations and interviews'.

This common description fails to account for ethnographic beginnings, that is, the practical and personal labour preceding entry into the field, labour which we must distinguish as data equal to that gathered during fieldwork; 'an individual presents a finished product to an audience, it is that what is judged [...] what is hidden is the long journey leading up to it' (Goffman 1959:52). Caine et al. (2009: 491) describe

this process as 'preliminary field-work', referring to the decisive early stages of research involving – prior to developing official protocols and ethics applications – 'exploration, reflexivity, creativity, mutual exchange and interaction through the establishment of research relationships with local people'. In outlining my own preliminary fieldwork prior to collecting field data at Freymarsh, I recognise the importance of gatekeepers, making connections, and understanding the culture of the setting in the ongoing and partial process of fieldwork (Caine et al. 2009). This allows me to construct the subject of interest at the boundaries. Without relying on preconceptions of the field or where I should be conducting research, I discuss how particular people enrol me into their world prior to collecting 'field data' in various ways (Latimer 1997). In what follows, I describe the mundane efforts and struggles preceding my entry into Freymarsh (and later Springtown).

Preliminary field-work: the application process

My study began by my doctoral supervisors organising a meeting with Dr Huston, a paediatric geneticist in Freymarsh. At this point, I had vague and ambitious plans for exactly what I intended to study. In the meeting, advice was tendered, naive objectives were suitably quashed, and recommendations were either accepted or politely rejected. A week later, Dr Huston organised a visit for me to meet Dorothy, a member of a governing body establishing policies for antenatal practice. Again, suggestions were offered and considered, with Dorothy expressing some concerns which I either accepted or rejected. Dorothy was nothing short of enthusiastic and generous with her time but the meeting was overwhelming and I soon realised how little I knew about the antenatal process. Only after these meetings, and a few weeks of intensive labour, did I feel confident enough to approach healthcare professionals with a relatively concrete idea for comment. Dorothy's attempts to enrol me in her agenda – she felt a study exclusively on Down's syndrome screening would be too narrow and so recommended researching prenatal screening more generally – accentuate how a researcher must grapple, negotiate, and articulate the trials and tribulations of both their own and other peoples' agenda. Nonetheless, Dorothy arranged for me to attend a training event organised by the Down's Syndrome Association (DSA) for assisting professionals in delivering information about Down's syndrome and screening for the condition in

antenatal care. In addition, I began to make contact with healthcare professionals, recommended by Dorothy, who could assist me with my endeavours. Three of these contacts – Jennifer, Carol, and Dr Karman – were indispensable figures in my preliminary field-work. Jennifer, a PhD student and former clinical geneticist, described her project and tendered advice about attaining NHS ethical approval. She claimed involving a charity organisation adds credibility to one's application by soliciting (lay) user involvement. In response, I pursued and gained sponsorship from two charity organisations: the Down's Syndrome Association (DSA) and Antenatal Results and Choices (ARC).

The other two suggested contacts were Carol, the Freymarsh antenatal department (FAD) manager, and Dr Karman, a consultant at the Freymarsh foetal medicine department (FMD). I approached Carol and after two meetings, she agreed to support the study. I additionally approached Dr Karman who responded immediately and enthusiastically, claiming I was welcome to conduct research at Freymarsh pending successful ethical approval since it would be in the interests of both parents-to-be and the institution. Prior to ethical approval, Dr Karman invited me to attend a multi-disciplinary meeting in which many Freymarsh professionals (consultants, sonographers, midwives, surgeons, cardiologists, neuroscientists) discussed the most recent 'cases' in which an unborn baby or mother has been identified as either having, or being suspected of having, a problem. After an hour, the meeting ended and I accepted Dr Karman's invitation to observe some consultations and '*get a taste*' of life at FMD. Following my day spent with Dr Karman, I decided it would benefit my project and ethical approval application to receive the input of other healthcare professionals at Freymarsh.

During the next six months, I met several professionals – together or separately and by telephone or email – such as managers, consultants, midwives, geneticists, and obstetric sonographers. Each offered support for the project, tendered guidance, established what they deemed the most suitable strategies for recruiting participants, and highlighted their concerns meriting attention, in their view, in antenatal care. Many professionals also proposed colleagues who may bestow advice regarding, and participate in, my study. This process had a snowballing

effect in which I gathered a glut of suggestions regarding what to research and the best means of doing so. This was vital for formulating my final research protocol.

One recommendation from professionals was that I should recruit someone within Freymarsh to champion my study since the NHS research ethics committee (REC) welcomes researchers having some level of support. Dr Karman assumed this role; I had my gatekeeper. Johnson (1990: 10) describes how gatekeepers are often selected on the basis of their attributes; access to privileged knowledge, for instance, can be a function of 'social status, position in an organisation, or comprehension of cultural knowledge'. This role of the gatekeeper – as an architect of trust and linchpin of a cohort – has been well-rehearsed within qualitative inquiry (Whyte 1955) yet their importance cannot be overestimated. Although access to hospital settings may not always be problematic, those unable or unwilling to go through gatekeepers may find it difficult (Pope 2005). Forging alliances with powerful gatekeepers in the organisation, together with influencing how group members perceive the research and enhancing the credibility of the project (and researcher), lessens the chance of an NHS ethics application rebuttal by enlisting the help of someone better placed in order to 'play the ethics games' (Reed 2007). As an 'outside ethnographer', namely as someone with no medical background and limited ties to Freymarsh, developing a level of intimacy, rather than being accrued through accumulating hours in the field, must be 'cultivated before the fieldwork proper begins' (Desmond 2007: 285). I concluded Dr Karman's sponsorship, acquired in my preliminary field-work, would undoubtedly ease this process.

Before, during, and after contacting and/or meeting with key contacts in the field, I developed my documents for submission to the NHS REC. I offered a breakdown of, among other things, what data would be collected, where this would be collected, how many site visits were expected, how participants would be approached, and how many participants would be recruited (Appendices 4-8). Completing the application proved to be a trying task. Some authors have associated the difficulty of gaining ethical approval with rigid stipulations ill-suited to qualitative projects and particularly observational work being enforced (Boden et al. 2009; Bosk and

De Vries 2004; Dingwall 2006; Pope and Mays 1995), although Hedgecoe (2008, 2012) disputes such claims. However, my research was approved pending minor amendments a few months after submission. The application culminated in a REC meeting (September 2011) in which questions were asked, and a decision was made, by people from medical and nonmedical backgrounds about the proposed study. My own meeting lasted fifteen minutes. Corrections were made following some minor concerns being raised and after resubmission in early November 2011, approval was granted two weeks later.

Fieldwork

After gaining ethical approval, I made contact with Dr Karman who identified a day to begin collecting field data at Freymarsh. On this day, we discussed my research and what I intended to analyse. I provided some general areas of interest and Dr Karman introduced me to some midwives in the Freymarsh antenatal department (FAD). The midwives and Dr Karman explained that FAD is essentially the 'home' of Down's syndrome screening in Freymarsh. Whilst NHS ethical approval was based largely on producing a formulaic and rigid protocol, I decided to enter the field with some flexible research interests, intended as a guideline rather than fixed stipulations, to guide initial observations. As Whyte (1955: 280) claims:

> 'I am convinced that the actual evolution of research ideas does not take place in accord with the formal statements we read on research method. The ideas grow up in part out of our immersion in the data and out of the whole process of living'.

Whyte's contentions correspond to my own approach. Ethnographers frequently enter the field as if it is *pre*-constructed. However, for Latimer (2008a), this is problematic since the field is a *lived* as well as a political and contested space, that is, it is experienced by people in very specific ways. Ethnographic accounts often treat the field as 'existing' (Latimer 2003) and people as 'cultural dopes' (Garfinkel 1967). This risks making a Procrustean bed for data, imposing an unwarranted order drawn from an analyst's own interpretations about wider structures and context (Horlick-Jones and Prado 2009).

As such, I reject the notion that Down's syndrome screening is self-evident or an effect of things which are given in the world. Instead, I performed a break from my own knowledge gathered during preliminary field-work and embraced the idea of Down's syndrome screening as a practice fragmented across different spaces. This epitomises Marcus' (1995: 95) description of 'multi-sited ethnography' in which ethnography moves from its conventional single site location to multiple sites of observations crosscutting and fracturing dichotomies such as local/global and micro/macro. Reformulating the micro-macro puzzle, Callon and Latour (1981) claim only micro-actors associating with other micro-actors construct networks. What we call a 'global economy', for instance, is a network of a large number of local economies. Conceiving of micro-macro in dynamic terms, they maintain an analyst cannot distinguish between macro-actors (institutions, organisations, social classes, states) and micro-actors (individuals, groups, families) on the basis of their dimensions. They are all the 'same size' (1981: 279), the difference between them brought about by the power relations and the construction of networks escaping our attention if we assume *a priori* that macro-actors are bigger to, superior to, and more complicated than, micro-actors; 'it is no more difficult to send tanks into Kabul than to dial 999' (1981: 299). I suggest, therefore, with Callon and Latour, an integrated micro-macro approach should be embraced by sociologists, with 'multi-sited ethnography' providing a means through which this can be accomplished; the macro, in turn, is always local and specific.

By 'tracking' (Marcus 1995: 95) Down's syndrome screening inside and outside the clinic walls, I am able to map its trajectory (Latimer 2008b). This reflects how the body in modern medical practice is fragmented and transformed into different 'representations' across sites (Atkinson 1995: 88). During fieldwork, I entered consultation rooms, offices, laboratories, hospital meetings, seminars, public symposiums, and several sites where Down's syndrome screening is 'done' (Garfinkel 1967). However, the vast majority of my fieldwork was spent observing the 'routine activities' (Garforth and Kerr 2010) of professionals in three places: Freymarsh antenatal department (FAD), Freymarsh foetal medicine department (FMD), and Springtown antenatal department (SAD). Crucially for my arguments

here, I show how conducting fieldwork at Springtown is attributable to 'tracking' over any active selection procedures. After attending FAD and FMD for one week, Dr Karman invited me to attend a privately-funded fertility clinic (Springtown) which also offered screening for Down's syndrome. Dr Karman runs the antenatal department at Springtown and believed I would benefit from conducting research here. Thus, Springtown was constructed by Dr Karman, not me, as a key site of interest.

Whilst carrying out fieldwork at two healthcare institutions was not my initial intention, it held significant benefits, the primary advantage being it allowed me to analyse the routines and repetitions of two settings over an extended period of time. In addition, it allowed me to comprehend the complexities, breadth, and richness of screening practices across different sites. Given recent indications that the NHS could be privatised (Campbell 2013), this fieldwork could take on even greater significance in future UK reproductive politics. Nonetheless, conducting a study in more than two institutions, particularly with only one researcher available, would have provided been overwhelming and would not have provided the level of detailed 'thick description' (Geertz 1973), of explaining human actions with as much detail as possible, necessary for conducting this research. Limiting my focus to two institutions, however, provided ample time and space to formulate deep, rich insights into the social life of each setting. In what follows, I describe the three settings where I spent most of my fieldwork.

Freymarsh antenatal department (FAD)

Freymarsh is an NHS institution. Alignments to notions of welfare are considered one of the key features of NHS hospitals in the UK since services are essentially 'free at the point of delivery' (Klein 2006: v). Access to free healthcare is viewed as the right of a citizen (Alderson et al. 2004) yet since the 1980s this alignment to welfare has been viewed as an anachronism (White et al. 2012). NHS hospital services have been increasingly inscribed with a political and economic rationality and confined by bureaucratic principles designed to achieve goals as precisely, unambiguously, and efficiently as possible. Rather than attempting to critique this rationalisation of the NHS, however, I reveal how such principles are enacted in

everyday interactions and the effect this has on both professionals and parents-to-be in antenatal care (more on this later).

Freymarsh's antenatal department (FAD) is located near other departments such as the delivery suite, maternity department, FMD, early pregnancy assessment, and gynaecology department. On arrival at the FAD, parents-to-be are greeted by a large open area beginning either with a small cafe to the right or a reception desk directly meeting one's gaze depending on which entrance is used. The loud and hectic room – professionals can experience slack periods with alternating episodes of chaos – is flooded with chairs frequently filled with mothers-to-be accompanied by both or neither partners and children. The walls are relatively drab excepting two television screens constantly displaying BabyTV, a channel played in antenatal waiting rooms nationwide, on the monitor. The channel advertises itself as sharing relevant information which helps parents-to-be 'make informed decisions for the health, welfare, safety and happiness of both themselves and their future baby'. Advertised with the tagline 'keeping you informed', the channel includes adverts for baby items (e.g. cots), advice (e.g. bullet-pointed guidance for reducing the risk of cot death), safety advice (e.g. scalds), and video clips of breastfeeding correctly. Near this waiting room are nine other rooms: an office for professionals/admin staff, a cloakroom, a medical supplies closet, a room dedicated to staff meetings, and five consultation rooms (three of which contain ultrasound equipment). Whilst many professionals enter FAD during each shift, midwives are those primarily occupying this space. FAD employs around fifteen to twenty midwives (see 'Table 1'), three maternity care assistants (Jennifer, Michelle, Rosie), and three admin staff (Pauline, Whitney, Yvonne). Approximately eight to ten midwives, two maternity care assistants, and two admin staff work one shift.

Freymarsh foetal medicine department (FMD)

Freymarsh's foetal medicine department (FMD) is located a short walk from FAD. A relatively small department, FMD is a referral unit providing a service to the local/regional population for those with a previous history of maternal/foetal conditions or whose current pregnancy requires intervention. It has close working links with many departments including FAD, genetics, radiology, cardiology, and

neonatology. Parents-to-be consenting to Down's syndrome screening are referred here if they opt for diagnostic testing following a 'higher-risk' result and/or if they choose to terminate a pregnancy following a diagnosis. When attending FMD, parents-to-be enter into a small waiting room located outside of six other rooms: two consultation rooms (where parents-to-be receive information about their unborn baby and consent is gained if a procedure is undertaken), an ultrasound scanning room (where most procedures take place), a rarely used small office with space for one person, a small consultation room now used as storage space, and the largest office where most professionals gather. One wall in the waiting room is adorned with a large picture display of recently born babies with cleft lip/palate and other conditions (the 'cleft board'). FMD is run by two consultants (Dr Karman and Dr Cassidy) and employs three head midwives (Elena, Francine, Joanna), four midwives (Emma, Lois, Nancy, Robyn), and one receptionist (Fiona)[29]. One consultant, one head midwife, two midwives, and one receptionist will typically work one shift.

Springtown antenatal department (SAD)

Springtown is a privately-funded fertility clinic located in a grand building situated in an affluent area. It provides a service for pregnant and non-pregnant women including those concerned about miscarriage, fertility, sexual health, and ovarian cancer. Parents-to-be attending the antenatal department (SAD) can pay for many ultrasound scans including early pregnancy scans, nuchal translucency scans[30], growth/wellbeing scans, and cardiac scans. Diagnostic procedures (amniocentesis and CVS) can be offered although parents-to-be are recommended, if consenting to this test, to undertake it in the NHS (as no payment is required). On entry, clients approach the reception desk and are directed to the waiting area containing one television, ten chairs, and a water cooler. SAD is a tiny space with plain corridor walls adorned with pictures of both unborn and newborn babies. SAD contains three rooms: an ultrasound room, a bloods room, and a consultation room. The

[29] Professionals from other departments such as cardiology, radiology, or neuroscience are called upon to help with certain cases. In this thesis, only four such professionals are cited: 1) Annie, a sonographer; 2) Jodi, a cardiac physiologist; 3) Roxanne, a sonographer; 4) Dr Torres, a cardiologist. They are cited as 'Annie (FMD sonographer)', 'Jodi (FMD cardiac physiologist)', 'Roxanne (FMD sonographer)', and 'Dr Torres (FMD cardiologist).

[30] Hereafter, I use the term 'NT scan' when referring to a nuchal translucency ultrasound scan.

ultrasound room, where many parents-to-be spend most of their stay in SAD, is a dark space containing a large ultrasound machine, two chairs, a large television monitor, a computer, and two photographs of water babies[31]. The ultrasound machine consists of a transducer, a central processing unit, a monitor, and a keyboard. The machine displays body tissue in shades of grey according to its density. The ultrasound scan allows for the visualisation of unborn babies and the measurement of their anatomy (and so the gestational age). Among other factors, the gestation time determined here is used for medical decision-making.

The SAD employs two consultants (Dr Finley and Dr Karman), five sonographers (Esther, Heather, Lisa, Olivia, Sophie), four nurses (Francine, Isobel, Keri, Victoria), and four admin staff (Bethan, Dominique, Hannah, Juliana). One consultant or sonographer and one nurse will work each shift. At least two admin staff work a shift in an office located near SAD. The vast majority of Springtown professionals also work in Freymarsh. For the most part, they employ the same roles in Springtown as in Freymarsh even if bestowed with different titles. For example, Francine – a 'nurse' in SAD and 'head midwife' in FMD – performs similar roles at each institution (see 'Table 1').

There are two clear or rather medically-based reasons why parents-to-be choose to pursue Down's syndrome screening in Springtown (privately-funded clinic) rather than Freymarsh (NHS institution). First, Down's syndrome screening in Springtown is promoted as more clinically accurate (i.e. better detection rate and lower false-positive rate) than Freymarsh. Second, parents-to-be may want to have Down's syndrome screening and receive a result as early as possible, with Springtown offering the procedure earlier in the pregnancy than in Freymarsh. I am clearly simplifying complex decision-making processes here. There are likely to be several other justifications for consenting to Down's syndrome screening in a privately-funded clinic such as parents-to-be worrying after previous pregnancy complications and/or pursuing more 'personable' care. However, earlier and more

[31] The pictures show a young Caucasian male smiling and holding his newborn child. Both are photographed underwater. Lisa (SAD sonographer) explains unborn babies have a natural diving reflex and so avoid inhaling water into their lungs.

accurate results are two reasons why parents-to-be would choose to screen for Down's syndrome in Springtown rather than Freymarsh.

Professionals in Freymarsh and Springtown

A table specifying each professional's role in the Freymarsh antenatal department (FAD), Freymarsh foetal medicine department (FMD), and/or Springtown antenatal department (SAD) is provided below:

Table 1: Professionals in FAD, FMD, and/or SAD

Name	FAD role	FMD role	SAD role
Amy	Midwife	-	-
Angela	Midwife	-	-
Annie	-	Sonographer	-
Bethan	-	-	Admin staff
Camilla	Midwife	-	-
Dr Cassidy	-	FMD consultant	-
Dominique	-	-	Admin staff
Elena	-	Head midwife	-
Emma	Midwife	Midwife	-
Esther	-	-	Sonographer
Eve	Midwife	-	-
Dr Finely	-	-	Consultant*
Fiona	-	Admin staff	-
Francine	-	Head midwife	Nurse
Gail	Midwife	-	-
Hannah	-	-	Admin staff
Heather	-	-	Sonographer*
Isobel	-	-	Nurse
Jennifer	Maternity care assistant	-	-
Joanna	-	Head midwife	-
Jodi	-	Cardiac physiologist	-

Juliana	-	-	Admin staff
Dr Karman	-	Consultant	Consultant
Keri	-	-	Nurse
Lindsay	Midwife	-	-
Lisa	Radiographer*	-	Sonographer
Lois	Midwife	Midwife	-
Maggie	Midwife	-	-
Marianne	Midwife	-	-
Martha	Midwife	-	-
Michelle	Maternity care assistant	-	-
Nancy	Midwife	Midwife	-
Nicola	Midwife	-	-
Olivia	Radiographer*	-	Sonographer
Pauline	Admin staff	-	-
Rita	Midwife	-	-
Robyn	-	Midwife	-
Rosie	Maternity care assistant	-	-
Roxanne	-	Sonographer	-
Sophie	Radiographer*	-	Sonographer
Susan	Midwife	-	-
Tara	Midwife	-	-
Terri	Midwife	-	-
Toni	Midwife	-	-
Dr Torres	-	Cardiologist	-
Victoria	-	-	Nurse
Whitney	Admin staff	-	-
Yvonne	Admin staff	-	-

*This professional had no major involvement in Down's syndrome screening in the respective institution.

Collecting data

I spent approximately one year collecting field data. Over two-hundred hours of observations are supplemented with document analysis (e.g. policy documentation and antenatal leaflets) and sixteen interviews with professionals. Whilst my fieldwork can be described as a triangulated approach, the crux of my data stems from observing the 'front-stage' (medical consultations, waiting rooms) and 'back-stage' (offices, professional-to-professional interactions, small talk) of antenatal care (Goffman 1959). In his exposition of how spaces are arranged socially into front and back regions, Goffman (1959) explicates the spatial dimensions of interaction and the subsequent negotiation of roles; one might accomplish an identity in the presence of others during a front-stage interaction yet conduct themselves differently during back-stage interactions. The doctor, for instance, may manage and negotiate their performance by appearing empathetic in a patient consultation but complain to colleagues about that very patient in the (safe) back-stage of an office. Observing the front-stage alone, as such, is a grave sampling error since it mistakes a part for the whole (Bosk 1992). By observing both the front-stage and back-stage, I reveal how the front-stage of a consultation is only one component of Down's syndrome screening and is not, on its own, a microcosm for all aspects of medical work (Atkinson 1995).

Selecting observations as my primary method of gathering data is grounded in the theoretical foundations identified in chapter two. Rather than gathering stories via interviews alone, my strategy of entering the field and tracking Down's syndrome screening is grounded particularly in ethnomethodology. The approach is often sceptical of methods and claims abstracted from the lived experience and ordinary world of people (Garfinkel 1967). Ethnography and particularly observational data, for ethnomethodologists, are viewed as the best means through which one can analyse people's methods and accounts (Garfinkel 2002; ten Have 2004), that is, how social activities are done within interaction and how social order is made 'observable-and-reportable' in such interactions relative to their practical purposes (Garfinkel 1967: 1). In sum, I selected observations as my main method for collecting field data since I was guided by an interest in producing an in-depth description of a research site and the working lives of people within it. By

including what other methods exclude (an analysis of situated occasions), I do not view individuals as suspended in a single context within a single time frame but rather as situated beings whose interactions with both human and nonhuman elements (such as materials) are embedded with, and draw upon and circulate, social and cultural meanings.

The majority of my field data is taken from observations of consultations between professionals and parents-to-be dedicated to Down's syndrome screening. These consultations took place in both FAD and SAD. As such, FMD and other medical worlds (e.g. laboratories) were observed less frequently. During the fieldwork, I observed one-hundred-and-fifty consultations (seventy-five in each institution) in which screening for Down's syndrome was discussed and/or carried out. Whilst the vast majority of my arguments in this thesis stem from fieldnotes of such encounters, I spent much of my time in Freymarsh and Springtown 'deep hanging out' (Geertz 2000: 107), immersing myself into the culture of each setting on an informal level. This mainly involved frequenting offices, loitering, and chatting. Such actions are necessary throughout the fieldwork but particularly in the early stages so as to comprehend the general mechanics and processes of each setting. Whilst I was often an active participant in various scenes (such as engaging in conversations), refraining from asking outright questions and remaining fairly muted produced details which I would not have thought to ask myself. In so doing, I observed and retained information which others in the settings often deemed trivial or taken-for-granted.

So how were data specifically gathered? During my first few days in Freymarsh and Springtown, I was consistently asked about my presence. I provided a short 'cover story' (Bosk 1979: 194) – along the lines of 'I am a PhD student in sociology interested in Down's syndrome screening' – which was often met with enthusiasm and invitations to accompany each professional into consultations. In the following months, I was regularly invited by professionals to escort them around the clinic and into consultations. During fieldwork, I observed Down's syndrome screening consultations, cytogenetic and biochemistry laboratory work, phone calls made to parents-to-be, administrative duties, amniocenteses, '4D baby-bonding' ultrasound

scans, multi-disciplinary meetings, and other medical procedures. My involvement in the majority of consultations unfolded in the same way: professionals would notify me about a potential 'case', parents-to-be would be asked if I could observe the encounter, consent would be provided, and I would scribble fieldnotes during the consultation and after it had concluded. Outside of consultations, my daily routine would consist of attending the clinic, greeting professionals, and engaging in conversation whilst occasionally leaving to write up fieldnotes.

As time progressed, I became interested, in unison with the theoretical traditions inspiring my intellectual philosophies, not in peoples' actions *as* individuals or in their supposed failings but rather as situated social and cultural beings enacted and positioned by routine and institutional discourses (Foucault 1983; Garfinkel 1967; Goffman 1959). Rather than assessing professionals as failing to live up to preconceived set ideals posited by models and theories of best practice, I asked what professionals' conduct is accomplishing, why they are accomplishing these matters over others, and what socio-cultural effects they are embedded within (Latimer 2008b). Acting 'according to the emergent logic of the situations in which they found themselves' (Horlick-Jones 2005: 297), professionals are concurrently treated as both active participants in the world and as restricted, that is, as *not free* agents positioned in certain ways (Latimer 2003).

What becomes most important, then, are not exclusively the professionals' 'accounts' (Garfinkel 1967) of what they do, as in the interview, but rather what they do, that is, their shared rhythms and routines which may support/negate accounts and illustrate how Down's syndrome screening is done 'in action' (Latour 1987). This *doing* of screening is also a technical accomplishment; the materiality and spatial arrangement of Freymarsh and Springtown enacts particular relations and performs certain roles (Sandelowski 2003). By focusing on the social practices and cultural materials of Freymarsh and Springtown, thus, I explore who or what is privileged and/or excluded, who is made accountable, what is figured as good or bad medical practice, the extent of 'slippage' between 'informal' ways of working and 'formal' accounts (Horlick-Jones 2005), how identity-work is accomplished,

and what/how 'typifications' (classifications or categorisations) are produced and reproduced in everyday practices.

My (weekly) presence at each setting would depend on three criteria. First, I would observe one setting on the basis that specific 'cases' would attend the department on that day or when a large influx of parents-to-be was expected. Springtown and FMD, for instance, only performed certain procedures on specific days. Second, I would wait for the manager of a department to invite me, or accept my request, to observe the setting. In such instances, my access can be described as opportunistic. Third, I would temporarily withdraw from settings to avoid intellectual fatigue and refine my focus by performing an *in-situ* analysis of previous observations. On my return, routine affairs were once more thrown into a new relief. In many ways, my approach can be compared to Duneier's (1999: 342) 'diagnostic ethnography' in which he observes the symptoms characterising people, gains knowledge of these symptoms, and returns to the field with new diagnostic tools (such as refined questions) to grasp symptoms. This straightforward amalgam of explain, interpret and render meaningful was my primary strategy for making sense of the worlds I observed.

After one year, I felt I had reached the point of data saturation and diminishing utility of fieldnotes. In addition, I feared the effects of research fatigue both for myself and participants (Clark 2008). In retrospect, I was guilty of compulsive data collection, compelled and inhibited by the prospect of omitting any possible detail which would further my analysis (Ortiz 2004). Still, having become a fixture of the scene (Duneier 1999) – as '*part of the furniture*' according to Bethan (SAD admin staff) and as a '*member of the family*' as defined by Robyn (FAD midwife) – I decided to leave the field.

Fieldnotes

I carried a notepad and made fieldnotes during consultations. On occasions during the fieldwork where I did not have my notepad, I made fieldnotes using my mobile phone. In the office or other less organised encounters, I relied on memory and created fieldnotes as accurately as possible in the setting itself or immediately

after fieldwork concluded. Whilst consultations seemed to constitute an acceptable environment in order to construct fieldnotes, I felt doing so within conversations would have made professionals curious and threatened by what I was writing. Writing fieldnotes meant on many occasions, I temporarily withdrew from the action moments after it occurred. Although observational work is sacrificed during such occasions, it is certainly more beneficial to have fewer well-recorded and illuminating observations rather than more half-reported and less-developed observations (Atkinson 1995).

My fieldnotes contain exhaustive descriptions of interactions, discourses, verbal and nonverbal practices, inanimate materials, the organisation and space of the setting, and some personal reflections. According to Latimer (2008a: 9), these can all be treated as textual matter since they are 'read' and interpreted; the spatial arrangement of the clinic and material objects contained within it, for instance, 'have a symbolic and an expressive dimension, that is, they are interpreted by social beings as conveying meaning'. Fieldnotes were mostly transcribed within twenty-four hours of an observation. I opted not to use a tape-recorder when observing as I feared it would over-formalise and disrupt the natural order of the clinic (though arguably, my presence already denaturalised the setting). In addition to worrying an overreliance on the recorder may have caused me to miss events not captured on tape, I felt the invasive presence of a tape-recorder could derail the natural sequence of talk and the rhythms of social life, with professionals reluctant to reveal information otherwise shared. This could lead, thus, to securing 'an accurate representation of a misrepresentation' (Desmond 2007: 292). As such, the majority of quotations presented in this thesis rely on my own memory and fieldnotes taken whenever appropriate and possible.

Interviews

Single interviews were conducted with eleven midwives, three sonographers, and two head midwives (N=16). The views of parents-to-be with respect to screening for the condition are undeniably valuable and a key locus enquiry which has flooded the sociological, psychological, and medical literature in particular (Aune and Möller 2012; Bryant et al. 2010; García et al. 2008; Gottfreðsdóttir et al. 2009a;

McNeill et al. 2009; Press and Browner 1998; Santalahti et al. 1998; Williams et al. 2005). In addition, the experiences of parents who have a child with Down's syndrome and had prenatal screening for the condition during the respective pregnancy are important if less common, though there are exceptions (Korenromp et al. 2007; Reist 2006; Van Riper and Selder 1989). Nonetheless, in order to tackle a subject area rarely addressed in sociology (an ethnographic analysis of Down's syndrome screening, its situated occasions, and the conduct of professionals), I draw on observations, document analysis, and interviews with professionals in the thesis which, taken together, embody the bulk of my fieldwork.

During fieldwork, interviews with professionals were largely used as confirmatory devices, that is, to balance and verify observational data and informal interviews (or what can be called conversations with a purpose). Atkinson and Delamont (2006: 166) claim it is a common failing of the social sciences to claim participants' voices 'speak for themselves'; they are not transparent indices offering a privileged route to the private domain of authentic personal experience. Similarly, I argue, drawing on ethnomethodological sensibilities (ten Have 2004), interviews can become speech acts producing versions of events, justifications of actions, and identity enactments. Such 'accounts' (Garfinkel 1967) should not be taken at face value – what Duneier (1999: 343) refers to as the 'ethnographic fallacy' – but as devices creating 'the realities they purport to describe' (Atkinson and Delamont 2006: 167). Rather than considering the output of interviews as a *resource* through which to make sense of the world, they represent a *topic* of study in their own right, a constructed account dislocated from ordinary life circumstances (ten Have 2004). This corresponds to Jerolmack and Khan's (2013: 1) idea of an 'attitudinal fallacy', of how researchers wrongly assume a consistency between attitudes and situated action. What people say, according to Jerolmack and Khan (2013: 13), is frequently a poor predictor of what they do; 'to escape the attitudinal fallacy, we must study interaction'.

In response, I rely not on a quotation-driven study which explains action at the individual level but rather on context-driven fieldwork. Observations put us directly in touch with social life in a way no other method can achieve, allowing a

researcher to seize 'the unscripted, unrepeatable, and often unutterable stuff of existence beyond the grasp of interview-based inquests' (Desmond 2007: 288). I do not, however, discount interviews as a method. I mirror Walford's (2009: 118) claim that one of the central tenets of ethnography is that multiple methods of data collection should be used. I highlight the value of carrying out observations in conjunction with interviews in which claims can be verified or refuted. This is not a question of truth or untruth. Rather, it reflects an attempt to comprehend contextually constructed meanings in interaction with one another and, in turn, to be aware of the asymmetry of power relations between researcher and researched. Indeed, whatever dispositions or repertoires of thought and action people bring to a social situation or reveal to an interviewer, their *in situ* actions are enhanced or constrained by the situation itself (Garfinkel 1967; Goffman 1983).

Face-to-face interviews with professionals were conducted between five and eight months into the fieldwork. Interviews were conducted later in the study for two reasons. First, I wanted to refine questions and identify the key points of enquiry before recruiting professionals for interviews. Second, I wanted to establish their trust before asking questions perhaps unsuitable were I not a regular fixture in their lives (Bourgois 1995). This meant I was able to create a comfortable 'back-stage' area for participants (Goffman 1959). Interviews were conducted at either Freymarsh or Springtown in order to capture context(s) and to allow professionals to draw on materials perhaps overlooked on leaving the respective institution. Susan (FAD midwife), for instance, suggested she preferred being interviewed at Freymarsh since she '*forget[s] all about this place when I go home and I would probably not be able to answer your questions!*' These situated interviews were conversational, audio-recorded, and ranged from thirty minutes to over two hours in length. The litheness of the interview schedule, a guide rather than a formal instrument (Bosk 1979), permitted the probing of responses for expansion if required. Questions invited professionals to reflect on their working practices, a means of observing how they 'see their own experiences, their own lives, and their interactions with others' (Atkinson 1998: 74). Examples of questions included 'what in your opinion are the major issues with screening for Down's syndrome?', 'how do you describe screening to parents-to-be?', and 'do you currently consider

prenatal screening for Down's syndrome as sufficient for the needs of parents-to-be and clinical practice?' Appendix 8 is a flexible interview schedule containing a number of questions which may or may not have been asked (depending on the answers of professionals).

I informed professionals they were to be recorded for transcription purposes, they were to remain anonymous, they could refuse to answer questions, and they could stop the tape-recorder and/or withdraw from the interview at any time. During interviews, it seemed professionals were sincere, direct, and eager to participate. Professionals sometimes used interviews as venting sessions or, as Elena (FMD head midwife) and Martha (FAD midwife) claim, to share information they had not previously discussed with colleagues or others. I now reflect on this openness and why I believe I was afforded seemingly unbridled access to their working worlds.

Researcher relations: gatekeepers, students, and toy-boys

During fieldwork at Freymarsh and Springtown, professionals were predominately unobtrusive and engaging on both a professional and personal level. I offer five intertwining reasons for this. First, my study was championed by Dr Karman and Carol. Neither Dr Karman nor Carol rarely, if ever, had to explicitly vouch for my presence around the respective institution yet my affiliated status was enough to limit questions regarding my presence and give me, *inter alia*, 'the authority to be present in the hospital settings' (Atkinson 1995: 13). Atkinson claims this position was justified further by displaying an identification card; I similarly made an effort to dress smartly and acquire an identification card, both 'props' (Goffman 1959) symbolising and legitimising my presence (Desmond 2007; Stephens et al. 2008). Second, although no expectations were made of me by professionals – at times the demands of medical work rendered me ornamental and extraneous (Bosk 1979) – I made active efforts to keep out of the way, to fill downtime with interesting conversation, and to be helpful by fetching drinks, directing people to the toilet[32], switching off the lights prior to an ultrasound scan, disposing of waste, and, in some cases at SAD, collecting parents-to-be from the waiting room. These efforts

[32] Ultrasound scans often require a full bladder in order to capture a detailed representation of the unborn child on the computer screen. As such, several mothers-to-be needed to use the toilet following a scan.

helped maintain relationships and assisted in gaining trust (Ayala 1996). An ethnographer can never know how much he/she is trusted but offering something is valuable currency when seeking observing rights (Duneier 1999).

Third, I entered a female-dominated environment as a twenty-three year old male. In Springtown and Freymarsh, the vast majority of professionals are female and aged approximately thirty to sixty years old. The disadvantages and advantages of being a female researcher inside and outside largely male settings have been well-rehearsed (Mazzei and O'Brien 2009; Pope 2005; Poulton 2012; Sallee and Harris 2011). However, little attention has been afforded to considerations of gender when males study settings containing a large majority of women, although Warren and Rasmussen (1977) and Ortiz (2004; 2005) offer exceptions. During fieldwork, I was commonly ascribed an identity as an adoptive son or a 'toy-boy'. Each label resulted in playful comments or crude jokes being made at my expense, with some conversations clearly designed to embarrass me. At times, I often played up to this role, responding with quips and jestingly embracing each ascribed identity[33]. At other times, I practiced what Ortiz (2005: 265) refers to as 'muted masculinity', reducing traits such as conversational dominance often associated with hegemonic masculinity (a trait many professionals seemed to dislike); 'put purely negatively, [female professionals] should not feel that you are an additional agent of medical authority' (Silverman 1987: 18). In sum, whilst there were some circumstances in which my male status was problematic such as trans-vaginal ultrasound scans whereby observing the invasion of bodily space was prohibited, my performative identity-work (Goffman 1959) as a young heterosexual male, involving the 'emotional labour' as described by Hochschild (1983), helped secure access and develop constructive research relationships.

[33] During early fieldwork at FAD, I was in the toilet when I was invited by another man to engage in 'cottaging' (anonymous sex between homosexual men in a public lavatory). I declined the invitation and on returning to the FAD office, I informed some professionals about the situation. This became a huge resource of humour for many midwives and other staff members, culminating in many jokes being made at my expense over the following weeks. The story became a source of rapport with professionals I had met and those I had yet to encounter, facilitating my access and becoming an icebreaker when forming relationships with professionals. I had, unwittingly, followed Goffman's (1989: 128) advice to be 'willing to be a horse's ass'. In sharing this story, I also hope to have answered Scott et al's (2011: 718) appeal for confessional tales from researchers about 'performing in (and messing up) their own shows'.

A fourth reason why my access was easily secured in the field relates to my status as a student. Whilst the researcher arguably occupies a more powerful position than participants in research, this is commonly reversed in medical settings with the researcher being the more junior party in terms of both age and status (Pope 2005). My junior status was confirmed by frequently being cited in the front-stage of consultations and back-stage of clinical life as 'the student'. Some FAD midwives recommended referring to me within consultations as a student, not a researcher, since it was felt the latter was, in the words of Nicola (FAD midwife), '*too formal*' and '*sounding too much like you're scrutinising the actions of [professionals and parents-to-be]*'. Professionals openly framed me as a student, arguably affording me a leniency and juvenile status which legitimised my presence. In addition, as a young smartly-dressed male with an ID badge and notepad, I was vulnerable to problems of mistaken identity as a medical student (Bosk 1979). On occasions, I was openly referred to in consultations as a medical student. This misidentification not only troubled me ethically (I often accepted this label without correction, compromising my role performance as a sociological researcher) but also may have led to me, as part of the assembled throng, to conduct research fairly uninhibitedly (Silverman 1987).

A final reason why I was able to gather data so un-problematically is my relatively unattached 'outsider' status. I use this term loosely. The positions of 'insider' and 'outsider', used so frequently in ethnographic accounts, should not be framed as fixed positions but rather as ever-shifting and permeable locations experienced differently by both researchers and participants (Desmond 2007). Still, I note that although Dr Karman and Carol sponsored my study, I had few alliances. One of the great successes of qualitative research stems from the fortunate willingness of other people to talk about their lives not only with friends and family but also with a relative stranger. Although in-depth fieldwork discredits the stranger label, I did seem to become a convenient 'sounding board' where professionals could air grievances, uncertainties, and discontents withheld from colleagues and intimate others (Bosk 1979: 196). It seems playing the quasi-therapeutic role – with few ties, devoid of judgement, and listening rather than talking (Thomas 2012) – contributed to my approval in the field. This explanation of the 'dramaturgical

complexity of role performance in the field', for Scott et al. (2011: 730), should not be viewed as unnecessarily self-indulgent but rather as valuable for revealing how emotion and identity-work are managed and negotiated during fieldwork.

The ethics of ethnography

Despite remarking on the rapport I believe was achieved, it is best to be humble about this since one never really knows how participants view the ethnographer. Indeed, Eve (FAD midwife) often quipped in the early stages of the study that I was '*spying*' on her and her colleagues and intent on airing their dirty laundry. I took Eve's comments as jest but cannot say with complete confidence I have interpreted her claims correctly. This corresponds to a concern with 'ethics in practice', of the everyday ethical concerns emerging during a study, rather than 'procedural ethics', of acquiring formal ethical approval (Guilleman and Gillam 2004: 261). Bosk (2001) claims ethnography frequently becomes a morally problematic activity; we do not inform subjects they are revealing data perhaps not in their best interests, we encourage discrepancies enriching analysis, we disclose but only incompletely, and we betray our subjects by manipulating relationships to collect data and by retiring to the office to convert experiences into text. For Reinharz (1984: 95), ethnographic writing often involves (symbolic) violence; we 'intrude into [our] subjects' privacy, disrupt their perceptions, utilise false pretences, manipulate the relationship and give little or nothing in return'. I do not subscribe to recognising social research as a take-hit-run approach yet I do recognise my ethnography, like all others, raises ethical concerns.

One problem of my fieldwork and of ethnography more generally is I assumed those who do not wish to be observed found ways to avoid this. However, this may not have been the case. Professionals could merely have exercised politeness yet silently objected to my presence. Similarly, if professionals were wary of my presence and desisted from behaving *naturally*, I might wonder how much was staged for my benefit. Whilst I believe our relationship was strong enough to withstand this possibility, its manifestation cannot be completely discounted. In addition, the notion of informed consent was problematic throughout fieldwork. Conforming to the extensive rigidity promised by research protocols is more of an

aspiration than a reality in hospital settings; plans must be modified after certain situations and the actions of the researcher and participants. Bosk (2001: 211) claims it is impossible to do a hospital-based ethnography 'without both violating informed consent and without breaking promises made to subjects about confidentiality and anonymity'. In Freymarsh and Springtown, it was unfeasible to inform every person walking into the clinic that they had entered a research zone and that recordings may be converted into publically-available information. Such a rigorous conformity to consent would produce repeated disruptions to interaction, heighten self-consciousness of participants, and would be socially peculiar (Bosk 2001).

Another problem of any qualitative study concerns the notion of anonymity and whether this is fully achievable. Since ethnographers have a duty to make the decoding process as difficult as possible, I provide pseudonyms for participants and the research settings together with an omission of minor details and changing some key attributes of participants with a view to preserving anonymity. This can be viewed as a remedy to the apprehension one faces when 'making private words public' in the context of a relationship based on trust between researcher and researched (Bourdieu 1999: 1). Despite pseudonyms transforming the specific into the general, those close to the scene may unmask these light cloaks. They may read it as a *roman à clef* and whilst social life provides wiggle room for evading previous claims, permanent texts do not. This is an enduring, if not unsolvable, problem of ethnography.

Whilst the preceding paragraphs focus on participants, one must recognise how ethnography is not just an intellectual/practical accomplishment for researchers but also an emotional accomplishment. Emotionality is often framed as a threat to research and gathering data (a loss of objectivity) rather than the potential harm to a researcher. However, qualitative research, and ethnographies in particular since they confront a researcher with a setting and its occupants for an extended period of time, can have emotional consequences for researchers perhaps affected by being directly implicated as a protagonist within the drama (Bloor et al. 2010; Coffey 1999; Scott et al. 2011). An ethnographer, or 'researcher-as-person' (Scott

et al. 2011: 718), can never be fully passive and objective since he/she has a personal investment in fieldwork and in building relationships.

In an analysis of the AIDS epidemic, Ayala (1996) describes his horror on entering a hospital (the fieldwork setting) and the emotional difficulties he encountered when confronting such suffering. Whilst I did not suffer from sleepless nights like Ayala, encounters in Freymarsh and Springtown – particularly in the challenging environment of FMD which, as Dr Karman (FMD consultant) claims, '*deals with the doom and gloom*' – could be emotionally draining. At times I was uncomfortable as an impartial ethnographer who must neutralise the melodramatic quality of the drama and quash my usual urges (such as to offer help or comfort). I could become overwhelmed and troubled by the enormity of some decisions of parents-to-be and professionals, with one specific observation of a feticide[34] disturbing many people – myself included – for hours after the procedure. Whilst of course my own trial cannot be compared to parents-to-be receiving devastating information or to professionals conveying this news, I sometimes felt I had stumbled into intensely personal moments. I left on such occasions after feeling too uncomfortable to remain present. Thankfully, for the vast majority of parents-to-be, pregnancies proceed without any major complications for them or the unborn baby.

In extending this focus on the emotional dimensions of fieldwork, I also highlight how despite largely being an uninvited intruder into Freymarsh and Springtown, I became fond of the vast majority of professionals who were the object of my gaze for so long. Our interactions were never limited to what can loosely be described as professional talk; we discussed television programmes, food, love lives, family, books, hospital and celebrity gossip, and on one occasion, erotic novels. During such instances, it was easy to 'settle down and forget about being a sociologist' (Goffman 1989: 129). After analysing data, however, I became aware that I might release details occasionally reflecting unfavourably on professionals. Bourgois (1995: 18) worried his work would be misread as reinforcing negative stereotypes of participants; 'under an ethnographic microscope everyone has warts and anyone can be made to look like a monster'. Similarly, I was anxious my work

[34] Feticide is an act which causes the death of an unborn baby prior to termination.

would be interpreted as a criticism of professionals. However, as will be shown in later chapters, I claim they are frequently positioned by organisational constraints inhibiting their practices in various ways. My intention is not to snatch secrets and put them in the public domain; healthcare institutions are dense environments, too complex to be normatively assessed and depicted as a tale of heroes and villains or saints and sinners. In keeping with Goffman's (1989) policies, thus, I suggest my role is to provide a clear analytical account as opposed to passing judgement on settings, conduct, or situations. I hope my ethnographic account, in viewing the social life of Freymarsh and Springtown unsentimentally and without any obvious bias, is both a fair and accurate portrayal.

