Reproductive decision-making, parenthood and the use of assisted conception: an exploratory study of the perceptions and experiences of women with Turner Syndrome

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Abstract

This research examines the way Turner Syndrome (TS) influences reproductive decisions, focusing on the role of social imaginaries of motherhood, reproduction, family and responsibility in framing options and shaping choices. It looks at why it is so important to women with TS that they have a choice of family-building options, and how they understand and make sense of the potential risks of pregnancy. It explores the reception of new reproductive technologies such as maternal egg freezing (MEF), the reasons mothers may choose to freeze their eggs and the perception of its potential impact on family relationships.

TS is a rare chromosome disorder affecting 1:2500 women, which usually causes infertility. While women can conceive using egg donation, most will face a high-risk pregnancy; little research explores how they evaluate the emotional and physical risks. Decisions taken in childhood can affect the reproductive choices available to a woman with TS in adulthood, but little is known about how mothers of girls with TS approach these decisions. Technologies such as MEF can be used as an analytical lens to examine women's thinking on biological kinship, intrafamilial obligation, risk, choice and maternal duty.

Using constructivist grounded theory, 30 photo-elicitation interviews were conducted with women with TS and mothers of girls with TS. The principles of Universal Design were used to plan for and accommodate the psychosocial aspects of TS that may affect an interview.

Firstly, Kafer's (2013) concept of 'crip time' was applied in three ways, strange temporalities, imaginative live schedules and eccentric economic practices, showing how women with TS and mothers of girls with TS found ways to manage, circumvent and normalise the timing challenges of living with TS. The term 'courtesy mandated motherhood' describes the social pressure on mothers to plan for their daughter's reproductive future, using Kafer's "curative imaginary" as an analogy for the pressure to take action to circumvent childlessness. This study

conceptualises maternal egg freezing (MEF) as an eccentric economic practice which potentially enables women with TS to have a genetically related child. MEF could also act as a hope technology (Franklin, 1997) enabling mothers to give their daughter hope that she could become a mother.

Secondly, Crossley's (2007) concepts of 'situated freedom' and 'genuine choice' explored to what extent women with TS have agency in making reproductive choices. Participants valorised the possibility of having reproductive choices, seeing this as empowering as well as providing a woman with TS with ways to become a mother. Mothers used the availability of choices to support their daughters' emotional management of infertility, extending the concept of psychological IVF (Adrian, 2015) to MEF, and to adoption as well as ARTs. Social imaginaries acted as models for responsible ways to manage disclosure and risk.

Thirdly, this thesis shows how the practise of intensive mothering (Faircloth and Gurtin, 2017) affects expectations of maternal duty. A strong affinity can mean infertile women have family support to become mothers. However, most participants viewed intrafamilial donation as potentially disruptive to the social family, so preferred anonymous donation over a genetically-connected donor.

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SWEENEY: Birth, and copulation, and death.
That’s all, that’s all, that’s all, that’s all,
Birth, and copulation, and death.
DORIS: I’d be bored.

T. S. Eliot (1958) “Fragment of the Agon,” Sweeney Agonistes in *TS Eliot: The Collected Poems and Plays: 1909-1950*. Harcourt, Brace. pp80–81.

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1 Introduction

Turner Syndrome (TS), also known as gonadal dysgenesis, is a rare, non-heritable X-chromosome condition that affects 1:2500 women. The two most consistent signs of TS are short height and no or non-functioning ovaries, but it is also linked with other signs such as delayed puberty, cardiovascular and renal disorders, and mild cognitive impairments (Bondy, 2007). As most women with TS cannot conceive naturally, if they wish to have a family, they need to choose from options such as egg donation, adoption, or surrogacy.

However, the decision to use egg donation (either from a known or an anonymous donor) is complicated by the potential risks of pregnancy. Many infertile women prefer to carry a pregnancy so that their partner can become a genetic parent (van den Akker, 2010), but the physical health problems associated with TS mean pregnancy may be high risk for both the woman with TS and the foetus (Karnis et al, 2003).

Reproductive preservation technologies can offer further solutions: some mothers of girls with TS have frozen their own eggs for their daughter to use in later life. Ovarian tissue freezing, currently available in the UK for girls with cancer, is a future option for girls with TS who have ovaries. Although this technology has been developing over the last ten years, most of the research on this topic relates to girls and women with cancer, rather than women with TS, a condition that is not life-threatening.

This research examines the way TS influences reproductive decisions. It looks at why it is so important to women with TS that they have a choice of family-building options, and how they understand and make sense of the potential risks of pregnancy. It explores the reception of new reproductive technologies such as maternal egg freezing, the reasons mothers may choose to freeze their eggs and the perception of its potential impact on family relationships.

This introduction provides an overview of the thesis, giving a brief summary of the main three themes around which the thesis is structured and describing how the thesis is structured. It begins by explaining why this research topic is important and timely.

1.1 Aims and objectives of this study

TS was first discovered in 1938 and since then a considerable number of research papers have been published on this topic, the great majority of which focus on TS as a medical condition (Sandberg, 2018). The outcome of this has been to improve the medical understanding of TS, enabling the development of more effective treatments for conditions associated with TS and better screening, both before and after birth (Gravholt et al, 2017). There is also a body of literature on the psychosocial impact of TS, which looks at the profile of associated cognitive impairments such as difficulty with mathematics and spatial awareness, and related issues such as social anxiety (LePage et al, 2013; Bondy, 2007; Lakshman et al., 2016; Lawrence et al., 2003; Burnett et al., 2010; Wolstencroft et al., 2019). The outcomes of psychosocial research are focused on improving educational attainment, social integration, and the ability to form relationships in adult life (Hutaff-Lee et al, 2019; Lagrou et al, 2006). Yet by comparison there is a very small body of qualitative research that explores the lived experience of TS and its impact on reproductive decisions; research on this topic has not increased in parallel with the increase in medical interest.

As reproductive technology continues to develop, more reproductive options than ever are available to women who cannot conceive naturally. Yet, even though one of the most consistent signs of TS is infertility, there is little qualitative research that explores what women with TS make of these technologies, or how they perceive and evaluate the risks (both emotional and physical) of using them. Decisions taken in childhood can also affect the reproductive choices available to a woman with TS in adulthood; the option to take up reproductive preservation, if it is a potential treatment, needs parental consent and, often, financial support from the family. There is little qualitative research on how mothers of girls with TS approach these decisions.

The first UK mother of a girl with TS who is known to have frozen her eggs for her daughter did so in 2005 (HC Deb, 12 May 2008); in the 15 years since then, there has been little subsequent research on the reception of maternal egg freezing, or how its use may affect relationships within the family, either within the TS community or beyond. The ethical challenges posed by technologies such as intergenerational egg donation are discussed in bioethical guidelines and papers (such as ASRM, 2003; ASRM, 2012; ESHRE Task Force, 2011), but there is little empirical research for them to refer to.

The present research was an opportunity to partially redress this imbalance. Qualitative research on reproductive choices was undertaken both with women who have TS and with mothers of girls with TS. This study addresses the following three research questions:

1. How women with TS perceive and navigate the decision to have a family and the potential associated health risks of pregnancy;
2. How mothers of girls with TS perceive and navigate decisions about their daughter's future reproductive options;
3. How technologies such as egg donation, egg freezing, and ovarian tissue freezing are perceived within families affected by TS.

The present research explored the way in which women make reproductive decisions in the context of TS, and the factors that influence mothers' decisions when they consider their daughter's future reproductive options.

The exploration of decision making in this study related to any type of reproductive option that was available: women with TS were invited to participate if they were planning to have or had unsuccessfully tried to have a family, already had a family, or decided to be child free. Women expressed a range of views about the pros and cons of specific family-building options which could be considered conventional, in the sense that they are in accord with those expressed by infertile people in general (see for example van den Akker, 2010). Consequently, they have not been repeated in detail here. Half of the women with TS in this study preferred the use of ARTs, some preferred adoption, while others were undecided or had not had children. However, women's decisions were situational, relating to their individual risks as a woman with TS and to other factors, such as the views of their partner and the availability of finances. This is discussed in detail in Chapter 6.

The research questions also focused specifically on the reception of new technologies such as maternal egg freezing (MEF) and ovarian tissue freezing (OTF), and their perceived risks. The TS community is one of the few where MEF is widely known about and discussed, and consequently views on this technology are informed by the unusual circumstance of women having used it or knowing others who have. This community also includes potential users of reproductive preservation technologies such as OTF. It can be hard to resist the use of reproductive technology when it is presented as an easy solution to infertility (Sandelowski, 1989), yet women with TS are significantly more at risk in pregnancy than other users of ARTs (Karnis et al, 2003). Consequently, it is important to scrutinise the way that women with TS, and mothers of girls with TS who may be making decisions on behalf of their daughter, balance the pressure to use ARTs against the perceived risks (whether relating to health, emotions, relationships or finances) in order to better understand why ARTs might be used or rejected. As such, the context of TS is an ideal setting in which to consider the way in which socially-shared beliefs about maternity, fertility, and family duty impact both on reproductive choices in general and the perception of new reproductive technologies in particular.

A qualitative approach was taken to this research, as it was the most appropriate way to explore in depth women's feelings, thoughts, perceptions, and reasoning (Bryman, 2012, ch17). This aligned with the interpretative epistemological approach, constructivist grounded theory, that was the chosen methodology. The research findings are presented around three major themes which emerged from the qualitative interviews.

1.2 Framework of this thesis

The findings of this thesis are structured into three data and discussion chapters covering three different aspects of reproductive decision making in the context of TS: the significant way in which TS affects timing and how that, in turn, affects reproductive choices; the way women with TS frame their response to reproductive choices and risk; and the perceived role of the family in supporting a woman with TS to have a child. They are linked together through the use of social imaginaries, “shared understandings of forms of social life and social order" (Jasanoff, 2015, p4) which shape expectations about, amongst other things, relationships and reproduction. Social imaginaries are often future-focused; they enable people to anticipate their expected life course and the type of social relationships they will have with others. In the context of reproduction, imaginaries express shared social ideals about maternity, such as the expectation that all women will want children (Russo, 1976), that infertility will be traumatising (Greil et al, 2010), or that mothers should support their daughter through infertility (Faircloth and Gurtin, 2017). As imaginaries reflect shared social norms, they also reflect a shared vision of both desirable and undesirable futures. They enable people to anticipate possible future outcomes of their current circumstances or choices, and in this way, can shape the decisions that people make in order to avoid or actualise that imagined future outcome.

Each chapter is briefly outlined next.

1.2a Timing

TS has a significant impact on timing throughout life, particularly during childhood. This in turn has an impact on decisions related to reproduction. Most girls with TS fall behind their peers in physical development at an early age and meet their growth milestones later (Gravholt et al, 2017). Due to a lack of oestrogen, puberty is absent or delayed (Naess and Gravholt, 2009). Girls may also be less emotionally mature than their peers (Wolstencroft et al 2019). Yet they are most often diagnosed around or before the age of 7 (Bondy, 2007), meaning that they have to manage an infertility diagnosis as a child, while they are starting treatment for TS and just as they and their peers are going into puberty. In turn this means the parenting experience of a mother of a girl with TS is different from that of her peers, since they are managing the growth, psychosocial and fertility implications of their daughter's condition while she is still a child; the infertility diagnosis means they are often giving thought to their daughter's future family-building options before she has reached puberty.

The impact of 'lateness' in childhood has an impact on reproductive timing: women with TS are usually older than their peers when they have their first relationship and sexual experience (Boman et al, 1998) and are less likely to be married than their peers (Bondy, 2007). However, women are usually advised to have children younger, as the health risks associated with pregnancy increase with age. This presents a challenge to many women with TS, as the anxiety and shyness often associated with the condition means it can be harder to meet a romantic partner. Disclosure of infertility can also be stressful; women with TS described the importance of finding the right time to talk to a partner about this.

Roth's (1963) work on the collective norming of social timetables is used to provide a framework against which the experience of women with TS and mothers of girls with TS can be contrasted. Garland Thomson's (2011) concept of the 'misfit' is used to explain the experience of nonconformity with normative social timing, while Kafer's (2013) theory of 'crip time' is used to explain how women perceive and manage their experience of temporal misfitting. Kafer's (2013) concept of the 'curative imaginary', a social norm where disabled people are expected to be working towards a cure for their condition, is used as an analogy for the approach taken by mothers of girls with TS to planning for their daughter's reproductive future. The motherhood mandate (Russo, 1976) presents motherhood as not only desirable for all women, but required, while the imaginary of infertility presents a future of unhappiness and rejection, an undesirable condition that should be avoided. Accordingly, mothers are likely to feel that their daughter will want to have children, and to feel pressure to make that possible.

1.2b Framing reproductive choices

If women with TS wish to have a family, they are faced with difficult choices. Most cannot conceive naturally. Women with TS who use egg donation are less likely to have a live birth than other users of IVF (Calanchini et al, 2019). There is a high rate of miscarriage, premature birth, stillbirth, foetal anomaly, and maternal death (Abir et al., 2001; Hewitt et al, 2003; Karnis et al, 2003). As a result, pregnancies are usually considered high risk. Nevertheless, egg donation is often preferred over other forms of family building as it gives the experience of pregnancy and a genetic link to one parent (van den Akker, 2010).

This study explores the reasons why participants valorised the availability of reproductive choice for women with TS. In a social context where individuals are viewed as personally responsible for their health, and choice is presented as a form of personal empowerment (Lahad and Hvidtfeldt, 2019; Novas and Rose, 2000), participants frequently used the language of choice to describe how they approached reproductive decisions. The heterosexual imaginary (Ingraham and Saunders, 2006) is used to guide expectations that a male partner is likely to want children. The concept of responsibilisation is used to show how and why women with TS framed their dilemmas as 'responsible' in two different contexts: the timing of disclosure to a partner, and the perceived risk attached to reproductive options. The concept of 'psychological IVF' (Adrian, 2015) is introduced and applied to mothers discussing future reproductive options with their daughter.

Crossley's (2007) concepts of 'situated freedom' and 'genuine choice' are used to examine how reproductive choices are made in the context of TS and how women with TS manage risk, since choices may be limited by health as well as social and structural factors. Choices are guided by an imaginary which illustrates what responsible behaviour looks like in the context of disclosure of TS to a partner, or when making potentially risky reproductive decisions. A responsible choice is defined as being 'informed'; this chapter explores women's understanding of the risks of pregnancy, and the non-medical factors which influence women's understanding of the risks of their choices.

1.2c Family solidarity

This chapter explores how family solidarity works in the context of TS, and the limits of family support for women with TS in having a family. Mothers may influence their children's reproductive choices, potentially affecting their attitudes to sibling egg donation as well as their views on which choice to make. As a parent, they may also be presented with decisions that affect their daughter's future reproductive options, such as pubertal egg freezing. Some mothers of girls with TS have chosen to freeze their own eggs for their daughter to use in later life (Gidoni, 2008). This provides her with the option to have a child that is genetically-connected to her as well as to her partner.

The perceived limits of maternal support for their daughter's reproductive choices are discussed in the context of family solidarity theories (Morgan, 1996; Smart, 2007). It looks at the role of family imaginaries such as 'the family we live by' (Gillis, 1996) in framing family duties. This chapter explores how maternal egg freezing is viewed by women with TS and mothers of girls with TS, and how women balance the importance of having a child with a genetic connection with the potential disruption to family relationships that may be caused by interfamilial and intergenerational donation. It explores mothers' motivation for using MEF and the perceived problems with this option, such as role confusion and coercion. It examines how ideas of maternal duty may explain why mothers might choose to freeze their eggs, and also why women with TS might choose or reject it as an option. Finally, it looks at ovarian tissue freezing (OTF) as a potential alternative reproductive technology to MEF, and why this may be a more promising option that intrafamilial donation.

1.4 Overview of the thesis

This thesis is structured into seven chapters, including the introduction.

Chapter 2 is a review of the empirical literature related to TS, beginning with its medical and psychosocial signs, the impact of TS both for women with TS and their mothers, and its implications for reproductive choice. On some topics, such as egg freezing in early puberty, there is very little literature directly related to TS, so the more general topic of medical egg freezing is explored. The conceptual literature related to the three main themes of this thesis is introduced here and further developed in chapters 4, 5 and 6.

Chapter 3 describes the reasons for taking constructivist grounded theory as the methodological approach to the study, and how the method, photo elicitation interviews, has been applied. It explains why adjustments were made to the recruitment and data collection method and the use of Universal Design as the framework in which this was done.

Chapters 4, 5 and 6 combine a description of the research findings with an analysis of the data using concepts related to those topics. Chapter 4 is an exploration of time as it relates to the lived experience of TS and to the experience of mothering a girl with TS. It contrasts Kafer's (2013) concept of 'crip time' with Roth's (1963) characterisation of time as a 'career' to illustrate the impact of repeatedly being out of synch with peers. It looks at the way a focus on the future influences mothers’ thinking around maternal egg freezing.

Chapter 5 looks at the impact of TS on perceptions of reproductive choices and decision making. It describes and explains the reasons why participants valorised reproductive choice for women with TS. It discusses why women frame their choices as responsible, looking specifically at the way women with TS explain how they approach disclosure to a partner, and how they assess the risk attached to reproductive options.

Chapter 6 explores family solidarity in the context of TS, and at the reception of maternal egg freezing, why mothers might freeze their eggs and the reasons women may or may not use them. It explores the boundaries of maternal obligation by examining mothers’ perceptions of whether and how it is appropriate to influence their children's reproductive choices.

Chapter 7 presents the conclusions of the research.

2 Literature review

The present study focuses on reproductive decision making in the context of TS, with a particular focus on the perception and use of reproductive technologies. There is a considerable body of literature on the medical issues associated with fertility and TS, but very little qualitative research which examines the way women with TS manage compromised fertility, or how they make reproductive choices. This literature review provides context for the findings which are described and discussed in the chapters that follow, and the concepts used to analyse them.

2.1 Approach to the literature review

The methodology used in the present study was constructivist grounded theory (Charmaz, 2014). In classic GT, the literature review is written after data collection and analysis, in order to avoid imposing preconceived ideas on theory development. By contrast, constructivist GT makes use of existing theory to develop 'informed grounded theory' (Thornberg, 2012), arguing that a critical engagement with the literature can enhance the quality of the work (Charmaz, 2014, pp305-310). Accordingly, literature searches were conducted to inform the research proposal and to contextualise the formal and annual reviews and were also conducted regularly throughout the research study.

The full literature review in this chapter was completed after writing the findings and discussion chapters and consequently is related directly to the findings and theoretical analysis, discussed in chapters 4, 5 and 6. The selection of literature was driven by two factors: literature related to the research questions, which contextualised the findings, and development of theory. The findings and discussion chapters were written around the following overarching themes:

1. Timing, and the way women and mothers address the lack of conformity with timing norms
2. Perceptions of choice, responsibilisation and risk
3. Family solidarity and family obligations

As part of the analysis, two mind maps were drafted (one for women with TS and one for mothers of girls with TS: see Appendices 19a and b) which grouped codes together and enabled a focus on those parts of the findings that related to the interview questions. Relevant bodies of literature could then be identified; concepts were either developed within the analysis, or rejected, through a process of constant comparison. For example, the significance of timing for both mothers and women with TS emerged from data analysis. However, for women with TS, timing related more to normalisation with peers, disclosure and 'lateness', while for mothers it related more to the management of TS and to the reasoning behind, and timing of, her own reproductive decisions, where they may have an impact on her daughter. This also meant that some bodies of literature which have been widely used to look at the experience of chronic illness, such as biographical disruption, have not been included in this thesis. In this way, the broader literature in the topic was sifted to use only what was relevant.

In summary, the literature review was written iteratively, relating back to the original data, and the analysis in the discussion chapters was revised iteratively. The literature searches and search strategy are described fully in Appendix 1. This literature review looks first at the medical literature on TS and the technological options available for women with TS in order to explain and contextualise the challenges of living with and managing the condition, and the reasons why fertility options may differ from woman to woman.

2.2 Turner Syndrome as a medical condition

This section surveys the medical and psychosocial literature on TS. It describes the complex nature of TS as a syndrome and the impact of TS on women's daily life, providing contextual information which informs the later discussion on women's perceptions of their reproductive choices. It describes the reproductive technologies available to women with TS. It also briefly describes the implications for parents in managing the physical and emotional health of their daughter with TS.

Turner Syndrome (TS) is a chromosome disorder affecting 1:2500 women (Bondy, 2007); one of the woman's two X chromosomes is missing or damaged. The two most prominent and consistent features are short stature and infertility. There are several chromosomal variants of TS but broadly 'classic TS' refers to a woman all of whose cells are affected by TS while in 'mosaic TS', the missing chromosome appears in some cells, usually lessening the impact of TS. TS is associated with a pattern of symptoms which include absent or delayed puberty, hypothyroidism, hearing loss, and renal issues. Cardiovascular issues and hypertension, particularly the risk of aortic dissection, affect 25-50% of women with TS (Karnis, 2002). TS causes developmental disorders of the reproductive system: most women with TS are born without ovaries and cannot conceive naturally (Vergier et al, 2019). TS is also linked with psychosocial issues, such as anxiety, and mild cognitive impairments (Cameron-Pimblett et al, 2017; Bondy, 2007).

TS is a syndrome: a condition which is characterised by a group of symptoms, each of which may appear to varying degrees, or not at all (Mazzocco, 2006). In addition, there are several chromosomal variants of TS, each of which is linked with different conditions (Gravholt et al, 2017; Cameron-Pimblett et al, 2017). When diagnosed in the womb or in early childhood it is not always possible to predict which characteristic features of the condition will be developed by the individual girl (Gravholt et al, 2017). These variations mean that, while it is possible to generalise about the types of health, social and reproductive challenges faced by women with TS, individual women may have symptoms that differ to some degree from their peers, and may be affected to a different extent, which in turn may mean they have different reproductive options.

2.2a Diagnosis and management

The age at which TS is diagnosed can have a significant impact on the effectiveness of treatment and on the opportunity to conduct reproductive preservation.
TS is most frequently diagnosed at around the age of 8, due to slow physical development in comparison to peers. It is also diagnosed during adolescence, due to delayed puberty; and in the womb, through analysis of ultrasound scans and prenatal genetic testing (Naess and Gravholt, 2009; Tudor et al, 2017), and a small minority are diagnosed from age 20 onwards (Lee and Conway, 2014). Daily growth hormone injections enable most girls with TS to reach an average adult height. Growth hormone treatment has only been available in the UK since the late 1980s (Betts et al, 1999) and it was not available to some women with TS who took part in this study.

Up to a third of adolescents with TS start puberty naturally (Ackermann, 2014) but in the majority, puberty is established through hormone replacement therapy, which is then continued until the average age of menopause (Bondy, 2015; Gravholt et al, 2017). As well as helping her develop an adult woman's body, hormone treatment gives a woman a better chance of carrying a healthy pregnancy (Burt et al, 2019). Late diagnosis has fertility implications, as beginning treatment late may make it more difficult for a woman to carry a pregnancy.

2.2b Psychosocial effects

The psychosocial impacts of TS can affect some women's ability to build friendships and relationships.

Some girls with TS have difficulty with social understanding, such as interpreting body language and knowing how to meet expectations of behaviour in social situations (LePage et al, 2013; Bondy, 2007; Lakshman et al., 2016; Lawrence et al., 2003; Burnett et al., 2010; Wolstencroft et al., 2019). Some women find this easier once they begin taking oestrogen (Conway, 2002), while others continue to be affected in later life and as a result, may find it harder to build and sustain social relationships (Hutaff-Lee et al, 2019). Women with a hearing impairment (also associated with TS) could find this a barrier to social interaction (Hutaff-Lee et al, 2019). TS is linked with social anxiety and shyness (Burnett et al., 2010; Ross et al., 2000; Rickert et al., 1996; Cardoso et al, 2004; Lagrou et al, 2006). Girls with TS can be socially immature compared with their peers (Wolstencroft et al 2019). Some women with TS report that they have been the target of bullying and teasing, in part due to typically having short stature or not fitting in with their peers, which can negatively affect their self-esteem (Collin, 2013; Cragg and Lafreniere, 2010; Sutton, 2005).

Infertility is a major concern for most women with TS and can present a barrier to finding a partner (Sylven et al, 1993; Sutton et al, 2005). Women with TS in Pellatt's (2005) study explicitly constructed infertility as a 'dis-ability' or a 'reproductive impairment' (Pellatt, 2005, p95), where the absence of ovaries or ovarian function positioned them outside the normative narrative of womanhood, reflecting the way TS affected their self-esteem. The impact of infertility is comparable to peers who have premature ovarian failure: women with TS have similar levels of shyness, difficulty in relationship formation, and depression (Gould, 2013; Cardoso et al, 2004). The need to disclose infertility to a partner results in some women delaying beginning a relationship, while others avoid relationships completely (Carroll, 2017; Clauson et al, 2012; Kay et al., 2015; Sutton et al., 2005). Women with TS are less likely to be married than their peers (Bondy, 2007) and are usually older than their peers when they have their first sexual experience (Boman et al., 1998; Rolstad et al., 2007). Nevertheless, most women coped well with the challenges of living with TS (Gould et al, 2013; McCauley and Sybert, 2006).

The communications issues associated with TS are also discussed in chapter 3, which examines the potential effects of this factor on data collection.

2.2c Reproductive potential and risk

Around 20% of women with TS become mothers either via ARTs or by natural conception (Gould, 2012; Stochholm et al, 2012). Risk was an important factor in the reproductive choices of most women with TS who took part in the present study; the understanding, perception and management of risk in pregnancy is discussed in Chapter 5 and a summary of the medical risks is described here. Women with TS have an increased mortality rate compared to the general population, due to associated conditions such as diabetes and hypertension (Schoemaker, 2009; Ackerman, 2014). Most women with TS who wish to have a pregnancy need to use IVF, as only 5% of women with TS can conceive naturally (Bernard et al, 2016; Mavridi et al, 2018). Whether women conceive naturally or through the use of egg donation, there are significant barriers to a healthy live birth.

Women with TS are much less likely to have a live birth than peers, at around 19% per IVF cycle (Calanchini et al, 2019; Abir et al., 2001; Mercadal et al., 2011; Doger et al, 2015). This is due to the high rate of miscarriage, premature birth, stillbirth, and foetal anomaly. The miscarriage rate is double the national average (Hewitt et al, 2013; Great Britain. National Institute for Health and Care Excellence, 2019). There is a high risk of foetal anomaly (Hewitt et al, 2013). The stillbirth rate is 7% (Abir et al. 2001) compared to 0.4% nationally (Great Britain. Office for National Statistics, 2018). Women have twice the average rate of pre-eclampsia, caused partly by pre-existing cardiovascular issues and compounded by the increased risk of pregnancy-related hypertension in donor egg pregnancies (Pecks et al, 2011; Hagman et al., 2011). The risks increase with age, so if a woman with TS wishes to get pregnant, she is usually advised to do so in her 20s; this reduces the chance of miscarriage and pregnancy complications, and of chromosome abnormality in women who can conceive naturally (Donadille et al, 2019; Pimblett et al, 2017). Women with TS have, on average, a 2% risk of maternal death (Karnis et al, 2003) compared to 0.001% in the general population (Great Britain. Office of National

Statistics, 2018). Natural childbirth is avoided where possible due to the strain it can put on the heart.

Cardiac checks are advised for women before they have fertility treatment; screening does not always happen and when it does, it does not always identify women at risk. Around 10% of pregnant women with TS who develop aortic dissection have no prior cardiac risk factors, meaning that even women whose pre-conception cardiac check reveals no problems may have serious problems in late pregnancy (Hewitt et al, 2013; Soderstrom-Anttila et al, 2019).

The risk rates cited in this section are generalised across the whole population of women with TS, but an individual's risk is also affected by factors such as TS karyotype and the impact of any of the associated conditions (Pimblett et al, 2017). For example, the majority of women with TS have cardiac issues but some are affected to the degree where they are advised against getting pregnant, while in others, the risk can be managed by close monitoring during pregnancy (Soderstrom-Anttila et al, 2019): pregnancy is potentially safe for some women with TS, depending on their circumstances.

2.2d Reproductive options available to women with TS

Women with TS may be able to have a family via egg donation, adoption or surrogacy, but there are additional options: some girls with TS may be able to freeze eggs or ovarian tissue for their own future use, while some mothers of girls with TS have frozen eggs for their daughter's use in later life.

Although adoption is often considered as an option that does not involve the use of reproductive technology, it may be less easy for single women with TS to adopt compared to women with no health conditions; the adoption process requires a medical (Great Britain. Department of Education, 2013, pp66-67). TS itself does not present a barrier (Oktay et al, 2016) but it increases the likelihood of having a related condition, such as diabetes, that some adoption panels may consider to be a risk.

Up to 30% of pubertal girls with TS have an ovarian reserve and are potentially responsive to ovarian stimulation (Grynberg, 2016) enabling them to have their own eggs frozen. The age at which it needs to be performed means that the girl needs to be physically and psychologically mature in order to withstand the emotional and physical demands of treatment (Oktay et al, 2010). Egg freezing for both social and medical reasons has a live birth rate of 25% (Great Britain. Human Fertilisation and Embryology Authority, 2018) but, to date, there are no recorded births from eggs frozen by women with TS (Hewitt et al, 2013).

Ovarian tissue freezing (OTF) could also enable girls with TS to have their own genetically-related child. It involves the use of abdominal surgery to collect ovarian tissue, or a whole ovary, from girls with an ovarian reserve, which is then frozen and reimplanted in adulthood (Borgstrom et al, 2009). It has been performed successfully in girls with TS as young as 8 (Jadoul et al, 2010; Oktay et al, 2010). Only pubertal egg freezing is currently available in the UK for girls with TS (Yasmin et al, 2018), though OTF is available for girls with cancer. Currently OTF has an estimated live birth rate of around 25% and there have been around 130 live births (Donnez and Dolmans, 2017) but the very small numbers involved mean there is little information about long-term success rates. A live birth has been recorded following ovarian tissue reimplantation in a woman with TS, but this was from a fresh ovarian tissue donation from her unaffected twin sister (Donnez, et al 2011). Other births have been reported, but not to a woman with TS (Rodriguez-Wallberg and Otkay, 2012).

Maternal egg freezing (MEF) is a way for a mother to preserve genetically-related eggs for her daughter. Egg freezing uses the same protocols as IVF, where a woman takes ovarian stimulating drugs for 10-14 days and then undergoes a surgical procedure to collect the eggs, but instead of being fertilised and reimplanted, they are frozen. There are barriers to using this option. Women freezing their eggs for

donation to a family member have to be healthy and fertile. The average age of first-time mothers in the UK is 28.8 (Great Britain, Office for National Statistics, 2018). Women are not able to donate eggs while they are breastfeeding (Seed Trust, 2019) so the timing of any procedure may be affected by the wish to breastfeed the girl with TS or subsequent children. Girls with TS are most often diagnosed around the age of 7 (Bondy, 2007), so mothers may have a narrow window of opportunity to arrange the procedure and may be too old to donate by the point of diagnosis. While NICE recommends that the NHS offer egg freezing to women undergoing cancer treatment it is not clear whether NHS treatment is available to women whose fertility is compromised by other health conditions, or to relatives who want to store eggs on their behalf. NHS funding is lacking even for female fertility preservation for cancer treatment (Abdallah et al, 2017). This leaves families with the option of treatment in a private clinic, which costs upwards of £3500 per cycle, not including annual storage fees (HFEA, 2017).
BFS Practice Guidelines (Yasmin et al, 2018) advise that women with mosaic TS may be suitable patients for reproductive preservation, but reliable statistics on success rates for women with TS who have used egg freezing, MEF and OTF are not yet available.

2.2d(i) Intrafamilial egg donation

Most of the qualitative literature on intrafamilial donation is on sibling donation, and while only one participant in the present study had a child through sibling egg donation, this literature raises a number of issues that are common to intrafamilial donors.

A potential advantage of sibling egg donation is that both parents maintain a close genetic connection with the child (Bortoletto et al, 2018; Laruelle et al, 2013; Lessor et al, 1993; Sauer, 1988; Winter and Daniluk, 2004). They know where the eggs come from, and there is no wait to find a donor. Sibling egg donation is safe: the reproductive outcomes of intrafamilial donation are similar to that of unrelated donation (Hasson et al, 2016; Rienzi et al, 2009). In research on known egg donation, most sibling donors reported that they were motivated to donate because they were close to their sister and valued the opportunity to help her (Bracewell-Milnes et al, 2016; Lessor et al, 1993; Purewal and van den Akker, 2009; Winter and Daniluk, 2004). For example, Lessor's study on how women navigated donating eggs to their sister found that most sibling donors used the language of gift-giving to talk about their donation, language which simultaneously detached the donor from a maternal relationship with the child and acknowledged the strong mutual trust and love between the sisters. Moreover, most people find sibling egg donation ethically acceptable (Lessor, 1990). Most families have a positive outcome from sibling donation (Purewal and van den Akker, 2009; Jadva et al, 2011; Yee et al, 2007) and find ways to manage the perceived challenges of the social relationship between donor and donor-conceived child, such as role confusion. Related donors and recipients described using strategies that disambiguated motherhood from the genetic relationship, such as being clear who the mother is, talking about the donation as a gift, and giving the donor a role in the child's life different from that of a mother, such as godmother or aunt (Parys et al, 2016). Other families preferred to manage the relationship by maintaining secrecy or by minimising the importance of the genetic link (Wyverkens et al, 2016). These negotiations are part of a larger picture of strategic naturalisation of family relationships created through the use of ARTs (Thompson, 2002; Nordqvist and Smart, 2014), where recipients of donated gametes often seek to establish parenthood through non-genetic means by, for example, privileging pregnancy over genes.

One of the few studies to explore families' views on intrafamilial egg donation in the context of a genetic disorder (Haskovic et al, 2018) focused on galactosaemia, a metabolic disorder that can cause ovarian failure and which is usually diagnosed at birth. Fourteen women with galactosaemia and 19 mothers and sisters of women with galactosaemia took part. Affected women had no concerns about role confusion in sibling donation and considered egg donation to be problematic only if the sister had not completed her family, suggesting that it may make her more likely to want to be involved with the child. All participants agreed that having a close genetic link was the main benefit of intrafamilial donation. Sibling donation is also reported in a case report (Rybak, 2009) discussing a request from two sisters who carried the fragile X mental retardation 1 (FMR1) gene, a heritable disorder. Both sisters felt that the option for the recipient sister to have a child with a genetic link outweighed the potential risks to the donor sister's egg reserve.

According to one recent survey on the public's views on intergenerational gamete donation, which did not ask about mother-to-daughter donation, most participants agreed that intergenerational donation was acceptable; the three most common concerns were that it may complicate family relationships, that there was a potential for coercion, and that it might have a negative impact on the resulting child (Bortoletto, 2018). Clinicians and bioethicists have raised concerns that when donation is intrafamilial, voluntary consent may be compromised if family members, or an individual's sense of duty or obligation, have undue influence over the decision (ASRM, 2003). However, when the donation goes from the older to the younger family member, this choice is sometimes positioned as being aligned with the caring role of a parent, which appears to override concerns about consent (Klitzman, 2017). When discussing maternal egg freezing, some mothers said they felt a sense of moral obligation to donate to their daughter (Haskovic et al, 2018) Other women from Haskovic's study raised concerns about role confusion, feeling that the hierarchical relationship that exists between mother and daughter would override the maternal status given to the birth mother of a child. However, these concerns may overlook the impact of family culture. In some families it is considered normal for family members to treat a new-born baby as if it belonged to everyone. It is also common for the opinions of a new mother who is low in the 'motherhood hierarchy' in the family to be ignored by more experienced mothers in the family (Notko, 2006). These behaviours may cause conflict when mothers feel that their agency to make decisions about their child is overridden by other family members, but this is not caused by role confusion based on genetic parenthood. Ethical guidance on intrafamilial and intergenerational donation (ASRM, 2003; ASRM, 2012; ESHRE Task Force, 2011) does not explicitly mention variations in family culture, family hierarchies and motherhood status in which some behaviour, in some social contexts, is considered normal, while in others, it may be considered to breach appropriate boundaries.

Mother-to-daughter egg donation is thought to be rare (Jadva et al, 2011). There is little qualitative research on MEF, and a lack of information about the motives of mothers or, more generally, on the reception of this technology. The HFEA does not collect this data; personal correspondence with the Executive Officer of the Turner Syndrome Support Society (TSSS) suggested that up to eight UK mothers of girls with TS may have frozen their eggs for their daughter's use in later life (Smyth, A. 30/9/19, email), and to date, only one appears in the literature (Sinclair, 2008). The lack of patient-centred research in this area highlights gaps in the literature on intrafamilial egg donation, in particular on the family context of sibling egg donation, and on the reception and use of maternal egg donation by families most likely to be affected.

2.2d(ii) Egg freezing

Egg freezing gives girls and women the potential of having a genetically connected child in later life. It is a less invasive procedure than ovarian tissue freezing but it is still physically and emotionally demanding.

Much of the literature on medical egg freezing relates to pubertal girls and women with cancer. In this context, decisions about freezing have to be made before treatment can start, as chemotherapy can result in infertility; this may mean that participants' reasons for choosing, and feelings around, egg freezing are specific to the context of a potentially life-threatening disease, where a decision about reproductive preservation needs to be made within days (Peddie et al, 2012). TS is not life-threatening and, while still limited, the time available to make a decision on egg freezing is generally longer (Morgan et al, 2019).

In the context of TS, egg freezing needs to be undertaken when the girl is a young teenager (Morgan et al, 2019). When an adolescent was going through egg freezing, it was usual for close family to be involved during the process of egg collection, providing the girl with emotional support and helping to make decisions about egg storage and disposition. The emotional needs of adolescent girls freezing their eggs are different from those of adults, because, for example, they may have no experience of transvaginal procedures, they may be treated in a fertility clinic alongside adult couples, parents may need to be present to give consent, and girls may need emotional support from parents and clinic staff (Inhorn et al, 2017).

Although the medical literature reports that a number of girls with TS have frozen their eggs, there is no qualitative literature specifically on this topic. A medical case report recorded the results of two rounds of egg freezing with a girl with TS aged 14 (Oktay et al 2010). The report did not dwell on the patient's motives, simply noting that it was the treatment of preference for the girl and her parents. Little is known about the reasons that girls with TS and their parents may choose egg freezing, or how they feel about it.

2.2d(iii) Ovarian tissue freezing (OTF)

There is little research on the way women perceive ovarian tissue freezing (OTF); most research papers are medical or bioethical. However, the research that has been done has identified important potential benefits to performing egg freezing or OTF. Firstly, it has been found to improve women's psychosocial well-being by increasing their chances of having a genetically-connected child. A prerequisite for this was that the adult women who undertook the treatment were provided with counselling that gave them realistic expectations about the success rates of future treatment (Hewitt, 2013; Lotz et al 2015). A questionnaire survey (Lotz et al, 2015) of 147 women who had preserved ovarian tissue, including two women with TS, found that no women regretted having tissue frozen even though a third no longer planned to use it. As only 3% of women had had their tissue reimplanted while 27% were too young to start a family at that point, there may be more findings to come from this group if they are surveyed in future.

Studies of the efficacy of reproductive preservation technology were, understandably, medically focused; they did not explore, and sometimes did not mention, the participants' motivation for taking part in studies (Jadoul et al, 2017; Hreinsson et al, 2002). Borgstrom et al (2009) suggested that the ease of recruitment for their study meant that fertility was a high priority for the 57 participants with TS and their families. However, in another recent study, only 12% of suitable women took up offers of reproductive preservation treatment (Talaulikar et al, 2019), and there was no commentary on the reasons for this. Consequently, there are gaps in knowledge on aspects of reproductive preservation that relate to patient understanding and motivation, which would benefit from further research with a qualitative approach. This could include an exploration of women's motivation for choosing preservation, the reception of OTF in girls and women and their families, perception of the potential risks, the way families manage intrusive medical intervention in a child when there is no risk to life, and decision making on how frozen eggs or tissue may be used in later life.

2.2e The parent's role in managing TS

TS is most frequently diagnosed while women are still children, and consequently the implications of the diagnosis also affect their families. It can have a significant impact on parents, who need to manage the condition on their daughter's behalf until she is able to do so herself. There are three main areas which parents may need to address: medical management, educational and social issues, and disclosing and discussing the fertility implications of TS.

TS is a complex condition which requires specialist treatment in diverse medical disciplines such as cardiology, nephrology and endocrinology (Padidela and Clayton, 2017). Current best practice guidelines recommend that girls and women with TS should have annual health checks (Gravholt et al, 2017). Most families have to manage growth hormone compliance (Clarke, 2015) and subsequently, hormone treatment, but if girls are affected by any of the other conditions associated with TS, such as frequent ear infections or digestive or dental disorders, they may need additional, regular treatments. Each visit to the doctor needs parental supervision, which places demands on parents' time (Collin, 2012 p45). Most often, as with other chronic childhood illnesses, it is the mother who manages the day to day care (see e.g. Beresford and Sloper, 2000 p82; DiOrio et al, 1999; Hutchinson 2003; McNeely et al, 2002; Ralph et al, 2013; Reay et al, 1998; Reay, 1999; Ryan and Runswick-Cole, 2008; Swain et al, 2006).

In addition to medical issues, there may be academic or psychosocial issues to address with the girl's school. There is a characteristic cognitive profile associated with TS (Gravholt et al, 2017). While girls with TS have intelligence in the normal range with strengths in verbal IQ (Abir, 2001; Temple and Shephard, 2012), cognitive deficits in information processing, executive functioning, short term memory, and attention span can lead to poor academic performance, difficulty in concentrating and difficulty with mathematics and spatial awareness (Mazzocco, 2006; Rovet, 1993; Culen et al, 2017; Temple and Shephard, 2012; Hong and Reiss, 2012; Ross et al., 2000). The behavioural issues associated with TS are linked with the signs of autism, meaning that TS is also associated with neurodiversity (Wolstencroft et al, 2019). Girls who are affected may require additional educational support and this may necessitate repeated contact between parents and their daughter's school (Collin, 2012 p46; Williams, 1995).

The diagnosis of TS might come as a shock to parents (Starke et al 2002; Sutton et al, 2006) who may have to manage their feelings of distress around this, as a separate issue from the management of their daughter's condition. Parents of disabled children are frequently the main information source for their child about their health condition (Beresford and Sloper, 2000), so they need to understand the condition well enough to be able to explain it; parents of girls with TS did not always find it easy to find or make sense of medical information (Starke and Moller, 2002). Parents reported that they had difficulty both in understanding the implications of TS and in discussing this information with their daughter (Sutton et al, 2006); they often wanted guidance on how and when to disclose (Dennis et al, 2015; King et al, 2016) and, in common with other parents of children with a condition that affected infertility, sometimes relied on clinicians to disclose the infertility diagnosis (Nahata et al, 2018).

Deciding when to disclose the condition, and who to disclose to, is another challenge that parents of girls with TS share with other parents of children with a health condition (Metcalfe et al, 2008). Parents of girls with TS found parent groups to be a helpful source of support and information about TS and the various options for treatment (Collin, 2012 p184; Starke and Moller, 2002). Disclosure is complicated by girls' age at diagnosis and the need for age-appropriate information. Young children may not have a good understanding of fertility: the ability to grasp the need for, and impact of, medical treatment is related to maturity (Balen, Fraser and Fielding, 2006; Lagrou et al., 1998; Loughlin, 2006). Girls with TS may not realise the potential value of fertility interventions when they need to be performed. It is usually as they reach puberty that they start to be concerned about fertility, and it often remains a significant concern for the rest of their lives (Loughlin, 2006). It was often difficult for parents to discuss fertility with their daughter due to the perceived social stigma of infertility and the distress they thought it would cause her (Sutton, 2006), a topic which is discussed in more detail in section 2.5.

Current research into TS is heavily weighted towards medicine. For example, in one review of the scientific literature on TS (Sandberg, 2018) only 10% of papers (out of nearly 1300) focused on psychosocial research. Most of the psychosocial research studied the educational, cognitive and social skills implications of TS, and only a small proportion focused on reproductive decisions or on the reception of reproductive options. Medical case studies give some indication of how women with TS and mothers of girls with TS may feel about, or be affected by, these issues, but are lacking in detail. For example, the first case of maternal egg freezing in the literature is described in Gidoni et al (2008)'s case study of a Canadian mother who froze her eggs for her six-year-old daughter with TS. The mother decided against freezing her daughter's ovarian tissue due to poor outcomes of naturally-conceived pregnancies in women with mosaic TS and instead froze her own eggs.

Two sentences describe the mother's motives; most of the case report describes the protocol for her egg freezing cycles and goes on to a general discussion of the ethics of intrafamilial donation. This is, of course, the purpose of a medical case report, but it demonstrates that, even though there may be a considerable body of medical literature on a topic, gaps in the literature may remain on the reception of the technology and the decision-making process around its use.

This brief summary of medical and psychosocial literature has described the main features and impact of TS in order to provide context for a later discussion of women's reproductive choices. While most women with TS say they would like to have a family, barriers to family-building are not only related to the potential physical risk of pregnancy and the availability (or otherwise) of reproductive preservation options, but also to the psychosocial effects of TS and infertility; some women with TS can find it harder to make friends, tend to begin sexual relationships at an older age than their peers, and are less likely to be married. Ultimately this means they are less likely to have children. The topic of pregnancy risk has been introduced, solely from a medical perspective. Finally, some of the implications for parents were discussed, in particular how time-consuming and emotionally demanding it can be for them to manage their daughter's health and educational issues and provide her with emotional support.

2.3 Reproductive timing

Timing, both in terms of childhood development and of reproduction, was one of the major themes identified in the present study as being vital to understanding the lived experience of women with TS. Both women with TS and mothers of girls with TS were sensitive to the ways in which they did not conform with normative expectations of timing. Whether infertility itself is considered to be a disability is contested (see, for example, Lim, 2018; Sternke and Abrahamson, 2015), but the impact of TS meant that both women with TS and mothers of girls with TS were sensitive to the ways in which they did not conform with normative expectations of timing throughout life, especially in childhood.

One useful way to present the normative trajectory of the life course is to perceive it as a linear progression through time with a standardised timetable (Roth, 1963, p72). An individual life, and each related series of events within it, could be characterised as a career; each career has an end-point or goal, definable stages of progression, and clear points of 'promotion' where people move from one stage to another. The goals, and the expected timetable of progress towards them, are socially constructed. Peers both act as a reference group against which individuals can assess their personal location and relative progress along the timeline, and as peer pressure to conform to an expected timetable (Roth, 1963 p100).

The notion of a 'career' could also be applied to an individual's private life, where social expectations within families and across wider society influence women's attitudes about the preferred age of marriage, reproductive timing, and the steps they need to take to be in the right circumstances to have a family. Each individual is part of a cohort with similar expectations and hopes and a shared understanding of the appropriate age or life stage for these to occur (Bergnehr, 2009). Within this setting, women aim to achieve a number of life goals before they get pregnant: completing their education, getting secure employment, having a secure home and, most importantly, meeting a partner who also wants children (Sol Olafsdottir et al, 2011). These 'clues for constructing timetable norms' (Roth, 1963 p95) act as markers of progression on the ‘reproductive timetable’ and as points of comparison with peers (the reference group). This is enforced through social norms such as the socially acceptability of publicly questioning and discussing a woman’s progress towards maternity. As conformity is viewed as a marker of success, the timetable is ‘enforced’ by well-meaning family, friends and acquaintances through behaviour that identifies women who are non-conforming and alerts them to their difference, for example by giving unsolicited advice on finding a partner, talking about the ticking biological clock or referring to age-related fertility decline (Lahad, 2012).

Individuals have to account for their lack of conformity with social timing expectations, and consequently have 'a tendency to make the norm conform with their experience' (Roth, 1963 p3), for example when patients describe the duration of their stay in hospital as ‘normal’ by defining a normal duration in ways that include their stay. However, there is a limit beyond which explanations become unsustainable. When a person is too far behind their peers they are seen as a ‘timetable failure’ (Roth, 1963 p106), and are no longer considered part of the reference group. Hence, everyone in a social group is under the same type of social pressure to progress along the reproductive timetable at a similar rate to their peers, regardless of how feasible it is for them to achieve the life goals of financial security, partner and children in the socially expected sequence.

In her theoretical work on cultural representations of disability, Garland Thomson (1997) critiques this practice of norming around social timetables, arguing that societies are organised around a universal ideal, which she conceptualises as the ‘normate’ (Garland Thomson, 1997, p8), which represents the average or majority. In the context of reproduction, social norms set and enforce a reproductive timetable which takes the average person, or the majority in society, as a basis for comparison. She refers to this as the ‘normate’ because, rather than representing an ideal, it simply describes the most common life experience, while outliers from the social norm are presented not merely as less common than the average but stigmatised as ‘misfits’. A minority of the population may have greater difficulty in aligning their personal schedules with the socially-accepted timetable or may never be able to achieve a successful outcome as defined by the average. Misfitting can describe the lived experience of an incongruent relationship between normative reproductive timing and an individual schedule which has been disrupted by chronic illness and infertility. Where 'fitting is a comfortable and unremarkable majority experience of material anonymity' (Garland Thomson, 2011, p597), misfitting draws attention to ways in which people differ from the normate and makes those differences public, for example when Deaf people are fitted with Cochlear implants to enable them to hear, rather than sign language being a commonly accepted form of communication. This process, when applied to reproductive timing, could be called the 'genealogical imaginary' (Bühler, 2015), a term which describes social norms around reproductive timing, including the idea that there is an optimal age range at which to become a mother, and that the generations should be kept in alignment. It accounts for disciplinary behaviour around reproductive timing, such as criticism of both older single mothers by choice and teenage mothers (Daly and Bewley, 2013; Golombok et al, 2016; Hadley et al, 2016), misfitting groups that are a target for public critique and concern, as are 'grandmother mothers' (Bühler, 2015), women who are perceived to be late in reproducing. In defining misfitting as 'a shifting spatial and perpetually temporal relationship' (Garland Thomson, 2011, p592) between social expectations and people's ability to comply with them, Garland Thomson argues that the person and their circumstances form a 'mutually constituting' relationship. A change in circumstances, support and attitudes (such as anticipating the needs of disabled people and providing an accessible environment) can alter the degree to which people experience misfitting; consequently, a misfit between the person and the expectations placed on them can be used to critically examine the way the world is designed around the majority who 'fit'.

When people fail to conform to the accepted timetable for their 'career', they stand out against their peers; in misfitting, they are no longer anonymous, and may be forced find ways to account for their lack of progress. A number of normalising strategies may then be used (Roth, 1963, p108): revising the perspective on how long it might take to achieve a goal, choosing different reference points, or bargaining around timing, for example by shifting the priority of important life events so as to be able to achieve them all at some point. As chapter 4 goes on to describe, each of these strategies is used by women with TS and mothers of girls with TS in order to manage or alleviate the social pressure around reproductive timing.

2.3a Timing and TS

While medically, TS is not defined as a disability, associated conditions may be, if they have a 'substantial' and 'long term' effect on daily life (Great Britain. 2010). Yet many of the 'temporal dislocations' (Robertson, 2015, p10) faced by families affected by TS are directly related to the impact of TS. Its symptoms and the degree of their severity almost always affect the timing of girls' physical and emotional development, and women's reproductive timetables, in comparison to their peers. They also usually require significant, lifelong medical intervention. For these reasons, it is useful to view the impact of TS on timing using Kafer's concept of 'crip time' (Kafer, 2013 p26), developed to theorise around the stigmatising effect of social timing norms on disabled people. The use of the insider term 'crip' is a way to de-centre normative narratives of time: 'crip time' refers to 'the extra time often needed to accomplish something' (Kafer, 2013 p26) and this relates both to the impact of managing a disability and the impact of ableist barriers on the time it takes to carry out everyday activities.

The signs of TS (see section 2.2) that have an impact on timing include physical development that is slower than peers, delayed or absent puberty, and later sexual and emotional development than peers, as well as the reproductive timing challenges associated with infertility. Normative narratives of social time have a narrow focus on the life course and the peer group, a perspective which Roth describes as peculiar to the middle classes in Western culture (Roth, 1963, p97). When time is considered in this narrow way, women with TS experience misfitting at many points. Kafer (2013) presents a different perspective, describing disability and illness as an orientation in and to time. She argues that the concept of how long things take is based on a normative idea of the way minds and bodies work; the perception of delay, particularly as a negative, is part of an expectation of 'compulsory able-bodiedness' (Kafer, 2013, p29). In other words, disabled people become misfits due to the expectation that everyone should conform with normative standards that take no account of varying abilities; its 'compulsory' nature is due to a lack of accommodation for those who cannot conform. Compulsory able-bodiedness presents lateness (which could be described as temporal misfitting) as an effect which must be corrected to fit a social norm defined by the non-disabled population. She calls for a reorientation to time, an approach that is intrinsically flexible, which recognises that people who are differently situated will have different definitions of what it means to be 'on time'. In this way she seeks to challenge normative expectations of timing to acknowledge and accommodate the impact of living with a disability or impairment, and to ensure that the ways in which women can 'fit' are expanded.

2.3b Future imaginaries and reproductive timing

Decision making around fertility and parenthood is informed by, amongst other things, hopes and desires for the future, which in turn are partly shaped by social ideals of motherhood and reproduction.

When people make a choice, they often consider the various potential outcomes; their thinking around what is preferable is informed by social imaginaries, which can be defined as "the ways people imagine their social existence, how they fit together with others [...] the expectations that are normally met, and the deeper normative notions and images that underlie these expectations" (Taylor, 2004 p23). In other words, decisions take into account shared values which underpin the perceived social acceptability of the various options and outcomes of a choice and the degree to which, in both the present and the future, they are perceived to meet the expectations placed on individuals by family, friends and wider society. For example, a society's belief in the importance of the nuclear family may be expressed structurally, through laws forbidding single women or same-sex couples from accessing adoption or fertility treatment or through providing tax benefits for married couples, as well as through social disapproval or ostracism expressed by peers and family. Social imaginaries express a shared idea of what is considered normal and also of what kind of behaviour is transgressive.

Imaginaries can be used to express reproductive norms and to guide reproductive choices. The 'motherhood mandate' (Russo, 1976) presents motherhood as an imagined future role for all women. The 'family we live by' (Gillis, 1996) expresses an imaginary of family life which guides decisions about family building, as well as family obligations and duties. The genealogical imaginary (Bühler, 2010) describes socially-accepted views about the right age and circumstances in which to become a mother and has been used to account for the stigmatisation of older mothers. When choosing a sperm donor (Mamo, 2005) or egg donor (Hudson, 2019), women having fertility treatment used cultural understandings of genetic inheritance to imagine what their future child might be like, based on a description of the donor's characteristics, and used that to guide their choice. Imaginaries can also express ethical values: Banks et al (2006) describe how, when considering the ethics of sex selection, some people use their own moral values to imagine how they would inform the choice a 'good parent' would make; for example, a good parent would prefer the option that gave their child the best chance to reach their potential.

In the context of fertility, imaginaries may present reproductive technology as facilitating "collectively held, institutionally stabilised and publicly performed visions of desirable futures, animated by shared understandings of forms of social life and social order attainable through and supportive of advances in science and technology" (Jasanoff, 2015, p4). These shared understandings may be articulated as descriptions of thoughts, feelings and expectations about how to achieve parenthood as well as in the choices that people make. Decisions may also be guided by individual imaginaries, the possible outcomes of a range of potential choices that an individual envisions for themselves, based on their personal circumstances (Lennon, 2004). Social and individual imaginaries are mutually constituting, informing both what is preferable in general, and the preferences of an individual.

The envisioning of desirable futures to aim for, or undesirable futures to avoid, illustrates how shared social values operate to frame the options available, including the framing of a childless future as a socially unacceptable choice. As the family is primarily defined as a heterosexual couple with children (Crabb and Augoustinos, 2008; Thompson 2005), infertility puts at risk potential motherhood, replacing it with an imaginary of rejection if a woman cannot carry a child for her partner; the imaginary of rejection expresses the stigma of infertility, where rejection is viewed as a likely outcome of the inability to have children. Technologies of 'anticipatory biomedicine' (Bach and Krolokke 2019), such as ovarian tissue freezing, are interventions which are presented as facilitating motherhood, encouraging their users to anticipate the future need for treatment and also to anticipate what the outcome might be if the technology is not used. The use of ARTs has been linked with future-focused thinking through the concepts of anticipated decision regret and the mobilisation of hope around the future outcome of treatment. Anticipated decision regret (Tymstra, 2007) describes how decision making is informed by the prospect of regretting the outcome in the future, whether the response to the choice was to take action or to do nothing. It has been applied to reproductive decisions in many contexts, including egg freezing (Baldwin, 2018), PGD (de Jong et al, 2013) and sterilisation (Mertes, 2017). When decisions need to be made by parents on behalf of a child which have implications for the child's reproductive future, and the child is too young to ask, the decision-making process may be partly informed by the desire to avoid closing off future reproductive options, leaving a future choice open to the child when they are an adult.

Parents often have hopes and aspirations for what their children might become (Nordqvist, 2017), imagining their future life in ways that relate closely to the parents' ideals of achievement. ARTs are 'hope technologies' (Franklin 1997, p176), useful both in their own right and for the way in which they can be mobilised for emotion management. IVF is described as being useful for the 'hope it promises, as much as, if not even more than, a 'successful' outcome, which leads it to be seen as a desirable option' (Franklin, 1997 p192). In a pronatalist social context, particularly for parents who value children and a family life, reproductive preservation could maintain the hope of future genetically-linked grandchildren. Its use is potentially empowering: it provides a choice, and the future outcome of treatment remains open; in turn, its use may defer the need to address infertility, or move on to other forms of treatment, until another time.

2.3c Mothers' perceptions of their daughter's reproductive future

Mothers of girls with TS also have to navigate reproductive timing issues around maternal egg donation within a broader cultural narrative of reproductive chrononormativity (Freeman, 2010). In this context, Kafer's concept of the 'curative imaginary' appears to be useful as it provides an account of the social pressure on disabled people to assimilate into the mainstream by constantly looking forward to a cure, an expectation which can also be applied to infertility. Kafer describes how ideas of time, as they relate to disability, focus less on the present life of a disabled person and more on their future, where that future holds a possibility of being rehabilitated or cured of their condition. A 'cure' is a normalising treatment that enables disabled people to function according to society's expectations. Kafer terms this approach the 'curative imaginary', an understanding of disability which 'not only expects and assumes intervention, but also cannot imagine or comprehend anything other than intervention' (Kafer, 2013, p27). For example, she challenges the priorities of disability charities that fundraise to find a future cure for a disabling condition, while overlooking the existing needs of disabled people. While it is common for disabled people to wish for a cure, the 'curative imaginary' views disability itself as a condition that requires a normalising intervention: the disabled person is expected to be working towards and wishing for a cure, rather than to accept and learn to live with their condition. A focus on the future, therefore, is linked with 'compulsory able-bodiedness' (Kafer, 2013, p27), where progress towards a cure is not only expected but required.

The concept of the curative imaginary can be used as an analogy for the social expectations that women will become mothers. It mirrors the presumption, central to the idea of mandated maternity (Russo, 1976), that infertility is an undesirable condition which must be alleviated (for example, through adoption) or treated (through the use of ARTs). In a society which privileges maternity, motherhood is understood as 'constituting the central core of normal, healthy feminine identity, women's social role and ultimately the meanings of the term woman' (Gillespie, 2000, p225). There is a social expectation for women to have children (Hudson, 2019). Consequently, motherhood is valorised and non-motherhood is stigmatised. The curative imaginary involves the expectation that disabled people will work towards a future cure for a disabling condition, and similarly, women who are infertile are expected to be seeking a way to have a family. For mothers of girls with TS, who may be faced with decisions that affect her reproductive future while she is still a child, making a choice about her future desire to become a mother may be influenced by a social context that expects women to become mothers. Robertson (2015, p9) suggests that, as paying attention to their child's future life chances is considered part of the role of a mother, where a child has a disability (or, in this case, infertility):

> *"The mother's caring role is amplified to include a kind of future-fear, whereby the mother must balance every decision she makes not just against the present but also against an imaginary curative future and/or a seemingly unimaginable noncurative future."*

The curative imaginary also manifests as hope that a medical solution will arrive in the near future, and in the context of fertility, can be linked back to the concepts of hope technologies and anticipated decision regret. The future imaginaries of both disability and infertility, then, are informed by the expectation that people not only will want to, but should, seek a solution which normalises them with the general population.

2.4 Framing reproductive choices

The second major theme to emerge from the findings was the value placed on having and making reproductive choices. Infertility was perceived as a constraint on the ability of women with TS to exercise reproductive agency, and providing choices was viewed as a way to empower her. This section examines research on reproductive choices in the context of a high-risk pregnancy and the way decisions are affected both by perceptions of risk and by social expectations of the way people should behave when making a choice.

2.4a Research on reproductive decisions

Family-building intentions are often expressed as population-level trends that describe social changes at a macro level, which are elicited from quantitative data and analysed using a model such as the theory of planned behaviour (TPB) (Balbo et al, 2013) or traits-desires-intentions-behaviour (TDIB) (Wagner et al, 2014). For example, Berrington (et al, 2015)'s research on commitment and childbearing shows how the sequencing of marriage and pregnancy has changed over time in the UK. While population-level research such as this collects data about people who have not had children it focuses mainly on factors that affect quantum intentions (the number of children people want) and parity-progression intentions (how many more children they want) of the majority. Although they provide a useful backdrop against which to contrast the experience of women with TS, this approach is not useful for examining the decision-making processes of a small group of people with a rare disorder linked with high-risk pregnancy, who are not easily able to get pregnant.

Qualitative research on reproductive decision making in the context of a genetic condition tends to focus on how couples with a serious and potentially life-threatening heritable disease such as BRCA2 (Donnelly et al, 2009) or SMA (Boardman, 2013) decide whether and how to have a family. Similarly, there is a body of research on parental decisions around foetal genetic abnormality, such as Hershberger et al.'s (2012) research which described how couples at risk of having a child with a genetically-inherited condition went through four stages in decision-making: identifying the problem, contemplating the options, making a decision, then following it through. Another example is Rapp's (2004) research, which described how women decided whether or not to use prenatal genetic diagnosis and, if an anomaly was discovered, how they then made a decision about whether to continue their pregnancy. In both of these two strands of research, the focus is on the parent's concerns for the child's future health, rather than their own. The present research focuses on the experience of women with TS. Some women with TS can conceive naturally, but it has not been established whether TS is heritable (El-Shawarby et al, 2010). The main focus of concern is the elevated risk of pregnancy complications to the woman with TS and a high risk of miscarriage.

For these reasons, women with TS have more in common with other women with congenital heart diseases (CHD) because they also make reproductive choices that may result in a high-risk pregnancy. The literature on risk perception is examined next.

2.4b Risks

There is considerable medical evidence of the risk in pregnancy that affects many women with TS but beyond describing concerns about the cardiac risks (van Hagen et al, 2016) there is little research on how risk affects their attitude to decision making, which is why congenital heart disease is a useful comparator. CHD is a leading cause of death in pregnancy; women with CHD who wish to conceive are given risk advice prior to conception and monitored regularly throughout the pregnancy and birth (Dob and Yentis, 2006).

Women viewed having a serious heart condition as a significant barrier to pregnancy and used it to explain decisions to avoid pregnancy or limit their family size (Peters et al, 2002). Knowledge of the potential risks meant that they carefully considered their decision to conceive, which in turn meant that, although their decision was informed, worries about the risk caused significant stress during the decision-making process as well as during pregnancy (Peters et al, 2002).

Although women usually took their doctor's advice regarding pregnancy decisions, the medical advice they received about risk was not always well-understood. Ngu et al's (2014) study found that women with CHD whose condition had been well managed tended to believe that it could continue to be safely managed in pregnancy. Those who had given birth had decided to go ahead with the pregnancy believing that that, if their doctor had not warned them against it, the risk could be monitored and controlled. One study found a significant level of inaccurate knowledge about pregnancy and CHD, and 37% of women did not recall being told about the risks associated with pregnancy by their doctor (Kovacs, 2008).

This speaks to a wider issue with the understanding of medical risks. Behaviour that is socially constructed as 'responsible' (Novas and Rose, 2000) is guided by information provided by experts, and individuals are expected to be capable of evaluating this information to inform their decisions. This can result in more freedom, because there is greater individual choice, but alongside this is the potential for an individual to be blamed, and for negative events or outcomes of their choices to be seen as 'their fault' (Beck-Gernsheim and Beck, 1995 p40). When risks are described in the literature, they are often expressed as a generalisation that applies to everyone with that condition; in TS, prevalence of the associated signs (and consequently the associated risk) is sometimes expressed as a range (Gravholt et al, 2017). The risk to any single individual may vary from the general statistic (Samerski, 2007), potentially making it more difficult for women to apply risk advice to their own circumstances, particularly in health conditions like TS which have varied impacts.

Robinson et al also highlighted in their work on patients' perception of risk in pregnancy that an individual's level of scientific knowledge affects their risk perception (Robinson et al, 2015). Because it is not always easy for people to interpret statistics about risks, women may not know how to evaluate the risks and benefits of the different options but also may not feel they can ask for the information they need (Rapp, 2004; Roberts, 2006). As Rapp observed, "recognition of risk and consequent steps to contain it entails a kind of scientific literacy" (Rapp, 2004 p314). Yet, the more fully that individuals understand the risk of a particular choice, the more likely they may be to take risks, while those who overestimate risk are likely to be risk-averse (Cook and Bellis, 2001).

In addition, the understanding of risk can be subjective, and risk levels may be interpreted based on the situated experience of individuals, so the same risk may be interpreted differently by different people (Lupton, 1999). Although women tend to be marginally more risk-averse than men (Nelson, 2014), there is evidence that women are willing to take risks in some circumstances: female infertility patients who did not already have children rated multiple pregnancy and its associated risks to the mother and foetus as more acceptable than fertile women with children. The longer a woman has experienced infertility, the more likely it is that she will be willing to accept risks in treatment (Newton et al, 2007). One motive for this is the perception that taking a risk may give a better chance of achieving a pregnancy, which could also draw a close to the physical and emotional stress and the expense of infertility treatment (Lieblum et al, 1990), meaning women reassess the risk of treatment balanced against the potential risks in other areas of life.

Lee et al (2013) shows that medical risks are only one consideration which informs women with a high-risk pregnancy when they make decisions relating to risk: even when they fully understand medical advice, they also take into account other factors such as the reliability of the source, where medical information sits alongside other perceived risks, and the importance of the decision (Lee, Ayers and Holden, 2015). Women who do not trust their doctor may place a higher value on other sources of information (Lee, Ayers and Holden, 2012) even though they may be negatively judged if they do not prioritise medical advice. When making a choice, they are also taking into consideration the social and relationship risks in their circumstances; the clinicians may only be aware of their medical risks. The power imbalance between patients and clinicians means that the doctor's views on risk, and their scientific knowledge, may be prioritised over the patient's (Lee et al, 2016) and a woman who does not accept this advice may be judged as consciously putting themselves and their child at risk of harm.

Furthermore, if knowledge and perception of medical risk does not fully explain why people take risks (Cook and Bellis, 2001) this would suggest that more medical information does not necessarily lead to a more predictable response to the advised risks. Information forms a key role in the decision making of responsible citizens, yet medical knowledge only forms part of the decision-making process. If women do not have the means to evaluate information about risk, this presents a barrier to making an informed choice.

2.4c Choice

Current debates in the sociology of decision-making focus on how far it is possible for an individual to make decisions independent from the influence of structural factors such as class. The individualisation thesis (Beck, 1992; Beck-Gernsheim and Beck, 1995) describes a shift in society that has led to the weakening of social structures which define group identities, such as gender, race and class. In turn, as individuals are less constrained by social structures, greater value is placed on individual agency, characterised by an understanding of individuals as able to influence their health outcomes by taking actions based on informed choices. Individualisation positions the individual and society as being in conflict with each other, with an increase in individual agency seen as challenging the influence of social structures over decision making (Brannen and Nilsen, 2005). In a society which promotes individualism, agency is highly valued as a means for an individual to take control of their life and direct it as they choose (Beck and Beck-Gernsheim

2002). Consequently, choice is viewed as entwined with agency, since it is not possible to exercise agency unless there are a number of options to choose from. While the individualisation thesis does not appear to give much weight to structural factors which present barriers to a free choice, individuals are still expected to conform to patterns of expected behaviour which are defined as appropriate.

Increasing the number of options can present new problems, however. Greater choice opens women up to greater scrutiny; framing decisions as a choice leaves that choice open to critique. In turn that can create social expectations of appropriate behaviour, which can function as social pressure on a woman to make a particular choice. For example, legalising abortion has meant that giving birth can be seen as a choice rather than an inevitability, which has raised the question of whether the choice to give birth in particular circumstances was a responsible one (Denbow 2015 p82). The use of prenatal genetic diagnosis (PGD) may be framed as a woman's choice, but in practice, its acceptance, and the decision about how to act on a positive result, depends on 'personal and collective value judgements' about disability and pregnancy (Rapp, 2004 p91). Women who chose to use PGD felt a sense of having to account for the decision they made based on the test results and this could manifest as worries about being judged as selfish, whether they chose to give birth to a disabled child, or whether they chose to have an abortion (Rapp, 2004). The availability of choice may increase pressure to make the choice that is socially expected, or face being judged negatively or blamed (Denbow, 2017). Women who carry a genetic disorder may feel the need to enact socially expected behaviour around making reproductive choices, such as by framing their choice as responsible (Raspberry and Skinner, 2011). A woman's choice to use ARTs may appear to show her asserting control over her circumstances. However, if she perceives the genetic connection as vitally important, and ARTs as the only way that she, or her daughter, could have a genetically-connected child in the future, this may compromise her judgement, leading her to make a choice that is against her own best interests or that she later regrets (Harwood, 2009). Having reproductive choices, then, does not mean that women are completely free to choose, since the decision is still made within a social and relational context which shapes their choice.

Having several options to choose from can also be problematic because it presents people with a decision that previously they did not have to make. The ‘paradox of increased choice’ (Zeiler, 2004) refers to the assumption that having more than one option is an unqualified good thing. However, this could make the decision more complicated as it meant women (and their partners) would first need to decide whether they wanted to make a choice at all, before making a decision about which reproductive option they wanted to use. Increased choice, therefore, could sometimes hamper decision making even though in principle it was intended to facilitate it.

Family sociologists have critiqued the individualisation thesis as exaggerating the degree to which free choice and agency are possible (Chambers, 2012; May and Nordqvist, 2011). Women’s choice may be influenced by cultural and familial experience and preferences, such as the cultural preference for a genetic link to a child: infertile couples often favour a family-building option that helps them retain a genetic link to the child in at least one parent. Many infertile women who need an egg donor prefer to conceive a pregnancy using a related donor, while options that exclude a genetic link to at least one parent, such as adoption, tend not to be the first choice (van den Akker, 2010). Fertility intentions and expectations of family size may be influenced by practices within a person’s own family and close social network (Monkediek, 2017). Expectations around the importance of motherhood may be transmitted intergenerationally: the mother’s pronatalist attitudes may be reproduced in the relationship between mother and daughter, even when other expectations, such as whether a mother should work outside the home, may be different (Bartholomaeus and Riggs, 2017). As Boardman (2013 a and b) shows in work on families affected by a heritable disease, reproductive choices can be influenced by personal experience of living with a condition or having close relatives who are affected, what she called ‘experiential knowledge’. This can make a decision more difficult, as people have to resolve the tension between respecting an existing disabled family member and using PGT or PGD to avoid having children with that same heritable disorder (Boardman, 2013a, 2013b).

