Becoming pregnant after a baby loss: improving inter-pregnancy care for women with type 1 and type 2 diabetes - a qualitative exploration of women's experiences and healthcare professionals' perspectives.

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Abstract

Women with diabetes (WWD) are four times more likely to experience baby loss: miscarriage, stillbirth, neonatal death, or termination of pregnancy for medical reasons. Preparing for pregnancy reduces risks. However, only 50% of women with diabetes seek healthcare support to prepare for pregnancy, even after baby loss.

Women may feel an overwhelming urge to become pregnant again as soon as possible after baby loss. The inter-pregnancy interval, the time between the baby loss and the start of a subsequent pregnancy, for women with diabetes averages 12 months, highlighting a small window of opportunity to support women with diabetes to both grieve and prepare for subsequent pregnancy.

This qualitative research explored WWDs' experiences and healthcare professional (HCP) perspectives using semi-structured interview data from 30 participants (WWD= 12; HCP= 18) from the UK and Ireland. Data were analysed using Reflexive Thematic Analysis.

Three levels of analysis were conducted: 1) descriptive themes that captured the barriers faced in the inter-pregnancy interval; 2) explanatory themes, where theory (liminality, biomedicalisation, and neoliberal strategies of responsibilisation) was used to interpret the data further; 3) synthesis of themes using a stigma syndemic framework to shed light on the tensions between experiencing a baby loss, living with diabetes and preparing for a subsequent pregnancy.

The findings connect areas of research seldom explored together, providing new insights into potential reasons why WWD do not 'optimally prepare' for pregnancy after experiencing a baby loss. I argue that WWD are disproportionately affected by various stigmas in the inter-pregnancy interval, which, when experienced simultaneously, have a synergistically negative effect. The stigmatising self-recrimination that WWD may feel at the intersection of baby loss and diabetes poses a particular challenge. The existing support available in the inter-pregnancy interval is inadequate to help WWD prepare for subsequent pregnancy after baby loss, as there is too much focus on individualistic factors and solutions to manage.

COVID Statement

This statement acknowledges the direct and indirect impact of the COVID-19 pandemic. Regarding direct impact, it was necessary to adapt the research methods from what I had initially intended to accommodate the nationally enforced social distancing measures. I originally planned to advertise and recruit for this study through the National Health Service (NHS) and conduct in-person interviews. I had begun gaining relevant ethical approvals when the pandemic broke out. I was able to redesign my advertising and recruitment strategy so that the process would take place entirely online through social media and virtual networks, and interviews would take place online, as described in detail in the methods chapter.

The scope of this thesis did not dramatically change in light of the disruption caused by the COVID-19 pandemic, and I am satisfied that the adjustments made did not negatively impact the rigour or quality of this study. However, the pandemic indirectly affected my personal life and physical and mental well-being, and caring for a toddler while trying to manage the project at the height of the pandemic took its toll. I was awarded a three-month funded extension to mitigate some of the disruption caused. However, I kindly request that due consideration is given to the unique pressures experienced during a significant portion of this project and the considerable impact this unprecedented worldwide event has had, and in some ways, continues to have, on my ability to complete doctoral work.

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List of Abbreviations

BMI: Body Mass Index

BMJ: British Medical Journal

CGM: Continuous Glucose Monitoring (technology)

CMACE: Centre for Maternal and Child Enquiries

COVID-19: Coronavirus disease 2019

DAFNE: Dose Adjusted for Normal Eating and Exercise

DESMOND: Diabetes Education and Self-Management for Ongoing and Newly Diagnosed

GP: General Practitioner

MODY: Maturity Onset Diabetes of the Young

NBCP: National Bereavement Care Pathway

NHS: National Health Service

NICE: National Institute for Health and Care Excellence

NPID: National Pregnancy in Diabetes

ONS: Office for National Statistics

RCM: Royal College of Midwives

RTA: Reflexive Thematic Analysis

UK: United Kingdom

USA: United States of America

WHO: World Health Organisation

Terminology

Language has great power. In recognition of this, I use the terms' women' and 'mothers' throughout this thesis. However, I acknowledge that it is not only people who identify as women who access perinatal services and that my research refers to all people with diabetes who have experienced baby loss and gone on to have a subsequent pregnancy (Draper *et al*., 2022). Likewise, I refer to 'women with diabetes' as the term 'diabetic' can have negative and stigmatising associations related to being labelled as a condition rather than being seen as a person (National Health Service [NHS] England, 2018). At times I use inverted commas to emphasise the constructedness and contestability of what I am saying. For example, when referring to women with diabetes being ‘optimally prepared’ for pregnancy.

I also use the phrase ‘baby loss' to refer to all pregnancy and perinatal losses for three main reasons. Firstly, to honour the personhood parents assign to their losses (Layne, 2000); Secondly, referring to 'baby loss' was intended as a supportive acknowledgement of those who personally experience pregnancy loss at any gestation in an attempt to avoid what has been referred to by Lovell (1983) as 'the hierarchy of loss' whereby losses earlier in pregnancy are assumed to have less of an impact (Browne, 2023); Thirdly, the Stillbirth and Neonatal Death charity 'Sands', who collaborated on this research project, advised me to use 'baby loss' when recruiting participants, as this was the preferred terminology among their service users. However, equating all pregnancy loss with 'baby loss' as a matter of course runs the risk of marginalising other ways of feeling and understanding, or, worst case, rendering different experiences as illegitimate or even suspicious (Browne, 2023), which was not my intention.