Data analysis

Data are analysed using 'situational analyses' which captures the complexities and instabilities of everyday working life in Freymarsh and Springtown (Clarke 2003: 571). Situational analyses is a renovation of grounded theory in which the researcher 'becomes not only analyst and bricoleur but also a cartographer of sorts' (2003: 571). Clarke (2003: 553) offers 'situational maps and analyses' as supplements to the basic social process analyses typical of grounded theory, a 'very popular and epistemologically sound approach to qualitative research'. Grounded theory involves coding data, determining if codes appear elsewhere, condensing codes into stable and analytically ambitious categories, and integrating categories into a theoretical analysis of an area or a 'substantive theory' (Glaser and Strauss 1967). With deep roots in interactionist sociology and pragmatist philosophy, grounded theory could be interpreted as a theory/methods package with an interpretive, constructionist epistemology (Clarke 2003).

Clarke (2003) claims grounded theory, however, is not sophisticated enough to 'fully take into account the sea of discourses in which we are continually awash in the postmodern era' (2003: 559). She suggests situational analyses – paralleling Geertz's (1973) 'thick descriptions' and influenced by the postmodern turn yet still 'epistemologically/ontologically based in the pragmatist soil that has historically nurtured symbolic interactionism and grounded theory' (Clarke 2003: 555) – draws attention to irregularities, fragmentations, positionalities, and instabilities

in which to comprehend complex worlds. For Clarke, the approach can be used to analyse observations, interviews, documents, and other discursive materials. Since the codes and categories of my analysis can be generated and applied across many data sources, the new mapping approaches are especially useful for multi-site research (Clarke 2003; Marcus 1995; Rapp 2000). This became particularly useful for cross-comparisons between Freymarsh and Springtown (Silverman 1993).

Throughout the fieldwork, material was grouped together to establish connections and disconnections in observations and the accounts of participants. One of the main benefits of ethnography is that the final product is compiled of a collection of material across many situated occasions (Latimer 2008a; Silverman 1993). These data – fieldnotes, interview transcripts, secondary document analyses, reflections about events – are 'made up' (Latimer 2008a) by the researcher. As such, although materials are often qualitatively different, crosschecks are possible. Rather than offering a truer representation of reality, crosschecking provides an analysis of *how* a reality is constructed via multiple voices, positions, and so forth (Latimer 2008a). In this study, for example, interview transcripts were treated not as voices expressing individual needs but as 'accounts' (Garfinkel 1967) involving identity-work and strategic performance (Goffman 1959). Additionally, they were materials to crosscheck with fieldnotes for capturing patterns and identifying any deviations (Silverman 1993) to upset original interpretations or provide further explanations. What one 'reports' at one moment, in turn, may not be 'observable' in another (Garfinkel 1967), meaning 'shifts' (Latimer 1997, 2000) and multiple discourses circulating different ideas, rather than merely routines and repetitions, come into view. These shifts are not merely 'infractions' (Goffman 1971) but reveal how professionals make their 'moves' and account for their conduct when screening for Down's syndrome. This reveals the dynamism of our supposedly stable social life, adds rigour to arguments so we can make claims on strong grounds, and thickens our descriptions as well as interpretations (Geertz 1973; Latimer 2008a).

Data were read alongside literature, allowing for an inductive and processual approach, until intricacies and relationships were identified. During fieldwork, I developed categories, interpretations, and crude inferences highlighting key areas

of enquiry and where my future focus could be directed. By saturating categories and grounding my theory, I fashioned findings into a coherent pattern and continued fieldwork until, perhaps, some chance occurrence cast light on a new way of analysing the data created. Data were initially analysed using a computer software package. I abandoned this tactic shortly after an unsuccessful attempt to manage data. I opted for analysing data by hand since computer technology, by allowing me to manage large volumes of data, threatened to trade resolution for scope (Seidel 1992). Throughout the thesis, I mostly provide quotes lifted out of fieldnotes/interviews and extensive sequences of data rather than short snippets to avoid fragmenting my account of professionals' daily activities (Atkinson 1995). Fieldnotes and transcripts are also presented as polished editions of messier collections. The fillers, incomplete thoughts, and pauses common in the speech of professional and parents-to-be are deleted to recover the articulate and often poetic character it fulfilled in its original oral performance (Bourgois 1995).

Explicating explications: a problem of ethnography?

Carrying out this fieldwork required great flexibility, patience, and a serious investment in time and energy. Consultations could be long and frustrating, I could find myself waiting for hours with little to occupy myself with, appointments were cancelled at the last moment, observations could become tedious, interviews were rearranged when professionals were summoned for work elsewhere, fieldnotes could be overwhelming in length and intricacy, and so on. The ethnographer, it seems, must be prepared to 'cut [themselves] to the bone' (Goffman 1989: 127). Alongside such practical difficulties are some clear limitations with ethnography more generally. For instance, it remains difficult to discuss situations and conduct for a universal professional service on the basis of one study (Bosk 1992). However, it should be noted Freymarsh is an NHS institution and, as such, shares similarities, in spite of local effects and variations, with other hospitals, an example being the universality of policy stipulations for Down's syndrome screening across NHS hospitals. I argue Freymarsh constitutes a situated example of NHS screening in the UK (although some parents-to-be screen in privately-funded clinics, the vast majority – as statistics reveal – screen in NHS institutions). My analysis of two local and specific settings, therefore, answers broad universal questions about the place

of Down's syndrome in reproductive politics. That said, I must leave it to others to test my observations against their own and hope they translate to other venues (Duneier 1999).

Another issue is ethnography is highly interpretive. Many of the details explicated in the fieldwork are interpreted and not objectively described (Clifford and Marcus 1986). Here, one may face accusations of 'explicating explications' (Geertz 1973: 9). Fieldwork cultivates in the construction of the ethnographic text, a construction of social history containing interpretations of behaviour created by the researcher. Appreciating the deconstructionist cliché of 'culture as text', I am aware this text is created and not objectively reported, an impressionistic sketch laced with my own interpretations as opposed to a perfect snapshot (Bosk 1992). This, however, does not translate to ethnography having reached a point in paralysis in which we cannot trust ourselves to collect data and offer findings with useful applications. Instead, ethnographers should proceed with an awareness of the debates around ethnographic authority, the limits to their claims, and the situated nature of their findings.

Summary

In this chapter, I described my approach and some of the practical, ethical, and social issues emerging during fieldwork. I provided details on my preliminary field-work, my entry into the field, the three main sites of interest (FAD, FMD, and SAD), my experiences of conducting fieldwork, how I crafted and used fieldnotes, why I used certain methods, my relationships with participants, and the ethics of ethnography. After describing my strategy of 'situational analyses' (Clarke 2003) and the data yielded from this analytic approach, I outlined the limitations of both my own research and of ethnography as a whole. In what follows, I produce a written representation of two healthcare institutions. In this frontline account, I describe my attempts to uncover the everyday pattern of professionals' working lives and particularly how they go about their everyday business of communicating information to parents-to-be about Down's syndrome screening. Interested in everyday working practices and general types rather than specific people, I reveal how screening for Down's syndrome occupies a key position in the 'politics of

reproduction' (Ginsburg and Rapp 1991), invigorates parental expectations, and highlights the significance of dominant body-society relations (Latimer 2013). Over the next four chapters, I show how producing soft data makes for rethinking hard questions about some of the most important and profound dilemmas of antenatal medicine and, in turn, the human condition.

Chapter Five
The Organisation of Down's Syndrome Screening

The following four chapters outline some key findings of my study. In the next two chapters, I explore how Down's syndrome screening is organised (chapter five) and performed (chapter six) in Freymarsh and Springtown. In chapter five, I show how the sedimentation of Down's syndrome screening in antenatal care as a routine practice contributes to it being 'downgraded'. I define downgrading as practices which denigrate and minimise the importance, value, and reputation of someone or something. This is particularly common in Freymarsh in comparison to Springtown. At Springtown, parents-to-be are offered an appointment time. Only one sonographer and one nurse work during a shift so professionals do not have the opportunity to prioritise one procedure over another. Whilst they certainly value some working practices over others, this rarely manifests itself in practice. As such, the majority of my arguments in this chapter concern Freymarsh.

I capture how Down's syndrome screening is *made* routine and undervalued as a trivial, non-prioritised task in the organisation of clinical life in three interrelated ways. First, I identify how the task of conducting Down's syndrome screening consultations is relegated to midwifes and sonographers who act, using Bosk's (1992: 63) definition, as an (unwitting) 'mop-up service', that is, as cleaning up the dirty work of the clinic. Undesirable tasks, Down's syndrome screening included, pollute the purity of the clinical space. As such, they become reassigned to non-consultants. Second, I explore how professionals implicitly and explicitly define Down's syndrome screening, both inside and outside consultations with parents-to-be, as a routine affair. Third, Down's syndrome screening consultations, as everyday encounters, are categorised by midwives and sonographers as tedious duties not permitting the performance of an authentic midwife/sonographer role. These practices, as well as having clear crossovers with my arguments in chapter six, play a key role in downgrading Down's syndrome screening at Freymarsh and Springtown.

To be clear, I am not laying the blame for the downgrading of Down's syndrome screening exclusively at the feet of professionals. Indeed, it is over-simplistic and offensive to conclude professionals deliberately downgrade this procedure. As a collective, Freymarsh and Springtown professionals are conscientious, working tirelessly at difficult and complex tasks, and committed to the cause of parents-to-be. The ongoing classifications of screening for Down's syndrome are therefore attributable to the organisation of healthcare and how professionals, positioned in particular ways, are frequently victims of various pressures, not least time restrictions and the threat of legal action. Their work, in turn, is inhibited and patterned according to each institution and the various negotiations, routines, and stipulations enacted in the clinic (Kerr 2009; Timmermans and Berg 1997).

Down's syndrome screening in Freymarsh and Springtown

In Freymarsh, Down's syndrome screening is located, for the most part, in the antenatal department (FAD). The first interaction parents-to-be have with FAD is when attending a 'booking clinic' around ten weeks into a pregnancy. This involves a community midwife performing a dating ultrasound scan[35] and providing parents-to-be with information on prenatal screening and aspects of pregnancy management including but not limited to alcohol intake, exercise, and the consumption of folic acid. It is at this point parents-to-be are offered screening for Down's syndrome and a range of diseases including HIV[36], syphilis[37], hepatitis[38], and rubella[39] (I return to the meaning of categorising Down's syndrome alongside diseases later in the thesis). Parents-to-be who accept Down's syndrome screening

[35] A dating scan is an ultrasound scan occurring around eight to fourteen weeks into a pregnancy. The scan is used to check how many weeks pregnant a mother-to-be is, whether it is intrauterine, whether it is viable, and whether it is a multiple pregnancy. Sonographers will also check the ovaries for cysts. Parents-to-be often receive a picture of the unborn baby at the end of the scan.

[36] HIV (human deficiency virus) is a virus causing the acquired immunodeficiency syndrome (AIDS). It attacks the immune system, allowing opportunistic infections and cancers to thrive.

[37] Syphilis is a sexually transmitted bacterial infection which mothers-to-be can pass onto their unborn baby.

[38] Hepatitis is a condition defined by liver inflammation and characterised by inflammatory cells in the tissue of an organ.

[39] Rubella is a viral infection. It is usually a mild condition but can be more serious during a pregnancy.

in Freymarsh, around 65% according to Dr Karman (FMD consultant)[40], will return to the department approximately six weeks later to undertake the quadruple test.

On entry to the department, parents-to-be approach the reception desk, account for their visit, and are told to take a seat before being collected by the midwives or maternity care assistants (MCA) depending on their care trajectory. Before moving to the seating area, the receptionist asks parents-to-be to hand over their red folder containing personal and physiological details of the parents-to-be, screening leaflets, and pregnancy management information on, for example, diet and travel safety. The folder is collected by an MCA who delivers it to a trolley holding a blue box. The blue box is positioned directly in front of the midwifery office door so midwives can notice a folder once delivered. Folders, as material extensions of parents-to-be, are collected by a midwife who, on reading the details inside the folder, determines which professional should meet with parents-to-be and the timing/immediacy of their appointment. Once midwives collect a folder, the respective parents-to-be are summoned to one of five rooms, each a short walk away both from the waiting area and office. Parents-to-be who accept Down's syndrome screening are invited by a midwife into a small room to discuss the finer details of the procedure. The small room contains a two-piece sofa, three plastic chairs, a desk, and a computer. Chairs are commonly occupied by a midwife and parents-to-be with the sofa, set against the back wall, occupied by myself and occasionally children. After a midwife describes the procedure and gains consent for screening, parents-to-be are led into a different room where a nurse extracts blood from the arm of a mother-to-be. It is here, according to FAD midwives, where Down's syndrome screening is 'done'.

Parents-to-be at Springtown book a nuchal translucency ultrasound scan (referred to hereafter as 'NT scan'), usually ten to eleven weeks into the pregnancy after a dating ultrasound scan, by telephone. Appointments are logged by administrative

[40] As a reminder, many professionals working at Springtown also work at Freymarsh. However, the reference to Freymarsh or Springtown in parentheses is used to signify where I observed the vast majority, if not entirety, of each respective professional's work. As an example, Dr Karman is a consultant in both Freymarsh and Springtown but was observed most frequently in the Freymarsh foetal medicine department. Hereafter, I use FMD when referring to the Freymarsh foetal medicine department.

professionals (hereafter referred to as 'admin staff') who offer an appointment slot and notify parents-to-be of other ultrasound scans available at Springtown. Around twelve to fourteen weeks into a pregnancy, parents-to-be attend Springtown antenatal department (SAD) for an NT scan. After alerting professionals of their presence, parents-to-be are told to sit in the waiting area. If parents-to-be are waiting for a long time, they are offered drinks and an apology by the nurse.

Parents-to-be are eventually collected by a nurse, or occasionally the sonographer or myself, who leads them into the clinic. After having their blood withdrawn, mothers-to-be consenting to an NT scan enter the ultrasound room – often alongside partners and other family members – to undertake the procedure. A sonographer sits on one chair and the mother-to-be is invited to lie on the bed with a partner commonly sitting on the remaining chair. Family members and/or friends can stand beside the bed. Paper towels are placed around the abdomen of the mother-to-be, ultrasound gel is applied, and the sonographer switches on the large television screen connected to the ultrasound machine. This produces a larger image of the womb for parents-to-be and others to see as the sonographer focuses on the smaller monitor. A sonographer describes the procedure, measures the anatomical features of the unborn baby, and explains a result will be delivered in a few days time. Once more, sonographers acknowledge SAD as primarily where Down's syndrome screening is 'done'.

Hand me Down's[41]

The modern hospital is a complex organisation in which the work of medicine is distributed to different people and across departments (Atkinson 1995). This is certainly true in pregnancy/childbirth which have been increasingly medicalised in the twentieth century as part of the obstetrics project. Responsibility for much of this care has been seized by (technical) consultants from (nontechnical) midwives (Olarte Sierra 2010). Hiddinga and Blume (1992) show whilst twentieth century obstetrics concerned itself initially with what it categorised as pathological

[41] 'Hand me Down's' is my own term. It is a play on Down's syndrome and the idiom 'hand me down' referring to how something is passed on to one person after being discarded from another.

births, it slowly colonised the entire process of pregnancy by perceiving mothers-to-be as abnormal and by defining pregnancy as inherently pathological, that is, a crisis requiring intervention. Although midwives reclaimed aspects of pregnancy and childbirth following backlashes about this increasing intrusion, commentators suggest the (male) appropriation and medicalisation of pregnancy, rooted in a patriarchal model centuries in the making, persists today (Cahill 2001).

So what about Freymarsh and Springtown? Who performs what care (particularly Down's syndrome screening) and why? Previous research identifies how Down's syndrome screening is carried out by midwives (Dormandy et al. 2006; Ekelin and Crang-Svalenius 2004; Samwill 2002), doctors (Burton Jeangros et al. 2013; Driscoll et al. 2009; Marteau et al. 1993), or midwives and doctors interchangeably (Pilnick 2004; Smith et al. 1994; Williams et al. 2002a) rather than genetic counsellors and clinical geneticists. In Freymarsh, Down's syndrome screening belongs to a midwife. If parents-to-be receive a lower-risk result, this is confirmed via a letter with no further screen or test recommended. If receiving a higher-risk result, they are invited into the FAD by telephone for counselling with a midwife. In Springtown, Down's syndrome screening is primarily the role of sonographers. Delivering news of a lower-risk result for Down's syndrome to parents-to-be by telephone is the duty of admin staff with no medical education or training. For a higher-risk result, counselling is done via telephone by a nurse (Francine)[42] or admin staff member with no medical training (Bethan).

In both institutions, consultants' involvement in Down's syndrome screening is often limited to performing diagnostic tests (amniocentesis/CVS) and managing parents-to-be with previous pregnancy complications. Parents-to-be are shifted from the antenatal departments at Freymarsh and Springtown to FMD at Freymarsh once a problem is suspected, such as those with a higher-risk result for Down's syndrome following screening and who subsequently consent to diagnostic testing. Whilst Springtown is not officially affiliated with FMD, parents-to-be who have had an NT scan, received a higher-risk result for Down's syndrome, and have consented to diagnostic testing are referred to FMD because they do not have to

[42] Francine is also an FMD midwife. FMD is where I observed her working life most frequently.

pay for the procedure and because they are under the care of the same consultant as in Springtown (Dr Karman). During a conversation with Springtown (SAD) admin staff, they explain to me why sonographers, not consultants, are assigned the task of screening for Down's syndrome via an NT scan:

> Gareth: So how do you decide who does the NT scans?
> Dominique: It's just one of the sonographers.
> Hannah: Whoever it is who works on that day does them.
> Dominique: But we usually do them on Fridays and Saturdays when Dr Karman isn't working[43].
> Juliana: Everyone wants Dr Karman for their NT scans but we don't want to clog up Dr Karman's clinic with NTs and all that easy stuff. Dr Karman does 'Care Package' clients too.

When asked how the fate of NT scans is decided, the SAD admin staff suggest they are delegated to the days a sonographer, not Dr Karman, is working. This allocation of care is based on the reluctance to '*clog up Dr Karman's clinic with NTs and all that easy stuff*', the classification of 'easy stuff' translating to tasks not requiring Dr Karman's expertise. The efforts of Dr Karman are better placed elsewhere in taking charge of cardiac scans[44], diagnostic testing (amniocentesis and CVS), and '*Care Package clients*', namely parents-to-be paying for fixed ultrasound scans and counselling sessions (Care Package clients often have earlier pregnancy complications such as recurrent miscarriages).

In Freymarsh, the task of carrying out Down's syndrome screening consultations is similarly demoted to midwives or, more accurately, the '*couch*'. In an interview, Lois (FAD midwife[45]) describes a couch's function when discussing her daily work:

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[43] This also explains why many of the extracts cited in this thesis involve Esther (SAD sonographer). Whilst other sonographers (Olivia, Lisa, and Sophie) also conduct NT scans during their shifts, Esther often works on Friday and Saturday when many NT appointments are allocated. This means Esther conducts a large amount of NT scans during her shifts. Heather (sonographer) was not trained in NT scans but was trained in 4D scans.

[44] A cardiac scan involves a sonographer, via an ultrasound scan, examining the two outflow tracts and four chambers of the unborn baby's heart. In Springtown, the scan is offered around twenty-four weeks into a pregnancy.

[45] Lois is also an FMD midwife but I observed her most frequently in FAD.

> I like doing hands-on midwifery with women because sometimes in clinic, you can be in the office doing results, you can be answering phones, and you're not doing much midwifery. One of the job roles that we do when we have an antenatal clinic is when the midwife is a couch, so they will do what the doctor wants like stretch and sweeps[46] or discuss things with the women and do CTG's[47]. It's hands-on midwifery work I like doing. The prepping for the clinic – its paperwork which is essential because it runs a lot smoother – but it's not what I feel part of what is a midwife's job and there's a lot of admin work involved. I don't think we're being utilised enough and they could be getting more admin staff in who could do that and release us a little more.

The typification of couch is both a noun (a piece of furniture) and a verb. To *couch* something is to arrange, to place and situate in a particular way. Lois defines the couch as someone who performs various duties on demand, that is, as someone who contributes to the arrangement and placing of Down's syndrome screening and other forms of care in the hospital. The role of the couch includes assisting doctors during the later stages of a pregnancy and, in Lois' own words, '*discuss[ing] things with women*', roughly translating as conducting consultations in which information about a pregnancy is communicated to parents-to-be. FAD midwives are allocated roles including a 'couch' and working with doctors in a 'specialist clinic', roughly defined as consultations – frequently in conjunction with doctors – whereby they interact with parents-to-be who have specific pregnancy concerns. FAD speciality clinics include breastfeeding, haematology, substance misuse, diabetics and thyroids, asylum seekers, cardiac issues, twinned pregnancies, HIV, and recurrent miscarriages.

The specific roles – or temporal identities – of a couch and specialist clinic midwife, among others, are displayed on a whiteboard in FAD. This reflects a Taylorist distribution of tasks in which professionals are allocated to particular roles; the

[46] A stretch and sweep, also known as membrane sweeping, is a technique of labour stimulation.
[47] Cardiotocography (CTG) is a technical means of recording the heartbeat of an unborn baby and uterine contractions during pregnancy. This is typically performed in the third trimester.

role of the couch, in turn, extends to what is commonly described by midwives as 'doing a Down's', namely conducting consultations in which Down's syndrome screening is explained to parents-to-be. Nancy describes the couch role as a '*sort of second hand woman'*. Since midwives rotate their primary job each shift, they take on the role of couch at different periods of time and, according to Nancy, '*it is the couch's duty to do the Down's*'. In the absence of a couch (if they are performing another task), the duty of conducting a screening consultation falls essentially to any midwife who, in Nancy's words, is '*free to do it*'. This lack of formality in the professional delegation of Down's syndrome screening consultations is reflected in the following exchange between Lois and Susan (FAD midwives):

> Camilla, Rita, Lois, and Susan (midwives) are in the office. Camilla and Rita are exchanging stories of today's 'misses'[48]. Two red folders have been waiting in the blue box for ten minutes. Lois turns to Susan:
>
> > Lois: Susan, are you free to do a Down's?
> > Susan: Yes, no problem.
> > Lois: There's another one after as well. I know you're not couch but Lindsay (FAD midwife) is busy doing a scan at the moment. Can you do that one too?
> > Susan: Yes that's fine.

Camilla and Rita overlook the presence of two red folders in order to discuss miscarriage cases. Since Lindsay, the 'couch', is occupied with other tasks, Lois asks Susan if she would '*do a Down's*' despite not being ascribed the couch role. Susan accepts this since she is currently liberated from other tasks, a common trend in FAD where calls of '*who is free to do a Down's?*' and '*there's a Down's in the box if anyone's available*' commonly fill the office air. Dingwall and Murphy (1983: 143) describe how in accident and emergency departments, 'bad patients' can be 'detained until there is sufficient slack for the doctor to attend to them'. Whilst parents-to-be who opt to undertake screening are not ascribed the status of bad patients, they are similarly 'filtered' by midwives under 'a rule of clinical priority'

[48] Parents-to-be who have had a miscarriage in their pregnancy.

(1983: 144). On a number of occasions, clinical tasks such as counselling parents-to-be following a miscarriage, or even discussing miscarriage cases as Camilla and Rita do in the extract above, took priority over conducting Down's syndrome screening consultations. Additionally, structural changes in FAD toward the end of my fieldwork lead to greater uncertainty about who was conducting screening consultations. The following extract illustrates how this ambiguity is played out:

> Eve, Rita, and Camilla (midwives) are completing paperwork in the office. Camilla tells me she is '*way behind on the bookings for my breastfeeding speciality clinic*':
>
> > Camilla: I'm the afternoon couch but I'm going to be very busy. I doubt I'll have the chance to even do the Down's.
>
> After completing paperwork, Camilla leaves the office to attend to another matter. Jennifer (MCA) enters with a red folder:
>
> > Jennifer: I've got a Down's and I have no idea who is doing them at the moment. There's a few just waiting there to be collected.
> > Eve: [Curtly] Well I'm not doing them today.
> > Rita: I have no idea who is supposed to be doing them actually.
>
> Frustrated, Jennifer leaves the room and returns the red folders to the blue box. She leaves to find a midwife who can carry out the consultation. Eva and Rita debate who should perform this task:
>
> > Eve: Camilla is too busy so she can't do them obviously.
> > Rita: Shouldn't it be Toni or Emma (midwives)?
> > Eve: It should be Toni doing them if Camilla's not around. What is she doing otherwise? Where has she been?
>
> Eve and Rita return to their paperwork. The folders are not attended to for another ten minutes.

Camilla's exclamation that she may not have an opportunity '*to even do the Down's*' implies screening consultations are 'done' in a restricted timeframe. In addition, they are unworthy of her time which is better allocated elsewhere by preparing '*[her] breastfeeding speciality clinic*' and performing other duties. In response to Jennifer's irritation about who is '*[doing] a Down's*' (midwives usually collect red folders but MCAs occasionally have to remind them there are folders waiting to be collected), Eve and Rita distance themselves from this role by attributing accountability to Toni and Emma. In Springtown, the notion that screening consultations can be done 'on a whim' is essentially impossible since only one sonographer ever works a shift. However, the following extract between Sophie (SAD sonographer) and Mr and Mrs Brown (parents-to-be) reveals how Down's syndrome screening can be performed on demand:

> Mr and Mrs Brown attend clinic for an early pregnancy scan[49]. During the scan, it transpires that the unborn baby is twelve weeks and five days old, not eleven weeks and six days old as Mrs Brown thought. This means the pregnancy is at enough gestation for Mrs Brown to undertake an NT scan:
>
> > Sophie: If you want, we can do the NT scan now [Mr and Mrs Brown look surprised and seem unsure]. The reason I say this is because if you have to book another appointment, you might be too late to do the NT scan since we need to do it before fourteen weeks really. They both cost the same.
> > Mrs Brown: I think you can just do it now, right [turns to Mr Brown]?
> > Mr Brown: That's fine by me.
> > Sophie: [Sophie starts measuring the NT] That looks lovely and small.
> > Mrs Brown: Is that a good sign then?
> > Sophie: Yes.
> > Mrs Brown: What about my bloods then?

[49] An early pregnancy scan is an ultrasound scan performed between seven and eleven weeks of a pregnancy to confirm the number of unborn babies, the presence of a heartbeat, the size of a sac/unborn baby, and the possible presence of internal bleeding.

Sophie: We can do them today if you want. I'm just going to take the measurements because baby is lying perfectly for it so it makes sense to do it now [Sophie measures the NT which is 1.52mm]. That's lovely and small. That means it will come back as a lower-risk [for Down's syndrome] based on the scan alone. Obviously we match that with the bloods and stuff though and this gives you a result. But based on the scan, it's good news [Mr and Mrs Brown smile]. You've got an active baby in there.

Mr Brown: At least one of them is!

Mrs Brown: Thanks love!

Since Mrs Brown calculated her pregnancy dates incorrectly, Sophie offers her and Mr Brown the opportunity to screen for Down's syndrome instead of having the consented-to early pregnancy scan. Sophie claims this is possible not only because the week of gestation is appropriate for the NT scan, but also because both procedures '*cost the same*' amount of money. After consenting to the NT scan, Mr and Mrs Brown are reassured they have received a lower-risk result owing to a '*lovely and small*' measurement, the former teasing the latter towards the end of the scan about her lethargy during the pregnancy (the significance of humour is explored further in chapter six). Here, performing a procedure without delay and without parents-to-be necessarily receiving any information about it unwittingly accomplishes the downgrading of screening and the reduction of its value as a medical procedure. It is hard to imagine (and I did not observe) a more invasive or complicated procedure would merit such casualness about its execution.

Training practices

This downgrading of Down's syndrome screening is further reflected by how midwives and sonographers are taught to conduct this care, namely the product of lay pedagogy rather than structured and formal training. Knowledge production, in this instance, is tacit, embodied, and passed on to from professionals to untrained professionals (Garforth and Kerr 2010). This corresponds to what Gail (FAD midwife), during one conversation, playfully describes as '*see one do one*'. This occurrence suggests an observation of a solitary consultation qualifies a midwife

for performing this role independently once a similar case presents itself in clinic. Such occasions become vocabulary lessons in which professionals gain knowledge of the appropriate vernacular for these consultations.

However, the little attention paid to training professionals in Down's syndrome screening consultations downgrades its importance and highlights how training is not a priority in this area (Cleary-Goldman et al. 2006; Sandall et al. 2001). In addition, only a few FAD midwives have received training in delivering a higher-risk result for Down's syndrome yet they are ascribed primary responsibility for this care. They are frequently eager to attend consultations in which parents-to-be receive a higher-risk for Down's syndrome with the intention of learning how to perform this transaction. The following extract illustrates a similar occurrence:

> Terri, Susan, Maggie, and Rita (midwives) are in the office. Angela (midwife) enters:
>
> > Angela: We've got a higher-risk [for Down's syndrome] in today. Who can do a higher-risk?
> > Susan: I've never done one but I'm happy to do it.
> > Angela: OK. Well is it Terri or Rita who have done the higher-risk before?
> > Rita: I can do it [Rita collects the folder from Angela].
> > Maggie: Can I sit in on the phone call Rita? I've never done one before.
> > Susan: Me too.
> > Rita: Bloody hell, I'll have an audience [laughs]. Yes that's fine, girls. The risk factor is 1:17 so the woman shouldn't be too surprised anyway because of her age. I'll call her in twenty minutes as I have some other work to do and the woman might not answer until after nine [a.m.] anyway.

Both Susan and Rita volunteer to '*do a higher-risk*', a consultation in which parents-to-be are told they have received a higher-risk result for Down's syndrome. The parents-to-be have to be notified of this appointment by telephone, hence Maggie's request to '*sit in on the phone call*' since she has not previously been privy to this.

Here, higher-risk consultations seem to represent a task which is highly valued, a duty contrasting with the treatment of everyday, routine screening consultations. Simultaneously, with few FAD midwives receiving training in delivering a higher-risk result and little resources being dedicated to this practice, Down's syndrome screening is subsequently accomplished as a downgraded practice. The following interaction between Sophie (SAD sonographer) and Isobel (SAD nurse) after an NT scan underscores one of the major issues this lack of training can provoke:

> Isobel and I are in the bloods room. Mr and Mrs Sutton (parents-to-be) leave the ultrasound room. Mrs Sutton is crying and Mr Sutton looks upset. They leave the clinic:
>
> > Sophie: I had a bad feeling about that one. As soon as I saw it on the screen, I thought there was a chance she had miscarried and she had.
> > Isobel: Poor girl.
> > Sophie: It's really bad for the girl as it's Friday and now she's got the whole weekend knowing this news before she can talk to anyone. I'm not qualified to discuss this with her and her partner and neither is Isobel.
> > Isobel: No.
> > Sophie: This is why it's problematic to have NT scans on the Friday. I feel bad with miscarriages because we just give them a form and send them on their way.

After the Suttons learn of a miscarriage, Sophie bemoans the '*problematic*' nature of organising NT scans before a weekend, resulting in her '*just [giving] them a form and [sending] them on their way*'. Here, Sophie is 'stepping out of a routine', implying that the 'correctness of the action needs to be explicitly renegotiated' (Berg 1992: 171). The legitimacy granted with routine articulations is absent, meaning Sophie has to account for her non-routine conduct (of allowing parents-to-be to leave the clinic without anyone '*[discussing] this with [Mrs Sutton]*'). Sophie further criticises the organisation of care since she is unqualified to '*discuss*' the miscarriage with Mr and Mrs Sutton yet she has been assigned the duty of carrying out NT scans for parents-to-be. The demotion of Down's syndrome screening down

the medical hierarchy, a hierarchy produced and reproduced precisely by these practices, to midwives and sonographers triggers profound (negative) affects for parents-to-be and further downgrades the importance and regard of the procedure in antenatal care.

The constituting of classes

Such practices correspond to what Latimer (1999: 179) calls the 'constituting of classes'. Latimer identifies how older people in acute medicine are not interpreted as appropriate medical material. Patients are categorised into a hierarchy of values constituting a moral order. Here, the complaints of older patients, positioned at the bottom of this moral order, such as breathlessness and chest pain are refigured from the medical into the social, that is, into discourse of the personal and psycho-social (Latimer 1997, 1999). This reclassification and (re)production of hierarchies of value means patients are discharged or made 'disposable' (Latimer 1999: 176) since they do not belong to the technical terrain of medicine. Disposal, for Berg (1992) and Latimer (1999), refers to how professionals engage in a mode of ordering which helps them keep their world in order and square accounts to themselves and others. According to Latimer (1999: 180), shifting a patient's identity does not mean disposing of people but rather part of their responsibility to categories of patients who they must, to some extent, 'give up' so they can care for those with whom they feel compelled to work. This constituting of classes, in turn, is endlessly accomplished. For Latimer (2008b: 164), it is 'what helps keep the medical domain in order'.

Such 'moves' (Latimer 1999: 180) are also evident in Freymarsh and Springtown. In the extracts above, it is clear Down's syndrome screening is constituted as a trivial procedure which can be performed on demand and as a non-prioritised task in the hierarchy of clinical value (shown not least by its relegation down the professional pecking order). It is '*easy stuff*' which '*clogs up*' the precious time of consultants since parents-to-be undertaking Down's syndrome screening, at least in the early stages, are yet to attain the status of clinical interest (Bosk 1992). According to Strong (1979: 225), doctors 'tend to prefer acute medicine' since they are 'trained to cure' and derive satisfaction from 'the speedy resolution of organic

problems'. Since Down's syndrome screening consultations do not promise this feat, their 'special skills' are reallocated to contexts in which they can be put to 'much greater use' (1979: 225). Although falling under the remit of obstetric care, it is relegated by consultants to midwives, thus establishing their territory and protecting the purity of the clinical space by consigning the polluting work of screening down the division(s) of labour. Screening consultations, as such, become downgraded as non-technical tasks which represent 'trivia' (Dingwall and Murphy 1983: 144) or 'matter out of place' (Douglas 1966: 36) in obstetric care unless diagnostic testing (amniocentesis or CVS) is required, namely, when *screening becomes diagnostic*.

'We do normality, we don't do pathology'

In the first part of this chapter, I identified how screening for Down's syndrome is downgraded through consultations, polluting the purity of the clinical space, being relegated to midwives and sonographers. In what follows, I describe how it can be further downgraded through how professionals classify this care and what such modes of organising, in turn, accomplish. In Freymarsh and Springtown, midwives and sonographers regularly describe Down's syndrome screening as a routine and expected component of a pregnancy trajectory. Speaking of her impending exit from FMD[50] during one conversation, Elena (FMD head midwife) claims:

> There's just more misery walking through the door every day. I've had enough. I'll go back to FAD to do the ordinary stuff. It'll be nice to go back to that as I've done it all before.

Elena claims her imminent departure from FMD is due to the increasing '*misery walking through the door*'. Relocating to the FAD, for Elena, represents a return to the '*ordinary stuff*'. This classification of '*ordinary stuff*' parallels Dr Karman's (FMD consultant) distinction during one conversation between the '*routine stuff*' of the FAD and the '*weird stuff*' of FMD, the latter referring to treating and managing

[50] As a reminder, FMD is a referral service. In the context of Down's syndrome screening, parents-to-be will only be referred to FMD from FAD if they decide to pursue diagnostic testing. This is where CVS or an amniocentesis is performed, where parents-to-be will be counselled about a result, and where parents-to-be can have a termination of pregnancy.

certain defects in unborn babies. In Freymarsh and Springtown, Down's syndrome screening is categorised as routine and ordinary stuff, a mundane component of antenatal life. For Berg (1992: 170), a routine refers to a set of actions 'repetitively carried out with a certain automatism' without explicitly reflecting on or legitimating the actions involved. In the medical problem-solving process, 'routines are of major importance' (1992: 170). The routine of Down's syndrome screening, by interconnecting with the routines of other tasks in the respective institution (creating organisational routines), can be classified as what Nancy (FAD midwife)[51], in the following extract, defines as '*normality*':

> Rosie (MCA) and Nancy are in the office. Nancy is on the telephone to Mrs Earl who is part of Nancy's specialist clinic for mothers-to-be with twin pregnancies. The conversation ends. Nancy turns to me:
>
> > Nancy: [Mrs Earl] is having a real rough time of it at the moment. Her feet, legs, and thighs have swollen massively. She's only a petit lady so it looks terrible. Her skin around there is rock hard too. I just hope it isn't anything serious like preeclampsia[52]. I recommended she should see someone. I said to her I'm a midwife, I'm not a doctor. But I would feel awful if I didn't say anything and then something happened to her or the baby. It doesn't sound right, does it? It does happen to women but at what point does it become pathological, you know? We do normality, we don't do pathology. Doctors do all the oedema[53], preeclampsia, and stuff. I'm not medical but that worries me, you know, is it physiological or pathological? Can you imagine what would happen if I didn't say anything?
> >
> > Rosie: You'd get in a lot of trouble!

[51] Nancy is also an FMD midwife but I observed her most frequently in FAD.
[52] Preeclampsia is a condition characterised by high blood pressure and a large amount of protein in the urine of a pregnant woman. It affects up to 10% of pregnancies and severe cases develop in 1-2% of pregnancies. Although most cases of preeclampsia cause no problems and improve soon after the baby is delivered, there is a risk of serious complications affecting the mother and her baby.
[53] Oedema is the medical term for fluid retention in the body.

> Nancy: That's my official licence gone. And I couldn't live with myself if something happened. Some of the women we have are a bit precious and demand our care but at the end of the day, you understand it because they want their babies to be healthy and who wouldn't?

After finishing her conversation with Mrs Earl, Nancy describes her symptoms and refers Mrs Earl onwards in hope '*it isn't anything serious like preeclampsia*'. Unsure when Mrs Earl's problems '*become pathological*', Nancy downplays her professional competence by deferring authority to doctors who '*do all the oedema, preeclampsia, and stuff*'. Importantly, Nancy claims '*we do normality, we don't do pathology*'; distancing herself from '*medical*' and '*physiological or pathological*' matters, she worries a failure to '*say anything*' would constitute both an emotional burden and potential loss of employment. Since Mrs Earl does not integrate into the category of normality, she is referred to a doctor.

However, since Down's syndrome screening is performed by midwives, it is not classified as pathological or as meriting the intervention of doctors. Positioned as an unproblematic and natural enterprise, screening consultations fall to midwives dealing with '*normality*', that is, to borrow Dr Karman's term, the '*routine stuff*'. This framing of Down's syndrome as a routine practice and non-technical matter often manifests itself in screening consultations. Toni (FAD midwife), for instance, describes the consultation to parents-to-be as '*just a chat*', whilst the likes of Tara (FAD midwife) frequently describe the procedure to parents-to-be as a '*simple blood test*'. The following fieldnotes are taken from a consultation between Lois (FAD midwife) and Mrs Patel (mother-to-be):

> Lois: Today we're going to chat about the Down' syndrome test. Have you had Down's syndrome screening before?
> Mrs Patel: Yes.
> Lois: Do you understand it then?
> Mrs Patel: I just had it last time, I didn't know anything about it. I wasn't told I was having it and I was just told that nothing is good news.

Lois: OK. So do you know much about Down's syndrome and affects it has?

Mrs Patel: Yes.

Lois: Well this is a blood test which doesn't affect the baby. You're provided with a lower-risk or higher-risk result. A lower-risk result means no further testing but it doesn't mean the baby definitely doesn't have Down's syndrome. The screen has a 70% detection rate and if you're lower-risk, you receive a letter saying this within ten working days. A lower-risk result can be 1 in 200 or something like 1 in 1000. The cut off is 1 in 150. So anything above that is a higher-risk and you'd get that within five working days so it's done quite quickly. You'd be offered an appointment within twenty-four hours and we'd offer you an amniocentesis where we check the fluid around the baby. It has a miscarriage rate though of 1 in 100. But if you do have a higher-risk result, we invite you in and we have a good chat about what you want to do about it. Have you thought about what you would do? Would you want to know whether you're a lower-risk or higher-risk?

Mrs Patel: Yes I want to know.

Lois: OK.

Lois fills in Mrs Patel's medical record. Lois leads Mrs Patel to another room for the quadruple screen.

After Mrs Patel accounts for her lack of knowledge regarding Down's syndrome screening ('*I just had it last time, I didn't know anything about it*'), Lois accepts Mrs Patel's claim that she knows about the condition itself (I return to knowledge of the condition in chapter 7) and subsequently provides information constituting the staple diet of Down's syndrome screening consultations: its non-invasiveness, the production of a lower-risk or higher-risk result, the source and timeframe of news, the prospect of diagnostic testing, confirming that parents-to-be want to undertake screening, and the accuracy of the procedure (admittedly the latter point is rarer). I suggest defining screening consultations as '*simple*' or as '*a chat*' reflects how midwives and sonographers constitute Down's syndrome screening in everyday

clinical life and how this downgrades it as an unproblematic practice. As a *simple* procedure, its value is downgraded. This can explain why parents-to-be consent to screening, naturalising and normalising what is supposed to be an *opt-in* rather than *opt-out* practice (Tsouroufli 2011).

The routinisation of Down's syndrome screening is reflected in the material and spatial organisation of antenatal care. Earlier, I referred to how structural changes in FAD caused confusion regarding who carried out screening consultations. This confusion also translated to the location of such consultations. When asked who carries out screening consultations (and where) following such changes, for instance, Camilla (FAD midwife) claims:

> We haven't really figured that one yet! The couch starts doing Down's, then they come over to clinic [with doctors], and then they do some clinic stuff [with doctors]. I don't think any of us know about it. It changes every week and we just end up doing them in whatever room we can get.

Camilla identifies how the couch, namely an allocated midwife conducting specific duties (including screening consultations), initially performs consultations until the classification of '*clinic stuff*' takes priority. In contrast, Down's syndrome screening is not allocated, at least at this moment, a permanent 'home' for carrying out consultations nor is repairing this seen as a priority. This lack of prioritisation is reflected in FAD by folders, on many occasions, resting in the blue box whilst other clinical tasks took priority. The blue box and red folders, in such instances, remain symbolic and are mobilised in ordering who or what is deserving of primary attention (White et al. 2012). Here, the hospital functions as a space of prioritisation. The following fieldnotes were taken during a morning at Freymarsh:

> I enter the office. Lindsay, Lois, and Rita (midwives) are busy at their desks. Lois is today's couch:
>
> Lois and Lindsay: Good morning!

Gareth: Morning! How are you both doing?

Lindsay: All good.

Lois: Good thanks. You?

Gareth: Good thanks. So I was told yesterday you've got ten consultations for Down's syndrome screening today, Lois. Is that right?

Lois: [Looking surprised] Really? I'll check but I haven't received any yet.

Lois leaves the office and returns from reception smiling with four folders in her hand. It is 09:15 and there were appointments at 08:00, 08:10, 08:20, 08:30, 08:40, 08:50, 09:00, 09:10, 09:30 and 10:00. It later transpires two consultations were carried out by another midwife. Lois leaves the office to collect the first parent-to-be.

It is in such situations that Down's syndrome screening becomes disposed of as not a priority. It is constituted as a trivial duty performed by a couch or the unattached, with other tasks becoming prioritised in the organisation of care. In addition, consultations are performed, as Camilla explains to me during one conversation, '*in whatever room we can get*'. The importance of material objects, or 'props' (Goffman 1959), in healthcare work has been explored elsewhere (Hillman 2007; Latimer 2004; Sandelowski 2003; White et al. 2012). Such casual attention to the significance of materials and space in the delivery of care is reflected during one consultation between Toni (FAD midwife) and Mr and Mrs Hayes (parents-to-be):

Mr and Mrs Hayes enter the room and sit on the chairs. Toni follows them into the room. The door is left propped open by a bin:

Toni: So are you OK?

Mrs Hayes: Yes but I've seen so many different midwives. I'm so confused.

Toni: Well today you're seeing me for your Down's syndrome screening. So you know this does not provide a yes or no answer?

Mrs Hayes: It's just the blood test, yes?

Toni: Yes. Your result has to be a 1 in 150 result or less to be considered higher-risk and so be offered an amniocentesis.

Mrs Hayes: So the figure has to be 1:151 or above for me to get away with it and 1:149 or less to not get away with it?

Toni: Yes.

Mrs Hayes: So a higher-risk can be a 1 in 150 or 1 in 2 then?

Toni: Yes. If you're higher-risk, we contact you and invite you into clinic. If you're lower-risk, we send you a letter telling you this.

Mr Hayes: So the letter is for good things and the phone call is for bad things?

Toni: Yes. If you're higher-risk, we call you in 3-4 working days but if they don't hear anything, this is a good thing.

Toni takes some details about future antenatal bookings and asks Mr and Mrs Hayes if they have more questions. Toni leads Mr and Mrs Hayes to the bloods room for their quadruple test.

Mrs Hayes conveys her confusion at meeting a multitude of midwives during her pregnancy care. Toni notifies Mrs Hayes she will be screened for Down's syndrome today, later providing information on the outcome of the procedure and the possibility of diagnostic testing should a higher-risk result be established. Mr and Mrs Hayes often crave and distinguish binaries in their accounts, with risk factors amounting to '*[getting]*' or '*not [getting] away with it*' and contact being established in the case of either '*good things*' or '*bad things*'. Whilst Toni does not seek reassurance from Mr and Mrs Hayes that they wish to undertake screening, an action encouraged by many midwives at Freymarsh (i.e. the notion that parents-to-be can opt out of the procedure should be reiterated), the importance of the door being propped open during the consultation highlights the informality and routine-ness of screening consultations.