The individualisation thesis has shaped public discourse around health and fertility (Chambers, 2012). An example in a research context is the absence of any acknowledgement of structural factors as relevant in accessing ARTs. For example, medical researchers Noyes et al report that ovarian cryopreservation "affords patients greatest reproductive autonomy" (Noyes et al, 2015) while Rienzi and Ubaldi state that fertility preservation is used to “guarantee female autonomy in reproduction” (Rienzi and Ubaldi, 2015 p1). These claims imply that preserving frozen ovarian tissue is by itself a guarantee of autonomy and that lack of availability is the main barrier to its use. This ignores cultural factors, such as geneticism and pronatalism, and financial and family circumstances, that may influence women's ability to choose it as an option (Purdy, 2006).

Furthermore, as several authors have shown through their empirical work, action taken to provide a choice may appear to be aimed at enabling future family-building, but that may not be its only intention. Adrian, for example, develops the concept of ‘Psychological IVF’ (Adrian, 2015, p303) to describe the way ART procedures, or the existence of an ART, can be used as an emotion management tool. In people undergoing fertility treatment, ‘hope technologies', such as IVF, enable patients both to maintain the hope that they will be able to have a family at some future point and to manage the disappointment of failed treatments or infertility (Franklin, 1997 p176). Clinic staff described a ‘psychological’ fertility treatment as one which, while it may have failed in achieving a pregnancy, had a positive outcome in terms of emotion management. For example, an unsuccessful treatment could enable couples to accept that they were not going to have a genetically related child, enabling them to move on to more potentially successful routes to parenthood, such as using donor gametes or adoption; they needed to lose hope in order to stop using that treatment (Franklin and Roberts, 2006 p210).

In the context of TS, women's family building choices may be affected by contextual factors other than attitudes to risk. Krawczak (2017) argues that the low rate of motherhood in women with TS is related less to concerns about the physical risk of treatment and more to structural inequalities such as the cost, and the barrier to relationship-building presented by the impact of infertility on self-esteem. Women who are not able to afford fertility treatment, or who do not have a supportive partner and family, may not be able to explore (and may therefore not know about) the risks of pregnancy. Research which focuses solely on the technical feasibility of ARTs overlooks the enormous financial cost of both fertility treatment and reproductive preservation, meaning access to treatment is more likely to be available only to women and girls whose families can afford to pay for it (Beckman and Harvey, 2005). Brannen and Nielsen (2005) contend that decision making can vary greatly depending on the social context and therefore concepts constructed from empirical analysis are more effective at explaining people's experience than concepts derived from a theory such as the individualisation thesis. The reason for this is that they are grounded in the participants' real-life experience, so are more sensitive to the effect of individual agency and to the barriers that people face in making choices in that specific context. This approach presents the individualisation thesis as present but bounded by structural factors which either enable or prevent people from putting their preferred choice into practice.

2.4d Stigma

This section discusses infertility and TS as socially stigmatised conditions and the pressure to find ways to navigate disclosure.

Stigma could be described as the "situation of the individual who is disqualified from full social acceptance" (Goffman, 1963, p9); in this context, both TS, and fertility problems linked to it, may be a source of stigma, for parents and clinicians (Wassermann and Asch, 2012) and for women themselves (Cragg and Lafreniere, 2009). TS usually affects women's growth, delaying puberty and meaning girls are visibly shorter than their peers, both factors which can draw unwanted attention, producing a response from others that is infantilising. The need to take growth hormone, and an awareness of the fertility implications of TS, mean that girls may grow up with a sense of not fitting in with peers that can ultimately affect their self-esteem (Sutton et al, 2005; Morris et al, 2020).

Further, in a socio-cultural context where fertility is valued, infertility is stigmatised (Greil, 2011). Cultural dialogues about infertility reflect dominant views about what is normal based on the maternity and reproductive timing choices of peers, where motherhood is not only expected but 'mandated' (Russo, 1976). Motherhood is seen as a socially important aspiration for women, while infertility is viewed as a form of failure (Finkler 2000; Faircloth and Gurtin, 2017). When normalcy is defined by becoming a parent, people who do not have a child, either through culturally-defined lateness or infertility, may describe themselves as feeling 'incomplete' (Becker, 2000).

Research on stigma has identified a distinction between 'felt stigma', a sense of shame and fear of encountering discrimination, and 'enacted stigma', where others actively discriminate based on the stigmatised condition (Scambler, 2009). However, felt stigma can be internalised, meaning that everyday social conversation can be experienced as if it was enacted stigma (Jansen and Saint Onge, 2015). For an infertile person, general discussions of parenting and pregnancy may trigger feelings of stigma and shame. This is exacerbated by the social acceptability of casual questions about fertility intentions, meaning women have to account for their status if they do not have children, and explain it (Thompson, 2005). Women who disclose that they are infertile may also have to disclose that they have TS, and may then be expected to explain the implications of this rare disorder to people who may never have heard of it. Goffman (1963, p5) describes the way that stigmatised people are seen as "not quite human": women who are infertile often describe their feeling that they are not a 'real' woman because the ability to conceive and carry a pregnancy is seen as a core part of what it means to be a woman (Letherby, 2002). Consequently, women with TS who are infertile may struggle to maintain a positive identity (Pellatt, 2007).

In the UK, where easy access to contraception has made it possible to be childfree by choice, involuntary childlessness may be conflated with being childfree; women may be subject to assumptions made about them that childless women are 'selfish', 'delaying' or 'not trying' (Bell, 2013, p290). As described in section 2.2b, this can be difficult to navigate since women who are infertile may not wish to disclose their circumstances, feeling that other people may think of them as a failure (Letherby, 2002). The more intensely the stigma of infertility is felt to be, the less likely it is that women will disclose it (Slade et al, 2007). One strategy used by women with TS is to deflect blame by describing their infertility as a health problem beyond their control, rather than being an intentional choice (Pellatt, 2005); however, using TS as a defence against criticism means they may have to disclose a health condition which is itself stigmatised. The perceived stigma of infertility, and the desire to fit in with peers who are becoming parents, is a major motivation for undergoing fertility treatment (Earle and Letherby 2002; Letherby, 2002).

The perceived stigma of infertility is also felt by mothers of girls with TS. Collin's (2012) study on the information needs of girls with TS and their families provides an insight into the extent to which mothers may feel they need to plan for their daughter’s future. Mothers reported that infertility was the most difficult part of the diagnosis for them to come to terms with; most said this was because being a mother was so important to them. Collin suggests that, for women whose identity and esteem is closely linked with motherhood, when thinking about challenges faced by their daughters in later life, mothers may experience ‘infertility by proxy’ (Collin, 2010, p272), as they grieve that their daughter may not become a mother. Also referred to as ‘courtesy stigma’ (Goffman, 1963 p30-31) this term describes the stigmatisation of people who have a close relationship with someone with a stigmatised condition, their understanding of the condition and the way they may in turn be treated similarly to the stigmatised person. One response to courtesy stigma is to accept the condition and provide a behavioural model showing wider society how to treat people with a stigma. This can be seen for example in family participation in biosocial groups (section 2.4g). However, Goffman suggests that the model of acceptance in turn may be stigmatising, as behaving with tolerance to stigmatised groups itself challenges social norms.

2.4e Responsibilisation

Responsibilisation describes the process of devolving responsibility for health care to individuals, rather than the state (Brown and Baker, 2012; Novas and Rose, 2000). Under the guiding principle of the 'governance of the self' (Rose, 1999), it is associated with particular types of decision-making behaviour which are considered to demonstrate personal responsibility.

The concept of somatic individuality views people as responsible for their own bodily care and for managing the associated risks and consequences of any health conditions they have. The somatic individual has a ‘duty to be well’ (Brown and Baker, 2012 p20). Individuals are socialised to see themselves as having agency, which empowers them to make their own decisions; they are expected to use their agency to make choices which support their health. Individuals take personal responsibility for the risks of behaviour or choices which may threaten their health, and ultimately, for the outcome, if they fail in their obligation to make the correct choices. In the context of growing medical knowledge about the genetic causes of illness, self-optimisation is a requirement for people with a genetic disorder; they are expected to act on this knowledge by adapting many aspects of their life based on the expert advice they are given and to manage their condition so that it has the minimum possible impact on their health (Leefman et al, 2017). The process of screening has been described as a ‘risk technology’ which “serves to magnify the sense of responsibility that people feel when they do ‘succumb’ to illness” (Galvin, 2002, p123).

As with the individualisation thesis, individuals are cast as having agency to make decisions, but social pressure is applied to nudge them to behave in ways which fit the social definition of responsible behaviour: citizens have rights, but they also have the obligation to avoid becoming a burden on the community. People are therefore encouraged to be self-reflexive and anticipatory about their life choices and prospects, focus on their own health maintenance and find solutions for themselves rather than expecting the state to care for them (Galvin, 2002).

In the context of reproduction, women are expected to make decisions which comply with socially-defined expectations of responsible behaviour in terms of their choices around conception, pregnancy and birth. As Leefman et al (2012) shows, knowledge is a key part of any responsible reproductive choice. In the context of a genetic condition like TS, if a woman is not informed of its impact, it is difficult for her to make appropriate decisions, or to consider who besides herself may be affected by these choices, and therefore how aspects of the condition 'ought' to be managed. In addition, social expectations are gendered, meaning that some individuals carry more responsibility than others. There are distinctive social demands on women (especially mothers) to make health choices that enhance their future fertility and, once pregnant, to ensure a healthy pregnancy and birth and a healthy foetus (Roberts, 2006). Mothers also have relational responsibilities, in that they have to consider the impact of health decisions on their children; decision making is socially embedded, and mothers have responsibilities to others as well as to themselves (Leefman et al, 2012). Reproductive choices are mediated through "a complex negotiation of personal desires, family values and diversity, religious faith, and financial constraints" (Raspberry and Skinner, 2011, p429). Because individuals are expected to produce one of a socially-accepted set of responses to risks, if a woman is attentive to the views of her clinician, family and friends, the degree of choice she may feel she has in any given health setting is potentially limited, and consequently her agency is also limited.

2.4f The influence of a partner

The views of a partner are an important consideration in a woman's decision about whether or not to proceed with a pregnancy (Kroelinger and Oths, 2001). Planned reproductive decisions are usually made jointly: most women who want children look for a partner who also wants children (Sol Olafsdottir et al, 2011). Partners significantly influence a woman's pregnancy intentions; women with a male partner are likely to adjust their preferred reproductive timing and family size to accommodate their partner's preferences (Dudgeon and Inhorn, 2004). Some men reported being under more pressure from their partner to start a family than from their friends and family, suggesting that in some fertile opposite-sex couples, men may influence their partner to delay until they feel ready (Sylvest et al, 2018).

The difficulty that some adult women with TS face in disclosing infertility to a romantic partner is frequently mentioned in the literature (see section 2.2b). Some women with TS reported that they tended to avoid romantic relationships due to worries about being unattractive, fear of rejection, and fear of being reminded of their infertility (Rolstad et al, 2007). The decision to disclose was perceived as a balance between the risk of losing the relationship and ethical issues such as the partner's right to know. In common with others with a genetic condition that affected fertility (Modi et al, 2010), women with TS often felt responsible for potentially denying their partner the opportunity to have a genetically-related child (Carroll, 2015). People with a genetic illness could face stigma and rejection when disclosing the condition to a romantic partner, so usually considered carefully whether, when and how to disclose (Klitzman and Sweeney, 2008).

2.4g Influences from support groups

The implications of having a genetic illness potentially touch on many different areas of a person's life. A diagnosis can change the way people relate to other family members, future partners, and their attitude to having children; it can prompt lifestyle changes, such as changing job, diet, exercise or managing medication; and it can bring individuals into social relationships with others based on a shared experience of living with the condition. Identity then can be increasingly 'geneticised' (Arribas-Ayllon, 2016) as individuals reflect on the far-reaching implications of their genes on their health and relationships.

Biosocial communities (Rabinow, 1992), such as the patient charities contacted to recruit participants for the present study, may form around a shared health condition: they can provide emotional support, can be a channel for health-related charitable or political action, and can be a source of advice for individuals to increase their health management knowledge. Biosocial groups could also be described as groups which are formed by people who share a trait that puts them at a particular type of risk (Hacking, 2006). Groups can evolve their own collective characteristics and ultimately, as "knowledge of genetic 'identities' will forge social ones" (Hacking, 2006, p88), they can come to define and give meaning to an important facet of an individual's sense of who they are. In this way they can also act as a risk management tool, for individuals learn how to be “skilled, prudent and active, an ally of the doctor” (Novas and Rose, 2000, p489). Biosocial communities can both counterbalance the expert advice that is given by clinicians with a different form of expert knowledge, that of the lived experience of the condition, and can also be a source of normalising pressure.

2.5 Family solidarity and family obligation

The third major theme of this thesis explores whether mothers of girls with TS perceive themselves to have a duty to support her to have a family, and what action, if any, they feel they need to take. This theme is explored using theories of family solidarity, a term which describes the perceived mutual obligations between family members, in particular the normative social expectation that family members have duties to support each other (Finch et al, 2003).

2.5a Approaches to family solidarity

The concept of family solidarity can be briefly defined as “the willingness of relatives to subordinate their *individual* interests – in part, if not entirely – to *collective* interests” (Dykstra et al, 2000). The family exists to care for, educate and socialise children: older members of the family, whether parents or other relatives, are expected to provide emotional and financial support to younger members, in turn receiving care and support when they are elderly (Bengston and Oyama, 2007). The specific type of obligations that apply depends on both the cultural context and individual circumstances (Dykstra, 2010); the basis for family obligation and the degree to which obligations exist has been the subject of much discussion within family sociology.

Functionalist approaches defined family members by the specific roles they played within the nuclear family (Chambers, 2012), but functionalism proved inadequate to describe new family forms, such as the complex network of relationships created through extended families or families headed by same-sex couples. The concept of 'family practices' (Morgan, 1996) developed to account for a more fluid understanding of family. The 'family practices' approach is a useful way to examine both the variety in responses to ethical dilemmas in family relationships, and the way decisions related to mutual obligation are underpinned by an understanding of what sorts of behaviour are appropriate in context of that family relationship. Morgan argued that family belonging is defined by a set of routine, everyday practices that are seen as distinctively 'family-related', such as keeping in touch or providing financial support. The family is engaged with bodily care, nurture, and physical intimacy, and so family practices are visible in tangible expressions of care. When people perform family practices, they acknowledge a family relationship exists and also, by repeatedly taking part in these activities, they build and maintain family relationships. Morgan (2011) acknowledged the circularity of this definition: people who are considered to be family are treated as family; people who are treated as family become family.

The 'family practices' approach looks at behaviour rather than biological connections, viewing a family as a mutual, but fluid and complex, social group, which consequently can encompass a broad range of different types of attitudes and behaviour. This involves more than a set of 'sentiments and obligations, accumulated over long periods of time, that define them to be about family and not some other set of relationships' (Morgan, 1996 p10). Family practices involve 'doing', which links this approach with concepts such as emotional work

(Hochshild, 1983), as family members are required to mask and manage their emotions in some situations, for example, to avoid conflict in a difficult relationship in order to maintain family unity. The family is a setting in which ethics is taught, understood and practiced, and where family members can express and practise views about the 'right thing to do' in family dilemmas or conflicts (Morgan, 2011, p175).

Finch and Mason (2003) explored the idea that family members have obligations to each other, finding that there was normative agreement that obligations existed but not on what the obligations were. Biological kinship provided a context for family obligation, but did not define it (Mason and Tipper, 2008). Instead, specific family obligations were seen as negotiated within the family and subject to family practices, rather than following fixed rules according to the roles a person should play depending on their position in the family. Solidarity forms within a relationship: a sense of obligation may develop through a process of "reciprocal assistance" built up over time (Finch and Mason, 2003 p165), and where support and help flows both ways within the relationship. Because of the close proximity in which they live, Finch and Mason argue, it is more likely that parents and children will develop a sense of commitment to each other, but the process itself can be applied to all types of family relationship. Expectations of intrafamilial support between adult children and their parents could also be guided more by the degree of emotional connection than by social norms; however, this was moderated by shared values regarding the level of support that was thought to be appropriate (Albert and Ferring, 2017). While kinship of origin is ‘in no sense chosen’ (Mason, 2008 p33), suggesting a degree of fixity in biological connections, a feeling of affinity, based on physical resemblance and shared characteristics, could help to reinforce a sense of relatedness, and strengthen a feeling of family duty (Mason, 2008). Obligations are therefore fluid rather than fixed and depend on many factors such as the perceived strength of the relationship between family members (Bengston, 2001).

A further development of the idea of family practices is the concept of 'personal life' (Smart, 2007), a term chosen specifically because it does not have the baggage associated with the concept of 'family' which is perceived as largely nuclear, white, middle-class and heterosexual. Instead family obligations are formed between 'persons not positions' (Smart, 2007, p48). This is a broader way to describe important relationships which are not centred solely around biological kin or marriage, including configurations such as families of choice and same-sex relationships. The notion of commitment is critiqued as too narrow to encompass the richness and depth of a family relationship: it "reduces the individual to a one-dimensional being cognizant only of duty and it robs the person of precisely the realm of the magical and transformatory which imbues much of daily life with meaning" (Smart, 2007 p78). Decisions that relate to family are responsive to the quality of the relationship, which may be "intentional and thoughtful... actively sustained, maintained or allowed to atrophy" (Smart 2007, p48). Smart argues that as well as relating through the realities of interpersonal relationships with the 'family we live with' (Gillis, 1996) people relate to each other through an understanding of the family they 'live by'; in other words, family practices are informed by an imaginary of family life.

2.5b Genetic connections

A counterbalance to family practices approaches, where family is considered to be chosen through a repeated pattern of inclusive behaviour, is the centrality of genetic connectedness to people's choices when using ARTs, and the questions it poses around family belonging.

The biological link has come to be seen as fundamental to defining kinship in Western society, where family relationships based on blood ties were considered to be 'natural' (Strathern, 1992). The close and bilateral relationship between a person's blood ties and their family suggests an almost interchangeable relationship between genes and kinship, as one can so easily stand for the other (Franklin 2013). Until the development of ARTs that enabled gamete donation, which created genetic relationships beyond the social family, the genetic link could be considered as a shorthand way of defining family relationships and the kinship obligations that are assumed to go along with them.

As the use of ARTs became widespread, Rabinow (1992, cited in Franklin, 2013) speculated that their use would effect cultural change around the definition of kinship. Rather than being defined by 'natural' genetic facts, it would come to be defined predominantly as a biosocial relationship, with the genetic relationship having lesser importance. However, this has been challenged by Finkler et al (2003), who argued that, counter to the increasing social focus on individual choice, which emphasises that people can choose family based on affective or socially-created ties, the use of ARTs strengthens the distinction between biological and social relatedness and therefore entrenches the definition of family as based on biogenetic links: "Increasing medicalization of kinship thus subverts […] the ideology of choice regarding the people one selects as one's kin." (Finkler et al, 2003). Genetic links are immutable, so this restricts the definition of family solely to people who are genetically connected. Family relationships based on genetic links have a 'transilient' quality: genes act as a 'conduit of relatedness' (Nordqvist and Smart, 2014) whereby genetic connection "cascades" through family networks, linking everyone who is part of it.

However, people continue to exercise a degree of choice over who they treat as family, both in the context of a genetic relationship, and with family created via the use of ARTs. For example, both gamete donors and recipients have been observed to leverage existing definitions of kinship to create connection or disconnection, such as by defining family resemblances as based on shared experiences and attitudes rather than physical similarity. This emphasises the importance of social rather than biological family (Smart and Nordqvist, 2013; Thompson, 2005). More generally, it is common for people to acknowledge biological family as 'real family', but to also use kin terms to describe emotional proximity, regardless of the genetic relationship (Mason and Tipper, 2008).

This is reflected in attitudes to ARTs. When choosing fertility treatment, maintaining a genetic connection between the child and at least one parent is an important factor in the choice (Hendriks et al, 2017). Leaving aside other deciding factors, such as affordability, if a genetic connection is not possible then an option involving pregnancy is preferred, while parenting options that involve a non-genetically related child are usually not the first choice if another option is available (van den Akker, 2010). The term 'fertility preservation' itself privileges the genetic link, since ARTs that are framed as preserving fertility are aimed at preserving the option for women to have a child with a genetic connection to the mother, rather than the ability to have a child at all: "the very meaning of fertility (and, in turn, infertility) is redefined to emphasize the genetic connection" (Martin, 2011 p540). A social context where the genetic link is highly valued may affect the preferences of women with TS and mothers of girls with TS.

2.5c Perceptions of the mother's role

The present study includes an exploration and discussion of mothers' role in the reproductive choices of their daughters; therefore, it is important to examine the expectations placed on mothers in order to understand the context in which they make decisions.

In Western society, women are perceived as being responsible for maintaining the family's emotional and physical health and for providing care (D'Agincourt Canning, 2006; Dykstra, 2010; Finch and Mason, 1991). Kin-keeping duties such as domestic tasks and related kinds of practical support were largely expected of women rather than men, and this also extends to the mothers' role in caring for children.

Mothers are also held accountable for producing healthy children (Rapp, 2004 p309). Rapp describes how the concept of maternal responsibility operated with her participants, who were pregnant women deciding whether to have prenatal genetic diagnosis, and then deciding whether to have an abortion. She suggests that in a culture where “pregnancy and motherhood are culturally marked as such totalizing female responsibilities […], women’s decisions surrounding prenatal testing take on a weight they might not have if the burdens were more widely and socially distributed” (Rapp, 2004 p308). Other studies of parental reproductive choices suggest that parents of children with a heritable disorder or disability may carry a sense of guilt and responsibility for their child’s condition: for example, Donnelly et al.’s (2013) participants with the heritable BRCA2 gene felt responsible for unknowingly passing on the gene, and also responsible for limiting the impact of their risk once they knew about it. Even though this is not relevant in the case of TS, which is not heritable, the tendency for mothers to take responsibility for their child’s health condition may influence the behaviour of some mothers of a girl with TS.

The current trend towards intensive mothering has widened the definition of good parenting so that mothers are held “responsible for all aspects of their child’s development […] and no cost, physical or otherwise, is considered too great in her efforts to optimize her child” (Faircloth and Gurtin, 2017 p4). These duties include planning for the child’s future (Rapp, 2004). Women are expected to shape their children into the adults that they become, and to aspire to a specific ideal of involved motherhood, even if it comes at a high cost to themselves:

> *“Our understanding of the ethics of maternity and parenting has been deeply influenced by an ideology of motherhood that […] prescribes maternal sacrifice as part of the natural female role.”* (Lowy, 2018, p160).

Although family relationships are conceptualised as relatively fluid and dependent on the quality of the relationship, there is a degree of normative agreement, and gendered, role-based expectations remain evident in attitudes towards mothers. The role of mother appears to be subject to different expectations of agency and obligation from that of other adults. Duncan (2012) argues that the individualisation thesis ‘misrepresents and romanticises the nature of agency’ (Duncan, 2012, p2) by assuming that individuals can make choices outside of social settings. In his research, mothers who had the greatest access to resources which could support them in remaining in work, such as domestic help and childcare, were more likely to choose to become stay at home mothers, at least while their children were young. This behaviour was 'structured by external norms concerning obligations to others' (Duncan, 2012 p9) such as the normative definition of a ‘proper mother’ as one who did not work. ‘Gendered moral rationalities’ (Duncan, 2012, p9) describe pragmatic responses to the pressures on women to be good mothers, by defining the ways in which a woman who worked could still be a ‘proper mother’, in ways which took into account the practical requirements of current circumstances as well as social norms. This supports the family practices approach, which demonstrates that behaviour around family is not only a conscious expression of agency, but also routinised and unconscious, shaped by habit, social expectations and norms.

McCarthy et al’s (2000) work on parental responsibilities found that most parents agreed that looking after their children was an absolute moral imperative, while in other moral dilemmas related to family obligation, there were socially acceptable excuses for not providing support, such as inability, or the person requesting help not being deserving of it (Finch and Mason, 2003). They suggest the moral value of looking after your own children may be “one of the few remaining unquestionable moral assertions” (McCarthy et al, 20 p800). This non-negotiable moral imperative conflicts with the social construction of adults as “in a position to make choices, so that to present oneself as being without choices is to present oneself as powerless and not fully Adult” (McCarthy et al, 2000, p793). The discourse of individualism did not apply to mothers, who were expected to compromise their happiness in favour of their children’s welfare while they were in her care.

Role-based expectations continue to guide family obligations in other family relationships, such as that of grandparents. For example, Mason et al (2007) looked at the role of grandparents in the life of their adult children and young grandchildren, finding that their behaviour was grounded in two conflicting principles, ‘being there’ and ‘not interfering’. ‘Not interfering’ was considered to mark a boundary between acceptable and unacceptable behaviour within the relationship, such as following their adult child's disciplinary rules for their grandchildren. The meaning of these principles in practice was negotiated over time. For grandparents who regularly cared for their grandchildren, the 'hands off' norms of grandparenting came into conflict with the 'hands on' norms of parenting, as they did not feel able to parent in the way they would choose [Mason et al, 2007, p692] Grandmothers more often felt that they had already brought up their own children and did not necessarily want to act in a mothering role with their grandchildren; they were often happy with a more hands-off relationship. The implications of this finding are potentially relevant to the anticipated behaviour of mothers freezing their eggs for their daughter towards their social grandchild.

In the context of TS, several studies show how the TS diagnosis affects mothers and their thinking around fertility. Starke and Moller (2002) suggest that mothers are more likely than fathers to see their role as developing and shaping the child. In their interview study involving 44 parents (33 mothers) of girls with TS, mothers saw it as important to get accurate information about how they could work within their daughter's TS symptoms to achieve this most effectively. Sutton (et al, 2006) interviewed 97 women with TS and 21 parents about diagnosis and disclosure. No gender breakdown was given for the parent participants, but the women with TS who were quoted did not mention fathers in their discussion of infertility disclosure. Parents reported that they found a discussion of infertility particularly challenging and needed support to find appropriate ways to tell their child. Difficulty in disclosure meant that some girls had found out in an unplanned way, which was traumatic for them.

2.6 Conclusion

This chapter has provided a summary of the literature related to TS, first describing the medical and psychosocial impact of TS and its effect on reproduction, then presenting literature and concepts related to the three overarching themes that emerged from the research findings.

TS has a significant impact on the normative trajectory of timing in the life course, especially in childhood, and on women’s ability to comply with norms of reproductive timing. Theories that look at the impact of disability on social timing in general are used to explore the social expectations around family-building placed on both women with TS and mothers of girls with TS.

Next, theories of choice and decision making were described and critiqued. The option to use ARTs for conception or reproductive preservation is often presented as providing women with a choice, but women's choices are limited in many ways: social expectations, perceptions of risk, health, finances and personal responsibility all act to restrict the women’s reproductive options.

Finally, family solidarity theories are used to frame mother's thinking and decisions around their daughter's reproductive options, and to explore the perceived limits of support for their daughter's reproductive future. Although theories of obligation focus more on negotiation, relationship-building and affinity as determinants of mutual obligation, motherhood also has specific responsibilities attached to it which may have implications for mother’s decisions on whether and how to facilitate their daughter’s future fertility options.

While the impact of TS provides a context for the reproductive decisions that women need to make, and the technology available to them, the literature on these topics is heavily weighted towards medical and theoretical papers. For some topics there is very little qualitative research to describe how women perceive the choices available to them, or the reception of the ARTs available.

The following chapter presents the methodological approach to the research.

3 Methodology

Little research has been conducted in the area of reproductive decision-making in women with TS and their families: the technologies that may be available to women are relatively new (e.g. egg freezing) and the condition itself is rare. This chapter will discuss how Constructivist Grounded Theory (GT) was the most effective approach to the research question. It will explain the rationale for taking a qualitative approach, and why this methodology was chosen over others. It discusses the accompanying method, photo elicitation interviews, and shows why it was a good fit with Constructivist GT. It then describes the way the research was conducted, and its limitations.

The present research study seeks to answer three research questions which explore the impact of TS on families affected by it, and specifically on women who have TS, and mothers of a girl with TS. The research questions were:

1. How women with TS perceive and navigate the decision to have a family and the potential associated health risks of pregnancy;
2. How mothers of girls with TS perceive and navigate decisions about their daughter's future reproductive options;
3. How technologies such as egg donation, egg freezing and ovarian tissue freezing are perceived within families affected by TS.

The research questions require an exploration of participants' subjective feelings, thoughts, perceptions and reasoning, all of which align with an interpretative epistemological approach (Bryman, 2012 p26). While there is a considerable amount of medical research on TS, there is very little qualitative, interpretive research exploring the experiences and perceptions of women with TS, their views on fertility, or the impact of TS on the wider family. As well as being an appropriate approach to answer the research questions, a qualitative study is also appropriate to address this gap in the literature.

3.1 Epistemological approach

The present study is exploratory and qualitative. While participatory research approaches are often appropriate for use with minority, marginalised or disabled participants, they were not considered suitable for this study for feasibility reasons. TS is a rare disorder and participants live throughout the UK; travel would have been onerous. Some participants had young children, making it harder for them to be involved consistently. Some participants with TS may have issues with time management and social understanding; these factors were part of the rationale for conducting face to face interviews (see section 3.3). Consequently it could potentially be difficult to meaningfully involve them at a distance. This meant both that on-going participation could be a potential challenge and also that active participation could be restricted for some groups of people whose views were important to the study. Consequently, this approach would be difficult to achieve within the time and financial constraints of a PhD study.

The approach that was taken is informed by Constructivist Grounded Theory (Charmaz, 2014) as a means of studying individuals' perceptions and beliefs about their circumstances. This section describes the epistemological orientation of the research project and why Constructivist GT was used as the methodological approach. It discusses common criticisms of grounded theory and shows both how these have been addressed by the constructivist approach, and also within this specific piece of research.

Grounded Theory (GT) currently consists of three broad traditions: classic GT developed by Glaser and Strauss (Glaser and Strauss, 1967), Straussian GT developed by Strauss and Corbin (Strauss and Corbin, 1997), and constructivist GT, developed principally by Charmaz (Charmaz, 2014).

Constructivist GT evolved as a way to generate theory based on an in-depth, iterative analysis of the data. The data collection method is often an intensive interview, a type of interview where questions are worded as openly as possible, to encourage participants to respond. Data are coded using 'gerundive codes' (words with an 'ing' ending) which code for actions. These identify processes and are intended to draw out emerging stories in the data. Through an iterative process of constant comparison, filtering out codes which are less relevant, codes are refined into categories: collections of codes that have the greatest significance for the analysis. These are then refined into theoretical codes, which integrate related codes to provide a theoretical understanding of the data. Data collection continues until categories are ‘saturated’: no new or relevant data is emerging. Throughout the process, the researcher writes memos: notes which document their thoughts, feelings, ideas and impressions, which are used for reflection and theoretical development. After data collection is complete, the researcher compares theoretical categories against the literature in order to situate the research within it (Kenny and Fourie, 2015).

The present study explores the perceptions and experiences of women with TS and mothers of girls with TS, and the data it produces is personal and subjective. The constructivist view of qualitative research is that knowledge is co-created between the researcher and participant through the relational interactions of a research interview and is a process of shared meaning-making (Riese, 2018). Constructivist GT, a methodology that emphasises the subjective nature of knowledge, is an appropriate way to generate data about thoughts, feelings and perceptions and to describe and analyse the decision-making process (Charmaz, 2014, p17). It is ontologically relativist, holding that knowledge of the world is limited by an individual’s perception and circumstances, and that contextual knowledge can be gained through engaging with them. “’Discovered’ reality arises from the interactive process and its temporal, cultural, and structural contexts” (Charmaz, 2000, p. 524). Although Glaser stated that classic GT is a ‘conceptualising methodology’ that could be used with any type of data and was not directly linked to any epistemological position (Kenny and Fourie, 2015), Charmaz (2000) takes issue with this statement. She argues that when research is defined as a rigorous process of uncovering pre-existing knowledge, undertaken by a neutral observer, this is implicitly an objectivist position: it suggests a belief that there is a truth to be discovered that goes beyond the subjective views of the participants, or the participants and the researcher. Instead, she argues that knowledge is created within the participant's social context and is therefore relative to that specific context and perspective, mediated through the researcher's influence on the process of data collection and analysis. Consequently, attention must be paid to the way participants' experiences and views are given weight and represented, and to researcher's own preconceptions and reflections on the research process.

Constructivist GT positions the researcher, as an individual, as having an unavoidable influence on the research data that is collected, as well as on the way it is analysed; consequently, it is essential for their subjective views and experience to be articulated (Charmaz, 2014, p27). Blaikie (2000) suggests that people tend to reflect on their values and motives only when something happens to disrupt their expectations. The researcher's role is to access or even provoke this reflection: "Researchers must examine rather than erase how their privileges and preconceptions may shape the analysis, but it also means that their values shape the very facts that they can identify." (Charmaz, 2014 p13). Through reflexive processes such as memo-writing, not only are the researcher's preconceptions brought to light, but any expectations based on previous knowledge or experience are purposely disrupted in order to more effectively generate concepts and theories.

Another reason for choosing constructivist GT specifically is that it successfully addresses criticisms of GT as a research approach. Realist critics of constructivist GT, such as Carter (2002) and Layder (1998), critique both the epistemological status of the knowledge, that theory can be generated by participant interviews without putting the findings in context within the field, and its epistemological position, that knowledge is subjective and context-specific.

In classic GT, the literature review is conducted after data collection is complete (Glaser and Strauss, 1967). Layder (1998) contends this approach is flawed, because it generates theory based solely on participants' subjective knowledge, which may not be supported by other evidence. Social science research is analytic as well as descriptive, and this should include the ability for the researcher to describe and evidence participants' logical flaws and false beliefs without appealing solely to the researcher's views. Constructivist GT researchers conduct a brief literature review which is sufficient to be able to proceed with data collection. The purpose of this is to develop 'sensitising concepts' (Blumer, 1969, in Charmaz, 2014, p30), points of departure which give a general direction to the data collection. As the research progresses, the researcher reviews the literature related to each of the theoretical categories that they are developing; creating a full literature review is an ongoing process that begins before data collection starts and continues during the process of analysis, and both informs and is responsive to research findings (Charmaz 2014). In these ways, the research findings are put into the context of other research in the field, and both the participants' and the researcher's positions are clearly located within it. The researcher can show in the analysis when participants take a view which runs contrary to other evidence, or where they may have misunderstandings (for example, about the nature of their health condition). In this study the main literature review was conducted after data analysis, although relevant literature was collected throughout. This was a pragmatic choice: a wide number of topics were discussed during the interviews; some lines of enquiry that initially looked promising turned out not to be relevant, while new topics were raised that had not been anticipated. This approach focused most of the literature searching and review onto literature that was directly related to the research findings.

However, there are several further ways in which Constructivist GT research incorporates other sources of knowledge besides that generated from research data (Charmaz, 2014, p306). Prior knowledge of the field and use of existing theory both have an important role in Constructivist GT and are used as a way to enhance the quality of the work. Existing theory may be incorporated, but is subject to critical scrutiny (Thornberg, 2012). Researchers should take a critical stance to their pre-existing knowledge, approaching the project with 'theoretical agnosticism' (Henwood and Pigeon, 2003). Existing theoretical concepts may provide a starting point for data collection, but they should ‘earn their way’ into the research by demonstrably being grounded in the data itself (Glaser, 1978, in Charmaz, 2014, p153). In other words, researchers should be led towards theory by the data they collect, rather than collect data that informs a specific theoretical perspective. In this study an initial literature review was conducted before data collection to gain an understanding of the challenges faced by women with TS; this and the informal interviews with people with expertise in TS helped the researcher to avoid basic misunderstandings about TS, important given the sensitive nature of the research. They also helped to develop sensitising concepts which were a starting point for the interview questions. For example, it helped to identify that women with TS were reluctant to disclose to a partner (Clauson et al, 2012; Kay et al., 2015; Sutton et al., 2005) and the particular difficulties experienced by mothers in coming to terms with their daughter’s infertility (Collin, 2012; Donnelly et al., 2013).

Grounded theory has also been critiqued because it is argued that social theorists are not using language in the same way as lay participants (Carter 2000, Layder 2005). When lay participants refer to ‘common sense’ concepts such as ‘race’, the shared understanding of what it means may be clear enough for them to be understood in ordinary conversation, but it is not a precise enough basis on which to develop concepts. Further, the language used by participants to describe categories or concepts may omit key aspects of their meaning and context, which is a barrier to theory development (Carter, 2000). These additional factors make an essential contribution to theory development but could not be found solely in participants’ descriptions of practice. Instead they are gained from the researcher’s exploration and knowledge of existing social theory.

However, Constructivist GT theories are not only drawn from the data but are explicitly intended to incorporate the social world that participants inhabit, such as using *in vivo* codes which use the participant’s own words. The researcher looks critically at concepts and categories used in the research data and should ‘examine hidden assumptions in our [the researcher’s] use of language as well as that of our participants' (Charmaz, 2014 p115). When the researcher creates and refines codes, this is a process of interpretation and is subjective: 'we choose the words that constitute our codes. Thus, we define what we see as significant in the data and describe what we think is happening' (Charmaz, 2014 p115). So, while the researcher may use the literature, prior knowledge, and other ways of relating the research analysis to existing social theory, their analysis is ultimately still constructed and subjective.

A further critique of the interpretive approach that Constructivist GT rests on is that lay accounts are partial, because it is difficult for lay participants to set their own experience in a broader historical and societal context (Carter, 2000). Consequently, it is argued the knowledge gained from them is also partial. However, this criticism describes a limitation of research in general; it is the reason research findings are presented in context of other research in the field and is also the reason qualitative research is evaluated against quality criteria. For Constructivist GT, Charmaz proposes using credibility; originality; resonance; and usefulness (see section 3.7) in order to assess how well the conceptual framework of the research fits the data. This study explored topics which have attracted little research attention to date, and consequently there is only a small body of directly-related literature against which to present the social context of reproductive choices, particularly around maternal egg freezing and ovarian tissue freezing. Lay accounts may indeed be partial but at this point in time, they are still enough to produce important insights. Constructivist GT therefore provides an explanatory framework through which the decision-making process of a sample of women with TS and mothers of girls with TS can be described and theorised, and which may be confirmed or superseded by subsequent research.

The method used alongside Constructivist GT was photo elicitation and it was adapted using a Universal Design approach. The approach to data collection is described next.

3.2 Research design and methods

The research strategy describes the approach to answering the research question, including the reasons for choosing photo elicitation as a data collection method and the development of interview material. Any method that was used would have to align with the epistemological stance of constructivism.

Although semi-structured, face-to-face interviews are a standard and highly effective method of data collection, flexible and open enough to enable the participant to express their perspective (Bryman, 2012 p467), other methods were considered, such as the option of collecting data using an online diary study. The following section discusses why photo-elicitation interviews were used in the present study and why this was an appropriate choice.

3.2a Photo-elicitation interviews

A variant of semi-structured interviews, intensive interviewing, is usually used to collect data in a Constructivist GT approach (Charmaz, 2014). In an intensive interview, the interviewer uses open questions throughout to encourage the participant to give their perspective. The interview questions consciously avoid eliciting descriptive information and instead focus on feelings, thoughts and reasoning; the purpose of doing this is that this information is most likely to lead to the development of new theory. The researcher follows up any new lines of enquiry in the interview, and these are then incorporated into a revised interview schedule for the following participants.

Photo elicitation interviews are an adaption of standard semi-structured interviews that include photographs selected by the participant (Harper, 2002). Photographs are brought to the interview and the discussion is, at least initially, focused around them. In this method photos, as well as interview questions, are used to encourage the participant to articulate memories, feelings, and opinions, as prompted by the photos and by the researcher (Harper, 2002). They can be used very effectively in intensive interviews (Liebenberg, 2012), as the way the researcher words their questions takes the same approach to using open questions and focusing on eliciting thought processes and feelings. Harper argues that photo elicitation 'mines deeper shafts into a different part of human consciousness than do words-alone interviews' (Harper, 2002, p13).

Researchers who have used photo elicitation report that most participants find it easy to engage with. Allen (2011) found that, although she asked participants to choose existing photos, some participants were so engaged by the method that they took new photographs as a way to explain a point to her, sometimes planning and setting up shots in order to do this. The time that participants take to choose photos helps them think through what they want to say in advance, meaning they come to the interview having prepared what they would like to say (Liebenberg, 2009).

This method is effective for discussing sensitive subjects (Liamputtong, 2007). It enables participants to share private information in a way which is does not intrude on their daily life, for example by depicting intimate family events which the researcher could not access otherwise (Frith and Harcourt, 2007). It also enables the participant to plan in advance what they want to say and take the lead in the interview by sharing their views, without being prompted by questions (Liamputtong, 2007 pp143-144). In this way, it could be empowering for participants (Clarke-Ibanez, 2004), and in turn this could potentially alter the power relations between the researcher and participant in the participant's favour (Luttrell, 2010). In the present study it was also used as an important part of a range of adaptions (Pauwels, 2015) (see section 3.3).

The images were not included as part of the data analysis. Although different methods of analysing visual material were explored (Konecki, 2012; Mey and Dietrich, 2017) ultimately the results did not add to the interview data analysis because the participant's reason for selecting the image and their feelings about it were already described verbally in the interview. (See Appendix 18.)

3.3 Accommodating potential differences

The psychosocial literature on TS often describes a specific cognitive profile associated with TS (chapter 2 section 2.2b). Some of its symptoms, such as difficulties in social understanding and social anxiety, could potentially make an interview more difficult or uncomfortable for the participant. Women with TS often have a hearing impairment as a result of frequent childhood inner ear infections (Hutaff-Lee et al, 2019), and this may require the researcher to adapt their behaviour to a participant who may be lip-reading. For these reasons, while also bearing in mind that TS is a spectrum and some participants may be unaffected, it was important to consider women's potential needs in advance of the interview, and plan ways in which accommodations could be made.
This section describes the approach that was taken to determine what kind of adjustments might need to be made, and how they were applied in practice.

3.3a Universal design

The approach to incorporating adaptions in this study was influenced by the principles of Universal Design (UD) (Story et al, 1998). UD originated in architectural design practice; it is a process that encourages the "design of products and environments to be usable to the greatest extent possible by people of all ages and abilities" which "respects human diversity and promotes inclusion of all people in all activities of life" (Story et al, 1998, p2). Its intention is, wherever possible, to ensure that the needs of disabled people are always integrated into the design of products, services or buildings.

UD is a set of guiding principles which do not give specific advice on their interpretation and use in different contexts. Perhaps for this reason, it has not always been applied in an inclusive way. Attempts to codify universal design into measurable guidance or standards which are easy to follow have sometimes resulted in designers privileging guidelines over people's experience of using the product, service or building (Ellcessor, 2015). Another challenge is that measures taken to meet the needs of one group of disabled people can sometimes conflict with the needs of another, if the design fails to take into account the diverse nature of disability or to include disabled people's experiential knowledge (Bickenbach, 2014).

UD originated as a practice which was not linked to an epistemology (D'Souza, 2004; Hamraie, 2013; Imrie, 2011). Because its approach to design sees disability as one of a range of human needs which the designer needs to accommodate within a single design, it is a good fit with the social model of disability. This model defines disability as the interrelation between the impairment and the physical and social environment, and the way these factors co-constitute barriers to disabled people (Barnes, 2011). While ‘impairment’ rests on a biological definition, ‘disability’ is due to the effect of an environment which is not adapted to the needs of disabled people; barriers can be removed or alleviated by altering the physical environment, and changing attitudes (Lid, 2014). This places responsibility on the researcher, as the person who designs and conducts the research, to learn about the potential barriers placed on participants by the recruitment approach and data collection method, and proactively make adjustments to alleviate them.

Another important feature of the UD approach is its understanding of disability as a relationship between the disabled person, their environment and the people around them. In the context of a research interview, this sees the relationship between participants and researcher as “a political relationship shaped by relevant power dynamics” (Ellcessor, 2015, Conclusion section). This means the researcher is responsible for proactively making adjustments to their research practice and for responding positively to participants who ask for adjustments. This approach places the potential needs of participants at the heart of the research design, and in de-centring the researcher's role of 'expert', may alter the power balance in the interview in favour of the participant. The constructivist view of qualitative research is that knowledge is co-created between the researcher and participant through the relational interactions of a research interview (Riese, 2018). Removing barriers to communication, where possible, could enable participants to more easily 'give voice' to their experience (Letherby, 2003, pp114-116), which in turn could facilitate a better understanding of it.

There are seven guiding principles of UD (Story et al, 1998, pp34-35), not all of which were relevant to the present research. They are listed in full below and Principles 1, 2, 3 and 6 were applied here:

1. **Equitable use**, meaning the same method could be used by people with diverse abilities.
2. **Flexibility in use**, meaning the method accommodates a wide range of preferences and is adapted to the participant's preferred pace.
3. **Simple and intuitive use**, meaning the method should be easy to understand, require no prior knowledge, and minimise complexity.
4. **Perceptible information**, meaning design communicates information effectively regardless of the user's sensory abilities.
5. **Tolerance for error**, meaning that the design minimises hazards and the adverse consequences of accidental or unintended actions.
6. **Low physical effort**, interpreted as an interview which, while it covered a sensitive and potentially upsetting subject, avoided causing the participant any additional discomfort or fatigue.
7. **Size and space for approach and use**, meaning that the design is accessible regardless of user's body size, posture, or mobility.

Appropriate design requires a good understanding of the implications of diverse abilities in the research context, and particularly in relation to cognitive impairment, where the design should “consider[ing] the variety of human abilities in receiving, comprehending, interpreting, remembering, or acting on information” (Story et al, 1998 p26). The first step was to find out how the distinctive pattern of cognitive issues associated with TS might affect the research design, and the method in particular, by discussing this with experts in TS. This would then enable the method to be adapted in appropriate ways.

3.3b Informal fact-finding discussions

There is a body of published research which describes the symptoms closely associated with TS, briefly described in Chapter 2, Section 2.2a and b. However, even research which directly investigates the impact of related psychosocial or cognitive issues rarely describes whether researchers have made adaptions to the method, or what they have done (Gould, 2013). Academic research papers described the potential issues but did not provide guidance on how the needs identified by the research could be accommodated in subsequent research practice, so this needed to be sourced in another way.

To elicit this information, four informal discussions were arranged with four women with expertise in TS who were experienced in treating or supporting families affected by TS and who understood the potential communication issues across the TS spectrum. They were: two consultant gynaecologists who ran specialist TS clinics, the Executive Officer of the Turner Syndrome Support Society[1], and a young woman with TS who had a child via sibling egg donation. The discussions elicited practical advice on potential issues that could arise and gave ideas for how they could be addressed.

The informal discussions helped to identify the following issues as areas of particular focus: impaired working memory; difficulty in time management; delayed response to questions; social anxiety; poor social understanding; impaired hearing; and a tendency to take words literally, without necessarily picking up on the nuance of humour or irony. Based on these criteria, Disability Support team at De Montfort University discussed the proposed adjustments and made further helpful suggestions.

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[1] She has given her permission to be identified.

3.3c Adjustments

These are the adjustments that were made to the way the research was conducted, in order to accommodate the potential need of (some) participants with TS.

Table 1: Adjustments

Issue	Adjustment/researcher behaviour
Impaired working memory	Providing an interview agenda and consent form in advance; providing key information by video; using participant photos to structure the interview agenda; leading the participant back to the subject if they digress, then using follow up questions to explore their later points once they have finished; allowing for breaks; inviting follow-up emails with any further comments.
Difficulty in time management	Providing an interview agenda and consent form in advance; using participant photos to structure the interview agenda; leaving the interview length open-ended; checking the time available for the interview and focusing on key topics within that time; inviting follow-up emails with further comments.
Delayed response times	Providing an agenda in advance; anticipating that the participant may need more thinking time and waiting longer for a response; leaving the interview length open-ended.
Social anxiety	Providing videos of the researcher; providing an agenda in advance; use of photo elicitation; clear instructions on photo selection; option to have a supporter present; interview location the participant's choice; allowing for breaks.
Social cognition issues	Providing key information in an alternative format, video; sending interview information in advance; using plain language; asking direct questions; avoiding metaphor; verbalising thoughts and feelings normally expressed through body language such as encouragement to speak further.

Hearing impairment	Travelling to the participant’s preferred interview location; sitting in the location they requested; speaking while facing the participant where possible; ensuring mouth is visible; providing a transcript for videos.
Taking words literally	Using plain language; avoiding humour or irony until it is clear this is appropriate; asking one question at a time;

Another reason for considering adjustments to the research method came from a general concern that some mothers of girls with TS may have had access needs. It is common for disabled people not to disclose that they have a disability, particularly if it is related to age, or when the affected person can continue with their day to day life with little interruption (Great Britain. Department for Work and Pensions, 2014). Equally, some women with TS may have had a disability that was unrelated to TS. Both groups in the sample could have benefited from an approach to participation that was flexible, adjusted around their schedule and preferences, and which attempted to minimise the potential emotional impact of discussing such a sensitive topic with a stranger.

One of the limitations of taking this approach to adaptions is that the impact was not measurable; this is discussed further in section 3.9. However, some people did make use of the additional features, such as the video on photo selection. A third of participants cried during the interview; all chose to continue after taking a short break. One participant chose to give additional comments via email after the interview. A third of participants disclosed that they had a hearing impairment in advance; others did not disclose this until the interview took place, such as one participant who said she had a hearing impairment as the interview started. She had already made use of the option to hold the interview at her home, where there was no background noise. Several other participants disclosed that they had either had issues with social understanding or anxiety, and it was helpful to have considered the potential impact of these issues in advance and made plans to accommodate them.

The intention of using a research process that was informed by the principles of Universal Design was to improve the quality of research by increasing participants' ease of engagement with the researcher. This has shown both the importance of planning adjustments in advance and the way consultation with people with expertise in treating and supporting women with TS helped to identify what was needed. Ultimately, the adjustments that were made were found to be useful to some participants (Fearon, 2019).

3.4 Sampling and recruitment

The purpose of the research was to explore the reproductive choices of women with TS and mothers of girls with TS in the UK. Consequently, the initial sample was purposive, and theoretical sampling was used in the main sample to reflect minor adjustments made to the sample of women with TS that needed to be recruited (Charmaz, 2014 p193).

Given that the research questions required an exploration of the views of women with TS and families affected by TS and the impact on reproductive choices, this led the selection of the research sample. It needed to include women with TS who had found out about their reproductive options, and consequently knew and had a view on what was available to them in their personal circumstances. As it is possible to have an informed preference without taking any action towards it, they did not necessarily need to have tried to have a family, but they needed to have considered the options and to have views they wanted to share.

The experience of women with TS was the focus of the research. However, mothers of girls with TS were also included in the sample and the following section explains the reasons for this.

3.4a Reasons for including mothers

There were three reasons for including mothers in the research. The first is that the research explores the impact and reception of new reproductive technology, and one of the technologies in question was maternal egg freezing. This is the mother's reproductive decision about the use of her own genetic material (eggs), taken by the mother either on her own or in consultation with her partner, if she has one.

The second is that decisions about reproductive preservation usually need to be taken while the daughter with TS is still a child. The research explored views on technology such as ovarian tissue freezing and ovary freezing, not currently available to girls with TS in the UK but which has to be done in childhood while ovaries are functional. It also explored egg freezing, which has already been used with some young women in the UK. As parental consent is needed for this treatment, it was important to include an exploration of what parents thought of these options, and the reasons they may or may not choose to use them with their daughter.

The third reason is that evidence suggests that mothers tend to have more of an influence than fathers over their child's reproductive decisions and sexual behaviour and are more likely to discuss sex and reproduction with their children than fathers (Beresford and Sloper, 2000 p82; DiOrio et al, 1999; Hutchinson 2003; McNeely et al, 2002; Ralph et al, 2013; Reay, 1999; Ryan and Runswick-Cole, 2008; Swain et al, 2006). A mother's views about reproductive technology and the importance (or otherwise) of genetic motherhood could influence the choices of their daughter with TS. Her views may also influence the reproductive choices of other children in the family, for example in encouraging a fertile daughter to donate eggs to her sister with TS.

In general, teenagers are more likely to talk to their mothers about sex and contraception (DiOrio et al, 1999). Mothers rather than fathers tend to be the parent who talks to daughters about contraception (Swain et al, 2006). Mothers can influence their daughters over timing of first sex, especially if they have a strong relationship; this can encourage the daughter to use contraception (McNeely et al, 2002), and to engage in less risky sexual behaviour (Hutchinson 2003). Mothers are more likely to be told if their underage child is pregnant and have more of an influence than fathers in their child's decision about abortion (Ralph et al, 2013). Mothers are also more involved in the day to day management of their child’s treatment. When children require additional care, the mother is more likely than the father to take the child to medical and other appointments (Reay, 1999; Ryan and Runswick-Cole, 2008). Children tend to ask their mother more often than their father if they have any questions about their condition (Beresford and Sloper, 2000 p82). Consequently, the mother is more likely both to know the details of her daughter’s condition, and to be making or conveying decisions about it to medical and educational professionals.

In the context of a PhD study, where the number of participants needed to be feasible to complete the study in the time available, exclusion criteria had to be applied. To include partners and fathers could have provided important data about men’s input into reproductive decisions and their attitudes to new reproductive technologies. However, this would have come at the expense of interviewing fewer women with TS or mothers of girls with TS which would potentially affect data saturation. As there is currently very little qualitative research available about women’s views on fertility, fathers and partners were excluded from this study.

In order to speak to women who had considered maternal egg freezing, recruitment needed to be targeted at women for whom egg freezing would have been available, even if there were barriers to taking it up. Egg freezing for fertility treatment has been available since 2000 (Argyle et al, 2016), but the ten-year limit on storing frozen eggs for medical use was lifted in 2008, meaning a mother’s frozen eggs would be available to her daughter in later life, even if they were frozen when she was a young child (HC Deb, 12 May 2008). Similarly, ovarian tissue freezing has only been available for ten years (Jadoul et al, 2010). These were factors in the decision to focus recruitment on mothers of younger girls.

3.5b Inclusion criteria

Taking the above into account, the inclusion criteria for the two sample groups were therefore as follows:

1. **Women with TS**: Women of childbearing age who are currently planning or trying to conceive. Women who have had a family either by adoption, egg donation or surrogacy. Women who had considered the options available to them and decided to remain childless. Women who want children and who have explored different options but for whom there are barriers to taking up one or more of those options.
2. **Mothers of girls with TS**: Women who have a daughter with TS and who have either considered egg freezing on her behalf or have discussed their daughter's fertility options within the family.

All participants needed to be aged 18 or over; this was to include women who were most likely to be facing a reproductive choice in the near future, or who had already done so. As the data collection method was face to face interviews, for ease of access, all participants were required to be based in the UK.

3.4c Phasing

The research was conducted in two phases: the first was a pilot phase with the initial sample of eight participants and the second, the main phase, with the remaining 22 participants. This allowed for the research sample and the interview schedules to be tested and adjusted if necessary.

For the main sample, minor amendments were made to the screening questionnaire (Appendix 4) and the website advertising for phase 2 to reflect minor changes to the inclusion criteria. The inclusion criteria were amended to reflect the adoption of theoretical sampling, which aimed to recruit women whose experiences could extend the findings on sibling donation and on decision making in the context of classic TS. The initial sample attracted more interest from women with mosaic TS, whose experience of TS could differ from that of women with classic TS and who were more likely to be fertile. Few women had come forward for whom sibling donation was an option, but part of the research focus was to explore the impact of infertility on families. The sample needed to reflect the breadth of experience of women with TS considering reproductive choices and to collect data which would answer the research questions.

The screening questionnaire was amended to ask if the woman with TS had brothers or sisters. This was to focus on women who may have had the option of sibling egg donation. It also asked what form of TS she had, because a sufficient number of women with mosaic TS had been recruited in phase 1. The recruitment material was amended to refer to 'classic TS' to align with this, and there were no further changes.

3.4d Sample size

Selecting a sample size for the study required a balance to be struck between the number of interviews it was feasible to conduct in a PhD project, and the number needed to reach theoretical saturation, which can be difficult to predict in advance (Charmaz, 2014 p108).

A crude measure of selecting sample size is described in Mason's (2010) research; this reports that, in 429 doctoral theses which used a Grounded Theory approach, the mean average number of participants was 32, and the mode was 25. While useful, this is not in itself a measure of quality, as the number varied depending on the study topic. Guest et al.'s (2006) analysis of the relationship between sample size and category development found that 92% of the final number of conceptual categories had been identified within the first 12 of 60 interviews. They argue that there is a relationship between the number of interviews needed to reach data saturation, the homogeneity of participants, and the breadth of topics discussed. Charmaz (2014) argues that, when using a process of constant comparison to develop theoretical categories, a small number of interviews is unlikely to be sufficient, particularly where interviews are the only source of data. A larger number of interviews is likely to be required for research where interviews are the only source of data (Charmaz, 2014 p108).

Taking these factors into account, the sample size chosen was 30: 15 women with TS and 15 mothers of girls with TS. This was reviewed after the initial eight interviews were completed and coded, and during the final phase, when the decision was made to interview more women with TS than mothers of girls with TS (in total there are 19 women with TS and 11 mothers). As there were common patterns appearing across a number of interviews in both groups, at this point it was felt that the data that had been collected was sufficient. In the context of a PhD study, taking into account timing, the fact that theoretical sampling had been conducted for the main sample, and the quality and breadth of the data that had already been collected, the sample had reached 'theoretical sufficiency' (Dey, 1999, in Charmaz, 2014, p215). In other words, pragmatically there was enough data to work with, so data collection was concluded.

3.4e Recruitment strategy

Recruitment took place in two phases.

Recruitment of the initial sample (4 women with TS, 4 mothers of girls with TS) began in August 2016. This initial phase was designed to test the effectiveness of the research design and see whether any related topics were raised that might have been overlooked. The Turner Syndrome Support Society, a patient charity which supports girls and women with TS and their families, and Facebook advertising were used to recruit participants at this stage.

Before recruitment of the initial sample began, publicity material was produced both digitally (a project website and Facebook page; appendices 11 and 14) and in print as flyers (see Appendix 12). The Facebook page was a requirement for running Facebook advertising, which was used to recruit both women with TS and mothers of girls with TS (see Appendix 2). Recruitment for the second, main phase of the study used a wider range of print and digital recruitment methods. The researcher attended the TSSS annual conference in October 2016 and 2017 to distribute flyers. For recruitment of the main sample, advertising and recruitment requests were placed in the following locations, as described in Table 2.

Table 2: Recruitment channels for the main sample

Websites/social media	**Paid online advertising**	**Print**
Research project website Research project Facebook page Websites for mothers, such as Mumsnet Fertility Friends Donor Conception Network Twitter, and CRR retweets TSSS Facebook Ragdolls UK Facebook and Twitter	Facebook The Voice newspaper (included website and Twitter)	Article in the TSSS magazine, *Aspect*, April 2017 Flyers at TSSS conference, October 2016 and 2017 The Voice newspaper

The TSSS advised that a summary of the key information, including a project introduction, consent and advice on choosing photos, was presented in video format (see Appendix 10). This was used on the project web site and Facebook page. The aim of using videos was to help prospective participants to establish trust in and familiarity with the researcher, as well as to provide an alternative way for participants to access information about the project.

Snowball sampling (Bryman 2012) was also used. Participants were asked to pass on the researcher's details to other interested parties. This happened several times with members of the TSSS, where the project had been advertised on their closed Facebook forum, and some participants knew each other. This made it particularly important to avoid disclosing who else had participated and what they might have said, as the personal stories of longstanding members were familiar to many in the community. The identity of the mother who had frozen her eggs for her daughter is already known within the TS community (though not outside it). Participants' quotes were curated to avoid including potentially-identifying information and numbers were used to refer to participants, rather than pseudonyms (Damianakis and Woodford, 2012).

Enquirers were sent the URL of a screening questionnaire (see Appendix 4) asking for demographic information to determine whether they met the inclusion criteria, such as their age and type of TS, whether or not they had children, whether they or their daughter had mosaic or classic TS, their progress to date with reproductive decisions, and, if they had children, their family-building method.

No participants from an ethnic minority responded to advertising for the initial sample, so more targeted advertising was developed for the main sample. A paid advertisement appeared in *The Voice* (online and print newspaper) in June 2017, and a Facebook advert was created which linked to the article and used its imagery (see Appendix 2). It is not possible to target advertising by ethnicity on Facebook, so instead it was targeted by geographical location, at urban areas with a relatively high minority ethnic population. One minority ethnic woman with TS came forward as a result, but, as she had not explored any reproductive options, she did not fit the inclusion criteria and could not be included in the study. All the research participants were white.

Some potential avenues for recruitment were discarded as it became clear they were not appropriate. Initially there was an intention to attend TSSS open days and regional group meetings but following discussion with the organisers of some regional meetings, this did not seem appropriate. Meetings are a rare occasion when families could meet with other families who were affected by TS. Girls could talk with other girls who understood what it was like to live with TS. The important social element of these events could have been disrupted if a researcher had been present.

The recruitment strategy produced a sample of 30 women in total, 19 women with TS and 11 mothers of girls with TS. Demographic information about participants is available in Appendices 5a, b and c.

3.4f Sample – women with TS

In total 19 women with TS took part in the research, aged between 21 and 60 (see Appendix 5a). Six were diagnosed at, or soon after, birth. Five were diagnosed aged seven or younger, seven were diagnosed as teenagers, and one as an adult. As diagnosis methods improve, the age of diagnosis is dropping; currently the median age of diagnosis is 7, for women under 25 (see Chapter 2 section 2.2a). Older participants had usually been diagnosed later in life.

The participant's age had an impact on the kinds of treatments that were available to her, as did the way the syndrome had affected her. Growth hormone has only been available in the UK since the late 1980s (Betts et al, 1999); it was not available to four women with TS who took part in this study.

Eight participants were married, five were engaged or had a long-term partner, and six were single. Five participants had children, this included: three women who had used egg donors (two anonymous donors, one sibling donor), one who had successfully adopted after failed egg donation and one participant had conceived naturally. According to some studies, fewer than half of women with TS ever marry (Gould, 2013; Sutton, 2005) compared to 66% of the whole population (Great Britain. Office of National Statistics, 2018). Compared to the wider population of women with TS, the women in this study were more likely to be in a relationship.

Fourteen participants did not have children. Of those, eight had explored fertility options (either as a single woman or with a partner) and had a preferred option but were yet to put this into action for reasons related to their current circumstances, such as needing to save money towards fertility treatment. Three could not proceed with either fertility treatment or adoption for health reasons and had remained childless. One felt they needed more support in order to become a single parent and did not wish to progress at that time. One was still trying to decide between adoption or egg donation, and one had decided not to have children.

Approximately 20% of women with TS have children either naturally or through the use of ARTs (Gould, 2012; Stochholm et al, 2012). Across the general population, 82% of women have children by the age of 45 (Great Britain. Office for National Statistics. 2018). The proportion of women with TS who do not have children, compared to those who do, is reflected in this small sample, although given the age of the participants, becoming a parent was still a possibility for most. Although the sample is not representative demographically, it needed to reflect the breadth of experience of having TS, and interviewing more women with mosaic TS, who were more likely to be fertile, would not reflect the experience of most women. In turn this may not reflect the way women with TS approached reproductive choices.

3.4g Sample - mothers

Eleven mothers of girls with TS took part in the research (see Appendix 5b), and their daughters ranged in age from 5 to 27. The age of the mothers ranged between 33 and 52.

Eight were in relationships with the father of their daughter with TS, while three had subsequently divorced or separated from them. For six mothers, their daughter's diagnosis was made during pregnancy or at birth, four when she was between the ages of 2 and 5, and one was diagnosed aged 15. The average age of diagnosis is around 7, so the daughters of mothers in the present study were diagnosed at a younger age than average.

Two mothers both had daughters who had children: one had twins via egg donation aged 24 and the other, who had mosaic TS, had conceived naturally aged 22. Even though the majority of women with TS do not have children, no mothers participated who had daughters who had reached their mid-20s and who did not have children.

Three mothers had no other children besides their daughter with TS. The remaining eight mothers all had two children or more; two of them had daughters who could potentially become egg donors (for their sister with TS) when they reached adulthood. One mother had frozen her eggs for her daughter's use in later life.

Nine mothers said that their daughters were too young to be actively planning having children, either because of their age, or because they were still in full time education; they had still given thought to fertility, partly due to the timing of treatment and partly because of external deadlines, such as school sex education lessons, which prompted a discussion at home. Most of the mothers in the present study were of an age where they could have frozen their own eggs if they had chosen to, and their daughter could have accessed egg freezing if she had viable eggs. Two mothers had an unaffected daughter as well as a daughter with TS and could give a view on their personal approach to sibling egg donation.

3.4h Strengths and weaknesses of the sampling approach

Most participants were recruited from advertising via TS charities, and most advertising was online. Printed leaflets were distributed at TS conference, a family-focused weekend at a hotel, which may exclude some types of potential participants. As a result, the sample consisted of women who were homogenous in some characteristics. Half of the women with TS were educated to degree level or above and the majority of those in employment were in jobs classified as managerial or white collar (ILM, 2012). Most of the mothers were educated to degree level or above. Of the seven mothers who were employed, six were in managerial jobs or the professions. All but one were living with their partner and children. The mapping between social class and type of employment is not straightforward (Savage et al, 2013), particularly for women, who may have taken jobs that allow flexibility for childcare, especially given the amount of time that may be needed for healthcare management. However, these characteristics suggest that most of the participants were middle class.

TS is a rare disorder and infertility is a hidden characteristic; this meant it was not straightforward to recruit participants. Efforts were made to attract an ethnically diverse group of participants by advertising in relevant publications, but they were not effective. Twenty participants were recruited via TSSS channels, three by word of mouth, three from social media and other online advertising and one each from the DC Network and Ragdolls UK. (Two did not say.)

However, there were also strengths to this approach. Facebook advertising was able to reach a wider group of people than the membership of TS-related discussion groups; some participants were recruited who were not linked with the patient charities or who heard about the study by word of mouth. Although TS patient support groups may often be set up and run by parents (Krawczak, 2017), Ragdolls UK is a patient charity run by a woman with TS, and potentially that may have reached a different group of participants. The adaptions that were available to participants were not described in any detail in the recruitment material, but women who heard about the project via word of mouth may have been encouraged to take part, knowing that their needs could be accommodated. Finally, the concept of 'effective frequency', the number of times a person sees an advertising message before they take action, mean that (up to a point) the repetition of requests for participation in different places may have had a cumulative effect on the decision to participate even if only the final or most memorable prompt was listed (Todri et al, 2020). It is common for health research to recruit participants mainly or solely from patient groups; this can result in a homogeneous sample both in terms of social class and attitudes (Vat et al, 2017). The use of social media (Thornton et al, 2016) and other research strategies (Brackertz, 2007) can help overcome that limitation. One of the strengths of this study is that participants were recruited via a number of different routes.

3.4i Participant numbering

In recent years the process of pseudonymising research participants has come under scrutiny (Damianakis and Woodford, 2012); Lahman et al, 2016). Ethical approval can be dependent on the participants' identity remaining confidential, so participant's real names are rarely used in published research, particularly if it is on a sensitive topic. This leaves the researcher with the task of selecting pseudonyms; yet when participants are able to choose their own pseudonyms, they put considerable effort into choosing names that have personal significance (Allen and Wiles, 2015). Further, names can be suggestive of age, ethnicity and class, and if the researcher selects them, this could impose their view of the participant onto the reader. To avoid this issue, in this study participants are referred to by a reference number.

As some research has suggested that it is more acceptable to participants to describe them by their characteristics, provided the characteristic is not stigmatised (Corden and Sainsbury, 2006), a brief description of the participant's circumstances has been used alongside each quote, avoiding the use of identifying information, e.g. using an age range rather than an exact age.

3.5 Research ethics

This section describes the planning undertaken to gain ethical approval for the project and some of the issues that arose during the data collection process. It was particularly important to consider the ethical issues posed by the inclusion of images in data collection, and the sensitive nature of the research.

The study was designed with reference to the British Sociological Association Statement of Ethical Practice and the ESRC National Centre for Visual Research Methods Review paper (Wiles et al, 2008) which outlines best practice on the use of photos as research data. Ethical approval was received for the data collection pilot phase from the Faculty Research Ethics Committee (FREC) in August 2016 and for the main data collection phase in April 2017 (Application no 1824; Appendix 3).

3.5a Participant care

Because infertility can be a sensitive and potentially painful topic, particularly for women who are considering ways to have a family, steps were taken to minimise the potential harm that could be caused through discussing this topic in depth.

Participants knew the topic of the research in advance, and the subjects that the researcher wished to discuss. Participants were offered options that might increase their comfort, such as the option to have the interview at the participant's home or another place where they felt comfortable, a supporter being present if they wished, and breaks whenever the participant wished, or the researcher felt it might be needed. During the interview introduction, the researcher made it clear that they did not have to answer any questions and gave a suggested form of words to flag that they wanted to move on to another topic.

As discussed above, the research method, photo elicitation, was chosen partly because it empowers participants, which may have given them additional confidence to say when they were not comfortable. Photos provided a focus for the participant, putting them in control of the agenda and enabling them to choose how they wanted to present their experience and its impact on their life.

Participants were provided with sources of support both in the PIS and at the end of the interview. They were referred to Fertility Friends for online peer support, and the TSSS and Fertility Network UK for professional support. They were encouraged to contact the researcher if they wished to discuss any issues after the interview, and the researcher sent them a follow-up email after the interview. Several people responded to this with a request for further information about topics discussed during the interview, such as the success rates of frozen maternal eggs used in treatment.

Some participants may have had the pattern of cognitive impairment and anxiety associated with TS, and this needed additional consideration. The steps taken to plan around this possibility, and their effectiveness, are described in section 3.4, but included taking advice on mitigation from DMU's Disability Advice and Support team, using a screening questionnaire to establish individual interview accommodations in advance, and offering to take the participant through the consent form and information sheet by phone or Skype before the interview. A hearing impairment is a common symptom of TS; the researcher had experience of working with people who lip-read.