Importantly, this shifts in FMD. Here, much more attention is paid to 'performative architecture' (Stephens et al. 2008). Developing Thrift's (2006) concept of the 'performative building', Stephens et al. describe how the physical space of a stem

cell bank becomes central to its performance as a sterile and scientifically-legitimate institution. Ritualistic treatments of technologies and geographies act 'as accrediting artefacts of the Bank's legitimacy within a diversity of social networks and affiliations' (Stephens et al. 2008: 89). In FMD, the space is similarly inscribed with symbolic meaning by professionals. Consider the following fieldnotes from a consultation between Dr Karman (FMD consultant) and Mr and Mrs Parnell (parents-to-be):

> I follow Dr Karman into the room. As I enter, Elena (FMD head midwife) is sitting with Mrs Parnell. Dr Karman asks me to close the curtain. Mr and Mrs Parnell's unborn baby has been previously diagnosed with a heart defect. Dr Karman tells Mr and Mrs Parnell whilst the defect is '*manageable*', the unborn baby requires surgery after childbirth and delivery at another hospital better-equipped to handle the case is recommended. Elena leaves the consultation and ensures the curtain remains closed.

Dr Karman similarly reflects on spatial organisation in accomplishing care during a conversation we have in the early stages of my fieldwork:

> Dr Karman leads me to a large room, telling me it is dedicated to performing an amniocentesis or CVS as well as other procedures. Dr Karman explains parents-to-be are later invited back to FMD should a diagnosis be established and then shows me the room where this news is delivered. The room is large containing a desk, three chairs, and a bed:
>
> > Dr Karman: The room for delivering the news is much bigger than we used to use. It was the size of a cupboard. Now when you're delivering news of this nature, that's inappropriate isn't it?

In the first extract, Dr Karman and Elena are vigilant in ensuring the curtain remains closed during the consultation. In her study of a maternity unit, Burden (1998: 15) describes how curtains are used to maintain or preserve privacy, with patients positioning them as a form of 'signalling' to both peers and professionals

in an attempt to seek information or support. In FMD, the use of curtains corresponds to delivering appropriate care, that is, of ensuring it remains closed in the consultation involving Mr and Mrs Parnell. In the second extract, Dr Karman highlights the inappropriateness of a room '*the size of a cupboard*' when '*you're delivering news of this nature*'. The performative architecture of Freymarsh and Springtown involves technologies not only demarcating divisions of labour (e.g. FAD maternity care assistants deliver the folders to the blue box to be collected by FAD midwives) but also signifying privacy and the constituting of classes in the clinic.

In FMD, FAD, and SAD, care becomes a social and material achievement, with the materiality of the space often being conducive to the nature of the consultation (González-Santos 2011). For Down's syndrome screening, whilst doors were not always propped open during consultations, such an incident is indicative of its downgrading in the clinic since little attention is afforded to the environment in which consultations take place. The triviality of Down's syndrome screening can also be reflected by my relatively unproblematic access to consultations. Without introduction but with consent, midwives/sonographers and parents-to-be always accepted my presence without objection. In contrast, procedures which were categorised as '*serious*' (such as feticides) or '*invasive*' (such as amniocentesis or trans-vaginal ultrasound scanning) required a more active engagement with issues surrounding my entry. This observation shows how Down's syndrome screening is downgraded as a routine and unproblematic procedure for which I am bestowed entry. Indeed, Down's syndrome screening is constituted as a devalued and downgraded task. Positioned lowly in a hierarchy of clinical priorities (Latimer 1997) and classified as a *chat* or *simple test*, it is upheld as a routine component of antenatal care. Tsouroufli (2011) similarly concludes that the fast processing of women, promotion of screening as a safe test, and professionals' expectations that parents-to-be would opt for the procedure routinises the offer of screening.

'Hands-on midwifery work'

I have described how midwives and sonographers do not prioritise Down's syndrome screening in their daily work. In the clinic, patients are subjected to

categorisation processes, an (unofficial) taxonomy commonly corresponding to perceived moral fitness demarcating the appropriateness of their presence (Becker 1993; Berg 1997; Hillman 2007; Jeffery 1979; Latimer 1999; Dingwall and Murphy 1983; White et al. 2012). Whilst moral and critical appraisals of patients in FAD and SAD are rarely observed, certain tasks are preferred and thus prioritised. This highlights another way in which the organisation of antenatal care downgrades Down's syndrome screening, namely, by routine screening consultations being cast as mundane and tedious duties not allowing professionals to fulfil integral components of their identity-work. Classifications of desired and undesired roles are highlighted during a conversation with Lisa (SAD sonographer) about her imminent shift at Freymarsh[54]:

> Lisa: I've got my kidneys, gall bladders, and livers now. I hate them. I spent the morning doing prenatal stuff but we change it up so I'll be stuck doing them now.
> Gareth: So you don't like them?
> Lisa: You just don't enjoy them as much. It's not pregnancy stuff. It's boring, you know? Instead I'm going to be doing all of the yuk stuff [laughs].

Lisa complains about carrying out consultations which involves '*all of the yuk stuff*', translating to patients who have problems with their kidneys, gall bladder, or liver. She prefers the '*pregnancy stuff*', a role she defines as a more enjoyable component of her daily routine. Similarly, we can return to Lois' (FAD midwife) distinction cited earlier in the thesis between '*hands-on midwifery work*' against tasks which she says do not reflect '*part of what is a midwife's job*'. So what work constitutes *hands-on midwifery work* compared to tasks which are not *part of what is a midwife's job*? Whilst Lois includes the task of '*discuss[ing] things with women*' as normal midwifery, small acts of separation – often 'buried in habit' (Douglas 1966: 9) – are made within this more condensed network of professional tasks. Down's syndrome screening, in turn, often falls short of being *hands-on midwifery work*.

[54] Lisa works in both SAD and the Freymarsh radiology department. Our conversation follows an interview which was organised during her lunch break.

Consider how Lindsay (FAD midwife) describes Down's syndrome screening consultations during an interview:

> [Consultations] are repetitive. [...] I wouldn't say it was boring but it does get a bit repetitive. You're just providing information.

Similar to Lindsay, other midwives and sonographers have described Down's syndrome screening consultations as dull and routine, a pedestrian component of their working practice. For Lindsay and other professionals, boredom stems from the repetitive nature of consultations since their care is limited to providing factually correct medical information (Bosk 1992). During a conversation, Esther (SAD sonographer) describes the discrepancies potentially emerging since Down's syndrome screening represents a routine practice:

> I get bored of saying the same thing over and over. You have to try and make it sound different and interesting every time. It's like a performance. [...] The difficulty is sometimes you're saying the same thing over and over again. Sometimes you can't remember whether you've said certain things or not, so it absolutely is a performance. It does become routine. And you've got be very careful that it doesn't come across to the women that you're scanning which is why I couldn't do it day in, day out.

Esther claims she is '*bored of saying the same thing over and over*', identifying the professionals' labour in ensuring the '*performance*' of a '*routine*' procedure is never fully revealed. The tedium cited by Esther is reflected in the following fieldnotes taken from a consultation between Jackie (FAD midwife) and Mr and Mrs Wotton (parents-to-be):

> Jackie: Let me weigh you first [Mrs Wotton is weighed]. Are you here for the Down's syndrome screening?
> Mrs Wotton: Yes.

Jackie: Do you know that you're not going to find anything from this test? It is only going to tell you whether your baby has a high or low chance of Down's syndrome.
Mrs Wotton: Yes.
Mr Wotton: Yes that's all in the information anyway.
Jackie: OK. Amniocentesis will be offered if you come back as a higher-risk. The cut off here is 1:150 which means if you're 1:150 or higher, you're a higher chance.
Mrs Wotton: So if it's higher than 1 in 150, that means I have a high chance?
Jackie: Yes. With the amniocentesis, a needle is put in the stomach and this takes out some fluid which is sent to the labs and this can say whether your baby is affected. Do you have any more questions?
Mr and Mrs Wotton: No.

Jackie fills in some details on the medical record. She takes Mrs Wotton to the bloods room to have the quadruple screen. I return to the office. As I write up notes, Jackie enters the office. Angela (midwife) is working at another desk:

Jackie: [Turning to me] You can sit in with me on more if you want. You'll get bored of hearing the same thing over and over eventually. It gets repetitive and boring after a while. The brain shuts down and the mouth starts playing when doing Down's syndrome screening!
Angela: Yes [laughs]!

The '*repetitive and boring*' nature of screening consultations, Jackie quips, gives rise to '*the brain [shutting] down and the mouth [starting] playing*'. A similar sentiment is expressed by the admin staff at Springtown who describe themselves as '*parrots*' and '*like recorded messages*' (Hannah, SAD admin staff), signifying the rudimentary and anodyne nature of communicating information around Down's syndrome screening.

Professional identity-work

It seems the reason why Down's syndrome screening is constructed as boring and routine is because it is not part of the highly valued hands-on midwifery work which becomes important for performing a meaningful professional identity. This is particularly vital for FAD midwives since the entirety of midwifery, according to Elena (FMD head midwife), constitutes '*a Cinderella of the whole antenatal service*' since '*the big guns are up on the delivery suite*'. Elena highlights how some aspects of antenatal care are professionally impure and regularly promise a low intra-professional status. Some midwives claimed they '*bear the brunt of complaints*' (Francine, FMD head midwife) and doctors do not receive the same (negative) treatment which she and other midwives experience, attributing this to '*the doctor midwife psychology*'. During one exchange, Amy (FAD midwife) suggests '*other departments don't actually get that midwifery is a really important part of antenatal care*' whilst Rita (FAD midwife), after I asked her during one conversation how her day was progressing, answered 'u*nderstaffed, underpaid, and working with new systems that no-one knows how to follow!*'

Although Rita's complaint was light-hearted, it reflects other complaints made by midwives and sonographers. Several professionals, though particularly midwives positioned arguably as 'gatekeepers without turf' (Bosk 1992: 72) and part of an unwitting mop-up service, often distinguish themselves as occupying an unsteady or at least undervalued role in antenatal care. In his study of genetic counsellors, Bosk (1992) suggests such professionals are fully aware they are a mop-up service and acknowledge the tasks which fall within their demoted role. In contrast, FAD midwives and SAD sonographers do not seem to openly identify themselves as a mop-up service. Nonetheless, constructing and retaining a meaningful professional identity is of paramount importance since midwives commonly view their role as undervalued. As such, hands-on midwifery work provides crucial material for this construction. Asked about her job roles, Susan (FAD midwife) explains:

> You do a lot of screening, a lot of deciding if people are higher-risk or lower-risk pregnancies, you do speciality clinics which are really interesting like diabetics, anti-D clinic, and rheumatology clinics. There

> are loads of positives working in FAD. [...] I'm not a fan of looking at blood results, checking them off, and sending out letters. I feel like it's a waste of a midwife's role. But I like doing my haematology clinic because I get to know my women as well. Because they're such high-risk women, we work quite a lot together and if they get any problems, they can call me.

Susan describes the '*positives*' of working in FAD together with the less desirable roles of '*looking at blood results, checking them off, and sending out letters*'. She defines the latter tasks as '*a waste of a midwife's role*' whilst conveying the enjoyment of her own haematology speciality clinic. On a number of occasions, FAD midwives claimed ownership over their own '*speciality clinics*' which are valued as enjoyable tasks appropriate for identity-work. Susan's enjoyment stems from '*[getting] to know my women*', claiming ownership over '*high-risk women*' who she is able to establish a relationship with. Lindsay (FAD midwife) similarly identifies the opportunity to help parents-to-be and '*sort out their problems*' as one key component in formulating a meaningful identity. Camilla (FAD midwife) likewise claims she likes speciality clinics since '*you get to know women and their case*'. During one conversation, Francine (FMD head midwife) describes how she would not want to work in FAD since her role in FMD involves '*more rewarding work*':

> We all have our own areas of interest. I don't like kidneys. They don't interest me very much. But I like everything else. They're a bit, it sounds awful, but a bit common and mundane. I like the cases that you can actually feel that you're offering the families support and advice so they can get some benefit, however hard the decision they're making is. Whether it is to continue or not to continue [a pregnancy], they feel they've got someone to turn to. It's a really nice feeling to be able to do that. It is very satisfying which I don't really get as much in normal midwifery because if it's normal, a lot of women just go through pregnancies and don't really need extra support. I like to feel more useful really. [...] Not to sound morbid or sick but I almost prefer it when there

> are problems so we can help them rather than when the baby is normal and healthy and we're all forgotten about.

Francine suggests professionals '*have our own areas of interest*', claiming kidneys are '*a bit common and mundane*' whilst placing value on care which offers embodied opportunities of '*[feeling] more useful*' and '*offering the families support and advice*'. Such opportunities, for Francine, are not accessible in '*normal midwifery*'. This shows how professionals embrace tasks providing them with an opportunity to help and work in a manner they imagined prior to qualification. During an interview, Sophie (SAD sonographer) similarly describes her preference for undertaking '*tough cases*' which offer a chance to '*reassure*' parents-to-be if '*things are not going to plan*'. Similar to Sophie's classification of the '*bad things*', roughly translating to tasks tendering a space in which professionals actively assist help parents-to-be, Gail (FAD midwife) describes cases in which '*there is not a good outcome*' as '*interesting*':

> These make the work a little bit more interesting if you like than where you've got the run of the mill stuff. When you've got some things a little bit more out of the ordinary, it can make it a little bit more interesting, can't it? We all need variety and if you're doing the same things day after day, you can get a little bored or it can get a little samey.

Gail crafts a distinction between the '*interesting*' work which offers '*variety*' and the '*run of the mill stuff*' which breeds boredom and is '*a little samey*'. Such tasks often translate to care professionals define as '*emotional*' (Elena, FMD midwife). The same professionals reflect on the emotionality of their work, exerting great efforts to sustain a distinction between *home-life* and *work-life*. When asked about her job during an interview, Elena (FMD head midwife) explains:

> It is a very emotional job. I'm not saying you don't get involved with patients but when you're delivering bad news to someone, there's another ten women out there and you've got to do exactly the same thing with them. The unthinkable is a reality here and it relates to a lot of stuff

> that happens in [FMD]. [...] It's challenging for you and it's challenging for the parents. [...] I always make a point of not wearing my uniform when I leave for home and it was a little change I did. Because I used to do take the emotions of the work home but then, I did that sort of very physical thing of taking the uniform off and putting my clothes on before going home. Because a lot of it is protecting yourself as well as sort of giving the information. [...] There are still times that you still get stuck up on some patients but I think we're all human. It's natural.

In an environment in which, according to Elena, '*the unthinkable becomes a reality*', professionals must adopt tactics to manage this '*emotional job*'. Elena suggests her uniform sustains a physical barrier between work life and home life. Many other professionals say they had self-protecting strategies for preserving emotional and moral distance from their work. Gail (FAD midwife), for instance, suggests developing '*a dark or black sense of humour*' as a '*way of coping with things*'. Whilst Elena's role is in FMD, a department in which '*bad news happens*' (Francine, FMD head midwife), such contentions can be extended to include FAD midwives and SAD sonographers. Professionals claim that in order to avoid undermining the principles of professionalism, they have to '*be detached from patients in some respects*' (Rita, FAD midwife) and '*draw the line and still be a professional*' (Martha, FAD midwife) even if it is '*hard to switch off*' (Susan, FAD midwife).

The 'emotional labour' (Hochschild 1983) involved for professionals in healthcare institutions (Kerr 2013; Larson and Yao 2005) and midwifery specifically (Deery 2009; Hunter 2004) has been reported elsewhere. However, by considering what tasks professionals define as 'emotional' accomplish, I show how they are highly valued by midwives and sonographers and considered as an important component of becoming a competent professional. Duties which afford professionals an opportunity to invest in, help, and '*get to know*' parents-to-be are often those preferred and prioritised in the clinic. Down's syndrome screening does not tender this prospect. Professionals fail to build a relationship with parents-to-be during screening consultations because the latter commonly attend the clinic only on one occasion, meaning they rarely have a hospital career, and because consultations

are frequently conducted in a short timeframe. Others have identified the conflict between the time professionals have to explain Down's syndrome screening and the time required to fully discuss the procedure (Sooben 2010; Williams et al. 2002a). During a conversation, Esther (SAD sonographer) describes the difficulty of conveying empathy within a restricted encounter:

> You can't show empathy during some procedures because you've only got ten minutes to do the scan and people get annoyed because when other people have problems which take up time and the clinic's run over time, how can you possibly give compassionate care if you're constantly thinking my time with patients is going to overrun?

In FAD and SAD, the timeslots allocated for quadruple screens and NT scans are ten minutes and twenty minutes respectively. Consultations rarely extend beyond this period of time yet their premature conclusion is much more common. In FAD, more time is dedicated, for example, to counselling parents-to-be who experience a miscarriage in the current pregnancy and to managing parents-to-be attending speciality clinics. In SAD, more time is dedicated, as another example, to performing five-view cardiac ultrasound scans rather than NT scans. Within restricted encounters, the capacity to '*show empathy*' (Esther, SAD sonographer) and invest in parents-to-be, that is, to establish '*patient contact*' (Amy, FAD midwife) and '*sort out their problems* (Lindsay, FAD midwife) is not possible, tasks which are enacted by professionals as important to their working knowledge and self-understanding. As a time-restricted and, in assuming the discourse of professionals, *unemotional* task, Down's syndrome screening is thus downgraded in the clinic.

Summary

In this chapter, I captured how screening for Down's syndrome is organised as a routine practice and how it is downgraded in many ways which accomplishes and re-accomplishes identities and hierarchies (mostly between the separate tasks in antenatal care and between foetal medicine and midwifery). Its downgrading is accomplished in three ways. First, Down's syndrome screening is relegated from

consultants to midwives and sonographers not always officially trained in the practice. In developing Latimer's (1999) 'constituting of classes', I revealed how parents-to-be are categorised into a hierarchy of values constituting order in the clinic. Since Down's syndrome screening pollutes consultants' technical world, it is reclassified as belonging to the realm of midwives and sonographers who 'mop-up' (Bosk 1992) the mess. However, my arguments go beyond Bosk's (1992) work. Bosk shows how professionals have work shifted onto them because of a pre-existing medical hierarchy; doctors (highly-esteemed) relegate tasks to genetic counsellors (lowly-esteemed). However, I captured how this medical hierarchy is accomplished and re-accomplished around the classification and subsequent non-prioritisation of Down's syndrome screening. Categorising screening, at least initially, as a nontechnical matter (and so not belonging to obstetrics) protects the purity and value of obstetric care. Through the constituting of classes, thus, Down's syndrome screening is a resource for reproducing divisions between professionals and their tasks.

Second, Down's syndrome screening is downgraded through being constructed as a simple and routine component of antenatal care accomplished in both social processes (descriptions of being a 'simple test') and cultural materials (FAD doors being propped open and FMD curtains being closed). FAD midwives particularly highlight how their work is concerned with 'normal' rather than 'pathological' (or technical) care. However, so much of midwives' daily routines involve surveillance and monitoring mothers-to-be such as taking bloods and performing ultrasound scans, contributing to creating a pathological pregnancy. This relation between everyday midwifery work and Down's syndrome screening shows how the latter is entangled in 'motility', referring to how people or things are moved in different spaces of discourse which invokes specific affects by altering the very essence of such entities (Latimer 2013; Latimer and Munro 2006; Munro 2001). Professionals shift the 'world' (Latimer 1999; Munro 1999) of screening through interactions whereby they switch discursive domains. Rather than interpreting this conduct as deviant or contradictory, I identify a motility in which professionals shift backward and forward between different spaces of discourse and possibilities for conduct, that is, shifts shifting the world (Latimer 2008b).

In the context of Down's syndrome screening, professionals switch discursive domains to recognise how, in one moment, screening is a downgraded assignment (counselling parents-to-be before the procedure) but in another moment is upgraded work when it gets 'serious' (a higher-risk result requiring counselling). In many ways, Down's syndrome screening occupies a liminal space; it is often not valued or deemed worthy of FAD midwives' primary attention, for instance, but it is relegated from FMD consultants for whom it is not yet *clinical enough* to merit attention. Down's syndrome screening is emplaced in midwifery and sonography yet, concurrently, it does not become their primary professional concern (at least in midwifery). Despite such shifts, Down's syndrome screening is mostly produced and reproduced as a routine and 'normal' aspect of pregnancy, accomplishing its downgrading in the clinic.

Third, in their 'ordering work' within the clinic (Latimer 1999: 160), midwives and sonographers produce and reproduce classifications which, in turn, cast Down's syndrome as a familiar character in this drama. It is positioned as a trivial and non-prioritised task which is not part of 'hands-on midwifery work'. FAD midwives particularly, in a world in which they are asked to perform a wide range of duties, 'attach to' (Latimer 2013) and invest value in tasks affording them a chance to become acquainted with parents-to-be. This sits alongside assignments commonly defined as 'emotional' such as delivering news of a miscarriage or helping parents-to-be suffering a different yet equally serious setback in their current pregnancy. However, professionals frequently detach from Down's syndrome screening who constitute it as an undesirable duty due to its monotony and incapacity to regularly offer the rewards identified above. Parents-to-be are often the 'raw material' (Becker 1993: 34) for professionals' identity construction and performance of competence (Latimer 2000). As such, other clinical tasks, such as specialist clinics, which provide a 'steady flow of interesting cases with sufficient time to savour each one' are privileged (Dingwall and Murphy 1983: 143). Professionals align with and attach to a world in which screening is depersonalised, mundane, and banal. Hands-on midwifery work, as part of their domain of expertise, is elevated

to the heroic. Down's syndrome screening, thus, is not 'real midwifery' (Hunter 2004: 268) and is accomplished as a downgraded practice.

In the following chapter, I describe the conduct of care when professionals offer Down's syndrome screening. The routine nature of screening is produced and reproduced in two ways. First, professionals ascribe accountability to parents-to-be under the rhetoric of 'informed choice' and 'non-directive care'. Second, NT scans are reconfigured as entertaining opportunities to meet the unborn baby (the 'social') over potentially detecting a chromosomal condition (the 'medical').

Chapter Six
The Conduct of Care

In chapter five, I explored how Down's syndrome screening is downgraded and what this accomplishes in relation to hierarchies and identities in the clinic. In chapter six, I extend this focus by describing two ways in which the sedimentation of Down's syndrome screening as a 'routine' aspect of antenatal care is produced and reproduced. First, midwives and sonographers reassign the responsibility of Down's syndrome screening decisions to parents-to-be by citing governing professional discourses, namely informed choice (or reproductive choice[55]) and non-directive care, which frame intervention as flawed care. Adherence to these care-oriented principles not only performs 'good care' but allows midwives and sonographers, in their daily conduct, to 'dispose' (Latimer 1999) of screening and avoid responsibility for decision-making by assuming distance from the issues at hand. Second, ultrasound scans are frequently constructed, often by parents-to-be and on occasions by sonographers, as trouble-free and entertaining opportunities to meet the baby and reproduce kinship rather than to detect potential concerns. This emphasises the *social* over the *medical* dimension of the procedure. Taken together, such instances contribute to the naturalisation of Down's syndrome screening in antenatal care.

Regarding the chapter title, I opt for the term 'conduct' over 'behaviour'. Conduct involves considering what professionals, primarily midwives and sonographers, do to organise the world, albeit not in any way they please (Latimer 2008b). Speaking on the notion of conduct, Garfinkel (1967) claims that the social is forever a matter of moral form whilst Foucault (1983) argues what counts as moral is always influenced by technologies of power or programs for conduct. Far from being free to conduct themselves as they please (they are not given *carte blanche* to always behave as they see fit), professionals become 'conduits' (Latimer 2008b) whose doing and being produces and reproduces power effects. This is clear in chapter

[55] I use the terms *reproductive choice* and *informed choice* synonymously. Professionals in Freymarsh and Springtown recognised both terms as interchangeable.

five with how the process of Down's syndrome screening is (de)valued and positioned as trivial. In chapter six and particularly during the focus on the rhetoric of informed choice, I show how professionals draw on discursive grounds and rules as well as cultural materials in order to legitimate and account for their conduct (rather than behaviour).

'It has to be your choice'

I begin this chapter by identifying how 'informed choice' and 'non-directive care', a transposable discourse infiltrating Down's syndrome screening and antenatal care more generally, is enacted in the clinic and what this accomplishes. Notions of choice and autonomy are at the heart of current Western biomedical discourse. Reproductive technologies in particular are heralded as a route to liberation since they offer parents-to-be information about, and control over, offspring (García et al. 2008; Kerr and Cunningham-Burley 2000), although this may not always be empowering (Lippman 1994; Shakespeare 2011). In recent years, there has been a shift in Western healthcare systems from an overwhelmingly paternal medicine to an informed choice model (Mol 2008; Williams et al. 2002a), reflecting a departure from impersonal 'corpse care', of a clinician treating the body mechanically as a silent and docile object with personal markers stripped away (Foucault 1973; Leder 1992), to individualised 'consenting care' in which the responsibility of decision-making is usually assigned exclusively to patients (May 1992; Mol and Law 2004). This 'logic of care' (Mol 2008) places an emphasis on looking and listening to 'grant patients their life as well as knowing them as if they were dead' (Mol and Law 2004: 44). In a broader and more egalitarian view of (holistic) care, patients are to be considered as individuals with a right to participate in decisions.

One way for understanding how professionals define informed choice and non-directive care is to look at the information provided to parents-to-be and what details are omitted from consultations (Bosk 1992). In a setting in which the enactment of bureaucratic regulations transforms work into a distinct ceremonial order (Strong 1979), one must attend to how policy is translated and gets talked into practice and how it is enrolled, enacted, or deferred by professionals during care. In both Freymarsh and Springtown, both midwives and sonographers

emphasise their alignment with the entwining principles of non-directive care and informed choice when screening for Down's syndrome. In FAD, parents-to-be are tendered a multitude of booklets and information on this procedure. One booklet reads:

> Only you can decide whether to have the test or not. Some women want to find out if their baby has Down's syndrome, and some don't. All women are offered a screening test for Down's syndrome but the decision whether to have the test or not is yours. You can discuss with your midwife what you want to do. They will support you whatever you decide.

This booklet, much like similar literature and policy documents, highlights whilst parents-to-be '*can discuss*' procedures with midwives, they are the '*only*' ones to decide about screening. Individual choice is a common rhetorical device in policy frameworks for Down's syndrome screening, focusing on the individual rather than the social context of screening and testing (Kerr 2003). Professionals claim they abide by such stipulations, with Nancy (FAD midwife) emphasising during a conversation that parents-to-be '*should make their own personal choice and be true to themselves*'. I asked Camilla (FAD midwife) during an interview how she defines informed choice:

> Informed choice is giving them as much information as you can, the pros and cons, looking at the whole thing, what the consequences are of having it or not having it and what it'll mean to them. Once you feel you've given the information and they seem to understand what you're saying, and they can give you that back, then I'd say they're making an informed choice. [...] [Parents-to-be] sometimes ask me if many people have the test. So I say "some people will do this" and try to show them there are different outcomes and you don't have to just say yes or no.

Camilla describes informed choice as '*giving them as much information as you can*' including the advantages/disadvantages and outcomes of screening. Camilla claims

this offers parents-to-be a chance to '*[make] an informed choice*'. However, her suggestion of telling parents-to-be '*some people will do this*' arguably undermines the ideal of informed choice by influencing the decisions of parents-to-be. This is made more explicit elsewhere. In NT scans, for instance, Esther (SAD sonographer) regularly suggests amniocentesis is '*advised*' if a higher-risk result for Down's syndrome is established. Esther's comments, intended or not, can undercut the principle of informed choice. Describing amniocentesis as '*advised*' does not constitute a 'choice', advice being translatable to subtly disciplining parents-to-be into making certain choices. Advice, then, can be explicit (Silverman 1987; Strong 1979) or implicit (Latimer 2007; Pilnick and Zayts 2012). However, as Schwennesen and Koch (2012: 283) note, undercutting the rhetoric of informed consent does not *always* translate to bad practice. Whilst not always immediately compatible with the non-directive ethos, professionals' conduct can constitute 'good care' by supporting parents-to-be to make meaningful choices often on the basis of uncertain knowledge, for example, telling parents-to-be, as claimed in Camilla's account, '*some people will do this*'. Rather than this being described as a serious problem of oppressive power resulting in coercive moments of decision-making, such actions are categorised as ensuring informed choice since non-directive care may not always be the most suitable response (Burton-Jeangros et al. 2013; Ivry 2006; Williams et al. 2002b).

Despite Camilla's account showing how policies are made and unmade in everyday affairs, she aligns with definitions of informed choice and non-directive care as defined by other professionals, policies, and booklets. Amy (FAD midwife) likewise suggests to parents-to-be during one screening consultation:

> Our job is to give information to make an informed choice. Because it has to be your choice because then you have to live with the choice afterwards.

This is not to say, however, this is always an easy task. Midwives and sonographers commonly identify the difficulties of ensuring fully informed choice. Sophie (SAD sonographer), for instance, claims parents-to-be '*will have their own interpretation*

of the facts'. Along with citing the discrepancies of '*interpretation*' between parties (Gammons et al. 2010) and how conveying information to parents-to-be is difficult (Heyman et al. 2006; Pilnick et al. 2004), Sophie suggests parents-to-be often solicit advice. In response, Sophie suggests her care is limited to '*[telling] them the facts*' since '*it's an individual decision*' and '*I can't tell [parents-to-be] the answer*'. A similar sentiment is expressed by many other midwives and sonographers.

Professionals' criticisms of Down's syndrome screening

This alignment with promising informed choice and non-directive care, however, sits uncomfortably alongside three criticisms midwives and sonographers have of Down's syndrome screening: 1) quadruple screening is not as accurate as an NT scan; 2) screening creates undue anxiety; 3) screening reflects eugenic purposes since Down's syndrome is categorised as 'compatible with life'. Whilst I discuss the latter criticism in chapter seven, I address the first two criticisms here.

Quadruple screening in FAD is criticised by some professionals for its inaccuracy. During one conversation, Maggie (FAD midwife) claims:

> It just seems quite a strange test. I wouldn't have it. I might have the nuchal translucency scan. I don't really think the quad test really tells you anything anyway, does it? You've got your low-risk result so you are low-risk but you can still have your baby with Down's syndrome or you can be high-risk and you can still have a baby with Down's syndrome. I don't really think it makes much difference in my opinion.

Maggie doubts the quadruple screen '*really tells you anything*'. Her criticisms are shared by many professionals who quote quadruple screening as approximately 80% accurate, meaning around 80% of unborn babies of Down's syndrome receive a screen-positive result. The remaining 20% of women with pregnancies affected with Down's syndrome will receive a screen-negative result (so only four out of five women undertaking screening and having baby with Down's syndrome will find out prenatally via the quadruple screen). The NT scan in SAD, in contrast, is quoted as being around 90% accurate. Maggie subtly refers to this when claiming

that she '*might have the nuchal translucency scan*'. Much like Maggie, Amy (FAD midwife) says she would not undertake quadruple screening herself, although she is careful to reiterate '*it is an individual choice*' and '*my opinion doesn't mean I should influence anyone else not to have the test done*'. Eve goes a step further by referring to quadruple screening as '*rubbish*' since *'you don't get definite answers*', although reiterates she would not reveal this criticism to parents-to-be since '*I can't put my opinion across to someone*'.

The accuracy of the screening test is an important criticism. However, a more common denouncement from professionals concerns how screening, in their view, needlessly solicits anxiety and unpredictable trouble for parents-to-be. As such, I focus on this criticism for much of the chapter. Feelings of fear and anxiety among parents-to-be before, during, and/or after Down's syndrome screening have been recognised in previous accounts (Aune and Möller 2012; Burton-Jeangros et al. 2013; Green and Statham 1996; Heyman et al. 2006; Hunt et al. 2005; Ivry 2006; Markens et al. 1999; Marteau 1995; Pilnick et al. 2004; Remennick 2006; Williams et al. 2005). Clarke (1991) argues that the implicit assumption of screening is that parents-to-be will find the resulting information powerful and beneficial. However, this is challenged by Clarke on the premise that it can produce serious dilemmas for parents-to-be. Similarly, Williams et al. (2002b) claim professionals in their study viewed the very offer of screening as limiting women's choices. In Freymarsh and Springtown, Down's syndrome screening is often classified as what Camilla (FAD midwife), among others, refers to as a '*can of worms*':

> After a consultation, Camilla tells me she has thought about what she'd do if she '*came back as a higher-risk [for Down's syndrome]*':
>
> > Camilla: Most [parents-to-be] are just like "oh I'll have [screening] anyway". I don't think most of them realise it can open up a can of worms. If they're not going to have the amniocentesis if they're a higher-risk result, what's the point in having the test in the first place? Otherwise they're just going to have a worrying pregnancy. I couldn't believe it when I found out that three out of four kids with Down's

> syndrome came back as a lower-risk result. The lower-risk isn't really that reassuring then is it? It makes you think what is lower-risk?

Camilla criticises Down's syndrome screening since it can '*open up a can of worms*'. If parents-to-be would not entertain the prospect of agreeing to diagnostic testing if a higher-risk result is established, Camilla doubts the suitability of undertaking screening since it could promise a '*worrying pregnancy*'. Together with Camilla highlighting how the production of scientific artefacts requires interpretation ('*it makes you think what is lower-risk?*'), Susan (FAD midwife) similarly associates the naturalisation of screening, of parents-to-be accepting screening since it is widely perceived as '*just an extra test so I'll have it done*', with a lack of perception among parents-to-be regarding the procedure as having '*huge implications*'. This arguably contradicts the work of Cunningham-Burley and Kerr (1999) who claim clinicians and scientists retain their own cognitive authority and avoid criticisms of their practice by stressing the benefits of choice and how new technology in this area can potentially alleviate disease. The following extract illustrates this difference:

> The consultation is over. It lasted twenty to twenty-five minutes (longer than usual). Mr and Mrs Ingram seemed unclear as to why they attended clinic today and what Down's syndrome screening entails. After they leave, Lois turns to me. She says '*well that was difficult*' and laughs whilst shaking her head:
>
> > Lois: The absolute classic is parents having these tests just because they can. Just because they're available, they're like "I might as well have it". And they don't really think about what might happen afterwards with these results. They don't think about whether they want an amniocentesis or think they might be a higher-risk. It's a can of worms really. It's the same with other testing as well like HIV, rubella, syphilis, and that. They're like "oh we might as well". Well, no, not you might as well! These tests have massive implications. And with the amniocentesis, they can have a full test and discover other things aside from Down's

> [syndrome][56]. It's a minefield really. If you detect something else, do you tell them? There was a woman last week who had a one in thirteen result for Down's [syndrome]. When we told her that she had a one in thirteen chance, she said "I just thought I'd come back as a low-risk. Now I don't have a clue what to do". If people are going to have the test, they should probably know what they'd do with that result afterwards.

In this account, Lois claims the '*classic*' is parents-to-be undertaking screening compliantly '*because they can*'. Citing the case of a mother-to-be who received a 1:13 risk factor, she accuses parents-to-be of not considering the '*massive implications*' of screening for a range of conditions and adverse health outcomes. According to some midwives and sonographers, accusations can be directed to parents-to-be who accept screening uncritically on account of its availability. They charge parents-to-be with not engaging with the relevant antenatal literature and their docile acceptance of screening programmes, Down's syndrome particularly, without considering the potential consequences of their actions (i.e. receiving a higher-risk result and having to make a decision regarding diagnostic testing). Nonetheless, for many professionals, screening/testing can '*discover other things aside from Down's [syndrome]*' and so, in turn, '*poses more questions than answers*' (Gail, FAD midwife), '*causes a lot of stress*' (Francine, FMD head midwife), constitutes a '*slippery slope*' (Rita, FAD midwife), and '*alters the course of pregnancy completely and can leave [parents-to-be] in a position of whether or not they want to continue with the pregnancy when initially it started out for them as a simple test for Down's syndrome*' (Lois, FAD midwife). By identifying Down's syndrome screening as inducing undue anxiety, midwives and sonographers subtly condemn it.

Informed choice in everyday practice

In this chapter, I have identified a contradiction in the accounts of professionals: they condemn screening yet spend much of their day aligning with principles of

[56] After an amniocentesis, a sample of amniotic fluid is sent to a cytogenetics lab for analysis where chromosomes are analysed. This potentially leads to the detection of conditions including, but not limited to: Down's syndrome, Edward's syndrome, Patau's syndrome, cystic fibrosis, muscular dystrophy, sickle-cell disease, neural tube defects (spina bifida and anencephaly), and Tay Sachs disease.

informed choice and non-directive care. Personal criticisms are suppressed by citing such rhetoric as taking priority in antenatal care. Sooben (2010) describes how professionals remain detached when delivering screening information, with Clarke (1991) suggesting this is so they do not become legally accountable for the decisions of parents-to-be. Professionals are encouraged to suspend all values and judgement about how they believe one should behave and how a decision should be made (Bosk 2001; Cunningham-Burley and Kerr 1999). This is announced explicitly in the following fieldnotes taken from a consultation between Susan (FAD midwife) and Mr and Mrs Payton (parents-to-be), an extract atypical in length yet typical in its depiction of professionals aligning with the rhetoric of informed choice and non-directive care:

> Susan: So do you know anything about this Down's syndrome test?
> Mrs Payton: No.
> Susan: Well if you wish, we can check your bloods today using your age, whether you smoke, the results of the blood test, and your weight to calculate a risk factor for Down's syndrome. It's not definite in that it won't give you a diagnosis. You'll just be put into a category of higher-risk or lower-risk. A lower-risk result which is a 1 in 150 result or more means you'll get a letter. But it's important to remember that you could have a 1 in 100,000 risk of having a child with Down's syndrome but it doesn't mean the baby definitely doesn't have the condition. It just means there's a 1 in 100,000 chance it will. A higher-risk result is on the other side, so a 1 in 150 or less result. So you could have a 1 in 12 risk or 1 in 30 risk of having a kid with Down's syndrome, for example. But if you do have a 1 in 30 risk, the baby is still unlikely to have Down's syndrome. Do you understand?
> Mrs Payton: Yes.
> Susan: So if you're higher-risk, an amniocentesis is offered. Do you know about amniocentesis?
> Mrs Payton: Yes.

Susan explicates the finer details of screening after Mrs Payton claims she knows little about it. In many consultations, parents-to-be recurrently appeared confused about their presence in clinic ('*I can't remember why we're here to be honest*'), were unaware of what the procedure entails ('*I just said yes for every test*'; '*I haven't really thought about it*'; '*I don't know about it but my brother and his wife had it so I thought we would have it too*'), and had not considered the implications or possibility of diagnostic testing ('*so what is amniocentesis?*'; '*I don't really know what I'd do but I'll have the test now as I just want to know if something's happened or if something's wrong*'). In addition, much like the participants in Pilnick et al's (2004) study, many decisions to accept screening seemed to be accounted for as a formality in the hope everything would be well. Nonetheless, in this consultation, Susan explains Mrs Payton will be '*put into a category of higher-risk or lower-risk*' since a diagnosis is not provided and that a lower-risk result does not necessarily translate to not having a child with Down's syndrome. After offering more examples of risk factors, Susan continues:

> Susan: So would you go on to have an amniocentesis, and do you want the blood test or not? [Mrs Payton hesitates].
> Mr Payton: I would want to know [if the baby had Down's syndrome] but she wouldn't want to do anything so it's pointless even having this test.
> Mrs Payton: Do lots of people have the test?
> Susan: It depends.
> Mr Payton: I'd have the test if I was a woman.
> Susan: If you have a higher-risk result and decide not to have an amniocentesis, the result might stress you out for the rest of the pregnancy. You'll spend the rest of the pregnancy worrying [Mr and Mrs Payton pause].
> Mr Payton: It's a catch twenty-two really.
> Susan: We can only give all of the information and it's up to you whether you decide to have the test.

Mrs Payton appears hesitant to answer after Susan asks whether she would '*go on to have an amniocentesis*' and whether she would '*want the blood test or not*', with

Mr Payton claiming he would '*want to know*' yet his partner would '*not want to do anything*' (presumably meaning Mrs Payton would not opt for terminating a pregnancy following a positive diagnosis). It is clear Mr and Mrs Payton have not previously thrashed out the finer details of Down's syndrome screening, a trend reported elsewhere (Gottfreðsdóttir et al. 2009b). Susan's account at the end of the extract involves the first explanation that after '*[giving] all of the information*', it is '*up to you whether you decide to have the test*'. This, however, is supplemented with a warning that a result could '*stress you out for the rest of the pregnancy*' (what Mr Payton calls a '*catch twenty-two*'). The consultation resumes:

> Mrs Payton: [Turns to Susan] What do you think?
> Susan: I can't decide for you. An amniocentesis provides a definite diagnosis and means you could either continue or terminate the pregnancy. Obviously the termination would be offered for medical reasons.
> Mr Payton: So it's a personal preference, [Mrs Payton].
> Mrs Payton: [Anxious. Turns to Susan] What do you think?
> Susan: It's your choice.
> [...]
> Mr Payton: You'll probably be alright, [Mrs Payton]. You're young.
> Susan: Yes. If you do want the test, you'll have to do it soon as you're already eighteen weeks and four days pregnant and we can't offer the test after about nineteen weeks. Remember the only way you'll know for sure is through amniocentesis. This is only screening today.
> Mr Payton: It's only a blood test, [Mrs Payton].
> Mrs Payton [After a long pause] I think it'd be good to know if I was higher-risk. So quite a lot of people have this test?
> Susan: I don't know the exact statistics but it's a personal choice whether or not to have the test.

Mrs Payton seeks advice by asking Susan once if other mothers-to-be undertake screening and twice what Susan '*[thinks]*'. She responds by once more emphasising '*it's your choice*'. She later agrees with Mr Payton's claim that Mrs Payton is young

so she will '*probably be alright*' and claims a decision needs to be made promptly since the test will not be available soon owing to the current weeks of gestation. It continues:

> Mrs Payton: [Unsure] There's lots of decisions to be made. It adds stress doesn't it? I'd rather not have it done.
> Susan: OK. Well you'd probably end up in the lower-risk category anyway with your age and weight.
> Mrs Payton: So what would you do?
> Susan: I can't say.
> Mr Payton: [Irritated] Love, she's already told you twice that she can't say and it's a personal decision!
> Susan: Why don't you go for a walk and come back in ten minutes to see what you want to do?
> Mr and Mrs Payton: OK.

Mr and Mrs Payton leave. Susan turns to me and breathes a sigh of relief:

> Susan: That's why we do these consultations. Otherwise she would have the bloods and not know what they were for.

Mrs Payton returns after one minute without her partner and tells Susan she will not have the blood test.

Mrs Payton cites the '*stress*' accompanying the '*decisions to be made*', with Susan reassuring her '*you'd probably end up in the lower-risk category anyway with your age and weight*'. Susan once more rejects Mrs Payton's question about what she would do in this situation, with Susan telling the Payton's to '*go for a walk*' and return to let her know '*what you want to do*'. After their departure, Susan outlines the benefits of consultations for ensuring parents-to-be '*know what [screening is] for*'. There are many acts of negotiation taking place here between each party. Mrs Payton tries to enrol Susan in decision-making by emplacing trust in Susan to make the decision for her. This is a trend I noticed in other consultations at FAD. In

patient-centred consultations, parents-to-be sometimes seem reluctant to engage in individual decision-making and take the role ascribed to them, preferring to defer authority to the expert professional (Pilnick and Dingwall 2011). However, Susan disposes of her responsibility for Down's syndrome screening with broad references to the rhetoric of choice. This choice must be reached after Susan has performed her primary duty of communicating medically-based information about the procedure and its outcomes (Bosk 1992). This is similar to Springtown in which care is primarily confined in perimeters of tendering medically accurate information. Sonographers regularly provide the same (medically-based) account for Down's syndrome screening during an NT scan: they say they are measuring the nuchal translucency, how its enlargement is connected to chromosomal conditions, how this results in the production of a risk factor, and how diagnostic testing can be offered should a higher-risk result be established. In doing so, they can avoid responsibility for decision-making. Such strategies involve professionals taking comfort in the principle of 'safety in numbers'; their care is suitable since colleagues do the same thing and '[normalise] the action as legitimate within their shared universe of meaning' (Scott et al. 2013: 431).

Despite the high ideals of informed choice, the practical realities of information provision, shaped by the emergent logic of everyday rituals, delivers an encounter perhaps contrary to professionals' intentions (Strong 1979). In the clinic, the 'messiness of mundane practices fail to submit to theoretical ideals' (Mol 2008: 43). Indeed, the stating of options does not always amount to the neutral provision of advice since some options have the force of a directive (for instance, to draw on an example used earlier, '*advising*' an amniocentesis). Professionals' methods of information provision – embedded and consumed in a complex array of cultural, medical, political, economic, and social practices and pressures – is very likely to influence certain decisions (Browner et al. 1996; Kerr et al. 1998; Lippman 1994; Pilnick 2008; Rapp 2000). Some commentators have censured professionals for providing information which is far from neutral and nondirective when screening for Down's syndrome (Marteau et al. 1993; Shakespeare 2011; Skirton and Barr 2007; Tsouroufli 2011). Others doubt whether fully autonomous and informed decision-making within the context of Down's syndrome screening can ever exist

(Pilnick 2004; Williams et al. 2002a, 2002b) whilst some are sympathetic for professionals who struggle with balancing professional and private moral values (Farsides et al. 2004; Williams et al. 2002a).

This points to how care is accomplished in the interactions, materiality, and practices of the antenatal space. It is only possible in a heterogeneous collective human and nonhuman network with decisions made in interdependent relations (Schwennesen and Koch 2012); care is something you *do* as opposed to something which *is* (Latimer 2000; Mol 2002). At its heart inter-subjective and a matter of process, care is commonly an open-ended and unsettled entity involving the body, emotions, and identity-work, a practice stratified and distributed across time and place which is always achieved and never attributable to an impartial account (Mol 2008). Since knowledge is produced and reproduced during interactions, what we regard as a choice is never a value-free activity and is always subjected to various influences, few of which are straightforward or transparent.