A third of participants, most of them mothers of girls with TS, were upset to the point of tears during the interview; as well as discussing fertility, participants also shared other major life events such as relationship breakdown, attempted suicide and stillbirth. These events do not appear in the data chapters but came up in the interviews while discussing the participant's life history. For example, one participant described her suicide attempt, which followed her TS diagnosis in her mid-teens, the start of hormone treatment initiating puberty, and her father's sudden death shortly before this. This was part of a narrative explaining her long struggle to accept the TS diagnosis and take medication regularly. The researcher responded sympathetically, offering support and asking if they wished to continue, pause for a break, or stop the interview. All participants agreed to continue after a break. Once the interview had concluded, the researcher reiterated that support was available and that they could get in touch to discuss the subject again as and when needed. Although nobody followed up soon after the interview, one participant approached the researcher at TSSS conference some months later to discuss some of the issues and feelings that the interview had brought up.

3.5b Consent

All participants were adult women and there were no issues related to capacity to give informed consent. Two consent forms were used with all participants; one for taking part in a recorded interview, and the other for giving permission to use photos in publications (Appendix 7a and 7b). The consent to record form was signed before the interview began, and the photo consent form was signed at the end, when participants were reminded they could withdraw consent for up to a month after the interview if they wished.

Participants were given guidance on what to consider when selecting images to advise them about some of the issues that may arise if photos were shared. Visual data was anonymised according to best practice guidelines (Wiles et al, 2010). Participants were asked to state on the consent form, by signing checkboxes for each option, if they gave permission for the photos to be used for data analysis and/or for publication.

Where participant-generated images included people other than the participant, consent would need to be obtained from these individuals if the image was to be used in published material. This only arose in one instance, where a participant felt able to give consent to share a photo of her late grandmother and herself as a young child. Her reasoning was that as her grandmother was dead, few people would recognise her, and as an adult she was not recognisable from the photo of herself as a child, an example of the nuanced decisions participants can make around photo publication (Wiles, 2008). No other participants gave permission to publish photos that included individuals, even if they were not identifying.

3.5c Accountability

Accountability describes the relationship between the researcher and the stakeholders and the impact of the research; and is considered a measure of ethical research (Shakespeare, 1996).

The research was conducted with the agreement that participants would be sent a summary of the research findings after the thesis has been submitted if they had consented for the researcher to keep their contact details for this purpose.

The thesis was supported by a DMU bursary; consequently, the University is a stakeholder in the research. This funding enabled the researcher to conduct the research without sponsorship from any other parties who might have an interest in the outcome.

Where presentations and publications used the name and branding of the University and the Centre for Reproduction Research, this took place in a formal meeting or conference setting, and the status of the research and researcher was made clear to the audience.

3.5d Data security

Only the researcher had access to identifying data about the participants. Each participant and each piece of research data were given a code (shown in the participant list) which allowed them to be anonymously linked together. The document recording the links was stored in a password-protected folder on the researcher’s DMU data storage space, separate from the audio and photographic data.

Digital copies of the interview audio recordings and photographs were stored in a password-protected space on the De Montfort University network. A backup copy of the audio recordings was erased once the interview was transcribed. Transcriptions of the audio data were anonymised. Three interviews were transcribed by a professional transcriber and three by a colleague in the Centre for Reproduction Research. Neither knew the identity of the participants and both adhered to professional standards of confidentiality, the GDPR and the BSA Guidelines on Ethical Practice.

3.6 Interviews

The academic literature on TS, conversations with experts on the impact of TS and the priorities of women with TS and their families, and patient literature from the TS charities, all formed part of the process of becoming more informed about the kinds of issues that were important to participants. In turn, this informed the development of sensitising concepts which were used as interview topic areas, for example disclosure outside the family, reproductive preservation, and deciding whether to have a family.

3.6a Writing the interview schedule

As the interview was based around images provided by the participant, the order of topics that it covered was led by the participant rather than the researcher, so it was difficult to predict the course of the interview. The development of interview schedules for both groups of participants was a complex and lengthy process.

Two interview schedules were developed, one for each sample group, containing standard introductory and closing text, a set of standard questions to be used with each image, and then a set of questions related to each topic (diagnosis, disclosure, decision making, attitude towards fertility, attitudes towards reproductive preservation, and so on) (see Appendices 5a and 5b).

Two separate participant information sheets were required for the two sample groups (see Appendices 6a and 6b).

3.6b Conducting the interviews

Once eligibility to participate had been established and participants had confirmed that they were willing to be interviewed, they were sent information in advance of the interview, this included an interview agenda giving a brief list of topics that would be covered, the relevant participant information sheet and the combined interview/photo consent forms (Appendices 5a and b). This was to give participants time to think about what they wanted to do regarding consent for sharing the photos they were asked to bring. Although the implications of agreeing to permit publication of photos (such as publicly sharing identifying information that was personal or which other members of the family might consider to be private) were also discussed in the introduction to the interview, participants often brought identifying photographs of themselves, their children or other family members, so it was essential that they considered this in advance. This way, they were able to select items that could be shared if they wished.

All 30 interviews were conducted either at the participant's home (n=17) or at a nearby location which they had chosen (n=13), usually a cafe. The shortest interview lasted an hour, and the longest lasted 3 ½ hours, with most lasting 1 ½ to 2 hours. All of the interviews were digitally recorded with consent; notes were not taken so the researcher could focus on the participant.

Participants were asked to bring three photographs to the interview, to help them express their thoughts and feelings about the research question. Each interview began with a discussion of the consent form and an explanation of what would happen during the interview, with the participant signing to give their consent to participate. The participant shared their first photo and, if they had not sent it to the researcher in advance, a camera phone was used to take a photo of the participant's phone screen or photo, to keep a record. The photos usually prompted a lengthy and wide-ranging discussion about fertility and family that included most of the interview topics. When that came to an end, the interview schedule was used as a prompt for any topics which had been missed. At the end of the interview, the photo consent form was signed by both the researcher and participant; this was done at the end rather than the beginning so the researcher could discuss the implications of sharing any photos (for example those with identifying content), if necessary.

The length and ordering of the topics covered in the interview was led by the participant and the photos that they brought to the session. 172 visual images were collected, rather than the expected 90. Only one participant did not bring any images, while half brought more than three. Some participants brought not only photographs but other items that were meaningful to them, such as poems, songs or their baby book, suggesting that participants engaged well with the method.

3.6c Reflexivity

Reflexivity refers to the researcher's own awareness of, and critical reflections on, the way they may have influenced the research process: the co-constructed nature of qualitative research means attention needs to be paid to the researcher as well as to the participants (Charmaz, 2014). Charmaz identifies one of the benefits of using constructivist GT is that opportunities for reflexive research practice were built in to the design of the methodology precisely because researchers may have "preconceptions that emanate from such standpoints as class, race, gender, age, embodiment, culture, and historical era [that] may permeate an analysis without the researcher's awareness" (Charmaz, 2014, p156). Constructivist GT also acknowledges that the researcher comes to the research with prior knowledge. Reflexivity in the process of using constructivist GT is achieved by the use of techniques which encourage researchers to scrutinise their preconceptions, such as by writing memos (Thornberg, 2012).

Although, like many of my participants, I am a white, middle-class, middle-aged woman, the research interview setting did not put us on an equal footing. I was conscious that participants may feel disempowered in the interview, and potentially unable to challenge lines of questioning that they disagreed with or avoid questions they did not want to discuss. This was part of the reason for selecting photo elicitation as a method; alongside the provision of a research agenda in advance, I hoped that the time allowed to choose photographs and decide what to tell the interviewer would empower participants to feel more in control of the interview.

As I did not share the participants' experience of having TS or being the mother of a girl with TS, preparation was vital: gaining a better understanding of the field, and the challenges that fertility poses within families, could potentially minimise the distress caused in the interview by making me more aware of the areas where I was ignorant and which may be particularly hard for participants to discuss (Berger, 2013). Conducting a brief literature review gave an overview of what was known about fertility and TS and meant I could develop relevant sensitising concepts that informed the direction of the interview questions. The informal discussions with experts were another way to establish that the research was relevant to families with TS. They elicited vital information about the varying perspectives on TS and reproductive choices. These conversations were also invaluable in giving me information about the potential impact of the psychosocial issues associated with TS; this enabled me to make adjustments to the way the research was conducted. It also meant that I was aware of the variation inherent in TS as a syndrome, its potential effect on reproductive choices, and anticipated that participants would have different experiences and views. Furthermore, although the interview was topic-based using open questions to encourage the participant to respond as they chose, the grounded theory approach gave me the flexibility to include issues raised in one interview in later interviews.

I was aware that in some respects I held both insider and outsider status (Merriam, 2001); most participants seemed to want to establish where we stood in relation to each other. As a novice researcher who had never previously met any women with TS, I was an outsider, although, as a woman who has no children for social reasons, I had been in a similar situation to some participants who were single but wanted to have a child with a partner, and others who had no children. Several years before beginning this research I had been a trustee of a charity which recruited egg and sperm donors for people with fertility issues. Through this voluntary role, I had heard of TS but knew very little about it; one of the reasons I was drawn to this research was that it was very different to my previous experience, which I felt may be a useful way to minimise my own preconceptions. I was familiar with ARTs and the kinds of issues that prospective parents faced when using donated gametes. This gave me an understanding of the type of fertility treatment that some participants (mothers as well as women with TS) were contemplating or had been through. Information associating me with this role is easy to find online and I was concerned that this might affect participants' attitude towards me. Fertility can be seen as a core component of an idealised version of womanhood that marginalises other forms of femininity, such as the experience of women who do not have children (Schippers, 2007). There can be negative perceptions that women without children cannot fully understand, or are hostile to, the experience of motherhood (Letherby, 2003).

Ultimately, few participants asked whether I had children or was married, but most wanted to know why I was interested in TS specifically, and whether it had affected anyone in my family. A few participants also guessed that I do not have TS although I am a plausible height for some taller women with mosaic TS. They could recognise from their longstanding experience within the community that I did not have the physical characteristics usually associated with TS; some told stories about how they had recognised other women with TS through these features, and one had even prompted another woman to get a diagnosis because she recognised the characteristics of TS. Although having the 'TS look' is stigmatised, it is also a sign of belonging to the community. Despite having attended TSSS conference twice, and having interviewed many women with TS, I still find it difficult to discern these features; that level of recognition could be considered an 'insider' ability. However, this is an example of the way that being an outsider may have enabled me to elicit ideas and shared understandings which may be taken for granted within the community, but which need to be explained to an outsider.

When researching such an emotional topic, particularly when participants become upset, it was difficult not to have an emotional response to some of the compelling life stories I was told. Some of these stories stayed with me and there was a risk they may have dominated the analysis, overshadowing other accounts which were just as important to the research but expressed in ways which were less poignant (Mauthner & Doucet, 2003). I discussed this issue with supervisors and also took care to ensure the analysis and cited quotes were balanced, reflecting the views of the full range of participants.

3.6d Theoretical saturation

Thirty interviews were conducted in total. In stopping at 30, there had to be a balance between the need to achieve theoretical saturation and the pragmatic requirement to draw data collection to a close at the appropriate stage of the study. Saturation is not a well-defined concept precisely because it is so dependent on how much the participants vary and the breadth of the research question; while some researchers have suggested formulae for achieving saturation (e.g. Francis et al., 2010) it is impossible to be certain whether conducting further interviews would have produced more data. There is a 'cultural residue of larger numbers having greater impact' (O'Reilly, 2013 p195) which exerts pressure to continue. However, when addressing a topic such as infertility, which some participants found very upsetting, it could be considered unethical to recruit more participants than were really required (Francis et al., 2010). The quality and breadth of the interview data that had already been collected was enough to provide findings and develop contributions towards theory.

This section has described the way interviews were planned and conducted, and the next section will move on to discuss the data analysis.

3.7 Analysis

Grounded theory analysis begins with coding, which in this study was conducted using NVivo. Codes are labels that describe what the data is showing, summarise the researcher's understanding of their meaning and provide a basis for further analysis. Each interview is transcribed and coded as the research progresses, and the researcher writes theoretical memos: notes on personal observations about the data and unanswered questions about the relationship between the codes which are the beginnings of a developing theory. These questions and observations are used to direct theoretical sampling - ideas about potential theories which are explored in subsequent interviews.

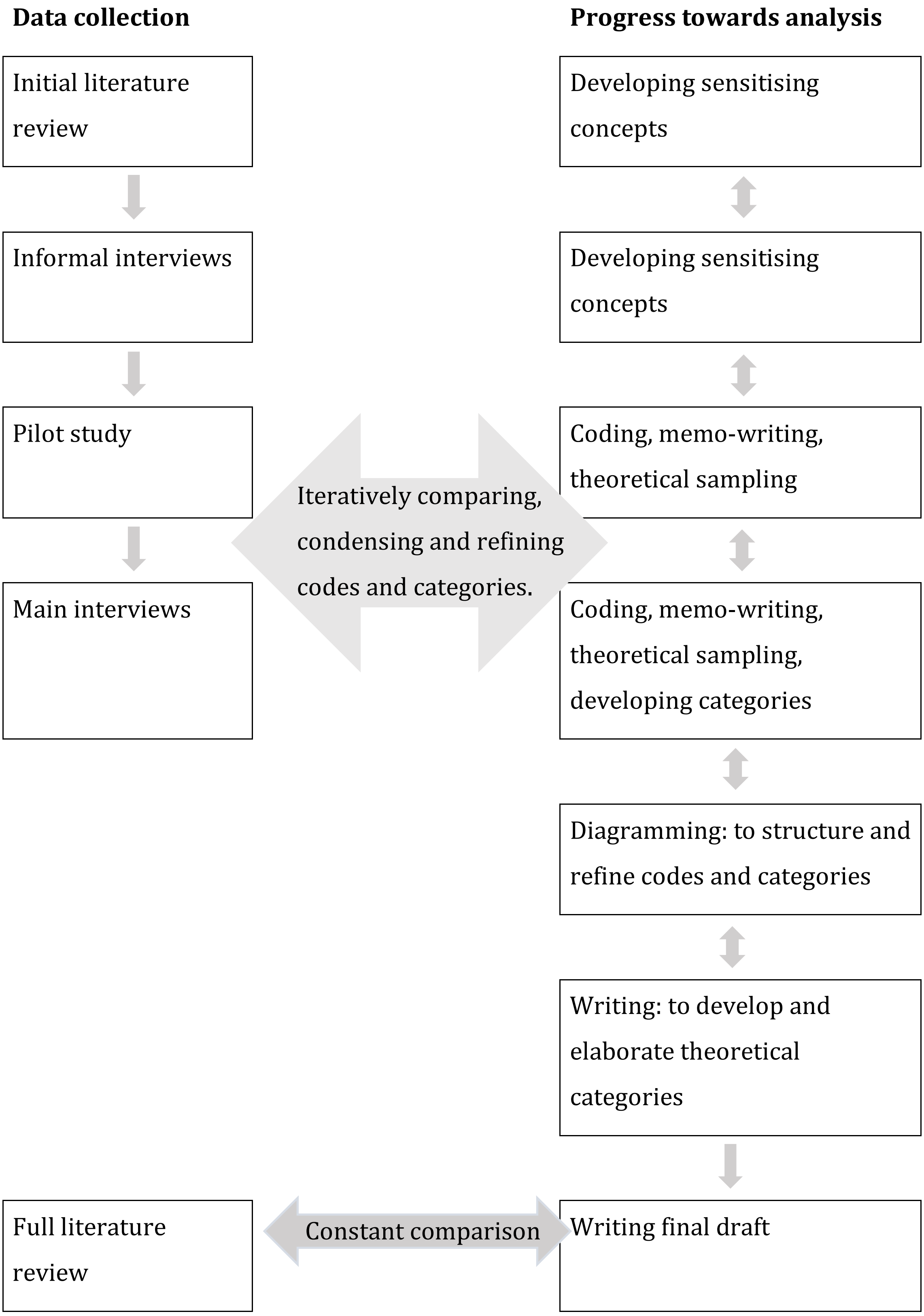
Through a process of induction, codes are then abstracted into categories, groups of codes linked by shared characteristics, including the range of variation within the category. Conceptual categories are selected as being the most important for further development, as they are made up of the most frequent codes in the data and the codes that are most closely related to the research questions. Through an iterative process of comparison between categories and memos, an emergent theory is developed, which is then compared against the existing literature and contextualised within it.

This section begins by giving an outline of how the grounded theory analysis was conducted in this study, goes on to describe the process of writing and refining codes and categories, and then gives an example of how this was achieved.

3.7a Outline of the process

Figure 1 below shows the development of the analysis as the research progressed.

Figure 1: Outline of the analysis process



3.7b Coding

In constructivist GT, coding begins immediately the first interview has been transcribed and continues throughout the study.

Interviews were transcribed and coded in NVivo throughout the period of data collection in order to ensure that any new themes that were identified could be discussed in later interviews. Some in vivo codes were used (e.g. 'Girls with cancer have eggs, girls with TS don't, so ovarian tissue freezing (OTF) might be pointless') but most of the first-pass codes used gerundive titles such as 'Drip feeding diagnosis in an age-appropriate way'. Coding with gerunds is an “heuristic device to bring the researcher into the data, interact with them, and study each fragment of them” (Charmaz 2014 p121). This type of coding is explicitly interpretative: the researcher focuses on identifying the action, feeling or intention that is being expressed in the text. The purpose is to generate codes which identify implicit meaning and processes, as this is more likely to lead to theory development.

In order to group and structure the codes, they were imported into mind mapping software (see Appendices 19a and b). Initially codes were grouped together by category (e.g. under the general heading ’fertility’) and were later extended and refined into conceptual categories (e.g. ’Being a mum in other ways’, which discussed routes to motherhood besides natural conception that included fertility treatment, step-parenthood and adoption, as well as opportunities to show maternal care, e.g. as an aunt). This process facilitated the development of categories by making it easy to identify the volume of codes associated with each category and the range of views held on that category. By referring back to the content of the codes it was possible to see how they were linked together.

Interviews with women with TS were coded separately from those with mothers of girls with TS. In total, the interviews with women with TS produced 576 codes, while the interviews with mothers produced 426 codes. Much of it is not included in the thesis, as a large portion was not directly relevant to the research questions. The rationale for this is described next.

3.7c Data selection

The codes and categories had to be sifted to ensure that the developing theory focused on data that could provide an answer to the research question. This was achieved partly by reviewing the content of the codes and categories and partly by writing up the findings into two summaries which described the data but did not include analysis, and then sifting out the categories that were not related to the research question. Summary 1 looked at the context in which reproductive decisions were made and elaborated seven categories. For women with TS, this was 'keeping control of who knows', 'every step towards motherhood takes courage' and 'other ways of being a mum'. For mothers of girls with TS, this was 'grieving about infertility', 'taking the blame', 'mothering as management' and 'finding the right time'. Summary 2 looked at women's feelings about ARTs and produced a narrative description of the situational factors that acted as barriers or facilitators to reproductive choices, such as the presence or absence of a partner, finances, risk, and intrafamilial influences such as a sense of family duty.

The large number of codes generated in both sets of data reflects that the interviews covered a very broad range of topics. Much of this was not directly relevant to reproductive choices or the perspectives or circumstances that explained them. TS affects most aspects of a woman’s life and the conversation was not restricted to fertility but also included their response to the diagnosis and the impact of TS on education, friendships, and employment. This background information was very helpful for contextualising the data about reproductive choices, but inevitably, a large portion of the data was coded but not used in the analysis.

Topics such as views about prenatal genetic diagnosis (PGD) and abortion for TS, the impact on the mother's relationship with the father of the girl with TS, and much of the discussion of the challenges of daily life are not included unless they had a bearing on reproduction.

The experience of receiving the TS diagnosis was always discussed in the interview by both mothers of girls with TS and women with TS. There were some very poignant and traumatic diagnosis stories, but this topic has also been omitted from the analysis because there did not seem to be a relationship between the experience of diagnosis and the way TS was managed throughout life, either in relation to disclosure or to reproductive choices, which usually did not become an issue until many years later.

Writing up the summaries of descriptive findings particularly helped identify areas which could be sifted out. For example, women with TS and mothers of girls with TS had views in common with other women affected by infertility, such as their general preferences for reproductive options that maintained a genetic relationship with at least one parent, over options that did not. This topic has been described and analysed widely in other research and is discussed here only where directly relevant or if it provides new insight.

There were some codes and categories in common between the two sample groups, such as feelings about being a mother, the relative importance of biological family and its link to risk perception, and notions of maternal duty. These have been incorporated into the theory development, as described in the following section.

3.7d Refining the categories

After initial coding, the codes were refined into categories. These are a collection of related codes that express ideas and findings around the same topic.

Table 3: Categories related to the experience of women with TS

Categories	**Description**
Keeping control of who knows	Strategising around disclosure of the TS diagnosis and its implications in school and work, with friends and partners, for example: Having a standard way to disclose Equating not telling with feeling ashamed Telling anyone new is a big effort
Taking steps towards motherhood takes courage	The multiple challenges faced by women with TS in getting to the point where they are able to have a family, such as barriers to meeting a partner.
Being a mum in other ways	Looking for other outlets for the desire to become a mother, such as being an aunt, working in childcare, having pets.
Balancing different influencers	The way women with TS perceive and manage the pressure from multiple sources (family, peers, in-laws, partner, normative expectations of timing and family-building) to have a family or to choose a particular reproductive option.

Table 4: Categories related to the experience of mothers of girls with TS

Categories	**Description**
Grieving about their daughter's infertility	Feelings about their daughter's fertility issues, and how it affects their thinking around future reproductive options. e.g. Projecting distress about infertility into the future Worrying about what daughter has to go through with infertility Feeling sad about not being a grandparent

Taking the blame	Feeling responsible (or being held responsible) for their daughter having TS
Mothering as management	The enormous amount of management that it takes to ensure that girls with TS get the right medical treatment and an appropriate education
Finding the right time	Addressing the timing challenges of both daughters and mothers being out of synch with peers, such as looking for age-appropriate ways to discuss puberty and fertility with their daughter, planning for school sex education, and discussing (or having) fertility treatment at a much younger age than usual.
Investing in future family	How thoughts about the future inform decisions in the present regarding their daughter's future fertility and family-building options.
Being a dutiful mum	The idea that being a mother involves a particular type of behaviour towards children, and the impact that has on attitudes towards reproductive planning.

Table 5: Categories related to the experience of both groups

Categories	**Description**
Valorising choice	The perception that it is important for the woman with TS to have a choice, or even many choices, of how to have a family.
Negotiating family relationships	The complexities of intrafamilial and intergenerational gamete donation and their perceived impact on social relationships within the family.

Although the data from the two sample groups were coded and analysed separately, they have been combined in the findings and analysis chapters, where it made sense to do so.

The reason for this is that women with TS and mothers of girls with TS have faced some of the same issues but from a very different perspective: both have a perspective on diagnosis, disclosure and reproductive risks. Some issues are separate: women's experience of growing up with TS, their thinking on reproductive choices in adulthood and their view of the options. Mothers had views on maternal egg freezing and other reproductive preservation technologies from a parent's perspective, and the issues raised by mothering a girl with TS.

In order to make it easier to understand the distinct perspectives of each group, data is discussed separately where the experiences are different, and where they are discussing similar issues from a different perspective, they are presented as sub-sections of a single topic area. For example, Chapters four, five and six combine findings and analysis and contain data from both groups, used where it is relevant. Chapter 4 explores the impact of TS on normative expectations of timing, both across the life course (particularly in childhood) and also around relationships and fertility. Both women with TS and mothers of girls with TS have the experience of being out of synch with their peers, and in the first half of the chapter, both perspectives are discussed. The second half of the chapter, which addresses the timing of maternal egg freezing and the reasons mothers might want to do it, focuses on the mother's views, while a discussion of the reception of maternal egg freezing includes perspectives from both groups. This approach was intended to give a fuller picture of perceptions of these experiences, but to foreground the group of participants if they were the most affected.

In this way, the analysis was further developed from the two descriptive findings summaries. Using constant comparison resulted in the categories being extended; some were renamed to more accurately reflect what they were describing. At this point three main theoretical categories were developed which form the final body of the thesis:

1. Timing
2. Decision making and risk

3. Family solidarity

As an example of how the categories lead into theoretical codes, one of the unanswered questions that came out of the pilot interviews was why mothers of girls with TS felt so strongly that they needed to plan for her reproductive future. This is reflected in codes related to the perceived role of a mother, such as 'being a mum means supporting your child through fertility treatment' and 'giving a child the best chance in life is a parent's duty'. This became part of a category 'Being a dutiful mum' which brought together codes related to wider perceptions of the kind of things that mothers 'ought' to do for their children, whether that be related to fertility planning or managing medication. At the write up phase it became clear that a number of overarching factors influenced these perceptions: ideas around what their daughter might want in the future based on often tentative, normative beliefs around a woman's role, beliefs around who should help her, who should make reproductive choices, and perceptions of the role of the family and family relationships in supporting their daughter's (possible future) desire to have a child.

These theoretical categories "integrate and solidify the analysis in a theoretical structure" (Charmaz 2014 p19). They are used to bring together related categories in a way that gives them a form and enables a story to be told around them. The way this has been done in the present study is shown in the combined data and discussion chapters: 4, 5 and 6 respectively.

The introduction to each chapter explains how the chapter has been structured, where the data from the two groups is reported separately, and where the data has been integrated.

3.7e Memos

As required with the methodology of Constructivist GT, memos were written during the process of data collection and analysis (Charmaz, 2014, ch7). As well as aiding the researcher’s reflexive process and theory development, they were made to keep track of key points that participants had shared, to elaborate on codes and categories, and to track analytic ideas. Two edited examples are shared here, the first from women with TS, and the second from mothers of girls with TS.

> **'TS sisterhood'**: the identity of some women with TS was bound up with a group of friends with TS, where they share common traits but also a sense of being intimately understood.
>
> **'Mums want to feel normal too'**: normative expectations of what a woman is supposed to be doing affect women across the whole of the life course, where they are constantly dealing with others’ perception that their situation is negative.

The first memo identified the important influence of biosocial groups for friendship, emotional support and for feeling normal. This is explored in chapters 4 and 5. The second noted issues of emotional work and the pressure to fit in with normative timing, which is explored in chapter 4.

3.7f Integrating the literature review

The last stage of analysis was to write the literature review. By this point the categories were well developed and lent themselves to a selection of specific bodies of literature; for example, the category 'taking steps towards motherhood takes courage' pointed toward literature on the barriers and facilitators to fertility treatment, perceptions of risk, motivators for single motherhood and the influence of a partner in reproductive choices. The category 'valorising choice' pointed towards literature on reproductive responsibility, emotion work around the infertility diagnosis and choice as a way to manage stigma. The constant comparison process was also used in the literature review to ensure that the literature selected was relevant and the analysis was contextualised within it.

3.8 Research quality

While measures such as reliability and validity are considered important for assessing the quality of quantitative research, these are measures that cannot easily be imported into qualitative research (Bryman, 2012 ch17). There are many different approaches to qualitative research quality assessment but Charmaz (2014, pp336-8) developed one specifically for use with Constructivist GT. She defined four quality criteria for evaluating constructivist GT research which are appropriate to the method: credibility, originality, resonance and usefulness.

3.8a Credibility

In the context of Constructivist GT, the credibility criterion relates to the way the research has been conducted and whether the analysis follows on from a description of the findings. In the present study, credibility was established in a number of ways.

This chapter presents a full description of the way the research was conducted, giving justifications for each decision. As described in sections 3.1 and 3.2, the present study used an appropriate methodology to answer the research questions, an appropriate method for collecting data, and developed conceptual analyses based on a thorough foundation of data. This is supported by the very positive response given by participants to the data collection method, photo elicitation interviews, as was demonstrated by the length of the interviews, the number of images brought for discussion, and the deeply personal nature of the information that was shared. Photo elicitation required participants to choose photos in advance of the interview and to think about what they wanted to say to the researcher. The purpose of doing this was to enable participants to consider and share their own thoughts and feelings without being prompted throughout by researcher questions; this may mean the findings more accurately reflect the perceptions and feelings of participants.

The appendices and other supporting documents (such as audio recordings) which document the way that the research was conducted are available along with a description of the development of the analysis. A discussion of the perceived limitations of this research has also been included.

As well as monthly progress meetings with supervisors, and regular audits of writing and concept development, the research project passed a formal review and three annual reviews conducted by a reviewer outside the home research centre. An article on the use of photo elicitation and universal design was published in a peer-reviewed journal (Fearon, 2019). In addition, the researcher has presented at national and international conferences where the methodology, findings and data analysis has been critiqued. This presented opportunities to discover and apply new perspectives and theories and to improve the quality of the research.

3.8b Originality

Constructivist GT research should also contain originality, which can be defined in one of three ways: an analysis in a new area; an original treatise in an established area; or an extension of current ideas (Charmaz, 2014 p189). The present research contributes to knowledge in two of these ways: firstly, by providing a qualitative account of a topic which has attracted very little research attention to date, and secondly, by extending the use of several existing concepts related to motherhood and reproductive choices into new areas.

The present study has produced findings and analysis that have the potential to be useful to other researchers in the field. It has addressed gaps in the academic understanding of how, when and why women with TS decide to have a family and the way reproductive technology is perceived and understood in families affected by TS. It has contributed to a very small body of existing qualitative literature on intrafamilial and intergenerational egg donation. It has explored perceptions of and attitudes to new reproductive technologies such as ovarian tissue freezing. In demonstrating the future-focused thinking around reproductive decision making in the context of TS, it has extended existing concepts based on future imaginaries, such as the application of Kafer's (2013) concept of the curative imaginary to infertility. It has demonstrated the use of Universal Design, rarely applied in reproduction research, as an approach to adjusting research methods to accommodate the needs of participants. Finally, some findings may also be transferable to families with children who have had an infertility diagnosis in childhood for other reasons, as there is little qualitative literature about the use of ARTs, for example, in children affected by gonadotoxic cancer.

3.8c Resonance and usefulness

Resonance refers to the extent to which the research question and findings have meaning for its audiences; when they do, this suggests that the research accurately reflects the wider views within the community and may have applicability to related groups, such as, in this case, other families affected by childhood infertility (Charmaz, 2014). The usefulness of the research relates to its impact: the potential it holds for future research, and its contribution to knowledge.

The present study describes the factors that affect reproductive decision making in the context of TS and how women go about making choices. Although Constructivist GT is primarily directed at developing or extending theory rather than simply describing social behaviour (Charmaz, 2014), research that provides a "thick description" (Geertz, 1973), that is, a fuller description and interpretation of participant's behaviour, feelings and motives, is important for three reasons. Firstly, it may help to increase resonance. A detailed description may enable participants to more easily judge how well the research has captured their own experience and understanding. Secondly, it provides a fuller context; this facilitates a better understanding of the decision-making process, and how and why women make reproductive choices. Thirdly, a thick description is more likely to lead to "thick interpretation" (Denzin, 1989, in Ponterotto, 2006), where the researcher gives conceptual meaning to the participants' experiences. The present study has both described and provided an interpretation of participant's behaviour and thinking, linking it to existing theories and concepts.

Providing detailed descriptions has potential benefits in making it easier for participants and other researchers to understand and relate to the research findings; the full findings have not yet been presented so its resonance and usefulness have yet to be established. Furthermore, establishing the usefulness of a piece of research may be easier for experienced than for novice researchers, as it relies upon them having the ability to evaluate their own work (Corbin and Strauss, 2015). However, the importance of this topic was confirmed by the support received from the two Turner Syndrome patient charities who agreed to advertise for participants: the Turner Syndrome Support Society, and Ragdolls UK. The Donor Conception Network UK also advertised the project after it had passed their own ethical review.

A presentation made to the TSSS Conference in October 2017 was well received and provoked a useful and interesting discussion, but as it took place at an early stage in the data analysis, it only presented a portion of the findings. Participants who have consented will be sent a summary of the research findings after the thesis has been submitted, as will the organisations who helped with participant recruitment, and the findings will be presented to the TSSS. Although the usefulness of respondent validation as a measure of research quality is contested (see e.g. Bryman, 2012, ch17), research dissemination could be considered a part of accountability to participants, and part of ethical research practice.

3.9 Limitations

The limitations of the study relate to the recruitment and targeting of the sample. The age of the women in the sample may have been influenced by the recruitment material, which asked for views on treatment options such as maternal egg freezing (MEF) and ovarian tissue freezing (OTF). These treatments have only been developed in recent years, so women whose daughters were diagnosed as teenagers or older, for whom these technologies were not an option, may have decided not to participate.

Even though over 80% of women with TS do not have children (Gould et al, 2013), no mothers took part who had childless adult daughters with TS. Mothers who participated had daughters who were still children, or whose adult daughters had become a mother either through natural conception, egg donation or adoption. This appears to be a gap in the sample; however, it may be partly the result of targeting the recruitment for mothers at women who had younger children rather than adult daughters.

Although social media was not the only recruitment medium, it has a very large reach (see Appendix 2 for details of advertisement targeting and responses). The demographic of Facebook users is skewed towards younger people (Ofcom, 2015, p8) and this may have biased the sample towards younger participants.

The initial sample of eight participants was recruited using Facebook advertising, the communication channels of the TSSS and snowballing (via Facebook shares and tags, and word of mouth). At the time, it was possible to target Facebook advertising at users with 'Turner Syndrome' listed as one of their interests; this functionality was subsequently withdrawn before the main sample was recruited. This was successful at targeting potential participants, but it limited Facebook recruitment of the pilot sample to women who were comfortable to be open with their Facebook friends that they or a family member had TS. It may have excluded people who were more private or who did not add this interest on their profile.

It is not possible to be certain whether the adjustments made to accommodate potential cognitive impairment had the desired effect of putting participants sufficiently at ease to feel that they could share their thoughts and feelings openly. According to prevalence estimates, communications issues affect approximately 40% of women with TS, and anxiety around 25% (Gravholt et al, 2017). This suggests that 7 or 8 of the 19 women with TS who took part may have benefited from these types of measures. Although the screening questionnaire asked whether participants had any issues that needed to be taken into account in the research interview, most did not disclose other issues in advance, and some may not have disclosed at all. As discussed in Chapter 4 section 4.2b, women with TS made strategic choices about who they disclosed to, and when; most do not disclose if there is no good reason. This may account for the lack of disclosure in this study. The wording of the screening questionnaire may also have had an impact. All participants were asked whether they had “any physical or other disability which might affect the interview”. Framing cognitive issues and social anxiety as a disability may have deterred some women with TS from discussing this before the interview, even though half of them said during the interview that they were affected either in childhood or currently. Women may have been affected to some degree but not to an extent which they considered disabling. Women who were more affected may have decided that they did not want to take part. This reaffirms the importance of discovering participants’ potential needs and making accommodations before the interview took place.

Demographic data collected from participants identified another limitation of the study: the lack of minority ethnic participants in the sample. The incidence of TS is the same across all ethnicities (Dotters-Katz et al, 2016). However, in Sandberg et al's (2018) US-based study, drawn mainly from members of US TS societies, 15% of participants were 'not white' compared to the population of the US as a whole, where 23.5% of the population is not white (US Census, 2018). This suggests that ethnic minority populations may be under-represented as research participants in existing studies on TS (and perhaps also as members of patient groups). In the UK, where 86% of the population is white (Great Britain. Office for National Statistics, 2018), a sample that reflected the general population may have included 4 or 5 participants from ethnic minorities.

Despite using targeted advertising, only one woman with TS from a minority ethnic background came forward and she had to be excluded from the study because she did not fit the recruitment criteria. The requirement for a representative sample in quantitative research rests on the assumption that demographic factors, such as age or ethnicity, may affect people's understanding or experience of the same situation. Qualitative research samples do not have to be demographically representative, as qualitative research instead aims to elicit rich descriptions of participants' perceptions and interpretations of their experience (Hammarberg et al, 2016). The purpose of theoretical sampling is to ensure that the research contains a diversity of experience. Research evidence suggests that people from ethnic minorities may be less likely to participate in research (Redwood and Gill, 2013) although this is disputed by some researchers (e.g. Brown et al, 2014; Wendler et al, 2005) who argue that inclusivity is affected by factors such as trust, recruitment methods and participants' access to researchers.

However, it is not certain that having a broader sample might have made a difference to the research findings: researchers sometimes attribute responses to or decisions about fertility to ethnicity, religion or culture, when they are made by patients from a minority ethnic group, while similar decisions made by majority ethnic participants may be attributed to individual choice and agency (Chattoo, 2015). Access depends on the researcher's ability to access, as well as the participant's willingness to come forward; access can be about an attitude of mind, experience and good contacts in the field (Riese, 2016). A research sample should be made up of participants who are most likely to give answers to the research question, and the findings may have been different if these groups had been present in the sample. A more longstanding relationship between the researcher and the TS community might have addressed that issue.

3.10 Summary

This chapter has given an account of the process of developing a qualitative research project from the original research questions. It has described why the methodology and method were chosen and explained how the research project was planned.

The following three chapters describe and discuss the research findings. Chapter 4 is themed around social and reproductive timing and addresses the way women with TS, and mothers of girls with TS, respond to the timing challenges posed by TS. Chapter 5 explores how and why narratives of choice and responsibility are deployed in explanations and justifications of family-building choices. Chapter 6 examines how theories of family solidarity apply to perceptions and experiences of the use of ARTs and reproductive preservation in families affected by TS, particularly with respect to maternal egg freezing.

4: ‘Governed by time’: TS, social imaginaries, and reproductive timing

This is the first of three chapters covering the three major themes discussed in this thesis. This chapter addresses the way women with TS, and mothers of girls with TS, respond to the timing challenges posed by TS throughout life.

TS has a significant impact on a woman’s ability to comply with social expectations of developmental and reproductive timing. Its impact means that girls tend to achieve some expected growth milestones later than their peers or younger siblings. At the same time, as the majority of girls with TS are diagnosed before puberty, they have to address the challenging issue of infertility at an early age. The experience of non-conformity with the social norms of timing across the life course can lead to an uncomfortable sense of constantly being ‘out of synch’ with peers (Roth, 1963).

This chapter links the concepts (introduced in Chapter 2 section 3) of social imaginaries of reproduction and motherhood with social norms of reproductive timing. Social imaginaries can be defined as "that common understanding that makes possible common practices and a widely shared sense of legitimacy" (Taylor, 2004 p24); they shape shared expectations both that women should become mothers, and the circumstances in which that should happen. These expectations are anticipatory, enabling women to generate an imaginary of their own life course and expectations about their future self, or their daughter’s future. Social imaginaries express shared expectations of social timing by articulating the appropriate points in the life course when particular events should take place, such as the right age for sex education, puberty, onset of menarche, marriage, and conception. By extension, a socially-accepted understanding of the right or appropriate age for these events also means there is a shared understanding of when timing does not comply with social norms. The early diagnosis of infertility can disrupt a child’s imaginary of their future life course as becoming the mother of children that are naturally conceived (Jones, 2020), but the impact of TS and timing goes beyond reproduction.

The first section of this chapter describes the way TS affects timing throughout childhood as well as in fertility, exploring the ways in which women with TS and mothers of girls with TS understand themselves to be outside normative timing. This is framed using Roth's concept of social timetables which describes how life events are understood as a ‘career’ across the life course. As there are many points in which both girls with TS and women with TS do not fit normative expectations of social timing, Garland Thomson’s (2011) concepts of ‘normate’ and ‘misfit’ is deployed to frame the sense of dissonance and stigma that both groups have with their peers, showing how families affected by TS manage and attempt to normalise issues of timing.

Next, Kafer’s (2013) insider concept of ‘crip time’ is applied to reproductive timing in the context of TS, both for mothers and for women with TS. It uses the three components of crip time suggested by Kafer to explore how women with TS and mothers of girls with TS manage the stigma of being 'late' or 'early': strange temporalities, imaginative life schedules and eccentric economic practices.

While social timetables establish ways of looking at time in a social context and account for the pressure to be ‘on time’, social imaginaries guide what people expect to have achieved and consequently the way social norms inform decision making about timing. The final part of this chapter explores the use of imaginaries when mothers make reproductive choices on behalf of their daughter. In this thesis, the concept of the curative imaginary (Kafer, 2013) is used specifically as an analogy for infertility, rather than for the whole syndrome. It is used to examine the way in which normative expectations of reproductive timing, combined with the necessity to make some decisions that affect reproduction while their daughter is too young to express her wishes, can inform mothers’ planning for their daughter’s future reproductive options.

First, social theories about timing during the life course will be used to contextualise attitudes towards reproductive timing.

4.1 Social timing norms

The concept of time as a linear progression through life (Roth, 1963), with definable goals and a socially-defined timetable in which to achieve them, is a useful foil against which to contrast the way women with TS depart from social timing norms. This way of conceptualising time is explicitly competitive, as peers use each other as a measure of their own location along the timeline and progress towards expected life goals.

In the present research, the concepts of 'normate' and 'misfit' (Garland Thompson 2011) are used to show how people whose life experience differs from the normative experience are not neutrally defined as outliers, but instead stigmatised and expected to conform. Kafer (2013) builds on this concept by reframing normative conceptualisations of social timing as they relate to disabled people using the insider term 'crip time'. This acknowledges that disabled people may need more time to accomplish activities, partly because the requirements of their disability are not considered or accommodated in wider society.

The impact of TS almost always affects girls' social timing, to varying degrees, with respect to physical growth, emotional development, and reproduction, when measured against their peers. As this chapter goes on to describe, women with TS and mothers of girls with TS deploy normalising strategies in order to alleviate the social pressure around timing, such as using a different social reference group, and negotiating the timing of important life events to present them as 'on time'.
Kafer uses the concept of 'compulsory able-bodiedness' (Kafer, 2013, p29) to argue that normative ideas of the way minds and bodies work not only hold disabled people to standards which may be unachievable in their circumstances, but more than that, there is a constant expectation to normalise. Disabled people are expected to be aiming to become able-bodied and consequently little attention is

placed on ways to accommodate their needs. In challenging normative measures of social timing, Kafer aims to expand the ways in which disabled people can 'fit'.

In challenging ideas of what constitutes normative timing, Kafer has applied Halberstam's (2005) concept of 'queer time' to disability. This concept subverts normative ideas of timing in order to 'open up new life narratives and alternative relations to time and space' (Halberstam, 2005, p2). The intention is to provide a framing that liberates people who misfit from the oppressive constraints of normativity, and to demonstrate the positive, empowering, and creative ways in which they have found a way to fit.

The concept of queerness challenges normativity of timing, and of expectations around relationships and family building. A queer discourse offers "a competing discourse to the one that assumes reproduction is a focal part of a person's life plan" (Richie, 2016, p368) by rejecting normative expectations of timing, motherhood and reproduction altogether, and instead celebrating alternative life paths, for example, by seeing infertility as a positive thing. The present study involved women who had considered their reproductive choices, and mothers of girls with TS who had thought about their daughter's future options. Most women with TS who took part wanted children themselves and all mothers had considered that their daughter might want to have a family. When women make a choice to have a family or mothers make a choice to plan for their daughter's future family-building options, particularly when this is partly due to social pressure, they are focusing on activities which reinforce, rather than undermine, normative expectations of reproductive achievement. IVF could be seen as a way for people with fertility issues to assimilate with the mainstream population, so this activity could not be considered 'queer'. Yet this conformity is not uncritical or passive: as this chapter describes, even in choosing a normative life path, women have found ways to normalise the circumstances in which they find themselves and subvert normative expectations of timing.

4.2 Timing and TS

Kafer describes three of many potential ways in which crip time could be applied: strange temporalities, imaginary life schedules and eccentric economic practices. The following sections address ways in which they relate to the experience of women with TS and mothers of girls with TS.

4.2a Strange temporalities

Kafer (2013, p35) defines 'strange temporalities' as the way in which expectations of a normative timeline are interrupted in ways which make visible the difference between a girl or woman with TS and her peers; they are points at which she obviously misfits. This was a common experience for both women with TS and mothers of girls with TS.

4.2a(i) Women with TS

This section discusses the challenges for girls with TS in dealing with the issues raised by compromised fertility diagnosed in childhood or as a young teenager, and the way they find support from peers.

The physical growth of girls with TS is often characterised by delay. For girls who are diagnosed as children, often the first sign of TS is that she is not reaching expected growth milestones at health and development reviews (Gravholt et al, 2017). This is a visible way in which girls stand out from their peers; girls remain petite and short by comparison to peers, so throughout life may be treated as younger than they are (Cragg and Lafreniere, 2010). Women with TS in this study described the requirement to take daily growth hormone to reach an average height as another tangible sign of difference, which needed to be explained to the child's school and other carers, not least because the injections cause bruising (Kaptein, 2013) that several women commented was visible when girls changed for school games lessons.

Puberty may also be delayed, either due to late diagnosis, or for medical reasons, in order to allow growth hormone to achieve its maximum effect before bones fuse and no further growth is possible (Bondy, 2007). The social implications of this can be significant (Cragg and Lafreniere, 2010); women in this study described their sensitivity as children that hormone injections could be visible; parents usually informed the school, and additional arrangements needed to be made for holidays and sleepovers.

> *"As soon as growth hormone stopped, I was grateful. That was the big thing that made me stand out, or that made me think, 'OK, I have a thing'." [TSW15: woman with TS, late 20s, engaged, no children]*

> *"Because I had the injections and I did the injections in my thigh, so quite often I'd get a bruise on the site of the injection so my mum, at the start of every school year, when I got a new teacher, she would go in and say to them, 'look…' and she would tell them all about it." [TSW17: woman with TS, early 30s, single, no children]*

Yet the impact of TS also means that girls are facing issues that require emotional maturity far earlier than their peers. Around the age of 7 or 8, girls diagnosed in childhood may be told that they are not able to have a family naturally (Bondy, 2007). They have to face this well before their classmates have to consider their own future fertility. Some women described being told before they were old enough for the implications to be obvious, so while they initially accepted the diagnosis, it was something they thought about as they became aware of the implications over time.

> *"But obviously they'd told me the options in terms of IVF via egg donation and things like that, I was just like oh, OK, when the time comes, that's what I'll do, then. You know, and then just carried on really. You know I think it was only as I got older that I sort of realised more, sort of, how, not necessarily guaranteed it is, and all the other financial implications and all that sort of thing." [TSW17: woman with TS, early 30s, single, no children]*

The impact of finding out about infertility can be devastating, as young women come to terms with issues that can be difficult for grown adults to manage. One woman with TS, who was brought up knowing that she had TS, found out when she was 12 that it affected her fertility. She describes the huge sense of loss that she felt, and the way her feelings were dismissed by the adults around her due to her age.

> *"Because of the way we're brought up, you think you're fertile. It's just something you don't question, you don't wonder if I am or not at 10 or 11, when you first become aware of how things work. So when you find out you're not, it's not – my doctor's attitude is, you never were so you haven't lost anything. You never had any ovaries to lose. But to me, I did. There was children that I was going to have and the grandchildren I was going to have - I lost them. […] I think it's important to understand that you – that it's just the same as for a woman in her 20s or 30s who when she starts trying to have a child, realises that she's got polycystic ovaries or there's some sort of problem or something. And you have to go through that when you're 12, something which women struggle with when it affects them as an adult." [TSW14: woman with TS, early 40s, married, 1 child under 10 via egg donation]*

Some women with TS reported that they had what could be considered 'age-inappropriate' knowledge of fertility, which made them stand out from other girls at school. Puberty is initiated with oestrogen tablets (in the form of the pill or HRT) when girls are under the age of consent, and consequently, if they are open about this at school or with their peers, they may face assumptions about early sexual activity.

> *"People couldn't understand why I couldn't [have periods naturally]. Because I explained that I'd had to take tablets - it didn't mean, you know, it wasn't the same […] It was like, 'oh, are you on the pill?' [disapproving]. You know, 'my mam says you're on the pill'. No, no, no, it's not like that. Because I always tried to explain things to people, thinking that it was just because they didn't understand."*
> *[TSW13: woman with TS, early 50s, married, no children]*

In these ways, 'biological clock time' may be compressed for women with TS, who are often advised to have children younger if possible: a small stature affects the ability to carry a pregnancy and give birth safely, while the degree of any pre-existing heart or blood pressure problems tends to increase with age (Donadille et al, 2019). TS-related infertility potentially puts women outside most of the "paradigmatic markers of life experience, namely birth, marriage, reproduction and death" (Halberstam, 2005, p2) as women are less easily able to conform to normative expectations of relationship and reproductive timing.

TS presents girls and young women with fertility challenges while they are still children which usually do not have to be faced until women have the emotional maturity of adulthood, yet the condition means that girls are often less emotionally mature than their peers (Wolstencroft et al, 2019). In the strange temporality of TS, there is a disconnection between the normative trajectory of emotional maturity and the physical age at which girls learn about fertility issues. Girls may be simultaneously more mature than peers in terms of their life experience, but less mature than other girls their age, due to delayed emotional and physical growth.

Finding the support and friendship of other women with TS is an important way in which women can establish a different temporal fit. Some girls can have difficulties in social understanding and low self-confidence; this is linked to a lack of natural oestrogen, often alleviated when girls begin hormone treatment to initiate puberty (Conway, 2002). This can impact friendship-formation at any age but particularly at school, meaning that girls can be isolated, appear less emotionally mature than their peers, and have trouble fitting in.

> *"It is very stressful. Because you just don't know what to do with yourself at any point in time and you're always – you just don't know how to conduct yourself half the time or you read too much into things: oh, I said this, and their reaction was this, so that means they hate me!" [TSW9: woman with TS, late 20s, single, no children]*

Self-esteem issues associated with infertility and later emotional development mean that women with TS are less likely to find a partner at a young age (Gould, 2013): delay in beginning to have relationships results in a delay in meeting potential life partners.

> *"For me, I just didn't feel ready at the same time as my friends did. They were ready for all that. I was just quite quiet, shy and withdrawn and just happy in my box I suppose." [TSW16: woman with TS, mid-20s, single, no children]*

Roth (1963) describes how a person whose life is not aligned with the expected career timetable for their peers may find a better fit by comparing themselves to a different reference group. Women with TS who took part in this research had friendships at school or work, but most described the special affinity they felt with other women with TS, in particular the friendships they made through biosocial networks such as the Turner Syndrome Support Society.

> *"I felt so much more comfortable than I ever had with people at school, with anyone else I'd met. You just feel totally different. You feel like, they're totally on your wavelength, definitely. I think everyone feels the same. Going to that [TSSS] conference is a totally different ball game. You just feel totally at home, like ahhh! These people get me!" [TSW16: woman with TS, mid-20s, single, no children]*

> *"I think you can understand each other, and you can talk freely about what it means to have TS and how it affects us in our daily lives and kind of a support group as well." [TSW8: woman with TS, mid-20s, single, no children]*

In this way, a shared experience of misfitting creates a shared experience of fitting, showing that fitting is not only about the mismatch between the material body and the environment, but could also refer to the mismatch between neurotypicality and the characteristic pattern of neurodivergence related to TS (Gravholt et al, 2017). One woman with TS who was in her late 40s commented on the impact of improved medical treatment for the signs of TS and better support for girls with TS and their families in the 25 years since the TSSS was set up.

> *"I suppose their issues are getting more and more in line with their peers in what they do and when they do it, whereas probably in my day you did hit those milestones but they were probably later on than everybody else, you know, because I didn't really have a serious relationship till I was in my 30s, which is probably a lot later than my peers – well, I know it was. So, you know. Whereas the girls now, the women now with Turners, there's a lot of the women that are in relationships now in their 20s. It's great! It's absolutely great. And I think that's because of the society and the support." [TSW12: woman with TS, late 40s, married, no children]*

Girls and women with TS may experience temporal misfitting in many ways, such as having the physical appearance of being younger than their peers due to their height, and facing fertility issues earlier than their peers, but involvement with TS-focused peer groups is a way in which they can experience fitting. As the condition is now better understood, girls who had several of the characteristic conditions associated with TS could require numerous medical appointments. The intensive, regular nature of monitoring and treatment could become a management issue for some mothers, as will be discussed in the next section.

4.2a(ii) Mothers of girls with TS

For mothers of girls with TS, a sense of misfitting could begin when their daughter was a baby, and as she failed to reach the expected growth milestones for her age group.

> *"That's what made her different, was that she was just so much smaller than other people. There was nothing else different about her, she was normal in every other way." [TSM7: mother, mid-40s, married, 1 daughter and 1 son in their early 20s]*

In common with women with TS, mothers could feel different from their peers who were parents in having a child whose growth trajectory (and, sometimes, behaviour) did not fit the normative schedule. "Misfitting demonstrates how encounters between bodies and unsustaining environments also have produced segregation" (Garland Thomson, 2011, p4). Having less in common and being unable to share the challenges of parenting in the same way made some mothers feel distant from social groups based around parenting.

> *"I was part of an antenatal group here, I am still friends with the four mums, but none of them know what we are going through, or how we felt on a day to day basis." [TSM9: mother, early 30s, married, 1 daughter and 1 son under 5]*

> *"I also worked out pretty quickly which friends could cope with it and which friends couldn't. Like some just, you know… and that was surprising because it wasn't always someone that you expected." [TSM6: mother, mid-30s, married, 1 daughter and 1 son under 5]*

Mothers frequently described the intense nature of the scheduling and planning work they felt was required in order to manage their daughter's condition. The open-ended nature of a TS diagnosis (see Chapter 2, section 2.2) also made this challenging, as it was not always clear which of the large number of the characteristic features of TS may affect their daughter in future, or to what degree, a factor which made it hard to estimate the 'workload' involved. Mothers could feel they were driven by a schedule and deadlines over which they had no control, partly as they had to manage the medical appointments that were needed for different aspects of their daughter's condition.

> *"So, between the medical side and the school side, and then the sheer amount of appointments we go to. I mean, ours seem to be clustered together, so our daughter's first 6 weeks of school, I think she had 6 appointments to go to, and that in itself, I feel like I have a lot of information in my head about our daughter and her health and the people we have to see and the questions I need to ask and the things we need to know and pre-empting things might happen […] I feel like my head is full quite a lot. [laughs]" [TSM9: mother, early 30s, married, daughter and 1 son under 5]*

> *"I think she had 13 medical appointments in 12 months, whilst having a baby [sibling], and there's not many people you can leave a new born baby with [...] I was just trying to get through day by day week by week, when is the next appointment." [TSM6: mother, mid-30s, married, 1 daughter and 1 son under 5]*

Their schedule was both reactive, based on their daughter's response to treatment and her emotional maturity, and anticipatory, based on when her classmates started to reach puberty, the timing of school sex education lessons, and the point at which their daughter and other people might start to understand and ask about the implications of TS.

> *"There is that element of thinking about it for her, trying to foresee what the stumbling blocks might be and deal with them before they become a problem. I suppose it's a kind of, it's not even wearing, it's just... [sigh] next! Nothing is straightforward, and it would be nice for her if she could just, you know. Even with her tablets, how many tablets does she need? It's the constant thinking of, when's she going to have a break from oestrogen, is it going to be in the summer holidays or not?" [TSM1: mother, late 40s, married, 1 daughter, 1 son in their mid-teens]*

Kafer remarks, "rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds" (Kafer, 2011, p27). Mothers described how they managed timing challenges by prioritising. Fertility was not always a priority for some families while their daughter was a young child. Some mothers said that their day to day focus was not on the future, but the present: the demands of the girl's ongoing medical and educational needs absorbed most of the mother's attention. Instead, they explained how future fertility needs and the conversations that would need to happen around them were rescheduled to a point in the future when external circumstances made it more of a priority, and when the girl had more emotional resilience. For example, one mother had told her daughter that she had TS but had not discussed the fertility implications. She had been planning to tell her for some time, but her daughter had social anxiety and she wanted to time it at a point when it would not seriously affect her school work. As another mother commented, there was an awareness that telling needed to be done in a timely way, to avoid more difficult situations:

> *"One of the mums who hadn't told her daughter - she had told her about Turner Syndrome, but she hadn't told her about the fertility side - and it ended up coming from another girl at school." [TSM9: mother, early 30s, married, 1 daughter and 1 son under 5]*

Prioritising, then, was linked to the mother's 'workload' of managing TS: the number of issues she could cope with at any given point, and her assessment of what her daughter could cope with, both had an impact on when an issue would be addressed, and whether or not it could be deferred to the future.

Mothers described the challenge of finding the 'right time' to discuss important matters such as puberty and fertility with their daughter, and the need to find 'age-appropriate' ways to do so.

> *"It's difficult because you wouldn't talk to any other 14-year-old girl about how they're going to have a baby. [...] you know I don't discuss with my [unaffected] 12-year-old how she's going to have children or whether she's going to have children." [TSM3: mother, mid-40s, married, 2 daughters in their early teens]*

The need to have these conversations several years earlier than anticipated could cause discomfort, but it also required mothers to consider ways to convey potentially upsetting information to a child who may be less emotionally mature than their peers and perceived to be less well-equipped to be told. In having to approach the topic of fertility at a much earlier stage than they expected, mothers were conscious that they were not doing this at the ‘right time’, or necessarily at a time which was right for their daughter.

> *“So, for example our friends that are looking for an egg donor, I’ve said to her, that’s what our friends are doing. When we’ve got to that page of the book [‘Recipes of how babies are made’], that’s how they’re trying to have a brother or sister for their little boy.”*
> *[TSM10: mother, mid-40s, married, 1 daughter under 10]*

There was a general agreement that this needed to be a planned conversation because of the potential for their daughter to be upset.

> *“You've got to know how you are going to tackle it and how you’re going to approach it and when, and I am not saying that I know, that I've got a specific time line, ‘by the time our daughter is 6 so I am going to have told her’, but I know the next coming years, it’s got to be the topic of conversation.” [TSM9: mother, early 30s, married, 1 daughter and 1 son under 5]*

Providing information to their daughter about how her body worked sometimes gave her, by comparison, much more information than other girls of her age. Mothers were conscious that other adults may have a view of the ‘right time’ for a child to know about sex and reproduction, and how being perceived to have inappropriate levels of knowledge for their age could make a girl stand out.

> *“I was pulled aside because my daughter had too much information. They’d overheard her explaining something to another girl at school and they thought that was far too much information about the workings of the human body at whatever age group she was.”*
> *[TSM7: mother, mid-40s, married, 1 daughter, 1 son in their early 20s]*

In common with other mothers managing a child's health condition (e.g. Silverman, 1987, chapter 10) this mother felt she would have been criticised if she had not disclosed the TS diagnosis while her daughter was young yet was also criticised because her child knew 'too much'.

Several mothers responded to this issue by trying to manage classroom discussions of fertility in ways that made it more inclusive of infertility and delayed puberty, for example by talking to teachers in advance of school sex education lessons, to ensure the content related more closely to their daughter's circumstances. There was an understanding of sex education and puberty as a shared experience by a class of their daughter's peers in which their daughter could easily experience either fitting or misfitting, for example by managing assumptions that every woman could have children and that all the girls would need a period pack, or by being asked personal questions about the way her body worked. In this way mothers responded to normative timing by creating normalising narratives which supported their daughter in feeling that she belonged in her peer group.

> *"I want them to word something which goes something along the lines of 'not everyone will have babies naturally and that's okay, and there are lots of different families and different options, and IVF is possible for people'. I want that in there, but I don't think it's in there as part of the conversation […] Maybe that's why they feel different: because everything is always delivered as an 'average person' conversation. I just wish it was more inclusive, and I don't think it's an inclusive conversation for everyone." [TSM11: mother, mid-30s, separated, 1 daughter and 2 sons under 10]*

One mother had a daughter who explored egg freezing when she was a teenager but went into early menopause before she was able to proceed. She had accompanied her daughter to a fertility clinic for a fertility assessment when she was a young teenager and felt conscious that they stood out in the waiting room, as the typical patients were adult women, usually in heterosexual couples. She commented:

> *"But they were adults there with their mothers, and most of them were there with their partner, and I'm there with my 14-year-old daughter waiting to speak to someone about fertility treatment. You shouldn't even be thinking about having babies!" [TSM7: mother, mid-40s, married, 1 daughter and 1 son in their early 20s]*

She was conscious that the desire to preserve some reproductive function, if possible, had to be balanced against the physical and mental health stresses of having treatment.

> *"If I'd had my time again, I think that I would have insisted on some form of counselling… […] She got it when she was told at 14, it's too soon [for egg freezing]. And by the time she was 15½, 16, she was told it was too late. And then the world came crumbling down, just in her GCSE year." [TSM7: mother, mid-40s, married, 1 daughter and 1 son in their early 20s]*

For mothers, 'strange temporality' meant that as their daughter's social and physical development misfit with the socially expected schedule, in turn they misfit with peers who were mothers of unaffected children and whose growth and social development hit the expected trajectories. Mothers had to address issues they had never expected to consider with young children, for example in having conversations about fertility much earlier than the usual age. Mothers described how they coped with this by thinking of the work required to accommodate misfitting as a series of sometimes very challenging management tasks. In order to avoid becoming overwhelmed or overwhelming their daughter, some mothers prioritised and schedule the issues that needed to be addressed, deferring others to a later date if they could.

4.2b Imaginative life schedules

The second application of crip time described by Kafer (2013, p38) relates to the ways in which disabled people need to navigate or renegotiate their relation to time and timing based on their current or perceived future needs. This section focuses solely on women with TS and examines their approach to managing a disrupted life course.

Kafer argues that prioritising health or self-care can be a subversive act in a social setting which requires conformity to the social norms of timing based around productive, paid work. There are three ways in which TS delays or disrupts adult women's anticipated life pattern of marriage and children: relationship formation; disclosure of fertility status; and finding alternative pathways to parenthood. When women do not fit into the schedule expected of them, they have to construct an alternative way of understanding life progression through adulthood, and accounting for it to others.

Normative reproductive timing, based around the idea of the biological clock (Pasqualotto et al, 2008), affects women with TS because they are part of a wider peer group which, having reached adulthood, begins to focus on family formation and its perceived prerequisites. Having a partner is seen by many women as a precondition for having children (Sol Olafsdottir, 2011); there is a strong link between having a spouse or partner, and having a family (Berrington, 2017). Berrington's analysis of the British Cohort Study 1970 showed that 80% of childless women who were not married or living with a partner at age 30, and who expressed a wish to have children, did not have children by the age of 42. It is not always easy for women with TS to meet this precondition, as they tend to be late in forming relationships compared to their peers and to form relationships less often than the wider population (Gould, 2013). This, in turn, has a potentially significant impact on their fertility options.

Like many women considering pregnancy, most women with TS would prefer to have a partner first, yet relationship formation can be a barrier. For some women, the social cognition issues and anxiety associated with TS could affect their ability to initiate and build relationships, making it harder to get to know a potential partner in a dating setting. These participants described the impact of having a high level of social anxiety on their approach to dating:

> *"When I say about the social anxiety, I do panic about what people think of me all the time. I go away once I've met them and think, I've embarrassed myself. […] It [online dating] made me go, you know, no. This is making me so anxious and sick with anxiety that I just – I'm just going to cut this off. I'm just going to not message them and get on with life for a while." [TSW16: woman with TS, mid-20s, single, no children]*

> *"I've always been quite awkward around boys, and that's sort of… not an alien species sort of thing but I've never been able to completely feel relaxed in that sort of situation." [TSW17: woman with TS, early 30s, single, no children]*

Even if women did not have anxiety, the need to disclose the TS diagnosis and its fertility implications could present a barrier to them having a relationship. Women felt it was likely that a partner would want a biological child, so the conversation they needed to have about this was described as a likely point where the relationship might end. Sometimes women had never had a relationship or had never had one which had reached the stage where fertility and family-building became part of the conversation. Five women with TS said they pre-empted the possibility of rejection by repeatedly avoiding relationships that were likely to develop this degree of intimacy.

> *"I wouldn't want to take that from somebody else, that choice. So, it has blocked, it has definitely put a block or a barrier in that way, definitely." [TSW1: woman with TS, late 30s, single, no children]*

> *"I kind of let my husband get in because he had children. Probably it made me keep men at arm's length because I knew that if they were going to be with me it would have to be without children and how could I ask them to do that, it's a big ask, it's a huge ask. Was I going to be enough, you know?" [TSW12: woman with TS, late 40s, married, no children]*

Many women had developed a strategy for disclosing that they had TS, both in social settings and within relationships, which helped them decide when to tell, and enabled them to feel in control of the disclosure process.

> *"If I have a good relationship with someone then I would… you know, if it come up then I'd talk about it, but I wouldn't openly go, hey, this is my situation. Yes. [laughs] So it depends. Sometimes I'm very secretive – not secretive but careful about the things that I choose to say and who I would say it to." [TSW11: woman with TS, mid-20s, engaged, no children]*

> *"I never sort of openly come out and say it – it comes out in conversation about something else… because you can very easily bring it into a conversation when somebody else says something about children, about family, or you know somebody might even ask, do you have children, and at that point you can either just say no, and leave it at that, or you can say no, because I have… and you can decide then if you're going to say something." [TSW12: woman with TS, late 40s, married, no children]*

In a dating and relationship setting, because of the perceived risk to the relationship, women thought carefully about the right time and circumstances to tell a partner. This varied from within a few days, to several years, depending on how comfortable they felt and the level of their mutual commitment.

> *"I think I felt when the relationship started to become a sexual one, talk of contraception comes in, and I felt that was the time to disclose really." [TSW2: woman with TS, late 20s, engaged, no children]*

> *"We were coming to the point where it would have been unkind not to tell him. We were looking at buying a house and stuff, so…." [TSW5: woman with TS, mid-30s, cohabiting, one child under 10 via egg donation]*

According to Roth (1963), the schedule of the life course is perceived as a natural progression. However, this definition of the life course is itself socially constructed and therefore open to negotiation and reinterpretation. In the present study, this can be seen in the way that women revised their views on timing, and the ordering of life events prior to becoming a parent, as they shifted their 'time perspective' in relation to the barriers and facilitators in their own life. Women responded to the challenges of relationship formation by adapting their priorities: while the option to get pregnant, or to adopt, may have a time limit, there was no time limit on the possibility of meeting a partner. This was one reason why four of the five single women with TS who took part prioritised becoming a parent over forming a relationship.

> *"I'm not averse to the idea of a relationship at all, but for me, if I had to choose between a child and a relationship, the child would come first. I suppose that's just how I feel. I could cope with being single for the rest of my life. I don't know… I think I would find it very difficult not to have a child at some point." [TSW17: woman with TS, early 30s, single, no children]*

> *"When I've read stories of other people with Turners, relationships are a problem. That was something that is always – it doesn't always happen. So that is something I have to be realistic about and I'm OK with that. If it's just me [bringing up a child as a single mother], that's OK." [TSW9: woman with TS, late 20s, single, no children]*

Two further women with TS had explored adoption while they were single; one was unsuitable for health reasons and one had decided not to go ahead.

Lahad (2012) argues that because women are culturally expected to be chosen by a man rather than actively choosing, singleness is characterised by waiting for a suitable partner to arrive. Singleness becomes more stigmatised the longer a woman is perceived as having to wait, putting women under pressure both to become a mother and to find a partner. In the face of this difficulty, women who believed that, ideally, they would meet a life partner and have a child afterwards were prepared to make compromises to the timing of finding a partner: some single women with TS chose parenthood before a relationship with the child's father, if they were not in a relationship at the right time for them, or chose adoption as a single parent.

> *"I'm not going to wait around and find that I've missed – find that I'm 70 years old and I go, I didn't do it. You know, I could wait to meet the right guy and that might never happen, whereas I can adopt and know that I have control over that – I can do it. So, I don't mind doing it on my own." [TSW9: woman with TS, late 20s, single, no children]*

> *"I was like, I'm tired of that, I'm tired of trying to find a partner because I'm not good at it. I'm not good at picking guys. I just, I think that it works just by myself, so I'm going to do it just by myself. So I started looking into options. [...] One of the advice [I got] from the girls with TS is that it doesn't matter if you are ready, it's harder for us to even get to the point where we can have kids, so with or without a partner, if you're ready for it, go for it." [TSW8: woman with TS, mid-20s, single, no children]*

Most women with TS who took part in this study felt that for most people, fertility was a factor in choosing a partner, and this affected their feelings about whether they would be able to successfully form relationships. Some responded to this by adapting their preference to favour having a child before meeting a partner, while others circumvented issues of reproductive timing by finding a more compatible partner: one who already had children, who was happy to adopt, or who did not want a family. In this way they responded to being single by finding ways to make the timetable fit them, rather than passively waiting (Lahad, 2012).

Kafer suggests that crip time challenges 'the normative modalities that define time, such as productivity, accomplishment, and efficiency, as they urge us to something different' (Kafer, 2013, p40). Another way in which women with TS adapted to the possibility of not becoming a parent was through non-parental relationships with children. While some women with TS struggled with the emotions brought up by spending time with children or seeing friends and family become parents, others expressed pleasure in these relationships and in particular with being an aunt.

Participants who were aunts understood that 'involved aunthood' (May and Lahad 2018) was a bounded relationship which gave them a defined, non-parental role in the life of a child in their family, but one which enabled them to experience spending time with and looking after children.

> *"It's not obviously the same as being a mum, but it's just lovely to have them in my life, you know, and to be very involved like that." [TSW2: woman with TS, late 20s, engaged, no children]*

> *"I used to spend a lot of time with the girls when they were kids and that, running round, sleeping over, then my mum coming in and next morning and we were like this [mimes being flaked out] on the sofa because they'd kept us up half the night talking and messing around, and then up and wanting breakfast. Oh, it was all good fun. I got the most out of them, definitely." [TSW13: woman with TS, early 50s, married, no children]*

Most women with TS took part in this research had considered their reproductive options because they wanted to have a family (see Chapter 3, section 3.4), so women who did not want children were not well represented. For the sole participant who described herself as child free, aunthood was as much of a relationship as she wanted to have with children, a boundary that was within her control.

> *"Being an auntie of so many kids, [laughs] not being able to have kids of my own is something that I never felt I am missing out on, on anything, because I get those days when I am surrounded by kids, I have even done nursery runs, school runs, all that kind of thing." [TSW18: woman with TS, early 30s, in a relationship, child free]*

Women with TS who took part in this research valued the role of parent rather than rejecting it outright. Four women with TS approached the barriers to having a family at the expected time by looking at alternatives, such as forming a family as a single parent, either through adoption or through ARTs, rejecting the expectation that they would passively wait to be in the right circumstances to have a family. Others were able to enjoy having children in their lives through their relationship with nephews and nieces, either as a prelude to family-building themselves, or in its own right. As other research on early diagnosis of infertility suggests (Jones, 2020), women varied in the way they managed the implications of TS and imagined other, positive futures for themselves that did not always involve motherhood. Strategising around the timing of disclosure of fertility issues was one action which enabled women with TS to feel more in control, and potentially less vulnerable to rejection based on their fertility status.

4.2c Eccentric economic practices

A third component of crip time suggested by Kafer (2013, p39) relates to the creative use of resources for people whose circumstances mean they cannot obtain what they want or need in more traditional or normative ways. Kafer relates this to a rejection of expectations that disabled people should be economically productive members of society through having paid work even though many are unable to take employment. Instead, she describes how disabled people turn to alternative means of payment or income generation, such as bartering or co-operative living, as ways in which they can balance health needs with a low income. Participants in the present study also took a resourceful approach to identify non-normative ways in which their daughter could have a family.