Rather than repeating well-established arguments around how non-directive care and informed choice is or is not achieved in practice, however, I elucidate what this rhetoric accomplishes. The rhetoric of informed choice and non-directive care produces and reproduces the naturalisation of Down's syndrome screening as a 'normal' part of pregnancy. In addition, professionals align with this discourse and use it as a resource to effectively dispose of screening in antenatal care. Parents-to-be are instituted as rational decision-makers who, provided with clinically correct information, are able to choose between alternative courses of action (Silverman 1987). They are enrolled in and subjected to disciplining practices (Foucault 1972) which encourage self-management. In their descriptive accounts, professionals such as those cited in previous extracts are upfront in bestowing responsibility to parents-to-be, though particularly mothers-to-be, who should consider the consequences of their actions. Once positioned as active decision-makers, parents-to-be 'gain autonomy at the cost of being morally responsible for their actions' and are accountable when 'a gap exists between their knowledge of the parameters of good management and actual behaviours' (Allen 2013: 42).

Language barriers

Professionals' detachment from Down's syndrome screening and their relocation of responsibility to parents-to-be are evident in interactions between professionals (midwives/sonographers) and parents-to-be whose first language is not English. The difficulty of communicating information about Down's syndrome screening if the first language of parents-to-be is not English has been reported elsewhere (Hey and Hurst 2003). This is particularly a challenge for Freymarsh which serves a large population whose first language is not English. The problems a language barrier can create are outlined during an exchange following a consultation between Toni (FAD midwife) and Mrs Garcia (mother-to-be):

> The consultation has ended. Mrs Garcia seemed confused throughout the encounter. After Toni leads Mrs Garcia into another room for the quadruple screen, she returns to the room and turns to me:
>
> > Toni: I'm not sure if she understood that. There was a bit of a language barrier.

During the consultation, Toni appears more concerned with providing medically correct information rather than ensuring Mrs Garcia has correctly understood the procedure. In FAD, a translator is not offered, or at least immediately available, once undertaking Down's syndrome screening (partners sometimes translate for their partner). Following a similar consultation with a mother-to-be whose first language is not English, Emma (FMD midwife)[57] tells me:

> When the woman and the partner are foreign, it makes me a bit uneasy. You have to question whether they really fully understand the information you are giving to them. We get a lot of people in here, some from very different religious backgrounds, and they might not abort the baby because of their religious beliefs. But if they don't speak very good English, they may not know about this screening and if they wouldn't

[57] Emma is also an FMD midwife but I observed her most frequently in FAD.

> have the amniocentesis anyway, then they may not want screening in the first place. But they may not know about this if they don't understand.

Once again, the professionals' priority is providing clinically correct information, in line with organisational recommendations (Hillman 2007), over ensuring this data has been fully comprehended by parents-to-be. Although language barriers are a relatively extreme example, it highlights how Down's syndrome screening is downgraded in the clinic. It is interpreted as a procedure which does not demand the use of translators for potentially repairing fractured interactions. Resources, important indicators for what clinical tasks and/or patients are valued (Dingwall and Murphy 1983), are not allocated here. Instead, care is commonly constricted to providing clinically accurate information on *what is* as opposed to *what ought to be*. Professionals' criticisms of screening are made absent in everyday practices whilst alignment with the rhetoric of informed choice and non-directive care are made present. Once more, Down's syndrome screening is entangled in 'motility' (Latimer 2013; Latimer and Munro 2006; Munro 2001). In their 'moves' (Latimer 1999), professionals switch grounds to accomplish screening, in one instance, as a problematic practice (as not very accurate and as opening a can of worms) and in other instances, namely 'front-stage' (Goffman 1959) screening consultations with parents-to-be, as an acceptable and mostly trouble-free exercise.

It is this latter shift which accomplishes care as located within abstract medical categories and parents-to-be as fully responsible for decision-making in screening practices. Midwives and sonographers successfully 'dispose' (Latimer 1999: 177) of screening figuratively if not physically. Since Down's syndrome screening does not belong to the domain of professionals, parents-to-be are made accountable for decisions and, in turn, may feel to blame if any problems occur for not seriously considering the consequences of consenting to the procedure. In a healthcare system increasingly shifting responsibility, the 'responsible citizen' is reproduced in the actions and interactions of both professionals and parents-to-be (White et al. 2012: 72). Strategic boundaries are drawn between knowledge and its application, that is, professional expertise and the ignorance of parents-to-be allegedly not considering the wider consequences of their actions (Cunningham-Burley and Kerr

1999). Responsibility, as such, is deflected onto parents-to-be, reifying this dichotomy and detracting attentions from a critical consideration of professionals' responsibilities (Kerr et al. 1997). This nonalignment with parents-to-be and detachment from, and disposal of, Down's syndrome screening allows professionals, as I have shown in chapter five, to pursue and attach themselves to tasks which they invest with value and classify as favoured material for constructing a meaningful identity.

Sonography and sociality: visualising the unborn

In this chapter, I have captured how professionals detach from screening and how the ensuing responsibilisation of parents-to-be means professionals accomplish both the downgrading and disposal of the procedure. Many of the examples cited, however, concern FAD. In SAD, Down's syndrome screening is also downgraded by NT scans being constructed and reconstructed from occasions designed to distinguish defects into encounters tendering opportunities to meet the baby and reproduce kinship. This argument also extends to ultrasound scans with no association to Down's syndrome screening, namely a dating scan (roughly ten weeks into a pregnancy) and anomaly scan (roughly twenty weeks into a pregnancy). The dating scan and anomaly scan are available in both FAD and SAD. However, they are mostly undertaken in FAD since as an NHS hospital, each scan is free-of-charge. During interviews and in the 'back-stage' (Goffman 1959) of the clinic, midwives and sonographers often accuse parents-to-be, regardless of the ultrasound scan consented to, of not fully comprehending the implications of such procedures. In an interview, Rita (FAD midwife) describes her experiences after recent medical training in dating scans:

> I think women who haven't had a pregnancy before or whose pregnancies have always been fine almost see it as just a chance to see the baby and to find out when the due date is and how many weeks [pregnant] they are. They don't see it as a medical examination to make sure the baby is fine or to see if we can see any problems.

During an interview, Lindsay (FAD midwife) similarly claims:

> Some people are asking you "can you tell us the sex" [during a dating scan] and I haven't even flipped the monitor around yet to show everything's OK. It's part of the routine. I don't think people really think about what we're doing it for. [...] Women often bring toddlers and partners too because they see it as a nice scan and as getting a nice picture but it can be problematic if there's no heartbeat or something. But lots of them are quite sensible. They just want to know everything's OK on the scan so a lot of them just come as two really.

Although Lindsay classifies a range of parents-to-be as '*quite sensible*', she suggests some parents-to-be do not '*really think about what they're doing [the dating scan] for*'. She attributes this to the '*routine*' element of ultrasound scanning, that is, the expectation among parents-to-be that an ultrasound scan is designed to obtain a '*nice picture*' of the unborn baby. According to Lindsay, this becomes '*problematic*', however, when partners and family members attend only to discover the absence of a heartbeat. Similarly, Eve (FAD midwife) establishes a discrepancy between lay and professional knowledge; whilst most women '*come in with half their family*' and '*don't know what they're coming to clinic for half the time*', professionals are '*more interested in whether [the unborn baby has] two arms, two legs, and all its anatomy in the right place*'. Eve further highlights misconceptions of anomaly scanning since women view them exclusively as encounters which confirm the sex of the unborn baby. Olivia (SAD sonographer) similarly charges parents-to-be with constructing anomaly scans as '*sexing scans*', expressing her disapproval that they interpret the procedure as '*[having] a little look at the baby*'. Francine (FMD head midwife), privy to anomaly scans in her previous role in FAD, claims during an interview that an unborn baby's sex is often the first question posed by parents-to-be:

> Very few people appreciate we're looking for abnormalities. Even if you say we're looking for abnormalities, they still don't take it on board. It's reassurance for a lot of people and to get their pictures and to find out the sex of the baby because a lot of women will bring in half the family.

> The majority of the time this is fine but unfortunately, when you haven't got a good result, it's all the more devastating when it's not normal because you've got your extended family there. That's anomaly scans, NT scans, and dating scans.

Francine suggests anomaly scans are constituted by parents-to-be as opportunities to '*get their pictures and to find out the sex of the baby*'. She claims despite explicit reference to its main purpose, ultrasound scans are so engrained in the pregnancy imaginary that parents-to-be '*still don't take it on board*', opting to invite family members to attend which becomes problematic once a '*good result*', translated as the presence of '*normal*' markers, is not delivered.

Francine's criticism extends to both anomaly and dating scans together with NT scans for Down's syndrome. Martha (FAD midwife) suggests scans, as '*the glory bits of clinic*', are craved by mothers-to-be in particular since they '*are much more interested in having a scan and pictures generally than having anything else*'. Fears among professionals about parents-to-be imposing personal interpretations on the function and significance of ultrasound scans have been identified (Draper 2002; Mitchell 2001; Sandelowski 1994a). Ultrasound scans have long been recognised as a 'hybrid practice' (Taylor 1998) with medical and social meanings incorporated into consultations (Müller-Rockstroh 2011; Roberts 2012), not least in installing an extra monitor for parents-to-be to watch the unborn baby's movement and the subsequent production of 'baby's first picture' (Mitchell 2001). Draper (2002: 787) refers to this as a potential 'clashing of world-views' between the lay paradigm of the ultrasound scan as a social event and the expert paradigm of it as a screening event.

In Freymarsh and Springtown, whilst many of the professionals' accusations of parents-to-be misinterpreting the true intention of ultrasound scans are valid, they play an implicit contributory role. In unison with parents-to-be, sonographers play their part in configuring the NT scan, first and foremost, as a straightforward and entertaining opportunity to meet the unborn baby rather than detecting potential concerns. This mixing of biomedical purposes with social matters is accomplished

in two ways: 1) scans become a 'day out'; 2) scans offer a chance to reproduce kinship. This shows how ultrasound scans are not limited to providing information but also involve sharing meaning in which the logics of 'care' and 'choice' interconnect (Mol 2008). Since my focus is mostly on Down's syndrome screening, I mostly cite extracts taken from SAD observations and interviews with sonographers for the remainder of this chapter.

A day out

The personal and social implications of ultrasound scans, more than whether they are clinically effective (Müller-Rockstroh 2011), have been previously identified. Commentaries on visualising the pregnant-body interior claim they offer a chance for meeting the baby (Williams et al. 2005), medicalise a pregnancy and erase women in favour of the unborn baby (Martin 1998), devalue women's knowledge (Franklin 1991; Sandelowski 1994b), force parents-to-be to tackle moral dilemmas around their unborn baby (Gammeltoft 2007; Rapp 2000), make pregnancies seem more 'real' in the absence of embodied knowledge (Heyman et al. 2006; Williams et al. 2005), and prompt appropriate behavioural changes in a partner befitting that of a future parent (Draper 2002). Parents-to-be can experience a range of such conflicting emotions, with enthusiasm and enjoyment often sitting uncomfortably alongside fear and anxiety during a scan (Williams et al. 2005).

In Freymarsh and Springtown, ultrasound scans are constructed as important and meaningful events for visualising an unborn baby. I illustrate this point by citing fieldnotes taken during an echocardiography scan performed by Dr Torres (FMD cardiologist) in which a baby is suspected as having a heart defect:

> Dr Torres, Jodi (FMD cardiac physiologist), Mr and Mrs O'Neill (parents-to-be), and their three daughters (Cassie, Nina, and Sian) are in the scan room. Dr Torres begins and, after a few minutes of scanning, turns to the children]:
>
> > Dr Torres: Now you have to pay me for this show [Mr and Mrs O'Neill, Cassie, Nina, and Sian laugh]. And if you can't pay, you'll have to do your

mum's chores. You'll have to do the washing, cook the food, and massage her feet.

Mrs O'Neill: Not my feet, they wouldn't want to go anywhere near them!

During the scan, Dr Torres utters '*it looks good so far*', '*it all looks fine*', '*there's nothing abnormal here*', and '*there's nothing to be concerned about*':

Dr Torres: [Pointing and turning to Cassie, Nina, and Sian] Do you see the head and the brain there, girls?

Cassie: Is that the brain [points]?

Dr Torres: That is the brain. There's the head, the brain, two little legs trying to kick mommy [all laugh].

Jodi: Baby's legs are all stretched out there!

Dr Torres: I'm just trying to get a good profile. The girls came here for a show and mum has come here for a show, so let's give them a day out! You have a shy baby here, like you girls I think [turns to Cassie, Nina, and Sian].

Dr Torres scans for another few seconds:

Dr Torres: I think we can stop the scan there. Everything is fine though.

Mrs O'Neill: I'm so relieved. Thank you so much.

Mr O'Neill: Brilliant. Thanks doctor.

Following the suspicion of a heart defect being disproved, Dr Torres describes to Mr and Mrs Neill (parents-to-be), alongside their daughters who have attended the scan, how the daughters must '*pay a fee for the show*', how failure to pay will result in '*doing your mum's chores*', and how the unborn baby is '*shy*' and '*trying to kick mommy*'. Whilst Dr Torre's playfulness can also be attributed to an attempt to relax the O'Neill's following a suspected defect (Dr Torres also reassures the O'Neill's with utterances such as '*it looks good so far*' and '*there's nothing abnormal here*'), it additionally points toward how ultrasound scans, used principally for detecting potential defects in unborn babies, can be configured as what Dr Torres refers to as

'*a day out*'. Later in the day, Dr Torres is explaining a suspected large inlet ventricular septal defect[58] and dextro-transposition of the great arteries[59] to Mr and Mrs Hall (parents-to-be). After explaining the situation '*is incredibly rare and most cardiac specialists don't even have a clue about this*', Dr Torres draws a picture of the heart and associated defect to explain the situation.

Here, cultural materials are produced and utilised in the production of care, with sketches of cardiac defects and ultrasound scans becoming physical resources of knowledge and comfort. In the absence of a suspected defect, however, an ultrasound scan can be constructed as a day out, an entertaining and enjoyable excursion where parents-to-be can interact with their unborn baby. In SAD, the NT scan is commonly afforded such a reconstruction. The following fieldnotes are taken from the opening exchanges of a NT scan between Olivia (SAD sonographer), Mr and Mrs Fox (parents-to-be), and Mrs Fox's mother:

> Olivia: Baby's trying to stand up by the looks of things! Do you see the hand?
> Mrs Fox: Yes!
> Mother: Aw look at that. The heart looks like it's going well.
> Olivia: Yes it is.
> Mrs Fox: Aw I can see it moving!
> Olivia: Baby's having a little wriggle.
> Mrs Fox: Look at the arms there!
> Mother: He's doing the Usain Bolt [celebration]!
> Mr Fox: Flipping heck, this is amazing.
> Olivia: Seeing is believing isn't it?
> Mrs Fox: You don't think it's real until you see it like this.
> Mr Fox: It probably just feels like you've eaten too much curry! [Everyone laughs].

[58] An inlet ventricular septal defect is a hole in the septum near where the blood enters the ventricles through the tricuspid and mitral valves.
[59] Dextro-transposition of the great arteries is a cardiac defect in which the two main arteries carrying the blood out of the heart – the main pulmonary artery and the aorta – are switched in position.

Mrs Fox: It definitely makes it more real. [...] Is that a hand there?

Olivia: Yes.

Mrs Fox: Wow. I didn't know you could see so much at this stage.

Olivia: Baby's having a little dance in there now!

Mr Fox: Having a bit of fun!

Olivia: Do you see the arms moving? Baby looks like it's doing backstroke.

Mr and Mrs Fox: Yes [Mr and Mrs Fox laugh]!

Olivia: And the head there too. There's the nasal bone [points]. That's a good sign that it's there because if it's absent, that can be a sign of a problem.

Mrs Fox: OK.

Olivia: So what we're looking at today is the nuchal fold which is the fluid which collects at the back of your baby's neck.

Olivia proceeds to explain the NT scan, its outcomes, and the implications of such outcomes. Measurements are taken at an average of 1.06mm. Olivia explains a measurement under 3mm is '*good*'.

Olivia begins the scan by suggesting the unborn baby is '*trying to stand up*' and asks Mr Fox, Mrs Fox, and Mrs Fox's mother whether they '*see the hand*'. The explosion of visualisation technologies in medicine equally relies on professionals who must make imaging meaningful for everyone involved. Parents-to-be and sonographers engage in 'collaborative coding' (Roberts 2012: 299), fashioning meanings out of signs and symbols forged in conjunction with one another. Mr and Mrs Fox – in accord with Olivia and Mrs Fox's mother – describe the unborn baby as '*having a little wriggle*', as '[*dancing]*', as '*having a bit of fun*', and as '*doing the Usain Bolt*' together with identifying anatomical landmarks (e.g. '*look at the arms*', '*is that a hand?*'). Mr Fox describes the NT scan as '*amazing*', with his partner suggesting the pregnancy does not seem '*real until you see it like this*'. Olivia finally draws attention to the primary purpose of the scan with reference to the nasal bone, its presence reducing the prospect of a '*problem*' being found in the unborn baby.

As highlighted above, there is frequently a large degree of humour and informality during NT scans. The casualness is perpetuated further via chit-chat during scans such as professionals asking parents-to-be about plans for the weekend and how many other children parents-to-be have (or are planning to have). Whilst this informality and joviality occasionally emerges in screening consultations at FAD, this increases in SAD on receipt of a visual representation of an unborn baby at play on a large television monitor (not available at SAD). In the extract described above, Olivia and the Fox's prioritise the entertaining component of an ultrasound scan over establishing the purpose of this procedure. Such playful encounters are arguably harmless yet they reconstruct the NT scan as a fun day out. This reflects how parents-to-be occasionally claim they are unaware of what procedure they have undertaken. During one NT scan, for instance, Mrs Jackson (mother-to-be) is accompanied by her sister and mother and claims she '*does not know anything*' about the procedure. After Sophie (SAD sonographer) describes the scan, Mrs Jackson's sister video-records the imaging displayed on the monitor. After measurements are defined by Sophie as '*nice and small*', Mrs Jackson seems rather uninterested in this information and enquires as to the unborn baby's sex which Sophie claims she cannot determine at this early stage of a pregnancy.

The Jackson's pursuit of acquiring a material memory of the unborn baby and unmasking its sex, together with the sheer presence of other family members during the procedure, shows how scans can mostly become a day out rather than ensuring – drawing on Eve's earlier contentions – '*whether [the unborn baby has] have two arms, two legs, and all its anatomy in the right place*'. During other occasions, parents-to-be (or a mother-to-be) are accompanied by friends. The following fieldnotes are taken from a NT scan involving Esther (SAD sonographer), Mrs Fowler (mother-to-be), and two of Mrs Fowler's friends:

> Esther: Do you know much about the NT scan?
> Mrs Fowler: No, not really.
> Esther: Do you know it's a screening test for Down's syndrome?
> Mrs Fowler: Yes.

Esther: Well this screening test gives you a risk of having a baby with Down's syndrome. It measures a pad of fluid which collects at the back of the baby's neck. It appears between ten and fourteen weeks and disappears after fourteen weeks but we're still not quite sure why. But when it's enlarged, it's associated with chromosomal abnormalities.

Mrs Fowler: Is it just Down's syndrome?

Esther: No. It also looks for two other chromosomal abnormalities. Your bloods are taken and these are combined with the size of the baby, your age, and the NT which is calculated into a risk factor. This gives you a risk factor for Down's syndrome, Edward's syndrome, and Patau's syndrome. We can't screen for all abnormalities so we test for three of the most common, two of the most lethal. We like the NT under three millimetres and we need baby to be still so we can measure it. The good thing about this test as well is the false positive rate is lower[60]. That's one of the benefits you get of having the scan done earlier. You'll get the results on Thursday. Our cut-off here for a high-risk and a low-risk is 1 in 150. So if you get lower than 1 in 150, you'll get a higher-risk result and you'll be advised to have an amniocentesis. Baby gets a gold star because it's been the best behaved we've had tonight [Mrs Fowler and friends laugh].

Mrs Fowler: Good!

Esther: Baby's using your cervix as a bouncy castle there!

Mrs Fowler: I can see!

Esther: There are the eyes, nose, the Buddha belly [Mrs Fowler and friends laugh], arms, bum, legs, back of the head too. We check the back of the head to look for other abnormalities too.

Mrs Fowler: But is everything looking OK?

Esther: Everything is looking normal. The NT is nice and small. Oh look, there's two legs there!

[60] In screening, a false-positive means a mother-to-be receives a positive result but does not have an unborn baby with Down's syndrome.

After Mrs Fowler claims she does '*not really*' know about this screening procedure, Esther provides an explanation. After fulfilling her duties of providing medically correct information under the governing principles of non-directive care and informed consent, although the notion of '*[advising]*' Mrs Fowler to have an amniocentesis may breach this rhetoric, Esther quips Mrs Fowler's unborn baby '*gets a gold star because it's the best behaved we've had tonight*'. Esther subsequently claims the unborn baby is using Mrs Fowler's cervix '*as a bouncy castle*' before making the imaging on the monitor meaningful for Mrs Fowler and her guests by establishing anatomical features such as the eyes, nose, and '*Buddha belly*'.

Throughout NT scans, sonographers and parents-to-be identify physical features or movements of the unborn baby and ascribe these to personality traits ('*what a poser*', '*you've got a stubborn one*', '*baby is well-behaved tonight*', '*it's a very photogenic baby*', '*cheeky baby just flicked us the finger!*', '*you've got a very chilled out baby*'; '*the muppet won't behave, that little joker!*'; '*the baby's been very active so can you check it's not a frog instead of a baby!?*'), a favourable physical appearance ('*what a cutie*', '*our baby's beautiful*', '*you've got such a little doll there*', '*so pretty*', '*beautiful*'), and certain conduct such as dancing ('*baby's doing a little jig*', '*you've got a baby Michael Flatley in there*', '*baby's doing a bit of ballet*') and playing sports ('*you've got a rugby player in there*', '*baby's going to be a footballer with a kick like that*', '*we've got a future gymnast*'). The description of an unborn baby as a rugby player or gymnast often corresponds to hetero-normative gender ideals. During an NT scan, before determining the sex of an unborn baby, hetero-normative gender roles and expectations are often erected. Nonetheless, the ascription of personality traits, gender expectations, and behaviour – alongside the presence of friends during NT scans – frames the procedure as an enjoyable expedition as opposed to, in Rita's (FAD midwife) words, a '*medical examination*'.

Reproducing kinship

Ultrasound scans, particularly NT scans, are often attended by parents-to-be and other family members (most likely children). The attendance of children may be due to circumstance, rather than an active choice, such as not being able to hire a

babysitter. However, children often still attend the procedure along with fathers-to-be. In FAD, fathers-to-be and children – if present at all – regularly remain in the waiting room whilst mothers-to-be are invited for a consultation. In contrast, at SAD, they often attend the procedure. Their presence undoubtedly stems from NT scans being reconstructed as events in which parents-to-be welcome a new family member. Accounting for his and his wife's presence during an NT scan, for instance, Maurice (grandfather) claims his attendance can be attributed to '*[wanting] to come along today to meet our latest grandchild*'. The following fieldnotes are taken from an NT scan between Olivia (SAD sonographer) and Mr and Mrs Carlisle (parents-to-be):

> Olivia: Baby's swimming! There's the arm stretched right above the head, the stomach, and the leg [pointing].
> Mr Carlisle: Wow.
> Mrs Carlisle: Aw. This is much better than the last scan. We got such a terrible picture last time!
> Mr Carlisle: That is amazing.
> Olivia: So we're looking at the NT here. Do you see these white lines and the black fluid black in-between [points]? That's the NT and I can see it is tiny. We want it under three millimetres and it definitely is. Now are you going to turn over and give mum a good picture?
> Mrs Carlisle: He's being shy!
> Olivia: Baby's being difficult! I'll try and coerce baby into moving. Which way are you going to go, baby?
> Mr Carlisle: The baby must be like me. Never listens!
> Mrs Carlisle: He's got that from you! [Olivia takes measurements of the NT as 1.64mm and 1.70mm].
> Olivia: Lovely, fantastic, that's miles under. Are you going to roll over, baby?
> Mr Carlisle: He doesn't want to play at all does he?
> Mrs Carlisle: He's going "get off! Who the hell is that?"
> Mr Carlisle: He's stubborn.

Olivia: Yes, it definitely is a boy! [All laugh] Baby is being very naughty now.

Mr Carlisle: Come on! I think he's moving. Or she.

Mrs Carlisle. It's definitely a boy. He's just like his Dad!

Olivia: He's being very lazy. You can sleep all night, can't you baby?! I want to get a picture. Come on stop teasing! Baby's a little rascal.

After a few seconds, the unborn baby's face appears on the monitor. This is met with cheers from Olivia and Mr and Mrs Carlisle. Some pictures are taken and handed to Mr Carlisle.

Olivia identifies the unborn baby's movement as '*swimming*' and confirms some anatomical features for the benefit of Mr and Mrs Carlisle. Throughout much of the scan, Mr and Mrs Carlisle engage in what Kroløkke (2011: 26) defines as 'ultra-gasms', namely utterances or 'response cries' (Goffman 1981) conveying a sense of awe or amazement at the imaging on the monitor ('*wow*', '*aw*'). Prior to soliciting any information regarding the screening procedure, Mrs Carlisle praises the clarity of the imaging in contrast to the '*terrible picture*' she received following her previous scan. After establishing a seemingly small NT, Olivia urges the baby to '*turn over*' and *'give mum a good picture*'. Mrs Carlisle associates her unborn baby's movements to '*being shy*', referring to the baby as a '*he*' throughout much of the consultation in the absence of knowledge regarding the baby's sex. Mr Carlisle playfully associates the lack of movement to his own personality characteristics ('*he must be like me*. *Never listens!*'), before Mrs Carlisle confirms '*he's got that from you!*' This is what Becker et al. (2005: 1300) term 'resemblance talk', meaning the words and discussions about relatedness establishing what family is within a given family and which become an outward bodily expression of biological relationships. Mrs Carlisle later assumes the voice of the silent unborn baby by playfully urging Olivia to '*get off*'. Mr Carlisle attributes the lack of movement to a refusal to '*play*' and to the baby's '*[stubbornness]*', with Olivia accrediting this '*[naughtiness]*' and '*[laziness]*' to being male in her pursuit of a picture of the '*rascal*' to memorialise the occasion.

In the consultation between Olivia and Mr and Mrs Carlisle, the focus appears to be on ascertaining pictures of the unborn baby, on ascribing gender expectations, and on reproducing family. Morgan (1996) identifies family relationships as processes which are fluid, complex, and subject to adjustment. Kinship is a symbolic rather than 'natural' or exclusively biological driven cultural system (Franklin 1997; Strathern 1992) yet great significance is still attached to genetic or 'blood' relationships (Duster 1990; Rapp 1995). Such 'family practices' (Morgan 1996) emerge in the ultrasound room. Sonographers construct the imaging on screen *into* a baby by drawing on visible markers of personhood and familial resemblances, thereby 'weaving the foetus into a network of kinship relations' (Mitchell 2001: 134).

Along with attributing agency to the unborn baby (ascribing movements to human attributes including stubbornness, naughtiness, and gender), parents-to-be are bestowed an arena in which other family members not only attend but assist in welcoming a new family member. Familial exchanges are encouraged via the identification of anatomical features replicating either or both parents-to-be. In one example, Esther points out the '*nasal bone*' to which Mr Dalton replies '*I hope the baby has got [Mrs Dalton's] nose!*' Esther laughs but responds '*the nasal bone being absent can have problems linked with Down's syndrome so it's good it's there*'. Whilst Esther ascribes to the medical dimension of ultrasound scanning, Mr Dalton constructs a personal nonmedical interpretation. This is supplemented in offering parents-to-be an ultrasonic picture of their unborn baby, a material souvenir not only ascribing agency (and an identity) to the unborn baby but also reproducing kinship by creating a material memory of a new family member.

'A very different atmosphere'

I have outlined midwives' and sonographers' accounts which identify the problems caused by treating an ultrasound scan as a social event (such as when there is a miscarriage). However, sonographers routinely participate in constructing and trivialising Down's syndrome screening as an opportunity to meet the unborn baby. Esther (SAD sonographer) claims parents-to-be '*don't realise the NT scan is a diagnostic test*' since '*this is not relayed to women as a diagnostic tool*', meaning

parents-to-be undertake scans '*willy-nilly*'. If midwives and sonographers express such concerns, why do they continue supporting the practice? Why do they persist in promoting a jovial and informal atmosphere? If parents-to-be truly expect the output of NT scans to exclusively be the acquisition of '*pretty pictures*' (Lisa, SAD sonographer), why are they not scrapped? During an interview, Sophie (SAD sonographer) describes her approach when performing NT scans:

> People do have ultrasound scans just for fun. Personally, I always try and check everything's OK first because it's a very different atmosphere in the room if you've got a nuchal fold measuring 4.0mm to one that's measuring 1.2mm and you've got a baby lying there kicking its legs and waving because a nice small nuchal fold is very good news on a scan. I know we've got to check all other factors but if it's good news and it's positive, as long as everything's OK, I usually am quite relaxed and chat with people as that's what they want. They do want a first scan, they want nice pictures, and they want the baby waving.

Sophie suggests the perceived absence of any serious concern ('*[a nuchal fold] measuring 1.2mm*') allows her to create an appropriate atmosphere in which an unborn baby is not only announced when there is '*very good news*' but is also coded according to movements ('*a baby lying their kicking its legs and waving*) and validated through producing material memories ('*they do want a first scan, they want nice pictures, and they want the baby waving*'). Sophie, however, suggests the absence of '*good news*' would create '*a very different atmosphere*', intimating she would not produce '*waving*' images of the baby should a problem be suspected. There were occasions in which NT scans were utterly or relatively devoid of positive utterances framing it as an enjoyable day out. I observed only one NT scan where a problem was suspected. Esther (sonographer) told Mr and Mrs Tomkins (parents-to-be) she believed the unborn baby had cystic hygroma, a congenital multiloculated lymphatic lesion usually found in the left posterior triangle of the neck. Esther informed Mr and Mrs Tomkins cystic hygroma is linked to Turner syndrome. As Sophie intimates, the scan took on a 'very different atmosphere' in

which playful exchanges, regularly a staple of the ultrasound encounter, became absent.

During such events, sonographers adjust their body language and interpretation of the screen image to the emerging results. They distance themselves from parents-to-be and initially do not 'engage in any dialogue about what is seen on the ultrasound image', hopefully protecting them from a future surprise (Schwennesen and Koch 2012: 290). They attempt, in such instances, not to contribute to 'the enactment of the image on the screen as a living child' (2012: 290). However, even when the unborn baby is classified as 'normal', this does not mean the atmosphere is always jovial and informal. The following fieldnotes are taken from an NT scan between Esther (SAD sonographer) and Mr and Mrs Williams (parents-to-be):

> Mrs Williams: I'm a bit nervous because we're IVF[61].
> Esther: OK. Let's have a look. Do you see this black gap between these two white lines? That's the NT. When it's enlarged, it's associated with chromosomal abnormalities. We want the NT below three millimetres. [Esther continues to describe the procedure] There's the little Buddha belly there!
> Mrs Williams: Like mine then [smiles].
> Esther: Now let's look at that NT.
> Mr Williams: It's that bottom black line, is it?
> Esther: Yes. It's this line here to this line here [pointing]. We take three measurements and usually take the largest of them all.
> Mrs Williams: It's quite scary isn't it?
> Mr Williams: Just relax.
> Esther: Yes just relax. Where are you going to deliver?
> Mrs Williams: Watermont. Is this OK?
> Esther: Of course!
> Mrs Williams: We're consultant-led care as well. Does the baby have enough room in there?

[61] IVF (in-vitro fertilisation) is a process by which an egg cell is fertilised by sperm outside of the body. It is a major treatment for infertility once other methods of assisted reproductive technology have failed.

Esther: Yes, baby's got plenty of room. And baby looks to have the hiccups now!
Mrs Williams: But he definitely has enough room?
Esther: Yes. That's just me pressing down with the transducer so don't worry.
Mr Williams: So on looking initially, it's the size of [pause].
Esther: Small. It's a small size which is good.
Mrs Williams: Good.
Mr Williams: Great.

During the scan, Mrs Williams becomes '*nervous*' owing to her IVF treatment. Mrs Williams describes the scan as '*scary*', twice questions whether the unborn baby '*has enough room*', and solicits a response from Esther on the suitability of another hospital ('*Watermont*') for delivery. A number of parents-to-be are anxious prior to the scan and, admittedly, do not necessarily ascribe to constructing the procedure as an enjoyable excursion. This worry was most common in mothers-to-be over the age of thirty-five who, at a 'higher-risk' of having an unborn baby with Down's syndrome, frequently accounted for their decision to have screening by citing their age. When parents-to-be had previous pregnancy complications or other concerns, sonographers – explicitly or implicitly – toned down the enjoyable component of NT scans and prioritised medical information ahead of the personal and social meanings of the procedure. This is reflected in Dr Karman (FMD consultant) only undertaking NT scans, admittedly a rare occasion, with parents-to-be who have current/previous pregnancy complications such as recurrent miscarriages or a history of chromosomal conditions. Otherwise, Dr Karman is granted immunity from, to return to an earlier sentiment, the *easy stuff* which *clogs up the clinic*. Thus, NT scans are expected to proceed without a setback by producing a lower-risk result.

However, whilst not all screening consultations in Springtown are reconstructed as enjoyable days out and opportunities to welcome new family members, this is a common situation. The boundaries between the medical and social components of a scan are often shifting, permeable, and difficult to untangle (Roberts 2012). In

SAD, this can certainly be linked to sonographers working in a privately-funded institution. In exploring the concept of 'body work' offered by Twigg et al. (2011: 171), roughly defined as 'paid work on the bodies of others', Kerr's (2013) analysis of assisted conception suggests in privately-funded settings, care is overtly organised, more than NHS hospitals, around an ethos of individual consumption. Similarly, Strong (1979) argues doctors in privately-funded practice are more likely to personalise their communication, and be prepared to have their recommendations questioned, than in state-funded care. In the context of increasingly marketised healthcare, professionals must thus negotiate the tensions between medical care and consumer choice (Kerr 2009, 2013).

In SAD, sonographers were encouraged by admin staff to engage in marketing and customer relations by promoting or '*selling*' (Bethan, SAD admin staff) further ultrasound scans to parents-to-be following an NT scan. Indeed, Bethan frequently emphasises that Springtown is '*first and foremost a business*'. Such an ethos of individual consumption arguably leads sonographers to tailor their treatment and invoke greater empathy for clients in offering a service. In doing so, NT scans are constructed as 'consumable' (Taylor 2008). Consumption is part of a way of life, a series of rituals related to identity-work, membership, and belonging (Douglas and Isherwood 1979). In arguing that consumption is a collective and communicative rather than individual endeavour, Douglas and Isherwood show how people use goods to provide information about themselves and how patterns of consumption reveal the pattern of society. What is more, consumption habits, deemed as natural as skin, are 'criteria for membership and become weapons of exclusion' (1979: 59). In SAD, people are exercised as consumers so the scan becomes another occasion for consumption, that is, an enjoyable day out where parents-to-be meet a new family member. I discuss the notion of 'exclusion' and how certain identities are produced and reproduced – specifically the 'identity' of an unborn baby – further in chapters seven and eight.

Summary

I began this chapter by identifying the contradictions between the accounts and practices of professionals. They identify the substance of aligning with the rhetoric

of informed choice and non-directive care but concurrently criticise screening for Down's syndrome for its inaccuracy and its capacity to *open a can of worms*. However, professionals' conduct in practice shows how during consultations with parents-to-be, the discursive 'resource' (Garfinkel 1967) of informed choice and non-directive care is drawn upon to make their claims. That is, they bestow a glut of information to parents-to-be and, in essence, see what happens. For Bosk (1992: 10), the rhetoric of choice is a ground for 'patient abandonment'; the satisfaction of their care obligation is not 'taking charge of decision-making', acting but not acting decisively (1992: 27). In Springtown and Freymarsh, similarly, policies of informed choice and nondirective care, enacted by professionals by communicating neutral scientific representations of bodily processes, allows professionals to strategically distance themselves from full responsibility for screening whilst actively playing a key role in shaping this practice. In Konner's (1988: 366) terms, its description constitutes 'the safety of the norm', that is, one 'feel[s] safe because you do what everybody else is doing'.

Once more, my analysis goes beyond Bosk (1992) by identifying and exploring what this 'abandonment' specifically accomplishes, namely, that parents-to-be are enacted as rational and logical decision-makers. Professionals can subsequently detach from screening and accomplish it as a matter of concern for parents-to-be rather than themselves. As the decision for having screening or not rests with parents-to-be, professionals are not responsible and screening is therefore constructed as a matter of personal rather than professional concern (Latimer 2000). However, parents-to-be are often described as not being attuned to the seriousness of Down's syndrome screening and so submissively opt for the procedure. This trend has been recorded in this fieldwork and in the literature, with parents-to-be seemingly consenting to Down's syndrome screening as an instance of conformity rather than any active decision-making processes (Heyman et al. 2006; Lippman 1994; Marteau 1995; Pilnick et al. 2004; Santalahti et al. 1998; Tsouroufli 2011). This means choices are far from free, with the divide between voluntary choice and socially enforced coercion becoming blurred (Kerr et al. 1998). Combined with the reallocation of responsibility for decision-making to parents-to-be, this produces circumstances in which screening, performed via

locally-situated routines, is accomplished as an expected procedure in pregnancy rituals. The conduct of care, thus, produces the downgrading of screening (with decision-making not part of professionals' role) and, in turn, the naturalisation of screening as a 'normal' part of pregnancy.

In the second part of this chapter, I revealed how ultrasound scans are constructed as enjoyable days out where parents-to-be and family members meet an unborn baby and reconstruct kinship rather than occasions in which medical concerns about an unborn baby are identified. This accomplishes two things. First, Down's syndrome screening is produced and reproduced as a routine part of pregnancy. The rituals of opting for ultrasound scans, obtaining pictures, and inviting family and friends – as well as recreating family narratives – accomplish disengagement with the technology's main function. Professionals' imperative to merge medical information with a consumer-friendly performance implicitly, and inadvertently one suspects, trivialises Down's syndrome screening and downgrades its value as a medical procedure.

Second, Down's syndrome screening – by becoming constructed as a day out and particularly as a chance for reproducing kinship – accomplishes the production of (ideal) bodies and families. The ascription of physical features and movements of the unborn baby to personality traits, favourable physical appearances, and certain gendered conduct such as dancing and playing sports constructs certain types of expected bodies. This is reflected in NT scans becoming either 'days out' or encounters taking on 'a very different atmosphere'. Whilst the former reinforces ideas of a 'normal' body, the latter strengthens the category of an 'abnormal' or 'potentially abnormal' body. I build on this point more in chapters seven and eight where I attend to how Down's syndrome itself is classified within antenatal care. In chapter seven, I identify how Down's syndrome is made absent during screening consultations and is substituted with discourses of 'risk', 'problem', and 'abnormality' which accomplish and re-accomplish the condition as a negative pregnancy outcome. In chapter eight, I explore how such constitutions connect with cultural ideologies of perfection, how this implicates and disciplines mothers-to-be (particularly those aged thirty-five and above) into making certain choices,

and how the classification of the unborn baby with Down's syndrome as a 'foetus' dehumanises, and can lead to the effacement of, the 'baby' with Down's syndrome.

Chapter Seven
Constituting Down's Syndrome and Risk in the Clinic

In chapter six, I explored the conduct of care with respect to screening for Down's syndrome. I have shown how informed choice and non-directive care are used as a rhetoric which allows professionals to detach from and dispose of screening. This both institutes parents-to-be as rational decision-makers and naturalises Down's syndrome screening as a 'normal' practice. Additionally, I captured how ultrasound scans are cast as enjoyable days out and opportunities to produce and reproduce a future family. This accomplishes the naturalisation of screening as an expected routine and the promotion of ideal bodies and families. The identification of physical features and personality traits produces ideas around what bodies – in relation to biological kinship and wider cultural values – are prized.

I extend this latter argument in chapters seven and eight by exploring how Down's syndrome itself is classified in Freymarsh and Springtown. In chapter seven, I reveal how professionals often identify Down's syndrome screening as 'eugenic' and the condition itself, using their discourse, as 'viable' and 'compatible with life'. However, I show that the condition (and so its definition as a 'viable' pregnancy outcome) is rarely discussed during screening consultations. This relative silence is upheld owing to three observations: 1) the UK public is interpreted as 'knowing' what Down's syndrome is; 2) the organisation of care dictates that the condition is not important enough to justify explanation within consultations; 3) professionals frequently admit to holding minimal knowledge of Down's syndrome. In addition, I show how Down's syndrome, absent yet present, is organised and constructed within universalising discourses of 'risk', 'problem', and 'abnormality' which, perhaps inadvertently, fashion and sustain a pessimistic outlook of the condition. In sum, I argue the mundane interactions and implicit yet deeply embedded ideals emerging in Freymarsh and Springtown can highlight one reason why termination rates have remained between 89% and 94% for over twenty years across both England and Wales (Morris and Springett 2013).

Answering why termination rates remain high would be best addressed by seeking out parents-to-be with first-hand experience of receiving a diagnosis and having a subsequent termination of pregnancy. However, there are several potential pitfalls. How would one access such people? If they were located, would they participate? Would their consent be fully 'informed'? Would delving this deep into such personal worlds constitute unethical practice? Regardless of how sensitively a project is planned, one must be cautious of such topics, notwithstanding the emotional impact such a study has on a researcher (as discussed in chapter four). However, there are examples of previous studies exploring how and why parents-to-be choose to terminate or continue a pregnancy following a Down's syndrome diagnosis (Helm et al. 1998; Korenromp et al. 2007; Olarte Sierra 2010; Reist 2006; Skotko 2005; Tymstra et al. 2004).

'Compatible with life'

In Freymarsh (both FAD and FMD) and Springtown (SAD), professionals denounce Down's syndrome screening owing to the limited accuracy of screening and the creation of undue anxiety. Another criticism extends to the supposed eugenic purposes it satisfies. The troubled relationship between science, medicine, and eugenics in the context of reproductive technology has been previously recognised (Cunningham-Burley and Kerr 1999; Kerr et al. 1998; Kevles 1995), with some sceptical of the disassociation between scientific innovation and an old eugenics (Jones 1994; Shakespeare 1995). In FAD and SAD, a number of midwives and sonographers claim Down's syndrome screening, a practice they are primarily responsible for, represents a eugenic service. This mirrors Duster's (1990) claim that whilst the 'front door' to eugenics seems closed, the 'back door' of disease and disability prevention remains ajar. During a conversation after an NT scan, Esther (SAD sonographer) denounces screening as serving eugenic purposes:

> Mr and Mrs Jansen (parents-to-be) leave the room. Esther comments Mrs Jansen appears primarily concerned with obtaining pictures of the unborn baby. I ask if she thinks Mrs Jansen was '*formally informed about screening*':

> Esther: The only difference between eugenics and screening is informed consent. I have a real problem with screening for Down's [syndrome] because there's much worse out there. I fear it's eugenic. More severe conditions like Patau's [syndrome] or Edward's [syndrome] are rare but not compatible with life whereas Down's is compatible with life. Everyone wants the perfect pregnancy these days. In my grandmother's generation, they didn't expect healthy babies every time. Miscarriages, stillbirths, it was expected babies wouldn't always make it. But these days, we have all the technology to know about babies and their potential problems. We've experienced a cultural shift towards perfection. [...] What makes this a non-eugenic service is the idea of getting informed consent. But informed consent is not consent at all. It's not informed if parents do it as part of the routine of pregnancy. Parents are in a culture where they're expected to have all these tests and stuff. Scans like these and this care has been routinised so it's just consent, it's not informed consent. A number of patients still have no idea why they're in the hospital for a screen for Down's because it's so routinised and seen as what people are supposed to be doing.

Esther's rich and passionate denigration of screening practices corresponds to its naturalisation in the clinic and its '*eugenic*' agenda. Current measures supposedly securing parent-to-be approval for screening, for Esther, provide and promote an illusion of consent. For Esther, the rhetoric of choice is commonly and narrowly conceived as informed consent. She also identifies Patau's syndrome and Edward's syndrome as '*severe*' and '*rare*' conditions which are '*not compatible with life*'; Down's syndrome, in contrast, is '*compatible with life*', leading Esther to stress that '*there's much worse out there*'. Drawing on experiential and historical knowledge of family members, Esther positions prenatal technology as prompting a '*cultural shift*' fuelling parental expectations of predestined perfection during a pregnancy. She concludes informed consent is '*not consent at all*', with parents-to-be perfunctorily and inertly undertaking screening practices as '*part of the routine of pregnancy*'. Since they are '*expected to have all of these tests and stuff*', the notion of informed consent is farcical since parents-to-be, in Esther's view, become docile

bodies towing the line of expectations. This mirrors Bosk's (1992: 141) claim that what makes such practices acceptable is 'the high degree of individual choice that appears to be exercised' yet 'how fragile that choice might be' is unappreciated. During a later interview, Esther similarly suggests '*medicine takes over at the cost of quality of life*' and '*it's not us in the medical profession who should be denoting what quality of life is*'.