While it is common for parents to consider their children's future financial security, and for example, to start a savings fund for college, mothers of girls with TS were conscious that their child may need costly fertility treatment to get pregnant. Several mothers said that, having discovered that their daughter was infertile, they were saving up for her future treatment; if she did not want it, the money could have more conventional uses, such as for a house deposit.

> *"We'd already said, there's money aside, we will put money aside and we will save and if our daughter wants IVF, that's what she'll have." [TSM5: mother, mid-30s, married, 2 daughters under 10]*

Kafer defines resources more broadly than simply referring to money: as disabled people may look to their social network for mutual aid, women with TS, like other infertile women, sometimes drew on their social and familial networks, and the strength of their social ties, in order to find an egg donor. Three mothers had considered having another child who could potentially become a sibling egg donor, or had discussed with an existing daughter whether she would consider this option. One mother, whose daughters were in their early teens, described her daughters' response to this suggestion.

> *"When we thought about having another child, we thought if we had another girl then there's a possibility that she would donate an egg to her sister, and they've talked about it. But she's [daughter with TS] like, I'm not doing that because it won't be mine. She's very much, no, it won't be mine. […] I just sort of casually talked about just so it's almost sort of in their heads for when they are older." [TSM3: mother, mid-40s, married, 2 daughters in their early teens]*

The present research shows that, within the TS community, maternal egg freezing is emerging as a potential solution to concerns about the difficulty of finding an egg donor while at the same time enabling a woman with TS to keep a genetic link with her child. The decision-making process and relational complexities of maternal egg freezing are addressed in Chapter 6, but when eggs are considered as a resource, the benefit to the mother is the security of knowing that the eggs are available in the future and the mother has done as much as she can to help her daughter achieve motherhood in later life; the benefit to the daughter is a knowing that genetically-related eggs are available to her if she wants to use them.

However, maternal egg freezing is time-sensitive: the mother needs to have viable, healthy eggs, which is more likely when she is young. An age limit of 36 applies to donors who cut the cost of treatment by sharing some of the eggs they collect with another woman; in exceptional circumstances, known donors may be older if they are still fertile (Great Britain, HFEA, 2019, Section 11.3). At the time this treatment takes place, it is likely that her daughter with TS is still a child, who does not have a full understanding of the implications of infertility.

> *You can't, in five years' time, go, oh, I'm ready for that. And at the time, I probably was 31 at the time of diagnosis, I would say it has taken me a good three years, I definitely needed to get over our son's first 12 months, and within our daughter's, within the five years of her life, [various serious family events happened]. It just seemed to be one thing after the other. [...] It's probably more of a timing issue than anything else, I would say. [TSM6: mother, mid-30s, married, 1 daughter and 1 son under 5]*

There are significant advantages in using frozen maternal eggs: it can solve difficulties in finding a donor, enable women to know their donor, and maintain a genetic connection between the recipient and her child (ESHRE Task Force, 2011). These are intangible benefits that cannot easily be translated into a financial value. Yet deciding on this option requires a mother to project her daughter's future family-building wishes many years into the future and make decisions that are outside of the normative timing and setting for using reproductive technology. These challenges set her apart from the normative mothering role of her peers.

A future focus was also evident in the way that participants discussed the potential of reproductive technology to provide future options for family building – an example of the way in which ARTs act as hope technologies (Herbrand and Dimond, 2018). Most women who took part expected current fertility technology to be expanded in new ways. Almost all were enthusiastic about the potential of ovarian tissue freezing, even while expressing concerns about the procedure. For example, some were concerned about the potential side-effects and timing of the procedure, as it might need to be performed when a girl with TS is very young, and about how much choice the girl herself would have. Two participants talked about the future prospect of using artificial eggs generated from the woman's own skin cells, which would then enable her to conceive a genetically-connected child. Both ovarian tissue freezing and artificial eggs would avoid the potential complication of using a family donor while performing the double function of enabling the woman with TS to experience pregnancy and also producing a child with a genetic connection to her. This would normalise not only reproductive timing (as there would be no delay in finding a donor) but also would align the child's biological and social relationship with both parents.

The mother of a young girl with TS put forward another suggestion which would rely on community self-organisation: that mothers within the TS community could freeze their eggs and store them in an egg bank to share with unrelated women with TS in later life. This cache of eggs generated through biosocial links could cut the cost of finding a donor and avoid the perceived 'weirdness' of mothers donating eggs directly to their daughters.

> *"Maybe that's what we should do as mums, we should just put our eggs in an egg bank and say, let's just swap them around the community for people with TS. […] it would probably lower the cost though if we all said we'll freeze our eggs." [TSM11: mother, mid-30s, separated, 1 daughter and 2 sons under 10]*

Garland Thomson (2011, p604) directions attention to the 'productive power of misfitting', where the experience of misfitting enables people to identify creative ways to overcome the barriers they are presented with. This creative thinking was evident in the range of options that participants mentioned as potential solutions. However, the faith expressed in ARTs may fall short of its ability to deliver results. Viable human eggs have yet to be generated from stem or skin cells (Adashi et al, 2019). To date, ovarian tissue freezing for girls with TS has not resulted in a pregnancy (Donnez and Dolmans, 2017). In addition, the financial cost of these procedures can be significant. Maternal egg freezing necessitates spending a large sum of money for treatment at a private clinic and then paying annual storage costs for frozen eggs, at a time when a young family's budget may be constrained. Unlike Kafer's original conceptualisation of 'eccentric economic practices', which gives examples of ways in which disabled people can extend resources beyond financial limitations, the cost of maternal egg freezing puts this treatment out of reach for many families, and the same is likely to be true of other options that require the use of reproductive technology. Each of the options that participants suggested are ways to provide physical resources which enable women with TS conceive a child, but which come with a large financial cost attached.

In recent years, the normative reproductive timetable has been affected by social changes that have emphasised the importance of achieving life goals, such as finding a long-term partner, before having children (Huinink and Kohli, 2014). As a cohort, women in the UK are having their first child at a later age than previously (Berrington, 2017). Increasingly there is a disconnect between biological fertility – the time when a woman is most fertile and physically able to carry a child - and 'social fertility' – the time when it is socially acceptable for her to have children. Martin (2017) uses the term 'social fertility' to refer to the structural circumstances that enable women to have a child. She describes how some women see biological timing as being mismatched with the social conditions that allow them to exercise choice over reproductive timing, arguing that fertility is not only an attribute of the physical body but is related to factors such as employment, financial security and relationship status.

Martin's findings are a reminder that a reduced reproductive capacity is not the only barrier to having a family: many women misfit because their reproductive schedule is delayed due to age, finances, lack of access to fertility treatment, or lack of a partner. In this wider context, the family-building challenges faced by women with TS have notable similarities to other women; women who are considering freezing their eggs, for example, are often doing so to extend their reproductive schedule in order to achieve other goals first, such as finding a committed relationship (Baldwin, 2016, ch6).

This section has addressed Kafer's conception of crip time and the way it applies both to women with TS and mothers of girls with TS. 'Strange temporalities' related to the way in which the non-normative timing of physical and emotional development and the need to address fertility issues meant that both women and mothers misfit with the experience of their peers. 'Imaginative life schedules' described the way in which women with TS negotiate the challenges of non-normative reproductive timing. 'Eccentric economic practices' explored the way in which mothers of girls with TS planned for their daughter's reproductive future. This has presented a picture of the way that women with TS misfit when compared against normative expectations of social timing, and the way they and their mothers found ways to manage this.

The following section describes the way that ideas of a future cure link with other future imaginaries to place social pressure on mothers to consider reproductive preservation technologies.

4.3 The curative imaginary and reproductive futures

This section examines how mothers of girls with TS navigate reproductive timing issues around maternal egg freezing (MEF) within a broader cultural narrative of reproductive chrononormativity (Freeman, 2010). It explores how mothers' thinking about their daughter's choices is led by social imaginaries about the centrality of fertility to womanhood, and an imaginary of motherhood which may mean they have a strong personal sense of responsibility to address the effects of TS on their daughter’s fertility. All of the mothers in this study were aware of MEF as an option and four of them said they would have frozen their eggs if they could. Four more were ambivalent and the remaining three would not choose MEF themselves. The response of women with TS to the option of MEF is discussed in Chapter 6.

Social imaginaries "incorporate[s] a sense of the normal expectations we have of each other, the kind of common understanding that enables us to carry out the collective practices that make up our social life" (Taylor, 2004, p24). In the context of disability, the concept of the curative imaginary describes the shared understanding of disability as a condition that ought to be treated or remediated, and explains the social pressure placed on disabled people to always be looking forward to a cure for their condition. The focus on the future embedded in this concept has a particular resonance for fertility, which, like disability, is time-sensitive and dependent on context. Thinking around families is often future-focused as people have expectations about their own children having children or the possibility of making their own parents into grandparents (Crabb and Augoustinos, 2008; Nordqvist, 2017). The child is often used as a symbol for the future: arguments around reproductive futurity can be mobilised towards different and sometimes opposing goals. Eugenics has been practiced to prevent disabled women from having children and disabled children from being born; arguments about the 'wellbeing of the child' are deployed to support prenatal genetic diagnosis and therapeutic abortion (Rapp, 2004; Kafer, 2013, pp29). Yet fertility preservation and ARTs can facilitate conception and pregnancy in a woman with TS, which could then enable her to take her place in the family line and to have descendants. Reproductive technology can broaden the family-building options available, meaning that rather than being restricted by infertility, a woman's future could expand in a number of different directions.

The curative imaginary also manifests as hope that a medical solution will arrive in the near future: most participants mentioned that developments in reproductive technology may provide a means for women with TS to have a safe pregnancy and a genetically-connected child. The reference to these perceived benefits of experimental or novel technologies, such as ovarian tissue freezing or artificial eggs made from stem or skin cells, demonstrate the future-focused nature of thinking around reproduction.

The use of social imaginaries shows how women use expectations around motherhood and the life course to anticipate the consequences of their daughter's infertility, envisaging her future life both with and without children. A focus on the future was evident in the way mothers talked about MEF, particularly when trying to anticipate what their daughter might want or need in later life. There are two factors which particularly affect the way mothers respond to the option of maternal egg freezing: anticipated regret, and mandated motherhood.

4.3a Anticipated regret

Anticipated decision regret (Tymstra, 2007) describes the process whereby decision making is informed by the prospect of regretting the outcome in the future. Mothers had given considerable thought to ways in which they could help their daughter to adapt to a future where intervention was required in order to have a family, and to a potential future without children. They felt grief about their daughter's infertility, and worried about how she would come to terms with this in the future. Their sadness was often triggered by their daughter's behaviour when playing with dolls or interacting with other children, as well as by other people's normative expectations that she would be able to conceive naturally and would choose to have children in the future.

> *"Even yesterday, waiting for the trip, a friend was teasing her about her fringe: 'oh, when you're a great grandmother you'll…' – you know. They were laughing about her fringe and the first thought I come up with is, even if she ever does, they're not going to have her genes, and I think maybe she feels it too, because she gave me a little look." [TSM4: mother, early 50s, cohabiting, 1 daughter in her mid-teens]*

> *"I am not saying that she is not ever going to have her own family, cause in one way or another she might, but the fact that it is going to be a struggle and the fact that she is going to have to go through the pain and the heartache initially, I think, is really upsetting. […] the way she is trying to jig him [her baby brother] or rock him to stop him from crying are exactly the things I do. So I guess I see her as a mini-mother, and that's why I think to myself, I would assume that she would want children. But obviously as she is older, I won't make that assumption, it is her choice." [TSM9: mother, early 30s, married, 1 daughter and 1 son under 5]*

Mothers' consideration of the various ways in which they could support their daughter in having a family was motivated by the anticipation of her future disappointment in not being able to conceive naturally, and a desire to ease the potentially difficult reproductive journey that she might have to face as an adult. The projection of their daughter's future pain was an important factor in considering whether maternal egg freezing was a viable option. However, as discussed further in chapter 6, it was not a clear-cut choice. Some mothers worried that, whatever they decided to do, there was a risk that it would turn out to be the wrong choice.

> *"It just seems really big and I can't… but then I have mixed feelings because if I… she ever comes to me and says, why didn't you do that, it's too late. You then haven't given her that option." [TSM6: mother, mid-30s, married, 1 daughter and 1 son under 5]*

> *"I would probably go the other way, and that is that if they get to 20, and you haven't done it at four, and they're saying why didn't you do that..." [TSM8: mother, early 50s, divorced, 1 daughter under 10, 1 daughter and 1 son in their 20s]*

These concerns are evoked by projecting their daughter's perceived expectations into the future: the worry that their daughter might be angry or disappointed that genetically-related eggs were not available to her and would hold her mother responsible. The large time gap between collecting and freezing maternal eggs and their use, coupled with their daughter being too young to express a view at the point when eggs needed to be frozen, added complexity to the choice, and also made it harder for mothers to anticipate what their daughter might want. Tymstra (2007) notes that people can find it difficult to say no to using medical technology, partly due to concerns that they might look back with regret if they do not make use of it. Maternal egg freezing presents a potential solution to a problem, and because it is available, whether to engage with it can become a dilemma, no matter how small the percentage likelihood of success. This type of reproductive preservation requires a time-sensitive intervention, so it was not possible for mothers to take a laissez faire approach. Consequently, half of the mothers who participated were conflicted about rejecting the option of maternal egg freezing, even when they were doubtful about its use:

> *"In my own circumstances I was glad that it couldn't happen. If it had been possible and it was something that our daughter wanted, I would have done it, probably against my better judgement, and maybe lived to regret it." [TSM7: mother, mid-40s, married, 1 daughter and 1 son in their early 20s]*

> *"I know it is a dilemma, but I think if I had been in that position, I wouldn't be ruling it out." [TSM10: mother, mid-40s, married, 1 daughter under 10]*

In a pronatalist social context, where mothers are expected to make provision for their daughter, where a failure to plan for the future is perceived as a failure of mothering, and where the use of ART is considered a potential 'cure' for infertility, each of these factors can result in mothers feeling pressure to use maternal egg freezing even if they are not completely comfortable with it. The availability of maternal frozen eggs provided insurance for the future, in that genetically related eggs were available, but it could also defer the dilemma of whether to use them or not into the future, shifting the burden and responsibility of choice from the mother onto the daughter.

4.3b Mandated motherhood

Mandated motherhood (Gillespie, 2000) refers to the social expectation that motherhood will be a part of life for every adult woman, and where motherhood is understood as a core part of women's social role. Normative expectations of women are that they should value maternity and become mothers (Hudson, 2019).

The expectation that disabled people should be working towards a future cure mirrors the presumption, central to the idea of mandated maternity, that infertility is an undesirable condition which must be alleviated (for example, through adoption) or treated (through the use of ARTs).

Most participants commented that, whether or not they felt that maternal egg freezing was an appropriate or acceptable option, they assumed that mothers who froze their eggs were motivated by maternal love and a sense of maternal duty, thus seeing it as a logical part of the role of mother.

> *"I think it's coming from the right place, from a place of obviously love and again wanting to do the right thing and giving a gift to the girl." [TSW12: woman with TS, late 40s, married, no children]*

Mothers of girls with TS felt it was part of their role as a parent to plan for their daughter's future. This meant both in preparing her emotionally for a non-normative reproductive journey, and by anticipating what she would need to facilitate her future reproductive choices. Some mothers framed fertility and motherhood as an expectation that their daughter would have in adult life, and that meeting that expectation meant they needed to take action in the present. Mothers, then, are under pressure not only to support their daughter while she is growing up but, after a TS diagnosis, may also feel responsible for helping to secure her reproductive future. This mother froze her eggs for her daughter, reasoning that she would regret it if she was not able to offer her daughter the choice:

> *"I can remember thinking, how am I going to look her in the eye when she's 20something or 30something and she says, 'mum, no one's doing egg donation. Have you seen the length of the waiting list?' I found myself thinking, 'I can't look her in the eye saying, don't worry, somebody will donate for you', if I don't do what I can, when I can." [TSM1: mother, late 40s, married, 1 daughter and 1 son in their mid-teens]*

Friends and family can also put pressure on mothers to think about future fertility options, for example by discussing fertility in normative ways that anticipate that her daughter will want to have children. One mother described how various people in her immediate social circle had raised the topic of intrafamilial egg donation for her daughter, who was five.

> *"Someone once said to me, 'wasn't it a shame that you didn't have two girls.' And I was like, 'what? I didn't even know that they [sisters] could donate.' […] It's like you're making decisions for two-year-olds and they're going to be adults who make their own decisions. […] And other friends have said to me, oh do you think maybe her cousins… Other people are thinking about it, but I wouldn't." [TSM6: mother, mid-30s, married, 1 daughter and 1 son under 5]*

There was an awareness of the compromised reproductive potential of the woman with TS from the point of diagnosis onwards: mothers knew that their daughter may need to address fertility issues in the future. Both mothers and women with

TS talked about their desire to provide, or have, as close to a ‘normal’ experience of conception and pregnancy as was feasible given the potential barriers.

> *“You want to experience the pregnancy and have the baby from when it’s born, and you want all that, and there’s nothing wrong with it. I get it. […] it’s the closest to normal giving birth as you’ll ever get really, if you’re in a position where you can do that.”*
> *[TSW9: woman with TS, late 20s, single, no children]*

> *“It would then be your baby and you’d have that experience of the pregnancy and things like that.” [TSW11: woman with TS, mid-20s, engaged, no children]*

Pragmatic considerations limited some mothers’ choices. For example, one mother explained that was she was too old to freeze her eggs, so she and her husband were saving for fertility treatment for their daughter instead. Furthermore, some options were beyond the mother’s sole control. Several mothers had tried to conceive a second daughter who could potentially become an egg donor for their daughter with TS but had not been able to achieve this. Mothers were aware that sibling egg donation would require consent from both daughters, and even if one was willing to go ahead, the other might not.

When considering the future, mothers did not only consider motherhood, but also envisaged different future pathways for their daughter. Several mothers said that their daughter may decide to be child free. The mother of a girl with behavioural issues suggested she may find it difficult to find a partner in adulthood, and that she may not be approved to be a solo adoptive parent. Due to the potential risks of pregnancy (discussed in depth in Chapter 5), others said they would be relieved if their daughter decided not to pursue assisted conception. The challenge was that mothers were not able to predict how their daughter would respond to being infertile, nor could they predict what a future partner might want, so they could not protect her from future heartache.

When mothers talked about the possibility of their daughter having a pregnancy, they talked about the difficulty of establishing the risks of treatment in the future.

> *"You're kind of on this roller coaster […] because obviously there's more information and research coming out all the time, and then when I realised she would be able to have children, that she could carry a baby and all that side of things, then you know – oh brilliant, brilliant! And then you find out that, actually, they have much higher risk of all these other complications during pregnancy and your hopes are slashed again." [TSM10: mother, mid-40s, married, 1 daughter under 10]*

The difficulty of establishing the risk meant it was difficult to make a decision, particularly if the implications also related to the disposal of the mother's own genetic material. Some mothers felt overwhelmed by the complexity of the decision, and the different challenges this might bring in the future.

> *"What if she doesn't want to use your eggs? What happens to those eggs then? Do I give them to other people? I don't know." [TSM6: mother, 34, married, 1 daughter and 1 son under 5]*

There is currently no cure for TS, so egg donation could be viewed as a normalising treatment enabling a woman with TS to get pregnant and then become a mother in the same way as other women. Underlying the mothers' discussion of their daughter's future choices was the feeling that she may want to have a family and that therefore attention needed to be directed to helping her achieve this. Regardless of how mothers felt about the risks of fertility treatment or the prospect that their daughter may not wish to have a family, many felt that they should consider, and try to facilitate access to, a range of future options. Mothers did not seem to feel that it was acceptable to take no remedial action and instead, help their daughter to come to terms with infertility: as Robertson (2015, p5) puts it, there was no sense that infertility could be 'simply accepted as a possible way to be'.

Concern to provide for their daughter's future needs, and to protect her from the pain and stigma of infertility, could motivate a mother to take steps in the present to ensure reproductive preservation or future access to fertility treatment. Some mothers expressed a positive view of maternal egg donation, but others had feelings of reluctance, anxiety, or guilt that they had not frozen their own eggs. The concept of mandated motherhood, therefore, may also apply to mothers when analysing what action they consider taking in order to plan for their daughter's reproductive future, accounting for the social pressure on mothers to provide their daughter with reproductive choices in later life. In this way, it may act as 'courtesy mandated maternity' where the need to provide for the future possibility of having a child applies not to the daughter, but to her mother.

Kafer suggests that the stigma of disability means that disabled people risk being written out of the future, 'rendered as the sign of the future no one wants' (Kafer, 2013, p46). As 'the future has been deployed in the service of compulsory able-bodiedness/able mindedness' (Kafer, 2013, p27), often through eugenic methods, similarly, it can be used in the service of mandated maternity, with infertility and childlessness presented as the future no one wants. When mothers projected their daughter's feelings about motherhood into the future, they did not always assume that she would want children, but they felt it was likely enough that it would be a risk not to provide her with choices. In the absence of certainty, this could propel a mother to take action, or to feel guilty and anxious if she could not.

4.4 Conclusion

This chapter has examined reproductive timing in the context of TS, showing how women with TS fit or misfit with 'paradigmatic markers of life experience' (Halberstam, 2005) such as puberty and the onset of menarche. It has focused particularly on how Kafer's theorising around 'crip time' can illuminate timing issues in families affected by TS and used this to explore how both women with TS and mothers of girls with TS manage the way they misfit with expected social timing. It has looked at the way social imaginaries of reproductive timing, together with the motherhood mandate, act as pressure on mothers of girls with TS to plan for her reproductive future.

Kafer (2013)'s concept of 'crip time' was used to show how women can creatively respond to timing challenges. This was described using her three categories: strange temporalities, imaginative life schedules and eccentric economic practices.

'Strange temporalities' is a way to describe how TS disrupts the expected social and physical timing for girls. Some women with TS said that, as children, they had felt stigmatised by tangible signs of difference such the need for growth hormone injections or taking hormones from their early teens. Due to the psychosocial impact of TS, girls may be less emotionally able to cope with an infertility diagnosis at such a young age, which a mature adult would find challenging. The impact of an infertility diagnosis could be devastating, particularly if adults did not respond sympathetically.

Mothers of girls with TS described how they felt excluded from their peer group of parents as the life course of their children was so different. Consequently 'crip time' could be applied to mothers as a form of 'courtesy stigma' (Goffman, 1963). For both groups, biosocial connections such as the TSSS and online support groups provided an important way of feeling a sense of fit within a peer group where issues around timing and the challenges of living with TS were well understood.

The 'right time' to talk about fertility varied. Some mothers described the way the time-management challenges of having many medical and educational appointments meant that they prioritised day to day tasks, leaving a discussion of fertility to a point where it became relevant at school or in their daughter's peer group. Mothers also worked to normalise their daughter's experience at school, such as by ensuring in advance that lessons about puberty were inclusive.

Through reframing their approach to reproductive timing using ‘imaginative life schedules’, some women with TS who thought that they could not meet a partner before becoming a mother would revise their ordering of their desired prerequisites, considering single parenthood rather than passively waiting for a relationship. This extends Lahad’s (2012) description of single women waiting to meet a partner as a ‘gendered social phenomenon’ to women with TS, whose reproductive span is limited by health and fertility issues. Deciding not to wait meant that women with TS had more control of their own reproductive timing.

This chapter has presented the argument that crip time extends to reproduction in the context of TS. It has conceptualised intergenerational egg donation as a (financially costly) form of eccentric economic practice, the use of a woman’s family network to extend the resources available to help women with TS have a family.

This chapter has introduced the concept of social imaginaries and described the impact on decision making of the social expectation that every woman should become a mother, which operates alongside the social stigmatisation of infertility and childlessness. It has argued that imaginaries of maternity and fertility shape mothers' expectations about the way their daughter will feel about her fertility in the future, and inform decisions that affect their daughter’s reproductive future where she may be too young to express an opinion. In considering their daughter's future wishes, the social imaginary of a childless future becomes a future of disappointment and rejection if girls are not able to become mothers when they are older. The effect of anticipated decision regret was to focus on the daughter’s prospective feelings of unhappiness about infertility; ‘courtesy mandated maternity’, the sense of responsibility that mothers felt to find a solution, and the possibility that the mother would be blamed for not taking any action, combined with the need to make a decision before their daughter was old enough to express a view, tended to make mothers feel they ought to take action. Consequently, even though mothers were conscious that their daughter may not wish to have children, or may be happy to find alternative paths to parenthood, taking no action to secure her reproductive future could feel like a risky choice, one which was likely to mean their daughter's path to motherhood was more difficult and painful. Their choice may be to explore MEF, or it may be to make other plans, such as saving up for future fertility treatment.

5: “The more options the better”: framing reproductive choices

This chapter considers how women with TS frame reproductive decisions. In particular, it explores how and why narratives of choice and responsibility are deployed in explanations and justifications of preferred family-building options and how women use narratives of responsibility, blame, agency, and choice to discuss how they make reproductive decisions.

It also examines how the individualisation thesis (Beck, 1992) and the concept of responsibilisation (Brown and Baker, 2012) can account for this choice. 'Anticipatory logic' (Adams et al, 2009, p254) describes an orientation towards time such that the awareness of a future risk can be experienced as a moral imperative to anticipate it and plan for the future; consequently, awareness of a risk to future motherhood can lead women to feel that they should take action in the present to protect themselves against that risk in the future, Responsibilisation encourages future focused thinking as a way to manage or avoid risk; this is evident when women with TS consider far in advance how they are going to approach issues such as disclosure to a partner, and how they will navigate the reproductive choices open to them in their specific situation. In the context of fertility, individualisation presents people as 'active' citizens who take responsibility for their own future reproductive health and fertility by anticipating the behaviour and decisions that will be required and using that knowledge to plan solutions. The ways in which infertile women express responsible citizenship are underpinned by imaginaries of responsible motherhood and reproductive planning. The factors they take into account in deliberating and decision making about whether and how to become a mother, and whether or not to use ARTs, use social imaginaries as a reference point for conceptualisations of responsible behaviour.

The chapter begins with a description of the reasons it is seen as important for women with TS to have reproductive choices, and the role played by the prospect of having a choice in helping women with TS to manage their feelings around infertility. It then looks at two examples in which women use narratives of responsibility and choice: disclosure of infertility to a partner and managing the risk of using ARTs. While medical risk can be defined as 'the statistical probability that an event may occur' (Lupton, 1993 p426), it has come to be defined more generally as the likelihood of a negative outcome; women who took part in this study identified social, financial and relational, as well as medical, risks. In this chapter, Crossley's (2007) concepts of 'situated freedom' and 'genuine choice' are used to examine the extent to which women with TS have agency in their family building preferences, and the factors which might limit or extend the options open to them. While women with TS placed a high value on having a number of reproductive options for women to choose from, options which involve pregnancy carry a significant risk for many women with TS. Yet these options tend to be preferred by women seeking fertility treatment (van den Akker, 2010).

5.1 The importance of having reproductive choices

This section discusses the reasons why most women who took part in this study believed that having a choice of future reproductive options was a good thing.

Despite an awareness of the potential difficulties facing a woman with TS, the narrative used around reproductive planning was one which valorised having a choice. Both women with TS and mothers said that it was important that women with TS should be able to choose from a number of family-building options, even though they also described situational factors that might constrain a woman's reproductive choices in the future. The complexities introduced into the decision-making process, for example, by the need for third party reproduction, can curtail a woman's free choice, as treatment requires consent from third parties who are themselves free to choose whether or not to donate eggs. The value placed on having a choice guided their views on how mothers and women with TS should behave when planning for the future.

> *"The more options the better, really. It gives people a choice then." [TSW18: woman with TS, early 30s, boyfriend, child free]*

> *"As many avenues as she's got to choose from is always better than having very few things she can do." [TSW9: woman with TS, late 20s, single, no children]*

> *"I think the fact that these girls now have the options, that there are so many different options that they can explore and get what's right for them, is fantastic." [TSW10: woman with TS, early 60s, married, 2 children in their 30s via natural conception]*

Because choice is so closely linked with agency, this may initially suggest that women considered that increasing reproductive agency was an important guiding principle when considering reproductive options. However, ensuring that women with TS have the ability to make a choice also fulfils other functions, as the following section goes on to discuss.

5.1a Choice and emotion management

There were two reasons why participants thought it mattered to have a choice of ways to build a family. The first was that in reassuring girls they could still become mothers, it eased the initial pain of discovering the diagnosis; the second was that it helped women with TS manage their feelings in the longer term, providing some protection to their self-esteem against worries about desirability or relationship formation. Underpinning both reasons was the view that having a choice was empowering for women with TS.

5.1a(i) ‘Soften the blow’ of diagnosis

This section looks at how ‘having a choice’ was used as part of an intentional strategy to ease the pain associated with infertility disclosure, when parents were able to plan what to say. Women with TS who took part in this project represented the full range of age of diagnosis, from diagnosis in the womb, to diagnosis in adulthood (See Chapter 3 section 3.4d and Appendices 5a and 5b). Some had known since they were young children while others had not found out until they were older. Most participants had been told by their parents, or a clinician while a parent was present. One had been told by her clinician against her mother’s wishes, while four had found out in the same consultation as their mother. Some girls grew up knowing that they had TS but were told about the fertility issues later, when parents felt it was appropriate.

When women with TS described the way that their reproductive future had been presented to them when it was disclosed that they would not be able to conceive naturally, they said it had been made clear to them that they would still have choices over how to have a family. Women with TS described how parents presented more than one option, with one specifically saying that her mother had tried to ‘soften’ the harsh news about infertility.

> *“She always played it as ‘you won't be able to have children in the conventional way. The way that you will be taught, will not be an option for you’. It was never like ‘you can't have kids’ [laughs], it was never like that. It was always 'there will be other options', kind of, it was always softened.” [TSW15: woman with TS, late 20s, engaged, no children]*

> *"I think my mum was very focused on the fertility side of the diagnosis, about how I might get round it, that was quite a main focus for her." [TSW4: woman with TS, early 40s, married, 1 child under 10 via egg donation]*

> *"My stepdad, he kind of gently explained, 'oh you do know maybe with your condition that it might not be possible, but' – this, this and this…" [TSW11: woman with TS, early 40s, engaged, no children]*

This shows the 'emotional choreography' (Adrian, 2015, p308) performed by parents in helping their child to cope with the diagnosis, and how the anticipated availability of family-building options can ease the experience of anticipated infertility (Martin, 2010) by providing reassurance and hope to girls that they would still be able to have a family. Here, the concept of 'psychological IVF' (Adrian, 2015), where the availability of ARTs can be used as an emotion management tool, related not only to ARTs but also to the availability of adoption as a potential family-building option.

Mothers of girls with TS also described how they used the language of choice to talk around the fact that their daughter would not have a child naturally, and to reassure her that she would still be able to become a mother, even if it was not through natural conception. Contextualising the future as holding choices began even when girls were too young to fully understand the nature of conception and birth.

> *"We were speaking about babies having milk and she said, how do I get a baby in my tummy? And I said, like with the [growth hormone] needle, you'll need help to have a baby, but you absolutely can." [TSM6: mother, mid-30s, married, 1 daughter and 1 son under 5]*

> *"Now that you know you're infertile these are your options; you can do this…' So, you know, she grows up knowing, 'oh yes!'. So perhaps one day when it does sink in, that I can't have a baby, then it's like, 'oh yeah, but there is that option', and it's already there instilled in her, that she knows that already." [TSM5: mother, mid-30s, married, 2 daughters under 10]*

These comments also reflect the common assumption that IVF is a technology that can be relied on to successfully produce a desired child, perceptions which are not borne out by success rates in practice (Throsby, 2002).

Some older women with TS were in what would have been their reproductive years before egg donation was widely available and when adoption by single women was rare or not possible. When reproductive choice was so restricted, the language of choice was not appropriate. Instead, parents supported their daughters by introducing and normalising infertility, or talking openly about adoption. One woman with TS described how her mother had prepared her for the possibility that she would not have children, eventually judging that the right time to tell her she was infertile was at the age of 16.

> *"She definitely sort of equipped me, you know. […] you used to say, 'oh, when I grow up, I want three kids', and all this sort of thing, she used to say, 'well just, you know, not everybody can have them, you know.'" [TSW13: woman with TS, early 50s, married, no children]*

The way that the diagnosis was shared and discussed within families did vary, even in this small study, with some women with TS saying they were discouraged from ever discussing it. Within families that were more open, the narrative of having a choice was an important way for parents to help their daughter manage the initial infertility diagnosis.

5.1a(ii) Manage feelings around restricted options

The narrative of choice was also important to some women with TS in the longer term, as that it helped them to manage their feelings around the fact that they would not be able to have children naturally, or with an outcome where they had not had children. One woman with TS, who felt she had not received enough information about her choices, suggested that she would have coped better in the long term if her doctor or mother had discussed options with her and if plans had been in place from an early age.

> *"It is hard, when the choice is taken away. […] If the choice had been made [reproductive preservation] obviously you'd know that choice was there. I'd have coped better." [TSW1: woman with TS, late 30s, single, no children]*

Knowledge that there was a choice, which gave them hope that they could have a child in the future, could have a protective effect on a woman's self-esteem, shielding her from the potential stigma of feeling that she was different from other women.

> *"I've never really felt like I wouldn't be able to have children because there are so many options and that has kind of made me feel a lot better about it." [TSW11: woman with TS, mid-20s, engaged, no children]*

Another commented that knowing that she had options had helped her manage her feelings about fertility when her peers were talking about having babies, especially at school.

> *"I think, not so much as it sort of got to GCSE age, but maybe early secondary school, 12, 13: 'oh babies are so cute' and all the rest of it. But I suppose because […] I knew I had other options it didn't… I was just like, yeah, fine." [TSW17: woman with TS, early 30s, single, no children]*

Having had a choice could also be helpful even if it had not resulted in the woman becoming a mother. One woman with TS was single until her mid-30s. She did not want to have fertility treatment and instead explored adoption. Ultimately because she was single and had diabetes, she was ineligible to become a single parent by adoption. However, having been through the assessment process helped her to feel that she had done what she could and provided her with closure.

> *"I'm glad now looking back that I looked into it because I know, now I've looked into it, and it wasn't for me. So rather than sort of sitting here going, what if I could be sat here with two kids or whatever, you know, I'm actually quite happy with the decision now, so yes. But that has taken a long time." [TSW12: woman with TS, late 40s, married, no children]*

Although a woman's choice to have a child is often constrained by various factors in her personal circumstances, some women found the narrative around having choices was useful to counteract the negative impact of an infertility diagnosis and was both emotionally protective and empowering in the longer term.

5.1b Becoming reconciled to the limitations

Before being able to make a choice, women need to come to terms with infertility itself and the impact this has on restricting reproductive choice. Accepting infertility was described by some women with TS as a necessary precursor to making a decision, which allowed them to move forward emotionally to a point where they could decide how they wanted to have a family. This process was not always straightforward.

One woman with TS who was diagnosed at 16 had struggled to come to terms both with the diagnosis of TS and with its fertility implications. She saw accepting that she would not have a biological child of her own as key to being able to make a decision about what to do.

> *"I have to be OK with it, I don't have a choice. If I'm not OK with it that means I don't adopt, or I don't get kids from anybody else. And I'd miss out on an experience that I would like to have." [TSW9: woman with TS, late 20s, single, no children]*

Because she was initially traumatised by the diagnosis, she went through phases of struggling with medication compliance in her 20s because she found it hard to acknowledge to herself that she had the condition. This limited her choice, because she felt unable to think about her options and start putting plans into practice; potentially it also limited her choice in that lack of medication compliance may have affected her health to a point where pregnancy was inadvisable, an issue that did not affect her current preference. It was only 12 years after the diagnosis that she had recovered enough to be able to discuss fertility options.

One mother identified a prevailing narrative within the TS community that girls with TS were 'lucky to know' that they were infertile from a young age, because this increased their knowledge about their future options and therefore their control over how they addressed this knowledge.

> *"She has always been told – they do tell them all the time – that they are lucky compared to other people who only find out that they are infertile when they're in their 30s and trying for kids, because they know it and can plan around it. I'm not so sure that any girl with Turner Syndrome ever really thinks that they're lucky but that is definitely the word that they're given when they're given the news that they're infertile at seven, and again when they're eight, and again at nine, ten, eleven, twelve. That they're lucky." [TSM7: mother, late 40s, married, 1 daughter and, 1 son in their early 20s]*

This way of looking at a childhood diagnosis of infertility was also mentioned by four women with TS, who described the benefit of knowing from an early age, which gave them time to get used to the idea that they would need help to have a family, and meant they were not having to cope with the diagnosis at the point when they were trying to conceive.

> *"I've always thought that women who were told they can't have children – Turners not in it – after they've got married, they start trying for children, that I think is 20 times worse than anything I've been through. I think that must be terrible." [TSW13: woman with TS, early 50s, married, no children]*

While the perspective that it was harder to have an infertility diagnosis at the point when a woman was trying to conceive clearly resonated with some women with TS, the mother who discussed this narrative was concerned that this approach may prevent girls from going through a proper grieving process. This highlights that girls and women with TS are differently situated from other groups of infertile women. The distress of receiving an infertility diagnosis in adulthood is well recognised (Greil et al, 2010). Much of the literature on childhood infertility focuses on cancer, where there is a necessary compromise between preserving fertility and beginning life-saving treatment (Peddie et al, 2012). Women with TS may avoid going through the pain of diagnosis as adults, or at the point when they are trying to conceive, but hearing a diagnosis of infertility in childhood could also be very difficult and upsetting, as mothers acknowledged when they took steps to reassure girls that they may still become a mother in future. Furthermore, infertility is not an issue which is addressed only once, when the diagnosis is disclosed; it takes on different meanings for women with TS during the life course (Pellatt, 2005), and needs to be re-addressed as circumstances change.

Enabling women to choose from more than one reproductive option is viewed as enabling reproductive agency because it gives women greater control over their biological fertility (Mayes et al, 2018). The participants in this study felt that, in general, women with TS ought to be offered a choice, even if they had strong views about which family-building options were preferable in their specific circumstances. At the same time they acknowledged that their choices were constrained by structural factors such as being unable to afford ARTs, or personal values, such as the belief that adoption is more ethical than egg donation.

Having a range of choices was seen as important because it gave women more control in a situation where their options were limited due to TS. This could have a protective effect on women's self-esteem, particularly as it enabled her to participate in social situations where the discussion topic related to having children. Both the prospect and the act of making a decision was empowering since it enabled women to exercise agency and demonstrate that they had a degree of control over their circumstances (Lahad and Hvidtfeldt, 2019).

The context in which women with TS make reproductive choices emphasises their 'situated freedom' (Crossley, 2007 p557) in choosing their preferred family-building option. 'Situated freedom' describes the way that a woman's choices are limited by situational factors such as whether or not her health enables her to use ARTs to have a family. While she may in theory be able to choose from more than one family-building option, some may be unavailable to her depending on her circumstances. In addition, the ability to make a choice was framed partly as an attitude or state of mind where a woman had accepted her situation and was ready to make a decision within the limited choices available to her in her particular circumstances.

The next section looks at the influence of conceptions of choice on the perception of responsible decision making. Being seen to act as a responsible citizen means making specific, socially-sanctioned choices about reproduction. Risk and responsibility are entangled with the concept of reproductive agency because they are factors which shape women's thinking around which choices are socially acceptable. The following two sections describe and discuss the risk-management behaviour of women with TS.

5.2 Behaving responsibly towards a partner

In the present study, the influence of social discourses of responsibilisation is evident in the way that women with TS described how they managed the issue of disclosure of fertility issues to a partner. This information was relevant to partners because it potentially affected their own lives and their capacity to make decisions about becoming a father, such as whether to have a family together, and which option to choose. His ability to act as a good citizen by making an autonomous, informed choice depended on her disclosure of relevant information. Women with TS had given this issue considerable thought, and disclosed strategically with the aim of achieving diverse outcomes, which could include: treating a partner with respect and fairness; moving the relationship onto a more intimate footing; opening up a discussion of family-building which would enable her to judge the suitability of her partner in the long term; minimising the pain of losing a hoped-for long-term relationship; and minimising the risk of losing her partner due to 'late' disclosure of infertility.

Of the women with TS who participated in this study, eight were married, five had a fiancé or long-term partner, and six were single. All participants thought it was important to disclose their TS to a partner at some point in the relationship; all of the women with TS who were in a relationship, and most of those who had previously had partners, had done this with at least one partner. Not only could the need to disclose fertility issues and potentially face rejection be a barrier to relationship formation for some women (Sutton et al, 2005), but also, TS is linked with increased social anxiety and low self-esteem (Burnett et al, 2010). This may be another reason that more women with TS than in the wider population can find it hard to meet a suitable partner and sustain a relationship. The timing issues related to disclosure have already been considered in chapter 4; this section looks at women's experience of disclosing fertility issues to a partner, why some women did not disclose, and the way they used narratives of responsibility and blame to frame that decision.

In the 'heterosexual imaginary' (Ingraham, 2007) where one of the taken-for-granted assumptions of a heterosexual sexual relationship is that it could, at some point, lead to pregnancy, disclosing infertility was construed as a responsible act. Most women felt it was likely that a partner would want a biological child, so when they had the necessary conversation about TS and fertility, this was a point where they might split up. Consequently, there was a tension between the belief that they ought to tell a partner and the desire to have a long-term relationship; between being fair to a partner and achieving a relationship in which they could feel accepted. Invariably women were anxious about the outcome.

> *"Panic, again. And how he would react, and - how - if he would think 'oh no, let's just end it', because of it - that was always in my mind. You just never know how people are going to react." [TSW19: woman with TS, early 30s, single, no children]*

> *"It's hard. I've done it [disclosed to a partner] three times now and it's difficult. I wouldn't like to have to do it a fourth time." [TSW2: woman with TS, late 20s, engaged, no children]*

> *"You don't want to scare them off, you just don't know how they'll cope with anything like that […] would go, we're going a bit fast, or if you're going to admit to something or someone, that is a consideration because not every guy is going to be OK with that." [TSW9: woman with TS, late 20s, single, no children]*

As most participants had known about their diagnosis for years before they were ready to have a family, they had all thought about disclosure, and how their infertility might affect a partner. The obligation to behave responsibly was shown both in the strategies they chose for disclosure, and also in how women contextualised their choice not to disclose, or to disclose later than they felt they should have done.

5.2a Disclosure strategies

Women thought carefully about the right circumstances to tell a partner. This included considering the timing, the level of commitment they felt was appropriate to discuss something so personal, the risk of a bad reaction, and the way in which they explained TS and its effect on fertility. Most could identify a point at which they felt they ought to disclose.

> *"When I'd been with my husband for a couple of months and I knew that we were probably going to stay together, and it was sort of at that point where you knew that this was probably going to turn into a long-term relationship, that obviously then I felt that he had a right to know." [TSW4: woman with TS, early 40s, married, 1 child under 10 via egg donation]*

> *"I would try my hardest to gauge a good time: not too long, and not too quick [...] But I would definitely tell them, because leaving it too long is no good. Because then they might feel that you have lied to them, and that could cause dramas that are not necessary."*
> *[TSW19: woman with TS, early 30s, single, no children]*

> *"There's a definite order [staggering the level of information that is shared] [...], so Turner Syndrome in general, then the hormone replacement and the medical stuff, and then I had my ovaries removed, that was the last step. [...] Because it is quite a thing, particularly of how much information do I give, and what's going to make people run away." [TSW15: woman with TS, late 20s, engaged, no children]*

There was a sense that there was a right time to tell, which varied depending on the individual. It could come at a point where it became clear that the relationship was becoming established, or it could be earlier on, when it would cause the woman less pain if her partner walked away. It was also possible to wait too long to tell, which increased the potential risk that the partner would leave. One woman with TS felt in retrospect that she disclosed later than she should have, waiting until she could no longer put it off.

> *"It were probably about five years before I told him. We were buying a house, so… Not very good of me really but that's when I thought time were right." [TSW5: woman with TS, mid-30s, married, one child under 10 via egg donation]*

Because the disclosure took place before they had made a life-changing financial commitment to each other, the choice was framed as responsible, while at the same time she felt that she had waited longer than she perhaps should have.

Another strategy for alleviating the impact of disclosure was to discuss fertility in the context of the various options that were available for having a family; the woman with TS would disclose she had fertility issues and, in the same conversation, share what she had already discovered or researched herself about the family-building choices available.

> *"I think it's important to sit down and definitely decide that you're both wanting the same things, and have that conversation about, you know, it's probably not going to be as easy for me, but this is what is available and there is something that can help." [TSW11: woman with TS, mid-20s, engaged, no children]*

This could reassure the partner that if they wanted children, they would not have to leave and find another partner. It also worked to ensure their partner made an informed decision about his own family-building preferences. This is a very similar strategy to that used by mothers when talking to their daughters about the diagnosis.

This kind of strategic planning could be seen as part of an individualising discourse in which a woman who actualises her "neoliberal entrepreneurial self, which takes control of its fate and future happiness" (Lahad and Hvidtfeldt, 2019, p100) approaches a situation with a potentially negative outcome and makes choices which minimise or avoid it. For women with TS, then, the presence or absence of a partner, and their views on parenting and reproductive timing, could present either a barrier or provide support to a woman wishing to conceive.

5.2b Feeling accountable for a partner's choices

The effect of responsibilisation was equally evident in the accounts of women who chose not to disclose. Some women felt that if they disclosed infertility to their partner and he decided to stay with her, they would then be held to blame for preventing their partner from having a family, even if they discussed this with him and he decided to stay in the relationship.

> *"That's another big part of it, when you meet and get in a serious relationship you also don't want to feel like you're preventing them from that option of having a child." [TSW11: woman with TS, mid-20s, engaged, no children]*

In order to avoid putting their partner in the position where he might not feel able to leave them, one approach was to repeatedly avoid this degree of intimacy, a choice that was presented as responsible because it showed care and concern for a partner, although it could also be motivated by fear of rejection. Some women did not get involved in relationships at all, while others ensured that their relationships remained at a superficial level and ended when she felt it was reaching a point of growing intimacy, where she would have to disclose.

> *"I wouldn't want to take that from somebody else, that choice. So it has blocked, it has definitely put a block or a barrier in that way, definitely." [TSW1: woman with TS, late 30s, single, no children]*

> *"I kind of let my husband get in because he had children. Probably it made me keep men at arm's length because I knew that if they were going to be with me it would have to be without children and how could I ask them to do that, it's a big ask, it's a huge ask. Was I going to be enough, you know?" [TSW12: woman with TS, late 40s, married, no children]*

When women with TS struggled to disclose to a partner, it was often because they perceived infertility to be her problem, since it was her body that was affected; it was not seen as a shared problem that the couple could work out together. This meant that the woman with TS alone was held to be responsible for the outcome of the decisions made based on that fact. In the context of chronic illness, responsibilisation can operate as 'victim blaming' (Galvin, 2002 p117) which, together with the stigmatisation of infertility, and an imaginary of future rejection due to infertility, meant that some women with TS felt they were making this decision to protect their partner, as well as themselves. Therefore, when some women with TS made the choice to end a relationship rather than disclose, they took all of the responsibility for that choice, even though in most relationships, the decision about whether and when to have a child is made as a couple. The anticipatory nature of risk management can result in a future focused attitude (Novas and Rose, 2000) that assesses the viability of a choice by its projected future outcome. When women feel stigmatised by infertility, the anticipation of potential difficulties, such as the need to use ARTs, may lead them to subsequently take disproportionately greater responsibility for managing its consequences (Martin, 2010). In the present study, women's reasoning was based on normative assumptions that a partner would want to have biological children himself; this value was projected into an imagined future discussion where as a result he would reject her, or feel trapped into staying with her, and where she would be blamed, or feel responsible, for putting him in that position. Taking full responsibility for this choice, and acting to avoid future blame, also resulted in the woman with TS being in control of the outcome of the relationship, which enabled her to manage the risk of being hurt. One woman with TS said that, when talking this over, a male friend challenged her on this, arguing that in refusing to tell potential partners, she was taking away their choice as to whether to stay in the relationship or not.

> *"'That's not your decision to make,' he said. 'You're being very unfair, making that decision on somebody else's behalf.' He said, 'you've got to tell them, you can't not tell them, but once you tell them, that's up to them what they do about it.' [...] I kind of went, yeah actually, he's got a point." [TSW12: woman with TS, late 40s, married, no children]*

Paradoxically, some women framed their decision to give their partner the freedom of choice to have a child by taking away his option to build a family with her, and by denying him the information he would need in order to make an autonomous decision of his own.

5.2c Managing anxiety

Where TS had an impact on women's opportunities to form lasting romantic relationships, they often felt the need to show that they had done "everything in their power to be healthy so as to overcome the risks intrinsic to lack of action" (Galvin, 2002, p120). This meant acknowledging the role that TS may have played in their single status and describing how they had addressed it.

Some women had never been in a relationship which was intimate enough for them to feel they needed to disclose to a partner. Anxiety is common in women with TS, and it can have an impact on women's ability to initiate and build relationships, making it hard to get to know a prospective partner in a dating setting. Some women described the efforts they had made to manage and alleviate their anxiety so as to feel more at ease in social situations, which could potentially make it easier to find a partner.

> *"It's not for the want of… you know, I've tried to push myself and that sort of thing, but I suppose I get a bit scared, in a way."*
> *[TSW17: woman with TS, early 30s, single, no children]*

> *"You can kind of learn techniques for dealing with it [social anxiety] and that, I found, helped a lot. As I've got older it's also a bit less so now than it was when I was younger. I've got a lot more control over it now. I think a lot more clearly about it and I can analyse things a lot easier than I could." [TSW9: woman with TS, late 20s, single, no children]*

Anxiety is a sign of TS: the cause is not related to a fear of rejection due to infertility but having anxiety could make it more difficult for affected women to manage the fears around disclosure. Most women with TS stressed that they had taken responsibility for managing this aspect of the condition, partly with the aim of meeting a potential partner in future and being able to discuss fertility issues with him. Some women with TS expressed relief at discovering that TS was the cause of their anxiety, as they perceived it as a sign of a condition that was not within their control, rather than a personal failing. Managing anxiety was the responsible course of action, and would enable self-actualisation, either in meeting a potential partner, or in simply feeling less stressed in social settings. One participant commented that she had decided to take part in the research interview to challenge herself, as part of a series of tasks she had set herself with the aim of becoming more comfortable socialising with people she did not know.

> *"I've always been very shy and socially – a little anxious. It's quite a big thing just coming today, to be honest. It's not like… it's good for me – it's good to push yourself!" [TSW16: woman with TS, mid-20s, single, no children]*

The emphasis women place on making responsible choices is evident in the careful consideration given to issues such as disclosure and risk. The individualisation thesis and the concept of responsibilisation are useful ways to understand this behaviour. Both concepts describe the social pressure on individuals to take personal responsibility for their own health, and make rational, informed decisions in their own best interest based on guidance from experts. Individuals have a duty to be well and, to achieve this, they are expected to focus on managing the risks of a health condition to maintain health in the present and in the future. The need to make choices that achieve a positive future outcome can result in a future-focused attitude towards health: 'an obligation to act in the present in relation to the potential futures that now come into view' (Novas and Rose, 2000, p486). When a decision needs to be made, the perceived wisdom of each course of action is projected into the future and assessed by its perceived results.

These decisions were also underpinned by social imaginaries of maternity and heterosexuality, which meant that women anticipated specific kinds of expectations and responses from a partner, for example, to the disclosure of infertility. Women believed that the fertility implications of TS would have a significant impact on a partner as they were likely to want to have children. The emotional work involved in disclosing to a partner, managing the feelings of stress and anxiety beforehand, and planning the best way to respond meant women behaved strategically in their choice of what and when to tell. The choice not to tell a partner, but instead to end a relationship before this became an obligation, was also framed as responsible because it focused on the positive outcome for the partner. Finally, women who were affected felt that finding a way to manage the social anxiety associated with TS could help them achieve the friendships and relationships that they wanted in life; a sense of personal responsibility for making changes was evident in the way that women described how they took action to attain important life goals.

5.3 Managing risk

In her work on managing risk in childbirth, Crossley (2007) outlines three preconditions for making a 'genuine choice' which enable a woman to take responsibility for managing her own risk (Crossley, 2007, p557): first, being able to express preferences and desires; second, understanding the implications of a health condition and the choices that are available; and third, having the means and ability to judge between different possible outcomes, thus being able to make an informed choice. For the women in this study who were considering fertility treatment and pregnancy, the second and third conditions for 'genuine choice' were not always met.

5.3a Risk in pregnancy

Most women with TS are at increased risk during pregnancy and childbirth, as well as more generally. Across the life course, the death rate of women with Turner

Syndrome is three times higher than for the general population; the main causes are heart and circulatory conditions and diabetes (Schoemaker et al, 2008). Pregnancy elevates these risks considerably; although it is considered best practice in the UK to ensure that women with TS have heart health and other tests before proceeding with assisted conception, in practice not all women who go forward for fertility treatment are fully screened. Furthermore, even thorough screening cannot rule out the risk of complications (Söderström-Anttila et al, 2019). While some risks of pregnancy can be mitigated through single embryo transfer, regular monitoring, and medication, it is difficult to mitigate others, such as a high risk of aortic dissection, except by avoiding pregnancy (Karnis et al, 2003). Women with TS are usually advised to give birth via caesarean section: vaginal birth can put a strain on the heart, and a small stature means a small pelvis, which can make vaginal birth more difficult (Hewitt et al, 2013). Finally, as TS is a syndrome, some women are less affected by the heart and hypertension issues that can make pregnancy dangerous or inadvisable for others. This means that the enhanced risk posed by some conditions related to TS can be assessed on a more individual basis, for example, through cardiac MRI scans (Söderström-Anttila et al, 2019).

At the time of interview, five of the 19 participants with TS had children: four either through egg donation or adoption, and one had conceived naturally. Three had given birth via caesarean section, and one vaginally. Fourteen participants did not have children. Of those, eight had explored fertility options (either as a single woman or with a partner) and had a preferred option, but were yet to put this into action, while the remainder were still deciding or had decided against having children. The women with TS in this study were aware of the way TS affected them as individuals in their day to day life, but some of those who had not had children were not clear about whether it would affect a pregnancy and birth, or more generally, about the potential risks and uncertainties that can affect any pregnancy.

This was also the case for women who had gone through, or seriously considered, a pregnancy. The participant who conceived and gave birth naturally was diagnosed with TS after having her first child. At the time, there was less medical knowledge about the impact of TS on pregnancy and the risk to her was unknown; she was only advised about the likelihood of premature menopause and that she would need a caesarean. For younger women, the tension between the expectation to be informed and take advice, and the challenges of doing this in practice, was evident in their descriptions of their fertility treatment.

One woman with TS was referred to a clinic in Spain after having seen a fertility consultant in the UK. She conceived a daughter on her first cycle of egg donation, giving birth in the UK. She had no previous history of heart problems and did not recall being told explicitly that TS would present a potential risk in pregnancy.

> *"I never thought of a pregnancy as having risks because of being a Turner's woman." [TSW14: woman with TS, early 40s, married, 1 child under 10 via egg donation]*

She described how she had told the consultant at her initial assessment that she had TS and remembered that this was not raised as a potential barrier; nevertheless, she recalled having a pre-conception heart check and a heart check during her second trimester. She accepted the caesarean she was offered because of her small pelvis, believing that her gynaecologist was taking care to protect her because it had taken so much to achieve the pregnancy.

> *"This gynaecologist took one look at my husband and looked at me and said, you know, there's no way you're going to push out his baby, basically, let's book you in for a caesarean. But my feeling is they saw what I'd been through and basically didn't want me to go through the stress of a natural labour and all the risks that involves." [TSW14: woman with TS, early 40s, married, one child under 10 via egg donation]*

The participant did not say whether she was informed about the risks before treatment; this cycle had taken place over ten years before the interview. Risk management issues may not have stood out in her memory because, ultimately, they did not affect her or her daughter.

Two women with TS had egg donation without fully being aware of their level of risk prior to conception. One had an unsuccessful cycle of egg donation without having prior heart checks at the IVF clinic; she only discovered that she should have had tests when she had a regular check-up at her TS clinic and told the doctor that she was planning to have a second donation cycle. The tests showed that she was not at risk; she went on to have a successful conception and an uneventful pregnancy with a caesarean birth.

> *"The only risk that I could think of was the heart risk. And really, I don't think the IVF tested for that. It's only because I had an appointment [with the TS clinic] […] after the failed attempt and before the second, and we said, oh we'd had an attempt at IVF, we were waiting… we were looking to be able to do a second attempt - because that was a year later. And he said, we'd better get you to the [hospital] and check out your heart." [TSW5: woman with TS, mid-30s, married, one child under 10 via egg donation]*

The other participant who had used egg donation said that, despite being told about the risks in advance, they did not become real to her and her husband until the clinician raised the subject again on the day they were due to perform embryo transfer. Her husband was aware that there were risks attached to IVF but thought that related to the risk of the procedure failing or of having a multiple pregnancy, rather than to the risk of pregnancy itself.

> *"It was when the eggs were ready, and we were ready for the final bit of the treatment. And they said, are you aware of all the risks, so, I was kind of like… oh, yes, I am… but it's not until afterwards that I realised just how serious they could have been. […] And my husband hadn't even thought about it… what he'd thought more about at the time was IVF means you've got a higher risk of multiple births." [TSW3: woman with TS, mid-30s, married, 1 child under 5 via adoption]*

They went ahead with the embryo transfer, but it was unsuccessful and, having decided that it was too risky for her to carry a pregnancy, they opted for adoption. In women facing a high-risk pregnancy, knowledge of the potential impact on their health meant that women carefully thought through their decision to conceive. Although this meant that they could come to an informed choice, it also significantly increased the level of stress around decision-making and during pregnancy, if they went ahead (Peters et al, 2002).

For this participant, fully understanding the risks of pregnancy was not the only challenge. Prior to embryo transfer, she and her husband were given a choice of when to transfer the embryos. She talked at length about the difficulty of being able to make a decision about this: having the sense that this decision was vital to the overall success of the donation cycle, she felt she and her husband had insufficient medical knowledge to inform the choice.

> *"It was really hard to decide. […] I kind of wanted someone to say, it's going to be better to leave it a little bit longer because they will build up better, they'll be more established. Or say, actually, you could leave it longer but we're going to tell you not to because there's a higher risk of it not working." [TSW3: woman with TS, mid-30s, married, 1 child under 5 via adoption]*

This participant felt anxious and disempowered in being asked to make a decision with what she felt was insufficient guidance from knowledgeable clinicians. This mirrors the findings of other reproduction research where women have been asked to take decisions with complex ethical and medical consequences (Rapp, 2004; Roberts, 2006): in Rapp's research on pregnant women deciding whether to use prenatal genetic diagnosis, women did not feel they could ask for all the information they needed to make a choice, and did not understand how to evaluate the risks and benefits of the different options. Women were asked to make a choice without the knowledge required make the right choice for them. While the participants in the present study were, in general, very engaged with their own health management, most did not have medical training that would enable them to make a medically-informed choice, if that was required of them.

Although some women chose egg donation because they had a strong desire to carry a pregnancy, others chose family-building options that avoided pregnancy, as a form of risk management. Six participants preferred adoption to the use of ARTs and one preferred surrogacy. Three of the six women who preferred adoption, and the woman who preferred surrogacy, chose it partly because they were concerned about their risks in pregnancy. This small number of examples has suggested that when women with TS choose egg donation, they may not always be fully aware of the risks before treatment starts, even if they are otherwise well-informed about their health. An absence of screening before women begin fertility treatment may be partly responsible for this. The ability to make a 'genuine choice' requires an understanding of its implications, but some women with TS who had opted for egg donation did not have the information they needed, so they were less able to make an informed choice.

5.3b Impact of a partner on risk perception

The presence or absence of a partner could affect both the family-building preferences of women with TS and their attitude to the risk of pregnancy. A woman's pregnancy intentions are co-produced with a partner: women with a male partner are likely to adjust their preferred reproductive timing and family size to accommodate their partner's preferences (Dudgeon and Inhorn, 2004). In the context of TS, a partner's preference may influence a woman with TS to choose egg donation or may facilitate her own preference for it by providing the necessary financial and practical support, yet she would bear all of the risk of this choice. Some participants had considered what they would do if their partner wanted a biologically-connected child, saying that they might rethink their preference for adoption if their circumstances changed.

One woman with TS was currently single and planning to adopt but said she would be willing to have egg donation if a partner wanted to have a child.

> *"I think when you're not doing it alone, it's different. [...] If I was with somebody and that meant something to him [becoming a biological parent] […] then I would reconsider." [TSW9: woman with TS, late 20s, single, no children]*

At the time of interview, it was not clear whether she could have egg donation, as she had a heart murmur and bone density issues due to late diagnosis. However, the decision to choose solo adoption was a pragmatic one and, even knowing there were some risks to egg donation, she would be prepared to make that choice if her partner wanted it and if the risks were manageable.

The obligation for women with TS to consider the risk of pregnancy could be framed not only in terms of her own health but also the impact on the partner, the baby and other family members. Although this participant was otherwise healthy, fertility investigations uncovered a minor heart issue which could develop into a risky condition during pregnancy.

> *"As soon as my partner heard that he said 'yeah – no. You're not carrying the child, because it is not worth you not being there to raise the baby'. [laughs] [...] He was like, 'I would lose so much respect for you if you demand to do this. Because you would be putting your own desire over mine, your family's, and your future children. It's suggesting to me to you are not ready to be a mum if you are not listening to a medical professional say it is not safe.'"*
> *[TSW15: woman with TS, late 20s, engaged, no children]*

For this woman's partner, the responsible course of action to take would be to listen to the expert advice they were being given; to have egg donation would be irresponsible, since it would risk the woman's life and the future health of their child and would be going against the wishes of her partner and family. A woman who was 'ready to be a mum' would accept a professional's assessment of her risk, appreciate her responsibility towards others, and accept that they should choose other options; ignoring or discounting the risk was framed as irresponsible or immature. This example demonstrates the operation of shared imaginaries of motherhood, the values and behaviour that are expected from women who are trying to conceive, pregnant or who have children, and the decisions that intending mothers are expected to make in the context of high-risk pregnancy. As a result of the discussion they had after this investigation, they began to look at surrogacy, which would fulfil her partner's preference to have a genetically related child without putting the woman at risk.

If a partner was involved in the decision to have a family, that could potentially make the decision-making process more protracted: partners may not previously have had to consider issues such as risk in pregnancy which women with TS have often been aware of for many years. One woman with TS, who had been told it was likely she could safely carry a pregnancy, had a preference for adoption. She had recently become engaged, and while her fiancé also leaned towards adoption, he had not come to a decision about his preference. She was prepared to consider either, and to give him the time to decide.

> *"He's said before that he'd like to have children that are his, but I think he's still very much in two minds about it. To be honest, he's still young, he has time to make his mind up what he wants. He's a little younger than me - he's 22, so I need to give him a couple of years really!" [TSW2: woman with TS, late 20s, engaged, no children]*

Another woman with TS had had numerous discussions with her long-term partner about having a family. Although TS posed no risk, an unrelated health condition would severely affect her long-term health if she got pregnant, and she felt adoption was the best option. She commented that her partner was finding it hard to let go of the option of having a pregnancy, partly because he had never had to consider fertility issues before.

> *"He's starting to become more OK with it as well. He has accepted it, but this whole fertility thing I've been dealing with it for like ten years. It's still relatively new for him so he is going to be a bit behind in accepting it and stuff." [TSW7: woman with TS, early 20s, boyfriend, no children]*

As a partner may previously have had normative expectations of conceiving naturally and having a genetically-related child, this is not an issue they may have expected to face. Decision making was not only a rational decision based on a risk assessment; women and their partners also required some time to come to terms with the implications before being ready to choose one of the options open to them.

Because the risk of health problems in pregnancy increase with age, particularly heart and blood pressure problems, some women with TS were advised by their doctor to consider having a family earlier rather than later if they could. This advice could be experienced explicitly as pressure: one woman with TS recounted a conversation she had with her doctor when she was 22, where her doctor advised her to consider her different family-building options.

> *"At the time, when I didn't have a boyfriend and was very, very, very single, I was like, I don't want to think about this, and I remember getting really, really upset afterwards… She basically did the whole thing about being single: what is your plans, are you going to adopt, surrogacy, egg donation, it's going to take this long, so many years. You have to sign up to this register now if you want kids before the end of this age. You have to – actually, should have – thought about this two years ago. You should have found a partner when you were 20! Oh god!" [TSW15: woman with TS, late 20s, engaged, no children]*

As participants felt they had very little control over the timing of meeting a suitable partner, this advice could cause distress, while at the same time requiring women to take action that was beyond their sole control. Responsibilisation, then, created a woman's feelings of responsibility for anticipating and complying with normative expectations of the circumstances she should create before choosing to have a family, whether or not this was wholly within her control. It also shows that in the imaginary of motherhood, one of the preconditions is a committed relationship with a partner; this expectation acts as social pressure on women who have more difficulty than average in in forming relationships.

A woman's partner can affect her reproductive choices in a number of ways, such as by changing the preferred reproductive option or timing (Sol Olafsdottir et al, 2011). The absence of a partner can also affect women's preferences about whether and when they decide to have a family: the choices open to women with TS are often situated and may change as her circumstances change.

5.3c Responsible financial choices

Although the majority of women who took part preferred egg donation, the high risk of treatment failure led some women to question whether IVF was the best course of action they could take if they wanted to become a parent. Egg donation has a lower success rate overall in women with TS so if this option is available to a woman, she may require more rounds of treatment and greater medical observation during pregnancy (Hagman et al., 2011; Hewitt et al, 2013). Most fertility treatment in the UK is undertaken at private clinics and self-funded: the woman with TS (along with her partner or her family) has to pay for it herself. The high cost led women to evaluate whether the relatively low success rate was worth the money.

> *"And then the bottom line is, whether it would have worked or not. […] I was the main breadwinner. I was the one who was going out to work. It would have been extremely stressful." [TSW13: woman with TS, early 50s, married, no children]*

> *"I always remember my mum saying, 'you'd pay £8000 for a baby, wouldn't you', but you're not, you're paying £8000 for what bit of a chance, and how many £8000s does one spend." [TSM8: mother, early 50s, divorced, 1 daughter under 10, 1 daughter and 1 son in their mid-20s]*

For women with TS, most of whom had already lived with infertility for many years, the fear of IVF failure could be heightened. The anticipation of several expensive rounds of failed treatment could deter women altogether, as they felt they might not be able to cope.

> *"The biggest thing that's put me off the IVF really is just the fact that you could be investing all this money and all this time into it for no guarantee of success, that anything is actually going to work out, you know. And I think if that were to happen to me, you know, if I'd had these attempts and they just didn't work out, I think that would really break me emotionally." [TSW2: woman with TS, late 20s, engaged, no children]*

Two of the women in this study relied on family help in order to fund fertility treatment and a further two women preferred adoption due to the cost of IVF.

> *"I suppose I've just half written that [egg donation] off in my head because I won't ever – that won't ever even be a consideration for me, I don't have that money." [TSW16: woman with TS, mid-20s, single, no children]*

While any single woman or couple using IVF treatment could be in this position, the anticipation of low success rates in women with TS could lead women to prefer other options. A responsible decision was one that took into account the potential failure rate of treatment.

While a 'genuine choice', as Crossley (2007) conceptualises it, does not include a consideration of the viability of choices, whether women have the financial support needed to access ARTs does reflect their 'situated freedom'. To some women with TS, ARTs were out of reach for financial reasons while others, who could access treatment, made the decision to choose an option which they perceived as being a more reliable way of having a family.

There is also pressure for women with TS to avoid conceiving with ARTs because her health may pose a potential risk to the foetus. There is an 'an artificial conflict of interest between women and their fetuses' (Oakley, 1993 in Smajdor, 2006) where women are perceived as selfish for wanting to create a pregnancy which may provide a less than optimal environment for the foetus. Where women are held responsible for the consequences of a risky choice, because on an individual level they took the decision to get pregnant, they may also be judged for contemplating that choice at all. The availability of ARTs has acted to increase women's sense of personal responsibility for the outcome of their choices, since they now have to consider issues such as the impact on their health, the cost, and their partner's preferences. This is a counter-pressure to the normative expectation where natural conception, pregnancy and childbirth is privileged over other forms of parenting.

5.4 Conclusion

This chapter has explored how women with TS framed decisions about disclosure, pregnancy risk and reproduction using the language of responsibilisation and individualisation.

Most women who took part in this study viewed it as important that women with TS had a choice of how to have a family, even though some had doubts about some of the available options. As greater social importance has come to be placed on individual agency, so more importance has been placed on the availability of choices, since without a choice, it is not possible to exercise agency. This study has extended the use of 'psychological IVF' (Adrian, 2015) to the context of a childhood infertility diagnosis, showing how reproductive options including adoption were used by parents as an emotion management tool, giving girls hope that they could still become a mother.

Responsibilisation describes the sense of responsibility women had for complying with normative expectations of behaviour when living with a chronic health condition. The majority of women with TS receive their diagnosis as children or teenagers, long before they would be considering starting a family. This is a significant difference from women who receive a diagnosis as adults, and during fertility investigations, or in a life-threatening context. The time gap between diagnosis and the point at which women made a decision about having a family may encourage future-focused thinking around fertility; women with TS had given lengthy consideration to how they could best achieve a positive outcome, for example in the context of disclosure. In the absence of information about a (future) partner's views about fertility, women used social imaginaries which valued maternity and stigmatised infertility to anticipate, and manage, the possibility of rejection. This was evident in the language used to describe the choice to disclose or not disclose to a partner. It may account for the disproportionate sense of responsibility that some women felt for the impact on their partner's choices (Martin, 2010) and the presentation of the decision to end the relationship as protective of the partner's reproductive agency.

The language of choice is empowering and gives the impression of control; however, in practice, women with TS did not always have much control over the available choices. Using Crossley's (2007) concepts of 'genuine choice' and 'situated freedom' demonstrates how in practice the options available to a woman with TS can be restricted both by her understanding of the risks, and by her circumstances. 'Situated freedom' describes not only the limitations of choice due to infertility but also the way a woman's individual circumstances may make some options unavailable to her. Women who had not come to terms with the diagnosis may not to be in the right frame of mind to make a choice. Women had little control over whether or not they had a partner, their ability to pay for ARTs, or over the impact of her health on the reproductive options available to her. Furthermore, women who had a partner sometimes changed their reproductive preferences to reflect a joint decision. A 'genuine choice' needed to be an informed choice, but some women had undergone egg donation without being clear about the risks. Finally, the high failure rate inherent in ARTs, particularly for women with TS, meant that some women perceived the cost and emotional strain of repeated treatment cycles as a risk that should be avoided.

The next chapter looks at the impact of family obligation on women's reproductive choices.