Here, Esther produces classifications and divisions between 'compatible' and 'non-compatible' conditions, the former becoming a catch-all term for an unborn baby who is 'viable' (who can live) and who can enjoy a good 'quality of life'. In FAD and SAD, professionals construct Down's syndrome as 'compatible with life', commonly with reference to the separate conditions of both Edward's syndrome and Patau's syndrome which are 'incompatible with life'[62]. During a higher-risk screening consultation, Nancy (FAD midwife) describes these, along with Turner syndrome, as '*the nasty ones*' which are '*pretty much incompatible with life*'. In an interview, Amy (FAD midwife) claims whilst she would not terminate an unborn baby with Down's syndrome, she '*probably wouldn't continue with Patau's [syndrome] or Edward's [syndrome]*'. Wertz (2000) reports how professionals differ in their perceptions of how 'serious' a condition like Down's syndrome is. However, Freymarsh and Springtown professionals seem unanimous in identifying the condition as 'viable' and as offering a good 'quality of life'. During an interview, Francine (FMD head midwife) suggests that diagnoses of Patau's syndrome and Edward's syndrome are *'easier*' for parents-to-be when they must make a decision regarding a termination following a diagnosis:

> I think a misinterpretation some women have is even if they're told they've got a baby with Down's [syndrome], we'll be able to tell them what degree of Down's they have, the severity, which obviously we can't.

[62] Wilkinson (2010), a practicing physician, reminds the medical profession that a small proportion of children with Edward's syndrome, a supposedly 'non-viable' condition, survive to middle or late childhood or even adulthood. Criticising professionals who question the decision to continue a pregnancy following a diagnosis of Edward's syndrome, Wilkinson (2010) argues they should instead support and engage with parents-to-be who make this decision. His discussion revolves around a case in which a woman reports feeling abandoned and criticised by professionals for continuing a pregnancy following a diagnosis of Edward's syndrome (Thiele 2010).

> That's very difficult because a couple may be able to cope with a mildly affected Down's baby. But if they've then got behavioural problems, and cardiac issues, you can't give them that answer of to what degree the baby will be affected. Edward's [syndrome] and Patau's [syndrome] is easier. The people I've counselled with abnormal results or with a higher-risk result, if they know or if they've been told that they've got a baby that's incompatible with life, it's like having your 1 in 3 chance [result of having a baby with Down's syndrome] compared to your 1 in 100. They may not decide to terminate the pregnancy but they know in the back of their minds what's likely to happen to the baby whereas with Down's, they haven't got that. It's still in that grey area.

Francine highlights how the uncertain prognosis of Down's syndrome, a condition compatible with life yet one that varies considerably between each case in relation to a person's mental and physical condition (Tymstra et al. 2004), causes problems for parents-to-be in decision-making processes. She recognises although parents-to-be may choose not to terminate a pregnancy following a diagnosis of Edward's syndrome or Patau's syndrome, this diagnosis is '*easier*' than Down's syndrome since the latter is '*in that grey area*'. A minority of midwives and sonographers admit they would have screening as a gateway to diagnostic tests for information-gathering purposes rather than for terminating the pregnancy. However, the vast majority of midwives and sonographers condemn such practices owing to the compatibility of Down's syndrome and the need to direct resources elsewhere. During an interview, Lois (FAD midwife) explains:

> It is surprising we test for Down's syndrome when there are lots of things worse than it. For example, cystic fibrosis[63], and it's something like one in twenty people are carriers. I know the risk is lower of your child having cystic fibrosis but that would be a massive thing. It shortens your life expectancy a lot more than Down's syndrome does. So I do find it surprising in a way that there's so much onus on the Down's test. But

[63] Cystic fibrosis is an autosomal recessive genetic disorder critically affecting organs including the lungs, pancreas, liver, and intestines.

> once a screening test has been introduced, it's unlikely they'd take it away.

Lois categorises cystic fibrosis as a '*massive thing*' which is '*worse than*' Down's syndrome, before concluding the naturalisation of Down's syndrome screening prevents its withdrawal from medical practice. Amy (FAD midwife) similarly questions why Down's syndrome screening '*is highlighted because there are loads of other conditions out there that can be picked up*'. She predicts parents-to-be undertake screening because '*they probably just feel that since the test is there and we're offering it, they should take it*'. Likewise, Francine (FMD head midwife) suggests the routinisation of screening, at the expense of '*forgetting that a child could be born with cerebral palsy or autism*', shapes it as an '*anticipation engrained in them*' which '*cannot be taken away because we've started it*'. Nonetheless, professionals often embrace discourses such as 'compatible with life' and 'viable' as catch-all categories for criticising and downgrading screening practices.

The most common complaint, however, is that screening for heart defects, cited in Freymarsh and Springtown as the leading cause of death for unborn and newborn babies, is overlooked in favour of Down's syndrome screening. Dr Karman (FMD consultant) is critical of Down's syndrome screening, suggesting resources would be better allocated elsewhere since the condition is '*compatible with life*'. Bethan (SAD admin staff) likewise claims that when parents-to-be contact Springtown, she informs them that cardiac issues are more common than Down's syndrome with a view to '*selling the cardiac scans*'. This offer is frequently rebuffed, however, since '*it is all Down's, Down's, Down's!*' In an interview, Lisa (SAD sonographer) suggests:

> The NHS and a lot of people have a bee in their bonnet about Down's syndrome when the baby is far more likely to have a heart defect. But people have this big thing like it's terrible that the baby has Down's syndrome, whereas they're much more likely to have a baby with a heart defect. For the number of Down's syndrome babies you're detecting, they should put more money into screening for heart defects.

Lisa suggests extensive screening for heart defects – a more pressing concern for reproductive medicine – is disregarded in favour of detecting the '*terrible*' outcome of Down's syndrome. During an interview, Elena (FMD head midwife) dislikes screening not only because it detracts from more pressing clinical concerns, but also because Down's syndrome is a condition which is compatible with life:

> I think just because we can screen for Down's [syndrome], why should we? The money would be better spent elsewhere on cardiac issues and other problems. Because [people with Down's syndrome] are the gentlest, most loving people in the world. I wouldn't personally terminate a pregnancy for the condition but I wouldn't deny access to information. [...] I think Down's screening is a waste of time, effort, and money which could be well spent somewhere else for the sake of detecting how many Down's children [via prenatal testing]. And you could spend that money on giving them the most appropriate support and the family the most appropriate support you can get rather than just killing another human being because they just happen to be a bit different. I think it's just eugenics by another name. Enough is enough. I think having Down's syndrome has been demonised.

After suggesting monetary and professional investment should be focused on other screening programmes or raising awareness of the condition, Elena produces a generalising account of people with Down's syndrome as '*the gentlest, most loving people in the world*'. Although she remains detached by pledging allegiance to principles of nondirective care and informed choice, Elena claims she would not personally terminate a pregnancy following a diagnosis of the condition. She denounces it with reference to the estimated number of live births of babies with Down's syndrome in the UK. Elena claims '*enough is enough*', citing screening as '*eugenics by another name*' and concluding Down's syndrome '*has been demonised*'.

Such recommendations arguably extend the medical gaze by realigning a focus on surveillance practices other than Down's syndrome screening (Armstrong 1995; Foucault 1973). However, such recommendations are used here by professionals

as a resource for criticising screening and the provision of services. The positive image of Down's syndrome conjured up by Elena is reflected in her recognition during another conversation that Down's syndrome '*is nowhere near as bad as the other stuff*', the other stuff referring to occasions in which a condition becomes categorised, using professionals' discourse, as 'incompatible with life' or 'non-viable'. The following fieldnotes were taken at a multi-disciplinary team meeting[64] organised by FMD:

> Around fifteen professionals – obstetric consultants, head midwives, cardiac specialists, neurologists, and alike – are in the meeting. Dr Karman begins by welcoming staff and directing their gaze to the large projector screen in FMD displaying 'cases'. [...] Dr Karman provides an update on a case where the child of a couple was postnatally diagnosed with Down's syndrome. Dr Karman informs attendees *'they were disappointed but positive. They said "it's a shame but we'll love him anyway", so there you go*'. This was met with smiles from most attendees. Some called out '*that's great*' and '*good for her*'.

Such meetings frequently provoke disagreement yet equally become a mechanism in which forms of knowing are affirmed and reproduced (Latimer 2013). During this particular meeting, professionals applaud the absent parents for their attitude toward a Down's syndrome diagnosis. This echoes midwives' and sonographers' accounts when they construct a positive image of the condition owing to its compatibility with life. In their study on how scientists and clinicians understand the new genetics, Cunningham-Burley and Kerr (1999) identify how participants assemble strategic rhetorical boundaries between science and society. They subsequently direct attention to the valuable social implications of intervention, rather than to the science and technology itself, and subsequently protect their cognitive authority whilst distancing the new genetics from charges of repeating

[64] Meetings are held monthly. A wide range of specialists gather in FMD to discuss hospital 'cases' (parents-to-be attending the clinic). Dr Karman governs proceedings and directs the gaze of attendees at a large screen displaying a list of cases. The cases are recorded in a number of ways, including whether they are under the care of Freymarsh or referred from another hospital, the condition in question, the tests already undertaken, the 'next move', whether the baby has a chance of survival, the outcome (whether the baby has died and/or been delivered), and any other noteworthy contributions. The respective parents-to-be are not physically present in the meeting.

an old eugenics. Whilst the new genetics produces and communicates neutral information offering greater choice, eugenics is framed as a feature of totalitarian regimes and a politically distorted pseudo-science constituting a knowledge abuse (Cunningham-Burley and Kerr 1999; Kerr 2003; Kerr et al. 1997).

However, in Freymarsh and Springtown, professionals often align with a similar charge aimed at Down's syndrome screening, censuring the practice for its alleged eugenic agenda. Rather than appearing to hold negative views of Down's syndrome as previously claimed (Sooben 2010), these professionals seem to accept Clarke's (1994: 19) suggestion that Down's syndrome is 'one way, among others, of being human'. Such positive framings outwardly correspond to other research and autobiographical accounts of parents who have a child with Down's syndrome which recognise their situation as not one which should always be viewed as unwanted and tragic (Alderson 2001; Clark 2008; Groneberg 2008; Hodapp 2007; Lewis 2008; Skotko 2005; Thomas 2014; Van Riper and Choi 2011; Van Riper and Selder 1989; Voysey 1975).

Absence in antenatal encounters

So if professionals, as well as research and autobiographical literature, account for Down's syndrome in positive terms, how is it constituted in everyday affairs, that is, in screening consultations? Sooben (2010) claims that professionals provide a functional and brief description of Down's syndrome during screening which conforms to a biomedical problem orientation, with Bryant et al. (2006) similarly arguing antenatal settings provide little opportunity for people to discuss and explore their beliefs surrounding disability. In analysing the information provided around Down's syndrome in antenatal leaflets, Bryant et al. (2001) and Murray et al. (2001) likewise suggest that they contain false, misleading, and inconsistent information which fashion a negative image of the condition.

Interestingly, in Down's syndrome screening consultations in FAD and SAD, the condition is seldom addressed in explicit detail. At most, Down's syndrome is cited without any further clarification. The following fieldnotes are taken from an NT scan between Esther (SAD sonographer) and Mr. and Mrs. Jones (parents-to-be):

Esther: So here's your baby. You can see the heart beating away there. Little one's hiccupping as well [Mr. Jones and Mrs. Jones laugh].

Mrs. Jones: Maybe it's that sausage and chips I just had! [All laugh].

Esther: So we measure the nuchal translucency which is the pad of fluid at the back of baby's neck. When it's enlarged, it increases the risk of baby having a chromosomal abnormality. We do the measurement in combination with your blood-work so you will have some bloods done today. So the nuchal translucency and your age and your biochemical bloods and the length of the baby will give you a definite risk of three chromosomal abnormalities. We only screen for three, one of which is Down's [syndrome] which I'm sure you know but also we look at Patau's [syndrome] and Edward's [syndrome]. Now I don't know if you've seen about these on the internet but they're three of the most common, two of the most lethal. During this screening, you'll be placed in either the lower-risk or higher-risk bracket and if you're higher-risk, you're advised to have an amniocentesis. Oh God you've got a wriggly one here!

Mrs. Jones: It looks like it's doing the splits [laughing].

Esther: Yes, baby's doing a dance! We like the nuchal translucency to measure less than 3mm and your measurements are all under 3mm which is all great.

Esther begins the scan by identifying the unborn baby's position and its heartbeat, later interpreting its movement as a sign of '*hiccupping*'. Esther's reading of movement as hiccupping means the unborn baby can be viewed as an entity separate to the mother (and also by its label as a 'wriggly one'). Mrs Jones jokingly cites this as '*the sausage and chips I just had*', demonstrating how Mrs Jones reclaims her and her baby as an integrated entity. Humour is littered throughout the encounter; Mr and Mrs Jones are amused by the unborn baby hiccupping which is attributed to Mrs Jones' pre-scan conduct (eating), Mrs Jones frames the unborn baby's movement as replicating the splits, and Esther describes the unborn baby as doing a dance routine. This collaborative coding, essential to making the imagery on the ultrasound monitor personally and socially meaningful, reflects the intricate

shifts between threat and thrill, that is, the (clinical) information communicated around screening practices and the (non-clinical) performances of a sonographer, parents-to-be, and the unborn baby. The threat involves divulging details of nuchal translucencies, chromosomal conditions, and diagnostic tests. In contrast, the thrill involves offering parents-to-be an entertaining experience. Ivry (2009: 195) refers to this as the 'humour and horror' of ultrasound scanning.

But what happens to Down's syndrome here? Throughout the encounter, whilst the condition is cited, no further details on it are tendered by Esther nor solicited by the Jones'. Assumptions govern proceedings; the condition is shaped as something which the Jones' '*know*'. Interestingly, Esther describes the three syndromes screened for – Down's syndrome, Edward's syndrome, and Patau's syndrome – as '*chromosomal abnormalities*' and '*three of the most common, two of the most lethal*.' Esther refrains from clarifying which syndromes are lethal but rather relies on Mr and Mrs Jones calling upon tacit assumptions regarding which conditions are lethal and which condition is not. Similar to Garfinkel's (1967) 'et cetera' principal whereby people rely on others to understand the situation based on their own knowledge, Down's syndrome is framed as a taken-for-granted category requiring no further explanation of symptoms, prognosis, and the 'social realities' of the child who may have the condition (Rapp 1988: 150). The following extract reports on a screening consultation between Tara (FAD midwife) and Mrs Leslie (mother-to-be):

> Tara: So you know that it's a simple blood test, yes?
> Mrs Leslie: Yes.
> Tara: Great. Well we take your bloods and this will be sent off to the labs. You'll receive a letter in about seven to ten working days telling you your result. And this test goes according to your age so the older you are, the higher your risk is for having a baby with Down's syndrome.
> Mrs Leslie: OK.
> Tara: You will get a lower or higher-risk result. If your lower-risk, we won't do anything else but that's not to say that there's no chance that your baby has Down's syndrome.

Mrs Leslie: Yes [nods].

Tara: If you have a higher-risk result, we'll call you up and invite you in to offer an amniocentesis. Have you had an amniocentesis before?

Mrs Leslie: No but I've heard of it.

Tara: Ok. Well it's a large needle which goes into your tummy and this takes some fluid from around your baby which is sent off to be looked at. This is the test done to provide a proper diagnosis.

Mrs Leslie: Yes.

Tara: This test just tells you whether you have a higher-risk or lower-risk.

Mrs Leslie: Yes.

Tara: OK then. So you don't smoke and this isn't an IVF, no?

Mrs Leslie: No.

Tara takes more details from Mrs Leslie. After this, both Tara and Mrs Leslie leave the room so Mrs Leslie can have blood withdrawn for the quadruple screen.

The consultation begins with Tara describing Down's syndrome screening as a '*simple blood test*'. This constructs screening as a painless exercise, arguably threatening the principle of nondirective care designed to govern clinical practice. By framing screening as '*simple*', Tara could, albeit unwittingly, induce Mrs Leslie to undertake screening. Additionally, although Mrs Leslie's specific age is not highlighted, Tara's claim that older women have a '*higher-risk for having a baby with Down's syndrome*' may influence her decision. Nonetheless, my intention here is to recognise how Down's syndrome is overlooked during a consultation and is lost in the trappings of clinical jargon around risk results and diagnostic testing. Here, professionals concentrate on screening processes more than the condition itself (McCourt 2002; Williams et al. 2002b).

But what about consultations in which a Down's syndrome diagnosis is suspected after a higher-risk result is established? Within such consultations, the condition is rarely afforded much attention once again. Consider the following extract taken

from a consultation between Susan (FAD midwife), Mrs Garry (mother-to-be), and Mrs Garry's mother:

> Susan introduces herself and tells Mrs Garry she has received a 1:87 result. She explains the process which led to this 1:87 result. Susan tells Mrs Garry she is *'in the higher-risk group'* meaning she will be offered an amniocentesis. She explains the amniocentesis procedure whilst highlighting the 1% risk of miscarriage and other possible side effects including abdominal cramps and heavy bleeding. Susan then explains:
>
> > Susan: The result will only tell you for sure about three main chromosomal abnormalities: Trisomy 21 which is Down's syndrome, Trisomy 18 which is Edward's syndrome, and Trisomy 13 which is Patau's syndrome. Edward's and Patau's are serious chromosomal disorders and Down's syndrome you already know about. It varies from mild through to quite severe. So this will come to you in the first three days of analysis but then the rest of your chromosomes are analysed over two weeks. This could bring out some unexpected results, even things we don't know about yet. So you could know all of these things. How do you feel about having the test?
> > Mrs Garry: I'd be more worried if it was a 1 in 30 result. But it's 1 in 87 isn't it?
> > Susan: Yes. The number does make a difference. [Mrs Garry looks anxious about what decision to make] It's totally up to you. You don't have to decide today. You have to consider your feelings and then decide.
>
> Mrs Garry's mother asks how long they can wait before Mrs Garry can decide whether to have an amniocentesis. Susan explains there is currently an available timeslot for amniocentesis in two days' time. Mrs Garry says she will not accept this timeslot yet and will go home to discuss options with her partner. Susan accepts this, hands Mrs Garry a leaflet on having a higher-risk result, and says Mrs Garry can telephone her at any time if she has any questions. Mrs Garry asks questions such as '*who usually has amniocentesis*'

(Susan specifies '*it's totally up to you*') and claims the result was '*not as high as I was expecting anyway*'. She asks if the anomaly scan can detect Down's syndrome (Susan answers it might if the unborn baby has a heart defect) and if there is a timescale for deciding whether to have amniocentesis:

> Susan: Not really. But we do say it's better to have it sooner as it'll get harder to make that decision as the pregnancy goes on and you start to feel the baby kick and stuff.
> Mrs Garry: So the sooner the better really?
> Susan: Yes. But take your time in making the decision. We can do whatever you need us to do.

Susan asks if Mrs Garry has any more questions. She does not. Mrs Garry and her mother thank Susan before leaving the room.

After describing to Mrs Garry how she is '*in the higher-risk group*', Susan asks Mrs Garry how she feels about the test and reiterates this decision is to be made by her and her partner. Susan explains a timeslot for an amniocentesis has been booked, arguably dismissing the principle of nondirective care. Intimating that the gravity of the situation requires immediate attention could have an effect of disciplining Mrs Garry's conduct to undertake the procedure. Arguably, such claims are a form of pastoral power which governs bodies and organises actions (Foucault 1979). Power relations are enacted subtly, implicitly disciplining Mrs Garry into – or at best advising her to – conduct herself in a particular way. This is reinforced by Susan suggesting whilst Mrs Garry has full jurisdiction in deciding if and when she would like an amniocentesis, it would be '*better to have it sooner as it'll get harder to make that decision*', a decision presumably regarding a termination of pregnancy, '*as the pregnancy goes on and you start to feel the baby kick and stuff*'.

An important observation here involves Susan's explanation that an amniocentesis will initially provide information on Down's syndrome, Edward's syndrome, and Patau's syndrome. She also suggests amniocentesis can '*bring out some unexpected results, even things we don't know yet*'. Whilst Susan uses this to ignite reflection by

Mrs Garry on whether to undertake diagnostic testing, it also points toward the significance of incidental findings within reproductive practice. Bernhardt et al. (2013: 142) refer to this as producing 'toxic knowledge', whilst Alderson et al. (2004: 75) also speak of this as the 'dragnet' effect of screening which can involve women in decision-making about the future of a pregnancy they had not expected when first consenting. At this point, Susan defines Edward's syndrome and Patau's syndrome as '*serious chromosomal disorders*'; in contrast, Down's syndrome is framed as something Mrs Garry will '*already know about*' and which ranges '*from mild to quite severe*'. Again, no further information on the condition is tendered. In consultations, attention is focused instead on the designation of a risk factor, diagnostic testing, and the timescale of decision-making processes.

In such encounters, Down's syndrome shares similarities to Latour's (1999: 304) 'black box', a metaphor referring to the way in which 'scientific and technical work is made invisible by its own success'. In an analysis of how scientific knowledge is made durable, Latour (1991) suggests such work is only defined by its function; the complexity of a given system's internal workings is redundant providing it continues to serve its primary purpose and allows people to proceed in their daily activities. The inner workings of a black box are not open for debate since it has been accepted by the scientific community and society alike. Its output, therefore, retains the status of truth. Similarly, I suggest within screening practices, Down's syndrome becomes a curious black box, a 'known' entity remaining unopened and shrouded with the midwife/sonographer not providing, and the parents-to-be not soliciting or questioning, information around the condition. Following Latour, I turn my focus to unpacking how the black box of Down's syndrome is solidified and darkened, who is involved in this, and what this accomplishes.

The familiarity of Down's syndrome

Why is Down's syndrome made absent during consultations? I offer three reasons for this silence: 1) the familiarity of Down's syndrome; 2) the organisation of care; 3) professionals' limited knowledge of the condition. As alluded to in the extract between Esther and the Jones', Down's syndrome is constituted as a taken-for-granted category which is recognisable to parents-to-be, with several professionals

suggesting the UK public, at large, know about Down's syndrome. However, they claim this knowledge is limited to the noticeable anatomical features, or the 'face' (Latimer 2013), of people with the condition. During an interview, Amy (FAD midwife) explains:

> I don't think they understand the syndrome much unless they have a family member or friend who has a Down's syndrome person in the family. But I think they know what a Down's syndrome person looks like. They don't always know that a Down's syndrome person can live until they're sixty-five and seventy and they can live a relatively normal life in the sense that they get up in the morning, eat and dress, do all of the things that we tend to do.

Amy doubts whether parents-to-be, unless they know someone with the condition, hold detailed knowledge of life expectancy and the capacity to '*live a relatively normal life*.' Professionals feel mothers-to-be are not aware of the key features of Down's syndrome, a trend reported elsewhere (Bryant et al. 2006; Williams et al. 2002b) and which undermines the principle of informed consent. Amy suggests that despite a lack of awareness among parents-to-be, they often '*know what someone with Down's syndrome looks like*'. Similarly, Rita (FAD midwife) claims parents-to-be often convey their knowledge of Down's syndrome by stating people with the condition '*look that way*', referring to the distinctive facial features caused by the presence of an extra chromosome. Susan and Maggie (FAD midwives), among others, credit such awareness of the Down's syndrome 'face' to the familiar presence of people with the condition in UK society. In an interview, Camilla (FAD midwife) explains the difficulties of communicating information during a consultation to parents-to-be whose first language is not English:

> You often get women from other countries that don't speak English as a first language and maybe don't really understand what a baby with Down's syndrome is because of language barriers and cultural differences. Whether they really understand what we're asking of them or what we're trying to explain in consultations, I'm not convinced. Some

> people do say "I don't know what a Down's syndrome baby is." And you think, gosh, really [laughs]?

Camilla highlights the '*language barriers and cultural differences*' inhibiting one's knowledge of Down's syndrome. This is best accentuated in Camilla's concluding remark identifying her surprise at people not knowing '*what a Down's syndrome baby is*'. Similarly, Rapp (1988) notes how many recent US immigrants had no recognition of Down's syndrome whilst English-speaking communities generally knew about the condition. During consultations, my own observations reveal that Down's syndrome, in turn, was rarely explicated in any detail. Considering that '*it helps to know about Down's syndrome as this would affect whether [parents-to-be] have the screening or not*', as Lois (FAD midwife) highlights, and professionals often accuse parents-to-be of not holding great knowledge of the condition excepting facial features, why are no further details tendered? Susan (FAD midwife), among others, admits to '*not speaking about Down's syndrome*' but why is this?

One reason for this is the downgrading of Down's syndrome screening; ensuring that information on Down's syndrome is communicated is not a clinical priority. A second reason is the familiarity of the Down's syndrome 'face' hinders a broader discussion of the symptoms, prognosis, and 'social realities' (Rapp 1988) of people with the condition. A third reason for not discussing the condition emerges on account of both parents-to-be and professionals not wanting to consider it as a possible pregnancy outcome. During an interview, Lisa (SAD sonographer) claims this is because despite its compatibility with life, Down's syndrome is principally understood in negative terms:

> I think [parents-to-be] probably see [Down's syndrome] as very negative by and large. I don't think they know how much support they would get or if they're told what life would be like if they're given the diagnosis of a Down's syndrome baby. How much they're told will influence them whether they'd keep the pregnancy or not.

Whilst Lisa's contentions (such as Down's syndrome being seen as '*very negative by and large*') relate to terminating or continuing a pregnancy following a diagnosis, her claims are appropriate for considering how Down's syndrome is constituted in the early stages of antenatal care. Elena (FMD head midwife) conveys a similar thought by suggesting '*people's understandings*' reflect stereotypes such as '*the older person walking behind their elderly parents with the ankle socks*'. The following fieldnotes were taken in the Springtown office where parents-to-be book ultrasound scans:

> Gareth: Do you think people having the nuchal translucency scan know much about Down's syndrome?
> Dominique: Not really. I think they know about the facial features.
> Hannah: I don't think they want to know.
> Dominique: It's not fully entered their heads.
> Juliana: And they know about them being retarded.
> Dominique: I don't think they know because it's such a broad spectrum of how they are affected too.
> Hannah: Unless they know someone in the family [with the condition].
> Juliana: We get more questions about Patau's syndrome and Edward's syndrome. With these syndromes, they ask things like 'well what are they?' Because they aren't as well known so we tell them about that and that's it really. We bracket it in with Down's syndrome.

Dominique casts doubt on whether parents-to-be know about Down's syndrome excusing '*the facial features*', namely because the condition had '*not fully entered their heads*' and there is '*such a broad spectrum of how they are affected*'. Juliana suspects parents-to-be are likely to know about people with Down's syndrome having learning difficulties and so ask '*more questions about Patau's syndrome and Edward's syndrome*', two conditions '*bracket[ed] in with Down's syndrome*'. She attributes this to their unfamiliarity since the conditions are not '*as well known*' as Down's syndrome. Importantly, Hannah explains parents-to-be do not have much knowledge of Down's syndrome since '*I don't think they want to know*'. In a study on inflammatory bowel disease, Thompson (2013) describes the interactional

processes through which participants of a support group subvert the stigma of faecal matter. Members avoided soiled words involving direct references to faeces or defecation, silence thereby acting as a barrier against stigma, shame, and attributions of immorality. Similarly, Greenhalgh (1994) describes how Chinese women use silence as a means of resisting state policy around childbirth and maternal bodies. In Freymarsh and Springtown, Down's syndrome is likewise subjected to 'civil inattention' (Goffman 1971) whereby professionals and parents-to-be dis-attend to the condition; it is taboo, hidden, avoided, an elephant in the consultation room. Within screening consultations, the imagined damage caused by the potential presence of Down's syndrome, as a future deviant body, initiates reluctance (rather than resistance as explicated by Greenhalgh) from parents-to-be and midwives/sonographers to openly discuss the basics of the condition.

Down's syndrome amounts to what Taussig (1999: 7) describes as a 'public secret', namely the ideas of shared knowledge in a society that is seldom described or explicitly acknowledged. Symbolically invisible and at its core banal, public secrets become a powerful social glue and knowledge of 'knowing what not to know' (1999: 6). Notably, Taussig focuses primarily on the defacement of public secrets. During most of the consultations I observed, Down's syndrome was not defaced but rather remained a public secret. Although the condition was discussed with professionals in 'back-stage' (Goffman 1959) interviews, it was a hidden category rarely unmasked in consultations. The condition is made significant by its absence. At the crossroads between the unmentioned and unmentionable, it is subjected to a strange yet pervasive 'degradation ceremony'; the character of Down's syndrome is reduced to a lower social type since it is imagined as breaching normative expectations (Garfinkel 1956: 420). In sum, the condition is downgraded through its silence. It is in its familiarity (as a negative outcome) that Down's syndrome, curiously, becomes invisible.

The organisation of care

A second reason why Down's syndrome remains absent is that the organisation of care hinders interactions between parents-to-be and professionals. This is most

overt in FAD where a checklist is used to govern clinical practice. It includes eleven 'key points to discuss', in Camilla's (FAD midwife) words, during a consultation:

> After a consultation, Camilla fills in the checklist. Camilla asks if I have seen it and hands me the two-sided form. The first side of the form asks for details such as scan date, ethnicity, and weight. The second side contains a list of eleven points marked "Information Given" which must be clarified during consultations. These are:
> 1. Gestation at the time of test
> 2. Have you had any other screening test for Down's syndrome?
> 3. A low chance result ≥ 1:151
> 4. Low chance does not mean NO chance
> 5. Low chance result will be sent by letter within 10 working days
> 6. The low chance letter will not state the risk ratio
> 7. A high chance result ≤ 1:150
> 8. High chance screening result will be provided within 5 working days
> 9. An appointment will be offered within 24 hours of contact to discuss a high chance result
> 10. Have you considered the amniocentesis test that will be offered following a high chance result?
> 11. If you accept an amniocentesis diagnostic test an appointment will be offered as soon as possible following a recall

Camilla suggests '*in order to cover our backs*', midwives follow such rationalised stipulations with the intention of accomplishing appropriate care. Conformity to rationalised modes of conducting care – meaning care is essentially read off the page – arguably limits an extensive dialogue between each party. During an interview, Martha (FAD midwife) draws attention to the value of the checklist:

> It makes sure we're all practicing to the same standard so that one midwife doesn't go in and just skip through it. It standardises practice. With other things you can't be all the same but with Down's syndrome screening, what we say should be standardised before the test is done.

Martha suggests the checklist '*standardises practice*', meaning '*we're all practicing to the same standard*'. Lindsay (FAD midwife) similarly claims the new checklist is '*making a difference*' and suggests parents-to-be '*might not assume it's just a blood test and that people just have it*'. Likewise, Lois (FAD midwife) explains many aspects of antenatal care are reduced to '*tick-boxing, initialling, and that's it*', citing this as a positive development in the '*streamlining*' of tasks so there is not '*too much paperwork*'. Rita (FAD midwife) explains she likes the checklist since '*you've got it all there ready to remind you*' and suggests the consultation is '*just tick*', indicating her care is accomplished by ticking the specified boxes (Boden et al. 2009). The checklist is an 'immutable mobile' (Latour 1987), a textual form which represents knowledge and remains constant as it flows through various networks. For Latour, this becomes crucial to the routinisation of scientific knowledge and techniques. The immutable mobile of the screening checklist, then, is translated into practical situations (consultations) and whilst subject to reinterpretation, is dutifully followed by FAD midwives with the intention of providing informed choice without their own intervention. It also represents a response to potential lawsuits; by communicating all of the 'correct' information at hand, midwives can '*back-up*' by engaging in '*defensive practice*' (Gail, FAD midwife).

Interestingly, however, a conversation about Down's syndrome does not constitute one of the key points of interest on the checklist. With care increasingly structured on rational grounds in pursuing efficiency, standardised stipulations introduced by organisational cultures determine what information is necessary for sharing with parents-to-be (Bosk 1992). Although the checklist is exclusive to FAD, the absence of Down's syndrome during consultations in SAD can also be attributed to an extensive deliberation of the condition being framed as non-essential or, rather, as not quite making the cut within slim encounters. Operating within strict time constraints, professionals condense information and only provide details deemed significant for parents-to-be. Their conduct is shaped by wider organisational cultures which 'silence other cultural resources and world views' (Rapp 1988: 151). These limits, thus, lead to Down's syndrome being made absent.

Professional knowledge

A third reason for the absence of Down's syndrome in consultations corresponds to several midwives and sonographers admitting to lacking extensive knowledge of the condition. When asked about the knowledge of parents-to-be regarding Down's syndrome, Sophie (SAD sonographer) answers:

> I think a lot of them probably don't really know about [Down's syndrome]. I suppose it's just what you read about or people or families you know. [...] I must admit we haven't particularly been taught a lot about it. I know a lot to do about testing for it but I don't know a huge amount about the actual condition. I think it goes back to if you know somebody with it and we're taught things like the statistics, like 25% of them have cardiac problems. But you're not particularly taught about that when you do training and stuff.

After suspecting parents-to-be do not know much about the condition, Sophie associates her limited knowledge of Down's syndrome with a lack of training and suggests her familiarity with it extends exclusively to screening practices and statistics ('*25% of them have cardiac problems*'). According to several sources, however, the number of people with Down's syndrome who have cardiac issues is closer to 50% (NHS FASP 2012). This reflects research suggesting some healthcare professionals hold limited knowledge of Down's syndrome (Dormandy et al. 2006; Skirton and Barr 2010). This often includes little direct contact during medical training with people who have developmental disabilities (Cleary-Goldman et al. 2006; Driscoll et al. 2009; Skotko 2005). Others have suggested professionals also have limited knowledge of screening for Down's syndrome (Farsides et al. 2004; Hey and Hurst 2003; Samwill 2002; Smith et al. 1994; Williams et al. 2002c), but this was not observed at FAD or SAD.

My intention here is not to shame or chastise midwives and sonographers for their flawed or lack of knowledge around Down's syndrome. Rather, I intend to highlight that this knowledge is not attributable to incompetence but rather to relegating screening to professionals with – as they openly admit – limited knowledge of the

condition. In an interview, Francine (FMD head midwife), who spends much of her time in FMD, reflects on this lack of knowledge during an interview whilst discussing working in this department:

> I feel that in FMD, we are treated well by parents-to-be because they are sent to us having seen midwives or doctors [not in FMD]. And quite a lot of the time, the midwives and doctors will give them the very basic information and refer them here because most midwives and doctors don't like abnormalities. It's not in their realm of interest or knowledge so if an abnormality comes, I mean that is the best way because it's better not to explain if you don't know what you're talking about rather than giving information we're potentially going to contradict.

Francine suggests parents-to-be welcome their referral to FMD because midwives and doctors not in FMD '*will give them the very basic information*' and '*do not like abnormalities*'. However, it is frequently FAD midwives (and sonographers in SAD) who communicate information on Down's syndrome in the early stages of antenatal care. During one conversation in the office, Rita (FAD midwife) highlights the difficulties of explaining any condition without extensive knowledge of it:

> Even if you get a result meaning [parents-to-be] will be referred elsewhere, you're the initial person to see them. Sometimes I find that a bit difficult because they start asking you questions and I cannot always answer them because I'm not specialised in that area. So I feel a bit bad then saying "I'm not really the best person to speak to but I will get someone to speak to you".

Rita describes how it is '*a bit difficult*' when parents-to-be '*start asking questions*' which '*I cannot always answer because I'm not specialised in the area*'. Such observations implicitly reflect how Down's syndrome screening is downgraded in the clinic. It is cast as a mundane task relegated by professionals highly placed in a clinical hierarchy. Screening consultations are instead carried out by professionals

openly confessing to not possessing extensive knowledge of the condition; Down's syndrome, thus, becomes absent.

Notably, the condition may be afforded further details and reflection once a diagnosis is suspected and a higher-risk result must be explained to parents-to-be. However, similar to initial screening consultations, the majority of such encounters are conducted by midwives (SAD sonographers bestow this responsibility to a nurse or admin staff) who often claim they have a limited knowledge of Down's syndrome. During a consultation in which Mr and Mrs Knight (parents-to-be) are told they have a higher-risk of Down's syndrome, for instance, Eve and Amy (FAD midwives) describe what will happen after diagnostic testing:

> Eve: If the baby is diagnosed with Down's syndrome, you can wait till your full karyotype is in to see whether it's mild or severe.
> Mr Knight: What is severe then?
> Eve: I couldn't tell you that. Not now anyway.
> Mrs Knight: I think what my husband is asking is what would mild be?
> Eve: Well a number of people with Down's syndrome can go on to live till sixty years old, and [seems unsure and pauses].
> Amy: Yes, they can sometimes have learning difficulties. But if mild, they can appear quite normal.
> Eve: Yes. They can have a similar IQ level to other children. They can live good lives, some can live independently. [Pauses] It depends really.
> Mr Knight: I do have another question: where does Down's syndrome start?
> Mrs Knight: Where is it from?
> Eve: It's an extra chromosome. That chromosome will be placed somewhere in the genes. We're not sure why it happens.
> Mr Knight: I read it was when the cells were divided in the chromosomes.
> Amy: It's a chromosomal thing, yes. It's not genetic.
> Mrs Knight: [Turning to husband] There's nothing we can do about it, it's not one of us.

Eve: Yes it's not a genetic thing.

Amy: Yes.

Eve: It's a chromosomal thing.

It is rare that two midwives are present during an encounter, either for Down's syndrome screening or higher-risk results. On this occasion, Amy attended alongside Eve as a training exercise. During the consultation, Mr and Mrs Knight ask questions regarding Down's syndrome. A higher-risk result commonly causes parents-to-be to ask further questions regarding diagnostic testing and risk factors during a consultation, with a discussion of the condition rarely extending beyond midwives or other clinicians offering them a leaflet providing further information. This is an atypical case, a 'breach' (Garfinkel 1967) or 'infraction' (Goffman 1971) because the parents-to-be do solicit details from the midwives in a manner which unmasks the elephant in the room, namely, that they have limited knowledge of the condition. Eve and Amy (though particularly Eve) seem unsure about the condition and subsequently provide vague information. When Mr Knight asks what constitutes a severe prognosis, Eve specifies the life expectancy of individuals with Down's syndrome before Amy adds '*they can sometimes have learning difficulties*'. Towards the consultation's conclusion, Eve and Amy, previously providing what may be perceived as a relatively positive outlook of the condition, describe Down's syndrome as chromosomal but '*not a genetic thing*'. The parents interpret this as the condition not being hereditary and as something they can '*do [nothing] about*'.

Describing Down's syndrome as 'not genetic' (although Mr and Mrs Knight rightly interpret this term as signifying hereditariness[65]) corresponds to an organisational structure in which screening, as discussed in chapter five, is downgraded by consultants and relegated to midwives and sonographers, namely, the unwitting 'mop-up service' (Bosk 1992: 34). On rare occasions where information on Down's syndrome is shared or solicited, not only do midwives and sonographers commonly admit to lacking great knowledge of the condition (outside of the 'face', heart defects, learning difficulties, viability, and causation by an extra twenty-first

[65] As a reminder, there are three forms of Down's syndrome: Trisomy 21 Down's syndrome (94% of cases); Mosaic Down's syndrome (2% of cases), and; Translocation Down's syndrome (4% of cases). Only Translocation Down's syndrome can be hereditary.

chromosome), but the finer details of symptoms, prognosis, and future prospects – physiological and social – are absent or at best vaguely present in consultations. The importance of knowledge about Down's syndrome and other conditions for reproductive decision-making is emphasised by both professionals and other studies (Boardman 2010; Bryant et al. 2001), although this is usually discussed in relation to families with potentially hereditary conditions (Arribas-Ayllon et al. 2008; Lock et al. 2007). Nonetheless, in FAD and SAD, Down's syndrome – a predominantly non-inherited condition – is made absent in the early stages of antenatal care.

Risks, problems, and abnormalities

To recap, I have offered three reasons why Down's syndrome is often avoided through absent or at least ambiguous engagements. Arguably, one might consider these reasons as useful excuses. Professionals do not necessarily view a lack of knowledge about Down's syndrome, despite its widespread availability, as a deficit in performing duties. The absence of Down's syndrome, consequently, becomes a natural and enduring condition. So with the condition spoken *around* as opposed to spoken *about*, what existing discourses shape Down's syndrome in interactional exchanges? How is the condition discussed when, in turn, it is not discussed?

The most common vernacular organising and constructing Down's syndrome, a vernacular infiltrating prenatal screening practices (Heyman et al. 2006; Pilnick 2008) and antenatal care generally (Possamai-Inesedy 2006), is 'risk': parents-to-be receive a risk factor, diagnostic testing carries a risk of miscarriage (and heavy bleeding, abdominal cramps, infection, and premature labour), and older mothers-to-be are at an increased risk of having a child with Down's syndrome. Screening furthers a culture of risk within the clinic in which professionals and parents-to-be must embrace complex risk assessments before deciding whether to undertake screening (and perhaps diagnostic testing) and assessing the ultimate value of this intervention (Hallowell 1999; Rapp 2000).

In a trend reflecting the wider development of 'biomedicalisation' (Clarke et al. 2003), reproductive medicine positions mothers-to-be in a web of surveillance

wherein they monitor, measure, and seek knowledge of avoidable risks such as smoking and consuming drugs/alcohol during a pregnancy (Helén 2005). Lupton (1999: 60) identifies how pregnant women are subjected to advice and appraisal directed at 'containing risks', both those threatening their health and that of their unborn baby. She argues the female body is 'constructed and experienced through discourses, knowledges and strategies of risk', highlighting how risk emerges at various levels of meaning 'from the social structural to the cultural and symbolic' (1999: 61). Freeze (2008) similarly suggests that since childbearing is a public as well as private activity, pregnant women become vulnerable to advice, criticism, and surveillance, actively creating culture through their accountability and their need to rationalise conduct. Since Western society is preoccupied with trying to avoid risk (and thus blame), pregnancy involves heavily prescriptive codes of expected conduct administered via a scrutinizing public gaze (Lupton 1999). In FAD and SAD, for instance, mothers-to-be are burdened with information on risks including car safety, airline travel (DVT[66]), consumption (caffeine, alcohol, cigarettes, diet), sexual intercourse, exercise, parvovirus, breastfeeding, chicken pox, flu vaccines, and gardening (exposure to toxoplasmosis/manure).

When screening for Down's syndrome at FAD and SAD, risk becomes an accepted and privileged discourse, the commitment to which is exemplified in the following consultation between Lois (FAD midwife) and Mrs Roberts (mother-to-be):

> Lois: So this is just a chat about the Down's syndrome test. Do you know much about Down's syndrome screening?
> Mrs. Roberts: Not really. I know if it's abnormal, they'll offer me another test.
> Lois: Kind of. Do you know what Down's syndrome is?
> Mrs. Roberts: Yes.
> Lois: OK. This is a screening test which won't affect the baby. You'll be placed in a higher-risk or lower-risk category. The test is 80% accurate so lower-risk does not mean no risk of having a baby with Down's syndrome. If you're higher-risk, we'll offer you an amniocentesis. The cut

[66] Deep vein thrombosis is the formation of blood clot in a deep vein, predominantly in the legs.

off is 1 in 150 so you could be 1 in 148, 1 in 149, 1 in 150, and all that is higher-risk. So we offer the amniocentesis which takes fluid from around the baby and this says for definite whether your baby has an abnormality. But it does have a risk of miscarriage of 1% so if 1 in 100 women have the amniocentesis, one will miscarry. A higher-risk result will be given in five working days and an appointment will be offered within twenty-four hours. A lower-risk result will be given within ten working days and the letter will say how low-risk you are. But what I badly need to know is whether you want to know whether you're a lower-risk or higher-risk.

Mrs. Roberts: Yes, just so I can know.

Lois: So you would consider having the amniocentesis?

Mrs. Roberts: I'm not sure. I'd have to speak to my partner.

Lois: But you'd like to know whether you're lower-risk or higher-risk?

Mrs. Roberts: Yes. I can do something about it afterwards then if something is wrong.

Lois: OK.

The consultation is described by Lois as '*just a chat*', implicitly and immediately downplaying the significance of the event. Mrs Roberts acknowledges her lack of knowledge of screening which will detect anything '*abnormal*', a definition Lois provisionally accepts. Importantly, after Mrs Roberts confirms she knows what Down's syndrome is, no further details on the condition are offered; it retains its status as '*abnormal*'. Lois accepts this label and describes the screen as physically unproblematic ('*this is a screening test which won't affect the baby*'), glossing over the prospective '*can of worms*', as outlined by midwives and sonographers earlier in the thesis, which screening practices threaten to expose. Lois recounts what she perceives as apt information for accomplishing appropriate care such as the accuracy of screening, risk factor cut-off rates, prospective diagnostic testing, and the risk of miscarriage (as outlined in the screening checklist discussed above). The consultation far from represents '*a chat*' (a chat implies an inclusive two-way exchange), as described at the start of the encounter, with Lois one-sidedly reciting clinically correct information with the intention of promising the ideals of

reproductive choice and nondirective care (Bosk 1992). After Lois asks Mrs Roberts whether she wants screening, she claims she will '*just so [she] can know*', in her words, '*if something is wrong*'.

During the consultation, the discourse of risk is largely employed. The implicit assumptions shaping wider readings of risk paint a negative picture. A potential risk status not only shifts health(y) identities of mothers-to-be but also demarcates Down's syndrome itself as a 'risk', in effect, a threatening possibility. Pregnancies become 'tentative' (Rothman 1986), marred by the risk of impending disability and provoking anxiety rather than reassurance for parents-to-be (Marteau 1995). Importantly, Lois and Mrs Roberts each define the condition as '*abnormal*'/an '*abnormality*', a deviation from normative assumptions. The word '*risk*', however, principally shapes their understandings in this encounter. With Down's syndrome lacking a language of its own, it becomes subsumed by the 'linguistically and culturally more secure notion of risk' (Scamell and Alaszewski 2012: 218). The widely-circulated term risk carries negative connotations; if something is a risk, it is to be feared and avoided (Lupton and Tulloch 2002).

With risk indicative of a potential threat (Douglas 1992) and having 'connotations of danger and negative outcomes' (Shakespeare 1999: 673), its common use within screening encounters produces a negative portrayal of Down's syndrome as a preventable and perilous conclusion to a pregnancy. The knowledge of Down's syndrome as a 'risk' and 'problem', rather than as a 'viable' and variable condition, is therefore privileged. During consultations, much like clinicians in Cunningham-Burley and Kerr's (1999) study, there is little reflection among professionals, despite curbed protests of screening equating to eugenics, about the social aspects of disorder/disease definition and the social, rather than medical, problems of disability. In addition, during the consultation between Lois and Mrs. Roberts, the offer of an amniocentesis '*within twenty-four hours*' not only highlights the gravity of the situation but also marks potentially detecting the condition as offsetting the possibility of miscarriage caused by diagnostic testing. Similar attempts to swiftly book diagnostic testing were observed in Freymarsh, sometimes occurring before professionals informed parents-to-be of their higher-risk result. Provisional

bookings are scheduled both for practical purposes, namely, to save time in a busy environment, and for 'care' purposes, namely, so they could inform parents-to-be that a timeslot for diagnostic testing is available should they want it. However, whilst such actions are meant to be harmless, they arguably discipline parents-to-be into making decisions under the rhetoric of informed choice. Although hurrying the mother-to-be into making a decision may be defined as 'good care', it can also be construed as another system of disciplinary power (Foucault 1973).

The negativity of the risk discourse is reflected further in recent efforts made by midwives/sonographers and antenatal governing bodies to replace the word 'risk' with 'chance'; parents-to-be, for instance, should be told they receive a chance factor as opposed to a risk factor of having a child with Down's syndrome. During one conversation, Amy and Gail (FAD midwives) reflect on why this is the case, with Amy concluding '*risk sounds too negative*'. During another conversation, Amy describes the word risk as '*aggressive terminology*', with chance framed as '*softer*' and not sounding '*as much like a danger*'. By highlighting during an interview how risk '*is negative*' and that '*low-risk and high-risk is not the nicest way of saying a result*', Camilla (FAD midwife) suggests she tells parents-to-be the test will '*put you into one of two groups: one that we offer you the amniocentesis and one where we don't*' since risk factors/statistics '*can confuse people sometimes*'.

The discourse of chance is favoured by professionals not only because it is viewed as less *aggressive* than risk but also since, I suggest, it implicitly attributes a result to fate and luck. This potentially absolves parents-to-be (specifically mothers-to-be) from feelings of responsibility for not preventing such a risk. Whilst risk holds connotations with danger and as something which can be minimised or avoided if only due attention is provided, chance is synonymous with luck and fate. Since risk itself holds negative connotations, chance is categorised as the more appropriate and, according to Amy and Gail, commonly used discourse in screening practices. However, my observational work reveals whilst risk/chance was sometimes used synonymously, 'risk' is employed far more frequently than 'chance' in screening consultations (the discrepancies between what one *says* and what one *does* highlights one of the benefits of observational data). This oversight did not appear

to emerge as a conscious decision but rather as a product of the integration of a risk discourse in the everyday work of professionals.

Within screening practices, the figuring of Down's syndrome as a risk is reinforced with similar pervading classifications. At Freymarsh and Springtown, Down's syndrome – since it is not cited explicitly – becomes synonymous with '*problems*', '*bad news*', *'a bad scenario*', '*something wrong*', and, most frequently, '*abnormality*'. The following fieldnotes taken from an NT scan between Olivia (SAD sonographer) and Mr and Mrs Burton (parents-to-be) highlights this:

> Olivia: Now the NT [scan] involves measuring the fluid at the back of the baby's neck. This white line and this white line is where it is. We want that gap to be less than 3mm and I can say it looks tiny from first view.
> Mrs Burton: So that's a good one?
> Olivia: It is [Mr and Mrs Burton smile].
> Mr Burton: So getting to see all these babies must be quite a fun job.
> Olivia: Sometimes. It's not always nice news but it's usually all normal.
> Mrs Burton: So it's a bad scenario if the bit at the back of the neck is not there then?
> Olivia: No. The more it is, the higher the chance of abnormality. So a small measurement is good. [...] I'll get a picture of that now. The measurement is 1.6mm too which is brilliant.

In this consultation, Olivia repairs the impending danger of a '*bad scenario*' by highlighting the '*brilliant*' measurement which, in all likelihood, points toward the absence not of Down's syndrome but of the much vaguer '*abnormality*'. The nuchal translucency is categorised as a '*good one*', with most unborn babies being '*normal*' and falling under the rubric of '*nice news*'. Despite this reassurance being present in most consultations, a commitment to discursive categories of *risks*, *problems*, and *bad scenarios* – categories organising and shaping Down's syndrome as a universal – takes on even greater significance once you consider Francine's (FMD head midwife) suspicion that parents-to-be '*only really pick up keywords*'. Since professional conduct incites interpretive acts among parents-to-be, the discursive

categories tendered by them surrounding Down's syndrome classify it as a negative outcome. Furthermore, it imposes a collective category on it which blurs the considerable variation not only of the condition but also between people with the condition. In FAD and SAD, a negative image of Down's syndrome, coupled with no positive comments, seems to be presented (Sooben 2010; Williams et al. 2002b), with Alderson (2001) similarly arguing that a negative image of Down's syndrome can be frequently found in the medical literature.

The positioning of Down's syndrome as a risk, problem, or bad scenario (among others) is reflected, specifically in Freymarsh, in the early stages of antenatal care. Here, parents-to-be are offered screening for a multitude of conditions and diseases including but not limited to rubella, HIV, syphilis, rhesus disease[67], sickle-cell disease[68], thalassemia[69], hepatitis B/C, and Down's syndrome. During an interview, Maggie (FAD midwife) describes the impact this may have on parents-to-be:

> I think most people just assume [Down's syndrome screening] is something they're going to have. It's like we check their blood, their iron levels, we check their blood group, and we'll check their Down's syndrome blood at the same time. It's very common now. Everyone just takes it.

Maggie describes how the naturalisation of Down's syndrome screening can be attributed to parents-to-be assuming screening is '*something they're going to have*' along with other tests. Rita (FAD midwife) similarly says that screening is accepted by parents-to-be since it is offered together with screening for the likes of rubella and hepatitis B. She feels Down's syndrome screening, viewed as '*routine and what [parents-to-be] do*', should be '*separated from the rest of them*', criticising current

[67] Rhesus disease is when antibodies in the blood of a mother-to-be destroy her unborn baby's blood cells. It only occurs when the mother-to-be has rhesus-negative blood and father-to-be has rhesus-positive blood, leading to an unborn baby with rhesus positive blood.
[68] Sickle-cell disease is an inherited genetic blood disorder in which red blood cells develop abnormally. This effects the capacity to carry oxygen around the body.
[69] Thalassemia are forms of inherited autosomal recessive blood disorders. It is caused by the weakening and destruction of red blood cells. This affects the capacity to carry oxygen around the body.

practice for not formulating distinctions between the former and the latter. Maggie and Rita, together with other midwives and sonographers, acknowledge this trend to highlight the problem of Down's syndrome screening being framed as a routine practice. They suggest that parents-to-be do not critically reflect on its potential implications and lack an awareness of screening being an opt-in, rather than opt-out, procedure. During an interview, Lois (FAD midwife) claims:

> I think people have a tendency to accept what is offered to them because they think you wouldn't offer it if there wasn't a good reason to have it but they don't actually think about what can happen if they get a result they don't like. [...] With the initial booking appointment, I sometimes feel that women are coming in feeling really excited because they're pregnant and they have that first [dating] scan and most of the time, it's OK and it's all really lovely and happy. And then you go into a room and talk with them about all of the things that are not lovely and happy – HIV, syphilis, the Down's test, sickle-cell disease and thalassemia – all of these things and by the time they leave [the clinic], they often feel a bit worried and anxious and that's not the intention but it happens.

After suggesting parents-to-be accept screening on account of its accessibility, Lois argues the prelude of a dating scan ignites excitement and this is threatened when '*you talk with them about all of the things that are not lovely and happy*', namely the likes of HIV, syphilis, and Down's syndrome. The positioning of Down's syndrome, a condition categorised by many professionals as 'compatible with life', with diseases/disorders such as HIV and hepatitis B/C accomplish and re-accomplish it as one part of the abnormal whole. If parents-to-be do truly ask midwives to '*test me for everything*' as Eve suggests, Down's syndrome is cast alongside the likes of 'disease' and 'disorder', contradicting the positive imagery conjured up in the back-stage accounts of professionals.

The negative depiction of Down's syndrome is further buttressed in antenatal materials, including leaflets distributed to parents-to-be when attending FAD or SAD, which describe Down's syndrome solely pertaining to physiological defects

such as cardiac issues and, in one Springtown leaflet, the vaguely-defined '*other health problems*'. If parents-to-be read this literature which midwives and sonographers often accuse them of not doing, they are presented with a clinical representation constructing a narrow and adverse portrayal of the condition. It is not too fanciful to claim that offering Down's syndrome screening in the first instance, by its very nature, categorises it in negative terms, that is, as something worthy of early detection and potential elimination (Alderson 2001; Asch 1999; Burton-Jeangros et al. 2013; Kerr et al. 1998).

This supports the findings of Korenromp et al. (2007) who claim the decision to terminate a pregnancy is most frequently based on an understanding of Down's syndrome as 'an abnormality too severe', a burden 'too heavy' for the child, and people with the condition as not being able to ever 'function independently'. Similarly, Reynolds (2000: 894) claims that screening persists since 'a child with Down's syndrome is seen as a disaster by many potential parents'. In the early stages of antenatal care at Freymarsh and Springtown, regardless of professionals' accounts identifying it as a condition which is compatible with life and screening as serving a eugenic agenda, Down's syndrome is presented as an inevitable tragedy. I contend that this causes problems for parents-to-be once a diagnosis is suspected or established either prenatally or postnatally and offers a reason why, as specified at the beginning of the thesis, why roughly nine out of ten prenatal diagnoses of Down's syndrome in England and Wales end in a termination of pregnancy (Morris and Springett 2013)[70].

Summary

In this chapter, I have identified the discrepancies regarding the constitution of Down's syndrome. Professionals often cite Down's syndrome screening as eugenic with reference to discursive resources of the 'compatible' and 'viable' unborn baby. However, they frequently fail to discuss this, or Down's syndrome itself, during

[70] Independent termination statistics were not gathered at Freymarsh or Springtown. As such, I accept it is unjust to fully generalise extensive statistics on terminations following a diagnosis of Down's syndrome in England and Wales to only two settings. However, since the termination rates have remained between 89% and 94% in England and Wales for over twenty years (Morris and Springett 2013), the negative constituting of Down's syndrome in Freymarsh and Springtown suggests *one* plausible reason for this.

consultations. Down's syndrome is made absent through its familiarity, the organisation of care, and a lack of knowledge among the necessary professionals about the condition. Absent yet present, Down's syndrome is framed within the negative collectives of 'risk', 'problem', and 'abnormality'. Shakespeare (1999: 673) explains how professionals and medical texts use negative language in public rhetoric and how their clear values, implicit and subtle as they may be, reflect a consensus that 'disability is a major problem to be prevented by almost any means necessary'. Here, I capture how professionals talk this language into consultations. This challenges what I was told during interviews and conversations. Such formal encounters were not trouble-free gateways to truths but rather performative accounts. In these moments of disconcertment, I captured the discrepancies between what one *says* and what one *does*. I am not accusing professionals of purposefully distorting information and performing for my benefit. Rather, I claim how professionals' accounts of their conduct – of what they *think* they do – may not always correlate with what happens on the shop floor.

In the clinical setting, professionals communicate, do not communicate, or mis-communicate medical information and 'structural power arrangements, social knowledge, and popular meanings about medically defined disability' (Rapp 1988: 143). For Martin (1998: 125), the very language of biological science becomes 'as real in their effects on the way doctors and patients act in the world as the effects of an antibiotic or scalpel'. This language, for Martin, reveals deep and powerful cultural assumptions. In Freymarsh and Springtown, the definition of Down's syndrome as a risk or abnormality, defining the identity of the future child, is produced in medical discourse and is infused with values about what a 'normal' life entails (Olarte Sierra 2010). This, in turn, silences cultural norms and individual values which frame understandings of certain conditions (Shakespeare 1998).

Once more, this reveals how Down's syndrome screening is entangled in 'motility' (Latimer 2013; Latimer and Munro 2006; Munro 2001). It is this motility among professionals, particularly in their capacity to switch grounds (Latimer 2008b), which accomplishes Down's syndrome, in one instance, as a condition which is compatible with life since there are '*a lot of things worse than it*' (Lois, FAD

midwife) yet as a risk, problem, and abnormality in another. Presence is, at critical moments, magnified or diminished (Latimer 2008a; Strathern 1992). In the clinic, the viability of Down's syndrome and the condition itself is diminished whilst discourses of risk, problem, and abnormality are magnified. This produces and reproduces a shift of Down's syndrome from 'compatible' to being figured as one of the many risks in antenatal care. It is through this motility, and the most frequent shift to Down's syndrome as a risk or problem, in which the condition is aligned, before a diagnosis is suspected or established, as an emotional tragedy and future family disruption. In the clinic, professionals *make* and *unmake* the family by constructing divisions of 'normal' and 'abnormal'; the 'abnormal' person (with Down's syndrome), in contrast to the 'normal' person (without Down's syndrome) is imagined to be, and constructed as, unsettling biological kinship. This produces and reproduces, thus, an idealised version of what constitutes the 'normal' family.

I extend my arguments in chapter eight by describing how Down's syndrome is entwined in cultural ideologies of perfection, how mothers-to-be at an 'advanced maternal age' are implicated in this, and how the 'human' status of an unborn baby with Down's syndrome can be made and unmade in antenatal care.

Chapter Eight
Expectant Parents, Expecting Perfection

In the previous chapter, I captured how the subject of Down's syndrome is avoided in screening consultations and the discrepancies between professionals' positive accounts of the condition and its negative description in routine clinical practices. I extend this analysis in chapter eight. I begin by exploring how Down's syndrome is embroiled in cultural ideologies around perfection and imperfection. I encapsulate how these positions are created and replicated in the early stages of antenatal care in consultations (mostly NT scans) and via materials (performative architecture). These social practices and cultural materials accomplish Down's syndrome as breaching normative expectations of perfection in a pregnancy outcome (Rapp 2000; Remennick 2006; Rothschild 2005).

In what follows, I describe how this emphasis on perfection institutes parents-to-be as responsible for promising flawlessness in their unborn baby. Mothers-to-be are assigned primary accountability for decision-making processes (see chapter six). Confronted with endless reminders of 'perfect baby' outcomes, mothers-to-be over the age of thirty-five (at an 'advanced maternal age') are disciplined into considering their pregnancy as pathological and, potentially, screening for Down's syndrome as one means through which they assure a 'perfect' outcome. Finally, I identify how constitutions of Down's syndrome and cultural ideals of perfection are enacted by discursive shifts in FMD between 'foetus' and 'baby'. Whilst ultrasound scans and/or foetal movement often gives rise to a foetus *becoming* a baby, the identification of a suspected diagnosis can involve re-figuring the baby as, once more, a foetus. This shift not only allows professionals to accomplish emotional and moral distance from the issues at hand but also highlights the malleability of the human category whilst transforming problem bodies – including those with Down's syndrome – into potentially 'disposable' entities (Latimer 1997; Munro 2001; White et al. 2012). In this chapter, I will certainly not engage in moral arguments around abortion and whether terminating for Down's syndrome should be classified as acceptable practice. Instead, I explore the conditions under which a

termination for the condition is made possible and recognise, with Shakespeare (2000), how debates are more nuanced than simplistic 'pro-life versus pro-choice' or 'eugenics versus choice' arguments.

Producing perfection

In the previous chapter, I described how discourses (risk, problem, abnormality) sustain a negative constitution of Down's syndrome. These are commonly created and reinforced through the opposing and entwining discourses of '*normal*' and '*perfect*'. What constitutes normality and perfection is built into everyday language, particularly assumptions around how we organise particular bodies (Thompson 2013). The dualism of 'normal' and 'abnormal' is demarcated after twenty-four weeks of a pregnancy during which parents-to-be can legally terminate an unborn baby owing to, in the words of FMD, 'medical problems'. However, as recognised elsewhere, a termination of pregnancy is a grey area owing to a lack of specificity in the Abortion Act 1967 about what pregnancies can be categorised as 'viable' or 'non-viable' (HM Government 2014). Whilst a precise definition of what constitutes a serious 'medical problem' is difficult, its interpretation is not. Indeed, what is viewed as 'normal' or 'abnormal' is accomplished in the early stages of antenatal care before a diagnosis is suspected or established. In the following extract taken from an NT scan, Sophie (SAD sonographer) describes the procedure to Mr and Mrs Reed (parents-to-be):

> Sophie: Did you have the NT scan with your previous child?
> Mrs Reed: No. I've had it now because I'm a bit worried with being quite a bit older.
> Sophie: OK. [Sophie moves the transducer across the abdomen] There's the baby's head [pointing]. Baby is nice and flat here. And that's a nice and small NT.
> Mrs Reed: Great.
> Sophie: [Nuchal translucency measures at 1.56mm]. We're all fine here. It's actually one of the clearest scans I've seen. That's perfect that is. Baby is lying perfectly on its back. [...] That's all looking very normal and lovely. The NT is 1.5mm and we want it below 3mm so that's very good.

> The actual measurement is 1.56mm. So there's the little arm there, the hand there too.
>
> Mrs Reed: There's a history of anencephaly[71] in my family so could you check for that as well please?
>
> Sophie: Yes OK. [Mrs Reed turns to the monitor] That seems fine to me.
>
> Mrs Reed: Good. It's just there are three cases in my Mum's family. There's a history of spina bifida[72] and anencephaly.
>
> Sophie: [Looks back at Mrs Reed] That's a very, very normal looking baby to me. I would normally be able to see anencephaly. It is a very obvious abnormality. It all looks fine. I can't check for spina bifida though because it's too soon. It's a healthy looking baby there.

After Mrs Reed accounts for her decision-making by citing the worry stemming from her '*being quite a bit older*' than in her previous pregnancy, Sophie describes the baby's attributes (specifically the neck fluid) as '*nice and small*', '*perfect*', and as '*looking very normal and lovely*'. Sophie validates her contentions by referring to a measurement of 1.56mm as '*very good*' since it falls under 3mm. Sophie then constructs other features of the baby as '*normal*', with Mrs Reed seeking confirmation of this owing to a family history of other '*cases*', albeit not Down's syndrome. Sophie responds by telling Mrs Reed that she is carrying a '*healthy*' and '*very, very normal looking baby*'. Whilst Sophie discounts the '*obvious abnormality*' of anencephaly, the perceived absence of markers for Down's syndrome and any other '*abnormality*' means the unborn baby is seen as '*normal*'. Since sonographers only detect markers for a condition rather than a concrete diagnosis only available via further diagnostic testing, they rely on the provisional absence of indicators as a likely sign of a disability-free outcome. Much like in FAD, Down's syndrome, here, is categorised alongside other conditions (anencephaly and spina bifida) as an '*abnormality*'. Prenatal technologies, thus, represent apparatuses through which the unborn baby is categorised as normal/abnormal and perfect/imperfect.

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[71] Anencephaly is a cephalic condition resulting from a neural tube defect in which a major portion of the brain, skull, or scalp is absent. With few exceptions, most babies with anencephaly will not survive birth.

[72] Spina bifida is a congenital developmental condition caused by the incomplete closing of a neural tube.

The standards of 'normality' imposed by and governing obstetrics and the close monitoring of both mothers-to-be and unborn babies resonate with an idea of perfect, or at least desirable, people/future people (Olarte Sierra 2010). Feminist and disability scholars have critiqued the role of prenatal technologies in fostering expectations to give birth to 'perfect' children (Buchbinder and Timmermans 2012; Rapp 2000; Remennick 2006). But if technology is perceived as a resource that 'promises to produce the perfect child' (Landsman 1998: 77) and ensures a baby is healthy (Remennick 2006), one should ask what this category of perfection entails. If the perfect child represents an object of cultural desire, we must contextualise it to a particular society or institution. Buchbinder and Timmermans (2012: 61) suggest perfection, despite its 'implied universality and normative power', is a 'deeply contextual concept contingent on its cultural and historical framing', with children in diverse settings being evaluated on criteria ranging from aesthetic appearance (Rothschild 2005) to bodily proportionality (Stern 2002). Although Rapp (2000) and Buchbinder and Timmermans (2012) identify the quest for baby perfection as distinctly American, such an expedition is not confined to US waters.

In Freymarsh and Springtown, the pursuit of perfection is accomplished and re-accomplished in social practices, particularly NT scans. Since parents-to-be frequently struggle to establish the unborn baby's physiological structure during an NT scan, the sonographer – as 'host' or 'tourist guide' – strategically performs and transforms the chaotic image into an unborn baby and parents-to-be into families (Kroløkke 2011). During an NT scan, Sophie (SAD sonographer) describes what she sees on the large monitor to Mr and Mrs Stock (parents-to-be):

> Sophie: You see these white lines here on the monitor [points]? We measure between those and that's the nuchal translucency. We like them under 3mm. It's 1.26mm on first measurement which is fine.
> Mrs Stock: That's around the same as it was during the previous pregnancy. It was pretty small.

Sophie: Yes, perfect. It's nice and small which is great. Based on the scan alone, that's a very low-risk [Mr and Mrs Stock smile].

[...]

Sophie: [Sophie prints pictures of the unborn baby] These pictures look absolutely fine scan wise. It all looks good. All fabulous.

Mrs Stock: Good.

Mr Stock: Great.

Sophie: There we go [Sophie gives the pictures to Mr Stock]. It looks more human now. They move all over the place! [Mr and Mrs Stock laugh. Sophie continues the scan] Here you are; a beautiful baby.

Mrs Stock: Oh let's have a look then! [Takes picture from Mr Stock] It's a baby!

Mr Stock: How's the size of the baby?

Sophie: The size is fine and normal.

[...]

Mrs Stock: I was having it just for peace of mind really. I'm thirty-eight.

Sophie: Well you've got a perfect baby so you've got nothing to worry about! Yours is a nice and small one. I can see the one in your last pregnancy was 1.02mm which is really small. The smallest I've ever seen here is 0.98mm so.

Sophie ensures Mr and Mrs Stock can distinguish their unborn baby's features on the monitor. She describes the unborn baby as '*perfect*' with a '*nice and small*' measurement which, according to Sophie, points toward a '*very low-risk*'. We can see how metonymy is at play here; the ('*nice and small*') measurement comes to stand for both the mother-to-be and the baby ('*yours*'). Nonetheless, a perfect baby corresponds to imagining lower-risk futures. Reassuring utterances of '*it all looks good*' and '*all fabulous*' collude to shape expectations of perfection and of a '*beautiful baby*', with Sophie joking the unborn baby '*looks more human now*' since movement often obscures image quality. Ultrasound scans provide an ample opportunity for revitalising expectations among parents-to-be and for (hopefully) relieving their anxiety, particularly in the case of Mrs Stock who accounts for her reason to undertake screening ('*I'm thirty-eight*'). Sophie reduces her angst by

shaping her understanding of the nuchal translucency as '*nice and small*' with reference to her experiential knowledge ('*the smallest I've seen here is 0.98*').

During NT scans, producing perfection emerges not only through the reassuring utterances of '*normal*' and '*perfect*' but also through the sonographer and parents-to-be engaging in a process of 'collaborative coding' which becomes essential to making the imagery on the screen personally and socially meaningful (Roberts 2012). Here, the physiological attributes of the unborn baby are primary markers of perfection. Ultrasound scans create an encounter in which participants can distinguish the unborn baby as a consumable entity, together with providing opportunities for gendered and good parental performances, constructing familial relations, and gazing at the 'perfect' child (Gammeltoft 2007; Kroløkke 2011; Müller-Rockstroh 2011; Roberts 2012; Taylor 2008). Observations reveal that the perfect unborn baby, a culturally-contingent category, possesses desirable physiological traits such as '*cute toes*', '*little hands*', '*Buddha bellies*', '*button noses*', and '*big beautiful eyes*' among others. In addition, they '*perform*' when the camera rolls with their movement being playfully attributed to being '*active*', '*cheeky*', and/or '*naughty*'. This contributes to creating and sustaining cultural ideologies of both perfection and imperfection in a pregnancy outcome.

This culturally-contingent perfection is accomplished further in the cultural materials and 'performative architecture' (Stephens et al. 2008) of the clinic. This is particularly true in Springtown since it is a privately-funded company where there is more freedom, in comparison with Freymarsh, to encourage consumption (Kerr 2013) and pursue the objective of monetary profit through selling pregnancy goods such as 4D baby bonding scans, '5D-photo' products, and ultrasound DVDs. Freymarsh, in contrast, was not allowed to offer commercially-available goods, nor was it permitted to adorn walls with photographs of its own choosing. However, the hospital still organises pregnancy around discourses of perfection via materials including antenatal literature and media tendering 'advice' to mothers-to-be. In Freymarsh and Springtown, the pathways and flows constituting the building's physicality is symbolic in relation to the pursuit of perfection during a pregnancy. After every NT scan in Freymarsh and Springtown, for instance, parents-to-be are

tendered a picture of their unborn baby. Obtaining a picture is a key moment in the pregnancy ritual. Producing such materials not only help construct and maintain identities (Taylor 2008) but also accomplish ideas around the perfect baby. The following fieldnotes describe the SAD space, the first passage taken from my first day of fieldwork and the second passage taken from around five months into the study:

> Pictures of unborn and newborn babies are plastered around the clinic. [...] Lisa takes me into the room where ultrasound scans are performed. The room is approximately 4x4 metres with only four to five people able to comfortably occupy the space. The room is dark and contains three chairs, a trolley, a computer, and an ultrasound machine. The room's walls are adorned with two images of 'water babies'[73].

> A '5D-photo stand' greets me as I enter the clinic. I have not seen this before. The products on display are 3D-photo-laser engraved crystal glass objects, in a variety of shapes and sizes, depicting images of unborn babies, newborn babies, families, and a dog.

With its walls adorned with newborn/unborn babies (e.g. 'water babies') and its offers of purchasable keepsakes to memorialise the unborn (e.g. '5D-photo stand'), SAD accomplishes ideals not only around the perfect baby but also around the 'normal' future family. The combination of cultural materials and social practices in producing perfection is accentuated in the commercial availability of '4D baby-bonding' ultrasound scans which are performed around twenty-four to thirty-two weeks into a pregnancy. In SAD, this is advertised as having no benefit other than helping parents-to-be to 'bond' with their unborn baby, as providing reassurance, and as offering an entertaining experience for parents-to-be (Roberts 2012). In one flyer, Springtown describes the 4D scan as:

[73] As a reminder, the pictures show a young Caucasian male smiling underwater whilst holding his newborn child.

> [Producing] lifelike images like a moving statue allowing parents to clearly see their baby smile, yawn, blink or swallow etc. as they move inside their secret world.

The unborn baby is categorised as a smiling, yawning, and blinking '*moving statue*'. In other artefacts distributed by Springtown, parents-to-be are told they will see '*their unborn child at play*', receive a '*twenty minute video recording on a keepsake DVD and four to six colour photographs*', and that '*bonding between parents and baby has been shown to be stronger when the 3D image is seen compared to the 2D image because the picture of the baby is more realistic*'. Such materials, in unison with interactional exchanges in the scan room, organise the expected conduct of mothers-to-be – who can experience the benefit of '*bonding*' from the scan – and produces the unborn baby as a consumable entity (e.g. receiving a DVD and photographs).

But how does this relate to Down's syndrome? The 4D scan blurs the boundary between medicine and consumption and contributes to changing an anticipation of the perfect child into a normative expectation. I claim that any deviation is viewed as an undesirable outcome and can become the grounds for exclusion. Consumption plays a key role for membership, belonging, identity-work, and dividing people and events into different classes or groups (Douglas and Isherwood 1979). As markers and classifiers, goods carry meaning and stabilise order. The consumption of the 4D ultrasound scan, thus, becomes a ritual in which certain people can be divided and excluded, namely, unborn babies not aligning with cultural categories of perfection. When discussing the idea of prenatal perfection during an interview, Esther (SAD sonographer) claims:

> We want everything to be perfect and it's not. It's about having compassion for things that aren't necessarily perfect. [...] My experience has shown me once women are told there's an anomaly, whether it's an isolated cleft lip or club foot, the baby is no longer perfect. The women's imagination is often a million times worse than the real thing.

Esther suggests the majority of parents-to-be '*want everything to be perfect*' yet they should be equally prepared for situations in which '*things aren't necessarily perfect*'. She highlights how any '*anomaly*', regardless of prognosis, makes the unborn baby '*no longer perfect*' since the image conjured up in the imagination of mothers-to-be is '*often a million times worse than the real thing*'. Martha (FAD midwife) similarly claims during an interview that when mothers-to-be receive a higher-risk result, this means '*the fact that they're high-risk and their baby might not be perfect is all that they can see*'. In one conversation, Gail (FAD midwife) explains:

> The public don't like the thought of something that's not perfect. We want everything to be perfect. It's like we can't have anybody whose handicapped or not quite perfect. It's quite sad then when you do have a baby with Down's syndrome because of the way our culture is. It's like shameful isn't it? Like, this baby's not perfect but it's just life really isn't it?'

Gail suggests '*our culture*', referring to an abstract UK culture rather than medical culture, demarcates Down's syndrome as '*shameful*' and '*not perfect*'. For Gail, it is '*quite sad*' when an unborn baby has the condition because of '*the way our culture is*'. Here, I reveal what constitutes perfection is built into the interactions and materiality of FAD and SAD. Earlier, I highlighted the view of professionals that Down's syndrome is familiar to parents-to-be because of its 'face' (Latimer 2013), that is, the distinctive anatomical features of people with the condition. I suggest this also constitutes a reason why Down's syndrome is seen as a non-perfect outcome (Thomas 2014). During a conversation with Dominique and Hannah (admin staff) in the Springtown office, Dominique recognises the popularity of NT scans over cardiac scans '*even with educated women*'. After she attributes this to people being '*more frightened of Down's syndrome kids, the costs and that*', Hannah suggests the '*visible thing*' of Down's syndrome is not wanted by parents; cardiac defects, however, are not immediately visual and so, she concludes, '*the child becomes normal*'. Here, the 'face' of Down's syndrome is enacted as a metonym for disability more generally and, in turn, for a negative pregnancy outcome.

In a previous study, I described how feelings of 'sadness,' 'grief,' 'sickness,' 'fear,' 'failure,' 'blame,' 'anger,' and 'devastation' were expressed by mothers when discussing initial reactions to their child's diagnosis (Thomas 2014: 5). This often corresponds to mothers initially conceiving of their child as a 'monster', an individual outside the norm; '[i]t is only because, as human beings, we are living beings, that a morphological defect is, to our living eyes, a monster' (Canguilhem 2005: 187). The child with Down's syndrome is constructed as monstrous in two ways: figuratively, in the process of othering any person/future person deviating from outside the norm; and literally, via the dysmorphic features of those with the condition. For many mothers, the physical markers of Down's syndrome, a 'discredited stigma' whereby the individual's perceived stigma is visible (Goffman 1963: 49), initially contributed toward feelings of 'alien kinship' since the child disrupted normative maternal/familial expectations and threatened their continual presentation of normality (Rapp 1995: 81). I suspect the imagined 'face' of Down's syndrome, thus, represents an imperfect deviation in the embodiment of expectation (Rothman 1998; Rapp 2000). Since screening is based on the idea that we can prevent a life with Down's syndrome (Asch 1999; Alderson 2001) and with such technologies growing from and enhancing 'a set of ideals about a perfect health culture' (Nelkin and Lindee 1995: 191), the condition represents an unvalued outcome. Thus, children with Down's syndrome are viewed as 'impaired, imperfect, damaged goods, unsatisfactory merchandise on the commodity exchange of conventional kid culture' (Rapp 1999: xiii).

Perfection and older mothers: 'elderly primigravidas'

So how does this image of perfection and imperfection figure mothers-to-be and fathers-to-be? In chapter six, I suggested screening practices implicate parents-to-be, though mothers-to-be more than fathers-to-be[74], in relation to decision-making processes. Equally, mothers-to-be and especially those at an 'advanced maternal age' (Budds et al. 2013) are implicated in cultural ideologies around perfection during pregnancy. An increased maternal age, translating to women aged thirty-

[74] I realise this analysis is based on hetero-normative assumptions about partnerships. Only one consultation I observed involved a homosexual couple (Springtown). In this case, it would be more correct to say screening practices implicate the 'carrier' of the baby.

five and above, is the only known attribute increasing the risk of an unborn baby being diagnosed with Down's syndrome. The NHS has produced data specifying the risk factor of women based on their maternal age alone independent of any screening/testing. Whilst twenty-year-old women have a standalone risk factor of 1:1250 for having a baby with Down's syndrome, women aged thirty-five have a standalone risk factor of 1:400 and women aged forty have a risk factor of 1:100. The discourse of 'advanced maternal age', reinforced through the production of these risk factors, positions mothers-to-be aged thirty-five plus at an increased risk of having a child with Down's syndrome. Fieldnotes taken during an NT scan between Sophie (SAD sonographer) and Mrs Fallon (mother-to-be) illustrate this:

> Sophie: That's the nasal bone [points]. It's often absent in babies with Down's syndrome so that's good.
> Mrs Fallon: OK. I'm forty-two now so.
> Sophie: It's depressing when you read the literature isn't it?
> Mrs Fallon: Yes. I know I am a one in sixty-five risk on my age alone. That's the trouble when you put off having another baby.

Mrs Fallon's risk status after '*[putting] off having another baby*' troubles her, forcing her to act by undertaking screening. Sophie alleviates her anxiety by confirming the presence of a nasal bone, a positive statement contrasting with Mrs Fallon's population risk factor ('*I am a one in sixty-five risk on my age alone*'). Many mothers-to-be in Freymarsh and Springtown demonstrate little knowledge of their standalone risk factor but rather a vague awareness of an older mother-to-be being more susceptible to a Down's syndrome diagnosis. For instance, Miranda (mother-to-be) justifies her decision to undertake a NT scan rather than quadruple screening (the former is more accurate than the latter) by suggesting '*I had the blood test the last time I was pregnant but I'm older now so I got a bit worried*'. Risk discourse brings out social accounting practices in particularly forceful ways (Horlick-Jones 2005); it becomes a 'forensic resource [...] a language with which to hold persons accountable' (Douglas 1992: 22). During an interview, Lisa (SAD sonographer) explains why older mothers-to-be attend Springtown rather than an NHS hospital:

> The older you are, the more likely you are to have had more pregnancies with problems in. There's a perception that being an older mother brings with it medical problems as well so older women want a bit more tender-loving-care than they'd get in the NHS. I think someone early on in the pregnancy tells them "you're an elderly primigravida" [laughs] when you're a certain age and you think "God, really?" And then you realise you're suddenly categorised as higher-risk.

Lisa claims older mothers-to-be are more likely to experience '*medical problems*' in their pregnancy, meaning they often account for their attendance at Springtown with reference to their age. By light-heartedly citing the term '*elderly primigravida*', defined as a woman who is pregnant with her first child after the age of thirty-five (*primus* being Latin for *first* and *gravidus* meaning pregnant), Lisa highlights how older mothers-to-be are '*categorised as higher-risk*' during antenatal care. Armed with this risk knowledge, mothers-to-be may reconstruct their health identity as someone susceptible to having a baby with Down's syndrome. Possamai-Inesedy (2006) suggests women respond as if risk, as a concrete entity, actually exists; risks become actualised through anticipation and call for a person to respond. In the context of Down's syndrome screening, this response can involve undertaking a more accurate procedure, i.e., mothers-to-be aged over thirty-five having an NT scan at SAD rather than a quadruple screen at FAD. Mothers-to-be accounting for their decision to opt for screening by citing their age arguably points toward the procedure as one more facet of their regimes of ritual purity along with lifestyle choices (diet, taking folic acids, avoiding certain activities, and so on). Such rituals are produced and reproduced as part of, as Martha (FAD midwife) claims, their '*quest for the perfect child*'. Other research has recognised, indeed, that parents-to-be consent to screening as part of their pursuit of perfection, that is, by wanting to acquire reassurance that their unborn baby is healthy and disability-free (Olarte Sierra 2010; Lupton 2013; Remennick 2006).

Midwives/sonographers can additionally contribute to figuring older mothers as at-risk entities. Fieldnotes taken in a screening consultation between Toni (FAD midwife) and Mrs Hooper (mother-to-be) highlight this further:

> Toni: Have you thought about whether you want screening and testing?
> Mrs Hooper: To be honest, when I was offered screening, I just said yes for everything. But now I know about [the possibility of miscarrying after amniocentesis], I'll probably not have the amniocentesis but I want to know about the risk factor.
> Toni: So you're having the screening for informational purposes?
> Mrs Hooper: Yes.
> Toni: That's fine. To be fair, you're a good age anyway. When you get older, your risk of having a baby with Down's syndrome increases. When you get to thirty-five, it all goes downhill and when you get to forty, it goes *really* downhill!

Toni smirks as Mrs Hooper smiles uncomfortably.

After Toni asks Mrs Hooper if she wants screening, Mrs Hooper accounts for her current knowledge and her choices. Importantly, Toni reassures Mrs Hooper by classifying her as a '*good age*', supplementing physiological information with emotional responses. Toni also identifies those aged thirty-five and above as '*going downhill*', that is, a bad age. Here, the older mother-to-be is figured as problematic, an at-risk figure who may be subjected, or at least advised to be subjected, to further medical intervention via diagnostic testing.

In her work on paediatric and genetic medicine, Dimond (2013) claims that the category of (child) patient is 'fuzzy', extending to implicate a number of people including parents and family members. In Freymarsh and Springtown, a mother-to-be and unborn baby are, at moments, reduced to a single entity. In this metonymical move, mothers-to-be are ascribed the provisional status of higher-risk/lower-risk (Mrs Fallon: '*I was a 1 in 65 risk*'). Consider the following quotes taken from professionals during their interactions with parents-to-be: '*you'll be*

placed in either the lower-risk or higher-risk bracket and if you're higher-risk, you're advised to have an amniocentesis' (Esther, p. 157); '*the older you are, the higher your risk is for having a baby with Down's syndrome*' (Tara, p. 158); '*what I badly need to know is whether you want to know whether you're a lower-risk or higher-risk*' (Lois, p. 175). Similarly, Maggie (FAD midwife) suggests older mothers-to-be in particular '*have tended to look into [screening] probably a little bit more [than younger mothers-to-be] because they know they're more at risk*'. Mothers-to-be, thus, receive *their* risk; *they* are the ones at-risk in screening practices.

As some of the extracts above highlight, tensions often emerge during screening consultations between a mother-to-be's potential individual risk, her population age-related risk (e.g. '*I am a one in sixty-five risk on my age alone*'), and how she and professionals interpret risk ('*To be fair, you're a good age anyway*'). Nonetheless, with screening colonised by a risk discourse and both the mother-to-be and unborn baby being classified as one single entity, it is clear older mothers-to-be may feel anxiety and self-blame should expectations be breached (a higher-risk result and/or diagnosis). This depiction has been perpetuated by the media, with prevailing visual representations of pregnant women excluding the pregnant body of the older mother in favour of the younger, more 'perfect' mother (Budds et al. 2013). It is illuminated further in Springtown through offering parents-to-be 'Body Clock Testing', a procedure which makes it possible, according to the advertising leaflet, '*to predict future fertility*'. The leaflet urges women, and specifically women '*leaving it late*', to '*take control of their reproductive choices*' by undertaking a test which can cure '*the unknown*' by '*[taking] out the uncertainty*' which will help women to '*understand [their] choices*'. It reads:

> More and more women leave it until later to try for a pregnancy with nearly 20% of women leaving it until after 35 to start a family. Many however find that they have left it too late, even with help from treatments like IVF. A woman's natural conception rate falls from about 20% a cycle at 30 years old to 5% a cycle at 40. Although high profile celebrities like Amy Ryan, Madonna, Celine Dion and Halle Berry have had much publicised pregnancies in their late 30s and 40s, women's biological body clocks have not changed and for

> many it may be too late! The test has been developed amidst warnings of complacency from leading UK fertility experts. Couples are "sticking their heads in the sand" and one expert urged all 30-year-old women to take a "fertility MOT" test.

After supposedly certifying their claims with reference to scientific knowledge, celebrities, and '*leading UK fertility experts*', women are accused of '*complacency*' and as '*sticking their heads in the sand*' regarding reproductive decision-making. The leaflet draws on claims made by Professor Bill Ledger who urges all thirty-year-old women to 'take a "fertility MOT" test' since 'Britain is facing a fertility timebomb' (Hill and Asthana 2009). The urging and disciplining of these women to make particular decisions is exemplified with the picture accompanying the text, specifically a woman sleeping holding an alarm clock whilst facing the reader.

The social practices (e.g. screening consultations) and cultural materials (e.g. antenatal leaflets) of Freymarsh and Springtown accomplish the categorisation of 'at-risk' older mothers who, at an 'advanced maternal age', become accountable for their conduct. Whilst the vast majority of antenatal literature urges choice and autonomy, these discourses become problematic once this is highlighted alongside the risks prevailing with an advancing maternal age (Budds et al. 2013). This illuminates the dominant ideologies of motherhood prevailing in our risk culture in which parents, and particularly mothers, are constantly (re)positioned and where children become expressions and extensions of the maternal self. Wolf (2011: 71) claims in an era of 'total motherhood', a mother must identify and eradicate every 'risk' to their child regardless of the cost to themselves. In light of medical experts raising concerns about an increasing maternal age (Budds et al. 2013), although such claims have been disputed (Twenge 2012), moral codes discipline parents-to-be into viewing risks as calculable and preventable, urging them to be reflexively vigilant about their bodies even before conception in anticipation of pregnancy and motherhood.

As a reminder, in the waiting room of FAD, two televisions show BabyTV on repeat. Advertised as an information channel with the tagline 'keeping you informed', it

offers advice to parents-to-be on concerns such as appropriate cots, breastfeeding, and car safety. This depicts parenthood as something to be managed and disciplined into, a pedagogic accomplishment containing (moral) statements about the appropriate conduct of the 'good parent'. The subtle coercion of mothers-to-be into particular patterns of conduct reflects a form of pastoral power (Foucault 1979) whereby any deviation from what is interpreted as 'normal' is framed as irresponsible conduct.

In the context of prenatal Down's syndrome screening, the practice can be seen as the expected and responsible action for those at an 'advanced maternal age'; to not engage in risk-avoiding conduct, as Greco (1993: 361) maintains, is considered 'a failure of the self to take care of itself – a form of irrationality'. Responsible parenthood implies the acquisition of all available medical information about the health of an unborn baby (García et al. 2011), submitting to medical surveillance being perceived as potentially promising a healthy baby (Gottfreðsdóttir et al. 2009b). This can explain why some mothers-to-be, responsible for ensuring a perfect outcome, can experience feelings of blame, discontent, and responsibility if this expectation is not realised (Alderson 2001; Buchbinder and Timmermans 2012; Gross 2010; Ivry 2006; Landsman 2009; Latimer 2007; Rapp 2000; Thomas 2014).

Emphasising the health and 'normality' of the unborn baby, and the responsibility of mothers-to-be in ensuring this by conforming to medically ascribed standards, is grounded in an idea that an unborn baby is neither inherently perfect or imperfect but, rather, is 'a perfectible creature' (Ivry 2006: 459). In other words, an unborn baby's attributes are framed as the product of diligent mothers-to-be as opposed to emerging from a random assemblage of genes and chromosomes. As 'makers' of the perfectible (not 'ready-made') baby, thus, mothers-to-be are burdened with heavy responsibilities and can be disciplined into making certain reproductive decisions (Ivry 2006). This includes consenting to Down's syndrome screening. Discursive devices such as risk and perfection accomplish screening as a normal part of pregnancy and moral duty of the responsible mother-to-be, and certainly

the mother-to-be aged thirty-five and above, who must ensure a perfect pregnancy outcome.

Making and unmaking the unborn baby

In this chapter, I have captured how Down's syndrome screening intersects with cultural notions of perfection and how this implicates (particularly older) mothers-to-be. For the remainder of this chapter, I describe how a possible termination of a pregnancy is discussed within Down's syndrome screening consultations and other encounters predominantly taking place in FMD. I begin by citing the following extract between Nicola (FAD midwife) and Mrs Li (mother-to-be) in a Down's syndrome screening consultation:

> Nicola: I'm going to tell you about the test and then I'm going to take you through so you can have your bloods done. So you're offered the screening test today. It won't tell you if the baby has Down's syndrome but it provides a risk ratio which gives a lower-risk or higher-risk of the condition. If you're a higher-risk, we telephone you within three to five working days where you're invited back here. You'll receive counselling and you're offered a further diagnostic test called an amniocentesis. Have you heard of it?
>
> Mrs Li: Yes. I had one in the last pregnancy. Actually, I'm going back to Cambodia in a few days' time for three weeks. What can we do? I'm back on [date] when I'm having the second [anomaly] scan.
>
> Nicola: Well the amniocentesis should take place in three and a half weeks because if you wanted to terminate, it's leaving it very late in the pregnancy. [Mrs Li looks concerned] If you came back as higher-risk, would you have an amniocentesis? Because if not, you might have to think whether having this test would be the best option. You could be higher-risk but it could all still be OK.
>
> Mrs Li: I would rather know if I was higher-risk.
>
> Nicola: OK. Well if you ring in six days' time, we might have your result. If you're higher-risk, we can book you an amniocentesis over the phone. But you should really consider this because obviously the baby will be at

such an advanced gestation for amniocentesis and potentially a termination.