Chapter 6 ‘The dutiful mum thing’: family solidarity

This chapter explores the meaning of family solidarity in TS families by examining the perceptions and experiences of the use of intrafamilial donation. Intrafamilial egg donation can be seen as a form of family solidarity, where fertile family members may choose to help a woman with TS conceive a genetically-related child via the use of ARTs. It looks at the influence of social imaginaries on thinking around intrafamilial donation, specifically the maternal imaginary of the motherhood mandate (Russo, 1976), family imaginaries such as the “family we live by” (Gillis, 1996) which express expectations around family solidarity, and sociotechnical imaginaries that normalise the use of reproductive technology for family building (Bach and Krolokke, 2019). More broadly this chapter examines the impact of family responsibilities and obligation in the context of assisted conception and looks at how gendered kinship obligations affect expectations of what mothers should do.

It first examines how both women with TS and mothers of girls with TS viewed and understood sibling donation and maternal egg freezing (MEF). While the latter technology is rarely a reproductive option for women with TS at present, it can be used as an analytical lens to examine women’s thinking on biological kinship, the nature of the mother-daughter relationship, and perceptions of intrafamilial obligation; most participants had heard of MEF through the TS community (e.g. such as at the TSSS Conference or in online forums for women with TS or parents of girls with TS, where this topic has been widely discussed for some years). It discusses MEF and OTC as a form of ‘anticipatory biomedicine’ (van de Wiel, 2014; Bach and Krolokke, 2019) in which reproductive technologies can be used to fulfil expectations about future motherhood based on imaginaries of family-formation and maternity.

As one of the main topics of this thesis is the perception of maternal egg freezing, and siblings of girls with TS were not included in this study, this chapter focuses largely on the views of mothers of girls with TS, describing how mothers took responsibility for their child's future family-building, and how familial influences reinforced gendered expectations that this was her role. It also discusses how a sense of familial obligation could lead both mothers of girls with TS and women with TS to have particular expectations about the role the family could or should play in helping the woman with TS to have a child. The chapter then considers TS women's views on the reception of these novel technologies, and whether or not they feel that they have a duty to become a mother and by which means.

6.1 Sibling egg donation as providing a genetic connection

Sister to sister egg donation is widely perceived to be an acceptable form of intrafamilial gamete donation (Bortoletto, 2018; Lessor, 1990; Sauer, 1998). In the present study, some mothers had taken steps to enable the option of sibling egg donation, while one woman with TS had a child via eggs donated by her sister. Mothers have influence over their children's reproductive choices as they grow up (Beresford and Sloper, 2000 p82; Dilorio et al, 1999; Hutchinson 2003; McNeely et al, 2002; Ralph et al, 2013; Reay, 1999; Ryan and Runswick-Cole, 2008; Swain et al, 2006); this section explores whether women with TS and mothers of girls with TS felt it was appropriate for mothers to encourage their daughters to consider sibling egg donation, and the reception of this option within the family.

Two of the eleven mothers who participated had an unaffected daughter who could potentially become a sibling donor for her affected sister, and, of the participants with TS, one had a child via sibling egg donation and two had sisters who had offered to become donors but ultimately did not donate. Women with TS did not always have the option to use a known or family egg donor, due to their age, physical health issues or the lack of a female sibling or cousin.

Several mothers described how they had actively tried to conceive an unaffected daughter, hoping that, in the future, she would consider donating to her sister who could then have a genetically-related child. This mother was taking clomid to increase her chances of conception when she finally got pregnant with her daughter with TS after six years of trying; her daughter was diagnosed with TS in the womb. She was unable to conceive again, even after fertility treatment.

> *"I would have loved two [children]. That was my ideal, I wanted two. But, no. […] I just thought life was so unfair when I couldn't have any more – you see in the back of my mind I wanted a sister, so that they could donate eggs to [daughter]. […] I desperately wanted a sister for her because I knew if I stood up and said, yes, she can have mine [eggs], they wouldn't have them, because obviously mine were a bit rubbish." [TSM2: mother, early 50s, divorced, 1 daughter in her early 20s]*

For several generations, her family had consisted of only children, so her daughter had no cousins who could potentially become donors. She did not express any views on the ethics of sibling egg donation but had actively tried to have a child with this in mind and had also considered freezing her own eggs, both courses of action which she perceived would help her daughter in the future, and which were directly within her control.

Another mother, who had two daughters, had raised the topic of sibling egg donation with them when they were 12 and 14, thinking that a donation from the unaffected younger daughter could enable the elder daughter with TS to have a partial genetic connection with the resulting child. She felt that introducing the possibility at an early age might give them enough time to think it through without pressure, and in that way, it might become a choice they would voluntarily make as adults.

> *"They've talked about it when they were younger, and [younger sister] was like, 'oh no, you're not having any of mine, I need them!' [laughs] 'But you've got millions, you know!' 'Oh – OK'. So, it's just one of those things that you're, sort of, I just sort of casually talked about just so it's almost sort of in their heads for when they are older. If they were to talk about it, it wouldn't suddenly come as a shock to either of them, if it was something that they did want to investigate when they're older, but you know we had already broached the subject." [TSM3: mother, mid-40s, married, 2 daughters in their early teens]*

She described how her daughter with TS, aged 14 at the time of this discussion, was adamant that she would not want to use her sister's eggs, or eggs from an anonymous donor, or to take another route such as adoption, because the resulting child would not be 'hers'.

> *"I've sort of said to her, but if it was [sister]'s, then it would be part of you genetically. 'Oh, but it wouldn't be mine, it would be [sister]'s baby.' So that's where she is. She's just like, no. And I thought, well, you might change your mind when you're older, I don't know." [TSM3: mother, mid-40s, married, 2 daughters in their early teens]*

This mother felt that it was appropriate for her to introduce the topic and try to encourage her daughter with TS to think more broadly about her definition of motherhood, so she was aware that she had options in the future when she was ready to consider becoming a parent. It was not perceived as the duty of her unaffected daughter to provide eggs for her daughter with TS. Aside from introducing the topic, her approach was to stand back to let her daughters make a decision in their own time with no further intervention.

The use of reproductive technology which could provide a guarantee of a daughter was also mentioned by one mother, whose eldest child was diagnosed with TS aged 18 months, and who had been thinking over various options for several years. For her third and last pregnancy, she had considered conceiving a child using IVF with preimplantation genetic diagnosis and selecting a female embryo. Ultimately the cost acted as a deterrent, as did her perception that she was unlikely to receive approval to go ahead with PGD for this reason. She later conceived naturally and had a son, which ruled out the possibility of an egg donor from within the immediate family.

> *"Before I had my youngest son I considered going to a clinic in London that offered sex selection, but again that was £10,000 or something ridiculous, and you would have to go through ethical board panels to say the reason legitimately why, and I didn't think I would get through legitimately why based on the hypothetical that maybe that child would be open to donating eggs, because you can't force that baby as an adult to say OK, the only reason I exist is to make sure that my sister can have children later." [TSM11: mother, mid-30s, separated, 1 daughter under 10, 2 sons under 5]*

Despite the significant lengths this mother was prepared to consider in order to give her daughter a chance of having a related donor, she did not pursue it because she felt there would be limitations placed on her desire to use technology to create a 'saviour sibling' to provide donor gametes. She did not believe that a future daughter would have had an obligation to become a donor, fully understanding that, as an adult, it would have been her daughter's decision to go ahead or not, but felt that sex selection to provide a family donor could potentially compromise a future child's voluntary decision.

Only one participant with TS had a child via sibling egg donation from her younger sister. She was diagnosed with TS when she was seven and her sister was six. Initially, their mother had a conversation with her sister when she was 12 and asked her if she would become a donor, and her sister agreed. Although their mother had raised the subject initially, the participant waited until she was in a serious relationship before asking her sister if she would become a donor; she had also been told that she needed to have a child in her mid-20s for heart health reasons. Her sister, by then aged 29, had recently had her first child.

> *"Actually, I just asked her. I mentioned that me and [partner] wanted to go for the IVF, do you mind being a donor. She were like… I think she were quite pleased, excited to be an auntie. […] Obviously if she'd been a bit frightened of needles or, you know, frightened of the surgery and not wanted to do it then that would have been fair enough. We'd have made another decision after there." [TSW5: woman with TS, mid-30s, cohabiting, one child under 10 via egg donation]*

This woman with TS felt it was important that she was in the right circumstances to become a parent herself before going for fertility treatment, that her sister already had a child, and that she was willing to go through invasive egg collection. She also expressed how potentially risky and demanding the treatment was for the donor, and how she had felt that asking for another donation cycle might be asking too much from her. However, the request was also limited by her TS, meaning that waiting much longer for a donor would potentially make a pregnancy more risky.

One mother had tried to normalise the idea that some people needed help to have a family by regularly discussing fostering, adoption and egg donation with her two young daughters, in order to prepare her daughter with TS to be told about her fertility issues. This prompted her elder daughter, who was unaffected by TS, to ask if her four-year-old sister could have children. When her mother said that perhaps she couldn't, the girl said she would carry a child for her younger sister. Because of her daughter's age and lack of understanding of the implications, she felt that it would be unethical to try to influence her and decided not to mention it to her again.

> *"They have [...] an older half-sister so it's like a really good example, that she's your sister and she's my girl, but she wasn't in my tummy. So that is kind of a nice way to bring it into conversation. [...] Our elder daughter has said it, she was six years old and I would never remind her of that because I would never put her in the position where she felt like she had to do it. If she chooses when she's older then that's her choice, but I would never tell her what she said because you don't understand at six, what you're saying. It's wonderful in an ideal world to have two babies, give one to your sister. But life isn't really like that." [TSM5: mother, mid-30s, married, 2 daughters under 10]*

While most women who took part said that they would value having a genetic link with their child, the majority were wary of known donation from a donor within the family, mainly because of the perceived complexities of boundaries and role clarity also identified in earlier research on intrafamilial donation (Winter and Daniluk, 2000). Two women with TS had considered asking a sister if she would become an egg donor, but decided against, as they did not feel comfortable with the relationships it would create. They both felt that they would feel more like an aunt than a mother to the child, while they thought that the sister might feel and act like the child's mother.

> *"Relationship-wise I know it's not that, but to me I don't think I would have been able to see past the fact that biologically that's what that is." [TSW9: woman with TS, late 20s, single, no children]*

The voluntary nature of donation was emphasised by women who stressed that the offer to donate eggs, or the recipient's comfort in accepting them, depended on them having a strong relationship.

> *"If the situation allowed, she would do that. I think it was only then that you kind of realise the strength of those sibling bonds."*
> *[TSW15: woman with TS, late 20s, engaged, no children]*

Affinity was also a factor in whether women with TS would consider asking a sibling to donate. A relationship need not be poor; if it was distant that could present a barrier to making a request.

> *"I do have another half-sister but I don't have much contact with her." [TSW11: woman with TS, mid 20s, engaged, no children]*

> *"The eldest [sister] is, well, quite far away from me, and doesn't have her own kids yet, so I don't think they would agree. [...] I think, well my cousin who has a kid, we're close but not that close. She has her own life." [TSW8: woman with TS, mid 20s, single, no children]*

These examples illustrate how the intention to enable the woman with TS to have access to a source of genetically-related eggs via a sibling egg donor is limited by both practical and ethical considerations. Mothers who considered conceiving a daughter so their daughter with TS might have a family donor recognised that this was not the only reason to have another child. A future daughter would still have the right to choose, and the ability of mothers to control whether her daughter with TS could access a genetically-related donor was limited. Women who took part perceived that donation ought to be voluntary and took steps to ensure that they did not put pressure on their daughter or sister to either become a donor or accept a donation. Informed consent was also an issue, both when discussing donation with children and bearing in mind the onerous nature of egg donation; there were perceived limitations to what the recipient could reasonably ask from another family member that depended partly on affinity. When the donor and recipient were siblings, the quality of the relationship also affected whether the donation was seen as appropriate, implying that despite the family connection, sibling donation would be rejected if they did not get along.

Many of these reasons were echoed when women with TS and mothers of girls with TS were asked to consider their views on maternal egg freezing as a potential solution for women with TS, although intergenerational donation added another level of complexity to their perspective. The following section begins by looking at mothers' reasons for considering maternal egg freezing and goes on to explore the reasons why participants accepted or rejected the use of MEF.

6.2 Maternal egg freezing

Maternal egg freezing (MEF) is widely discussed in the TS community. The mother of a girl with TS who had frozen her eggs for her daughter was instrumental in changing the storage time limit for eggs frozen for medical reasons, and as she was part of the TS community, many women were aware of MEF and had discussed it. Of the eleven mothers in this study, one had frozen her eggs and six had considered freezing but not gone ahead; of these six, two had fertility issues, one was deterred by the cost, one was still thinking about it, and two were too old to donate. The reasons for not going ahead also related to timing and the risk of passing on a heritable disorder unrelated to TS. Some mothers who explored maternal egg freezing were not aware that frozen eggs could be stored for longer than ten years, or had considered freezing before the law change, and decided against it based on the age their daughter would be when the storage deadline expired. Three women with TS had mothers who had actively explored freezing their eggs but had decided against it for similar reasons.

This section looks at participant's views on MEF and identified its perceived benefits and disadvantages, highlighting the values and family norms underlying participants' accounts.

6.2a **MEF as a hope technology**

Hope technologies (Franklin 1997) are ARTs that hold out the promise of future successful treatment, and in this context, MEF enables women with TS to keep open the option of having a child in the future.

This hope may be slender, however. Evaluation of whether it is worth undertaking a course of treatment is usually a balance between benefits and harms (Balkanende et al, 2016). As well as the difficulty involved in establishing the emotional and relationship harms and benefits, this requires an understanding of the success rates of a given treatment when considering whether it is worth performing or not. The live birth rate of maternal frozen eggs is not known. Further, fertility patients vary both in their ability to evaluate statistical information such as success/failure rates in the context of their own circumstances, and in their interpretation of the way this applies to their own circumstances. Some may feel that even a tiny chance of success is a good enough reason to have treatment (Sandelowski, 1989). Furthermore, some women with TS, as well as mothers, felt they may use ARTs despite having doubts about the consequences. One woman with TS said that her desire to become a mother might have made her go against her own objections to using an intrafamilial egg donor, and that if eggs had been available, she might have ended up doing something that she felt uncomfortable with.

> *"Part of me would be willing to ignore the ethical side. I mean, let's face it, you read in the papers about sisters being surrogate mums for their sisters and things like that." [TSW10: woman with TS, early 60s, married, 2 children in their 30s via natural conception]*

In the present study, the difficulty of establishing what the daughter might want in the future caused anxiety to the mothers; they did not know how their daughter would respond if she knew her mother had had the opportunity to freeze maternal eggs but had decided against. Some said they had considered that their daughters may wish to be child free or may not want a male partner. Both mothers and women with TS mentioned that the eventual decision to use maternal eggs would be influenced by factors which were impossible to predict at the time the eggs were frozen, such as the feelings of the daughter's partner.

> *"It'll be to do with what happens in her life, who she's with, what they want. She might be a lesbian whose girlfriend has a functioning everything and they can do it all." [TSM5: mother, early 50s, cohabiting, 1 daughter in her mid-teens]*

> *"Whether she'll find a partner and get married and live happily ever after I don't know, but who does?" [TSM3: mother, mid-40s, married, 2 daughters in their early teens]*

> *"I know that having a family is not on everyone's to do list, so I guess I am assuming that it is on hers, but it may not be. There may be a day where she may say, you know, actually it is ok that I can't have children, because it is not for me anyway." [TSM9: mother, early 30s, married, 1 daughter and 1 son under 5]*

In the absence of guidance from the people most affected by these choices, participants' thoughts and feelings around the use of new reproductive technologies were often based round the imagined future wishes of women with TS, meaning mothers may rely on imaginaries such as the motherhood mandate, which meant they were inclined to believe it was likely that their daughter would want to become a mother. They also used the family imaginaries of the 'family we live by' (Gillis, 1996), applying ideals of the way mothers ought to behave towards their daughters to inform their own decision. In addition, the 'pull' of reproductive technology in presenting a possible solution (Sandelowski, 1989) may provide reasons for women to be drawn to these treatments despite their doubts. MEF enables mothers to use these technologies in the hope of providing a future solution for their daughter in a social context where genetic connectedness is valued.

6.2b MEF as a maternal duty

This section explores the deployment of narratives of maternal responsibility when mothers talked about their future planning for their daughter's fertility treatment, and how this was reinterpreted as an act of love.

Roberts notes that responsibilisation is gendered, with women (as mothers and potential mothers) being held responsible for the health and wellbeing of others as well as themselves. In the context of reproduction, women are considered to be "responsible for the lives of connected, or potentially connected, others" (Roberts, 2006 p70). Even though TS is not heritable, some mothers felt a sense of responsibility and guilt that their daughter had TS. Mothers of girls with TS talked in terms of their feelings of responsibility for offering a choice, and sometimes their guilt that they were not able to do more. Some women who took part also suggested that the voluntary nature of MEF might be compromised if mothers felt they should freeze eggs as a way to make up to their daughter for having TS, and for the fertility problems they would need to address as adults.

> *"Is this partly again out of guilt for the mum? The mum's trying to make this right, trying to fix it. There's that going on as well. My mum would have done it in a heartbeat. And I'm so glad that it wasn't available then because it would have put added pressure on me to have gone down that route and I don't quite know how I would have turned round to my mum and gone, actually, no."*
> *[TSW12: woman with TS, late 40s, married, no children]*

> *"I think they [mums] would have the choice to say yes or no, obviously they would, but I still feel like for me, that's putting quite a big ask on someone. So, I don't think personally I would explore that option. I wouldn't want her to feel any pressure overall."*
> *[TSW11: woman with TS, mid-20s, engaged, no children]*

One of the complexities of reproductive preservation treatments is that they need to be decided on while the recipient, the girl with TS, is a child and not able to make a decision in her own right. The socially-shared understanding of the aim of a good parent is "increasingly understood as both inoculating and preparing one's own children to thrive in the face of uncertain futures" (Rozen and Suissa, 2019 p127). There are multiple pressures on mothers of a girl with TS to explore potential solutions that will facilitate her future reproductive choices. The impact of a childhood infertility diagnosis, combined with the timing pressures associated with MEF, meant thinking around fertility was often future-focused. Even if mothers did not like MEF as a practice, their approach was informed by the desire to secure their daughter's reproductive future, and ensure she had a choice in later life.

The mother who had frozen her eggs had initially applied to be an egg donor, feeling that in helping to increase the overall number of egg donors, this might make it more likely that her daughter could find a donor in later life. Discovering that her motivation was partly because her own daughter was infertile, the clinic suggested that she choose a shared cycle, freezing half of the resulting eggs for her daughter and donating half to another couple. She followed the clinic's advice.

> *"I genuinely hadn't even considered [MEF]. I just thought, all I was doing, was hopefully taking somebody off the waiting list now, so that somebody would do that for her in years to come, and that was my entire motivation. [...] I did egg share, they got 24 or 25 eggs, and 12 went to somebody else and we kept 11 in the freezer for her. [...] And at that stage I thought, that's great, I've done what I set out to do, and that's fine." [TSM1: mother, late 40s, married, 1 daughter and 1 son in their late teens]*

The importance of having a plan in place for her daughter's future is evident in this quote. In common with others making an ethical decision with implications for the future (Banks et al, 2006), the value she placed on the importance of motherhood informed the values she perceived her daughter would be most likely to hold in the future and, consequently, helped her to decide how she should act in the present. Part of this mother's motivation came from imagining how she would feel if in future her adult daughter was struggling to find an egg donor, and the sense of responsibility and guilt that she had not done all she could. In her case, this meant freezing her own eggs which she defined as 'doing what I can'. She went on to say that it was part of her duty as a mother to anticipate what her child might need and support her through difficult situations.

> *"I felt as a mum, I know that in years to come, if she – if she chooses to have a child and finds she can't, I know that that would be upsetting for her and I know that my maternal role would be required to support my daughter, not in her having a baby, but to support her in going through something that she is struggling with." [TSM1: mother, late 40s, married, 1 daughter and 1 son in their late teens]*

This mother planned how she could secure her daughter's future fertility with no expectation of any support from outside the family. Egg donors might not be available at the point her daughter might need one; the NHS probably would not cover the cost of treatment, so the requirement to find a solution fell to the parents, and in the case of MEF, the mother in particular. She commented that she did not feel her daughter had a sense of obligation to use her frozen eggs. In her view, she had a maternal duty to plan for her daughter and this duty was discharged once the eggs were frozen. If her daughter then decided not to use them, in her view, this was her choice.

> *"If she chooses not to use them, I'm not going to get angsty about it because that's not my right. My obligation as a parent was to do what I could to help her, when I could, and it's her choice as to what she does with that going forwards." [TSM1: mother, late 40s, married, 1 daughter and 1 son in their late teens]*

Some mothers felt the pressure to freeze their eggs, but ultimately the challenges of their own circumstances and their doubts about whether it was advisable, as well as pragmatic issues such as not having the money, meant they did not go ahead. There were concerns about the treatment itself; for example, it is difficult to determine when a woman with TS is a child what options will be viable for her in adulthood, whether mothers are potentially placing their daughter at risk by providing the option for a high-risk pregnancy, or if the eggs will ultimately be used. Others decided that, rather than choose MEF, they would make financial provision for their daughter's future fertility treatment instead.

Although many women who took part had serious concerns with the practice of MEF, as discussed later in the chapter, most thought that offering to freeze maternal eggs was a natural part of the role of the mother and interpreted it as an act of love.

> *“You can understand it, like mums would do anything for their children, and if it gives them the option of having a closer genetically related child, you can completely understand it.” [TSW15: woman with TS, late 20s, engaged, no children]*

Mothers were motivated to freeze by the desire to secure genetically-related eggs for their daughter, to provide her with options, and also by a sense of maternal duty. One said that she had reluctantly investigated MEF, thinking it was the right thing to do for her daughter, but was relieved to find she was too old to become a donor. This meant she was not under pressure to make a choice that she viewed as ‘going too far’ in pursuing a genetic connection.

> *“I had done the investigation, and I was told they wouldn't allow me to freeze my eggs, and that was my reaction: thank goodness. Because really, in my own head, I thought that that was just, just a little bit going too far.” [TSM7: mother, mid-40s, married, 1 daughter and 1 son in their early 20s]*

Another mother said that she had considered freezing her eggs but had been daunted by the potential ethical complexity raised by her clinician. Combined with her age and the difficulty she had in conceiving her only daughter, she and her husband had subsequently decided that a better solution would be to save money for her future fertility treatment. Despite the strength of the pragmatic case for this choice, and her ambivalence about the advisability of MEF, she felt that, by not freezing her eggs, she had let her daughter down.

> *“The thing about someone else in the family giving her their eggs, I would have to come to terms again that I haven’t been able to do that for her. So maybe it’s that too. Maybe that’s what’s also making me feel less positive towards the idea.” [TSM10: mother, mid-40s, married, 1 daughter under 10]*

One approach also seen in earlier research on donation was to reinterpret the meaning of the genetic relationship carried by maternal eggs (Nordqvist and Smart, 2014). Some mothers said that maternal eggs were simply a resource for their daughter to use. One mother argued that once her eggs had left her body and been frozen, they no longer belonged to her. If her daughter used them, they would belong solely to her daughter – they would be 'her eggs'. The egg carried genetic information that would enable her daughter to have a child that was genetically related to her as well as to her partner, but the social relationship did not go along with it.

> *"If [daughter] had a kidney problem and she needed a kidney, I'd give her my kidney. It wouldn't be mine any more, it would be hers. She needs an egg, I'll give her an egg. I'm not giving her an embryo, I'm not giving her a child, I'm giving her an egg. So I'm facilitating her having her own child with her partner. It's not my child, it's not going to be her sister because it's not got the same mother and father. All she's got is her genetics." [TSM1: mother, late 40s, married, 1 daughter and 1 son in their late teens]*

The suggestion that she was "facilitating her having her own child with her partner" links with the concept of 'psychological IVF' (Adrian, 2015, p303) discussed in Chapter 5, where ARTs are used as a means of emotion management even when there is only a slender chance that they may be successful. This mother was consciously aiming to empower her daughter by providing a readily-available solution to infertility, in the form of a source of genetically-related eggs with no obligation attached. The purpose was to avoid the stress of a lengthy wait for an egg donor and to ease the potentially difficult process of her daughter disclosing infertility to a partner and negotiating what to do. She felt these were both worthwhile aims, even if ultimately the eggs were not used.

Another mother said that she felt, as a mother, she would have been happy for her daughter to use her eggs if they were needed and would have frozen them if she had been asked. She was very close to her daughter, who had subsequently used anonymous egg donation to have her family.

> *"I wouldn't have thought that about myself though [feeling an obligation to freeze eggs], if it was mine, what's mine is hers if you like, and I guess no one has ever asked me, no one has ever said to me, would you give me one of your eggs." [TSM8: mother, early 50s, divorced, 1 daughter under 10, 1 daughter and 1 son in their mid-20s]*

Neither of these mothers viewed the relationship between mother and daughter as a hard boundary, suggesting instead that it was the mother's role to provide what was needed for her daughter. This presents MEF as a 'maternal sacrifice', an act that both mothers considered to be within their understanding of the normal role of a mother.

Although mothers were perceived as being motivated to donate out of maternal love, most participants felt that MEF was a potentially problematic treatment, even if they understood mothers' motives or felt a sense of duty to explore it themselves. The next section explores the concerns that women identified, such as role confusion and appropriate boundary setting, the importance of affective ties between donor and recipient, and whether donating or receiving in this context could ever be truly voluntary.

6.2c MEF as a challenge for family roles and boundaries

A child who is born using MEF has genetic relationships with its mother and grandmother which are misaligned with the respective social relationships; the social grandmother is the biological mother, and this is perceived as a potential problem for establishing the mother's role. A number of participants, both women with TS and mothers, said that they were uncomfortable with MEF because of the potential for role confusion, and that they would feel that a pregnancy created via maternal frozen eggs would be the mother’s child and the sibling of the woman with TS. Some commented that it would feel odd to carry a child who they would consider to be their own sibling.

> *“I think there is something for me, about carrying your sibling which… it would be – If I’m honest, that would be odd for me, personally.” [TSW15: woman with TS, late 20s, engaged, no children]*

> *“I thought, wouldn't it be weird to get pregnant with your mother's eggs, so that is your brother or sister.” [TSM7: mother, mid-40s, married, 1 daughter, 1 son]*

Franklin (2013) observed that prioritising the biological over the social relationship in gamete donation demonstrates the power of biogenetic definitions of kin relationships. Further, in the imaginary of family life, the generations are separated by age, and the roles are not blurred. This may be a reason why so many participants were uncomfortable with intrafamilial and intergenerational donation, as they saw the family relationships that would be created through gamete donation as primarily based on genetics. For some, there was a ‘yuck factor’ associated with MEF. Using an anonymous donor instead was seen as a way of establishing clear boundaries and asserting the participant’s status as mother (Baetans et al, 2000).

> *“For me, having an anonymous donor allows me to feel like her mum.” [TSW14: woman with TS, early 40s, married, 1 child under 10 via egg donation]*

This discomfort with MEF did not necessarily extend to all forms of intrafamilial donation and did not mean that women saw no value in having a genetically-related child. On the contrary, when discussing fertility choices, most women with TS said that they understood and valued the genetic link between parent and child.

Most felt that their partner would want a biological child or would feel a sense of loss if they did not have one, and this became an issue when considering reproductive choices. The desire to maintain a genetic link informed the preference of some women with TS for using egg donation. One woman with TS, who was engaged and planning to have IVF with anonymous egg donation after her wedding, had discussed this at length with her fiancé.

> *"To me that is super, super important, for it to either be part of me or part of my fiancé. And obviously if we were able to have both then that would be amazing. Because like I say, I feel like when you're talking to your partner, and obviously they when they're healthy and everything like that, and they have always thought that they were able to have kids, that's a pretty big ask of them to be with someone who might not be able to do that." [TSW11: woman with TS, mid-20s, engaged, no children]*

Another woman with TS was single and considering adopting as a single parent, which was seen as a simpler, cheaper and less physically risky approach than IVF with double donation. She said that she would consider egg donation if she was in a relationship and her partner wanted to have a genetically-related child.

> *"I would understand if it did [matter] - because if I wasn't in this situation, that would mean so much to me." [TSW9: woman with TS, late 20s, single, no children]*

Another, who was engaged, could not carry a pregnancy for heart health reasons. She had always assumed that she would build a family through adoption but had changed her mind when her partner said he wanted to have a biological child.

> *“He was like, 'I always assumed egg donation and surrogacy is the first port of call, if we can' and I remember going, like ‘what? Because...’and he is like 'for you, you have always been resigned to the fact that it can't be yours, but it can be my child.’” [TSW15: woman with TS, late 20s, engaged, no children]*

While maintaining a genetic link is important, there are equally important reasons for making different choices. The prospect of using maternal frozen eggs in this context brought up the same kinds of concerns about relationship boundaries as intrafamilial donation in general. While only one participant mentioned the ‘incest vibe’ associating MEF with inappropriately intimate family relationships, a number of participants were concerned at the potential reaction of a partner to the use of MEF to have a child, interpreting that to mean his mother-in-law would be the mother of his child.

> *“I mean I’ve had friends who’ve offered to freeze eggs for me as well and it’s not got the whole incest vibe, but it still feels like that would always be their [the friend’s] kid.” [TSW7: woman with TS, early 20s, boyfriend, no children]*

> *“What if she wanted to have a baby using my egg but then the essence, if she was using the sperm of her partner, wouldn’t that be an even weirder dynamic because essentially her partner would have fathered a child with me, even if she gave birth to that baby, or through a surrogate. That could cause all sorts of emotional trauma, I would think, for their relationship.” [TSM11: mother, mid-30s, separated, 1 daughter under 10, 2 sons under 5]*

Boundary concerns were not always related to intrafamilial donation, as some women felt the same about known donation in general; the use of the word ‘weird’ encapsulated a sense of unease which was not easy to put into words.

> *"I just think personally that I'd feel really weird about using my mum's eggs for treatment, you know, something just wouldn't feel quite right about it, and it would be the same if it were my sister or anyone else you know. I don't know, I just don't feel comfortable with it." [TSW2: woman with TS, late 20s, engaged, no children]*

The discomfort with intrafamilial donation was not always about the potential genetic relationships it might create: one woman with TS said that she viewed her sister in law's eggs as in some way 'belonging' to her brother, that they were intended to provide him and his wife with genetically-related children, and that she would feel that she was encroaching on their relationship.

> *"My sister in law, if she were to offer me her eggs, I'm not sure if I would feel comfortable with that because that should be her and my brother's children." [TSW17: woman with TS, early 30s, single, no children]*

Aside from the potential boundary issues created through MEF, there were also concerns that family members might expect to have influence over the resulting child if they had helped to make treatment possible, even if they had not donated themselves, for example by giving the woman with TS the money for treatment. Accepting money was sometimes perceived to create an obligation which may allow a grandparent to have a role that they would not otherwise expect to have in a grandchild's life, and which might put the woman with TS in the position of defending her preferred boundaries from the expectations of her parents.

> *"It's the knowing them, but also having the relationship, because obviously there's the… where's the line in terms of influence over the resulting child and that sort of thing." [TSW17: woman with TS, early 30s, single, no children]*

Intergenerational donation potentially breaches a social norm where grandparents do not interfere in their grandchildren's upbringing; conversely, mothers are supposed to be ‘involved’ parents (Edwards, 2009; Mason et al, 2007). In other words, grandparents are not supposed to behave like parents. Some women who took part had an expectation that the mother of the woman with TS might usurp the social role of mother, which would belong to her daughter. This suggests that these participants took the view that the genetic relationship will overpower the social one, since they expected the mother to take a mothering role in her (social) grandchild’s life. Yet there is an existing cultural model for intergenerational care arrangements. As Becker (2000) observed, it is common for people to build on cultural models when describing complex relationships created through ARTs. One woman with TS suggested that MEF could be considered as a form of extended kinship care, where grandparents brought up their daughter’s child and acted as its parents.

> *“I suppose that’s a bit of a weird one, you’d be bringing up your own sibling. That’s been done, I’m sure! Yeah, I’m sure that’s been done before, going back thousands of years possibly. And more so grandparents bringing up children, not their own children but actually their grandchildren. That’s definitely happened.” [TSW5: woman with TS, mid-30s, cohabiting, one child under 10 via egg donation]*

The kinship care of children normally sees grandparents looking after their grandchildren, rather than the adult child looking after their parent’s child, so this arrangement mirrors the misalignment of biological and social roles in MEF. However, the participant normalised it by using a comparison to a socially accepted and relatively common social arrangement (Wijedasa, 2015). Describing the parent and grandparent as potentially interchangeable when they are engaged in childcare reinforces the idea of kinship roles as fluid and negotiable: the grandparent is not the parent, but they are filling the parent’s role part of the time. Re-framing the relationship between social grandmother and social grandchild through kinship care normalises it, making it more familiar and less threatening. This raises the question of whether people would be more accepting of MEF if they were able to draw a comparison to existing socially-accepted practices. In Mason et al's (2007) research, grandmothers were often happy to step back from the role of mother, as they had already brought up their children, and did not necessarily want to take the same level of responsibility for grandchildren (Mason et al, 2007).

Maternal frozen eggs have not yet been used in fertility treatment, so there is no experience of how this might affect family relationships; women who took part appeared to be applying their existing values around genetic family to either raise or minimise concerns about the social role of the maternal egg donor, again showing how family imaginaries can influence reproductive choices. MEF differs from sibling egg donation in important ways which might ease or resolve some of its perceived problems. In standard egg donation, the recipient is an adult who is considered to have agency over her choice to use a donor, and to take into account the implications, including whether or not to use a known donor. As MEF is performed while the recipient is still a child, and has no control over the decision to freeze, this may reduce any sense of filial obligation to use the eggs. The length of time between freezing maternal eggs and their use may help give mothers emotional distance and could potentially lessen any feelings of disappointment or rejection if they are not used. The sense of personal accountability that some donors feel for the success or failure of the treatment may also be helped by having a boundary of many years (Winter and Daniluk, 2004). Pregnancy could help avoid role confusion, as it acts to establish a woman's role as the mother (Nordqvist and Smart, 2014). The age gap between the mother and a social grandchild created from her eggs could also support this distinction between biological mother and social grandmother, as the mother would belong to the same generation as a grandmother, and it is more likely she would be treated as one. Finally, the use of the technology itself could also disrupt the sense of genetic relatedness as it acted to distance the genetic mother from her genetic offspring (Leve, 2013).

Participants made a distinction between the acceptability of sibling egg donation and MEF; generally, they thought sibling egg donation was less problematic, even while identifying similar potential problems of role confusion and family pressure which would deter them from using MEF. It was not always easy for participants to articulate why they were uncomfortable with intergenerational donation.

> *"My sister is my sister and she is [would be] helping. My mum is helping as well, but she carried me, so it would be difficult, yes. She carried me, that's what would make it a bit more weird." [TSW19: woman with TS, early 30s, single, no children]*

> *"I'm not really sure why, because it's contradictory, saying you can use your sister's, but you can't use mine, but – I don't know." [TSW3: woman with TS, mid-30s, married, 1 child under 5 via adoption]*

This may be related to the 'genealogical imaginary', the idea that there is a preferred reproductive age range and the generations should be kept in alignment (Bühler, 2015). However, the discomfort did not always mean that women disapproved of the use of a family donor *per se*: views varied, and some would have accepted another member of the family but felt it was inappropriate for a mother.

> *"I definitely would have been happier, if it ever was going to happen, if it was another female relative rather than me." [TSM7: mother, mid-40s, married, 1 daughter and 1 son in their early 20s]*

In the context of intrafamilial donation in general, some participants questioned whether MEF was really any less acceptable than other types of intrafamilial gamete donation such as donation between siblings or cousins, as the genetic link would be there with any family member, as would the potential boundary issues that came along with it. For that reason, this mother felt that using MEF was acceptable.

> *“Whether it be a sister or a cousin or an aunt or a mum - at the end of the day, it is all a genetic link [...] I don't think it would be any less wrong or any more right, if you get what I mean. I don't think it is wrong. No.” [TSM9: mother, early 30s, married, 1 daughter and 1 son under 5]*

Role confusion and boundary concerns were linked in intrafamilial donation, where recipient and donor knew each other, and therefore there was the potential for the donor to intrude in ways which were considered inappropriate for the social relationship but appropriate for the genetic relationship, a concern which also extended to the partner of the woman with TS. For this reason, anonymous donation was considered by some to be preferable because it was less complex.

6.2d MEF as a reflection of affective ties

As with the earlier discussion about sibling egg donation, the perceived acceptability of intergenerational donation was based partly on affinity, and MEF may be rejected if the relationship between mother and daughter was not both strong and positive. One woman with TS, who had a child via anonymous egg donation, vividly described her teenage sense of inferiority to her unaffected sisters as ‘feeling like the scum at the bottom of the gene pool’. She felt that her parents constantly compared her negatively to her high-achieving sisters and she felt disrespected by her family because she had TS. This affected her relationship with them in later life. She would not have chosen either sibling or maternal egg donation.

> *"The relationships with my family aren't there for that, really. It's not something I would have been comfortable with and I don't think they [sisters] would have been. [...] My relationship with my mum being what it is, that [MEF] fills me with absolute horror. [laughs]" [TSW14: woman with TS, early 40s, married, 1 child under 10 via egg donation]*

This contrasted with her imaginary of family life, where family members would respect and support each other. For this participant, the family she 'lived with' had disappointed her and their behaviour clearly fell short of the way she felt a family ought to treat each other, or the family she 'lived by' (Gillis, 1996). She felt that she had been mistreated as a child, and as a result was horrified by the idea of MEF, the implication being that if she and her mother had had a closer and more mutually respectful relationship, that corresponded with her idea of how a mother and daughter would ideally relate to each other, she may have felt more positive about MEF. The limitation in this case was that the participant would not accept donor eggs from someone who she felt did not love and respect her, suggesting that affinity was an important factor in the acceptability of intergenerational as well as sibling donation.

6.2e MEF as a potential source of pressure for daughters

In order to be considered ethical, MEF relies on the donation, and use or non-use of the frozen eggs, being a voluntary act for both mother and daughter. There were concerns that the mother-daughter relationship may affect ability of women with TS to make a choice to use maternal frozen eggs, or not, that was free from pressure or negative consequences for the relationship.

Both women with TS and mothers of girls with TS articulated three concerns about freedom of choice that were specific to the context of TS. These factors may apply in intergenerational donation in other contexts but were considered to be more pronounced in families affected by TS because of its psychosocial impact. First, that parents tended to be overprotective of girls with TS and possibly inclined to intervene in potentially inappropriate ways, with the best of motives; second, that girls with TS are very close to and strongly influenced by their mothers; and third, that women with TS tend to avoid conflict, so may be less able to go against what they think their mother wants. All of these factors suggested that it could be harder for mothers to resist becoming donors if they had the opportunity, and for women with TS not to use eggs that their mother had frozen for them.

> *"I was saying about girls with Turners being pleasers and wanting to please and do the right thing, I think that then puts pressure on the girl to use those eggs. As much as the mum might say you don't have to, it's entirely your decision, and all the rest of it, but I think in the back of the girl's mind it would be, 'my mum's sacrificed this, my mum's done this'." [TSW12: woman with TS, late 40s, married, no children]*

> *"A lot of these girls aren't growing up with that [independence], because they're mothered and babied, because they're small, partly. [...] That is how a lot of them are brought up by their own family so yes, when they get older and decide to go for fertility treatment, that has to be the hardest thing in the world for anyone, and I do wonder how these girls will manage it." [TSM7: mother, mid-40s, married, 1 daughter and 1 son in their early 20s]*

Some women with TS said that their willingness to use a maternal egg donor could depend on the expectations that were placed on them because of the donation. It would be acceptable simply to provide eggs in order that daughters had an option in later life, but unacceptable if the mother then expected their daughter to use the eggs, particularly if she viewed it as a way to become a grandmother to a genetically-related grandchild.

> *"So long as the child doesn't feel there's an expectation for them to produce grandchildren and that - I think if they just sort of harvested and left there in the clinic and the child is made aware that they're there, then you let them as an adult approach you then if you want to use them. It's no good going on and saying, oh, I'd like a grandkid [laughs]." [TSW5: woman with TS, mid-30s, cohabiting, one child under 10 via egg donation]*

In other words, women did not perceive MEF as a reciprocal duty, where a woman with TS would be obliged to use the eggs in return for her mother freezing them. However, women expressed concerns that guilt over maternal investment may mean that the woman with TS felt compelled to use the eggs, even if she would prefer to use an anonymous donor or did not wish to have a child. Believing that the existence of maternal frozen eggs may potentially act to pressure women with TS to use them, some women made suggestions that they felt might enable the recipient to choose more freely. For example, several participants suggested that mothers could wait to tell their daughter that frozen eggs were available to a point when she was considering how to start a family.

> *"I personally think if I was the mother, I would harvest eggs and not discuss the choice till they're all ready." [TSW1: woman with TS, late 30s, single, no children]*

MEF is a relatively recent practice and consequently, within the literature on intergenerational donation, when concerns are expressed about the potential for coercion, they are often based on the assumption that the daughter is likely to be the donor for the mother. The power relationship between parent and child is recognised in that context, but when the donation goes from an older to a younger family member, as in the context of TS, and the donor is in the more powerful position, it can be positioned as "stemming from maternal instinct, love, and selflessness", part of the caring role of a mother (Gidoni et al, 2008). This does not reflect the complexity of the social pressure on mothers to freeze, or on women with TS to have a biologically related child; nor does it address the potential difficulties of refusing maternal donation within a close family relationship.

This section has looked at participant's views on MEF and identified its perceived benefits and disadvantages. MEF was perceived as an act of maternal love, but in practice women identified a number of potential deterrents to its use. The benefits of MEF are that it provides a source of genetically-related eggs for the daughter, meaning she would not have to find and pay for an egg donor and she could potentially have a child with a genetic link to her; this may make her feel more confident when discussing infertility with a partner. Whether or not the eggs were used, they provided a way for mothers to help their daughters' emotional management of infertility. However, women who took part in this study identified a number of disadvantages with MEF. They were concerned about the potential for role confusion within intergenerational donation, where the mother might take on a maternal role with her social grandchild which her daughter would find hard to resist, and the 'yuck factor' of the daughter's partner conceiving a child with his mother in law's eggs. The use of MEF may depend on the mother and daughter having a good relationship. There were concerns that women with TS may be compromised by a sense of obligation to her mother, and that she might come under pressure to use a family donor if a donation had been made for her, or to provide her parents with grandchildren. However, participants less frequently identified that mothers were also under social pressure to provide for their daughter, and that may lead them to consider MEF, despite their doubts.

6.3 The sense of obligation to have a family

In common with many adult couples anticipating parenthood (Sol Olafsdottir, 2011; Langdridge et al, 2010), some women with TS felt responsible for giving their parents a grandchild. These feelings were a response both to direct pressure from other family members, and to their view of their role as a daughter. Some felt a duty to continue the family line, and a sense of responsibility for creating new kinship relationships for other family members. This could add to the distress that women with TS felt about infertility, as women compared the sort of family that they wanted to have with the family they had or thought they might be able to achieve. This gap between the real-life 'family we live with' and the imaginary of the 'family we live by' (Gillis, 1996) was most evident in the difference between participants' hopes and expectations and the way these were circumscribed by the impact of their TS.

Having the fertility issues associated with TS did not always protect women from normative expectations of motherhood being expressed by their family (Letherby, 2002). The views of their parents and the wider family on whether or not they should have children could sometimes be expressed in hurtful ways. One woman with TS, who was an only child, described her difficulty in building lasting relationships. She felt that asking a partner to accept her infertility was unfair and avoided intimate relationships where this might become an issue. Her mother was aware of this, but still said that she wanted grandchildren.

> *"She said, 'I wish I'd got grandchildren, you haven't given me any grandchildren yet.' And she's said it in supermarkets and situations and so I know her view on it. [...] I find that the hardest bit of it, actually, that my mum is impacted by it as well." [TSW1: woman with TS, late 30s, single, no children]*

Women felt upset and sometimes guilty about the impact of infertility on their mothers.

> *"I know she wants them [grandchildren] and she's hinting not very subtly at all. It's like, 'we need to make a start! This can take, you know, it's a long process [adoption]. You're nearly 30, you need to be thinking about it'. Oh my god, no pressure then!" [TSW9: woman with TS, late 20s, single, no children]*

Another woman with TS described her mother in law's desire for grandchildren. She had been aware from the beginning of her relationship with her husband that her mother in law did not want her son to marry a woman who couldn't have children. This was rarely mentioned openly, but nonetheless the participant had a sense of her disappointment.

> *"She never exactly made it obvious [that she is disappointed not to have grandchildren] but it's… it's a tricky one. I've always felt that that's what she thinks, and she can't understand why we've never done anything about that. I think that's mainly the thing. I don't know whether she blames me or anything like that, I've no idea."*
> *[TSW13: woman with TS, early 50s, married, no children]*

She went on to relate this disappointment to the sort of family life that her mother in law hoped to have when she had grandchildren, and to the impoverished family life that she felt she and her husband experienced without children, commenting 'things like Christmas, you know. Our Christmas is nothing.' While she looked back and stood by the decision that she and her husband had made not to have a family, she felt a sense of loss by comparison with her siblings, who both had children, and her mother in law, who had grandchildren from her other children.

Some women with TS said that their parents had never put pressure on her to have a family. One said the fact that her health might be compromised if she carried a pregnancy meant her parents had never put pressure on her to get pregnant. She was planning to have children with her fiancé, probably via adoption, but was relieved that she could do this in her own time.

> *"I have discussed it with them on several occasions yes [...] they seemed to think that with my heart it would be too risky. [...] I mean in a way I'm glad about that really. I'm glad I don't have any pressure put on me to give them grandchildren or anything because that's never nice." [TSW2: woman with TS, late 20s, engaged, no children]*

While women with TS often wished to provide grandchildren for their parents, this did not necessarily have to be through IVF.

> *"They both [mother and mother in law] thought, whatever, at the end of the day we'd have a child. A child is a child, to them it doesn't matter whether it's biologically related or not. Once it's our child, it's our child, that's it." [TSW3: woman with TS, mid-30s, married, 1 child under 5 via adoption]*

Some women felt relieved if their siblings were planning or had had children, since it meant that their parents were already grandparents, which put them under less pressure to have a family.

> *"As a young teenager, the older brothers had their own kids anyway, so there has always been kids around [...] ...probably for the length of my parents knowing, they didn't expect [any] from me anyway." [TSW18: woman with TS, early 30s, in a relationship, child free]*

> *"I feel like because I've got my brother [...] and obviously he's now married so I don't feel there is as much pressure in that sense. I feel like they [parents] will have hopefully have grandchildren at some point." [TSW17: woman with TS, early 30s, single, no children]*

This discussion demonstrates that MEF is not the only potential source of pressure on women with TS to have a family. Whether or not they have access to ARTs, some women with TS feel a sense of obligation to have a family and may feel under pressure to consider the available means of achieving that outcome. One reason to have a family given by women with TS was to provide parents with grandchildren, and there was sometimes overt pressure for them to do this. Family was seen as an important part of social life, which would be missing for the parents of the woman with TS as well as the woman herself. However, in each of these cases in this study there appeared to be little pressure to have a genetically-related child. The context of chronic illness and the fertility issues associated with TS may mean that women are under less pressure to have a pregnancy, and instead her family may suggest that she looks at options such as adoption or fostering. The sense of responsibility for providing grandchildren (whether genetically-related or not) could be one motivation for women with TS to explore ways to have a family.

6.4 Solidarity in the context of TS

Family solidarity can be defined as “the willingness of relatives to subordinate their *individual* interests – in part, if not entirely – to *collective* interests” (Dykstra et al, 2000). It is therefore linked with notions of support and sacrifice, the extent of which may be fluid and contextual (Smart, 2007). Perceived obligations to family may vary in type and extent, and may be influenced by perceptions of intergenerational, reciprocal, and maternal duty (Dykstra et al, 2010).

The present research showed how family practices were entwined with views on the importance of the genetic connection when thinking about intrafamilial donation. Most participants had a preference for women with TS to have genetically-connected child if this was feasible but identified a number of potential problems with the use of family donors. Most women said that sibling egg donation was less problematic than MEF but that both risked causing potential role confusion between the donor and recipient, making it harder to establish appropriate boundaries within the family. A consideration of the feelings of the prospective child was occasionally mentioned, but largely absent from discussions about MEF and sibling egg donation, where the main focus was on the relationship of the adults involved.

Intergenerational solidarity is usually seen as relating to the relationship between parents and their adult children (Notko, 2006). In the context of TS and reproduction, the present study focuses on the perceived obligations that mothers feel towards their daughter while she is still a child. Although some mothers introduced the topic of sibling donation to her daughters while they were still children, sibling donation is eventually negotiated between the two adult siblings. MEF is likely to be arranged on a child's behalf at a point in time when only the mother is an adult. While children are dependent on their parents, they are not able to make decisions in their own right, and the child has no choice in whether eggs are frozen. Normatively there would be no expectation of reciprocation: the flow of intergenerational support is expected to move largely from parent to child until the parents are elderly (Dykstra et al, 2010; McCarthy, 2000). This study found that daughters are perceived to have no reciprocal obligation to use frozen maternal eggs. The benefits of known donation are that it can give recipients a sense of control over their reproductive autonomy and reduce anxiety caused by the use of an anonymous donor (Gidoni, 2008). However, although there was felt to be no reciprocal duty for the woman with TS to use maternal frozen eggs, there were concerns that women with TS may find it particularly difficult to choose a different option knowing that eggs had been frozen for her. Affinity can both act as a reason to offer and to accept MEF, where a close relationship exists, or a reason to reject it, as making it too difficult to establish clarity in family roles. Concerns about the use of reproductive technologies need to be contextualised in a social setting where even women who cannot conceive naturally come under pressure to have a family.

The perceived limits of maternal solidarity could also be seen in the behaviour of mothers who had seriously considered having another child in order to provide their daughter with TS with the option of a sibling donor, or who had talked to an unaffected daughter about the possibility of donating to her sister. It was understood that siblings did not have the duty to donate eggs to their sister with TS and therefore mothers did not have control over the outcome; at the same time, they were motivated by the perception that the existence of a family relationship would make egg donation more likely when the girls were adults.

It is seen as part of a mother's role to socialise her child to conform with normative social expectations, where normalcy is defined by socially-situated ideas about 'what most people do' (Becker, 2000). The response to a diagnosis of infertility may potentially involve a mother taking, or feeling pressure to take, normalising actions that enable their daughter to have a child in later life. When a normative expectation is to have a family, a mother may feel responsible for managing a daughter's expectations about her future role as a mother, and how that should be performed. Mothers may also feel a sense of 'infertility by proxy' (Collin, 2010, p272), a form of courtesy stigma (Goffman, 1963 p30-31). Both in this study and in the literature (e.g. Sutton, 2006) infertility was found to be one of the most upsetting features of TS for mothers; several mothers who took part had also experienced reproductive traumas such as stillbirth or secondary infertility. Understanding the pain of infertility was a factor which guided mothers' decision making around reproductive preservation and around planning for future family-building.

Based on the cultural presumption that women want to become mothers, also known as the motherhood mandate (Russo, 1976), the mother of a girl with TS may reasonably predict that in the future her daughter is likely to want to have a family, in the same way as her peers. Consequently, mothers of girls with TS may be interested in exploring ARTs; these technologies act as normalising treatments that may help their daughter conceive and carry a child. Women who took part in this study articulated this sense of maternal responsibility as the obligation or duty of a parent. As one mother said regarding her decision to freeze her eggs:

> *"If I can do it, I must do it, to give her the best chance, because we both [participant and husband] feel that to give her the best chance in anything in life is the duty of a parent, and that's to [their son] as well, that's the duty of a parent." [TSM1: mother, late 40s, married, 1 daughter and 1 son in their late teens]*

Rapp (2004) sees mothers as the gatekeepers of normalcy when they make these choices. Within the context of prenatal genetic testing, her participants defined both new responsibilities and limitations around the way they defined maternal duty, a choice which was particular to their role as mothers. "The very fact of imagining (and more rarely, enacting) a limit comes with the territory on which gendered responsibilities encounter reproductive technologies" (Rapp, 2004, p309). Similarly, mothers who explore the use of maternal egg freezing could be seen as 'moral pioneers': they develop a view on the complexities of egg freezing in a social context that is unfamiliar with this practice, before their daughter is old enough to express a preference; in turn this positions their daughters as 'moral pioneers' when they eventually decide whether to use the eggs in later life. The discussion around the use of MEF defines the perceived boundaries of a mother's duty to provide their daughter with the opportunity to have a genetically related child, and the daughter's choice to accept it.

6.5 Ovarian tissue freezing: a better solution?

The difficulty of finding a balance between preferring genetic relatedness and the personal circumstances and concerns of individual participants is brought more sharply into focus when considering participants' views on ovarian tissue freezing (OTF), their reaction to its potential to enable a woman with TS to have a genetically connected child, and the way that is balanced with issues of family boundaries, consent and risk. None of the women who took part had used this technology or knew anyone else who had, and some of them had not heard of it before. These views, then, are spontaneously-constructed reflections on the potential of OTF for reproductive preservation which give an indication as to what participants valued.

OTF is an experimental reproductive preservation technique which involves removing and freezing an ovary, or sections of ovarian tissue, while it is still healthy. The frozen tissue can then be re-implanted later in life, potentially triggering a natural menstrual cycle and producing viable eggs. This technique gives women the chance to become pregnant with a genetically related child if she cannot, for reasons of age or illness, conceive when the collection process takes place (Hewitt et al, 2013). It may be suitable for girls with mosaic TS who have functioning ovaries at the time of treatment. OTF has been trialled with girls with TS outside the UK and is available within the UK for the reproductive preservation of cancer patients (Jadoul et al, 2017).

Nevertheless, the potential outcome of this technique had wide appeal for participants, with both women with TS and mothers of girls with TS saying that it was valuable because it may allow women with TS to have a genetically-connected child and a pregnancy, giving them an experience of becoming a mother which is close to that of most other women.

> *"I would bite someone's hand off if it was offered because it would be their child and that's what I would like her to have, that option. I mean, it might not work, but I would bite someone's hand off in a minute." [TSM11: mother, mid-30s, separated, 1 daughter under 10, 2 sons under 5]*

> *"I think it's fantastic! Anything they can do to help Turners." [TSM2: mother, early 50s, divorced, 1 daughter in her mid-20s]*

In contrast to intrafamilial egg donation, OTF could achieve a genetically connected child while avoiding the emotional complexity of egg donation using a known donor.

> *"It's more straightforward than having donor egg from a family member, though, because it will be her own, the girl with Turners' own tissue, own genes." [TSM10: mother, mid-40s, married, 1 daughter under 10]*

Another perceived advantage of OTF was that it allowed a 'normal' experience of conception, pregnancy and birth, and in this way, she could fit in with her peers.

> *"I think that's amazing! If the girl's then got that option when she's older, to try, I think that's as close as she's ever going to get to what a normal woman would do." [TSW9: woman with TS, late 20s, single, no children]*

OTF was therefore linked with a sociotechnical "imaginary of possibility and choice" (Bach and Krolokke, 2019 p16) which could give (some) women with TS the option to choose to have a genetically-related child in later life. Participants had varying levels of knowledge about OTF, and most were not clear at what age it might need to be done, or its potential risks; both of these factors would be an integral part of any decision-making process. Those who did know more raised concerns such as the potential for this treatment to compromise a girl's future fertility. While this mother was open to considering reproductive preservation in childhood, she commented that her husband would have questioned whether it was worthwhile to put their daughter through unnecessary treatment with no definite benefits in later life, particularly given that one potential unwelcome side-effect of OTF could be to compromise their daughter's future fertility.

> *"It's a decision that you'd be having to make, to preserve the ovarian function for the future, when actually they might have had their own ovarian function in the future anyway. So, you're maybe halving the possibility of having an ovarian function in the future by taking out one." [TSM7: mother, mid-40s, married, 1 daughter and 1 son in their early 20s]*

One study on OTF (Berjonneau et al, 2017) identified parental guilt and normative expectations of sexuality and reproductive planning as motives in parents' decisions to involve their daughter in OTF: most parents in this small study supported the use of reproductive preservation technology but, in contrast to the present research, had not considered that their daughter might not want a male partner or might not want children. As with MEF, there are difficulties in anticipating what the girl with TS would want, when she becomes an adult.

For frozen ovarian tissue to be available in later life, parents must take action while their daughter is still a minor; the girl has little influence over the decision. They make the decision on her behalf and, according to bioethical theories, should exercise that power in her best interest. When considering OTF, a child's right to have fertility preservation has been described as a 'right in trust' (Jadoul et al. 2010); that is, the right to have future options kept open until she is able to make her own choice. According to bioethicists such as such as Davis (1997) and Feinberg (1992) (cited in Jadoul et al, 2010) parents and the state have a duty to protect a child's interests, and they are expected to safeguard that right until the child is an adult and can make her own decisions. Yet it is not necessarily easy to decide what is in a girl's best interest. Medical viability can be determined by evaluating the "efficacy, feasibility and risks" (Jadoul et al, 2010, p621) of a treatment and using it only if it is likely to be successful. OTF is not likely to be suitable for most girls with TS as they do not have viable eggs. Late diagnosis may mean that ovaries are non-viable at the point when TS is discovered. The success rates of this treatment are also a consideration: OTF is still considered to be experimental, and no fertility treatment can guarantee a safe pregnancy or a live birth. A treatment may be medically viable but inaccessible due to its cost. As a practical way to enable women with TS to have a child, OTF is currently very limited, but it may still be of use to some girls.

The responses to questions about OTF do not reflect the decisions that women may ultimately make if OTF was available and they were fully informed about its implications. However, looking more widely at the social context in which reproductive choices are made, some fertile women are choosing social egg freezing in response to the imagined future risk of infertility; fertile women who freeze eggs to be used with a future partner could be viewed as enacting 'responsible reproductive citizenship' (Carroll and Krolokke, 2018). Similarly, mothers of girls with TS are subject to similar kinds of social pressure to anticipate their daughter's future reproductive needs, which may intensify as the technology develops. The discussion about MEF demonstrates that many factors moderate the desire to have genetically-related family. However, it does suggest that when considering ARTs, women value having a genetic link, particularly where it is uncomplicated by third party involvement, and it gives a close to 'normal' experience of having a child.

6.6 Conclusion

The option of intrafamilial egg donation has created challenges for families, as they look for ways to accommodate new types of relationship that were not possible before ARTs became available, and ways to address the disruption to normative social and genetic relationships.

This chapter has shown that there are limits to the perceived family obligation for mothers to provide support to women with TS to have a family. In aiming to balance the desire to maintain a genetic link between family members and the perception that social and genetic family roles should be aligned, preference was often given to the option that was perceived as being least disruptive to the social family. Whereas MEF was perceived as potentially disruptive to family relationships, because of the potential risks of role confusion and coercion, the response to the option of OTF suggests that one of its main perceived benefits was to maintain the simplicity of normative family relationships by aligning social and genetic family relationships. The ideal solution to infertility was one which avoided the risk of intrafamilial conflict; for most of the women in this study, that made MEF a potentially risky choice.

Most women who were uncomfortable with MEF described this as stemming from concerns about role confusion. Although this could be related to the perceived priority of the genes in defining family relationships (Finkler, 2010), sibling egg donation poses similar problems and yet is much more widely accepted. The majority of the mothers who took part were either willing to freeze their eggs or felt that, if not MEF, they should take another form of action to protect their daughter's future fertility options. This suggests that MEF is at least partly driven by a sense of maternal responsibility that is increasingly being expressed through the use of ARTs. This chapter shows how the pressure on mothers could act as a motivation to freeze their eggs, and how, as a result, mothers of girls with TS extended their maternal responsibility not only to their daughter but to their grandchildren. These findings reinforce the findings of Chapter 5 in demonstrating how MEF could be used as a form of emotion management, potentially cushioning women with TS from some of the impact of an infertility diagnosis.

This chapter also shows the important role that future imaginaries play in decision-making when its outcome is uncertain and years in the future. Both MEF and OTF could be seen as options that exemplify 'biopreparedness' (Bach and Krolokke, 2019 p10) by enabling mothers to anticipate and potentially prevent or circumvent infertility through the use of reproductive technologies. Like other ARTs, OTF "rests on the imaginary of infertility as a potentially harmful situation and an unhappy future" (Bach and Krolokke, 2019 p14). The shared social understanding of infertility as a status to be avoided, together with the pressure mothers felt to do what they could to plan for their daughter’s reproductive future, rely on imaginaries about the desirability of maternity allied with imaginaries of appropriate maternal behaviour towards their child. Both women with TS and mothers of girls with TS described the behaviour of their ideal family – the ‘family we live by’ – and used this family imaginary to guide their decisions or to predict the outcome of a choice. This chapter has shown how MEF could work as a hope technology that enables mothers to provide for a potential future need and to feel they have done their best for their daughter; while that may be the limit of maternal duty, it also deferred the decision as to whether to use the eggs to the woman with TS, as a future adult.

The final chapter will draw together the three strands of theory and discuss the theoretical contribution of this thesis.

7 Conclusion

There has been considerable medical progress in treating the conditions associated with TS since it was first discovered in 1938. The reproductive options of women with TS have been increased not only by new reproductive technology but also by prior developments in medical treatment, which have made pregnancy safer for women with TS. The use of growth hormone increases women's height, helping to minimise pregnancy complications caused by short stature, while hormone treatment matures the womb, making it more likely for a woman with TS to carry a pregnancy to term (Abir et al. 200). Both of these treatments have important social and health implications for women with TS, independent of their role in increasing the viability of pregnancy. In the context of chronic illness, ARTs could be seen as the culmination of a series of normalising treatments aimed at addressing the ways in which women with TS differ from their peers throughout their life.

This study set out to address the following three research questions:

1. How women with TS perceive and navigate the decision to have a family and the potential associated health risks of pregnancy;
2. How mothers of girls with TS perceive and navigate decisions about their daughter's future reproductive options;
3. How technologies such as egg donation, egg freezing, and ovarian tissue freezing are perceived within families affected by TS.

It began by identifying a number of gaps in the literature. Existing research on the use of ARTs in the context of TS is heavily weighted towards medicine (Sandberg, 2018); while some research has described the impact of infertility on families affected by TS, it has not investigated the decision-making process itself. Medical literature has identified risks in pregnancy both to the woman and to the foetus (Abir et al., 2001; Calanchini et al, 2019; Hewitt et al, 2013; Mercadal et al., 2011;

Doger et al, 2015), and research has considered the way this affects choices in the general context of congenital heart disorders but has not looked at its impact in the context of TS (Dob and Yentis, 2006; Kovacs, 2008; Ngu et al, 2014; Peters et al, 2002). Most work on fertility preservation examines its use for social reasons while medical research focuses mainly on the context of cancer treatment (Morgan et al, 2019; Peddie et al, 2012; Yasmin et al, 2018). Few studies have explored the experiences and views of women with TS towards reproductive preservation options. Similarly, the ethical and medical implications of intrafamilial and intergenerational egg donation have been discussed, but there is little empirical work which describes how and why mothers make reproductive choices in this context, or on the reception of those choices: for example, how women with TS feel about the possibility of becoming mothers using their own mother's eggs (Haskovic et al, 2018). A very small body of qualitative research exists on patient views of ovarian tissue freezing (Lotz et al 2015).

It is these factors which make an investigation of reproductive decision making in the context of TS so necessary, particularly in understanding the timing challenges of living with TS and explaining the effect of new reproductive technologies on perceptions of choice, risk and maternal duty. In deciding if they should use reproductive preservation, mothers have to decide whether their daughter may wish to have a family in future without being certain about her preferences. Consequently, OTF and MEF can be used as an analytical lens to examine women's thinking on intrafamilial obligations, the importance of biological kinship, and perceptions of maternal and intrafamilial duty. Equally important is the role of family imaginaries in informing women's decisions, enabling them to consider the potential consequences, risks and benefits of their choices.

The original contribution of this thesis relates first of all to reducing the gap in knowledge in the under-researched area of reproductive decision making in the context of TS. It has addressed how, when and why women with TS decide to have a family and the way reproductive technology is perceived and understood in families affected by TS. It has explored the way that women with TS make reproductive choices and how choices are affected by factors such as their perception of the risks of pregnancy. It has also examined the way mothers of girls with TS perceive their role in managing decisions that affect their daughter's future reproductive choices, adding to very small bodies of qualitative literature on MEF and on the patient perception of OTF. It has looked at the challenges currently posed by ARTs, and the way social expectations of reproductive timing and preferences have framed the perceptions of women with TS and mothers of girls with TS. It has considered the factors that had an impact on reproductive choices, including perceptions of family obligation, timing and the structural factors that limited choice.

The thesis also extends the use of existing concepts in several new areas. It draws on Constructivist GT, which aims specifically at theory generation: research should provide an account that is explanatory rather than purely descriptive (Charmaz, 2014, p235), move forward existing thinking on the topic and concepts used in the data analysis, and show where it sits in relation to the existing literature (Charmaz, 2014, p30). The present study moves forward existing theorising about reproductive decision-making in the context of life with a genetic disorder in the following ways.

It extends thinking around the multiple ways in which social imaginaries of maternity, motherhood, hope, and responsibility work together to shape reproductive preferences and choices, and consequently, shows how they can influence decisions. Social imaginaries frame and guide the expectations that people hold for their life, both in the present and, in particular, in the future. They express shared social norms and because of this, conversely, also define what kinds of situations, choices and practices fall outside social norms, and what choices or circumstances are potentially stigmatised. The three findings and discussion chapters show how social imaginaries function in three different ways:

First, it looks at the impact of TS and its effect on reproductive timing. It shows how the concept of the 'curative imaginary' can be productively used as an analogy for infertility, describing both the stigma of infertility and the social pressure towards normalisation. The timing of decisions about MEF or OTF often meant that mothers of girls with TS needed to make decisions about their daughter's reproductive future when she was too young to express a view, and social imaginaries of motherhood and the motherhood mandate acted as pressure to use ARTs, or actively make other plans. Second, work from Novas and Rose (2000) and Crossley (2007) shows how the discourses of choice, responsibilisation and risk are used by women with TS to account for their decisions, in turn elucidating the way imaginaries of responsible motherhood and responsible behaviour towards a partner framed the way women considered their choices about disclosure and family formation and the potential consequences and risks. Third, by showing how intensive mothering (Faircloth and Gurtin, 2017) affects expectations of maternal duty in the context of infertility, and by discussing why this is balanced against the preference for a genetic connection when considering the use of intrafamilial egg donation. Imaginaries of the 'family we live by' (Gillis, 1996) described expectations of the way family should behave towards one another and affected views on whether it was appropriate for mothers and sisters to donate eggs, and for daughters to use them.

The thesis also contributes to methodological literature by showing how research designs can be adapted to better meet the specific needs of this participant group. The psychosocial and cognitive aspects of TS, such as social cognition issues and anxiety, may have an impact on participation, meaning that accommodations for these factors need to be incorporated into research design. The process of making adaptions was guided by the principles of Universal Design, as was the selection of the research method, photo elicitation interviews, combined with other adaptions that are described more fully in the published paper on this topic (Fearon, 2019). The use of relevant adaptions was intended to make participants feel more comfortable and ultimately able to participate more fully in the research interview. This proved to be a useful approach to planning and implementing adjustments to the research design, which could be used much more widely, particularly since the psychosocial implications of infertility are not limited to women with TS.

The remainder of this chapter provides a more detailed summary of the original empirical and methodological contributions made in this thesis.

7.1 TS, social imaginaries and reproductive timing

In the context of reproduction, the motherhood mandate (Russo, 1976) describes the expectation that every woman will become a mother, an expectation which stigmatises infertility and childlessness. The social imaginary of infertility is consequently one which anticipates a future of unhappiness, frustration and rejection by potential partners. In the context of TS, girls and women with TS differ from their peers as they are unable to conform in some important ways. Kafer's theory of 'crip time' (2013) builds on Garland Thompson's (2011) concept of misfitting, which describes the social expectation to conform with a normative life experience, where people who do not conform are stigmatised as 'misfits' rather than being seen as outliers or being viewed as another way to be normal. Crip time was used to show how both women with TS and mothers of girls with TS find ways to manage, circumvent and normalise the timing challenges of living with TS.

Crip time was elucidated using Kafer's three categories: strange temporalities, imaginative life schedules and eccentric economic practices. 'Strange temporalities' described how TS disrupts the expected social and physical timing for girls and in particular, how girls are faced with the challenge of coping with an infertility diagnosis at a young age. This thesis has described the way that courtesy stigma (Goffman, 1963) can apply to mothers in this context. Mothers of girls with TS described how their anticipated trajectory of motherhood was disrupted, as they had to help their daughters to address issues that were beyond the normative experience of their own peers who had unaffected daughters. Through reframing reproductive timing using 'imaginative life schedules', some single women with TS described how they were not prepared to wait for a partner before having children, and in this way took control of their reproductive timing in the same way as other single women who want to have a family (Lahad, 2012). 'Eccentric economic practices' (Kafer, 2013, p39), describes the use of a social network, or alternative methods of payment such as bartering, to extend the resources available to a disabled person who has limited finances. This thesis presents the non-normative reproductive option of intrafamilial egg donation as an eccentric economic practice, which potentially enables women with TS to achieve the normative ideal of having a genetically-connected child.

In demonstrating the future-focused thinking around reproductive decision making in the context of TS, this thesis has extended Kafer's (2013) concept of the curative imaginary to the case of infertility. Because decisions around reproductive preservation need to be made considerably in advance of their use, choices are of necessity future-focused and anticipatory. This research showed how, as a consequence, mothers relied on social expectations and social values around motherhood to guide their behaviour, sometimes feeling pressure to make decisions that made them uncomfortable. This thesis drew a parallel between the curative imaginary (Kafer, 2013), in which people who have the stigmatised condition of disability are expected to be working towards a cure, describing the way in which women with the stigmatised condition of infertility are expected to desire motherhood and to work towards becoming a mother, often using ARTs as a preferred family-building solution. This thesis shows how the concept of mandated motherhood (Russo, 1976) can be extended to mothers of girls with TS, coining the term 'courtesy mandated motherhood', to describe the way that the social pressure and anticipated future distress, blame and stigma of infertility could pressure mothers into feeling they needed to provide for their daughter's reproductive future. In this way, this thesis extends the application of future-focused concepts based on imaginaries of motherhood, such as the motherhood mandate and anticipated decision regret (Tymstra, 2007), from women and couples making decisions on their own behalf. to mothers making choices about treatment which affects their child.

7.2 Framing reproductive choices

Imaginaries of responsible citizenship, motherhood and reproductive planning informed the way women with TS weighed their decision to disclose to a partner and their preference of how and when to become a mother; women used imaginaries to consider what responsible behaviour would look like in their particular situation, and to strategise about how to achieve the outcome they wanted in a way which demonstrated their choices were responsible. This was particularly relevant in the discussion of risk, whether it related to the risk of treatment, infertility or rejection by a partner: women felt that, as a responsible citizen, they should anticipate and plan for these risks.

Most of the women who took part in this study felt it was important for women with TS to have a choice of reproductive options, including the option to carry a pregnancy, despite the known risks. This study shows how the anticipated future availability of ARTs works as a hope technology (Franklin, 1997) and so can be used for emotion management, both to soften the blow of an infertility diagnosis and to keep alive the hope of becoming a mother in the future.

Using the language of choice is part of an 'individualising discourse' (Lahad and Hvidtfeldt, 2019, p100) which presents individuals as personally responsible for their health and life changes, and where choice is presented as a form of personal empowerment (Novas and Rose, 2000). Crossley's (2007) concepts of 'situated freedom' and 'genuine choice' were used to examine whether and to what extent women with TS have agency in making reproductive choices. Women with TS used the language of choice and responsibility, even when describing the limitations of their situation; the valorisation of choice was not solely related to the importance of enabling a woman with TS to become a mother, but also to helping her manage her emotions around infertility.

This thesis extends the concept of 'psychological IVF' (Adrian, 2015) which describes how couples having fertility treatment to conceive their own child may use IVF as an emotion management tool. It has shown how, when mothers freeze eggs for their daughter's future use, this provides the daughter with a choice of family-building options, helping her to manage an infertility diagnosis and giving her hope that she may have a genetically-related child in future. More generally, mothers used the availability of family-building options to empower their daughters by showing that they have a choice, and to reassure girls they can become a mother. In this way, psychological IVF is extended from IVF alone to family-building options more generally, including adoption. Mothers were concerned not only about their daughter's ability to have a family in the future but also her distress at the infertility diagnosis and the possibility that they might be blamed if their daughter thought their mother had not done enough. MEF may also perform a function for mothers who wish to freeze their eggs, showing that they have gone to the greatest possible lengths to support their daughter, thereby maintaining their relationship.

In practice women's choices were often limited by a lack of information about risks, the preferences of their partner, and their physical health, as well as structural factors like the cost of ARTs. In addition, egg freezing and OTF are only suitable for a subset of women who have the mosaic form of TS, within a window of time when they are still fertile. Yet the dilemmas raised by the availability of treatment have a wider impact: most ARTs are widely known and discussed within the TS community, and women had a view on the technology regardless of whether it was available to them or whether they would have chosen it. These choices rely on a social context where the use of fertility treatment is normalised and where there is pressure to use a treatment simply because it is available (Franklin, 1997), the so-called technological imperative. Women with TS may need support to resist the normalisation of ARTs because of their greatly increased risk in pregnancy. Decisions are taken in a social context in which genetic relatedness is highly valued and where the practice of intensive mothering (Faircloth and Gurtin, 2017) has changed expectations of mothering behaviour so that (middle class) mothers feel pressure to plan for their daughter's long-term reproductive future in the same way as they might for other aspects of their future success, such as education.

Furthermore, TS-related biosocial groups both share information and personal experiences of treatments and ensure that women with TS are informed about their choices; they can be a source of pressure on both mothers of girls with TS and women with TS to prefer a particular family-building option.

Despite the frequent use of the language of choice, in practice women's choices were informed by their social setting and limited by the structural factors which impeded them from taking their preferred option. This thesis shows how, through the pressure on mothers to freeze their eggs, responsibilisation of mothers of girls with TS extended their maternal responsibility from caring for their daughter and planning for her future reproductive options to enabling the birth of grandchildren.

7.3 Family solidarity

The present study explored the way family solidarity worked to support women with TS in having a family, focusing on the way new reproductive technologies can generate new pressures and constraints on families. These are guided by imaginaries of family life: the existing 'family we live with' and the imaginary of the 'family we live by' (Gillis, 1996) or the ideal family that people often used as a reference point when making decisions.

This thesis has presented insights into the discussions currently taking place within communities where intrafamilial egg donation is widely discussed as a potential option, showing how concepts of family obligation have been used to understand and explore a range of ARTs (Dykstra et al, 2000; Mason, 2008; Morgan, 1996; Smart, 2007). It has shown how, in some families, there is an assumed sense of solidarity between family members that may be used to increase fertility options. Mothers who had considered talking to their unaffected daughter about becoming a donor, or having a second daughter who could potentially donate eggs to their daughter with TS, knew that ultimately, their adult daughters would make the decision. However, they felt that the existence of a family relationship between two siblings would make this outcome more likely, and some felt they should take action to enable this, where it was feasible.

This study adds to the very small body of literature on the acceptance of MEF within families, the reasons why mothers might choose it, and the way daughters might feel as potential recipients. It supports and extends the findings of previous studies in identifying genetic closeness and availability of donated eggs as the main perceived advantages, and in identifying role confusion as a potential disadvantage, particularly with mother-daughter donation, due to the perceived impact of the pre-existing intergenerational family hierarchy (Haskovic et al, 2018). However, the findings of the present study differ from that of Haskovic et al (2018), which identified that mothers felt a moral obligation to freeze their eggs, while daughters said they would not feel an obligation to use frozen maternal eggs. In the present study, the worry that women with TS may feel coerced into using frozen maternal eggs was one of the main concerns attached to MEF, with both women with TS and mothers of girls with TS expressing this view.

Women who took part in this study perceived MEF as, in general, springing from caring maternal impulses that were seen as normal for mothers. Freezing maternal eggs was also seen by some mothers as a maternal duty, demonstrating how intensive mothering (Faircloth and Gurtin, 2017) has affected not only everyday parenting practices but can extend to planning for a child's future fertility. This was evident in the pressure that some mothers felt when they did not want, or were not able, to freeze their eggs. The obligation to offer maternal eggs was seen as an understandable (if often unacceptable) extension of the mother's maternal role but this obligation was unidirectional. The daughter was not perceived as having an obligation to use the eggs, although most women in this study acknowledged that situational factors such as the quality of the family relationship, feelings of guilt and filial duty, would complicate this choice. Attitudes towards MEF illustrate the fluidity of kinship obligations, as some women found it acceptable and others did not.

While the potential for a woman with TS to have a genetically-related child was highly valued, this thesis has demonstrated that many women in this study did not privilege maintaining a genetic connection at the expense of social factors, such as a strong family relationship between the donor and recipient. In this context, the preference for anonymous gamete donation (or another reproductive option) could be seen as an indication of a boundary of family solidarity within a family. In a social context where women with TS are perceived as having a very close relationship with their mothers, some suggested that women would want to avoid the perceived rejection of their mother's gift if they declined to use frozen maternal eggs. The quality of the existing relationship was also described as a factor: women with TS were not willing to accept eggs from family members with whom they already had a troubled relationship; often the preference for an anonymous donor was related to a wish to reduce the social complexity of using donor gametes and to minimise the potential for conflict within the family.

This thesis adds to a small body of existing literature on the patient understanding of OTF and the reasons women may find it a useful treatment. Because few of the women who took part had heard of OTF, and some expressed concerns that would be addressed in fertility counselling sessions if this treatment was more widely available, the findings of the present study can only be considered as a spontaneously-constructed opinion which illuminates participants' underlying values. Furthermore, girls with TS are differently situated than other girls and women for whom this is a potential treatment; many of the girls currently being treated with OTF are facing a life-threatening illness, while there are questions both about the heritability of TS and the impact of OTF on future fertility (El-Shawarby et al, 2010). MEF and OTC can be seen as a form of 'anticipatory biomedicine' (van de Wiel, 2014; Bach and Krolokke, 2020) in which ARTs can be used to maintain the potential for motherhood in the future, using imaginaries of ideal family-formation and mandated maternity to reason that this is a wise step to take on behalf of a girl who may be too young to express an informed view. This is evident in the findings of the present study which suggest OTF is valued over other forms of ART because it would enable the mother and child to have a direct genetic link; it would align the genetic and social relationship, not only between mother and child, but between the mother, child and other family members. Unlike intrafamilial donation, it would not introduce complex social interrelationships into the family which may have the potential to cause conflict, and which could therefore threaten family unity. Participants expressed concerns about treatment practices, such as the age at which ovarian tissue would need to be collected, and a more informed knowledge of these factors is likely to produce more nuanced views around the practice of OTF.

7.4 Suggestions for future research

This study has prioritised the experience of women with TS and mothers of girls with TS in seeking to understand more about the decision-making process in the context of TS and how it affects the family, but gaps in the sample (Chapter 3, section 3), show that this thesis presents a partial picture. Furthermore, the imbalance between the quantity of medical literature on TS and qualitative literature on the lived experience of TS suggests that more research attention should be paid to women with TS and their families. Exploring the experience of groups not included in this study present opportunities for further research, such as:

- Research that includes fathers of girls with TS (or, more generally, of children with compromised fertility) to explore their input into reproductive decisions.
- Research that includes partners of women with TS, to examine the impact of TS on their joint reproductive decisions.
- An exploration of the applicability of these findings to other chronic childhood illnesses that affect fertility, such as Klinefelter Syndrome.
- Research that is able to recruit more widely within the TS community in order to include the views and experience of women with TS who are not white and middle class.

7.5 Suggestions for amendments to policy and practice

Women with TS and their families and partners reported that they were not always clear about the risks linked to the technologies. Although the extent of the risk does depend on the way in which an individual woman with TS has been affected by the syndrome, clearer and more personalised information about the risks of reproductive options, including guidance on the potential to become an adoptive single parent, would be helpful.

A number of mothers of girls with TS discussed how they had intervened at their daughter's school to ensure that her sex education lessons were inclusive of girls who did not have periods naturally and women who would not conceive naturally. Given the number of couples who cannot conceive naturally, whether due to conditions discovered in childhood or in adult life, the topics of infertility and delayed puberty should be incorporated into sex education lessons as a matter of routine.

Although intrafamilial donation has been practiced for several decades (Lessor et al, 1993) the HFEA does not collect statistics on its prevalence; it is difficult to contextualise the practice without knowing how widespread it is, or whether patterns of use are changing. Information about changing family practices would be of use to fertility counsellors and clinicians as well as researchers.

Currently, ethical guidance on intrafamilial gamete donation does not always discuss the implications of variance in family form, affinity or perceived family duties on the voluntary nature of donation and the perceived harm to donors or recipients (see for example, ASRM, 2003). This thesis has demonstrated that, within the same culture, views vary on the social implications of kin relationships; it has identified that there is a risk of stigma for holding what are currently minority views on the use of some reproductive technologies, such as having positive attitudes to MEF. It would be timely to review guidance to explicitly incorporate references to different social and cultural family practices.

7.6 Conclusion

The availability of ARTs such as egg donation, egg freezing and ovarian tissue freezing have added complexity to reproductive decision making in the context of TS, a complex chronic health condition, by presenting women with the option to have a pregnancy which is likely to be high risk. ARTs also present choices which potentially impact the social relationships within the family, raising questions about intrafamilial obligations in the context of infertility caused by a chronic illness diagnosed in childhood.

In the existing research on the use of ARTs such as MEF, the complexities are speculative and based on a small number of studies on intergenerational egg freezing which either briefly describe case histories or elicit opinions from a potentially affected population. To date, there are no follow up studies on families created from frozen maternal eggs in which to contextualise these views. Women who took part appeared to be applying their existing, and varied, social values around family to inform their decisions, or their views about what they would or should do. This thesis shows the influential nature of future imaginaries when making reproductive choices in the absence of either personal experience or evidence based on empirical studies. In a social context where it is expected that women will become mothers, and where mothers feel pressure to plan for their daughter's future fertility, decisions are based on anticipating the future desire to become a mother and with it the associated risk, blame or relationship complications of making the wrong choice.

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Appendix 1 – Literature search strategy

Literature searches were undertaken throughout the research project. When focusing on an area where non-medical literature is so limited, searches were not restricted by time or discipline; anything in the English language that looked relevant was checked.

Relevant databases such as CINAHL, Scopus, PsychInfo, Google Scholar, Web of Science and EBSCO Host were searched regularly. Subject alerts were set up and checked weekly. Relevant articles were also sourced from snowball reference searches and citation searches of relevant articles, and by recommendation.

Google alerts

[[intrafamilial OR family OR maternal OR mother OR known] [egg OR oocyte donation]]
[[["turner syndrome"] or ["turner's syndrome"]]]
[[reproduct? and [decision making OR decision-making OR decisionmaking]]]
[[egg OR oocyte OR ovary] [freezing OR cryopreservation]]
["turner syndrome" learning disabilit?]

Zetoc alerts

Zetoc Alerts were set up for the following journals. Alerts were delivered weekly by email and if the abstract of an article was relevant, the article was downloaded for later reference.

- BMC Women's Health
- Culture, Health and Sexuality
- Fertility and Sterility – International Edition
- Human Reproduction Update
- Journal of Assisted Reproduction and Genetics
- Journal of Community Genetics

- Journal of Obstetrics and Gynaecology
- Journal of Reproduction and Development
- Society of Reproduction and Fertility Supplement
- Sociology of Health and Illness
- Social Science and Medicine

Human Fertility is not in Zetoc but articles in this journal appeared in other searches.

Search terms: maternal egg freezing

intergenerational "egg freezing"
intergenerational "egg donation"
intergenerational "gamete donation"
"maternal egg freezing"
"maternal egg donation"
medical "egg freezing"
"sibling egg donation"
intrafamilal "gamete donation"
intrafamilial "egg freezing"

NB: Most intergenerational egg freezing explores daughter to mother donation.

Search terms: ovarian tissue freezing

“ovarian tissue” freezing
“ovarian tissue” cryopreservation
“turner syndrome” “ovarian tissue” freezing
“turner syndrome” “ovary freezing”

Comparator illness search terms

Some comparator illnesses were also searched, chosen with guidance from and grateful thanks to Prof Ilana Löwy.

"maternal egg donation" cancer
"maternal egg freezing" cancer
"intrafamilial egg donation" cancer
intergenerational "egg donation" cancer
“Noonan Syndrome” + pregnancy OR maternity OR motherhood OR repro? “decision making”
phenylketonuria + pregnancy OR maternity OR motherhood OR repro? “decision making”
“Congenital adrenal hyperplasia” + pregnancy OR maternity OR motherhood OR repro? “decision making OR birth OR fertility”

Thesis searches

Searches for recent theses were made on DORA, DMU’s institutional repository, and on ETHOS, the British Library index of doctoral theses. Along with standard literature searches, this produced a very small number of directly relevant but unpublished dissertations and PhD theses. Due to the small number of published journal articles that relate directly to the topic of the thesis, some have been included in the literature.

Bawn, R. (2016) *The Use of Assisted Reproductive Technologies in Managing Genetic Risk: Intergenerational Oocyte Donation and Freezing in Turner Syndrome* Unpublished dissertation (BA) University of Durham.
Carroll, N. (2015) *Telling the Truth about Turner Syndrome: Disclosure of a diagnosis and infertility to a romantic partner*. Unpublished dissertation (MSc) Brandeis University.
Collin, J. (2013) *The Perceived Information needs of Girls with Turner Syndrome and Their Parents*. Unpublished dissertation (PhD) The University of Manchester.
Pellatt, J. C. (2005) *Living with Turner syndrome: the challenges and experiences of chronic ill health, body-image and infertility*. Unpublished dissertation (PhD) University of East London

Appendix 2 – Online advertising

Online advertising was used to recruit participants for this study. According to research by Ofcom (Great Britain. Office of Communications, 2019), Facebook is the most popular social media site: around 70% of UK internet users use Facebook at least once a month). In 2018 there were approximately 23M Facebook users aged 18-54 (Sweney, 2018). The number of people who do not use the internet increases with age, with 19% in the age group 54 or older never using the internet (Great Britain. Office of Communications, 2019) although 5.5M Facebook users are 55 or over (Sweney, 2018). So, even when advertising is targeted to all age groups, it is more likely to be seen by younger people.

a) Facebook advertising

Facebook advertising was used to recruit both the pilot sample and the main sample. The advertising was targeted to users who identified as women and by location; this was driven by two factors: local to DMU, Leicester, and local to the area where another interview had already been arranged.

Facebook advertising for the pilot sample targeted users who listed 'Turner syndrome' as an additional interest. After the pilot sample had been recruited, this option was removed, and it was no longer possible to target that way.
The target engagement was set as 'clicks', i.e. links to the website, but people who commented on the adverts were also contacted to ask if they wished to take part. Engagements came from adverts in the news feed so advertising in the right column was discontinued.

Pilot sample: 25 Oct 2016–1 Nov 2016

- Target: both groups in the sample
- Women 18-65 within 40km of Birmingham, Kettering, Leicester, Northampton, Nottingham
- Additional interests: Turner Syndrome
- Facebook news feed

- Reach: 363
- Engagement (likes/comments) 97
- Linked to the research website

Pilot sample: 21 November 2016 - 30 November 2016

- Target: women with classic TS
- Women 18-65 within 40km of Birmingham, Derby
- Additional interests: Turner Syndrome
- Facebook news feed
- Reach: 943
- Engagement (clicks) 24
- Linked to the research website

Main sample: 8 May 2017 – 8 May 2017 (daytime only)

- Target: both sample groups
- Women 18-50 within 40km of Birmingham, Derby, London, Sheffield
- Friends of people who 'like' the project 's Facebook page
- Facebook news feed, Facebook right column
- Reach: 1245
- Engagement (clicks) 23
- Linked to the research website

Main sample: 31 May 2017 – 3 June 2017

- Target: both sample groups
- Women 18-65 within 40km of Edinburgh, Galashiels
- Facebook news feed, Facebook right column
- Reach: 48
- Engagement (clicks): 4
- Linked to the research website

Main sample: 1 July 2017 – 3 July 2017

- Target: both sample groups
- Women 18-65 within 40km of Birmingham, Kettering, Leicester, Northampton, Nottingham
- Facebook news feed
- Reach: 402
- Engagement (clicks): 13
- Linked to the Voice advert

Main sample: 17 July 2017 – 19 July 2017

- Target: both sample groups
- Women 18-65 within 40km of Leeds, York
- Facebook news feed, Facebook right column
- Reach: 1495

- Engagement (clicks): 49
- Linked to the research website

Main sample: 25 October 2017 – 27 October 2017

- Target: mothers
- Women 18-65
- Facebook news feed
- Reach: 55
- Engagement (clicks): 5
- Boosted Facebook post

b) Advertising in *The Voice*

An advertorial was placed in *The Voice Newspaper* in June 2017. They also linked to it on their Facebook page, which had 600,000 followers at the time. No figures are available for the number of people who viewed the advertorial or promotional Facebook post.

LATEST NEWS: REVIEW: R&B rising star Mahalia makes her debut

Appeal To Women With Turner Syndrome To Partake In Research

Researcher Kristine Fearon offers details on how to get involved with study about the implications of starting a family for women with the condition

02/06/2017 05:30 PM

ARE YOU a woman with Turner syndrome (TS), or the mum of a girl with TS? Would you mind talking in confidence to a researcher about your thoughts on having a family?

I'm based at De Montfort University in Leicester, and my research explores how women with TS make decisions about how to have a family, what they think about the options they have, and the reasons they may or may not choose their option they prefer.

The choices people make can be affected by factors that are unique to that person and their situation: what their family thinks, what their partner or husband would like, the financial cost, and personal ethical or religious beliefs. There is very little research which looks at what women with TS think of the choices they have, and the reasons they may or may not choose them.

I'm also talking to mums of girls with TS, for two reasons: mums are usually concerned about their daughter's future fertility from an early age, and some mums have frozen eggs for their daughter's use in later life. I want to see what mums think of their daughter's options for having children, and how this is handled within the family.

If you're a woman with TS or mum of a girl with TS, and you've thought about or decided what to do about having children, whatever your choice, I would love to hear what you have to say.

The research is completely confidential and anonymous. If you're interested, please get in touch. You can find out more without feeling any obligation to take part.

Email: p15193445@my365.dmu.ac.uk
Web: http://turner-study.wixsite.com/ts-decisions
Facebook: https://www.facebook.com/tsdecisions/posts/1353866011370783

Read every story in our hardcopy newspaper for free by downloading the app.

Posted on: 02/06/2017 05:30 PM

Voice Newspaper
2 June 2017 ·

Turner Syndrome and reproductive decision-making, UK appeals to women with Turner syndrome to partake in research

VOICE-ONLINE.CO.UK

Appeal to women with Turner syndrome to partake in research

5 · 1 share

Appendix 3 – Ethics form

For Office Use Only: Date Submitted: ______________ Resubmission: _______ Ref: ____________

DE MONTFORT UNIVERSITY LEICESTER

De Montfort University
Faculty of Health & Life Sciences
Faculty Research Ethics Committee

APPLICATION FORM

TO GAIN APPROVAL FOR ACTIVITIES INVOLVING
HUMAN RESEARCH or HUMAN TISSUE RESEARCH

PLEASE READ SUBMISSION GUIDELINES BEFORE COMPLETING THIS FORM

Submission guidelines
(Oct 2013).docx

Further information and application forms are available at http://www.dmu.ac.uk/research/ethics-and-governance/faculty-specific-procedures/health-and-life-sciences-ethics-procedures.aspx.

For further information or advice please contact the Research and Commercial Office, Faculty of Health and Life Sciences, 1.25 Edith Murphy House, Phone: 0116 2506122 / 0116 2577891 or email: hlsfro@dmu.ac.uk

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1. Applicant name:

Kristine Fearon

2.Postal & email address:

106 Dunton Street
Woodgate
Leicester LE3 5EN

3. Supervisor(s) or co-applicants:

Cathy Herbrand, Nicky Hudson, Irenee Daly

4. Programme (if applicable):

Applied Social Science

5. Title of Research Project:

Turner Syndrome and reproductive decision-making: an exploratory study

6. Start date for the project:

October 2015

7. Expected end date for the project:
(FREC/RCO must be advised upon completion)

September 2018

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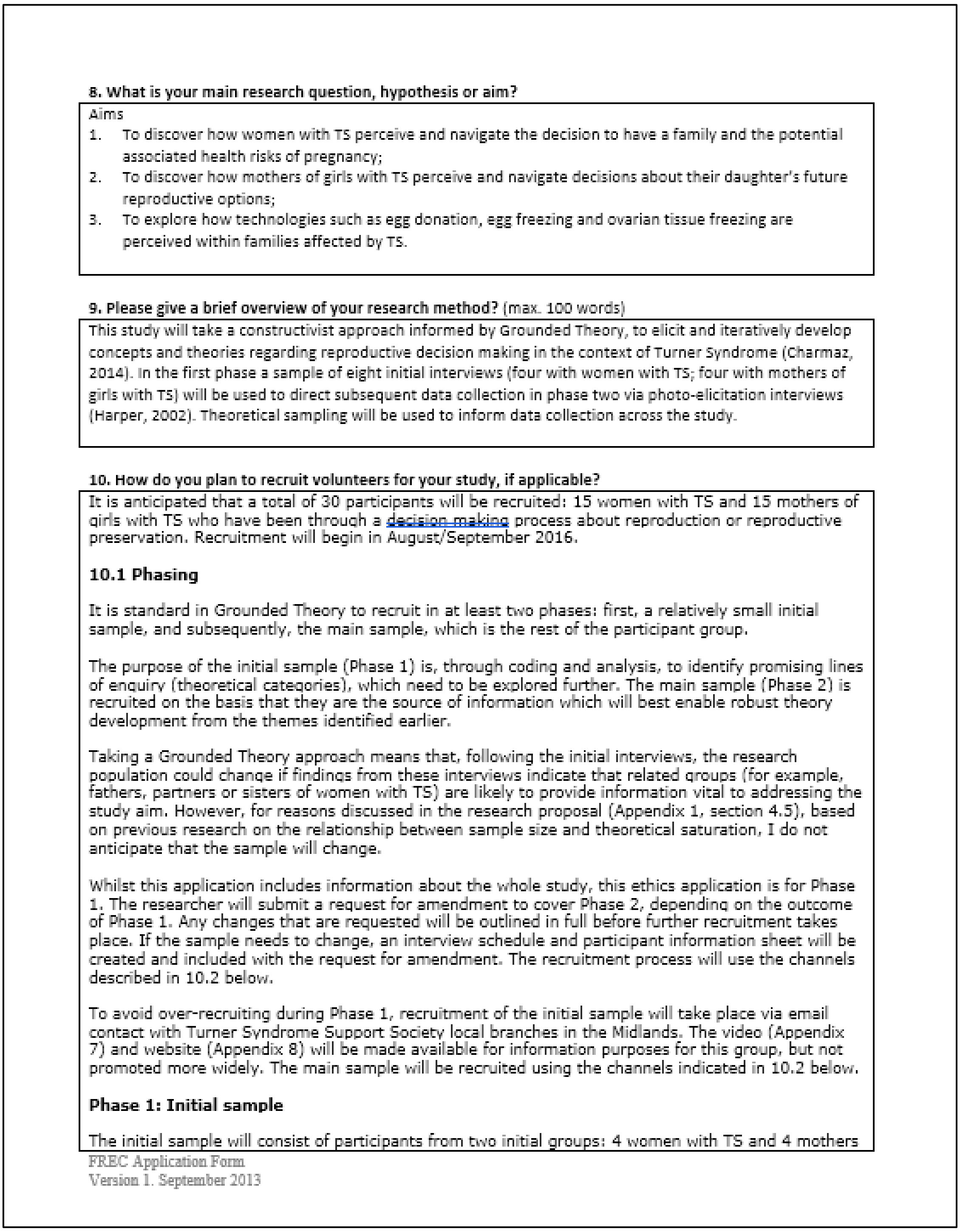
Version 1. October 2013



8. What is your main research question, hypothesis or aim?

Aims

1. To discover how women with TS perceive and navigate the decision to have a family and the potential associated health risks of pregnancy;
2. To discover how mothers of girls with TS perceive and navigate decisions about their daughter's future reproductive options;
3. To explore how technologies such as egg donation, egg freezing and ovarian tissue freezing are perceived within families affected by TS.

9. Please give a brief overview of your research method? (max. 100 words)

This study will take a constructivist approach informed by Grounded Theory, to elicit and iteratively develop concepts and theories regarding reproductive decision making in the context of Turner Syndrome (Charmaz, 2014). In the first phase a sample of eight initial interviews (four with women with TS; four with mothers of girls with TS) will be used to direct subsequent data collection in phase two via photo-elicitation interviews (Harper, 2002). Theoretical sampling will be used to inform data collection across the study.

10. How do you plan to recruit volunteers for your study, if applicable?

It is anticipated that a total of 30 participants will be recruited: 15 women with TS and 15 mothers of girls with TS who have been through a decision making process about reproduction or reproductive preservation. Recruitment will begin in August/September 2016.

10.1 Phasing

It is standard in Grounded Theory to recruit in at least two phases: first, a relatively small initial sample, and subsequently, the main sample, which is the rest of the participant group.

The purpose of the initial sample (Phase 1) is, through coding and analysis, to identify promising lines of enquiry (theoretical categories), which need to be explored further. The main sample (Phase 2) is recruited on the basis that they are the source of information which will best enable robust theory development from the themes identified earlier.

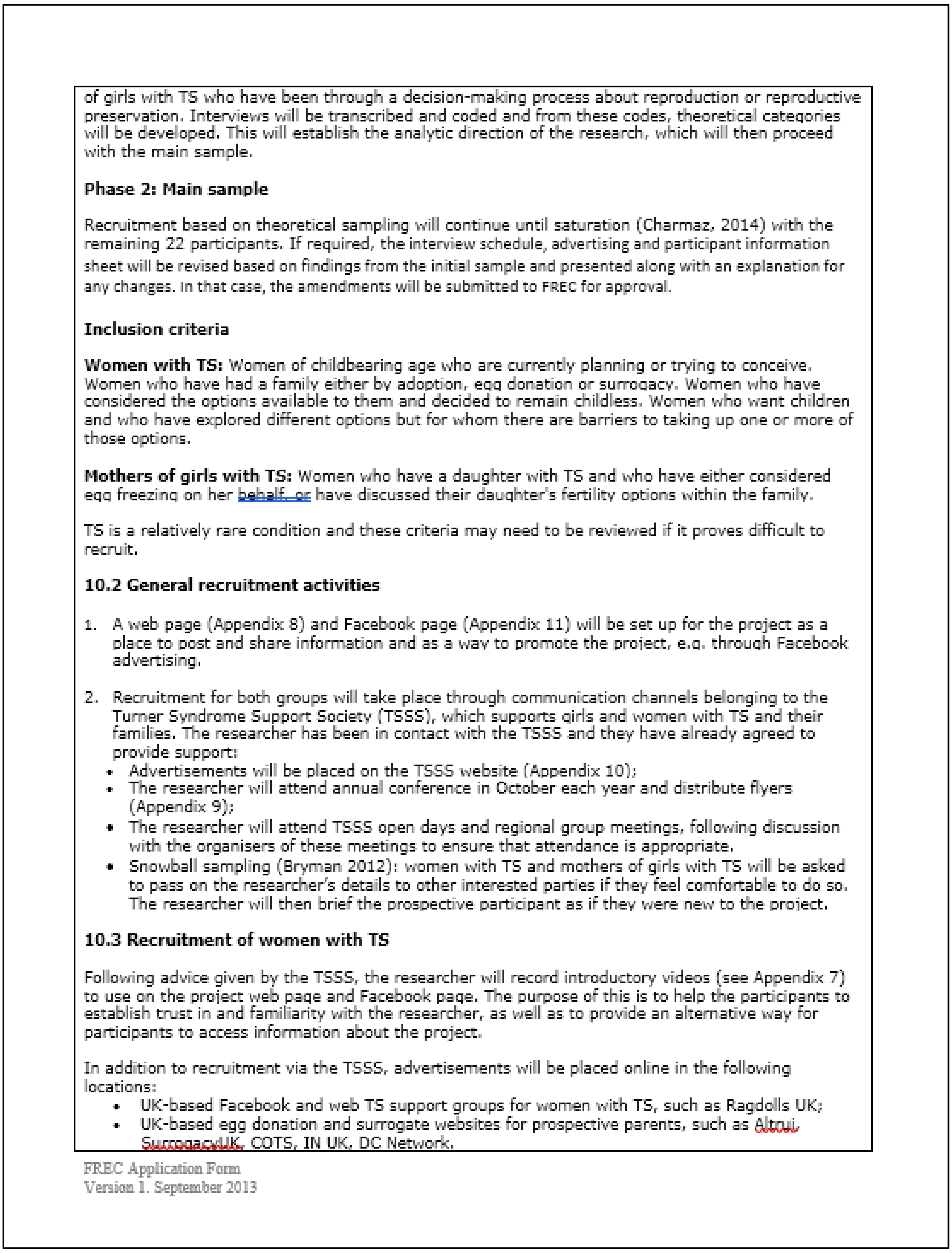
Taking a Grounded Theory approach means that, following the initial interviews, the research population could change if findings from these interviews indicate that related groups (for example, fathers, partners or sisters of women with TS) are likely to provide information vital to addressing the study aim. However, for reasons discussed in the research proposal (Appendix 1, section 4.5), based on previous research on the relationship between sample size and theoretical saturation, I do not anticipate that the sample will change.

Whilst this application includes information about the whole study, this ethics application is for Phase 1. The researcher will submit a request for amendment to cover Phase 2, depending on the outcome of Phase 1. Any changes that are requested will be outlined in full before further recruitment takes place. If the sample needs to change, an interview schedule and participant information sheet will be created and included with the request for amendment. The recruitment process will use the channels described in 10.2 below.

To avoid over-recruiting during Phase 1, recruitment of the initial sample will take place via email contact with Turner Syndrome Support Society local branches in the Midlands. The video (Appendix 7) and website (Appendix 8) will be made available for information purposes for this group, but not promoted more widely. The main sample will be recruited using the channels indicated in 10.2 below.

Phase 1: Initial sample

The initial sample will consist of participants from two initial groups: 4 women with TS and 4 mothers



of girls with TS who have been through a decision-making process about reproduction or reproductive preservation. Interviews will be transcribed and coded and from these codes, theoretical categories will be developed. This will establish the analytic direction of the research, which will then proceed with the main sample.

Phase 2: Main sample

Recruitment based on theoretical sampling will continue until saturation (Charmaz, 2014) with the remaining 22 participants. If required, the interview schedule, advertising and participant information sheet will be revised based on findings from the initial sample and presented along with an explanation for any changes. In that case, the amendments will be submitted to FREC for approval.

Inclusion criteria

Women with TS: Women of childbearing age who are currently planning or trying to conceive. Women who have had a family either by adoption, egg donation or surrogacy. Women who have considered the options available to them and decided to remain childless. Women who want children and who have explored different options but for whom there are barriers to taking up one or more of those options.

Mothers of girls with TS: Women who have a daughter with TS and who have either considered egg freezing on her behalf, or have discussed their daughter's fertility options within the family.

TS is a relatively rare condition and these criteria may need to be reviewed if it proves difficult to recruit.

10.2 General recruitment activities

1. A web page (Appendix 8) and Facebook page (Appendix 11) will be set up for the project as a place to post and share information and as a way to promote the project, e.g. through Facebook advertising.
2. Recruitment for both groups will take place through communication channels belonging to the Turner Syndrome Support Society (TSSS), which supports girls and women with TS and their families. The researcher has been in contact with the TSSS and they have already agreed to provide support:
   - Advertisements will be placed on the TSSS website (Appendix 10);
   - The researcher will attend annual conference in October each year and distribute flyers (Appendix 9);
   - The researcher will attend TSSS open days and regional group meetings, following discussion with the organisers of these meetings to ensure that attendance is appropriate.
   - Snowball sampling (Bryman 2012): women with TS and mothers of girls with TS will be asked to pass on the researcher's details to other interested parties if they feel comfortable to do so. The researcher will then brief the prospective participant as if they were new to the project.

10.3 Recruitment of women with TS

Following advice given by the TSSS, the researcher will record introductory videos (see Appendix 7) to use on the project web page and Facebook page. The purpose of this is to help the participants to establish trust in and familiarity with the researcher, as well as to provide an alternative way for participants to access information about the project.

In addition to recruitment via the TSSS, advertisements will be placed online in the following locations:

- UK-based Facebook and web TS support groups for women with TS, such as Ragdolls UK;
- UK-based egg donation and surrogate websites for prospective parents, such as Altrui, SurrogacyUK, COTS, IN UK, DC Network.

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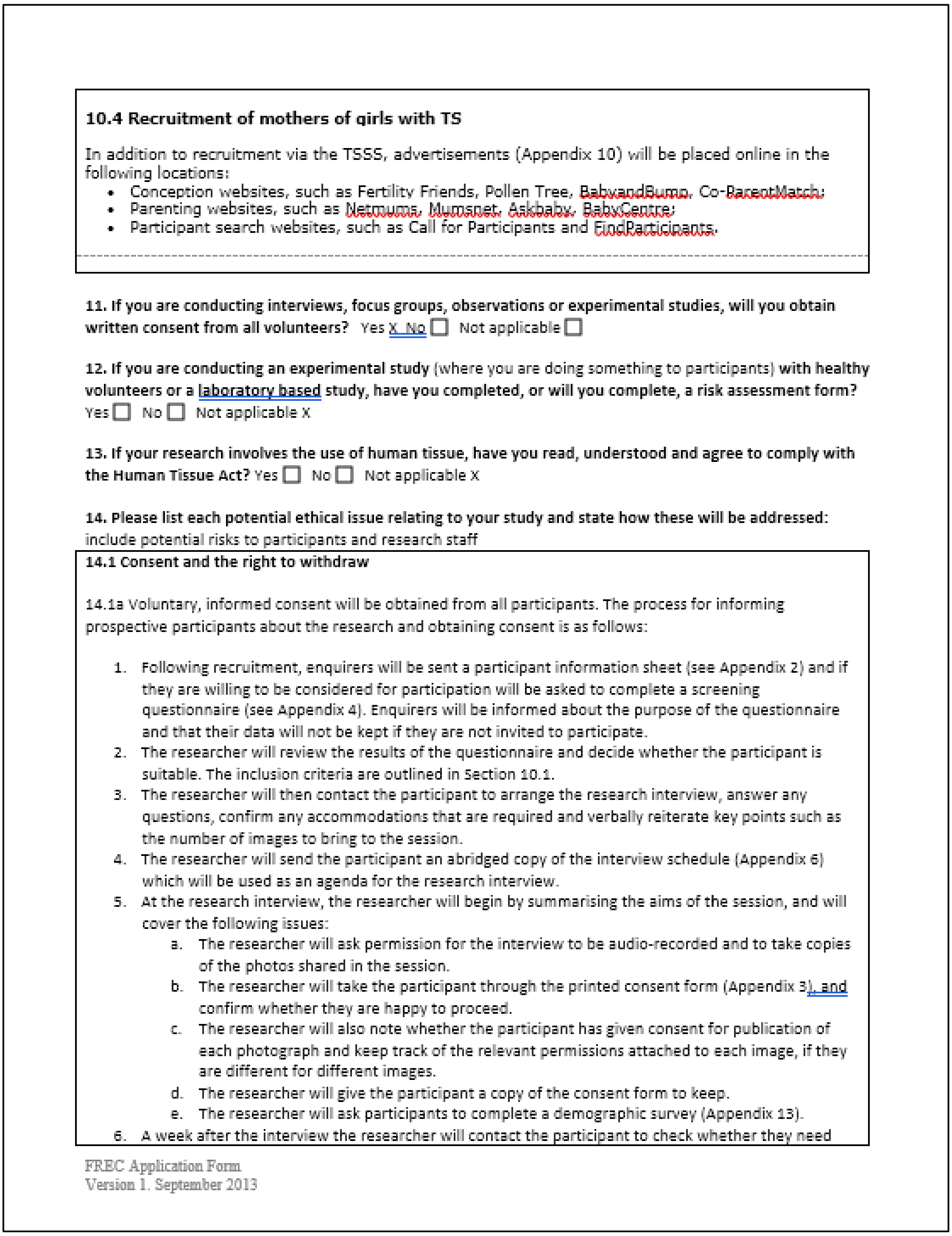

10.4 Recruitment of mothers of girls with TS

In addition to recruitment via the TSSS, advertisements (Appendix 10) will be placed online in the following locations:

- Conception websites, such as Fertility Friends, Pollen Tree, BabyandBump, Co-ParentMatch;
- Parenting websites, such as Netmums, Mumsnet, Askbaby, BabyCentre;
- Participant search websites, such as Call for Participants and FindParticipants.

11. If you are conducting interviews, focus groups, observations or experimental studies, will you obtain written consent from all volunteers? Yes X No ☐ Not applicable ☐

12. If you are conducting an experimental study (where you are doing something to participants) **with healthy volunteers or a laboratory based study, have you completed, or will you complete, a risk assessment form?**
Yes ☐ No ☐ Not applicable X

13. If your research involves the use of human tissue, have you read, understood and agree to comply with the Human Tissue Act? Yes ☐ No ☐ Not applicable X

14. Please list each potential ethical issue relating to your study and state how these will be addressed: include potential risks to participants and research staff

14.1 Consent and the right to withdraw

14.1a Voluntary, informed consent will be obtained from all participants. The process for informing prospective participants about the research and obtaining consent is as follows:

1. Following recruitment, enquirers will be sent a participant information sheet (see Appendix 2) and if they are willing to be considered for participation will be asked to complete a screening questionnaire (see Appendix 4). Enquirers will be informed about the purpose of the questionnaire and that their data will not be kept if they are not invited to participate.
2. The researcher will review the results of the questionnaire and decide whether the participant is suitable. The inclusion criteria are outlined in Section 10.1.
3. The researcher will then contact the participant to arrange the research interview, answer any questions, confirm any accommodations that are required and verbally reiterate key points such as the number of images to bring to the session.
4. The researcher will send the participant an abridged copy of the interview schedule (Appendix 6) which will be used as an agenda for the research interview.
5. At the research interview, the researcher will begin by summarising the aims of the session, and will cover the following issues:
    a. The researcher will ask permission for the interview to be audio-recorded and to take copies of the photos shared in the session.
    b. The researcher will take the participant through the printed consent form (Appendix 3), and confirm whether they are happy to proceed.
    c. The researcher will also note whether the participant has given consent for publication of each photograph and keep track of the relevant permissions attached to each image, if they are different for different images.
    d. The researcher will give the participant a copy of the consent form to keep.
    e. The researcher will ask participants to complete a demographic survey (Appendix 13).
6. A week after the interview the researcher will contact the participant to check whether they need

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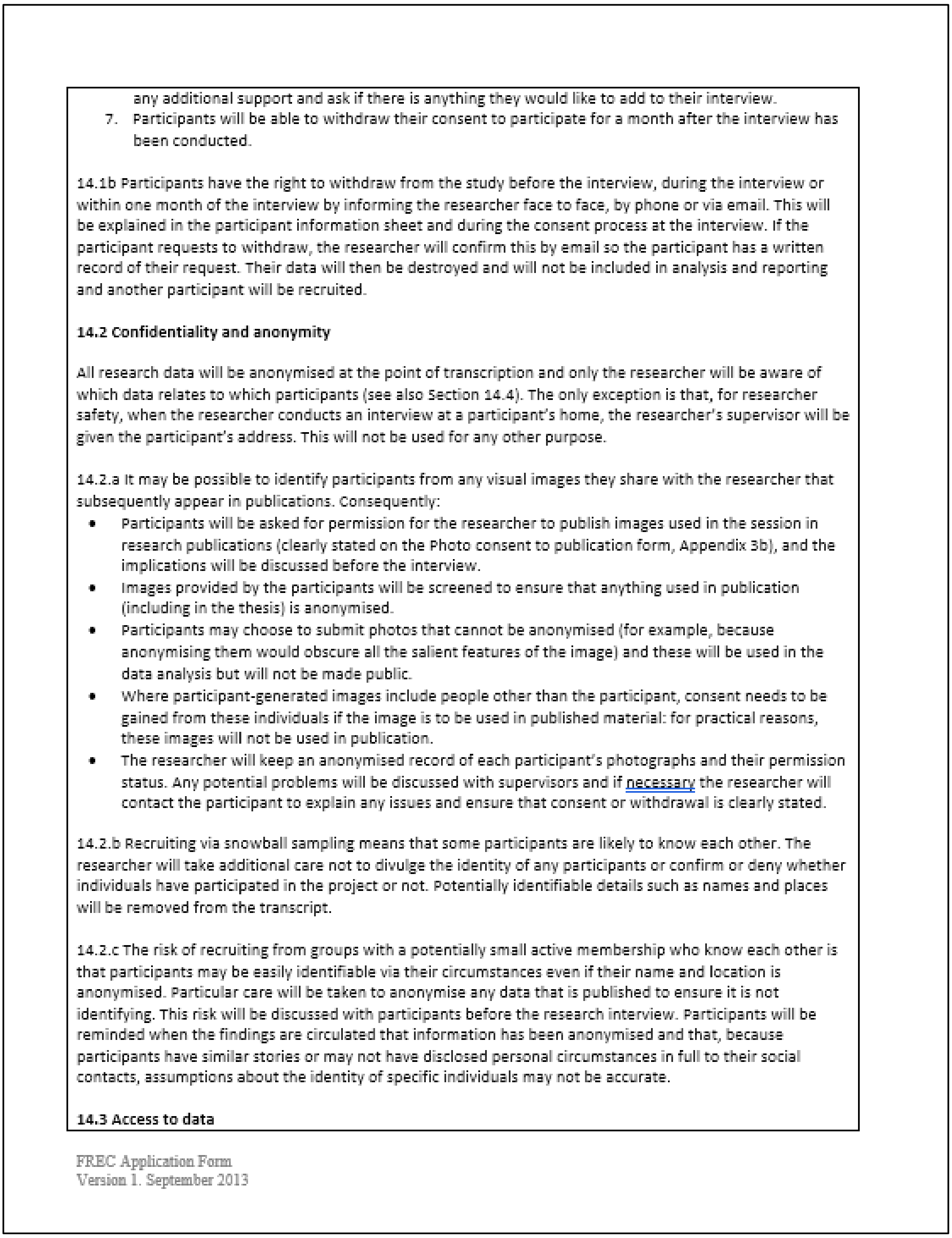


any additional support and ask if there is anything they would like to add to their interview.

7. Participants will be able to withdraw their consent to participate for a month after the interview has been conducted.

14.1b Participants have the right to withdraw from the study before the interview, during the interview or within one month of the interview by informing the researcher face to face, by phone or via email. This will be explained in the participant information sheet and during the consent process at the interview. If the participant requests to withdraw, the researcher will confirm this by email so the participant has a written record of their request. Their data will then be destroyed and will not be included in analysis and reporting and another participant will be recruited.

14.2 Confidentiality and anonymity

All research data will be anonymised at the point of transcription and only the researcher will be aware of which data relates to which participants (see also Section 14.4). The only exception is that, for researcher safety, when the researcher conducts an interview at a participant's home, the researcher's supervisor will be given the participant's address. This will not be used for any other purpose.

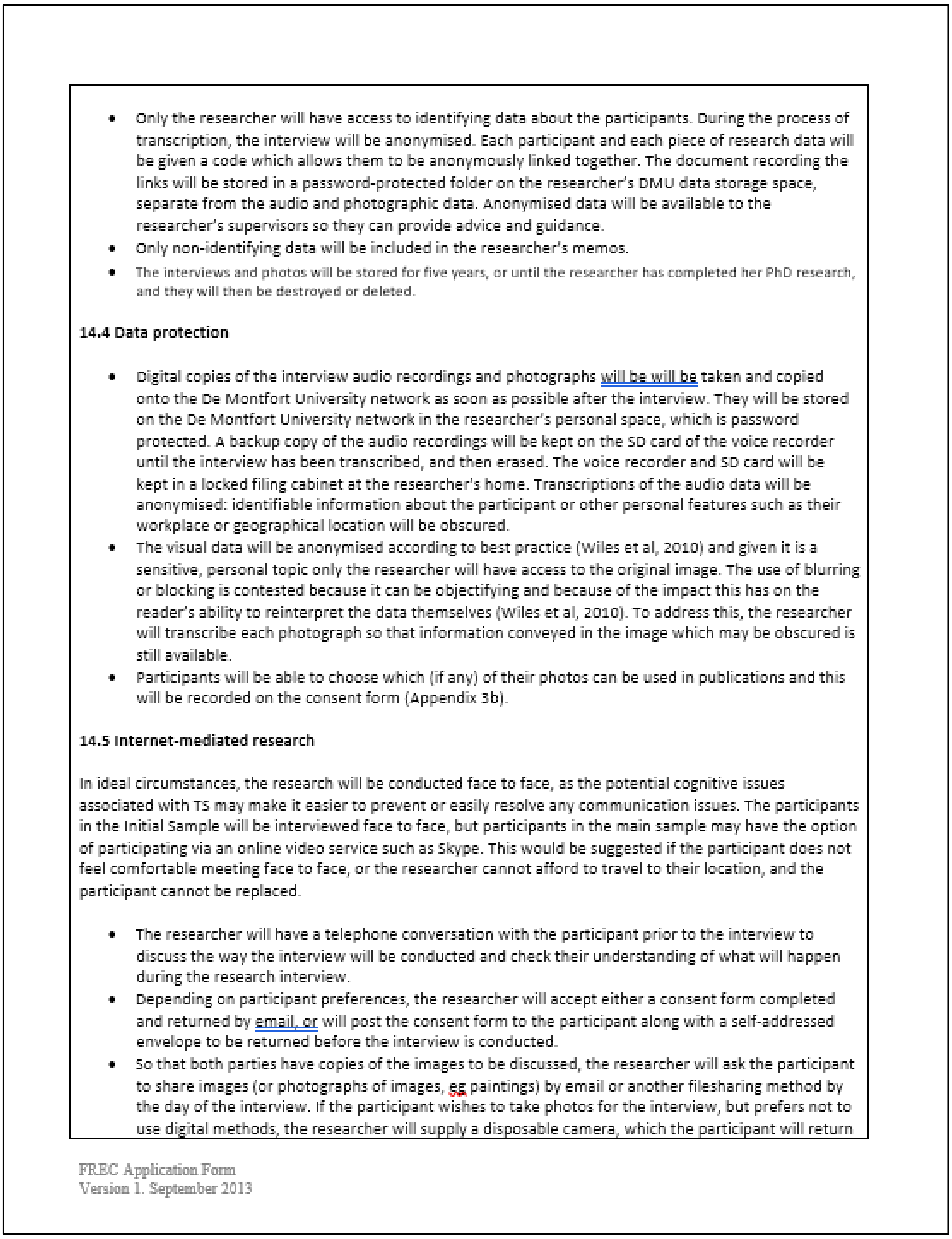
14.2.a It may be possible to identify participants from any visual images they share with the researcher that subsequently appear in publications. Consequently:

- Participants will be asked for permission for the researcher to publish images used in the session in research publications (clearly stated on the Photo consent to publication form, Appendix 3b), and the implications will be discussed before the interview.
- Images provided by the participants will be screened to ensure that anything used in publication (including in the thesis) is anonymised.
- Participants may choose to submit photos that cannot be anonymised (for example, because anonymising them would obscure all the salient features of the image) and these will be used in the data analysis but will not be made public.
- Where participant-generated images include people other than the participant, consent needs to be gained from these individuals if the image is to be used in published material: for practical reasons, these images will not be used in publication.
- The researcher will keep an anonymised record of each participant's photographs and their permission status. Any potential problems will be discussed with supervisors and if necessary the researcher will contact the participant to explain any issues and ensure that consent or withdrawal is clearly stated.

14.2.b Recruiting via snowball sampling means that some participants are likely to know each other. The researcher will take additional care not to divulge the identity of any participants or confirm or deny whether individuals have participated in the project or not. Potentially identifiable details such as names and places will be removed from the transcript.

14.2.c The risk of recruiting from groups with a potentially small active membership who know each other is that participants may be easily identifiable via their circumstances even if their name and location is anonymised. Particular care will be taken to anonymise any data that is published to ensure it is not identifying. This risk will be discussed with participants before the research interview. Participants will be reminded when the findings are circulated that information has been anonymised and that, because participants have similar stories or may not have disclosed personal circumstances in full to their social contacts, assumptions about the identity of specific individuals may not be accurate.

14.3 Access to data



- Only the researcher will have access to identifying data about the participants. During the process of transcription, the interview will be anonymised. Each participant and each piece of research data will be given a code which allows them to be anonymously linked together. The document recording the links will be stored in a password-protected folder on the researcher's DMU data storage space, separate from the audio and photographic data. Anonymised data will be available to the researcher's supervisors so they can provide advice and guidance.
- Only non-identifying data will be included in the researcher's memos.
- The interviews and photos will be stored for five years, or until the researcher has completed her PhD research, and they will then be destroyed or deleted.

14.4 Data protection

- Digital copies of the interview audio recordings and photographs will be will be taken and copied onto the De Montfort University network as soon as possible after the interview. They will be stored on the De Montfort University network in the researcher's personal space, which is password protected. A backup copy of the audio recordings will be kept on the SD card of the voice recorder until the interview has been transcribed, and then erased. The voice recorder and SD card will be kept in a locked filing cabinet at the researcher's home. Transcriptions of the audio data will be anonymised: identifiable information about the participant or other personal features such as their workplace or geographical location will be obscured.
- The visual data will be anonymised according to best practice (Wiles et al, 2010) and given it is a sensitive, personal topic only the researcher will have access to the original image. The use of blurring or blocking is contested because it can be objectifying and because of the impact this has on the reader's ability to reinterpret the data themselves (Wiles et al, 2010). To address this, the researcher will transcribe each photograph so that information conveyed in the image which may be obscured is still available.
- Participants will be able to choose which (if any) of their photos can be used in publications and this will be recorded on the consent form (Appendix 3b).

14.5 Internet-mediated research

In ideal circumstances, the research will be conducted face to face, as the potential cognitive issues associated with TS may make it easier to prevent or easily resolve any communication issues. The participants in the Initial Sample will be interviewed face to face, but participants in the main sample may have the option of participating via an online video service such as Skype. This would be suggested if the participant does not feel comfortable meeting face to face, or the researcher cannot afford to travel to their location, and the participant cannot be replaced.

- The researcher will have a telephone conversation with the participant prior to the interview to discuss the way the interview will be conducted and check their understanding of what will happen during the research interview.
- Depending on participant preferences, the researcher will accept either a consent form completed and returned by email, or will post the consent form to the participant along with a self-addressed envelope to be returned before the interview is conducted.
- So that both parties have copies of the images to be discussed, the researcher will ask the participant to share images (or photographs of images, eg paintings) by email or another filesharing method by the day of the interview. If the participant wishes to take photos for the interview, but prefers not to use digital methods, the researcher will supply a disposable camera, which the participant will return

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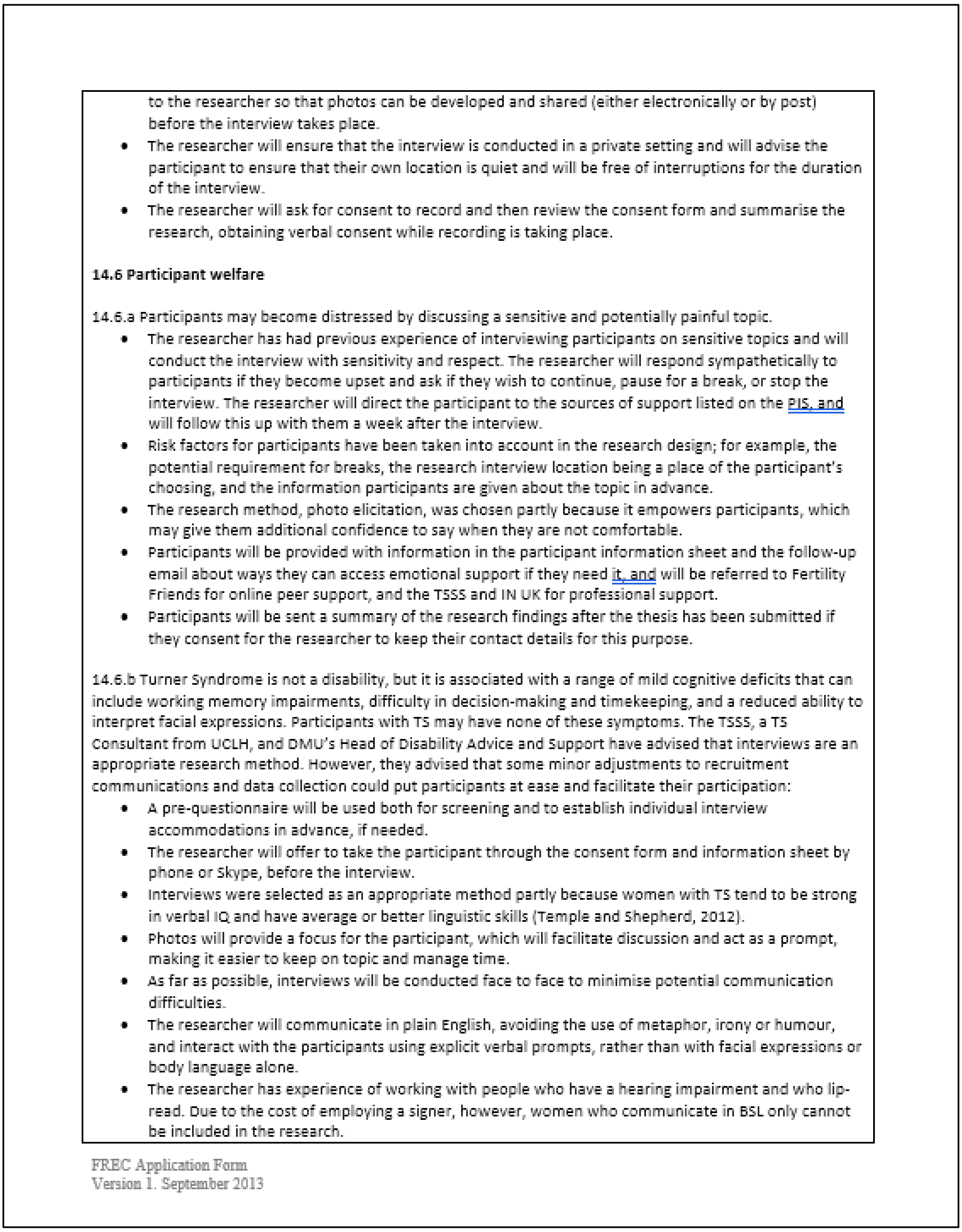

to the researcher so that photos can be developed and shared (either electronically or by post) before the interview takes place.

- The researcher will ensure that the interview is conducted in a private setting and will advise the participant to ensure that their own location is quiet and will be free of interruptions for the duration of the interview.
- The researcher will ask for consent to record and then review the consent form and summarise the research, obtaining verbal consent while recording is taking place.

14.6 Participant welfare

14.6.a Participants may become distressed by discussing a sensitive and potentially painful topic.

- The researcher has had previous experience of interviewing participants on sensitive topics and will conduct the interview with sensitivity and respect. The researcher will respond sympathetically to participants if they become upset and ask if they wish to continue, pause for a break, or stop the interview. The researcher will direct the participant to the sources of support listed on the PIS, and will follow this up with them a week after the interview.
- Risk factors for participants have been taken into account in the research design; for example, the potential requirement for breaks, the research interview location being a place of the participant's choosing, and the information participants are given about the topic in advance.
- The research method, photo elicitation, was chosen partly because it empowers participants, which may give them additional confidence to say when they are not comfortable.
- Participants will be provided with information in the participant information sheet and the follow-up email about ways they can access emotional support if they need it, and will be referred to Fertility Friends for online peer support, and the TSSS and IN UK for professional support.
- Participants will be sent a summary of the research findings after the thesis has been submitted if they consent for the researcher to keep their contact details for this purpose.

14.6.b Turner Syndrome is not a disability, but it is associated with a range of mild cognitive deficits that can include working memory impairments, difficulty in decision-making and timekeeping, and a reduced ability to interpret facial expressions. Participants with TS may have none of these symptoms. The TSSS, a TS Consultant from UCLH, and DMU's Head of Disability Advice and Support have advised that interviews are an appropriate research method. However, they advised that some minor adjustments to recruitment communications and data collection could put participants at ease and facilitate their participation:

- A pre-questionnaire will be used both for screening and to establish individual interview accommodations in advance, if needed.
- The researcher will offer to take the participant through the consent form and information sheet by phone or Skype, before the interview.
- Interviews were selected as an appropriate method partly because women with TS tend to be strong in verbal IQ and have average or better linguistic skills (Temple and Shepherd, 2012).
- Photos will provide a focus for the participant, which will facilitate discussion and act as a prompt, making it easier to keep on topic and manage time.
- As far as possible, interviews will be conducted face to face to minimise potential communication difficulties.
- The researcher will communicate in plain English, avoiding the use of metaphor, irony or humour, and interact with the participants using explicit verbal prompts, rather than with facial expressions or body language alone.
- The researcher has experience of working with people who have a hearing impairment and who lip-read. Due to the cost of employing a signer, however, women who communicate in BSL only cannot be included in the research.

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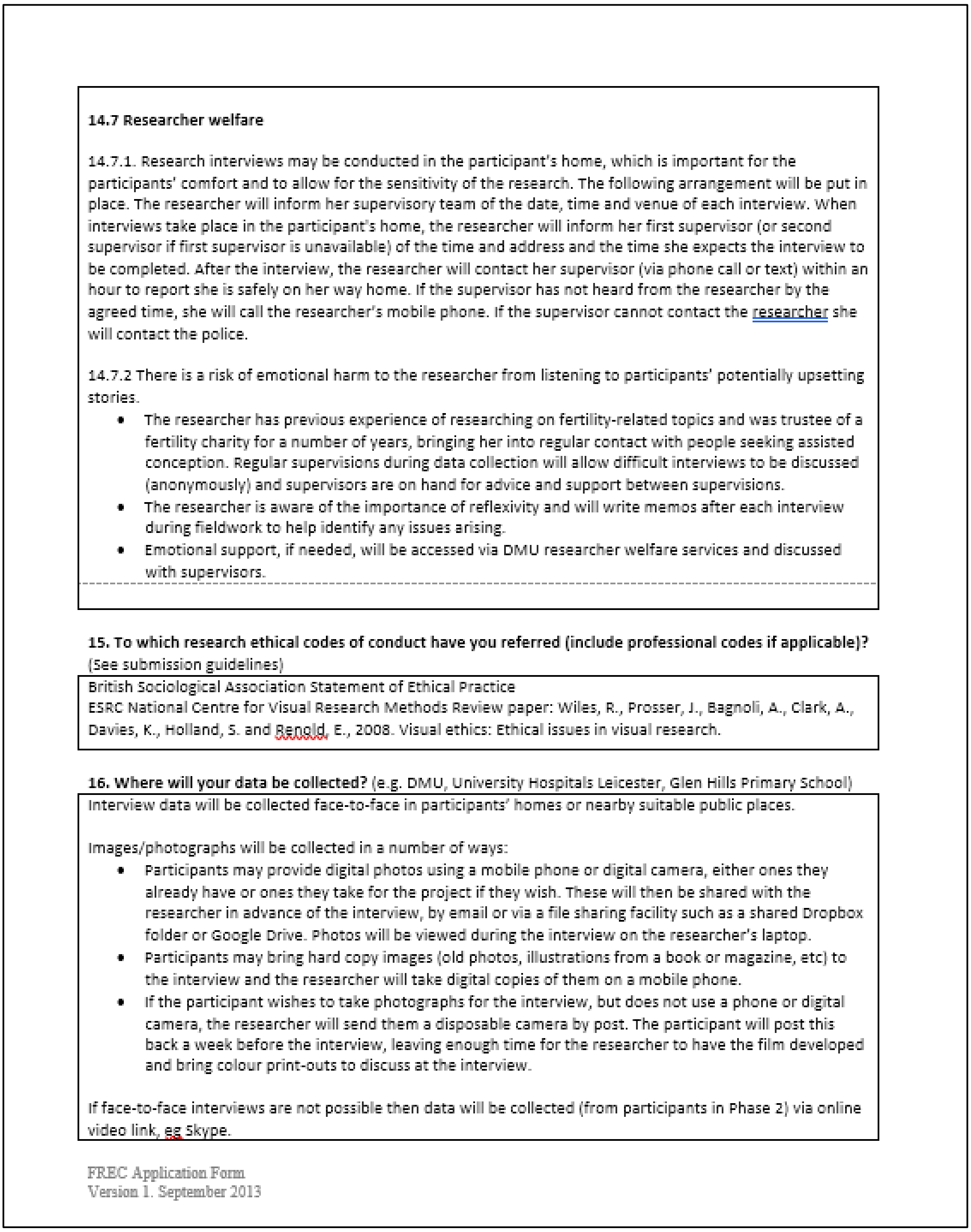


14.7 Researcher welfare

14.7.1. Research interviews may be conducted in the participant's home, which is important for the participants' comfort and to allow for the sensitivity of the research. The following arrangement will be put in place. The researcher will inform her supervisory team of the date, time and venue of each interview. When interviews take place in the participant's home, the researcher will inform her first supervisor (or second supervisor if first supervisor is unavailable) of the time and address and the time she expects the interview to be completed. After the interview, the researcher will contact her supervisor (via phone call or text) within an hour to report she is safely on her way home. If the supervisor has not heard from the researcher by the agreed time, she will call the researcher's mobile phone. If the supervisor cannot contact the researcher she will contact the police.

14.7.2 There is a risk of emotional harm to the researcher from listening to participants' potentially upsetting stories.

- The researcher has previous experience of researching on fertility-related topics and was trustee of a fertility charity for a number of years, bringing her into regular contact with people seeking assisted conception. Regular supervisions during data collection will allow difficult interviews to be discussed (anonymously) and supervisors are on hand for advice and support between supervisions.
- The researcher is aware of the importance of reflexivity and will write memos after each interview during fieldwork to help identify any issues arising.
- Emotional support, if needed, will be accessed via DMU researcher welfare services and discussed with supervisors.

15. To which research ethical codes of conduct have you referred (include professional codes if applicable)? (See submission guidelines)

British Sociological Association Statement of Ethical Practice
ESRC National Centre for Visual Research Methods Review paper: Wiles, R., Prosser, J., Bagnoli, A., Clark, A., Davies, K., Holland, S. and Renold, E., 2008. Visual ethics: Ethical issues in visual research.

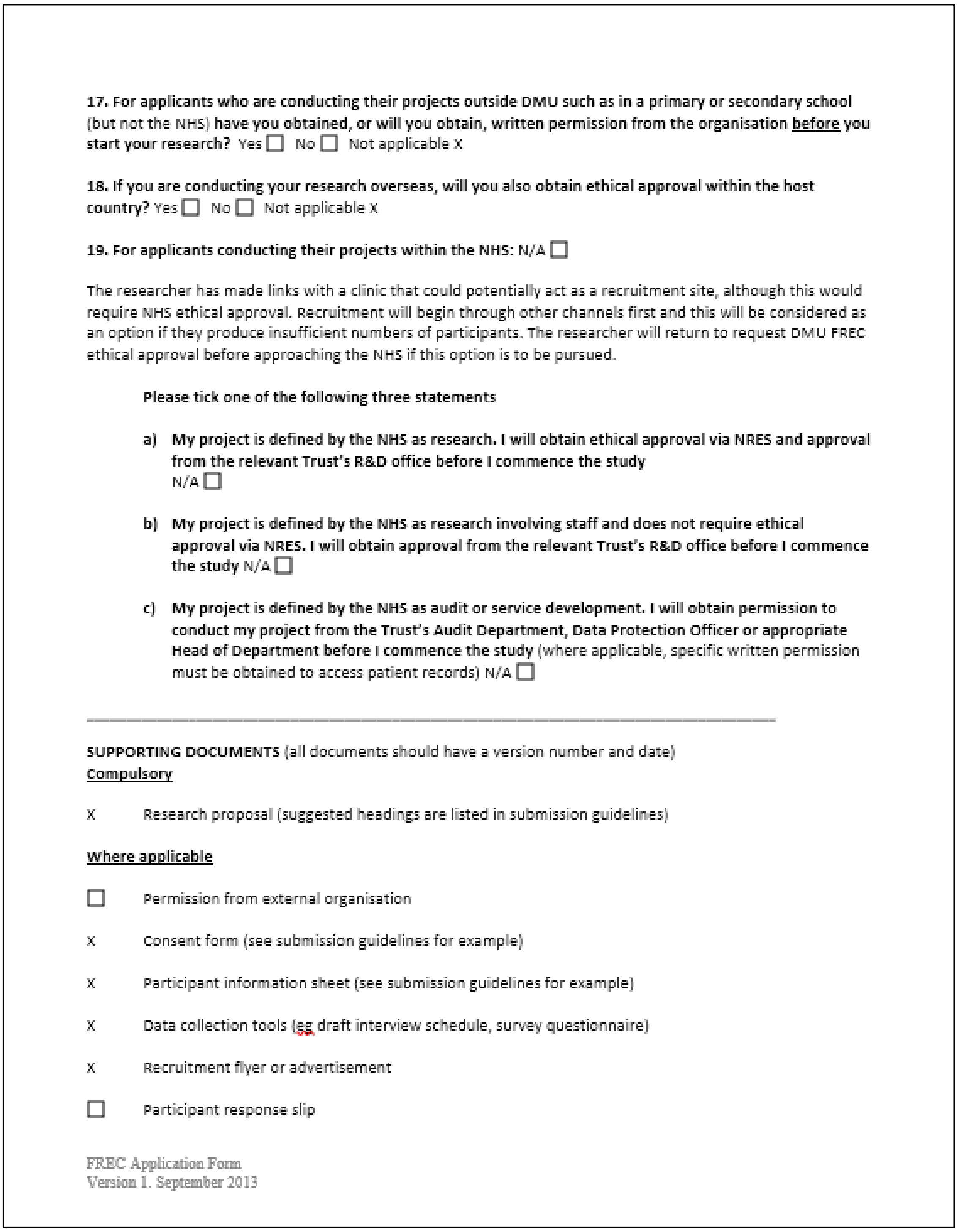
16. Where will your data be collected? (e.g. DMU, University Hospitals Leicester, Glen Hills Primary School)

Interview data will be collected face-to-face in participants' homes or nearby suitable public places.

Images/photographs will be collected in a number of ways:

- Participants may provide digital photos using a mobile phone or digital camera, either ones they already have or ones they take for the project if they wish. These will then be shared with the researcher in advance of the interview, by email or via a file sharing facility such as a shared Dropbox folder or Google Drive. Photos will be viewed during the interview on the researcher's laptop.
- Participants may bring hard copy images (old photos, illustrations from a book or magazine, etc) to the interview and the researcher will take digital copies of them on a mobile phone.
- If the participant wishes to take photographs for the interview, but does not use a phone or digital camera, the researcher will send them a disposable camera by post. The participant will post this back a week before the interview, leaving enough time for the researcher to have the film developed and bring colour print-outs to discuss at the interview.

If face-to-face interviews are not possible then data will be collected (from participants in Phase 2) via online video link, eg Skype.



17. For applicants who are conducting their projects outside DMU such as in a primary or secondary school (but not the NHS) **have you obtained, or will you obtain, written permission from the organisation** **<u>before</u>** **you start your research?** Yes ☐ No ☐ Not applicable X

18. If you are conducting your research overseas, will you also obtain ethical approval within the host country? Yes ☐ No ☐ Not applicable X

19. For applicants conducting their projects within the NHS: N/A ☐

The researcher has made links with a clinic that could potentially act as a recruitment site, although this would require NHS ethical approval. Recruitment will begin through other channels first and this will be considered as an option if they produce insufficient numbers of participants. The researcher will return to request DMU FREC ethical approval before approaching the NHS if this option is to be pursued.