Mrs Li: I understand.

Nicola: How old are you?

Mrs Li: Thirty-three.

Nicola: OK. If you did want an amniocentesis, you would be counselled beforehand. It has a 1% risk of miscarriage and if there's a diagnosis, you're offered a termination of pregnancy. You could come back as lower-risk but lower-risk does not necessarily mean no risk [of having a child with Down's syndrome]. OK?

Mrs Li: OK.

This extract highlights many points identified earlier in the thesis: the figuring of mothers-to-be as '*lower-risk or higher-risk*', the significance of maternal age ('*how old are you?*'), the absence of Down's syndrome, the notion of nondirective care being difficult to uphold ('*you might have to think whether having this test would be the best option*'), and the naturalisation of screening practices. For my intentions here, I highlight Nicola's frequent allusions to the word '*termination*'. Prior to having the screening test, Nicola cites termination on three occasions, using this to highlight the gravity of Mrs Li's decision-making and how delaying this becomes increasingly problematic as the pregnancy progresses. However, the option of hypothetically continuing a pregnancy following a diagnosis of Down's syndrome is never established. I observed similar occasions in other screening consultations including those where parents-to-be with a higher-risk result of Down's syndrome were invited back to Freymarsh to discuss the result[75].

To refresh, if a diagnosis of Down's syndrome or another condition is suspected following screening at FAD or SAD, parents-to-be are offered diagnostic testing. If this is accepted, they are referred to FMD since this care is available free-of-charge (Dr Karman works in both Springtown and FMD so is likely to deal with such cases). If a diagnosis of Down's syndrome is established, parents-to-be are offered

[75] In Springtown, parents-to-be receive higher-risk results via telephone. This is primarily done by Francine who also works at FMD. She often telephones these parents-to-be at night from her home. As such, observing these telephone calls was unfeasible.

a termination of pregnancy and are now under the care of FMD consultants. During one conversation, Dr Karman (FMD consultant) identifies some concerns after hypothetical diagnoses of Edward's syndrome or Patau's syndrome:

> I think when there's a problem, some mothers feel abandoned and require support. Some midwives say "well the foetus has Edward's [syndrome] or Patau's [syndrome] and it's going to die so what can I do about it?" They forget there is still a woman here who is pregnant and has all of these concerns.

Dr Karman acknowledges how women feel abandoned in receipt of a diagnosis and, as well as denouncing midwives, describes the unborn baby with Edward's syndrome/Patau's syndrome as '*the foetus*'. The following fieldnotes are taken from another conversation in which Dr Karman[76] uses similar language:

> Dr Karman, Roxanne (FMD sonographer), Robyn (FMD midwife) and Francine (FMD head midwife) are in the office. Dr Karman attended a hospital meeting yesterday where a range of obstetric professionals from Freymarsh and surrounding hospitals discussed '*the big issues in prenatal care*'. Dr Karman recounts the event:
>
> > Dr Karman: You wouldn't believe it. Maternity have more say in meetings over us. They had six main outcome factors: obesity, alcohol, breastfeeding, maternal satisfaction, caesarean, and good birth. So they talked about soft issues like breastfeeding, not stillbirth or foetal death. The focus has been completely lost. I was like well the best thing is an alive mum and alive baby, and the next best thing is a well mum and well baby. And everything else comes after that. You just can't believe it sometimes. They've lost the plot. They looked so horrified when I mentioned stillbirth and foetal death. There's too much emphasis on smoking, alcohol, breastfeeding and all that. Everyone's concentrating on

[76] Many of the extracts cite Dr Karman since there are only two practicing consultants in FMD. Dr Karman, as one of these consultants, deals with the vast majority of cases I observed.

this and if they get the fluffy pink pram and that. They want all of the soft stuff, not the bad stuff. That part of the pregnancy is all fine but they have to think of the bad stuff too. The primary outcome should be a good healthy baby. You just don't know what will happen during screening and the extent of the many different problems until birth.

Robyn: Exactly.

Francine: Too right.

Dr Karman: You can't win till afterwards. One percent of babies are born with CMV[77] where there are different severities. And it's not appropriate apparently. You can't tell them one in one-hundred babies will have CMV.

Dr Karman bemoans attention in pregnancy being exclusively projected toward '*soft stuff*', including '*breastfeeding*' and '*smoking*', rather than the '*bad stuff*', such as '*stillbirth*' and '*foetal death*'. Dr Karman's classification of '*bad stuff*' reveals a distinction between '*foetal death*' and '*a good healthy baby*'. In an environment in which professionals '*can't win till [after childbirth]*', Dr Karman opts for the term foetus over baby when discussing prospective death and/or termination. This label is also embedded in discourse once a potential defect/condition is diagnosed and a termination of pregnancy is offered. In FMD, once a termination of a pregnancy – for any condition – is considered to be a feasible option, discourses commonly shift from 'baby' to 'foetus'. In contrast, during consultations where the pregnancy is seen as 'viable' or 'compatible with life', the term 'baby' is commonly assumed[78]. Thus, it is here where the unborn baby can be made and unmade.

The frailty and litheness of the baby category is exemplified in a conversation between Victoria (SAD nurse) and Mrs John (mother-to-be) before an NT scan. When Victoria asks Mrs John '*so is this your first pregnancy?*', she responds '*no but*

[77] CMV (cytomegalovirus) is a virus which can be transmitted to an unborn baby before birth. It is a common cause of birth defects and has a range of severities.

[78] In England and Wales, under the Abortion Act 1967, abortions can only be carried out in a hospital or a specialist licensed clinic. According to the NHS (2013), the method of abortion depends on the length of the pregnancy. Methods include early medical abortion (up to nine weeks of pregnancy), vacuum aspiration or suction termination (from seven to fifteen weeks of pregnancy), late medical abortion (from nine to twenty weeks of pregnancy), surgical dilation and evacuation (from fifteen weeks of pregnancy onwards), and late abortion (from twenty to twenty-four weeks of pregnancy). There are two options for late abortion: surgical two-stage abortion and medically induced abortion.

this is my first baby'. Mrs John indicates the unborn baby in her prior pregnancy, ending in a miscarriage, was not a '*baby*'. Instead, this current (viable) unborn baby is afforded the status of baby. The following fieldnotes are taken from a discussion involving Dr Karman and Francine (FMD head midwife) of a possible 'feticide', an act causing the death of an unborn baby prior to termination:

> Dr Karman: [Walks into the office] This is not good. There's a feticide I have to organise for next week.
> Francine: [Dejected] What a bad Friday.
> Dr Karman: You're telling me. Placenta previa[79], early pregnancy, feticide and induction of labour [medically induced abortion] but lots of bleeding if delivered. [...] She wants to terminate after twenty-four weeks and she's currently around twenty-three weeks in. The prognosis is very poor so we're going to recommend a feticide. This is not good.

Dr Karman, upset, leaves the room. I ask Francine why the parents-to-be need to terminate the pregnancy after twenty-four weeks:

> Francine: So the baby can be registered as a stillbirth rather than miscarriage which is easier for funerals. I think it makes the baby seem more real.

Two minutes pass before Dr Karman returns to the silent office. Dr Karman invites me to attend the feticide. The unborn baby has been diagnosed with a '*severe cardiac defect*':

[79] Placenta previa is a complication in which the placenta is inserted partially or wholly in the lower uterine segment. It is the largest cause of antepartum haemorrhage (vaginal bleeding).

> Dr Karman: It's important for you Gareth because this screening and termination is after twenty-one weeks and six days[80]. Sometimes this happens with foetuses that have Down's syndrome. If they have a cardiac scan, then a test, then terminating a foetus with Down's [syndrome] can go beyond twenty-one weeks and six days. And to terminate a foetus with Down's [syndrome] after twenty-one weeks and six days is best through feticide.

I attend the procedure with Dr Karman. [...] Dr Karman refers to the unborn baby as 'the foetus' a few times during the procedure. Afterwards, I enter the office with Dr Karman and Francine:

> Dr Karman: That was unusual. It's usually quicker and more straight-forward than that. We usually inject potassium chloride into the left ventricle inducing immediate asystole[81] and cardiac arrest but the foetus was curled up.

Dr Karman and Francine reflect on a '*bad Friday*' in FMD, with Francine explaining the mother-to-be wants a termination of pregnancy after twenty-four weeks '*so the baby can be registered as a stillbirth rather than miscarriage which is easier for funerals*'. This action '*makes the baby seem more real*'. The practices highlighted in the consultation illustrate the contested and malleable nature of the unborn baby figure, shifting to foetus – using Dr Karman's discourse – from baby once a problem is suspected and, potentially, back to baby once more for a funeral. According to Olarte Sierra (2010: 206), an unborn baby which is terminated can still 'become' a baby for parents-to-be via memorials such as ultrasound pictures and keeping ashes; 'choosing to interrupt a pregnancy does not necessarily mean

[80] In FMD, the recommended gestation after which feticide should be offered as part of a termination of pregnancy is twenty-one weeks and six days gestation (Springtown do not offer this service as they are not equipped to perform this procedure). Notably, Buckley and Buckley (2008) estimate current screening practices in England and Wales reduce yearly live births of babies with Down's syndrome by approximately 660 and cause the loss of 400 babies without Down's syndrome following miscarriages from diagnostic testing. To date, there are no UK statistics on the number of pregnancy losses following diagnostic testing via amniocentesis/CVS or on the possible association between operator performance and miscarriage rates (NHS FASP 2012).

[81] Asystole is a state of no cardiac electrical activity (colloquially known as flatline) which may be one of the conditions used to certify clinical or legal death.

to re-interpret what was felt as a child into the term foetus'. However, whilst Olarte Sierra claims a termination does not necessarily suggest such a shift from baby to foetus, the language used in FMD indicates this can occur once a condition is seen as 'incompatible with life'.

Upset at the prospect of conducting a feticide since '*the prognosis is so poor*', Dr Karman invites me to attend the procedure since '*if [parents-to-be] have a cardiac scan, then a test, then terminating a foetus with Down's [syndrome] can go beyond twenty-one weeks and six days*'. When discussing this case, Dr Karman commonly employs the word '*foetus*' with the '*baby*' status being cast aside; indeed, the procedure is always referred to as a '*feticide*' which emphasises the word foetus over baby. The technical discourse of foetus points toward the strategies employed by professionals to help hollow out the emotionality of the term baby, both for themselves and for parents-to-be. Consider the following exchange between Annie (FMD sonographer) and Francine (FMD head midwife) regarding the feticide case described above:

Mr and Mrs Elton (parents-to-be) have opted for a feticide:

> Annie: All the family are there [during the ultrasound scan preceding the feticide] and [Mr Elton] was asking me to make out all these things as he couldn't. The eyes, head, heart, legs, and the Mum was like "aw look at her all curled up". They're such a lovely family, so supportive and close to one another. I don't often get affected by it but it's really hard sometimes.
> Francine: Yes and it's not like you're heartless.
> Annie: No definitely.
> Francine: You have to be detached.
> Annie: Well you couldn't do this job if you didn't.
> Francine: Exactly. It's crazy because I'm crying at stuff on TV all the time but my son asks me if I cry when I give bad news. I mean not usually. I suppose it's just part of the job.

Discussing the situation of Mr and Mrs Elton, Annie claims her work is '*really hard sometimes*', a sentiment supported by Francine who claims her conduct is not being '*heartless*' but rather a product of '*[having] to be detached*'. Annie contends that without assuming emotional distance from parents-to-be and the issues at hand, '*you couldn't do this job*'. Francine concludes the exchange by acknowledging such difficulties as '*part of the job*'. In an environment in which '*the unthinkable becomes a reality*' (Elena, FMD head midwife), professionals must adopt tactics to manage this emotional work. I want to suggest that assuming a technical discourse which strategically creates boundaries between the 'foetus' and 'baby' can help accomplish this. In their study of medical student training, Lief and Fox (1963) describe how the operating room's appearance and the serious conduct required of students justify and facilitate a technical and impersonal attitude to death. Body parts strongly connected with human qualities (face, genitalia, hands) are never dissected and tissues are depersonalised by removing a body from the room once an organ is removed. For Lief and Fox, this allows students to approach actions scientifically rather than emotionally, to develop a 'detached concern', enabling them to both dissect a cadaver without disgust and listen empathetically to a patient without becoming emotionally involved. Similarly, in FMD, one method of maintaining moral and emotional distance from the issues at hand, to adopt a 'detached concern' (Lief and Fox 1963), is figuratively shifting the baby to a foetus.

'Disposing' of Down's syndrome

So how does Down's syndrome figure in this? In the previous extract describing the feticide, Dr Karman (FMD consultant) refers to the foetus, not baby, diagnosed with Down's syndrome. This technical discourse seems contrary to the positive accounts provided by professionals earlier in the thesis, namely Down's syndrome as being 'compatible with life' and as promising a 'good quality of life' (although I identified how such accounts were replaced during consultations with discourses such as risk and abnormality). The following fieldnotes are taken from an interaction between Dr Karman and Robyn (FMD midwife) in the FMD office:

Dr Karman enters the office following a consultation with Mr and Mrs Pitt. I am handed a form by Dr Karman which contains details about Mr and Mrs Pitt and their unborn child:

> Dr Karman: The foetus has a lateral ventriculomegaly[82]. [Mrs Pitt] had a scan and it looks like two nerves are crossing over at the front of the brain. There is an agenesis of the corpus callosum[83] which means part of the brain is absent. It's a difficult consultation because it could be absolutely fine and the ventriculomegaly has no impact later on. But it could be associated with lissencephaly[84], also known as smooth brain. That's associated with a real handicap and not handicapped like Down's [syndrome] where there is such a wide spectrum [of prognosis].
> Robyn: Would you offer a termination with that?
> Dr Karman: [Nod's head] Yes. It's not really compatible with a good quality of life. It has associations with cerebral palsy[85] and other problems.

Dr Karman describes the case of a '*foetus*' diagnosed with lateral ventriculomegaly and an agenesis of the corpus callosum, suggesting this is a '*difficult consultation*' owing to the uncertainty of a prognosis. However, Dr Karman suspects the foetus could have lissencephaly, a condition '*associated with a real handicap*' unlike Down's syndrome '*where there is such a wide spectrum [of prognosis]*'. Finally, Dr Karman informs Robyn a termination will be recommended since it is '*not really compatible with a good quality of life*' and is indicative of '*other problems*'. It is clear Dr Karman, as a consultant, is the only professional who can realistically constitute if an unborn baby is '*compatible with a good quality of life*'. Although midwives and sonographers are often highly critical of screening because Down's syndrome is

[82] Ventriculomegaly is a brain condition which occurs when the lateral ventricles become dilated. It occurs in around 1% of pregnancies.
[83] Agenesis of the corpus callosum is a rare birth defect in which there is a partial or complete absence of the corpus callosum, the band of white matter connecting the two hemispheres in the brain.
[84] Lissencephaly is a rare brain defect caused by defective neuronal migration during the twelfth and twenty-fourth week of gestation. It is a form of cephalic disorder, meaning congenital conditions stemming from damage to or abnormal development of the budding nervous system.
[85] Cerebral palsy is a blanket term covering a range of neurological conditions which affect a child's movement and coordination.

'compatible with life', they have little say in clinical practice about what constitutes a compatible condition since they only take responsibility for parents-to-be when screening for Down's syndrome.

In FMD, it is not possible for professionals to explicitly advise parents-to-be to terminate a pregnancy following a Down's syndrome diagnosis for two reasons. First, a strict adherence to the principles of informed choice and nondirective care emphasises that parents-to-be must make their own decisions independent of professional intervention. Despite several professionals being critical of screening and testing for Down's syndrome, the interchangeable rhetoric of informed choice and non-directive care becomes a resource for suppressing these values. Notably, Dr Karman claims during another conversation that '*two out of three professionals will not perform a feticide beyond thirty-two weeks for Down's syndrome*' since '*it is not seen as obstructing the quality of life*' and '*it is ethically wrong to do a late amniocentesis if it's to determine whether to terminate or not*'. This shows how professionals formulate distinctions between whether a termination of pregnancy is appropriate or not with reference to the week of gestation. However, since most unborn babies with Down's syndrome are diagnosed before thirty-two weeks gestation, the rhetoric of informed choice and non-directive care is drawn upon in such situations to reallocate responsibility for decision-making to parents-to-be.

Second, as Dr Karman claims, there is a '*wide spectrum*' of the condition. This seems to be an irresolvable quandary for professionals and parents-to-be. Down's syndrome occupies a difficult position since it is enacted as 'compatible with life' yet can be offered as a legal reason for termination. At the interface of obstetrics, the impetus is on identifying 'pathological' cases (using the discourse from chapter five) and attempting to ensure the unborn baby is born alive or that the unviable foetus is terminated. Down's syndrome, however, endangers this distinction. During an interview, for example, Elena (FMD head midwife) claims:

> The question all parents ask before they make a decision about their pregnancy [and termination] is "What sort of Down's baby will I have?" And this is another biggie which will help them make a decision. But

> there's no way of assessing abilities and a prognosis. But then you sort of say "well if you look at any child, you don't know their intelligence, their emotionality, you don't know". I think it's that uncertainty which is the big push for some parents [to terminate], that unknown. I personally find that strange as all children are unknown. [...] And I'm sure there are a lot of parents, if this baby was sort of born out of the blue, they probably wouldn't [put him/her up for adoption] but it's because they have the choice [to terminate]. [...] I think people's perception of Down's syndrome is mostly from institutions still but I think what you put in is what you come out with, but that's true with any kid. But you've got to admire parents that go ahead with pregnancies after a Down's syndrome diagnosis, just as you admire parents who have to make that awful decision about not wanting to continue their pregnancies.

Elena suggests parents-to-be, after a Down's syndrome diagnosis, enquire about the prognosis. The inability to '*[assess] abilities and a prognosis*', for Elena, is a '*big push*' for some parents-to-be for terminating a pregnancy. Elena attempts to alleviate angst by identifying how uncertainty surrounds any child's future, later suggesting the negative image of Down's syndrome may still haunt reproductive practices. She concludes by '*[admiring]*' those who either continue or terminate pregnancies after a diagnosis of Down's syndrome. Elena's suggestion that the '*unknown*' of Down's syndrome constitutes a reason why parents-to-be terminate the pregnancy also explains why the condition is inherently problematic for FMD. Its uncertainty, together with responsibility for choices being transferred to parents-to-be, ensures Down's syndrome dwells in a betwixt and between state. It is neither fish nor fowl; the prognosis is uncertain yet a termination is offered. A solution to settling this uncertainty is to classify the unborn baby with Down's syndrome as a foetus, a discourse frequently utilised in FMD to describe those with the condition. According to Hillman (2007), the shifting of people and their subsequent transformation into the other is achieved on the basis of constituting them in particular ways. For Berg (1992), certain people are dissembled into traits and it is these traits which are used to order and classify them to achieve their best possible 'disposal' (Latimer 1997; Munro 2001; White et al. 2012).

Through an 'effacing of the face' (Bauman 1989: 216) in which people are positioned in a way which means they are not ascribed moral subjectivities, the appropriate figurative and literal disposal of non-conforming bodies (such as the future body with Down's syndrome) is accomplished. In antenatal medicine, as Roberts (2012: 301) claims, the 'search for anomalies [...] may undermine claims to foetal personhood'. Since 'its present position is ambiguous, its future equally', the unborn baby is 'often treated as both vulnerable and dangerous' since its status is indefinable without the intervention of medicine (Douglas 1966: 96). Douglas' analysis of dirt and how it indexes a contravention to a social order is a valuable asset here. For Douglas, that which transgresses boundaries is classified as dirt, as disorder reaffirming the validity, naturalness, and purity of that remaining within. Cultural categories, as public matters, cannot so easily be subjected to revision; its public character makes categories, in which 'ideas and values are tidily ordered', more rigid (1966: 40).

Using Douglas' discussion of dirt as matter out of place and the symbolic interpretation of the rules of purity and pollution, we can see how gestures of separation, classifying, and cleansing emerge in FMD. In the case of Down's syndrome, it is viewed as offending against order. The unborn baby with the condition is thus recast as disposable; 'eliminating it is not a negative movement, but a positive effort to reorganise the environment' (1966: 2). FMD, as stated, is in the business of attempting to ensure the unborn baby is born alive or that the unviable foetus is terminated. As such, the unborn baby – or rather foetus – with Down's syndrome, as an 'inappropriate element', is viewed as polluting since it is 'likely to confuse or contradict cherished classifications' (Douglas 1966: 36-7). By settling on an interpretation of Down's syndrome as a condition which parents-to-be can legally terminate for (as an 'abnormality'), ambiguity is reduced. According to Evans-Pritchard (1956), the Nuer treat unborn babies with anatomical defects as baby hippopotamuses accidently born to humans. Since such babies obscure the distinction between human and nonhuman, placing them in the river dismisses the indefinable and 'affirms and strengthens the definitions to which they do not conform' (Douglas 1966: 40). Given that Down's syndrome is such a variable and

complex condition as professionals recognise, transforming a (human) baby with the condition into a (nonhuman) foetus means that a termination is made possible, ambiguities are settled, and order is restored by professionals.

The cleft board

This analysis of how the baby status can be made and unmade extends to cultural materials and specifically the 'cleft board', a large display adorned on half of a wall in the FMD waiting room. Professionals encourage parents-to-be, after childbirth, to supply pictures of their baby with cleft lip/palate and/or congenital conditions such as spina bifida to the FMD. The following fieldnotes are taken from a consultation between Dr Karman (FMD consultant) and Mr and Mrs Holt (parents-to-be) whose unborn baby has an abnormal aortic arch[86]:

> Dr Karman: So would you like a late amniocentesis?
> Mrs Hunt: I plan not to because I want to concentrate on the heart side of things. And I've heard from a few of the people that if something was wrong, a number of other problems would have been detected by now.
> Dr Karman: Well not in all cases do all other problems show up in the scans or diagnostic tests. The heart is linked to other stuff but this may be the only sign. A heart defect will indicate abnormality in 5% of cases and the only way you can know whether there are any problems is by an amniocentesis. [Elena, head midwife, enters the room] But the likelihood is that the baby's chromosomal development is normal. That's 95% likely [Dr Karman smiles. Mr and Mrs Hunt smile back].
> Elena: You should book an appoint to come here again so we can keep an eye on everything.
> Dr Karman: Yes [Mr and Mrs Hunt nod]. Can you bring baby into the department after he or she is born?
> Mrs Hunt: Sure.
> Mr Hunt: Of course.
> Dr Karman: I'd like to add a photograph of him or her to the [cleft] board.
> Elena: Yes. If something is wrong, it's good for parents to see a picture

[86] An aortic arch is the part of the aorta, the largest artery in the human body, in the heart.

with the problem and see that there is still a baby here.
Dr Karman: Absolutely [smiles at Mr and Mrs Hunt].
Mrs Hunt: Yes it's nice to know that you're [slightly pauses].
Dr Karman: [Interrupting] It's nice to see the baby ahead of the problem.
Elena: Definitely.
Mrs Hunt: Definitely. It's nice to see that you're not on your own.

Mrs Hunt rejects Dr Karman's offer of a late amniocentesis because she intends to '*concentrate on the heart side of things*' and she doubts '*something [is] wrong*' owing to the absence of other symptoms. Dr Karman's response is far from nondirective, potentially inciting anxiety in Mr and Mrs Hunt by claiming '*other problems*' may be hidden. Dr Karman suggests an amniocentesis would resolve the uncertain status of the unborn baby and is '*the only way*' to establish an absence or presence of '*abnormality*'. Dr Karman tries to repair this by recognising that a '*normal*' baby development is '*95% likely*'. However, such a discourse is arguably suggestive of a '*problem*'. This is a problem potentially absorbed and interpreted by both Mr and Mrs Hunt, especially since Dr Karman initially suggests that '*a heart defect will indicate abnormality in 5% of cases*' rather than it being '*95% likely*' that '*the baby's chromosomal development is normal*'. In addition, one could attribute Elena's plea for Mr and Mrs Hunt's return as an extension of surveillance medicine and the medical gaze (Foucault 1973; Armstrong 1995). Nonetheless, I note Dr Karman's preference for the word baby over foetus once a pregnancy is 'compatible with life' rather than 'incompatible with life', that is, a condition for which a termination of pregnancy will not be offered.

Dr Karman also asks Mr and Mrs Hunt – despite a specific problem not necessarily being diagnosed other than an abnormal aortic arch – if they would bring their newborn baby into FMD so a photograph can be taken and added to the cleft board. If '*something is wrong*', Elena deduces, other parents-to-be in a similar situation will benefit from seeing '*that there is still a baby here*'. Dr Karman claims '*it's nice to see the baby ahead of the problem*' before Mrs Hunt adds '*it's nice to see that you're not on your own*'. Re-affirming the baby status of the unborn once a problem occurs seems to be of paramount importance to FMD. It encourages public parental

displays of satisfaction with the service and plays up the future years of normality (Silverman 1987). During an interview, Francine (FMD head midwife) highlights its importance:

> I think [the cleft board] is for women to come in and see their babies could be diagnosed with certain abnormalities but at the end of the day, they still look normal. I think because you can't see your baby apart from through the black and white images [via ultrasound scan], a lot of women picture some horrific things in their mind. Babies have gastroschisis[87] or spina bifida and they have images of these huge messes when in fact you're looking at something really small. So I think it's just to get things into perspective. So if we say baby's got a cleft or whatever, and they say "what's that going to look like", you can show them a picture and say "this looks like a normal baby". At the end of the day, it might have a structural problem but it will look like a normal baby. The other toss of the coin is that women terminate because of abnormalities and they say to me what will my baby look like when they deliver having terminated the pregnancy and I say, well, it will look normal. If they terminated a pregnancy for a brain abnormality, the baby will look normal and I think that's quite hard because a woman will have at the back of her mind "did I do the right thing? I know they're telling me it did have brain abnormalities but did it, and would it really be affected that way?" And it could be the same with Down's syndrome. They might terminate and look at the baby when the baby's born and think "he doesn't look very Down's syndrome, have they got it right, was it just a mildly affected Down's [syndrome baby], and could we have coped with it?"

Francine's account begins by her identifying the cleft board as beneficial for mothers-to-be to see '*their babies could be diagnosed with certain abnormalities but at the end of the day, they still look normal*'. Since many parents-to-be '*picture some*

[87] Gastroschisis is a congenital defect characterised by a structural defect in the abdominal wall through which the abdominal contents protrude.

horrific things' if receiving a diagnosis, the cleft board becomes a normalising technology which helps '*get things into perspective*' by revealing a baby which '*will look like a normal baby*'. Similar normalising technologies include offering 4D baby bonding scans free-of-charge to parents-to-be after a diagnosis of cleft lip/palate or another structural defect (these are offered at SAD/FMD but only take place at SAD). Such materials reveal the importance of (visual) 'normality', constituted as a perceived visual absence of *ab*normality. Interestingly, there is no picture of a newborn baby with Down's syndrome currently adorning the cleft board. In an interview, Elena (FMD head midwife) reflects on this together with the board's value:

> Parents look at it all the time and the most positive thing we've ever done here is put that up. But the only thing we haven't got up there is Down's [syndrome] because parents don't send pictures back of their Down's babies.

Elena perceives the cleft board as allowing parents-to-be to frame their unborn baby in a positive light by, as she articulates during the consultation with Mr and Mrs Hunt cited earlier in this chapter, '*see[ing] there is a still a baby there*'. I have already identified how the Down's syndrome 'face' (Latimer 2013), corresponding to the distinctive facial features caused by the presence of an extra chromosome, can signify a failure to fulfil expectations in the pursuit of perfection in a pregnancy outcome. Elena's and Francine's accounts taken together suggest a picture of a newborn baby with Down's syndrome may transform perceptions of parents-to-be and (re)produce normality, at least an artificial/aesthetic normality. However, the concrete absence of Down's syndrome on the board ironically reflects the absence of explicit details regarding the condition in screening consultations.

I argue that the absence of a Down's syndrome presence on the board relates to the denigrating portrayal accomplished in everyday clinical life. In the early stages of antenatal care, the future body of Down's syndrome is subjected to narrow and universalising constitutions of 'risk' and 'abnormality' whilst in FMD, the term 'foetus' is used when discussing the possible termination of unborn babies with the

condition. Müller-Rockstroh (2011) argues in such situations, professionals treat the unborn baby as an organ without taking account of its specificity of developing, moving and growing. With the unborn baby categorised as a foetus, its baby status is denied. This not only helps professionals retain emotional and moral distance from the unborn baby but may additionally help parents-to-be do the same when a termination of pregnancy is possible. Such practices, in addition to reflecting the absence of Down's syndrome on the cleft board, permit the effective disposal of the condition in antenatal care. Down's syndrome is an uncertain and unpredictable condition yet in the clinic, unborn babies with the condition are 'effaced' (Bauman 1989) and, essentially, made 'killable' (Haraway 2005: 38).

Summary

In this chapter, I explored how Down's syndrome screening can promote a notion of human perfectibility which, according to some authors, masks a motivation to eliminate all which does not meet society's increasingly rigid standards (Ginsburg and Rapp 1995; Lippman 1994; Rapp 2000; Rothschild 2005). It seems wider lines and obsessions around beauty and perfection shape understandings of disability, particularly with respect to reproductive practices (Buchbinder and Timmermans 2012; Landsman 2009). Pursuing perfection is largely aesthetic in character, with Down's syndrome – particularly its 'face' – constituted as a non-perfect pregnancy outcome (Thomas 2014). The future child with Down's syndrome, thus, is constructed as disrupting maternal and familial expectations, a threat to ongoing presentations of 'normality', and a deviation in the embodiment of prenatal expectation. In addition, I describe how an 'advanced maternal age', translating as mothers-to-be aged thirty-five and above, is embroiled in cultural ideologies of perfection and how mothers-to-be may, regularly undertaking Down's syndrome screening as one of the routines of ritual purity, subsequently feel to blame should any deviation in the expected outcome be encountered.

I also suggested that the notion of perfection intersects with a distinction made in FMD between the 'baby' and the 'foetus'. The unborn baby with Down's syndrome occupies a between and betwixt state as it is recognised as 'compatible with life' yet the condition can be used as a reason for terminating a pregnancy. Since the

condition cannot be 'fixed' or 'cured', a diagnosis can diminish or at least threaten the baby status. As gatekeepers to meaningful data, FMD professionals can subsequently transform a perceptibly healthy unborn 'baby' into an unhealthy 'foetus'; 'by definition, of course, we believe the person with a stigma is not quite human' (Goffman 1963: 5). These classifications restore order and accomplish and re-accomplish clearly-defined boundaries in the clinic. Just as Foucault (1983) presses there is no madness without reason, there is no abnormal without normal in antenatal care; it is in its asymmetry that the 'normal' baby without Down's syndrome is brought into view.

A combination of all of these factors – the value placed on producing perfection during pregnancy, an imperative for mothers-to-be to eliminate all 'risks', the making and unmaking of the baby into a foetus, and screening ultimately fostering the contention that unborn babies with Down's syndrome should be detected and terminated (Alderson 2001; Burton-Jeangros et al. 2013) – may highlight, as built on in chapter seven, one reason why termination statistics in England and Wales remain between 89% and 94%. In chapter nine, I conclude my thesis and discuss how this focus on one specific aspect of medical work raises important questions for both antenatal medicine and wider society.

Chapter Nine
Discussion

In the preceding chapters, I explored how Down's syndrome and screening for the condition is organised, negotiated, constituted, and (re)produced in the everyday practices of professionals in antenatal care. Drawing heavily on observations of screening consultations, that is, thick descriptions of slim encounters, I began my analysis in chapter five by exploring how Down's syndrome screening is organised and how it is downgraded by professionals in everyday conduct. Its sedimentation in antenatal care produces and reproduces both hierarchies and identities. Doctors are able to defend disciplinary boundaries and protect the purity of the clinic through screening consultations being relegated to midwives and sonographers. Doctors only attach to Down's syndrome screening once a diagnosis and potential termination is possible whilst midwives and sonographers, in contrast, appear reluctantly attached. However, midwives in particular minimise the value of screening by privileging other tasks, namely 'hands-on midwifery work', affording the successful construction of a meaningful professional identity. They dismiss Down's syndrome screening as 'boring' and 'routine', a tedious duty not connecting effectively with work-based expectations.

In analysing the conduct of care in chapter six, I captured how professionals further detach from Down's syndrome screening by reassigning responsibility for decision-making to parents-to-be. The transposable rhetoric of 'informed choice' and 'non-directive care' becomes a resource for shifting liability (and thus blame) and, albeit unwittingly, accomplishes screening as a 'normal' part of pregnancy. This analysis continued by attending to how ultrasound scans and specifically NT scans are reconstructed as a 'day out' to greet a new family member and reproduce kinship. This often trounces the medical agenda, namely of prenatally detecting potential conditions or other concerns with the unborn baby. Whilst the 'medical' dimensions of NT scans are discussed, its 'social' dimensions are widely promoted and its value as a serious procedure is simultaneously diminished. In addition, producing an unborn baby for parents-to-be to gaze at – a baby with distinctive

behaviours and physical features affiliated with personality traits and gendered conduct – contributes toward the configuring of certain types of 'normal' bodies.

I built on this concept in chapter seven by exploring how Down's syndrome itself is constituted inside and outside screening encounters. Professionals often condemn screening by citing Down's syndrome as 'compatible with life', a catch-all term signifying that someone with the condition can survive birth and enjoy a good 'quality of life'. However, such criticisms disappear during consultations. Down's syndrome is rarely discussed and subsequently made absent. I explained how this corresponds to its familiarity to the UK public, the organisation of care, and a lack of knowledge of the condition among professionals. Down's syndrome, however, becomes present inside and outside consultations through a dominant discourse which associates the condition with 'risk' and its ancillary categories of 'problem', 'bad news', and 'abnormality'. Professionals do not overtly identify the 'miserable lives of people with disabilities' like the geneticists in Kerr et al.'s (1998: 181) research. However, they instead implicitly construct Down's syndrome as a dismal pregnancy outcome and confine the condition to a purely technical definition of being outside the 'normal'.

In chapter eight, I extended this analysis to show how such discourses intersect with the production and reproduction of ideas around 'perfection' in the social practices and cultural materials of the clinic. This frequently implicates mothers-to-be, particularly those of an 'advanced maternal age'. These mothers-to-be may interpret screening as an instance of conformity and the chance to eliminate any 'risks' flagged up in antenatal care, this defining the responsible mother 'who does everything – takes all tests – to ensure foetal health' (Lippman 1994: 22). Finally, I show how a diagnosis, as both category and process, triggers a potential unsettling of the 'baby' status and its replacement with the technical category of 'foetus'. In the case of Down's syndrome, a contestable condition in the 'grey area' owing to its uncertain prognosis, there are contradictions and ambiguities. This surrounds the condition being defined as 'compatible with life' but also as something which can be used as a reason for legal termination. These contradictions and ambiguities are settled by constructing the unborn baby as a 'foetus' which deny an unborn 'baby'

its personhood. A termination of pregnancy is therefore made possible. The unborn baby becomes 'disposable' (Latimer 1999) both figuratively, recast as somebody or something not worthy of moral subjectivities, and literally, via termination. Such moves, in turn, restore local order and reinforce the boundaries between normal (babies) and abnormal (foetuses).

In sum, my thesis contributes to accounts around how medical work is organised and performed in everyday routines (Bosk 1992; Latimer 2000, 2013; Silverman 1987; Strong 1979) and how values around disability intersect with reproductive technologies (Ettorre 2002; Landsman 1998, 2009; Lippman 1994; Parens and Asch 2000; Rapp 2000; Rothman 1986; Rothschild 2005). It also extends the field in four explicit ways. Firstly, it draws on ethnographic data often missing in research on Down's syndrome screening, simultaneously highlighting the shifts between participants' accounts and what happens in everyday clinical practice. My ethnography of two healthcare institutions, thus, champions using observational fieldwork in explicating the implicit and exposing the taken-for-granted affairs of everyday life (Garfinkel 1967). Secondly, it supports the call to expose and reject universalising categories trivialising and unfairly classifying Down's syndrome as a 'disability'. This neat classification of 'disability' discounts the complexities and contradictions of Down's syndrome and prevents a thorough dissection of how the condition is constructed in the everyday practices of the clinic. Thirdly, I identify the sociological value of theoretical pluralism for analysing the mundane and ordinary routines deeply embedded in the fabric of medical work which produce and reproduce certain power relations and cultural values. Fourthly, it attends to the complex interplay of practices, discourses, and materials in deconstructing one of the most taken-for-granted aspects of pregnancy in the UK.

Generally, my thesis shows how medicine is accomplished and re-accomplished in ritual and mundane forms. Less generally, I highlight how screening for Down's syndrome represents a routine practice which has transformed obstetric medicine, invigorated parental expectations, shaped many issues surrounding the 'politics of reproduction' (Ginsburg and Rapp 1991), and reproduced certain body-society relations. I have drawn explicit attention to social practices and cultural materials

in which alignments are made, accounts are produced, typifications are erected and mutated, identities are accomplished, and knowledge is ultimately produced and reproduced in local settings. By separating the discussion of screening for Down's syndrome from other kinds of screening, I track the processes and associations and produce soft data which, as shown, raises hard questions about some of the most profound dilemmas of our time.

Specifically, I show how Down's syndrome occupies a rather odd position in the clinic. There are inherent shifts – I borrow and employ the term 'motility' (Latimer 2013; Latimer and Munro 2006; Munro 2001) when referring to this throughout the thesis – in antenatal care. These shifts are not interpreted as contradictions, deviancies, or unguarded statements which involve professionals 'slipping up' and cancelling out other pronouncements. Rather, I interpret them as examples of how professionals shift backward and forward between distinct discursive forms (Latimer 2008b). Early in Down's syndrome screening, for instance, doctors resist attaching to the practice since it has yet to reach the status of clinical interest. In order to protect the purity of the clinic, this duty is relegated to midwives and sonographers. Such professionals, though midwives particularly, however, similarly do not attach to screening since it does not constitute 'hands-on midwifery'. Thus, in Freymarsh and Springtown, screening becomes 'matter out of place' (Douglas 1966).

What is more, this motility emerges in how midwives (more than sonographers at least) claim they do not 'do pathology' yet spend most of their time monitoring and probing mothers-to-be in an unrelenting cycle of clinically oriented surveillance. But most importantly, perhaps, many professionals (midwives included) claim not only that screening has eugenic echoes and creates more problems than solutions but also that the condition itself is 'compatible with life'. However, much of their work downgrades Down's syndrome screening; it is not prioritised since other tasks are privileged, it is not allocated time and money (e.g. hiring translators) which represent essential resources for accomplishing a certain level of care, ultrasound scans become primarily cast as 'days out' rather than serious medical procedures, and so on. Whilst professionals are critical of the practice on medical,

socio-political, and moral grounds, screening for Down's syndrome persists as a natural and routine part of a pregnancy.

In addition, despite professionals' condemnations of Down's syndrome screening, everyday practices in the clinic render the condition absent. Symptoms, prognosis, and the 'social realities' (Rapp 1988) of a future child with the condition are eviscerated from everyday routines. Unborn babies with Down's syndrome, or at least those considered at risk of having the condition, are not given presence in the clinic, or wider policies, as people. Since it is conventional to appeal for 'normal' children (Shakespeare 2011), the moral value of the unborn baby with Down's syndrome appears to have scant purchase in antenatal care. With the condition lacking a language of its own, it is colonised by universal negatives such as 'risk', 'problem', and 'abnormality'. This black-boxes Down's syndrome and masks the sizeable physiological and intellectual variation of people with the condition. Such discourses act as 'a stuff mould into which processes and beings must be made to fit even at the cost of distorting them' (Martin 1998: 126). The notion that people with the condition vary considerably is eclipsed as well as the notion that disability more generally is shaped by cultural ideas of 'the normal' and a complex interplay of social, cultural, material, biological, economic, and political factors (Davis 1995; Ginsburg and Rapp 2013; Oliver 1990; Shakespeare 1999). Social conditions are as enabling or disabling as biological conditions. However, the former are interpreted as preventable and the latter as intractable givens (Lippman 1994; Shakespeare 1999).

Taken together, such developments highlight the complexity of a practice in which Down's syndrome itself is constructed as 'compatible with life' in one moment and in another as a 'problem' and legally-acceptable reason for terminating an unborn baby. For the most part, however, Down's syndrome is imbued with negativity and holds a metonymical status for matter out of place, that is, something which *should* be detected and, if a diagnosis is established, something which constitutes a reason for terminating a pregnancy (Asch 1999; Burton-Jeangros et al. 2013; Rothschild 2005; Saxton 2010). The classification of Down's syndrome – and disability more generally – is interstitial and indeterminate. In antenatal care, however, this is

rarely recognised. Agreeing with Silverman (1987) that the illness of a child (in this case an unborn child) and ideas around both medicine and family/kinship are discursively constituted in consultations, I have shown how screening for Down's syndrome is downgraded and how the condition, before a diagnosis is fully established or even suspected, is vitiated and constituted as an emotional tragedy and future family disruption. The interesting and ironic paradox, then, is the discipline which substantially increases the life expectancy and quality of life of the child with Down's syndrome after he or she is born also decreases the chance of an unborn baby with the condition coming into the world.

At this point, I reiterate that I do not subscribe to arguments about *all* population screening/testing as equating to a negative valuation of disabled peoples' lives (Gillam 1999; Lippman 1994; Parens and Asch 2000). It is unhelpful and insulting both to professionals and parents-to-be making difficult choices to use 'highly emotive rhetoric to denounce modern antenatal screening' (Shakespeare 1999: 682). This often manifests itself in claims that screening/testing is an egregious eugenic exercise evocative of Nazi Germany (Rock 1996). This simple classification discounts the complexity of an intricate issue, denies the meaning of impairment in conceptualising disability, upholds unhelpful distinctions (e.g. eugenics vs. choice), and is forever irresolvable since the label of eugenics has many meanings (Duster 1990; Shakespeare 1999, 2000, 2011). It is tempting to identify screening as a tale of triumph or tragedy, that is, of being wonderfully progressive or as nightmarishly evil. The reality, in truth, is much more complicated. Indeed, screening for Down's syndrome is different than screening families with a history of another condition (Shakespeare 2000). Additionally, Down's syndrome is different to the likes of Tay Sachs disease[88], achondroplasia[89], and Edward's syndrome. It would be wrong, therefore, to indulge in exaggerated hype about all current screening procedures and how genetic research and practice in its entirety translates to an 'old eugenics' (Kerr et al. 1998: 176).

[88] Tay Sachs disease is a rare and usually fatal autosomal recessive genetic disorder which causes progressive damage to the nervous system.
[89] Achondroplasia is a common form of short-limbed dwarfism.

Rather, drawing on my fieldwork, I reveal how mundane clinical affairs accomplish and re-accomplish Down's syndrome screening (and not *all* screening practices) as a routine component of antenatal care and the condition itself in negative terms. This, I claim, may suggest a reason why parents-to-be may terminate for Down's syndrome following a prenatal diagnosis. In his analysis on the social and ethical issues ignited by genetic technologies, Duster (1990) suggests there are different drives for terminating a pregnancy for foetal conditions, censuring simplistic and unfair accusations aimed at the alleged eugenics of modern medicine. Agreeing with Duster, I do not read screening as a planned plot against people with Down's syndrome and I do not entertain the argument that termination is *exclusively* attributable to discrimination against people with Down's syndrome. Decisions are complex and can be made with reference to wanting to prevent suffering or feeling that a family will be unable to cope with the strain of caring for a disabled child (Korenromp et al. 2007). Control appears to be with parents-to-be as much as it is with medicine.

However, I do show *how* a termination is made possible and how this might, in turn, be elicited through how everyday practices construct Down's syndrome as a tragic and adverse pregnancy outcome. Whilst I refrain from emotionally-charged eugenic accusations against Down's syndrome screening, I am equally wary of not idealising UK prenatal care as an arena free of enacting values around particular bodies or of UK society as tolerant of people with disabilities. Since one cannot consider screening and testing more generally apart from its eugenic roots (Kerr and Cunningham-Burley 2000), it might be fairer, then, to erect a division between 'historical eugenics', operating at the level of populations, and 'contemporary eugenics', operating at the level of individuals and families (Shakespeare 1995: 8-10). Screening for Down's syndrome, as shown in this thesis, is arguably associated with the latter. The race for a Down's syndrome diagnosis in the absence of a cure made possible by the availability of prenatal technology – and its sedimentation in antenatal care as revealed by this study – inadvertently serves as a commentary on which lives are valued and unvalued in society. The only option, thus, seems to be to terminate a pregnancy (Alderson 2001; Asch 1999; Shakespeare 1999; Sooben 2010), with screening consultations becoming specific and salient outlets for the

reproduction, reaffirmation, and reconstitution of Down's syndrome as a tragic pregnancy outcome.