Please tick one of the following three statements

a) **My project is defined by the NHS as research. I will obtain ethical approval via NRES and approval from the relevant Trust's R&D office before I commence the study**
N/A ☐

b) **My project is defined by the NHS as research involving staff and does not require ethical approval via NRES. I will obtain approval from the relevant Trust's R&D office before I commence the study** N/A ☐

c) **My project is defined by the NHS as audit or service development. I will obtain permission to conduct my project from the Trust's Audit Department, Data Protection Officer or appropriate Head of Department before I commence the study** (where applicable, specific written permission must be obtained to access patient records) N/A ☐

SUPPORTING DOCUMENTS (all documents should have a version number and date)
<u>Compulsory</u>

X Research proposal (suggested headings are listed in submission guidelines)

<u>Where applicable</u>

☐ Permission from external organisation

X Consent form (see submission guidelines for example)

X Participant information sheet (see submission guidelines for example)

X Data collection tools (eg draft interview schedule, survey questionnaire)

X Recruitment flyer or advertisement

☐ Participant response slip

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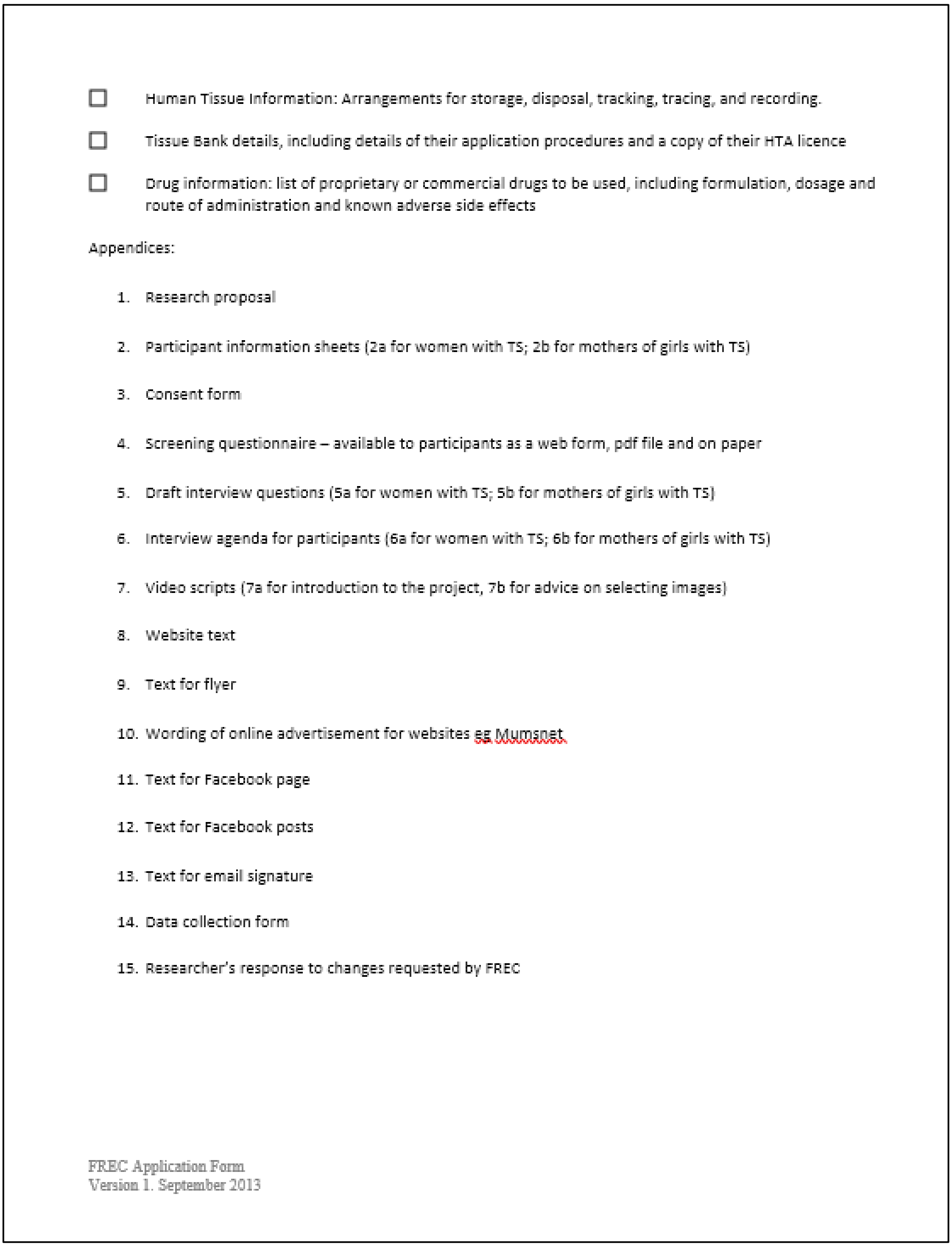


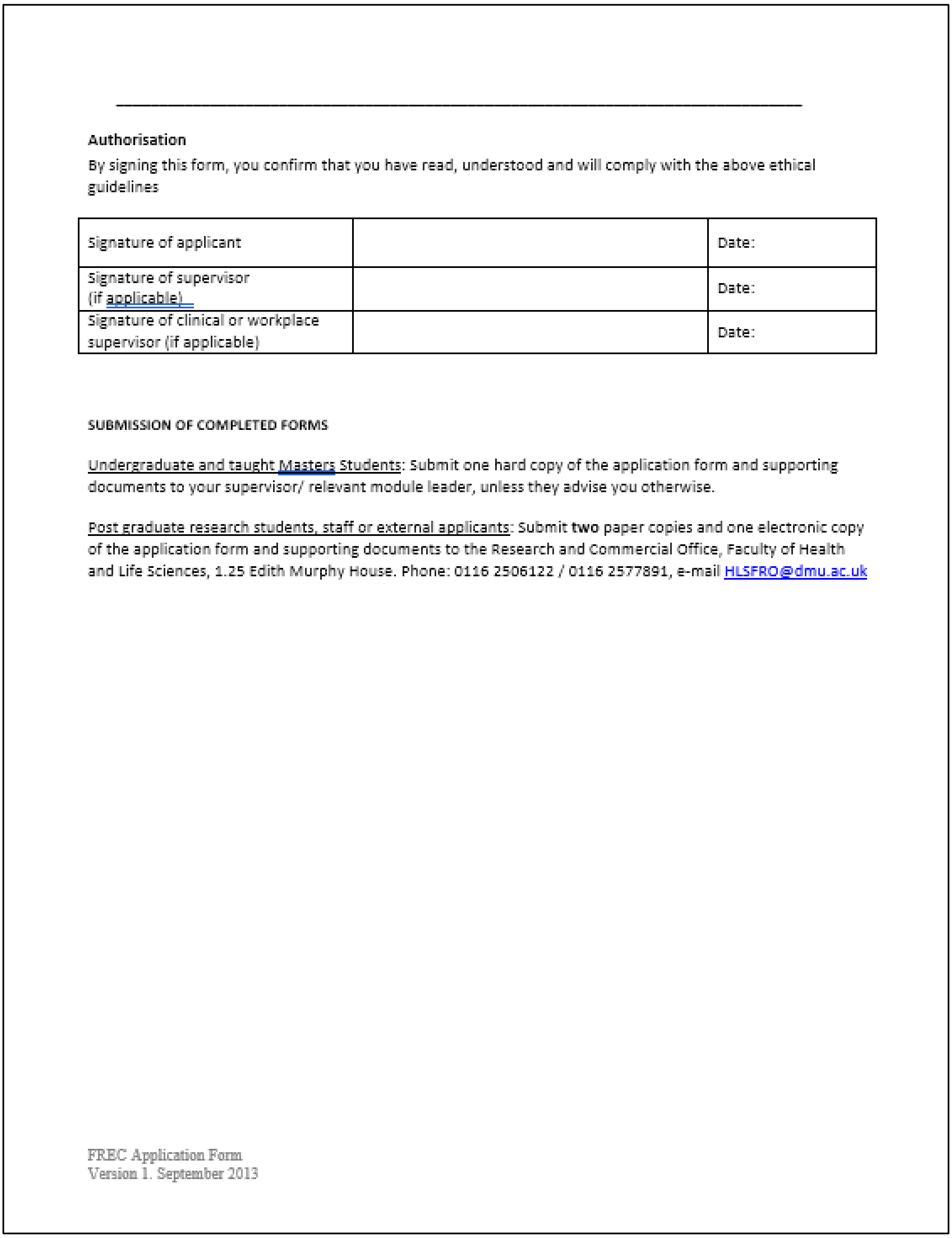
☐ Human Tissue Information: Arrangements for storage, disposal, tracking, tracing, and recording.

☐ Tissue Bank details, including details of their application procedures and a copy of their HTA licence

☐ Drug information: list of proprietary or commercial drugs to be used, including formulation, dosage and route of administration and known adverse side effects

Appendices:

1. Research proposal
2. Participant information sheets (2a for women with TS; 2b for mothers of girls with TS)
3. Consent form
4. Screening questionnaire – available to participants as a web form, pdf file and on paper
5. Draft interview questions (5a for women with TS; 5b for mothers of girls with TS)
6. Interview agenda for participants (6a for women with TS; 6b for mothers of girls with TS)
7. Video scripts (7a for introduction to the project, 7b for advice on selecting images)
8. Website text
9. Text for flyer
10. Wording of online advertisement for websites eg Mumsnet
11. Text for Facebook page
12. Text for Facebook posts
13. Text for email signature
14. Data collection form
15. Researcher's response to changes requested by FREC



Authorisation

By signing this form, you confirm that you have read, understood and will comply with the above ethical guidelines

Signature of applicant		Date:
Signature of supervisor (if applicable)		Date:
Signature of clinical or workplace supervisor (if applicable)		Date:

SUBMISSION OF COMPLETED FORMS

Undergraduate and taught Masters Students: Submit one hard copy of the application form and supporting documents to your supervisor/ relevant module leader, unless they advise you otherwise.

Post graduate research students, staff or external applicants: Submit **two** paper copies and one electronic copy of the application form and supporting documents to the Research and Commercial Office, Faculty of Health and Life Sciences, 1.25 Edith Murphy House. Phone: 0116 2506122 / 0116 2577891, e-mail HLSFRO@dmu.ac.uk

FREC Application Form
Version 1. September 2013

Appendix 4 – Screening questionnaire

Turner Syndrome and reproductive decision-making

Thank you for your interest in this study, which is looking at the reproductive choices of women with Turner Syndrome and mothers of girls with Turner Syndrome.

The purpose of this short questionnaire is to find out a little bit about you and your background, to see whether you are eligible to participate. Answering this questionnaire does not commit you to taking part.

I am looking for two groups of participants:

- Women with Turner Syndrome who have explored their options for having a family, whatever the outcome has been
- Mothers of girls who have Turner Syndrome and who have actively considered or explored their daughter's options for having a family

The information collected in this survey is totally confidential and if you do not become part of the study, your responses are permanently deleted.

It will take around five minutes to complete. Once you have submitted the questionnaire, you will hear back from the researcher within a week.

More about this study

This project is a PhD research study conducted by Kriss Fearon, research student at De Montfort University. If you have any questions about this research, please contact Kriss Fearon via email at p15193445@myemail.dmu.ac.uk. You could also contact my supervisor, Dr Cathy Herbrand, tel: 0116 250 6422, email: cathy.herbrand@dmu.ac.uk. If you would like to speak to someone outside of the research team, please contact the Chair of the Research Ethics Committee at De Montfort University, Professor Martin Grootveld, tel: 0116 250 6443, e-mail: mgrootveld@dmu.ac.uk.

1) I am:

☐ A woman with TS [goes to 2a]

☐ Mother of girl with TS [goes to 2b]

☐ Other: please state [goes to 2c]

2a) For women with TS

How old are you? [open box]

When you were first diagnosed with TS? [open box]

Are you in a relationship? [dropdown menu: no, married/civil partnership, divorced, widowed, other]

Do you have any children? If so, how many? [open box]

Please say a little about how you became a parent – eg via natural conception, adoption, egg/embryo donation, step-parent, other. [open box]

If you do not have children, have you considered any options or taken any action in relation to this? [open box]

[goes to 3]

2b) For mothers of a girl with TS

Number, age and gender of children [open box]

Age when giving birth to daughter with TS [open box]

How old is your daughter with TS? [open box]

Have you yet thought about ways your daughter would be able to have a family when she grows up? [open box]

Have you taken any action yet in relation to this? [open box]

[goes to 3]

2c) Other

Please tell me more about your interest in this project.

[open box; goes straight to submit form]

3) On the interview day

The interview may take up to two hours, including time to set up the equipment and allowing for comfort breaks if needed.

Is there anything you would like to tell me about that would make the interview more comfortable for you? Please select any of the options that you are happy with.

Would you prefer us to meet: at your home/ any suitable quiet public place? [checkboxes]

Would you prefer to be interviewed alone / with your partner or a family member? [checkboxes]

If you have a physical or other disability that might affect the interview, such as a hearing impairment, please tell me about it: [open box]

4) Contact details

Please let me have your contact details so I can get back in touch with you.

Email address [open box]

Mobile number [open box]

Location (postcode) [open box]

My preferred method of contact is: [open box]

The best time to contact me is: [open box]

Confirmation page

[To be displayed after form submission]

Thank you for your interest in this project.

The researcher will get in touch no later than a week from today.

If you would like more information or would like to follow the progress of the project, please check the website. [url of project website]

Appendix 5a - Participants, women with TS

	Age	Ethnicity	Age at diagnosis	Who delivered the diagnosis	Type of TS	R'ship status	Children	Family building method (if parent)	Family building options (if not parent)	Issues affecting the interview	Possible sibling donors
TSW1	Mid 30s	White	Birth	Doctor	Mosaic	Single	No	n/a	Lack of support from doctors has prevented taking steps to looking further.	N/D	No
TSW2	Late 20s	White	Birth	Parent	Classic	Engaged	No	n/a	Considered ED and adoption	N/D	1 sister too old
TSW3	Mid 30s	White	18	Doctor	Classic	Married	1	1 cycle ED did not work. Adopted; considering a second adoption.	n/a	None	1 sister too old
TSW4	Early 40s	White	15	Parent	Classic	Married	1	Egg donation via anon donor; natural birth	n/a	Hearing impaired, wears	No

										hearing aids.	
TSW5	Mid 30s	White	7	Parent	Mosaic	Long term partner	1	Sibling egg donation; caesarean	n/a	N/D	1 sister
TSW6	Early 50s	White	16	Parent	Classic	Husband of 10 years	No	n/a	Considered adoption, but age an issue	Hearing issues	No
TSW7	Early 20s	White/Non-UK	5	Doctor	Mosaic	Partner of 2 years, has discussed marriage and kids	No	n/a	Could carry a child but other health issues make pregnancy risky. Partner would like a bio child, but open to adoption.	Hearing issues, mobility issues	No
TSW8	Mid 20s	White/Non-UK	16	Doctor	Mosaic	Single	No	n/a	Planning ED in Spain or Greece. UK NHS waiting list too long	N/D	2 half sisters
TSW9	Late 20s	White	16	Doctor	Mosaic	Single	No	n/a	Looking at adoption. Would have ED if a	N/D	No

									partner wanted a bio child.		
TSW10	Early 60s	White	Birth of first child	Doctor	Classic	Husband	2	Natural conception, 2 x caesarean due to stature	Considered adopting a third.	Hearing issues	No
TSW11	Mid 20s	White	Birth	Parent	Classic	Engaged	No	n/a	Medically eligible for egg donation. Would consider adoption.	N/D	1 half-sister
TSW12	Late 40s	White	16	Parent	Classic	Married for 10 years	No	n/a	Did not want double donation. Could not adopt due to health.	Hearing issues	No
TSW13	Early 50s	White	Birth	Parent, and told about infertility at 16	Classic	Married for 22 years	No	n/a	Did not want ED. Dropped out of adoption anticipating rejection.	Hearing issues	1 sister.
TSW14	Early 40s	White	Aged 2	Parent; Unplanned disclosure of	Classic	Married for 13 years	1	Egg donation via clinic in Spain; caesarean	n/a	Hearing issues	2 sisters

				infertility by doctor at 12							
TSW15	Late 20s	White	Aged 4	Parent	Mosaic	With a partner for 5 years	No	n/a	Was told ED was too risky. Will try surrogacy first, then adoption if that fails.	N/D	1 sister
TSW16	Mid 20s	White	Aged 5	Parent	Classic	Single	No	n/a	Cannot afford fertility treatment so adoption is likely choice.	N/D	No
TSW17	Early 30s	White	3 days	Parent	Classic	Single	No	n/a	Prefers ED but needs a full cardiac check first. Will avoid if too risky. Family can help fund treatment. Adoption a possible next step.	Hearing issues	No

TSW18	Early 30s	White	Birth	Parent	Mosaic	Partner	No	n/a	Has considered options and is child free	Hearing issues	No
TSW19	Early 30s	White	14	Doctor	Classic	Single	No	n/a	Trying to decide between adoption and egg donation. Has not yet had a formal fertility consultation.	Hearing issues	1 younger sister

Appendix 5b – Participants – mothers of girls with TS

	Age	**Ethnicity**	**R'ship status**	**Children**	**Age when gave birth to daughter with TS**	**Age of daughter with TS**	**Type of TS**	**Age of diagnosis**	**Has daughter any children?**	**Potential sibling donor**	**Family building options considered**	**Action taken, if any**	**Issues affecting the interview**
TSM1	Late 40s	White	Married to father of children	1 daughter, 1 son	28	18	Classic	Shortly after birth	Too young	No	Yes, MEF, ED.	Frozen eggs via egg sharing	N/D
TSM2	Early 50s	White	Divorced from father, has a long-term partner	1 daughter	26	23	Mosaic	In the womb	2 x natural conception	No	Several - constantly since daughter was born	Explored MEF	N/D
TSM3	Mid 40s	White	Married to father	1 daughter with TS, 1 unaffected daughter	30	14	Classic	Shortly after birth	Too young	Yes	Has discussed sibling egg donation.	No	N/D
TSM4	Early 50s	White	Cohabiting with father	1 daughter	33	17	Classic	15	Too young	No	Yes	No	N/D

TSM5	Mid 30s	White	Married to father	1 daughter with TS, 1 unaffected daughter	31	5	Classic	In the womb	Too young	Yes	Yes	No	N/D
TSM6	Mid 30s	White/Non-UK	Married to father	1 daughter, 1 son	29	5	Classic	2	Too young	No	Yes	Considered MEF, too costly.	N/D
TSM7	Mid 40s	White/Non-UK	Married to father	1 daughter, 1 son	25	21	Mosaic	5	Daughter is planning children after finishing studies.	No	Yes. Worried about risk in pregnancy.	Explored egg freezing when daughter was a teen. POF began before treatment.	N/D
TSM8	Early 50s	White	Divorced and remarried	1 daughter with TS, 1 son, 1 adopted daughter	25	27	Classic	5	Daughter has twins via ED - caesarean	No	Has been an egg donor, fostered and adopted. Very concerned about risks.	Twins via ED.	N/D

TSM9	Early 30s	White	Married to father	1 daughter with TS, 1 son	28	5	Classic	in the womb	Too young	No	Considered MEF, egg donation and other options.	No	N/D
TSM10	Mid 40s	White	Married to father	1 daughter	36	8	Classic	in the womb	Too young	No	Saving for her future fertility treatment.	No	Hearing
TSM11	Mid 30s	White	Separated from father	1 daughter, 2 sons	25	8	Classic	2	Too young	No	Yes: adoption, fostering, egg donation	Daughter is too young. MEF costly and complex.	N/D

Appendix 5c – Participant demographics

This is a summary of the data collected using the form in Appendix 17.

Employment has been categorised using the International Standard Classification of Occupations ICSO-8 (ILM, 2012).

A5c(i) Women with TS

There were 19 participants in total. One person did not share their employment information.

Age	Number of participants
20-29	7
30-39	6
40-49	3
50+	3

Ethnicity	Number of participants
White British	17
White other	2

Education	Number of participants
GCSE	2
A level	8
UG degree	7
Higher degree	2

Employment	Number of participants
Full time	12
Part time	3
Not employed/student	4
Unpaid carer	1

Type of employment (ISCO classification)	Number of participants
264 Author	1
235 Education professional	3
241 Finance professional	1
243 Communications professional	1
325 Health associate professional	5
3343 Personal assistant	1
351 Technical support	1
411 Office support	1
532 Carer	1
911 Domestic helper	1

Relationship status	Number of participants
Married	8
Cohabiting	3
In a relationship	2
Single	6

Living arrangements	Number of participants
Alone	3
With partner/children	11
Shared house	5

A5c(ii) Mothers of girls with TS

NB One participant preferred not to complete the data collection form so ethnicity, education and employment information is not available for that person.

Age	**Number of participants**
30-39	3
40-49	5
50+	3

Ethnicity	**Number of participants**
White British	8
White other	2

Education	**Number of participants**
A level	2
UG degree	6
Higher degree	2

Employment	**Number of participants**
Full time	2
Part time	5
Not employed/student	3

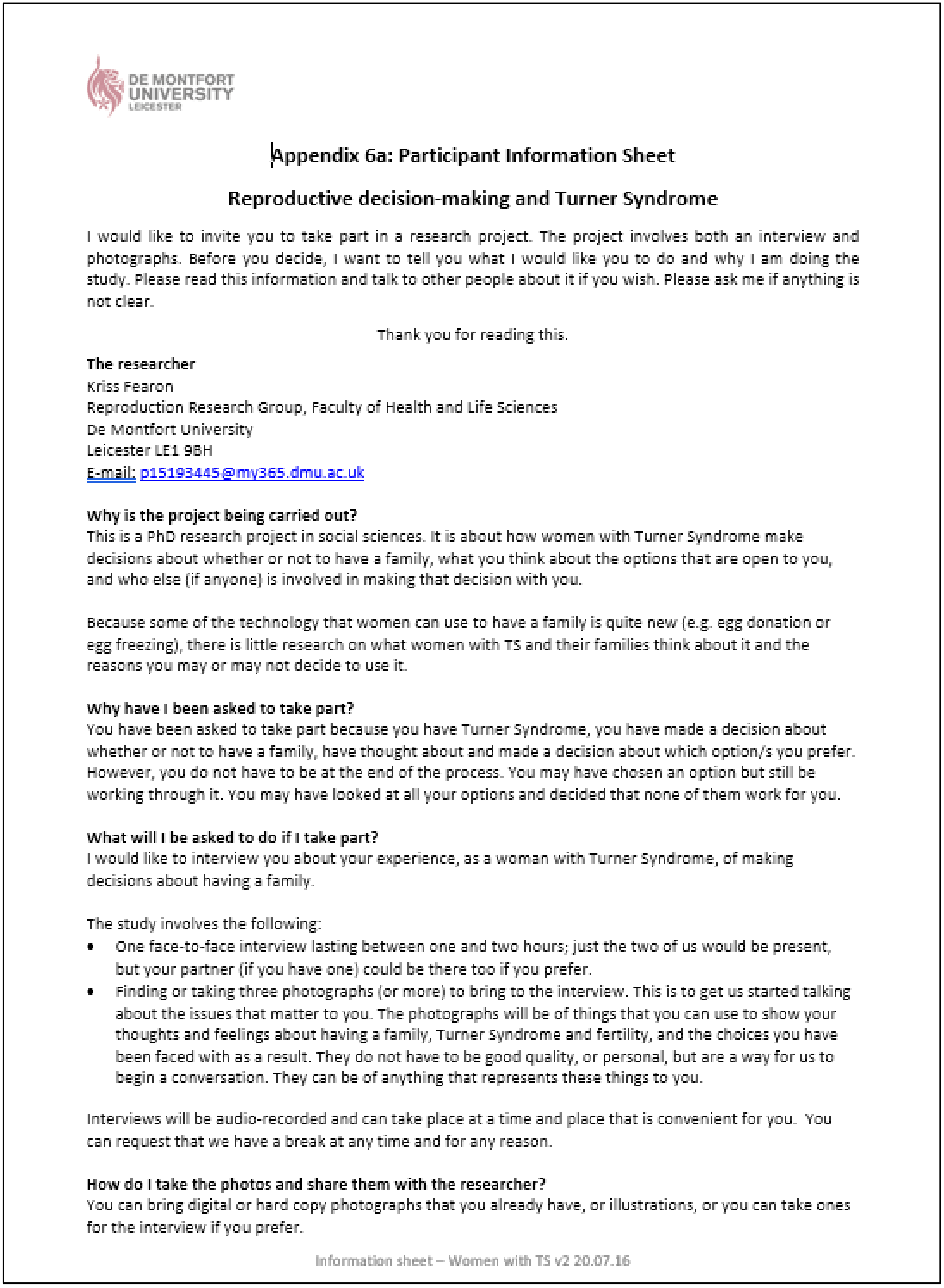
Type of employment (ISCO classification)	Number of participants
112 Senior manager	1
141 Hospitality manager	1
231 Teacher	1
243 Communications consultant	1
261 Legal professional	1
263 Mental health professional	1
411 Publishing assistant	1

Relationship status	Number of participants
Married	7
Cohabiting	3
Separated	1

Living arrangements	Number of participants
With partner/children	10
With children	1

Appendix 6 – Participant Information sheets

a) Women with TS



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Appendix 6a: Participant Information Sheet

Reproductive decision-making and Turner Syndrome

I would like to invite you to take part in a research project. The project involves both an interview and photographs. Before you decide, I want to tell you what I would like you to do and why I am doing the study. Please read this information and talk to other people about it if you wish. Please ask me if anything is not clear.

Thank you for reading this.

The researcher
Kriss Fearon
Reproduction Research Group, Faculty of Health and Life Sciences
De Montfort University
Leicester LE1 9BH
E-mail: p15193445@my365.dmu.ac.uk

Why is the project being carried out?
This is a PhD research project in social sciences. It is about how women with Turner Syndrome make decisions about whether or not to have a family, what you think about the options that are open to you, and who else (if anyone) is involved in making that decision with you.

Because some of the technology that women can use to have a family is quite new (e.g. egg donation or egg freezing), there is little research on what women with TS and their families think about it and the reasons you may or may not decide to use it.

Why have I been asked to take part?
You have been asked to take part because you have Turner Syndrome, you have made a decision about whether or not to have a family, have thought about and made a decision about which option/s you prefer. However, you do not have to be at the end of the process. You may have chosen an option but still be working through it. You may have looked at all your options and decided that none of them work for you.

What will I be asked to do if I take part?
I would like to interview you about your experience, as a woman with Turner Syndrome, of making decisions about having a family.

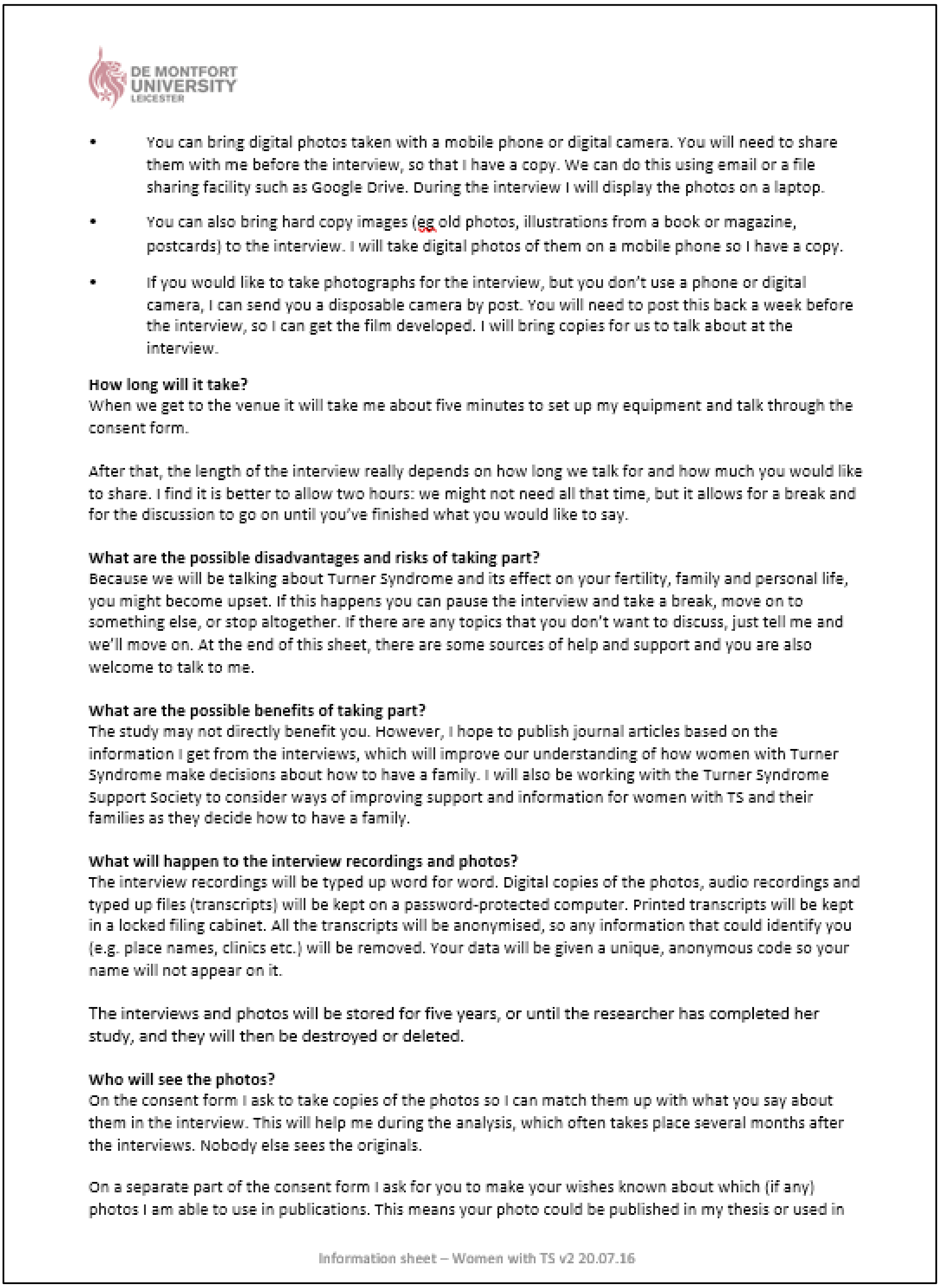
The study involves the following:

- One face-to-face interview lasting between one and two hours; just the two of us would be present, but your partner (if you have one) could be there too if you prefer.
- Finding or taking three photographs (or more) to bring to the interview. This is to get us started talking about the issues that matter to you. The photographs will be of things that you can use to show your thoughts and feelings about having a family, Turner Syndrome and fertility, and the choices you have been faced with as a result. They do not have to be good quality, or personal, but are a way for us to begin a conversation. They can be of anything that represents these things to you.

Interviews will be audio-recorded and can take place at a time and place that is convenient for you. You can request that we have a break at any time and for any reason.

How do I take the photos and share them with the researcher?
You can bring digital or hard copy photographs that you already have, or illustrations, or you can take ones for the interview if you prefer.

Information sheet – Women with TS v2 20.07.16



- You can bring digital photos taken with a mobile phone or digital camera. You will need to share them with me before the interview, so that I have a copy. We can do this using email or a file sharing facility such as Google Drive. During the interview I will display the photos on a laptop.
- You can also bring hard copy images (eg old photos, illustrations from a book or magazine, postcards) to the interview. I will take digital photos of them on a mobile phone so I have a copy.
- If you would like to take photographs for the interview, but you don't use a phone or digital camera, I can send you a disposable camera by post. You will need to post this back a week before the interview, so I can get the film developed. I will bring copies for us to talk about at the interview.

How long will it take?
When we get to the venue it will take me about five minutes to set up my equipment and talk through the consent form.

After that, the length of the interview really depends on how long we talk for and how much you would like to share. I find it is better to allow two hours: we might not need all that time, but it allows for a break and for the discussion to go on until you've finished what you would like to say.

What are the possible disadvantages and risks of taking part?
Because we will be talking about Turner Syndrome and its effect on your fertility, family and personal life, you might become upset. If this happens you can pause the interview and take a break, move on to something else, or stop altogether. If there are any topics that you don't want to discuss, just tell me and we'll move on. At the end of this sheet, there are some sources of help and support and you are also welcome to talk to me.

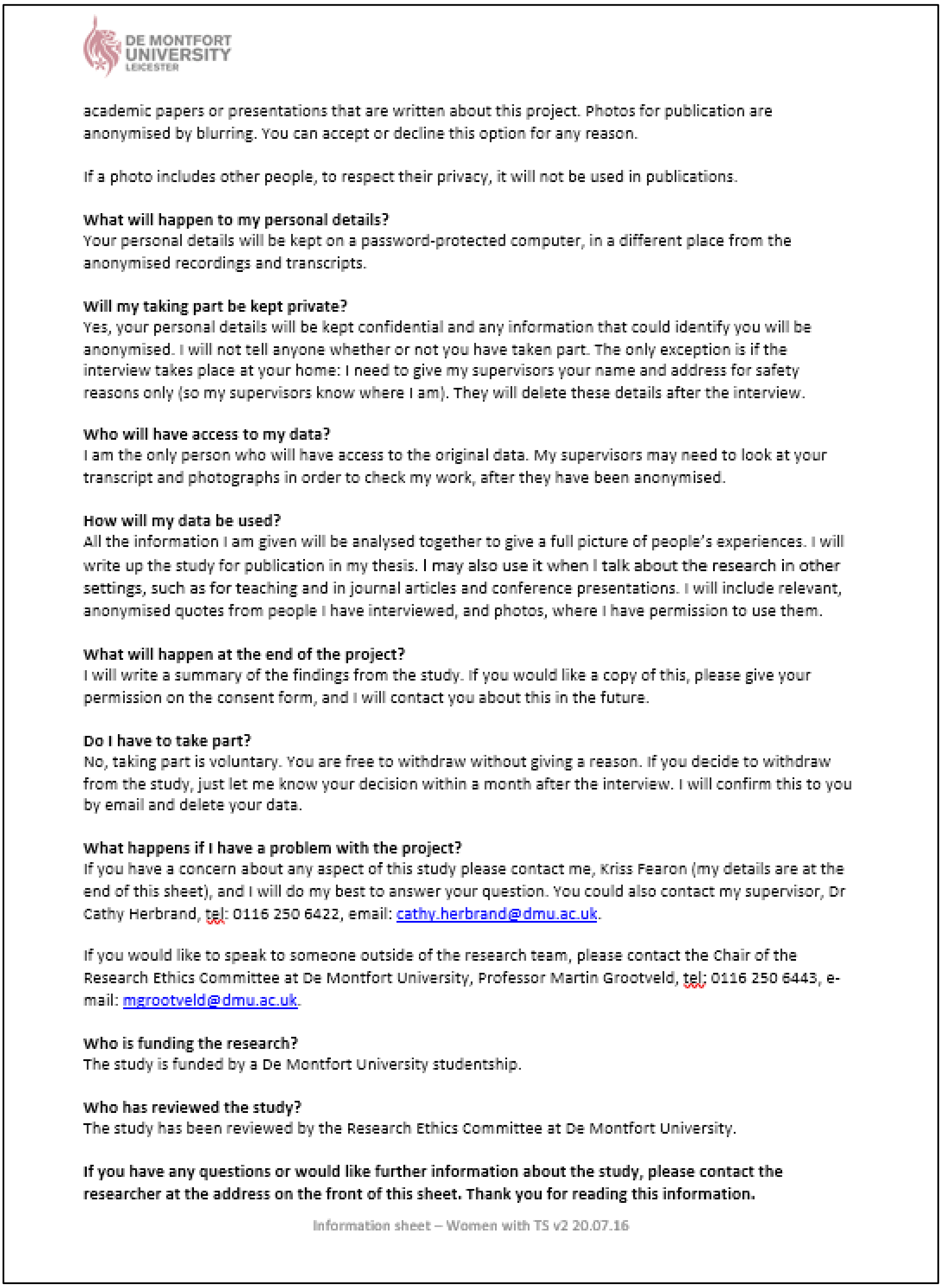
What are the possible benefits of taking part?
The study may not directly benefit you. However, I hope to publish journal articles based on the information I get from the interviews, which will improve our understanding of how women with Turner Syndrome make decisions about how to have a family. I will also be working with the Turner Syndrome Support Society to consider ways of improving support and information for women with TS and their families as they decide how to have a family.

What will happen to the interview recordings and photos?
The interview recordings will be typed up word for word. Digital copies of the photos, audio recordings and typed up files (transcripts) will be kept on a password-protected computer. Printed transcripts will be kept in a locked filing cabinet. All the transcripts will be anonymised, so any information that could identify you (e.g. place names, clinics etc.) will be removed. Your data will be given a unique, anonymous code so your name will not appear on it.

The interviews and photos will be stored for five years, or until the researcher has completed her study, and they will then be destroyed or deleted.

Who will see the photos?
On the consent form I ask to take copies of the photos so I can match them up with what you say about them in the interview. This will help me during the analysis, which often takes place several months after the interviews. Nobody else sees the originals.

On a separate part of the consent form I ask for you to make your wishes known about which (if any) photos I am able to use in publications. This means your photo could be published in my thesis or used in



academic papers or presentations that are written about this project. Photos for publication are anonymised by blurring. You can accept or decline this option for any reason.

If a photo includes other people, to respect their privacy, it will not be used in publications.

What will happen to my personal details?
Your personal details will be kept on a password-protected computer, in a different place from the anonymised recordings and transcripts.

Will my taking part be kept private?
Yes, your personal details will be kept confidential and any information that could identify you will be anonymised. I will not tell anyone whether or not you have taken part. The only exception is if the interview takes place at your home: I need to give my supervisors your name and address for safety reasons only (so my supervisors know where I am). They will delete these details after the interview.

Who will have access to my data?
I am the only person who will have access to the original data. My supervisors may need to look at your transcript and photographs in order to check my work, after they have been anonymised.

How will my data be used?
All the information I am given will be analysed together to give a full picture of people's experiences. I will write up the study for publication in my thesis. I may also use it when I talk about the research in other settings, such as for teaching and in journal articles and conference presentations. I will include relevant, anonymised quotes from people I have interviewed, and photos, where I have permission to use them.

What will happen at the end of the project?
I will write a summary of the findings from the study. If you would like a copy of this, please give your permission on the consent form, and I will contact you about this in the future.

Do I have to take part?
No, taking part is voluntary. You are free to withdraw without giving a reason. If you decide to withdraw from the study, just let me know your decision within a month after the interview. I will confirm this to you by email and delete your data.

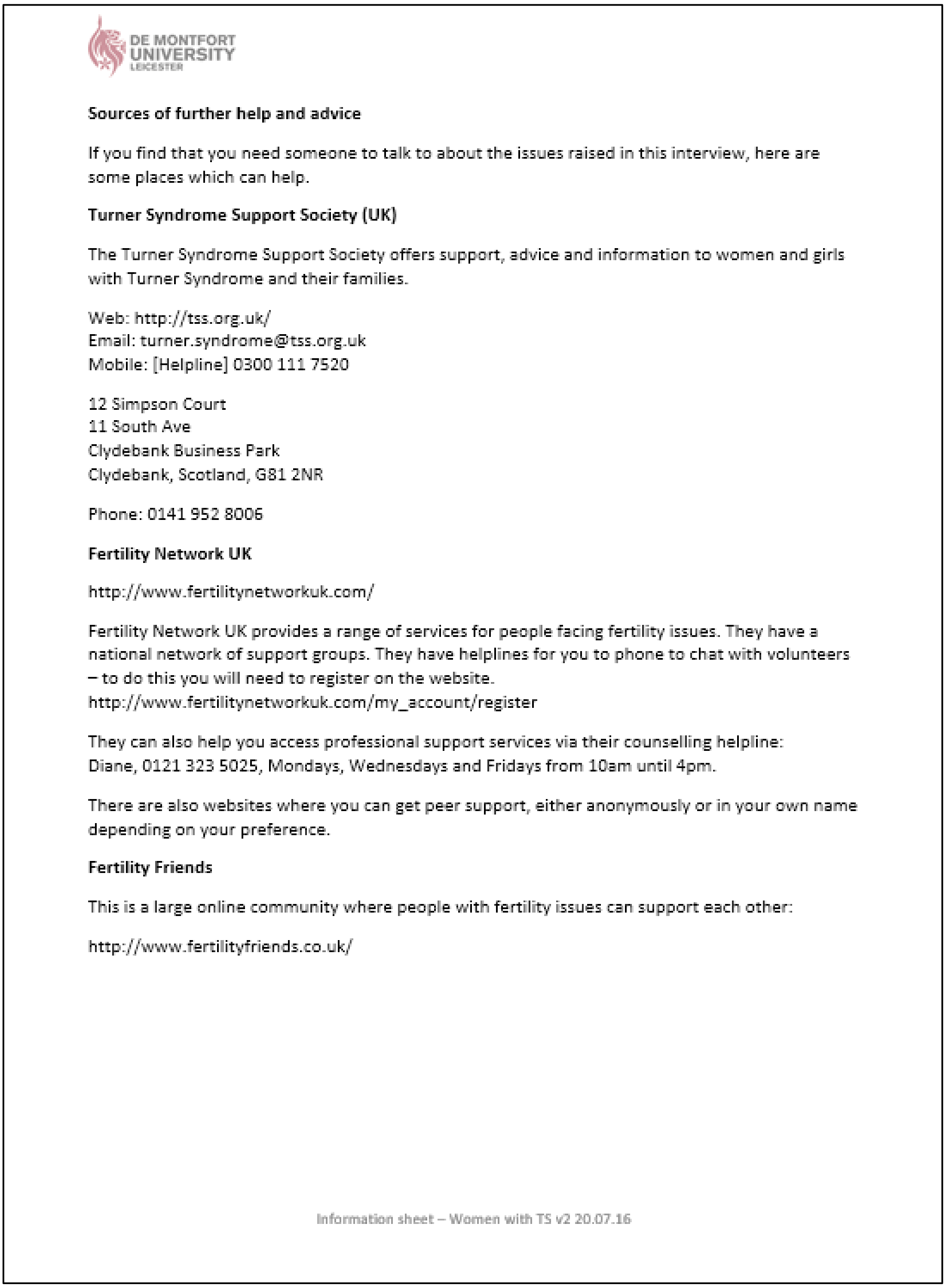
What happens if I have a problem with the project?
If you have a concern about any aspect of this study please contact me, Kriss Fearon (my details are at the end of this sheet), and I will do my best to answer your question. You could also contact my supervisor, Dr Cathy Herbrand, tel: 0116 250 6422, email: cathy.herbrand@dmu.ac.uk.

If you would like to speak to someone outside of the research team, please contact the Chair of the Research Ethics Committee at De Montfort University, Professor Martin Grootveld, tel: 0116 250 6443, e-mail: mgrootveld@dmu.ac.uk.

Who is funding the research?
The study is funded by a De Montfort University studentship.

Who has reviewed the study?
The study has been reviewed by the Research Ethics Committee at De Montfort University.

If you have any questions or would like further information about the study, please contact the researcher at the address on the front of this sheet. Thank you for reading this information.



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Sources of further help and advice

If you find that you need someone to talk to about the issues raised in this interview, here are some places which can help.

Turner Syndrome Support Society (UK)

The Turner Syndrome Support Society offers support, advice and information to women and girls with Turner Syndrome and their families.

Web: http://tss.org.uk/
Email: turner.syndrome@tss.org.uk
Mobile: [Helpline] 0300 111 7520

12 Simpson Court
11 South Ave
Clydebank Business Park
Clydebank, Scotland, G81 2NR

Phone: 0141 952 8006

Fertility Network UK

http://www.fertilitynetworkuk.com/

Fertility Network UK provides a range of services for people facing fertility issues. They have a national network of support groups. They have helplines for you to phone to chat with volunteers – to do this you will need to register on the website.
http://www.fertilitynetworkuk.com/my_account/register

They can also help you access professional support services via their counselling helpline:
Diane, 0121 323 5025, Mondays, Wednesdays and Fridays from 10am until 4pm.

There are also websites where you can get peer support, either anonymously or in your own name depending on your preference.

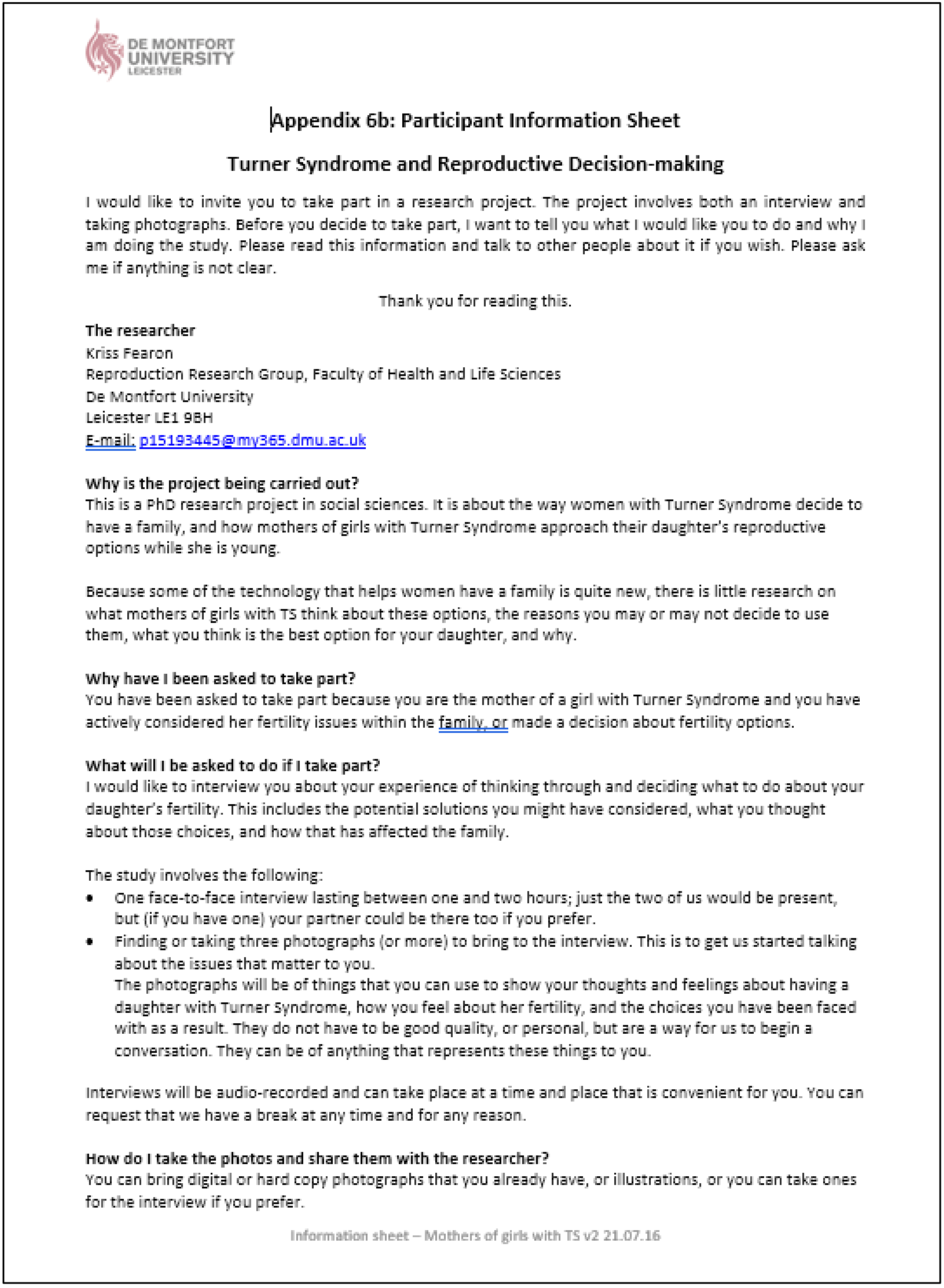
Fertility Friends

This is a large online community where people with fertility issues can support each other:

http://www.fertilityfriends.co.uk/

Information sheet – Women with TS v2 20.07.16

b) Mothers of girls with TS



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Appendix 6b: Participant Information Sheet

Turner Syndrome and Reproductive Decision-making

I would like to invite you to take part in a research project. The project involves both an interview and taking photographs. Before you decide to take part, I want to tell you what I would like you to do and why I am doing the study. Please read this information and talk to other people about it if you wish. Please ask me if anything is not clear.

Thank you for reading this.

The researcher
Kriss Fearon
Reproduction Research Group, Faculty of Health and Life Sciences
De Montfort University
Leicester LE1 9BH
E-mail: p15193445@my365.dmu.ac.uk

Why is the project being carried out?
This is a PhD research project in social sciences. It is about the way women with Turner Syndrome decide to have a family, and how mothers of girls with Turner Syndrome approach their daughter's reproductive options while she is young.

Because some of the technology that helps women have a family is quite new, there is little research on what mothers of girls with TS think about these options, the reasons you may or may not decide to use them, what you think is the best option for your daughter, and why.

Why have I been asked to take part?
You have been asked to take part because you are the mother of a girl with Turner Syndrome and you have actively considered her fertility issues within the family, or made a decision about fertility options.

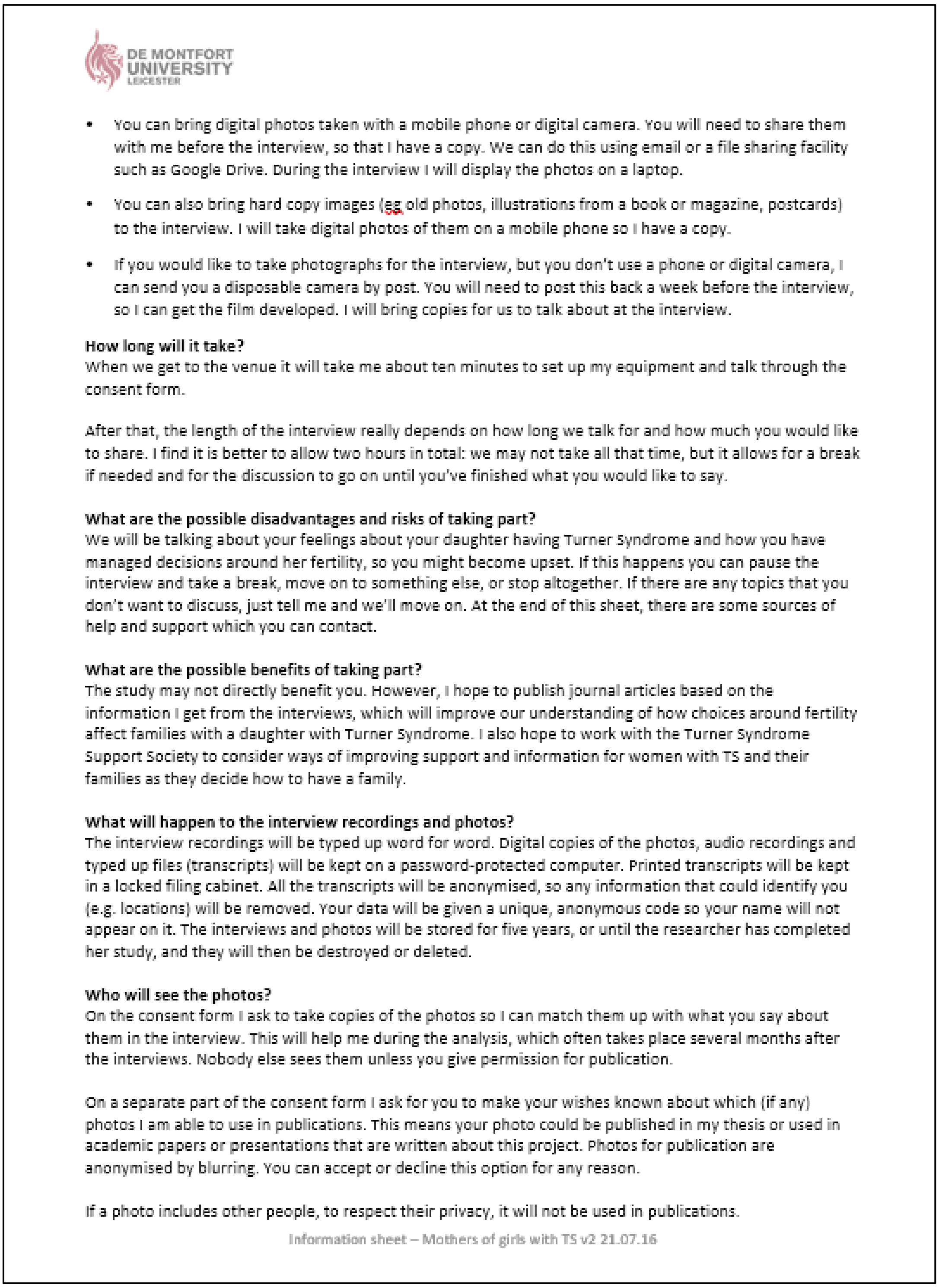
What will I be asked to do if I take part?
I would like to interview you about your experience of thinking through and deciding what to do about your daughter's fertility. This includes the potential solutions you might have considered, what you thought about those choices, and how that has affected the family.

The study involves the following:

- One face-to-face interview lasting between one and two hours; just the two of us would be present, but (if you have one) your partner could be there too if you prefer.
- Finding or taking three photographs (or more) to bring to the interview. This is to get us started talking about the issues that matter to you.
  The photographs will be of things that you can use to show your thoughts and feelings about having a daughter with Turner Syndrome, how you feel about her fertility, and the choices you have been faced with as a result. They do not have to be good quality, or personal, but are a way for us to begin a conversation. They can be of anything that represents these things to you.

Interviews will be audio-recorded and can take place at a time and place that is convenient for you. You can request that we have a break at any time and for any reason.

How do I take the photos and share them with the researcher?
You can bring digital or hard copy photographs that you already have, or illustrations, or you can take ones for the interview if you prefer.



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- You can bring digital photos taken with a mobile phone or digital camera. You will need to share them with me before the interview, so that I have a copy. We can do this using email or a file sharing facility such as Google Drive. During the interview I will display the photos on a laptop.
- You can also bring hard copy images (eg old photos, illustrations from a book or magazine, postcards) to the interview. I will take digital photos of them on a mobile phone so I have a copy.
- If you would like to take photographs for the interview, but you don't use a phone or digital camera, I can send you a disposable camera by post. You will need to post this back a week before the interview, so I can get the film developed. I will bring copies for us to talk about at the interview.

How long will it take?
When we get to the venue it will take me about ten minutes to set up my equipment and talk through the consent form.

After that, the length of the interview really depends on how long we talk for and how much you would like to share. I find it is better to allow two hours in total: we may not take all that time, but it allows for a break if needed and for the discussion to go on until you've finished what you would like to say.

What are the possible disadvantages and risks of taking part?
We will be talking about your feelings about your daughter having Turner Syndrome and how you have managed decisions around her fertility, so you might become upset. If this happens you can pause the interview and take a break, move on to something else, or stop altogether. If there are any topics that you don't want to discuss, just tell me and we'll move on. At the end of this sheet, there are some sources of help and support which you can contact.

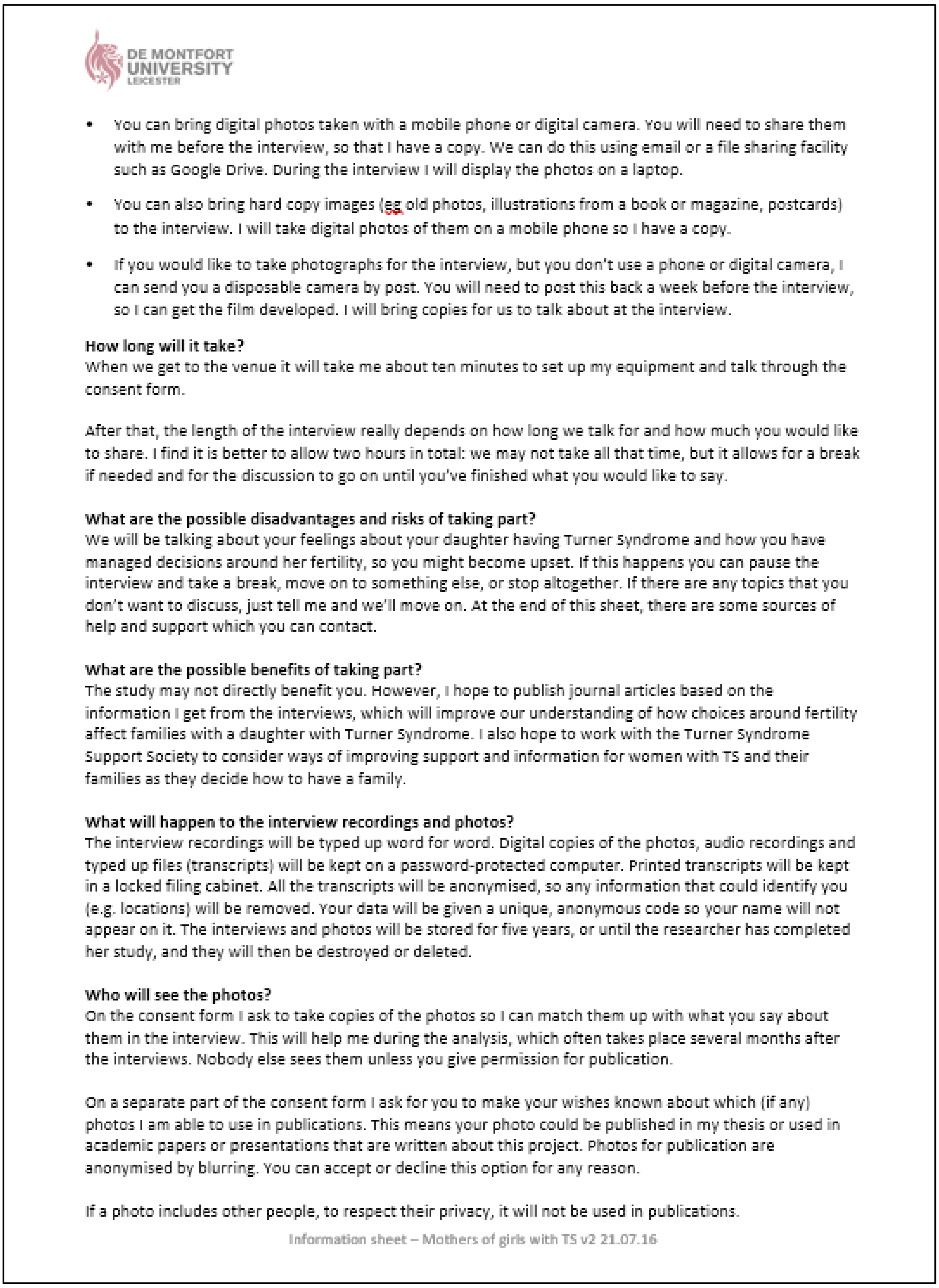
What are the possible benefits of taking part?
The study may not directly benefit you. However, I hope to publish journal articles based on the information I get from the interviews, which will improve our understanding of how choices around fertility affect families with a daughter with Turner Syndrome. I also hope to work with the Turner Syndrome Support Society to consider ways of improving support and information for women with TS and their families as they decide how to have a family.

What will happen to the interview recordings and photos?
The interview recordings will be typed up word for word. Digital copies of the photos, audio recordings and typed up files (transcripts) will be kept on a password-protected computer. Printed transcripts will be kept in a locked filing cabinet. All the transcripts will be anonymised, so any information that could identify you (e.g. locations) will be removed. Your data will be given a unique, anonymous code so your name will not appear on it. The interviews and photos will be stored for five years, or until the researcher has completed her study, and they will then be destroyed or deleted.

Who will see the photos?
On the consent form I ask to take copies of the photos so I can match them up with what you say about them in the interview. This will help me during the analysis, which often takes place several months after the interviews. Nobody else sees them unless you give permission for publication.

On a separate part of the consent form I ask for you to make your wishes known about which (if any) photos I am able to use in publications. This means your photo could be published in my thesis or used in academic papers or presentations that are written about this project. Photos for publication are anonymised by blurring. You can accept or decline this option for any reason.

If a photo includes other people, to respect their privacy, it will not be used in publications.



- You can bring digital photos taken with a mobile phone or digital camera. You will need to share them with me before the interview, so that I have a copy. We can do this using email or a file sharing facility such as Google Drive. During the interview I will display the photos on a laptop.
- You can also bring hard copy images (eg old photos, illustrations from a book or magazine, postcards) to the interview. I will take digital photos of them on a mobile phone so I have a copy.
- If you would like to take photographs for the interview, but you don't use a phone or digital camera, I can send you a disposable camera by post. You will need to post this back a week before the interview, so I can get the film developed. I will bring copies for us to talk about at the interview.

How long will it take?
When we get to the venue it will take me about ten minutes to set up my equipment and talk through the consent form.

After that, the length of the interview really depends on how long we talk for and how much you would like to share. I find it is better to allow two hours in total: we may not take all that time, but it allows for a break if needed and for the discussion to go on until you've finished what you would like to say.

What are the possible disadvantages and risks of taking part?
We will be talking about your feelings about your daughter having Turner Syndrome and how you have managed decisions around her fertility, so you might become upset. If this happens you can pause the interview and take a break, move on to something else, or stop altogether. If there are any topics that you don't want to discuss, just tell me and we'll move on. At the end of this sheet, there are some sources of help and support which you can contact.

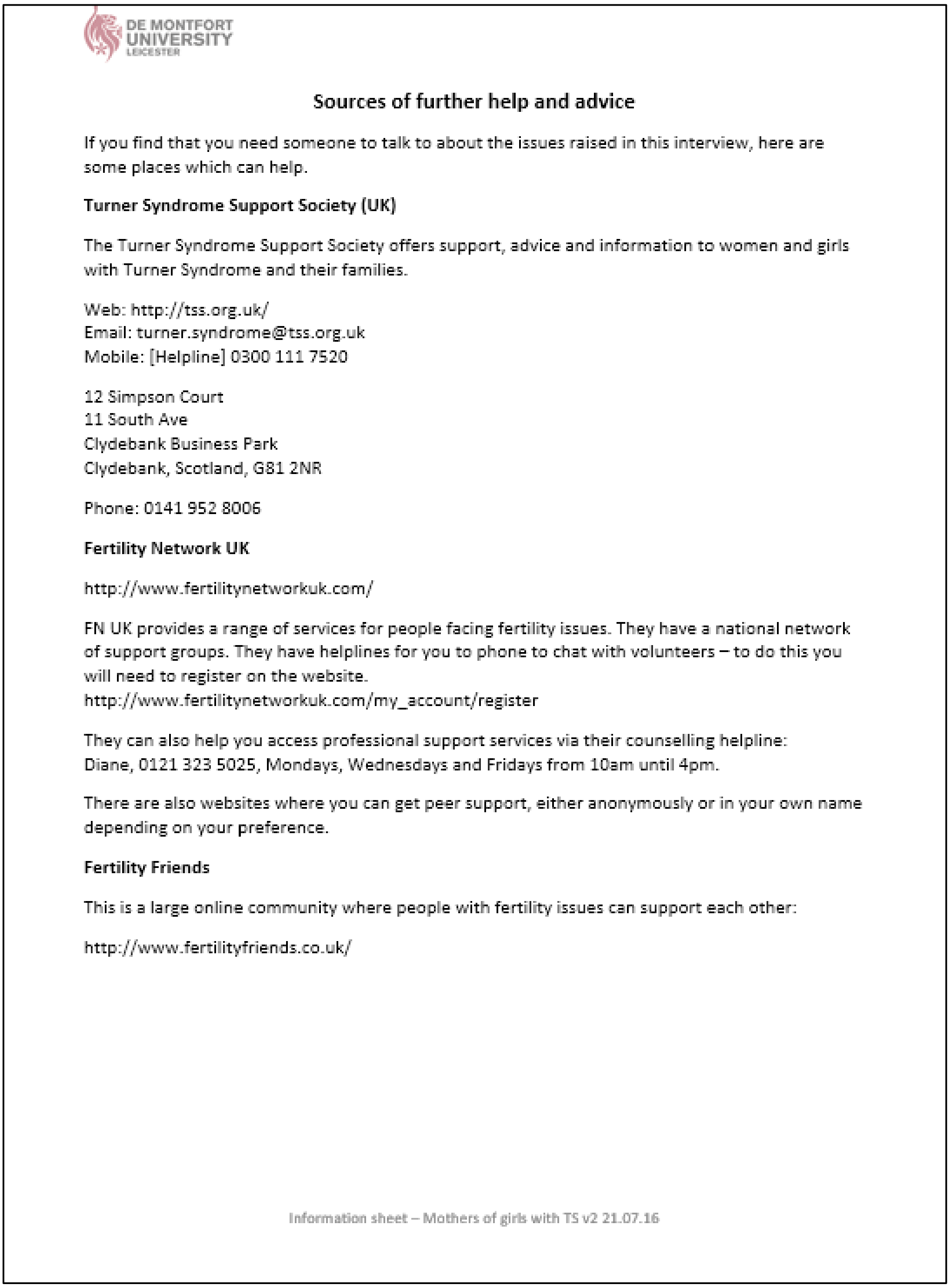
What are the possible benefits of taking part?
The study may not directly benefit you. However, I hope to publish journal articles based on the information I get from the interviews, which will improve our understanding of how choices around fertility affect families with a daughter with Turner Syndrome. I also hope to work with the Turner Syndrome Support Society to consider ways of improving support and information for women with TS and their families as they decide how to have a family.

What will happen to the interview recordings and photos?
The interview recordings will be typed up word for word. Digital copies of the photos, audio recordings and typed up files (transcripts) will be kept on a password-protected computer. Printed transcripts will be kept in a locked filing cabinet. All the transcripts will be anonymised, so any information that could identify you (e.g. locations) will be removed. Your data will be given a unique, anonymous code so your name will not appear on it. The interviews and photos will be stored for five years, or until the researcher has completed her study, and they will then be destroyed or deleted.

Who will see the photos?
On the consent form I ask to take copies of the photos so I can match them up with what you say about them in the interview. This will help me during the analysis, which often takes place several months after the interviews. Nobody else sees them unless you give permission for publication.

On a separate part of the consent form I ask for you to make your wishes known about which (if any) photos I am able to use in publications. This means your photo could be published in my thesis or used in academic papers or presentations that are written about this project. Photos for publication are anonymised by blurring. You can accept or decline this option for any reason.

If a photo includes other people, to respect their privacy, it will not be used in publications.



Sources of further help and advice

If you find that you need someone to talk to about the issues raised in this interview, here are some places which can help.

Turner Syndrome Support Society (UK)

The Turner Syndrome Support Society offers support, advice and information to women and girls with Turner Syndrome and their families.

Web: http://tss.org.uk/
Email: turner.syndrome@tss.org.uk
Mobile: [Helpline] 0300 111 7520

12 Simpson Court
11 South Ave
Clydebank Business Park
Clydebank, Scotland, G81 2NR

Phone: 0141 952 8006

Fertility Network UK

http://www.fertilitynetworkuk.com/

FN UK provides a range of services for people facing fertility issues. They have a national network of support groups. They have helplines for you to phone to chat with volunteers – to do this you will need to register on the website.
http://www.fertilitynetworkuk.com/my_account/register

They can also help you access professional support services via their counselling helpline:
Diane, 0121 323 5025, Mondays, Wednesdays and Fridays from 10am until 4pm.

There are also websites where you can get peer support, either anonymously or in your own name depending on your preference.

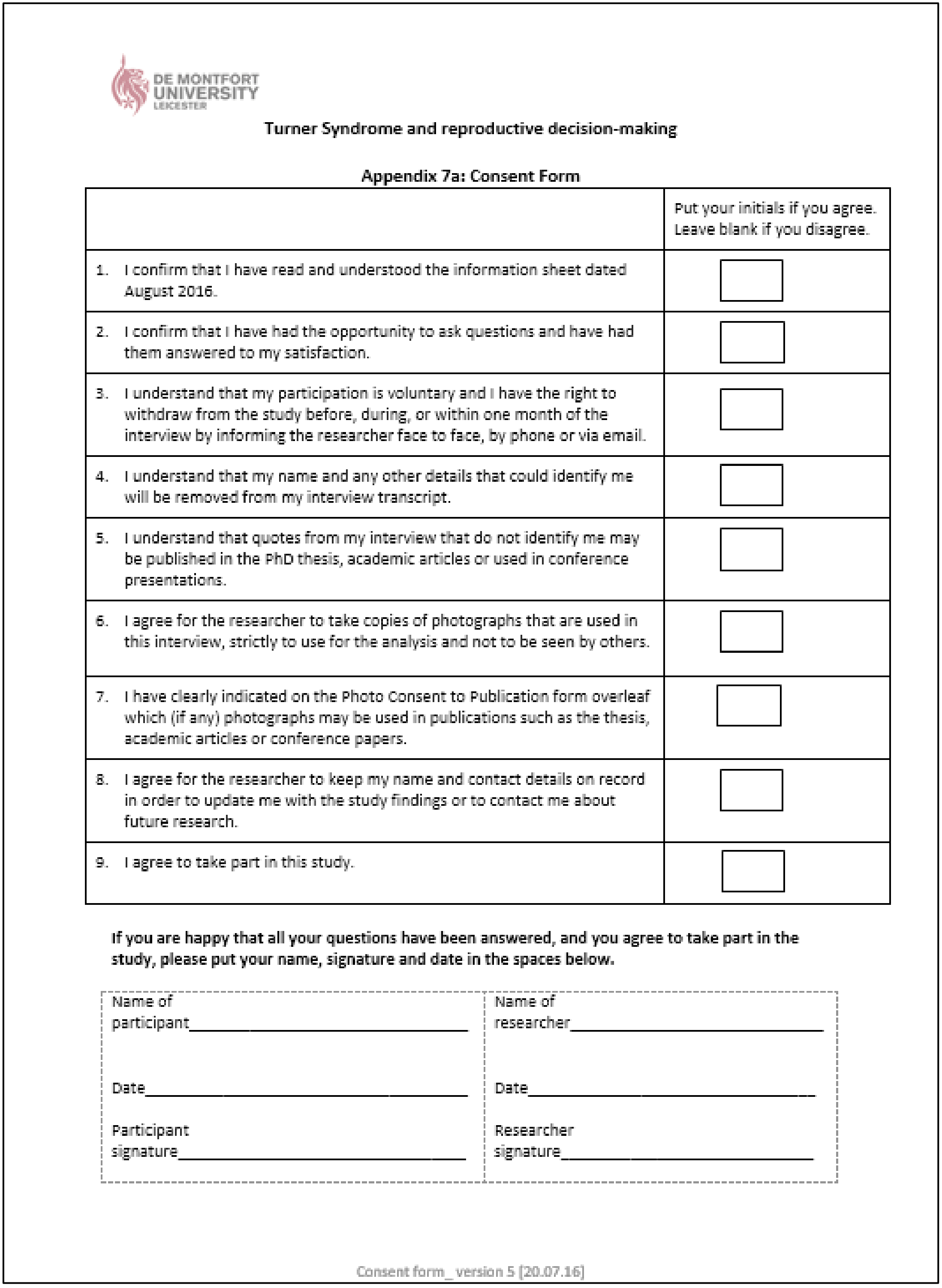
Fertility Friends

This is a large online community where people with fertility issues can support each other:

http://www.fertilityfriends.co.uk/

Appendix 7 – Consent forms

a) Consent to record form



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Turner Syndrome and reproductive decision-making

Appendix 7a: Consent Form

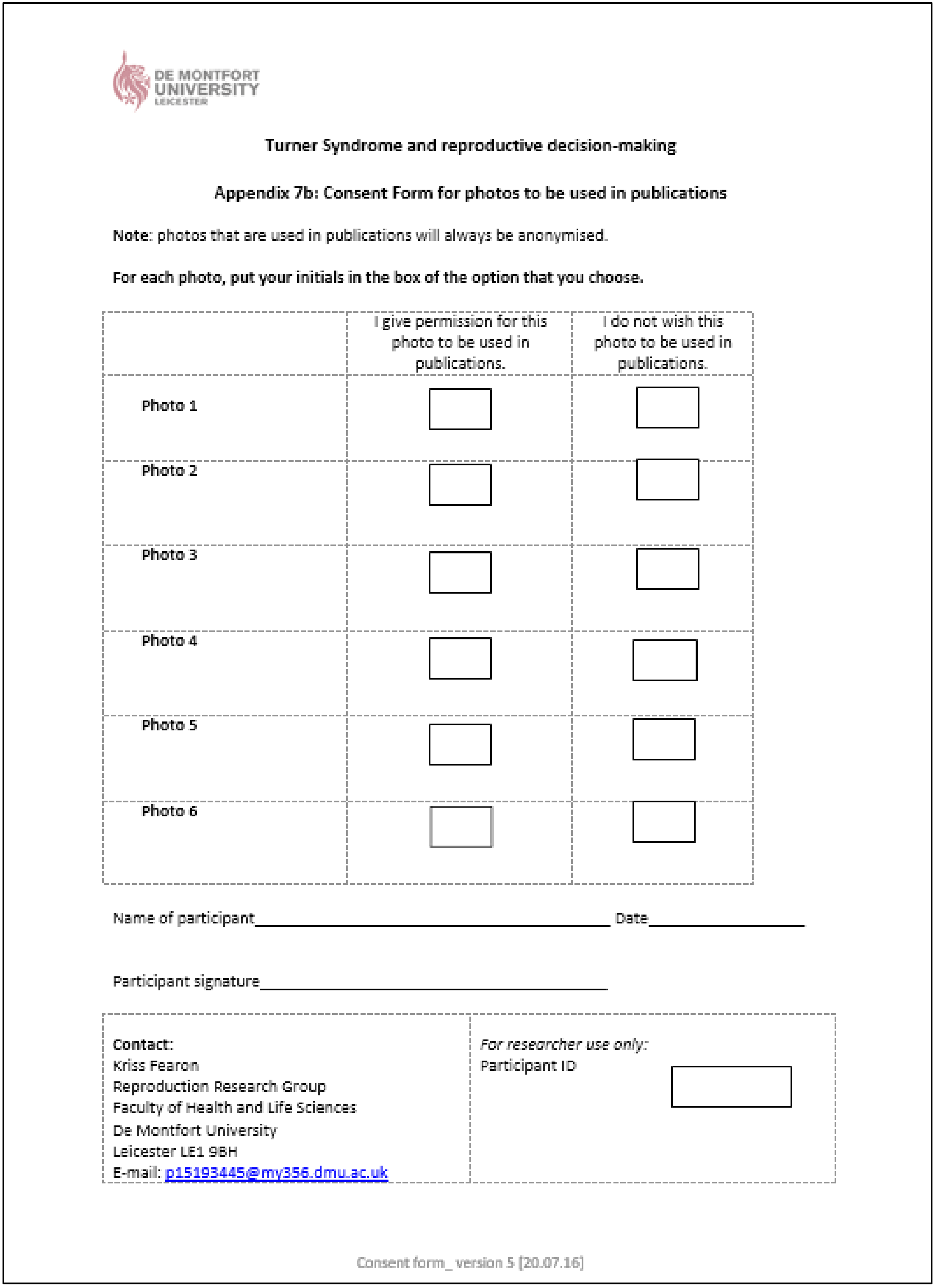
	Put your initials if you agree. Leave blank if you disagree.
1. I confirm that I have read and understood the information sheet dated August 2016.	☐
2. I confirm that I have had the opportunity to ask questions and have had them answered to my satisfaction.	☐
3. I understand that my participation is voluntary and I have the right to withdraw from the study before, during, or within one month of the interview by informing the researcher face to face, by phone or via email.	☐
4. I understand that my name and any other details that could identify me will be removed from my interview transcript.	☐
5. I understand that quotes from my interview that do not identify me may be published in the PhD thesis, academic articles or used in conference presentations.	☐
6. I agree for the researcher to take copies of photographs that are used in this interview, strictly to use for the analysis and not to be seen by others.	☐
7. I have clearly indicated on the Photo Consent to Publication form overleaf which (if any) photographs may be used in publications such as the thesis, academic articles or conference papers.	☐
8. I agree for the researcher to keep my name and contact details on record in order to update me with the study findings or to contact me about future research.	☐
9. I agree to take part in this study.	☐

If you are happy that all your questions have been answered, and you agree to take part in the study, please put your name, signature and date in the spaces below.

Name of participant________________________________	Name of researcher________________________________
Date________________________________	Date________________________________
Participant signature________________________________	Researcher signature________________________________

Consent form_ version 5 [20.07.16]

b) Photo consent form



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Turner Syndrome and reproductive decision-making

Appendix 7b: Consent Form for photos to be used in publications

Note: photos that are used in publications will always be anonymised.

For each photo, put your initials in the box of the option that you choose.

	I give permission for this photo to be used in publications.	I do not wish this photo to be used in publications.
Photo 1	☐	☐
Photo 2	☐	☐
Photo 3	☐	☐
Photo 4	☐	☐
Photo 5	☐	☐
Photo 6	☐	☐

Name of participant____ Date__________________

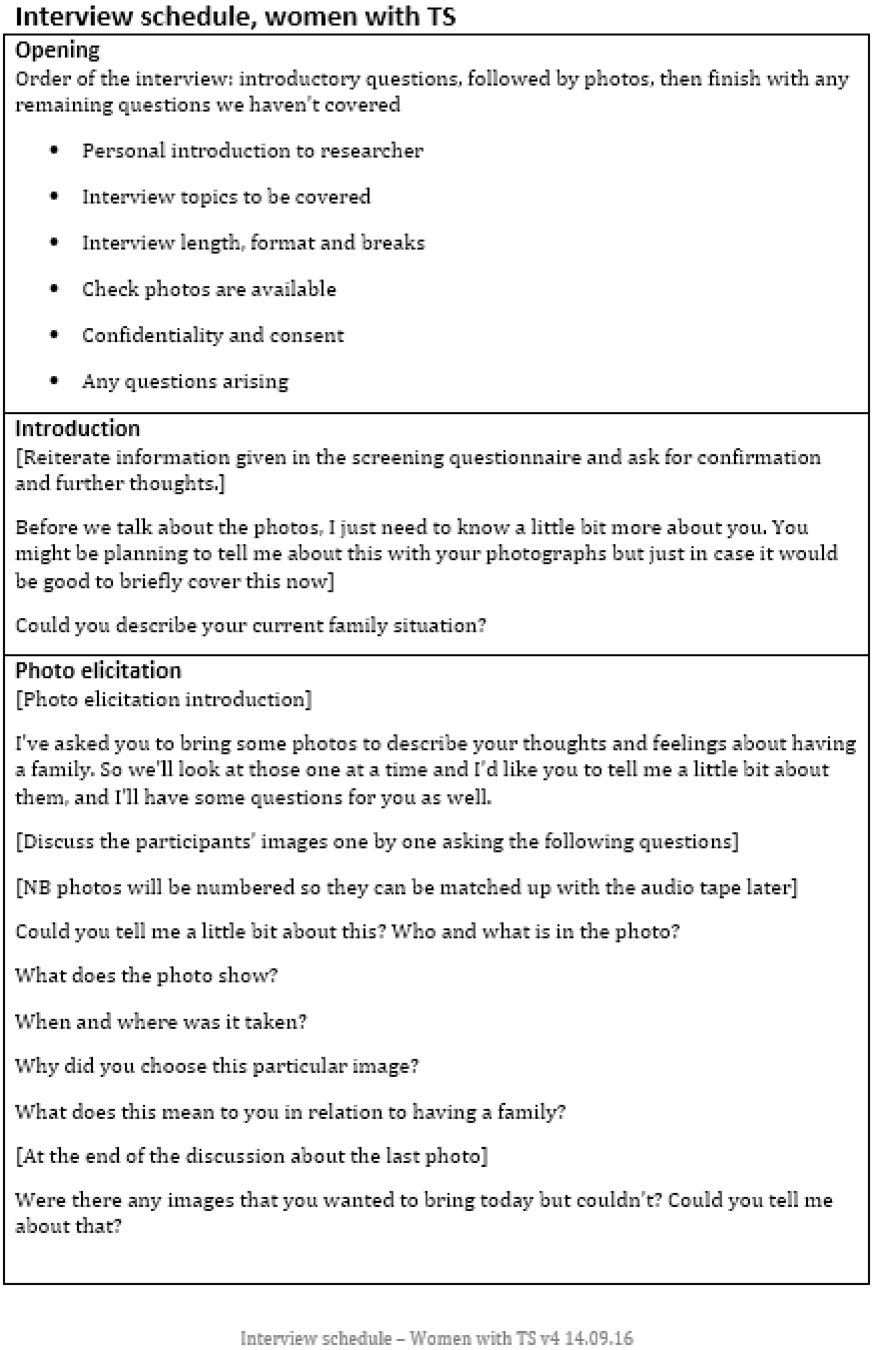
Participant signature____

Contact: Kriss Fearon Reproduction Research Group Faculty of Health and Life Sciences De Montfort University Leicester LE1 9BH E-mail: p15193445@my356.dmu.ac.uk	*For researcher use only:* Participant ID ☐

Consent form_ version 5 [20.07.16]

Appendix 8 – interview schedules

a) Women with TS



Interview schedule, women with TS

Opening

Order of the interview: introductory questions, followed by photos, then finish with any remaining questions we haven't covered

- Personal introduction to researcher
- Interview topics to be covered
- Interview length, format and breaks
- Check photos are available
- Confidentiality and consent
- Any questions arising

Introduction

[Reiterate information given in the screening questionnaire and ask for confirmation and further thoughts.]

Before we talk about the photos, I just need to know a little bit more about you. You might be planning to tell me about this with your photographs but just in case it would be good to briefly cover this now]

Could you describe your current family situation?

Photo elicitation

[Photo elicitation introduction]

I've asked you to bring some photos to describe your thoughts and feelings about having a family. So we'll look at those one at a time and I'd like you to tell me a little bit about them, and I'll have some questions for you as well.

[Discuss the participants' images one by one asking the following questions]

[NB photos will be numbered so they can be matched up with the audio tape later]

Could you tell me a little bit about this? Who and what is in the photo?

What does the photo show?

When and where was it taken?

Why did you choose this particular image?

What does this mean to you in relation to having a family?

[At the end of the discussion about the last photo]

Were there any images that you wanted to bring today but couldn't? Could you tell me about that?

Interview schedule – Women with TS v4 14.09.16

Growing up and living with TS

Could you tell me when you were diagnosed with Turner Syndrome? How old were you?

How does TS affect your day to day life?

What was the most important thing about having Turner Syndrome, to you, as you were growing up?

[If they were told as a child]

Were you told about the fertility implications of TS when you were diagnosed? How did you feel about this?

[If the participant had siblings]

Was your life different to that of your brothers and sisters, or friends?

Disclosure outside the family

Is your diagnosis known outside the family?

How do you share knowledge of your diagnosis, and who with? (school, college, work)

At what point would you normally tell? What kind of responses have there been?

Feelings about fertility and fertility options

When you were diagnosed, what was your understanding at the time of what it would mean for you?

Is fertility important to you? Would you like children?

[Feelings about family-building options]

After you were diagnosed, at what point were your fertility options discussed?

[If participant has mosaic TS] What was your understanding of how it might affect your fertility?

How did you find out what family-building options were available to you?

What did you think of these options? Did you have a preference?

Could you tell me how you feel about being a mother? How important is it to you?

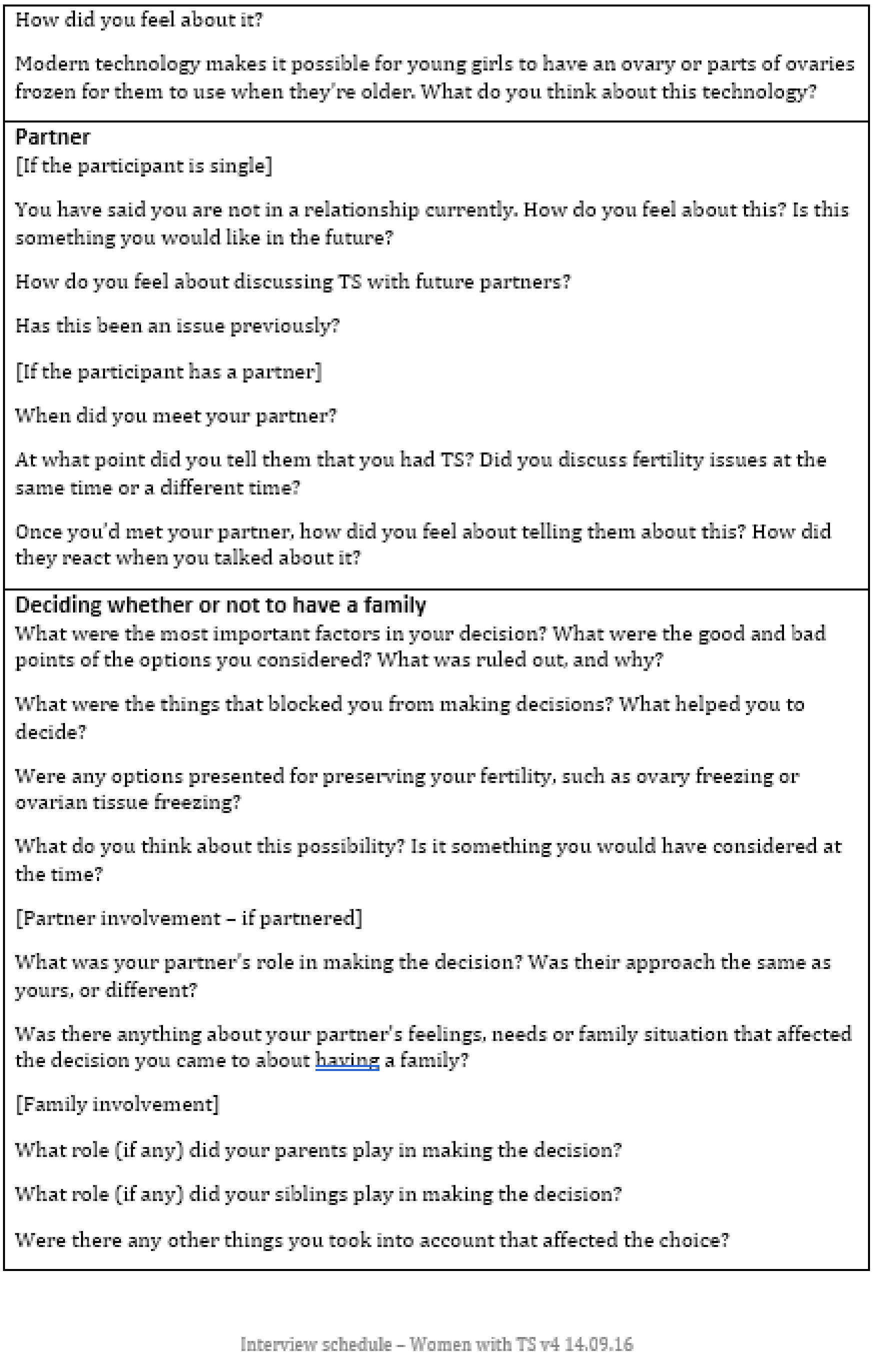
Do you have an 'ideal family'? How many children would you like?

Is it important that you have children who are genetically connected to you?

[If the participant had siblings]

Did you ever talk to your brother/sister about having a family? What kinds of things did you talk about?

Was egg donation ever discussed? Was the possibility ever raised of receiving eggs from a member of your family? How was this raised, and what was the reaction to it?



How did you feel about it?

Modern technology makes it possible for young girls to have an ovary or parts of ovaries frozen for them to use when they're older. What do you think about this technology?

Partner

[If the participant is single]

You have said you are not in a relationship currently. How do you feel about this? Is this something you would like in the future?

How do you feel about discussing TS with future partners?

Has this been an issue previously?

[If the participant has a partner]

When did you meet your partner?

At what point did you tell them that you had TS? Did you discuss fertility issues at the same time or a different time?

Once you'd met your partner, how did you feel about telling them about this? How did they react when you talked about it?

Deciding whether or not to have a family

What were the most important factors in your decision? What were the good and bad points of the options you considered? What was ruled out, and why?

What were the things that blocked you from making decisions? What helped you to decide?

Were any options presented for preserving your fertility, such as ovary freezing or ovarian tissue freezing?

What do you think about this possibility? Is it something you would have considered at the time?

[Partner involvement – if partnered]

What was your partner's role in making the decision? Was their approach the same as yours, or different?

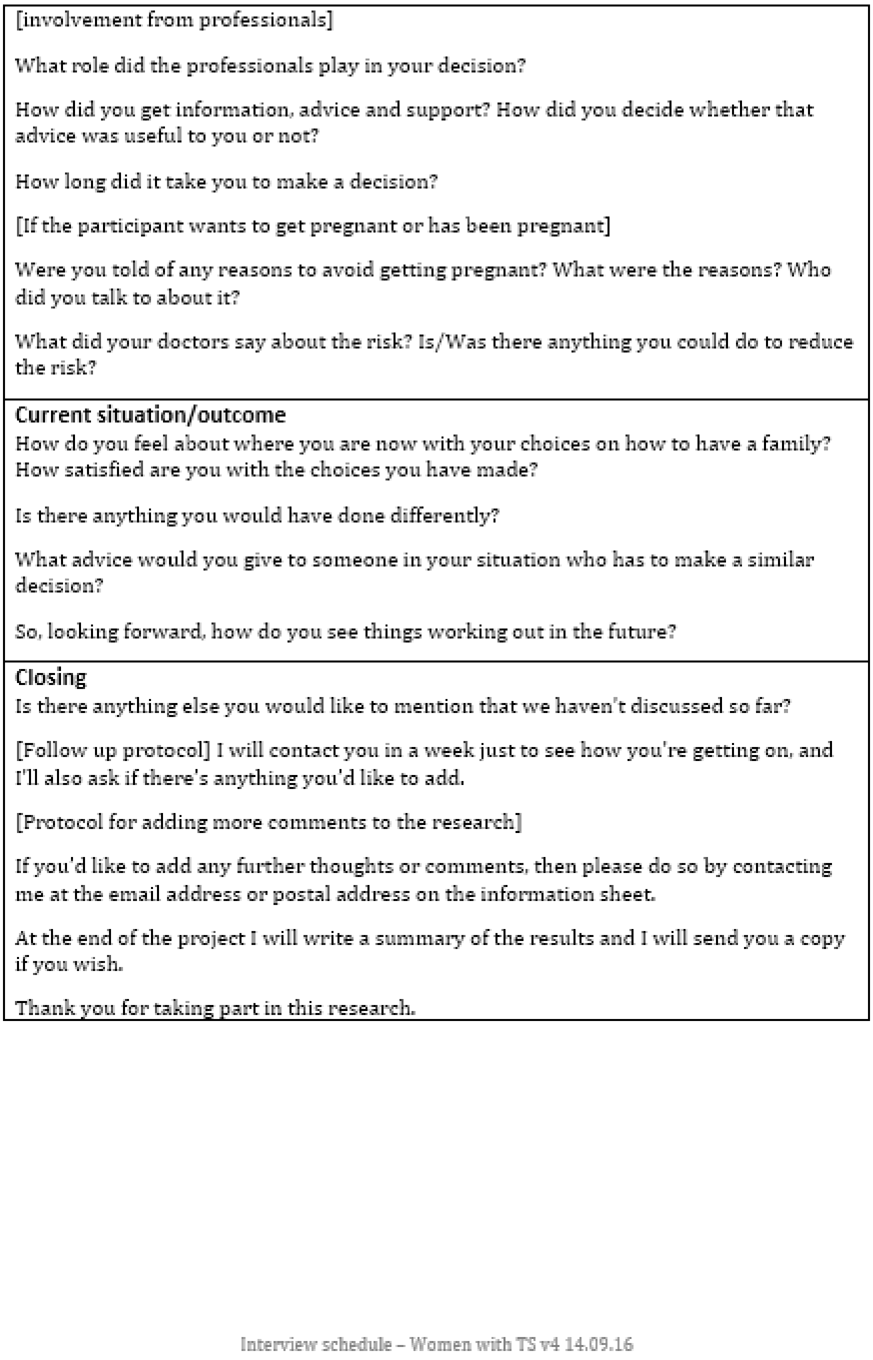
Was there anything about your partner's feelings, needs or family situation that affected the decision you came to about having a family?

[Family involvement]

What role (if any) did your parents play in making the decision?

What role (if any) did your siblings play in making the decision?

Were there any other things you took into account that affected the choice?



[involvement from professionals]

What role did the professionals play in your decision?

How did you get information, advice and support? How did you decide whether that advice was useful to you or not?

How long did it take you to make a decision?

[If the participant wants to get pregnant or has been pregnant]

Were you told of any reasons to avoid getting pregnant? What were the reasons? Who did you talk to about it?

What did your doctors say about the risk? Is/Was there anything you could do to reduce the risk?

Current situation/outcome

How do you feel about where you are now with your choices on how to have a family? How satisfied are you with the choices you have made?

Is there anything you would have done differently?

What advice would you give to someone in your situation who has to make a similar decision?

So, looking forward, how do you see things working out in the future?

Closing

Is there anything else you would like to mention that we haven't discussed so far?

[Follow up protocol] I will contact you in a week just to see how you're getting on, and I'll also ask if there's anything you'd like to add.

[Protocol for adding more comments to the research]

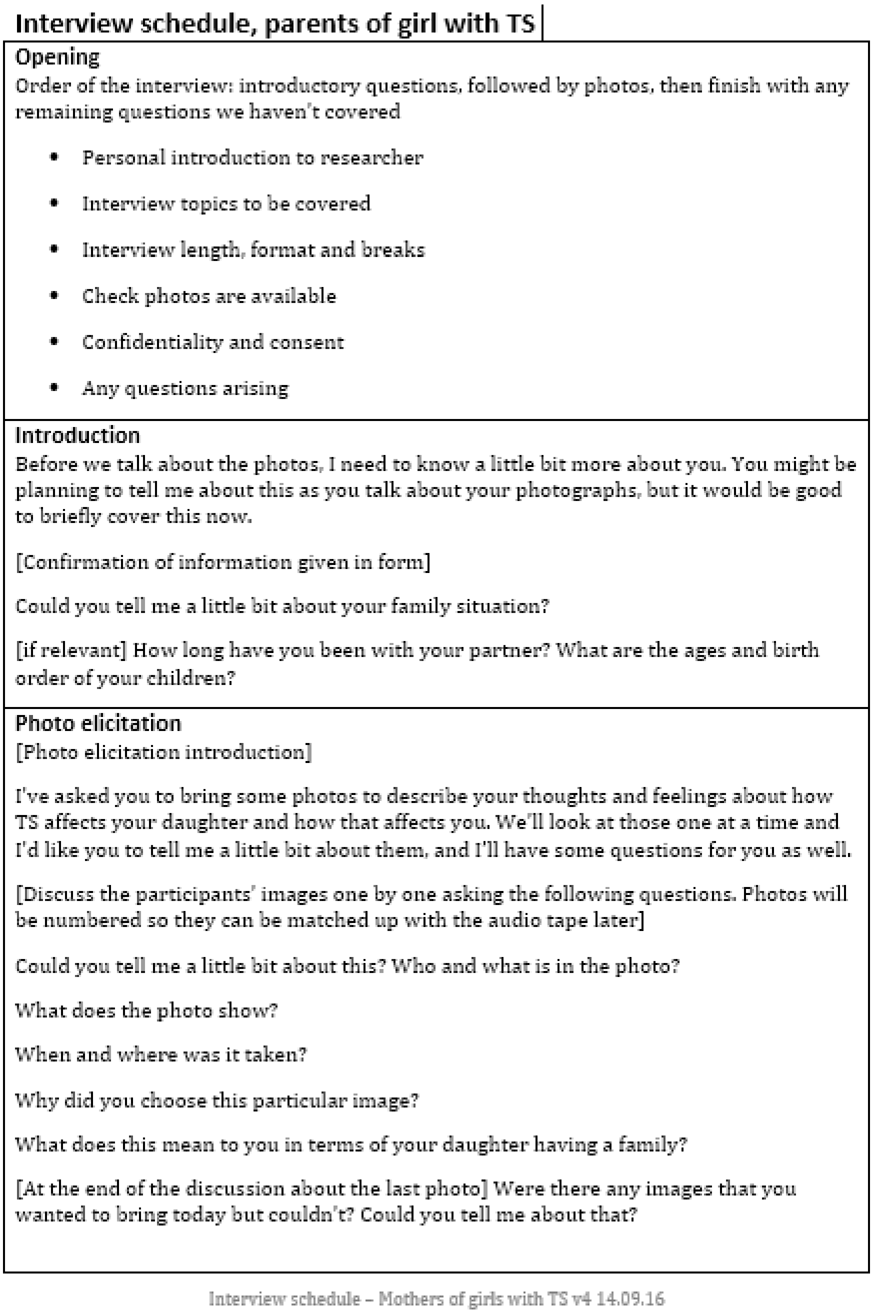
If you'd like to add any further thoughts or comments, then please do so by contacting me at the email address or postal address on the information sheet.

At the end of the project I will write a summary of the results and I will send you a copy if you wish.

Thank you for taking part in this research.

Interview schedule – Women with TS v4 14.09.16

b) Mothers of girls with TS



Interview schedule, parents of girl with TS

Opening

Order of the interview: introductory questions, followed by photos, then finish with any remaining questions we haven't covered

- Personal introduction to researcher
- Interview topics to be covered
- Interview length, format and breaks
- Check photos are available
- Confidentiality and consent
- Any questions arising

Introduction

Before we talk about the photos, I need to know a little bit more about you. You might be planning to tell me about this as you talk about your photographs, but it would be good to briefly cover this now.

[Confirmation of information given in form]

Could you tell me a little bit about your family situation?

[if relevant] How long have you been with your partner? What are the ages and birth order of your children?

Photo elicitation

[Photo elicitation introduction]

I've asked you to bring some photos to describe your thoughts and feelings about how TS affects your daughter and how that affects you. We'll look at those one at a time and I'd like you to tell me a little bit about them, and I'll have some questions for you as well.

[Discuss the participants' images one by one asking the following questions. Photos will be numbered so they can be matched up with the audio tape later]

Could you tell me a little bit about this? Who and what is in the photo?

What does the photo show?

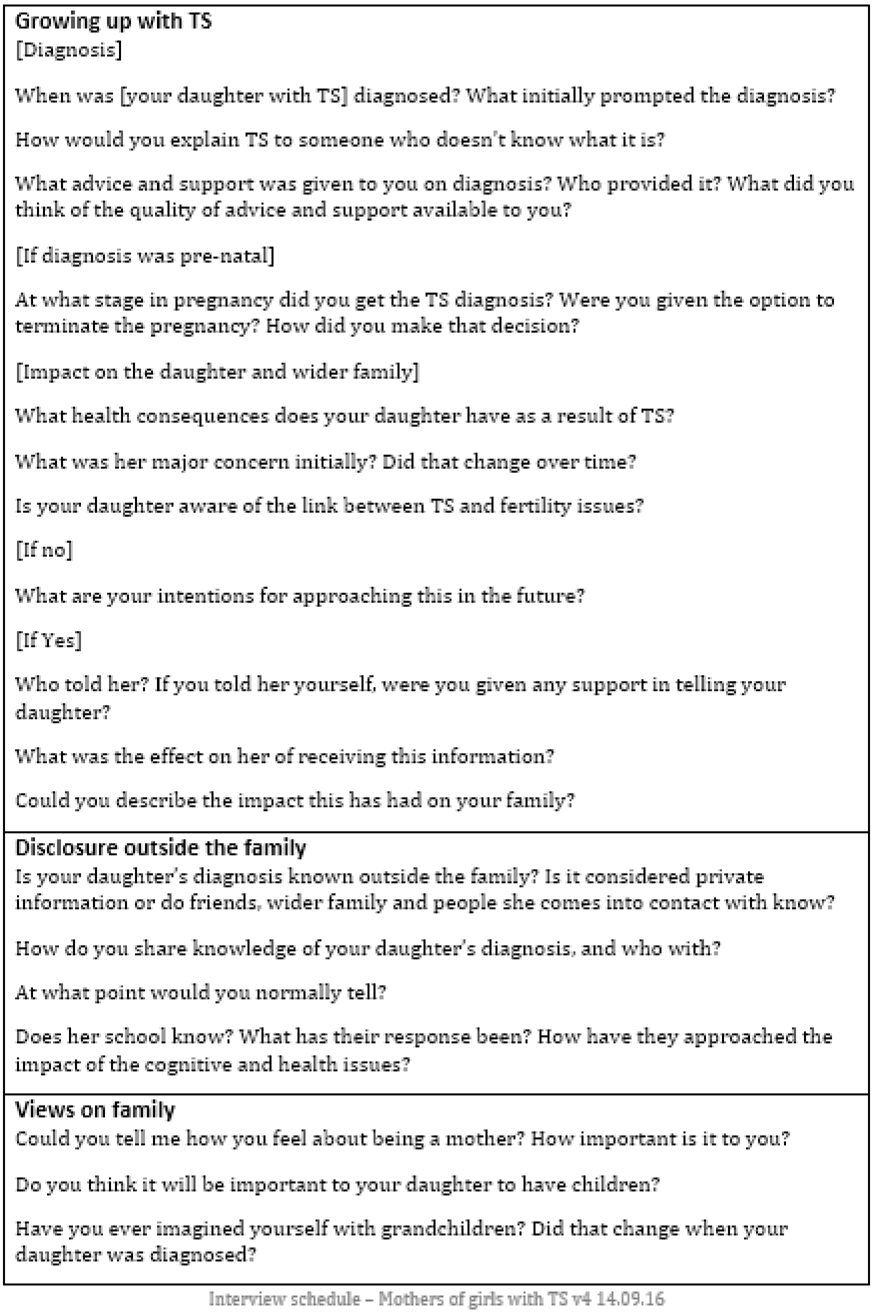
When and where was it taken?

Why did you choose this particular image?

What does this mean to you in terms of your daughter having a family?

[At the end of the discussion about the last photo] Were there any images that you wanted to bring today but couldn't? Could you tell me about that?

Interview schedule – Mothers of girls with TS v4 14.09.16



Growing up with TS

[Diagnosis]

When was [your daughter with TS] diagnosed? What initially prompted the diagnosis?

How would you explain TS to someone who doesn't know what it is?

What advice and support was given to you on diagnosis? Who provided it? What did you think of the quality of advice and support available to you?

[If diagnosis was pre-natal]

At what stage in pregnancy did you get the TS diagnosis? Were you given the option to terminate the pregnancy? How did you make that decision?

[Impact on the daughter and wider family]

What health consequences does your daughter have as a result of TS?

What was her major concern initially? Did that change over time?

Is your daughter aware of the link between TS and fertility issues?

[If no]

What are your intentions for approaching this in the future?

[If Yes]

Who told her? If you told her yourself, were you given any support in telling your daughter?

What was the effect on her of receiving this information?

Could you describe the impact this has had on your family?

Disclosure outside the family

Is your daughter's diagnosis known outside the family? Is it considered private information or do friends, wider family and people she comes into contact with know?

How do you share knowledge of your daughter's diagnosis, and who with?

At what point would you normally tell?

Does her school know? What has their response been? How have they approached the impact of the cognitive and health issues?

Views on family

Could you tell me how you feel about being a mother? How important is it to you?

Do you think it will be important to your daughter to have children?

Have you ever imagined yourself with grandchildren? Did that change when your daughter was diagnosed?

Interview schedule – Mothers of girls with TS v4 14.09.16

Fertility preservation/fertility treatment options

[Take account of the fact they might not know what the options are]

What fertility options are you aware of, that would be available to your daughter?

[If mother was under 35 at the time of diagnosis]

Did you consider freezing your eggs for your daughter? Was this option feasible at the time?

What did you think about it? What were the barriers to going forward? What would make you want to go ahead?

[If daughter has mosaic TS]

Were any options presented for preserving your daughter's fertility, such as ovary freezing or ovarian tissue freezing?

What do you think about this possibility? Is it something you would have considered at the time?

[If the participant has another daughter]

Did you consider the possibility that your daughter might be able to donate eggs to her sister? What did you think about this option? Did you talk about it within the family? How did you come to a decision about how to handle this?

What did you think the implications might be for your daughters? Do you think this could possibly affect in some way her future partner?

Were you aware of any health risks to a woman with TS if she goes through a pregnancy and birth? Was this a factor in your choice?

Was your daughter with TS involved in the decision making process at any stage? How were the options were presented to her?

What role did your partner and other family members play in this process? Were there any issues where you disagreed? How did you resolve them?

What role did the professionals play in your decision?

How did you get information, advice and support? How useful was it? How did you decide whether that advice was useful to you or not?

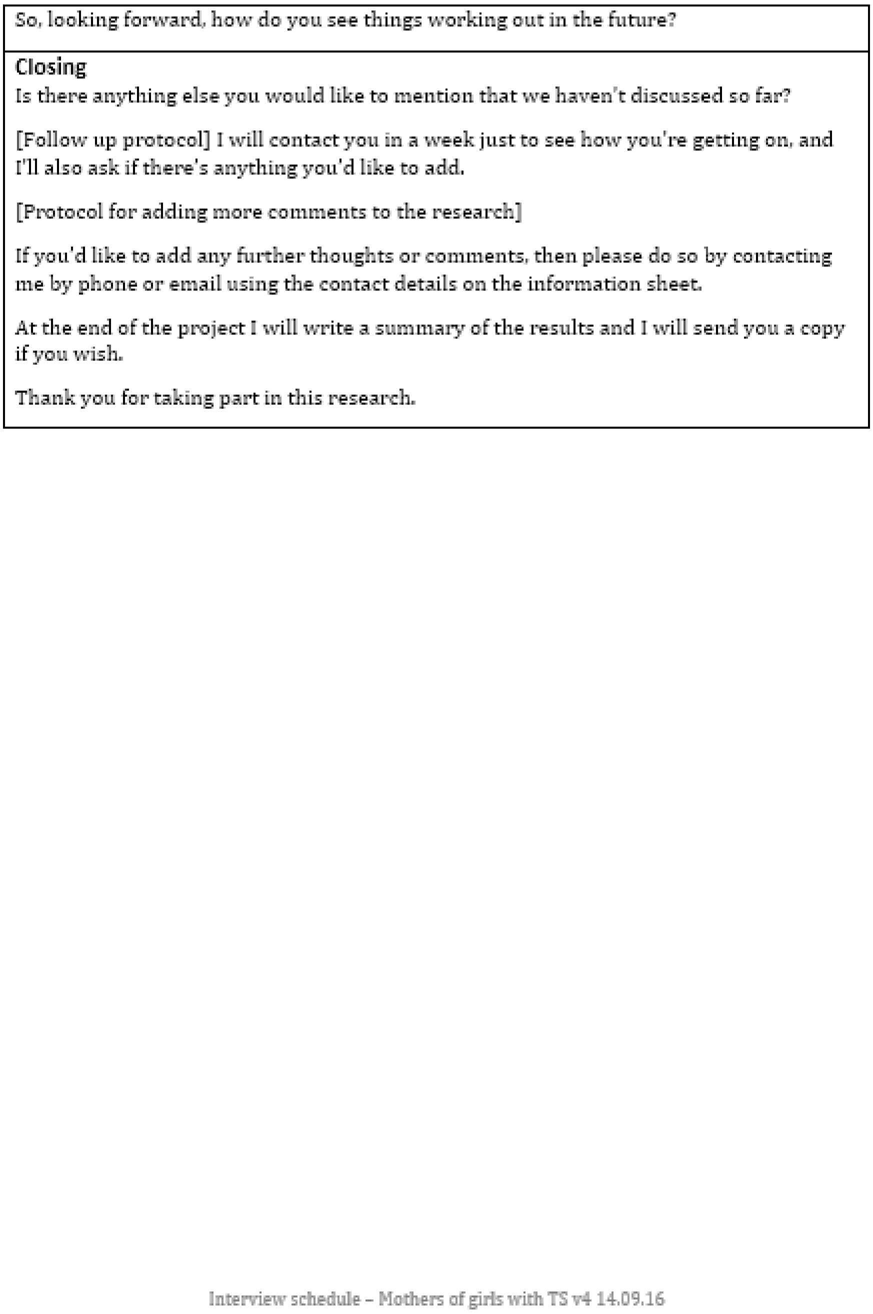
How long did it take you to make the decision?

Current situation/outcome

How do you feel now about the decision you have made about your daughter's fertility?

Is there anything you would have done differently?

What advice would you give to parents in your situation who have to face a similar decision?



So, looking forward, how do you see things working out in the future?

Closing

Is there anything else you would like to mention that we haven't discussed so far?

[Follow up protocol] I will contact you in a week just to see how you're getting on, and I'll also ask if there's anything you'd like to add.

[Protocol for adding more comments to the research]

If you'd like to add any further thoughts or comments, then please do so by contacting me by phone or email using the contact details on the information sheet.

At the end of the project I will write a summary of the results and I will send you a copy if you wish.

Thank you for taking part in this research.

Appendix 9 - Interview agendas

a) Women with TS

Title: Turner Syndrome and reproductive decision-making

Dear [participant]

I am writing to confirm the interview time, date and location we have agreed and to let you know the kind of topics we will cover.

The interview will take place at [time] on [date] at [location]. If for any reason you need to contact me on the day, please phone or text my mobile – the number is [number].

These are the topics I would like us to cover on the day:

> What it was like to grow up with TS and how you felt when you become aware of the fertility issues associated with it.
>
> Disclosure and how you handle telling people.
>
> Your feelings about fertility and how you feel about becoming a mother.
>
> The treatment options you are aware of and what you think of them.
>
> What happened when you discussed these options in the family, and what you think about any risks.
>
> Your relationship with your partner (if you have one) and how it may be affected by fertility issues.
>
> Where you are now with deciding to have a family, anything you would do differently; advice to others in the same situation.

This is also a reminder to bring three photographs with you to the interview – we will start off our conversation by looking at them first. If you have any questions about that or anything else, please feel free to contact me anytime.

Thank you so much for agreeing to take part. I look forward to meeting you soon.

Yours sincerely

Kriss Fearon
Researcher, De Montfort University

b) Mothers of girls with TS

Title: Turner Syndrome and reproductive decision-making

Dear [participant]

I am writing to confirm the interview time, date and location we have agreed and to let you know the kind of topics we will cover.

The interview will take place at [time] on [date] at [location]. If for any reason you need to contact me on the day, please phone or text my mobile – the number is [number].

These are the topics I would like us to cover on the day:

> Having a daughter with TS in the family; what it has been like for her growing up.
>
> Disclosure of your daughter's TS – how you handle telling people.
>
> Your views on family, and how important it might be to your daughter to become a parent.
>
> The treatment options you are aware of and what you think of them.
>
> What happened when you discussed these options in the family, and what you think about any risks.
>
> What advice you would have for other parents in your situation.

This is also a reminder to bring three photographs with you to the interview – we will start off our conversation by looking at them first. If you have any questions about that or anything else, please feel free to contact me anytime.

Thank you so much for agreeing to take part. I look forward to meeting you soon.

Yours sincerely

Kriss Fearon
Researcher, De Montfort University

Appendix 10
Video script 1 – welcome to the project

[200-260 words = 2 minutes] [398 words]

Hello. I'm Kriss Fearon, a researcher at De Montfort University in Leicester. I'm going to say a few words about the research project I'm doing, to explain what it's for, and who can take part.

This research is about how Turner Syndrome affects decisions about how to have a family. It's funded by De Montfort University in Leicester.

I'm looking for two groups of women to take part.

The first group is women with Turner Syndrome. I'd like to talk to you if you're currently planning a family or trying to conceive, or if you already have a family through adoption, egg donation or surrogacy, if you've considered all the options and decided not to have a family or if you want children but have come up against barriers which mean you can't take up the option you'd like.

The second group is mothers of girls with Turner Syndrome. If you have a daughter with TS and considered her fertility options or discussed this within the family, or maybe you considered freezing your own eggs for her future use. If this is you, I would love to talk to you.

I'm going to write up the research into a thesis for examination, and at the same time I'll also be talking about the findings at conferences and writing journal articles.

If you decide to take part, we will have an interview that lasts an hour to 1 ½ hours. We will meet up in a place that you are comfortable with, which is private enough to talk about a sensitive subject. I will also ask you to bring three photos which describe your feelings about Turner Syndrome and having a family.

If you take part, everything you say to me will be anonymised. I'd like to use quotes and photos from our interview so I can talk about the research in public, but everything I use will be anonymised. I will ask for your permission to do this on the consent form.

You don't have to take part if you don't want to, and if you do take part, you can change your mind up until a month after the interview. If you want to withdraw you just have to get in touch, and I'll write back to let you know I've deleted your details.

If you have any questions, or there's something you'd like to say, please do get in touch and we can have a chat.

Video script 2 – advice on choosing images

[396 words]

Hello there. I'm Kriss Fearon, researcher at De Montfort University, looking at issues around Turner Syndrome and having a family. I'm going to talk about the photos I'd like you to bring to the interview.

I'm asking you to choose three photographs to talk about in the interview. It's a really good way to get the conversation started. You can bring images that you've taken on a phone or digital camera, found on the internet or taken from a book or magazine. If you don't want to use digital photos please let me know and I can send you a disposable camera.

If you’re a woman with TS, the photos will be of things that show your thoughts and feelings about having a family, Turner Syndrome and fertility, and the choices you have been faced with as a result.

If you’re a mum, the photos will be about having a daughter with Turner Syndrome, how you feel about her fertility, how you handled this within the family and the choices you may have been faced with.

They don’t have to be good quality images, and they don’t have to be personal to you, they’re a way for us to begin a conversation. They can be of anything that represents these things to you.

If you’re having trouble deciding and you want to bring more than three photos, that’s fine.

I’d like to take copies of the photos so I can use them when I look back on our interview and analyse what we’ve said. I ask for your permission to do this on the consent form. They will be kept in a secure location and not linked with your name or any other personal details.

I’d also like to be able to use the photos when I talk or write about the research, such as at conferences or in academic journals. On the consent form, for each image, you can sign a box to say you agree to this, or you can sign a box to keep them private – it’s up to you.

Where necessary, I’ll anonymise any photos I use by blurring them.

If your photo includes people other than you, I will use it in the analysis but will not show it in any reports about the research. This is to protect their privacy.

If you have any questions, please do get in touch.

Video script 3 – explaining the consent form

[414 words]

Hello. I'm Kriss Fearon, researcher at De Montfort University looking at issues around Turner Syndrome and having a family. If you take part, you'll be talking with me. I'm going say a few words about the consent form for the project.

There are two reasons we use a consent form. One is to be sure that I've told you everything you need to know. The other is so it's clear what you agree or don't agree to when you decide to take part.

I'll ask you to confirm that you are taking part of your own free will, and that you're not under any pressure. If you decide you don't want to take part any more, you can withdraw by getting in touch with me, at any point up to one month after the interview.

You consent to keeping your identity private, so people who read the research won't know that you took part. This means I'll change your name and location, along with any other details that might tell someone who you are. I also ask for permission to use quotes from your interview that don't identify you, when I talk about the research in public.

I ask you to bring three photos to the interview that show your feelings about Turner Syndrome and having a family. We'll start off the interview by talking about them. I'll ask you to agree that I can use them alongside your words when I analyse the interview afterwards.

I will also ask you to say, for each photo, whether or not you give permission for it to be used in journal articles, presentations and other places where I am telling people the research findings. I will blur identifying areas of the photos so nobody can tell the identity of the people in them.

I’d like to audio-record the interview, so I can come back to it later and have an accurate record of what we said.

If you’d like to know what this research finds out, I can email you when the project is finished – this won’t be for a couple of years. I ask permission on the form to keep your name and contact details on record so I can update you.

Finally, you confirm that you want to participate by initialling the form.

Your consent on each of these points gives us both a clear record of what you want.

If you have any questions you are welcome to get in touch – I’d be very happy to hear from you.

Appendix 11: Website text

Website is live at: http://turner-study.wixsite.com/ts-decisions/

Home page: Turner Syndrome and reproductive decision-making

Intro text:

This research project is looking at the way Turner Syndrome affects reproductive choices.

I am exploring the way that women with TS make decisions about how to have a family and what they think about the options open to them. I will also talk to mothers of girls with TS to see how they have handled their daughter's fertility issues within the family, and what they think of their daughter's future reproductive options.

Who is the researcher?

The researcher is Kriss Fearon, of De Montfort University in Leicester. Before I joined De Montfort, I volunteered and worked in the fertility field for nearly 20 years.

- Portrait photo of the researcher

What happens to the research?

I hope to publish journal articles based on the results, which will improve our understanding of how women with Turner Syndrome make decisions about how to have a family. I also plan to work with the Turner Syndrome Support Society to consider ways of improving support and information for women with TS and their families as they go through this process.

How to get involved [new page]

I am looking for two groups of people to take part:

- Women with Turner Syndrome who have explored their options for having a family, whatever the outcome has been
- Mothers of girls who have Turner Syndrome and who have actively considered or explored their daughter's options for having a family

The research is conducted with a face-to-face interview either at your home or in a quiet public place where we can talk confidentially.

Does this sound like something you are interested in? You can get in touch to find out more without committing yourself to taking part.

If you have any questions, please get in touch. [link to contact details]

Video [new page]

- The three videos explaining what the project is about, consent and choosing photos

FAQs [new page]

- Text of the PIS forms

Contact [new page]

- Contact for further information

Appendix 12: Flyer

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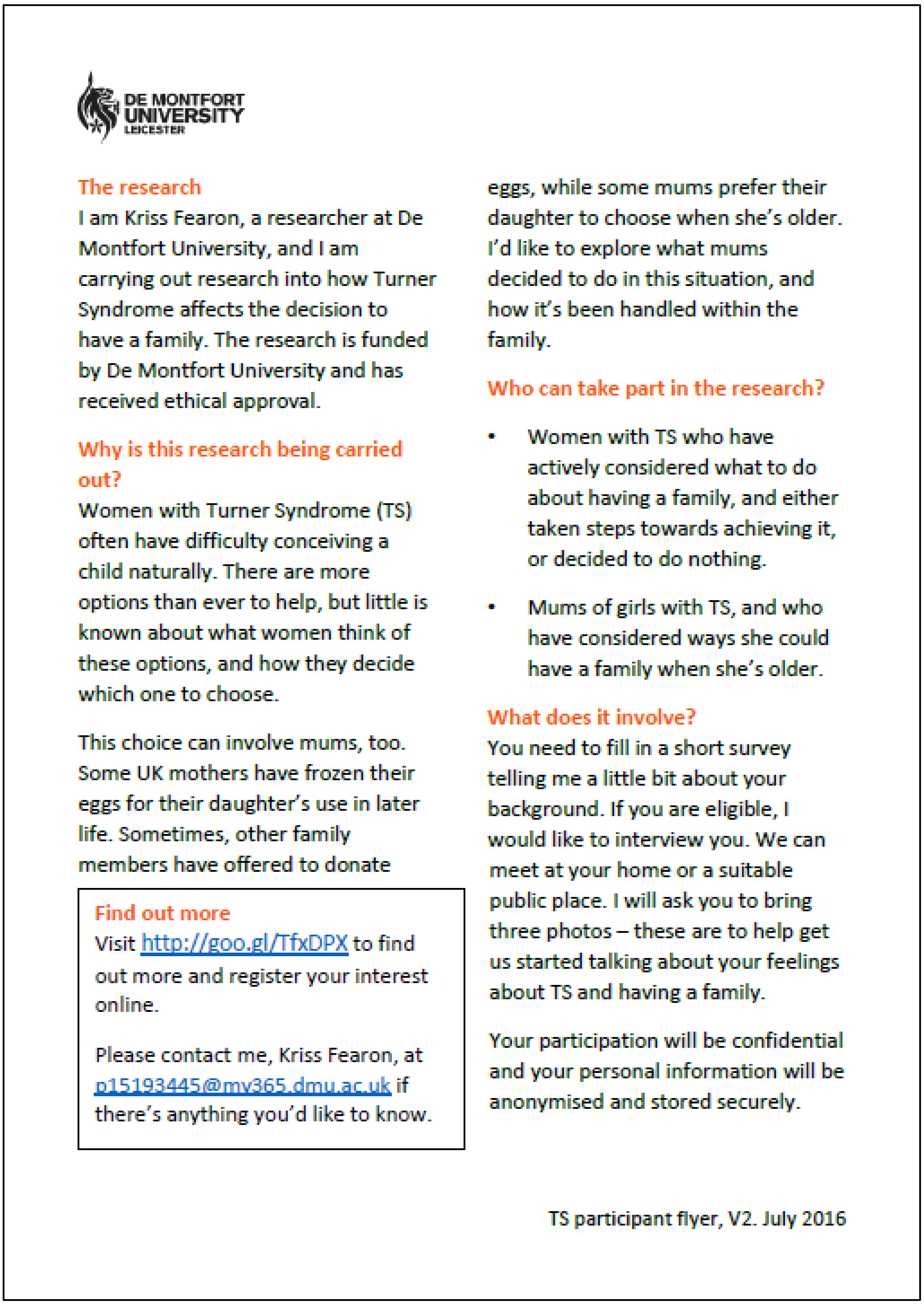
LEICESTER

Do you or does your daughter have Turner Syndrome?

Would you mind talking to someone about it?

I am looking for women to interview for a research project on how Turner Syndrome affects the decision about whether and how to have a family.

TS participant flyer, V2. July 2016



DE MONTFORT UNIVERSITY
LEICESTER

The research

I am Kriss Fearon, a researcher at De Montfort University, and I am carrying out research into how Turner Syndrome affects the decision to have a family. The research is funded by De Montfort University and has received ethical approval.

Why is this research being carried out?

Women with Turner Syndrome (TS) often have difficulty conceiving a child naturally. There are more options than ever to help, but little is known about what women think of these options, and how they decide which one to choose.

This choice can involve mums, too. Some UK mothers have frozen their eggs for their daughter's use in later life. Sometimes, other family members have offered to donate eggs, while some mums prefer their daughter to choose when she's older. I'd like to explore what mums decided to do in this situation, and how it's been handled within the family.

Find out more

Visit http://goo.gl/TfxDPX to find out more and register your interest online.

Please contact me, Kriss Fearon, at p15193445@my365.dmu.ac.uk if there's anything you'd like to know.

Who can take part in the research?

- Women with TS who have actively considered what to do about having a family, and either taken steps towards achieving it, or decided to do nothing.
- Mums of girls with TS, and who have considered ways she could have a family when she's older.

What does it involve?

You need to fill in a short survey telling me a little bit about your background. If you are eligible, I would like to interview you. We can meet at your home or a suitable public place. I will ask you to bring three photos – these are to help get us started talking about your feelings about TS and having a family.

Your participation will be confidential and your personal information will be anonymised and stored securely.

TS participant flyer, V2. July 2016

Appendix 13: Wording of online advertisement for websites

Do you have Turner Syndrome and have either thought about having a family, or have children? Are you the mum of a girl with Turner Syndrome?

My name is Kriss Fearon, and I'm a researcher at De Montfort University in Leicester. My research is about how Turner Syndrome affects the decision to have a family.

I'm looking for two groups of women to take part in a confidential face-to-face interview.

The first group is women with Turner Syndrome of childbearing age who have thought about ways to have a family, or have gone ahead and had children by any method: e.g. natural conception, egg donation, adoption or surrogacy. If you decided not to have children, I would also like to hear from you.

The second group is mothers of girls with Turner Syndrome who have considered ways to approach their daughter's reproductive options while she is young.

Because some of the technology that helps women have a family is quite new (e.g. egg freezing), there is little research on what women with TS, or their mums, think about these options, and the reasons you may or may not decide to use them.

Everyone who takes part can choose to receive a short report on the research findings after it is finished.

I would love it if you would speak to me. If you'd like to find out more, please contact me at p15193445@my365.dmu.ac.uk, or via the project website, http://goo.gl/TfxDPX

Appendix 14 - Facebook page

Name of page: Turner Syndrome and reproductive decision-making

Short description – up to 25 words

This research project is looking at the way Turner Syndrome affects reproductive choices, both for women with TS and mums of girls with TS.

Long description – up to 230 words

Do you have Turner Syndrome, and either have children, or have thought about ways to have a family? Are you the mum of a daughter with Turner Syndrome?
I'm a researcher at De Montfort University in Leicester, looking at the way Turner Syndrome affects the decision to have a family.

Because some of the technology that helps women have a family is quite new (e.g. egg donation or egg freezing), there is little research on what women with TS, or their mums, think about these options, and the reasons you may or may not decide to use them.
I am exploring the way that women with TS make decisions about how to have a family and what they think about the options open to them. I will also talk to mothers of girls with TS about their daughter's fertility issues and to find out what they think about their daughter's future reproductive options.

The study involves a confidential face-to-face interview, and everyone who participates will be able to receive a report on the findings.

If you are interested would like more information, please go to [website] or contact the researcher:
Kriss Fearon: p15193445@my365.dmu.ac.uk [phone no]

[Link to website]
[profile and cover images]

Appendix 15: Text for Facebook advertising posts

Do you have Turner Syndrome, and either have children, or have thought about ways to have a family? Are you the mum of a daughter with Turner Syndrome?

I'm a researcher at De Montfort University in Leicester, looking at the way Turner Syndrome affects the decision to have a family.

Because some of the technology that helps women have a family is quite new (e.g. egg freezing), there is little research on what women with TS, or their mums, think about these options, and the reasons you may or may not decide to use them.

I'm looking for women with Turner Syndrome of childbearing age who have thought about ways to have a family, or have had children by any method. If you decided not to have children, I would also like to hear from you. I'm also looking for mums of girls with Turner Syndrome who have considered ways to approach their daughter's reproductive options while she is young.

The study involves a confidential face-to-face interview, and everyone who participates will be able to receive a report on the findings.

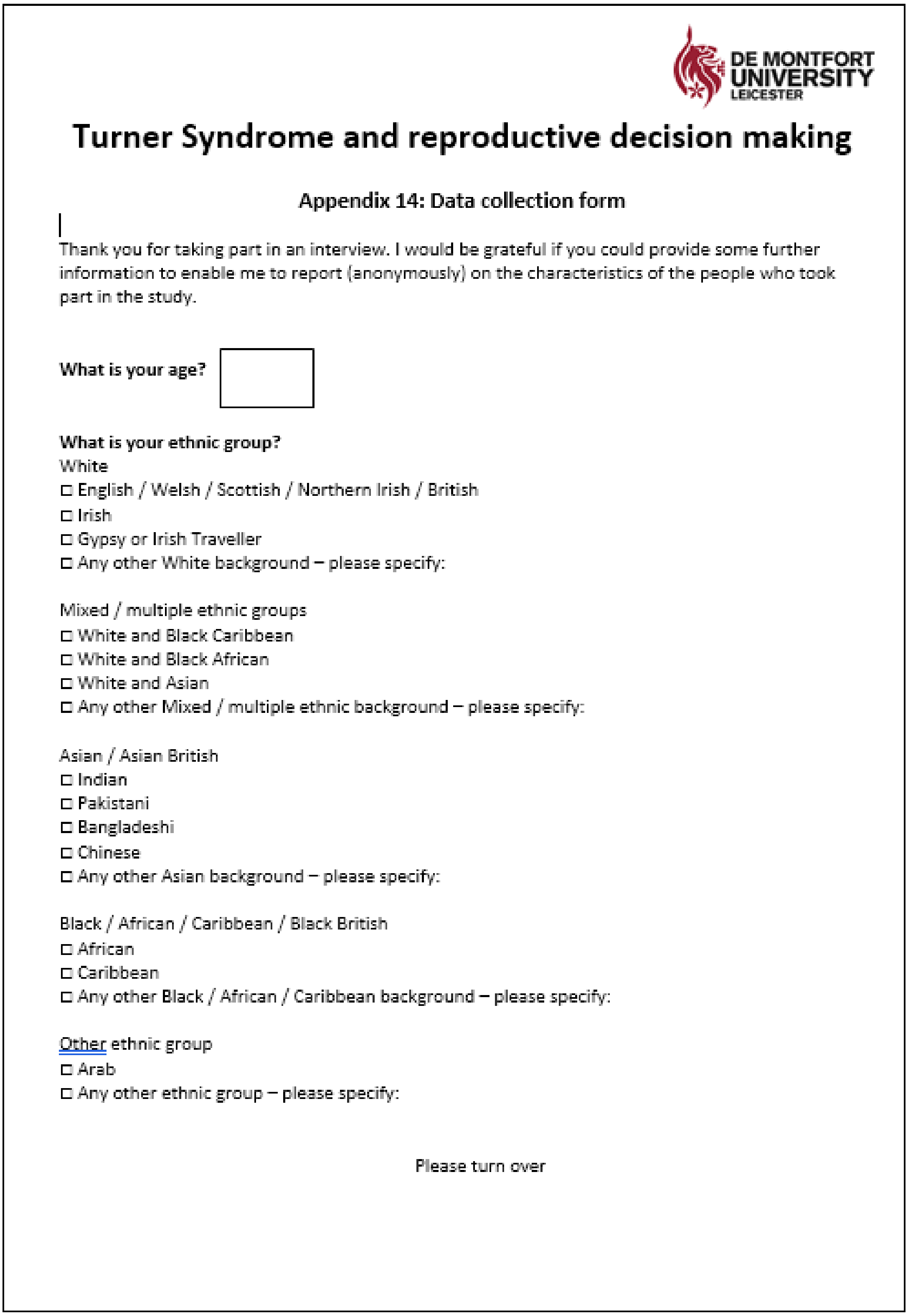
If you are interested would like more information, please go to [website] or contact the researcher:
Kriss Fearon: p15193445@my365.dmu.ac.uk [phone no]

Appendix 16: Text for email signature

To be used as an automatic footer on the researcher's De Montfort email, alongside the standard De Montfort footer.

Turner Syndrome and reproductive decision-making. Take part and find out more: [website]

Appendix 17 – Data collection form



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Turner Syndrome and reproductive decision making

Appendix 14: Data collection form

Thank you for taking part in an interview. I would be grateful if you could provide some further information to enable me to report (anonymously) on the characteristics of the people who took part in the study.

What is your age? ☐

What is your ethnic group?

White
☐ English / Welsh / Scottish / Northern Irish / British
☐ Irish
☐ Gypsy or Irish Traveller
☐ Any other White background – please specify:

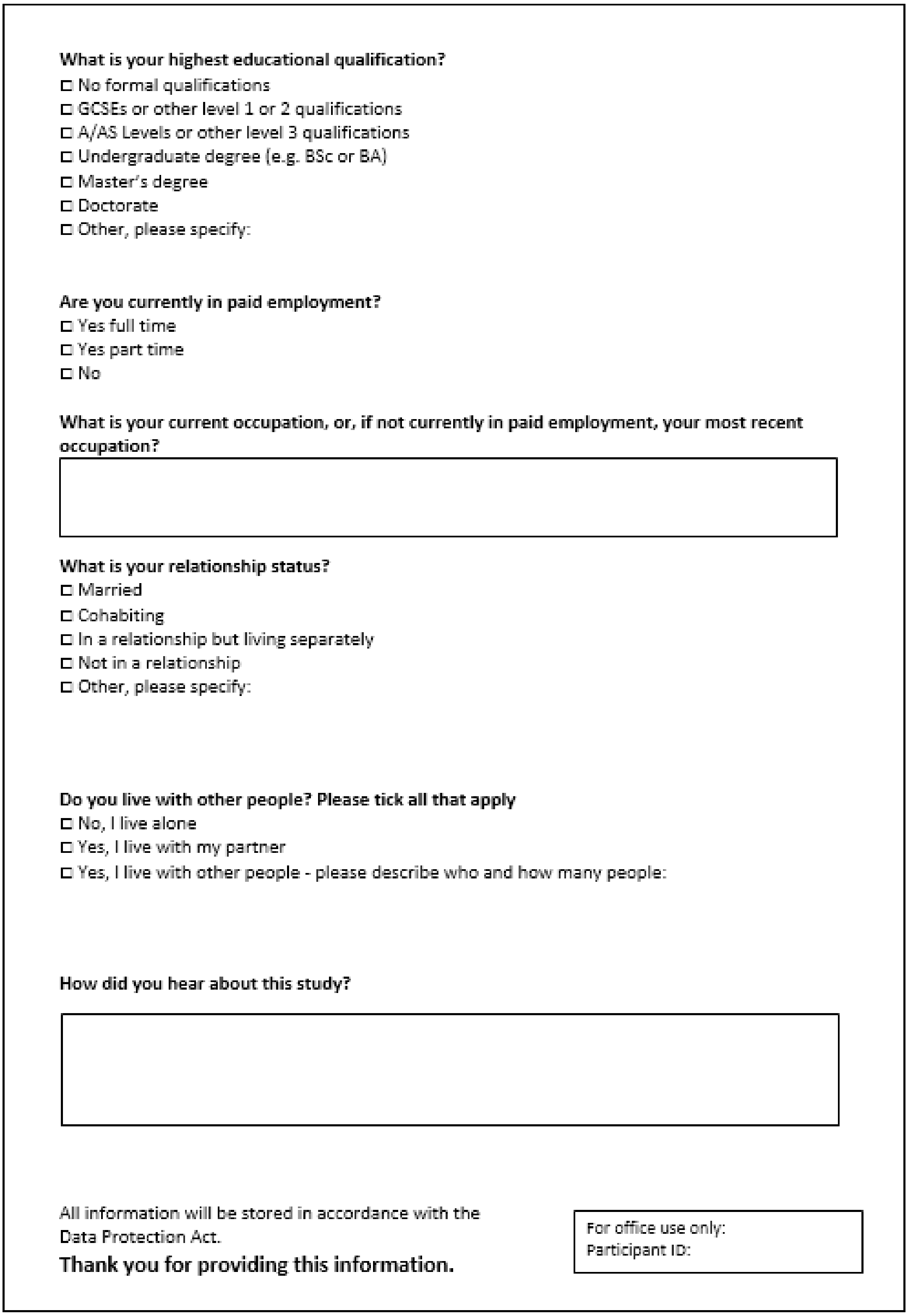
Mixed / multiple ethnic groups
☐ White and Black Caribbean
☐ White and Black African
☐ White and Asian
☐ Any other Mixed / multiple ethnic background – please specify:

Asian / Asian British
☐ Indian
☐ Pakistani
☐ Bangladeshi
☐ Chinese
☐ Any other Asian background – please specify:

Black / African / Caribbean / Black British
☐ African
☐ Caribbean
☐ Any other Black / African / Caribbean background – please specify:

Other ethnic group
☐ Arab
☐ Any other ethnic group – please specify:

Please turn over



What is your highest educational qualification?

☐ No formal qualifications
☐ GCSEs or other level 1 or 2 qualifications
☐ A/AS Levels or other level 3 qualifications
☐ Undergraduate degree (e.g. BSc or BA)
☐ Master's degree
☐ Doctorate
☐ Other, please specify:

Are you currently in paid employment?

☐ Yes full time
☐ Yes part time
☐ No

What is your current occupation, or, if not currently in paid employment, your most recent occupation?

What is your relationship status?

☐ Married
☐ Cohabiting
☐ In a relationship but living separately
☐ Not in a relationship
☐ Other, please specify:

Do you live with other people? Please tick all that apply

☐ No, I live alone
☐ Yes, I live with my partner
☐ Yes, I live with other people - please describe who and how many people:

How did you hear about this study?

All information will be stored in accordance with the Data Protection Act.

Thank you for providing this information.

For office use only:
Participant ID:

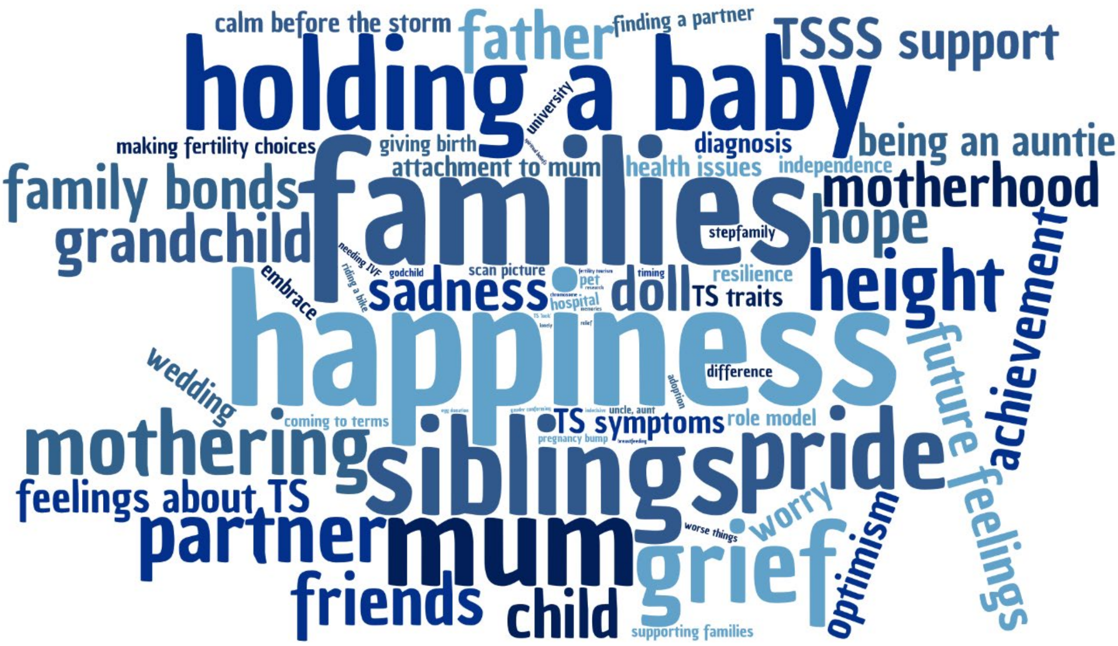
Appendix 18 – Image analysis

The present study used photo elicitation as a research method. Every participant was asked to bring three photos to the interview, and the session began with the participant discussing their images with the researcher. Initially, coding of the images from the pilot phase suggested that it could add a useful perspective on the verbal interview data, but this proved more difficult once all the data had been collected.

The original intention was to analyse the images using the visual grounded theory analysis method described by Konecki (2011). However, on trialling this, it proved to be inappropriate for the present study. Konecki's method is effective when applied to visual images where much of what the participant is trying to communicate is expressed through the image itself, such as his research using photos to analyse the living spaces of street homeless people. The images are coded using segments, pieces of textual metadata relating to different aspects of the image content, written by the researcher and then analysed as text. In the present study, where photos were used to encourage the participant to speak freely, most of the information that participants shared about the images was already conveyed verbally within the interview, and the coding would have been repetitive.

A second approach to image analysis also involved coding segments created by the researcher with the text based on responses to seven questions: What, Who, When/How long, Where, Why, With which, What for (Mey and Dietrich, 2017). Each image was coded with a single word or short phrase in response to the questions, incorporating some of the participant's description of the image, along with the researcher's description, to create textual codes that were then analysed.

After coding the images, creating a word cloud of the codes, and comparing them against the codes generated from the verbal interview data, it became apparent that the images were mainly illustrative. For example, they show the way in which playing with dolls, holding a baby, and similar behaviour was used as a way for the participants to express a range of feelings around motherhood, fertility and grief. This is interesting but it did not advance the development of theory over what had already been drawn from the verbal interviews.



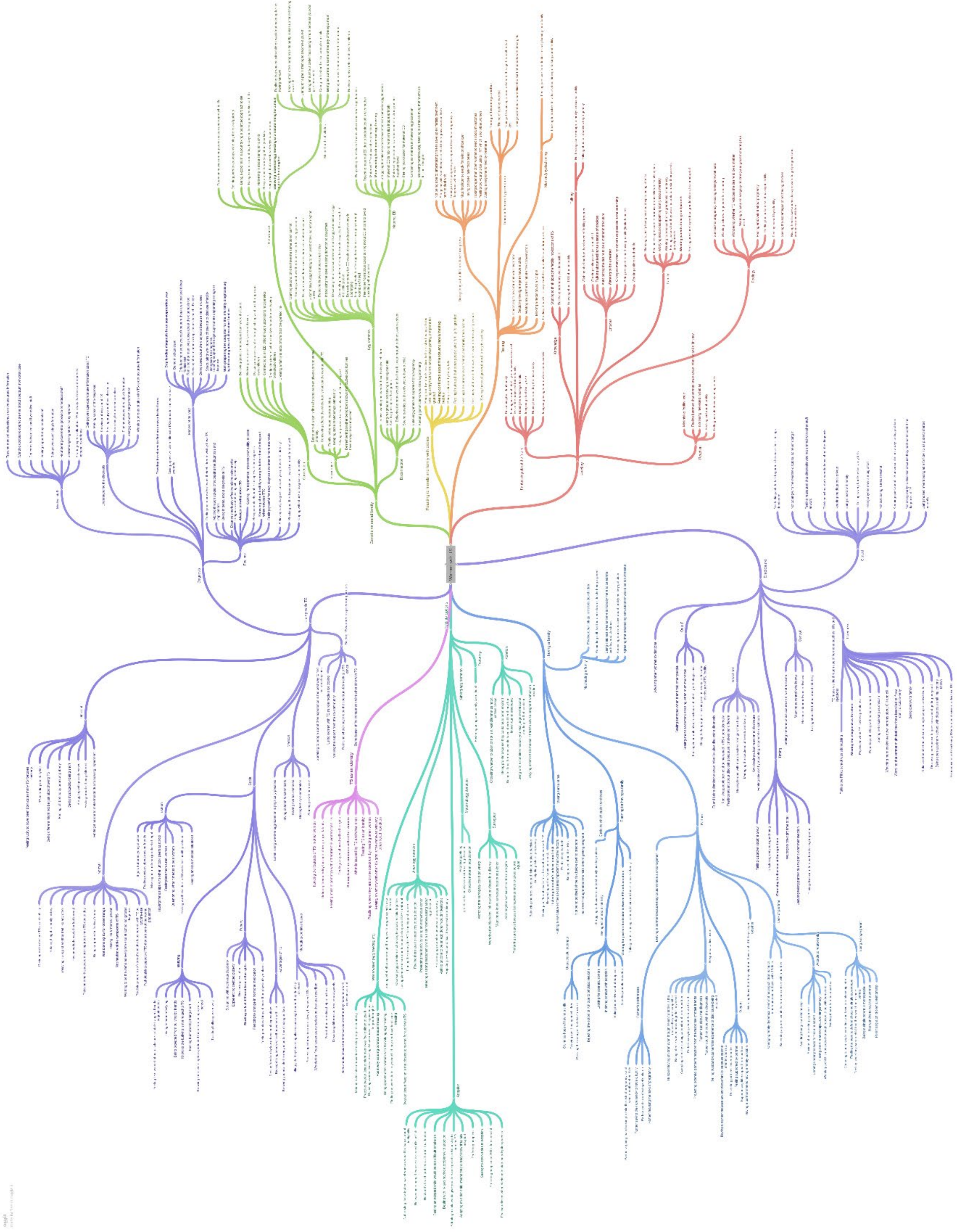
Some of the coding, such as ‘doll’ or ‘home’ lacked context and the additional problem is that the process of creating metadata was already an analytic task performed by the researcher, which seemed redundant given that it was largely based on interview text. As a result, a photo analysis has not been included in this study.

However, as a data collection method, photo elicitation was very successful at encouraging participants to focus on the topic and discuss their thoughts and feelings.

Appendix 19 – Mind maps

NB These images can be enlarged to 500% for legibility.

a) Codes for women with TS



b) Codes for mothers of girls with TS