This is amplified by the routinisation of this technology; 'the easier it is to blur the eugenic purpose of a technology, the more it is allowed to become routinised' (Ivry 2006: 460). The range of technology available for detecting potentially disabling conditions has increased geometrically yet it seems the fund of social knowledge accompanying such decision-making processes are limited (Ginsburg and Rapp 2013). Whilst this arguably turns parents-to-be into 'moral pioneers' (Rapp 2000), it seems few people have an understanding about what it might be like to live with the particular disability diagnosed (Franklin and Roberts 2006; Ginsburg and Rapp 2013). This emerges alongside a spread of disability consciousness which offers support to families of children with disabilities (Finger 1999) and reports family life is not the tragedy one initially expected it to be (Thomas 2014). Medicine, thus, must take responsibility for ensuring a fair and accurate depiction of conditions such as Down's syndrome is realised rather than reinforcing inequalities and stigmatisations.

It is entirely unfair, however, to lay the blame entirely at the feet of professionals who face mounting pressures to 'meet targets and adhere to forms of clinical governance' infiltrating the minutiae of clinical work (White et al. 2012: 79). Tensions between efficiency, economy, and care play out in everyday clinical life. The pressures facing midwives has been recently outlined in an anonymous letter from an NHS midwife published in a UK newspaper (Anon 2014). The midwife describes her exhaustion, fear, and demoralisation working in an increasingly understaffed system 'moving away from high-quality maternity care'. My point is that whilst professionals do play a role in the downgrading of Down's syndrome screening and how the condition is negatively constituted in antenatal care, they are clearly not solely accountable for such developments. There are a number of heterogeneous elements which have combined to accomplish and re-accomplish Down's syndrome screening as a routine affair and particularly the condition itself as a negative life event. This includes a history of people with the condition being institutionalised (Logan 2011), introducing prenatal testing (i.e. amniocentesis) for

terminating conditions other than Down's syndrome (Cowan 1994), the passing of abortion laws (Rapp 2000), the acceptability of medical screening as a knowledge practice (Armstrong and Eborall 2012), the medicalisation of pregnancy (Hiddinga and Blume 1992), a preoccupation with avoiding 'risks' (Beck 1992) and pursuing perfection in pregnancy outcome (Landsman 1998, 2009), recommendations of prenatal self-care which understands an unborn baby's health as perfectible rather than as through predetermined genetic and chromosomal constitution (Ivry 2006), and public discrimination against people with disabilities (Oliver 1990). Thus, many people, practices, and materials are complicit 'in the reproduction of a given ideology' (White et al. 2012: 79).

It seems the technological path to prevent the birth of an unborn baby with Down's syndrome, drawing on Ivry (2006: 459), is 'indexed as a back-stage business because of a historically charged politics of disability'. Nonetheless, I have shown how this depiction of Down's syndrome comes to life most powerfully and most effectively in antenatal care. Although disability being a catastrophic outcome is part of a broader discourse in Western culture (Oliver 1990), it is particularly strong in the context of prenatal screening. This correlates with the medicalisation of pregnancy as part of the project of obstetrics. Whilst I have previously suggested consultants relegate screening via a hierarchy of clinical value, obstetric medicine is not always absent from the early stages of screening. Its influence is felt in the division between 'normal' and 'abnormal' pregnancies and future bodies (Hiddinga and Blume 1992; Olarte Sierra 2010). Obstetrics introduced the notion of 'potential abnormality' in practice by gaining knowledge of, whilst diagnosing and treating, 'pathological' pregnancies.

Such categories of normal and abnormal remain today. As an indelible part of our medical and social culture, such technologies bring to life what counts as a 'normal' body. This construction of the normal body is an extension of our society which seemingly privileges the mind over the body, identifying cognition as essential to personhood. It seems, thus, obstetric medicine has played a key role in designing the politics of reproduction throughout the modern UK history. The language of medicine claims to be neutral and universal yet it produces and reproduces rich,

layered, and powerful messages via divisions of the normal and abnormal body (Rapp 1988, 2000); 'if you are not like everybody else, then you are abnormal, if you are abnormal, then you are sick' (Foucault 2004: 95). According to Foucault, these three categories – of not being like everybody else, of abnormality, and of being sick – are different yet have been reduced to the same thing. In Freymarsh and Springtown and antenatal care more generally, Down's syndrome is similarly implicated in such 'dividing practices' (Foucault 1983) as abnormal, sick, and not like everybody else. This reduces its character and changes what people with Down's syndrome are or could become. Rather than being figured as 'one way, among others, of being human' as Clarke (1994: 19) describes, the condition is embedded in a single class of 'abnormal' which shrouds the variable physical and intellectual difference of people with the condition under a blanket of universal and narrow categories. This undercuts and problematises the choice purportedly promised by reproductive technologies:

> 'The choices promised by the advocates of the new human genetics are also highly circumscribed by the personal, clinical and wider social context in which they are offered. Bodies remain docile when the options for their reinvention follow the conventions of beauty and health; and reproduction remains a fateful process because of the very ability to eliminate the undesirable in favour of a norm' (Kerr and Cunningham-Burley 2000: 294).

Whilst Kerr and Cunningham-Burley concentrate on the new genetics, their work is important for my arguments here. The rhetoric of 'choice', for Lippman (1994: 19), cannot be viewed as 'a real option when society does not truly accept children with disabilities or provide assistance for their nurturance'. As Kerr and Cunningham-Burley (2000: 289) show, the constant focus on curing or eliminating people with genetic defects, coupled with the development of new reproductive technologies framed as benefitting the collective, bears much in common with the modernist project to efface and eradicate the 'other' (Bauman 1989). The desire for a 'perfect child' has become a common refrain, as has the alleged anguish and misery caused by genetic conditions (Kerr and Cunningham-Burley 2000: 291).

Reproductive technologies, as revealed in this research, intersect with wider social and cultural preoccupations with certain bodies. Divisions of normal and abnormal produced and reproduced via the moral ordering work of contemporary hospital life seem to be widely enacted and consumed. Coupled with a society increasingly driven by consumer ideals, the unborn baby imagined as having Down's syndrome becomes an abnormal product, disrupting pre-set expectations of perfection in a pregnancy outcome (Lippman 1994; Rapp 1995, 2000; Rothschild 2005). Using Colen's (1995) concept of 'stratified reproduction', Ginsburg and Rapp (1995: 3) describe the ways by which 'some reproductive futures are valued while others are despised', this relating to the valuation of reproductive futures *and* the valuation of children. According to Ginsburg and Rapp, then, children with disabilities are not valued by both reproductive medicine and the wider public. This is particularly pertinent in antenatal care where those certified as worthy of being born exist beside 'imperfect' babies, that is, 'those who may be dispensed with' (Rothschild 2005: 3-4). By making screening and testing available for Down's syndrome, as shown in this study, one can argue this is already, by definition, problematising the birth of a child with the condition (Asch 1999; Alderson 2001; Lippman 1994).

My focus on the ongoing negotiations of Down's syndrome screening in the clinic not only reveals the overt and covert inclinations toward selective reproduction but also challenges simplistic or entirely beneficent readings of modern biomedical screening technologies. Prenatal screening and testing is a mixed blessing. It offers the possibility of detecting severe health conditions before birth and can prevent suffering for families yet it can also induce great anxiety in parents-to-be and provide a running commentary on what lives we value. Reproductive technologies, thus, raise urgent and disquieting questions, for the public and professionals alike, about our ideas of 'normality', of human variation, and when variation *becomes* a disability.

What next?

So what is the future for Down's syndrome screening? Recent developments in medical and scientific worlds include a group of US scientists announcing they are closer to 'treating' people with Down's syndrome having 'switched off', albeit in

isolated cells, the chromosome causing the condition (Jiang et al. 2013). According to Jiang et al. (2013), this increases the possibility of developing a 'chromosome therapy' for the condition which can improve treatment for common symptoms. Another group of US scientists have similarly found a way to reverse the condition in newborn lab mice by injecting a compound causing 'normal' brain development, potentially raising the possibility of 'reversing cognitive dysfunction in Down's syndrome' (Das et al. 2013: 1). Most importantly, a number of UK privately-funded clinics have recently offered parents-to-be an opportunity to undertake the Ariosa Harmony Prenatal Test, a non-invasive prenatal test (NIPT) for Down's syndrome and other conditions. This involves analysing cell-free DNA circulating in the blood of a mother-to-be in all single pregnancies and is advertised as the most accurate screening – 99% for Down's syndrome – available in estimating the chance that an unborn baby has a genetic condition (Ariosa Diagnostics 2013).

Since the test is non-invasive, it presents no risk of miscarriage or other adverse outcomes associated with CVS or amniocentesis. As such, the amount of mothers-to-be offered an amniocentesis or CVS after undertaking the NIPT is less than 1%. NIPT therefore offers an earlier and safer test causing fewer terminations and miscarriages. However, it also raises a number of concerns surrounding peoples' access to the technology, the provision of information, the emphasis on prevention as opposed to management (Kerr 2005), and the ability to detect conditions other than Down's syndrome and associated chromosomal conditions. The latter concern corresponds to an overriding fear that, as Latimer (2013: 192) claims, 'the normal is shrinking' at the same time as our consciousness of the riskiness of reproduction is intensified. With screening becoming more accurate, less invasive and more widely available, the 'normal' is threatened by the possibility of detecting more genetic duplications, deletions, translocations, inversions, and insertions. As the body itself is more fully probed and finely enumerated, the category of the normal shrivels and the parallel category of the abnormal swells.

Whilst I make no grand claims about NIPT or what will come of it here, I recognise how it may extend the dichotomy of normal/abnormal. In addition, I identify how it intersects with how Down's syndrome screening has become a routine affair in

the antenatal clinic. To illustrate this point further, I draw a comparison with the recent public dialogues organised by the Human Fertilisation and Embryology Authority on mitochondrial transfer (HFEA 2013). These events were arranged to seek public views on emerging techniques, specifically on their social and ethical impact, designed to avoid parents passing on genetically-inherited mitochondrial diseases to their children. Interestingly, no such debates were, or have since been, organised regarding NIPT or Down's syndrome screening more generally. NIPT has followed a linear path from scientific knowledge to technological application to its diffusion into routine practice; 'where new tests fit old paradigms, uptake is higher and concerns are more mute' (Kerr and Cunningham-Burley 2000: 289). Since Down's syndrome screening is such a routine procedure, the diffusion of NIPT into medical practice has been largely untroubled and unchallenged, a subtle reconfiguration rather than leaping into a brave new world.

This reflects how the drive toward Down's syndrome screening 'appears to come from medical agencies, not from lay people or through democratic debate' (Alderson 2001: 362). This drive to obtain a diagnosis in the absence of a cure, therefore, does not emerge from public consultations demanding this care. With no UK parliamentary discussion on Down's syndrome screening, policies are formulated by advisory committees and emphasise preventing (alleged) suffering and promising informed choice. Thus, I agree with Buckley and Buckley (2008) that policies permitting screening for conditions such as Down's syndrome should be reviewed through wide public debates before its development and diffusion. In addition, we should ask what or who is driving this practice, if screening is an unsustainable luxury as its increasing sophistication seemingly ushers in further uncertainty, and what accumulative effects the inclination to tinker has for reducing what constitutes 'normality' in our conceptions of certain (future) bodies.

Our relentless march toward scientific innovations renders the chance of putting a brake on the progress of prenatal screening for Down's syndrome as incredibly slim. Indeed, we may be kindling a fire we cannot control. Nonetheless, I call not for an end to reproductive choice or a ban on Down's syndrome screening but rather to develop a more nuanced and informed approach to screening and testing

(Shakespeare 1999, 2011; Williams et al. 2005). We are entering an era in which we may eventually be able to screen and test (and potentially terminate) for not only serious conditions but also for mild conditions and late-onset disorders (Pilnick 2004). As such, parents-to-be must be provided with balanced information about conditions screened/tested for in the UK so they can successfully digest this data and make a decision which is right for them (Boardman 2010; Sooben 2010). Here, it needs to be emphasised that as both my own and Latimer's (2013) studies have shown, how clinical consultations are enacted and performed is constitutive. That is, it is the implicit which is communicated in how screening is conducted. The implicit mediates the information shared within medical work and installs not just the need for a choice but *what choice* will be made. This means we should invest money both in the science and technology of this practice and the training and support which accompanies it (Shakespeare 2011). At this time, antenatal settings seem to provide little opportunity for people to discuss and explore their beliefs about disability (Bryant et al. 2006). This demands immediate attention in order to move closer towards promising 'informed' choice.

We must also be honest about the limitations of medical and scientific knowledge (Shakespeare 2011), witness a more careful regulation of technologies, and have more fundamental discussions around the values embedded in the knowledge and practices of screening/testing (Kerr 2003). Rather than focusing exclusively on the reproductive autonomy such techniques allegedly promise, rooted in discourses of certainty and responsibility, we must remove this fig leaf to genuinely engage with issues around Down's syndrome and what lives we value in modern healthcare systems and wider society. Skotko (2009: 823) fears as medical progress leaps ahead, people with Down's syndrome will gradually 'disappear' from society. It is important, thus, to fully engage with concerns surrounding Down's syndrome and other disabilities as a 'fact of life' not always to be eliminated in the drive for a 'perfect baby' (Shakespeare 2011: 40). By lifting Down's syndrome specifically out of the medical context, this will make it possible to 'speak in other languages' about the condition so parents-to-be can 'come to a decision from a more nuanced and knowledgeable position' (Rapp 1988: 155–6). Rather than focusing exclusively on abstract ideals such as autonomy and non-directive care when discussing how we

can improve healthcare practices (Mol 2008), therefore, it may be better to explore how one conveys information around conditions such as Down's syndrome prior to screening (Bryant et al. 2001).

With NIPT minimising physical risks and offering an earlier result, one suspects parents-to-be choosing to undertake Down's syndrome screening is set to expand, particularly with plans to diffuse NIPT into NHS practice. As such, these concerns become a matter of urgency. Via detailed empirical insights into Down's syndrome screening and a continued dialogue between respective stakeholders – including professionals, parents-to-be, policymakers, charity organisations, academics, and those with personal experience of Down's syndrome – we can 'continue to provoke and challenge, not relieve and mollify, policy-makers and experts' (Kerr and Cunningham-Burley 2000: 298).

Conclusion

My intention is not to propose specific policies or discourses designed to change or improve practice. More modestly, I hope my arguments will ignite more reflexive and pluralistic dialogues – and so better communication between professionals, parents-to-be, and the wider lay public – around prenatal screening for Down's syndrome and potentially other conditions too. We know knowledge implanted as innovation and absorbed by wider society creates new relationships, identities, 'biosocialities' (Rabinow 1996), and responsibilities. Screening and antenatal care, indeed, changes the way we think and act and alters our perceptions 'of self and other, of normality and abnormality' (Lippman 1994: 9). Spilling beyond the biological and into public arenas and intimate lives, screening is a potent site for uncovering assumptions buried deep in medical work and for exploring how ideas around family, parenthood, and personhood are produced and reproduced. In sum, by taking the politics of reproduction seriously, I reveal how analysing the 'terrible ordinariness' (Bosk 1992: xvii) of clinical life in Freymarsh and Springtown raises vital questions for professionals, parents-to-be, governments, and sociologists alike. All ethnographies become social history and Down's syndrome screening will move on. However, many of the dilemmas will remain the same, namely about

what lives we consider valuable as a society, and the cultural forms of the clinic will likely show remarkable stability (Atkinson 1995).

This study of one specific medical situation has broader appeal for considering the intersections of kinship, disability, motherhood, and healthcare communication. It illustrates how Down's syndrome screening is downgraded in everyday practices and how the condition is accomplished and re-accomplished as a negative life event, thus providing a commentary on what lives are valued, who is ascribed personhood, and who/what is instituted as 'normal' during pregnancy. With increasingly sophisticated technologies showing no sign of abating, antenatal medicine will continue to transform and shape reproductive politics and how the (future) baby with Down's syndrome is constituted in the UK and beyond for the foreseeable future. We must remember that sociologists are particularly valuable assets in exploring and making sense of such developments.

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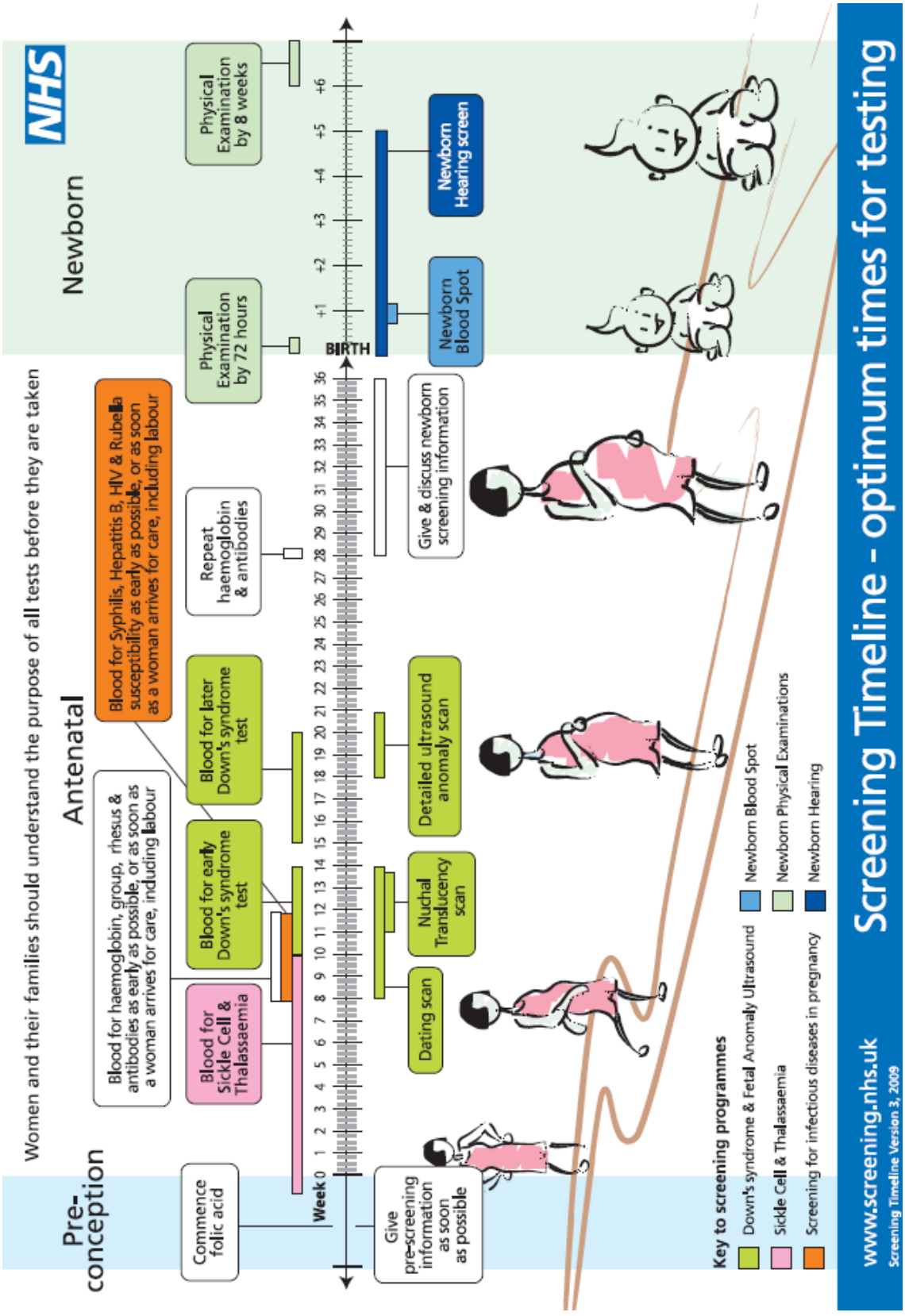
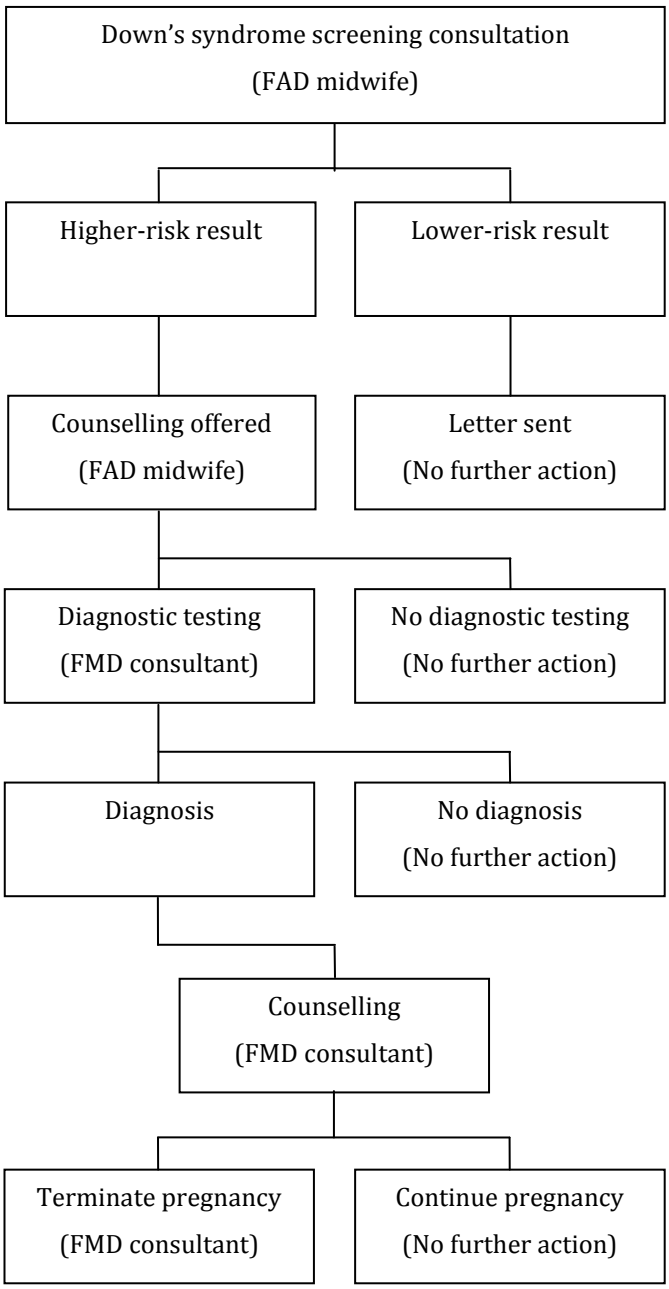
Appendix

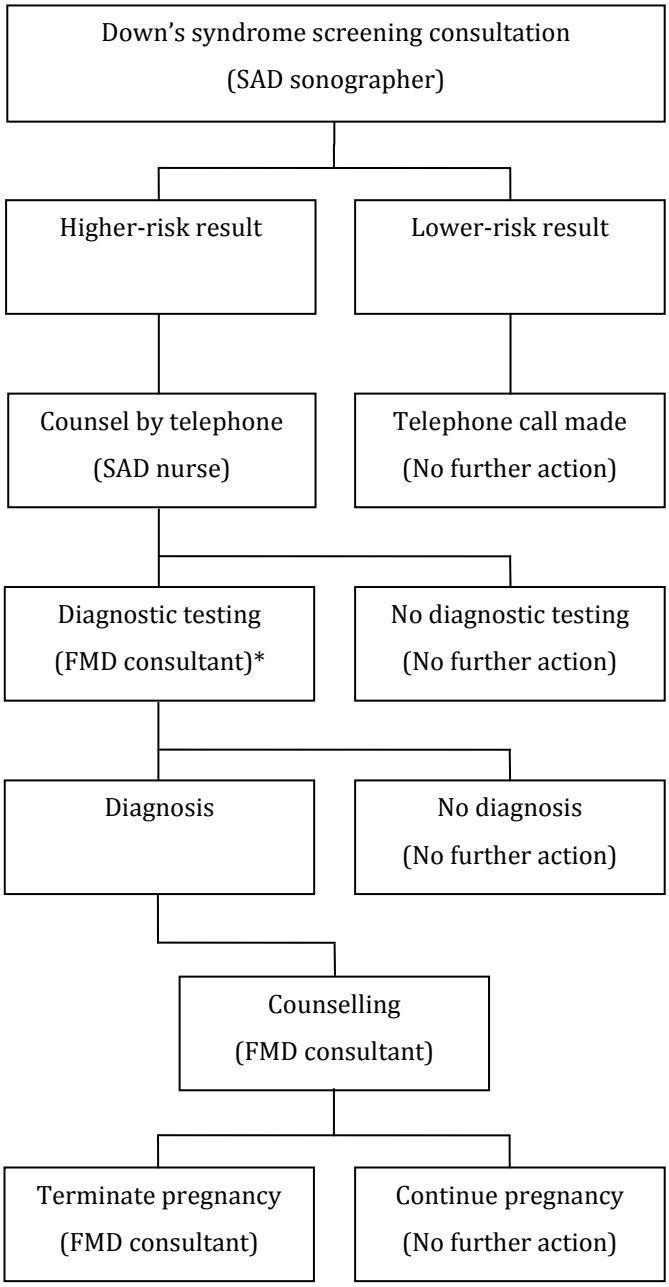
Appendix 1: Antenatal screening timeline



Appendix 2: Down's syndrome screening flowchart (Freymarsh)



Appendix 3: Down's syndrome screening flowchart (Springtown)



*When parents-to-be in Springtown receive a higher-risk result for Down's syndrome and decide to undertake diagnostic testing, they are referred to the Freymarsh foetal medicine department (FMD)

Appendix 4: Information sheet for professionals (example)

INFORMATION SHEET FOR PROFESSIONALS (FREYMARSH)

You are being invited to take part in a research study. Before deciding whether you would like to participate, it is important for you to understand why the research is being carried out and what it involves. This sheet outlines the purpose and implications of the study and provides more detailed information about its conduct. I am happy to answer anything which is unclear or needs clarification. Please take time to decide whether you want to participate. You will be able to keep this sheet and a signed consent form. If you would like to participate, please contact me by telephone, by email, by letter, or in person. Thank you for reading this.

This is not a clinical study. The purpose of this study is to examine the experiences of parents and clinical professionals for the duration of Down's syndrome screening and testing procedures in antenatal practice. Specifically, the objectives are to explore parents' understanding of Down's syndrome and their knowledge of testing which detects the condition, how clinicians communicate and parents perceive the notion of 'low-risk' or 'high-risk' during screening, why parents choose to undertake or avoid further diagnostic testing, whether clinical professionals view hospital resources as adequate for the needs of patients, and how parents who have undertaken a quadruple screen and/or diagnostic testing view their overall prenatal experience.

I would like your consent to observe the antenatal clinic and maternity services at the hospital. Observing clinical practices of the antenatal process involves the researcher being present during quadruple screens, consultations informing parents that their foetus has a high-risk of Down's syndrome, and diagnostic testing procedures (i.e. amniocentesis or CVS). I will not be providing nor interfering with prevention, diagnosis, or treatment. These events will not be audio-recorded, but notes will be taken. You will have to provide informed

consent, you can withdraw from the study at any time without explanation, and information which might identify you will be removed as far as possible.

After this, you may be approached for an interview which will last between 30 minutes and 1 hour. You may be approached for a second interview if necessary. If you agree, your interview will be audio-recorded for transcription purposes. You will have to provide informed consent, information which might identify you will be removed as far as possible, and you can withdraw from the interview at any time without explanation. When the research study stops, you will receive a summary of the study's findings on request so you can check that where you are quoted, it is both accurate and anonymous. The data collected will be published in a PhD thesis approved by Cardiff University and potentially through academic publications such as books, book chapters, and peer-reviewed journal articles. At the end of the study, your anonymised interview transcript will be submitted to the ESDS Qualidata unit at the UK Data Archive, which will store it and make it available to future researchers.

All information collected during the study will be kept strictly confidential. The research location and identities of everyone taking part in the study will be subjected to anonymisation. Any information which may identify you will be removed. Electronic or manual data collected (audio recordings, transcripts, typed-up field notes) will be either stored in a locked filing cabinet on Cardiff University security-controlled premises or on an encrypted, password-protected USB device, both of which will only be accessible by the researcher. Audio recordings and manual copies of field notes will be destroyed after use in accordance with Cardiff University regulations. A manual copy of your contact details will be kept in case you need to be contacted for a second interview and so you can receive a copy of the study's findings, but these will be shredded after the PhD thesis is completed. Please note that you have the right to check the accuracy of data held.

The research is being funded by the Economic and Social Research Council (ESRC). Information on antenatal screening and Down's syndrome made available by Antenatal Results and Choices (ARC) and the Down's Syndrome Association (DSA), organisations which both support this project, can also be provided to you on request. If you would like to request more information about the study or register an interest in participating, please contact me using the details provided below:

Gareth Thomas
Cardiff University School of Social Sciences
1-3 Museum Place
Cardiff
CF10 3BD
02920 875260
ThomasG23@cardiff.ac.uk

If you have read this sheet and have decided not to participate in the study, I would really appreciate some feedback and comments regarding why this was the case. You can do this by contacting me by email, telephone, or by letter. I would be grateful for any advice or constructive criticism you have concerning my project and the participant information sheets, as this will help me revise my approach and may bring about issues I have yet to sufficiently consider.

Appendix 5: Information sheet for parents-to-be (example)

INFORMATION SHEET FOR PARENTS-TO-BE (FREYMARSH)
Quadruple Screen, High-Chance Result, and Potential Interview

Introduction

My name is Gareth Thomas and I'm currently a PhD student at Cardiff University. As part of my degree, I am looking to study the experiences of parents that are taking part in screening and testing for Down's syndrome during a pregnancy. I am inviting you to take part in this research study. Your involvement will be voluntary, your medical treatment will not change, and I will not have access to your medical records. Before deciding whether you would like to participate, I would like you to understand why the research is being done and what it involves for you. Reading this sheet will take around 10-20 minutes. Part 1 of this sheet tells you the purpose of the study and Part 2 gives you more detailed information about the study itself. I am happy to answer anything which is unclear or needs explanation. Please take time to decide whether you want to participate. You will be able to keep this sheet and a signed consent form. If you would like to participate, please contact me by telephone, by email, or by letter. You may also confirm your interest in participating in this research with the healthcare professional responsible for your care. Thank you for reading this.

Part 1: Essential Elements of the Study

What is the purpose of the study?

It is becoming increasingly likely that parents will receive a diagnosis of Down's syndrome or at least given the option of having tests which would provide this information during a pregnancy. This poses huge decisions for parents expecting a child. Some studies have reported that parents have received inaccurate, incomplete, and sometimes offensive information on conditions such as Down's syndrome during antenatal care. Research has also indicated that some healthcare staff are concerned that they are not fully prepared to offer screening or deliver news of potential medical issues with the baby to expectant parents.

This study will look to see whether these trends appear in the NHS and will examine a number of different issues, including:

- Parents' understanding of Down's syndrome and their knowledge of testing which can detect the condition
- How healthcare professionals communicate and parents understand the notion of 'low-chance' or 'high-chance' during screening
- Why parents choose to undertake or avoid further testing during a pregnancy
- Whether healthcare professionals view hospital resources as appropriate for the needs of patients
- How parents who have undertaken testing view their overall experience during pregnancy

Exploring these issues may indicate whether prenatal events may be handled differently and could suggest possibilities which assist parents in making an informed decision regarding their choices. This will provide an important resource for both parents and healthcare professionals responsible for their care.

You have been asked to participate in the research as you are having a quadruple screen and/or have received a high-chance of Down's syndrome. If you are interested in participating, more information is provided below in the section entitled 'What will happen if you take part?'. If there is anything which is unclear, please contact me and I will clarify any questions you have.

Why you?

You have been selected because you have chosen to have a quadruple screen and/or have received news of a high-chance of Down's syndrome. If parents agree to participate in this research, I intend to be present during their quadruple screen and, if it occurs, the meeting in which parents are told that they have a high-chance of having a baby with Down's syndrome. I'm also hoping to conduct a number of interviews with parents. If you agree to participate by consenting to an interview

and/or by consenting to me being in attendance during your quadruple screen (and, if it occurs, the meeting in which you are told you have a high-chance of Down's syndrome), I will ask you to sign a consent form. Information which might identify you will be removed as far as possible and you are free to withdraw at any time without explanation. This will not affect the standard of care you receive. All information about you will be handled in confidence (see part 2). It is up to you to decide to join the study.

What will happen if you take part?

If you agree to take part, I will be in attendance during your quadruple screen procedure and, if it occurs, the meeting in which you are told that you have a high-chance of Down's syndrome. I will be taking notes during this test and I will focus on the following issues:

- The communication between yourself and the healthcare professional
- Your understanding of 'high/low chance', the tests which you have undertaken, and Down's syndrome
- What information you are provided with
- How you are cared for and treated by healthcare professionals
- Whether you want to undertake further testing
- Whether you appear happy with the care you have received

I will not be providing any form of diagnosis or treatment during these consultations and I will not be requesting extra time on top of what is already allowed for your care. In addition, you may be invited to participate in an interview which you can choose to refuse. You will also be asked to take part in the interview together with your partner, but you may request that you are both interviewed separately. There may be an opportunity for you to be interviewed individually if your partner does not wish to participate. You may refuse to let me attend your quadruple screen and, if necessary, the meeting in which you are informed about being at a high-chance of having a child with Down's syndrome, yet still participate in an interview (and vice versa). If you agree to participate in an interview, you will be asked to comment on a number of issues, including:

- What tests you have undertaken
- How you understand the tests that you have so far undertaken
- How you have understood 'high/low chance'
- Why you have chosen to have certain tests
- What information you have been provided with by healthcare professionals
- How you have been cared for and treated by healthcare professionals
- Whether you view your antenatal care as a positive or negative experience

The one-off interview will be audio-recorded so that I can type out exactly what was said during the interview. The interview will last around 30 minutes to 1 hour. Your interview may take place in the hospital, but you may find it more convenient for it to take place in your home. The location of the interview will be your decision. At each stage of the research, you will have to provide informed consent, you can withdraw from the study at any time without explanation, and information which could identify you will be removed as far as possible. Rarely, you may be approached for a second interview which you are able to refuse. If you agree to participate in a second interview, you will be asked to provide consent for this. A second interview is likely to last between 20 and 30 minutes. You will only be invited for a second interview if I think there are issues which were not addressed in your first interview.

When the research study stops, you will receive a summary of the study's findings on request so you can check that where you are quoted, it is both accurate and anonymous. I will take every measure to ensure that you cannot be identified by the information you provide during your interview. The data collected will be published in a PhD thesis approved by Cardiff University and potentially through academic publications such as books, book chapters, and journal articles. At the end of the study, your typed-out interview will be submitted to the UK Data Archive (UKDA). The UKDA will store the data and make it available to future researchers.

What are the potential disadvantages and risks of taking part?

I may ask you to comment on sensitive issues, such as how you understand and feel about Down's syndrome and antenatal screening for a child. The approach of the project has been carefully considered to ensure that it is carried out in an appropriate manner and ensures your wellbeing. I have experience in studies involving interviews with parents on delicate topics concerned with their children. I have also received training in designing, managing, and conducting research during a one-year Masters degree entitled 'Social Science Research Methods'. This was undertaken at Cardiff University and was completed in September 2010. I have also talked to a large number of healthcare professionals before the study. They have supported the project and have offered advice on how it may be managed. The project has also been supported by Antenatal Results and Choices (ARC) and the Down's Syndrome Association (DSA). Both of these organisations believe this is a valuable study and have offered to provide information to you if you wish to receive it.

If you become distressed during the study, direct accessible support will be available to you. A foetal medicine consultant is present during every morning within the Foetal Medicine Unit and specialist midwives are available for support between 09:00 and 16:30. Dr Karman, whilst also working as a consultant within the Foetal Medicine Department, will also be available out of hours on a mobile telephone should you require further support. If you participate in an interview in the hospital, this interview will be carried out in an area where access to back-up support from the healthcare team is available. If you participate in an interview in your home and you feel you require further support, you can contact Dr Karman out of hours directly. Dr Karman is happy to perform this role. You can also receive further support by contacting the Down's Syndrome Association (DSA) and Antenatal Results and Choices (ARC). If you would like to have this information, I can provide you with it at any time during the study.

Please note that you are free to withdraw at any point during the research without explanation. If you choose to do so, all of your data collected up until that point will be deleted consistent with Cardiff University policy.

What are the potential benefits of taking part?

The study will not help you directly, but the information you provide may help improve the way Down's syndrome and the relevant tests are understood and managed by both parents and healthcare professionals in the future.

What if there is a problem?

Any complaint about the way you have been handled during the study or any other concerns that you have will be promptly dealt with. Detailed information on this is provided in Part 2, which you should read before making any decision.

Part 2: Other Information

What will happen if I don't want to carry on with the study?

If you wish to withdraw from the study, please tell me immediately. Data already collected up to this point will be deleted. However, you may re-register an interest in participating at any time during the study.

What if I have a complaint?

If you have a concern about the study, please do not hesitate to contact me (02920 875260, ThomasG23@cardiff.ac.uk) or my academic supervisors Joanna Latimer (02920 876908, LatimerJE@cardiff.ac.uk) and Adam Hedgecoe (02920 870027, HedgecoeAM@cardiff.ac.uk). You may also wish to contact Dr Karman, a consultant in foetal medicine at Freymarsh and Clinical Supervisor for this project. If you remain unhappy and wish to complain formally, the hospital can provide a copy of its complaints procedure which explains how to proceed. Your first step will normally be to raise the matter with the practitioner (your nurse, midwife, or doctor) or with their organisation. For further details, visit: http://www.nhs.uk/choiceintheNHS/Rightsandpledges/complaints.

What happens if I am harmed while participating in the research?

In the unlikely event that something does go wrong and you are harmed during the research and this is due to someone's negligence, you may have grounds for legal action against Cardiff University or the NHS but you may have to pay your legal

costs. The normal NHS complaints mechanisms will still be available to you (if appropriate).

Will my taking part in this study be kept confidential?

You will not be identified in any report or publication unless you have given consent (you will be asked to sign a consent form indicating this). The research location and identities of everyone taking part in the study will be given fake names or numerical codes. The data you provide (audio recordings, typed-up field notes, typed-up interviews) will be stored either in a locked filing cabinet which only I can access on security-controlled Cardiff University premises or on a password-protected USB computer device. This data will have your name removed and replaced by a numerical code. The sheet containing these codes and your contact details will be kept as manual records in a locked filing cabinet on security-controlled Cardiff University premises. Your contact details will be kept in case you need to be contacted for a second interview and so you can receive a copy of the study's findings. After the PhD thesis is completed, your data and details will be deleted and/or shredded in accordance with Cardiff University regulations. Please note that you have the right to check the accuracy of data that I hold.

Who is organising and funding the research?

This study is sponsored by Cardiff University and is funded by the Economic and Social Research Council (ESRC).

What consequences will this have for the data?

The ESRC requires that each researcher provides data to be given to the UK Data Archive (UKDA). This data will include your typed-up interview which will be heavily edited to make sure that there is no identifiable data available. As such, they will be sent to the UKDA at a standard which would mean that it could be used by a third party. However, your details will still be anonymised in the data and any of your quotations will be selected carefully to make sure that you cannot be identified by their publication. The notes that I take during your quadruple screen (and potentially your meeting for a high-chance) will not be sent to the UKDA. These notes and your typed-up interview will also need to be kept for a minimum

of 5 years from the end of the project. This is in accordance with Cardiff University's data retention period. After 5 years, the data will be destroyed consistent with Cardiff University's 'Complying with Data Protection and Freedom of Information' legislation.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee to protect your interests. This study has been reviewed and given favourable opinion by an NHS Research Ethics Committee.

Further information and contact details

Thank you for taking the time to read this sheet. If you would like to request more information about the study or register an interest in participating, please contact me using the details provided below:

Gareth Thomas
Cardiff University School of Social Sciences
1-3 Museum Place
Cardiff
CF10 3BD
02920 875260
ThomasG23@cf.ac.uk

If you have read this sheet and have decided not to participate in the study, I would really appreciate some feedback and comments about why this was the case. You can do this by contacting me by email, telephone, letter, or via hospital staff/healthcare professionals. I would be grateful for any advice or constructive criticism you have concerning my project and the information sheets. This will help me revise my approach and may bring about issues that I have yet to consider.

Appendix 6: Consent form for professionals (example)

QUADRUPLE SCREEN/NUCHAL TRANSLUCENCY SCAN/HIGH-CHANCE RESULT CONSENT FORM (PROFESSIONALS)

	Please initial box
1. I have read and understood the information sheet dated ……. for the study. I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily.	☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.	☐
3. I agree to participate in a later interview, if this is necessary, which will be audio-recorded and will be anonymised.	☐
4. I acknowledge that my data may be used in the PhD thesis and academic/other publications.	☐
5. I consent to the researcher being present and taking notes during the quadruple screen/NT scan and, if necessary, the consultation informing the patient(s) about their child having a high-risk of Down's syndrome. NB: this will also require consent from the patient(s).	☐
6. I acknowledge that I can request a summary of the study and its findings. I acknowledge that these may also be made available to the Down's Syndrome Association and affiliated independent support groups.	☐

I agree to take part in the above study.

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Person Taking	Date	Signature

When completed: 1 for participant; 1 for researcher (original).

Appendix 7: Consent form for parents-to-be (example)

QUADRUPLE SCREEN/NUCHAL TRANSLUCENCY SCAN/HIGH-RISK RESULT CONSENT FORM (PARENTS-TO-BE)

	Please initial box
1. I have read and understood the information sheet dated ……. for the study. I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily.	☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	☐
3. I agree to participate in a later interview, if this is necessary, which will be audio-recorded and will be anonymised.	☐
4. I acknowledge that my data may be used in the PhD thesis and academic/other publications.	☐
5. I consent to the researcher being present and taking notes during the quadruple screen/NT scan and, if necessary, the consultation informing me about my child having a high-risk of Down's syndrome. NB: this will also require consent from the relevant clinical professional(s).	☐
6. I acknowledge that I can request a summary of the study and its findings. I acknowledge that these may also be made available to the Down's Syndrome Association and affiliated independent support groups.	☐

I agree to take part in the above study.

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Person Taking	Date	Signature

When completed: 1 for participant; 1 for researcher (original).

Appendix 8: Interview schedule for professionals (example)

INTERVIEW SCHEDULE (FREYMARSH)

Brief to interview:

This interview will focus on your professional experiences of Down's syndrome screening and testing procedures. The questions provided here are meant as a broad outline of what will be discussed, and you may be asked other questions based on what answers you provide. Your answers may be as long or as short as you wish. You may also refuse to answer certain questions without explanation. The interview is expected to last between 30 minutes and 1 hour.

Establish consent:

I would like to stress that everything you say will be treated as completely confidential and you will remain anonymous in any report that may result from this research. This interview will be tape recorded so that I can produce a transcript. At any time during the interview, you may stop the tape recorder if you wish. If you would still like to proceed with the interview, you will now be required to sign a consent form.

Questions

1. How long have you been practicing medicine?

2. How long have you been working within this speciality of medicine?

3. Currently, what are your professional roles in the prenatal process?

4. What do you think the main reasons are for parents choosing to accept or reject prenatal testing? Who do you think is the dominant figure in deciding this (mother, father, clinical staff)? Do you ever recommend that patients undertake certain tests?

5. How do you describe screening and test results to patients, and how do you ensure that patients completely understand what care they are receiving? In particular, how do you communicate the notion of a low-risk and a high-risk of Down's syndrome?

6. Generally, what are the reactions of patients once they find out that their child has a low-risk or high-risk of Down's syndrome? How do you manage these reactions? How long do you discuss the patient's options with them, and how much detail do you go into?

7. How do you think patients within antenatal care perceive the care they receive at your hospital? Do you think you have an active role in patients' decision-making (of prenatal screening and testing) during the pregnancy?

8. Do you think patients have a good understanding of Down's syndrome, particularly regarding their knowledge of screening for the condition, aetiology, genetics/inheritance, and the consequences of a child being at a high-risk or as being diagnosed with the condition?

9. Are you confident that parents, when receiving a high-risk or low-risk of Down's syndrome, know exactly what this means, and that they know the rationale behind why particular prenatal tests are being carried out? Are parents' expectations of the screening and tests realistic?

10. Do you think that the quality of information the hospital provides to parents regarding antenatal screening and Down's syndrome is sufficient for their needs and assists them in making an informed decision regarding their choices? If not, what do you think was missing?

11. Do you have particularly strong or clear views on the use of prenatal testing for a condition like Down's syndrome? Do you think the choice of a test should be available to everybody? What do you think the future of medical technology within antenatal care is?

12. What do you think of those parents who do decide to end their pregnancies? Do you support their right to decide? Do you think their minds would be changed if different information about Down's syndrome was conveyed to prospective parents?

13. Do you notice any clear differences between mothers and fathers regarding their opinions and decisions during the pregnancy?

14. What impact has the introduction of a quadruple screen, which is more likely than a triple blood test to detect Down's syndrome and has a lower false-positive rate, had for you and the parents?

15. Do you consider the prenatal tests currently used, and the policies stipulated by the NHS, as sufficient for the needs of parents and clinical practice? If not, what else do you think the hospital and its staff can do to improve its service and assist parents in making an informed decision regarding their reproductive choices?

16. If you have any more thoughts about your experiences as a clinical professional within antenatal care or anything else which you think is relevant, please feel free to share them now.

17. Finally, if the researcher would like to conduct a second interview with you, would you like to participate in this? This is completely your choice to accept or refuse. You will only be invited for a second interview if I think there are issues which were not addressed during this interview.

Interview End