Glossary of Terms

Baby Loss: An umbrella term that includes miscarriage, stillbirth, neonatal death and termination of wanted pregnancy for medical reasons, as described in more detail in this glossary of terms.

Diabetes Technology: There are three broad types of diabetes technology: 1) technology for taking insulin, which is used by everyone with type 1 diabetes and some people with type 2 diabetes. The most common way is to inject insulin with an insulin pen, but also includes insulin pumps; 2) technology for checking blood sugar levels, mostly used by people taking insulin or medication that causes hypoglycaemia. Testing blood sugar levels at home can involve 'finger pricking' using a blood sugar monitor, testing strips and lances (older technology), or an electronic Continuous Glucose Monitor (CGM) or 'Flash' (Libre) glucose monitor (newer technology) which attach to the body so there is no need for finger pricking; 3) technology to assist with managing the condition, for example, smartphone apps and ketone monitors (Diabetes UK, 2023a). Please refer to the Diabetes UK webpages for a more comprehensive overview (Diabetes UK, 2023a).

HbA1c: Refers to the haemoglobin A1c test. HbA1c levels refer to the amount of glycated haemoglobin (when glucose attaches to the red blood cells) in the blood (Diabetes UK, 2023b). As the body is unable to use the glucose that is attached to the red blood cells, it builds up in the blood, causing high blood glucose levels. HbA1c provides the average measurement of blood glucose (sugar) levels for the previous two to three months (Diabetes UK, 2023b). The ideal level for people with diabetes and those planning pregnancy is 48mmmol/mol (6.5%) or below (Diabetes UK, 2023b).

Hypoglycaemia: Low blood glucose (sugar) levels (>4mmol/mol (or 5%) (NHS, 2020a) which can be dangerous if not treated quickly.

Hyperglycaemia: High blood glucose (sugar) levels (>48mmol/mol or 6%) which can be serious if left untreated (NHS, 2022a).

Ketoacidosis: A serious condition caused from a severe lack of insulin that usually affects women with type 1 diabetes (Diabetes UK, 2023a). Without insulin, the body is unable to use sugar for energy, so starts to breaks down fat and muscle instead (Diabetes UK, 2023). When this happens, acidic chemicals called ketones are released into the bloodstream which can build up and become toxic, and if left untreated, can lead to a coma and death (Diabetes UK, 2023a).

Inter-pregnancy interval: The time between baby loss and conception of a subsequent pregnancy (Klebanoff, 2019)

Miscarriage: The spontaneous loss of pregnancy in utero up to 23 days and 6 days (NHS, 2022b).

Neonatal death: The death of a live new-born child up to 28 days after birth (Barfield, 2016)

'Optimally prepared' for pregnancy: 'Optimal' levels as set out in the NICE (2015a) NG3 preconception guidelines: taking 5mg folic acid, HbA1c < 48 mmol/mol and not taking statins, ACE inhibitors or other adverse diabetes medications that might harm the developing baby.

Stillbirth: The death of a baby before or during birth, after 24 completed weeks' gestation (NHS, 2021).

Structured Education Programmes: 'Structured education' should be offered to all people with diabetes when they are diagnosed, to help ensure they have the knowledge, training and skillset required to manage their conditions (Tidy, 2022). The structured education courses are delivered nationally, and there is a different course for type 1 diabetes and type 2 diabetes (Tidy, 2022). For people with type 1 diabetes, there is the Dose Adjustment for Normal Eating (DAFNE) course, which aims to help adults to lead a normal life as possible whilst also maintaining blood glucose levels within healthy targets (DAFNE, 2023). For people with type 2 diabetes, there is the Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND) programme, which aims to make adults an expert in their condition, by increasing knowledge and understanding and empowering the patient to make their own decision (Desmond, 2023; Tidy, 2022).

Termination of wanted pregnancy for medical reasons: If the baby is diagnosed with a lethal condition or serious disability through prenatal screening, or if pregnancy complications put the mother in danger, the pregnancy may be terminated (Tommy's, 2023).

Chapter 1. Introduction

1.1 Background

Over three decades ago, the St Vincent Declaration set out an ambitious five-year target to improve the pregnancy outcome for women with diabetes, a serious condition that causes blood glucose levels to become too high (hyperglycaemia) (NHS, 2022a), to that of the general population (Diabetes Care and Research in Europe, 1990; Murphy *et al*., 2010a). Despite improvements in diabetes treatments and obstetric care, this goal remains unmet today (Lavender *et al*., 2010). Diabetes is increasingly recognised as a global epidemic and is the most prevalent pre-existing chronic condition affecting pregnancy in the United Kingdom (UK) (Berg, 2005), affecting approximately 1-2% of pregnancies (Royal College of Midwives [RCM], 2022) which equates to between 6,800-13,600 pregnancies in the UK annually.

The number of pregnancies affected by diabetes has increased in recent years (NHS Digital, 2019). This increase is mainly attributed firstly, to higher rates of overweight and obesity in the general population, which frequently leads to type 2 diabetes (National Institute of Health and Care Excellence [NICE], 2015a) and secondly to an increased prevalence of pregnancies in older women (NICE, 2015a; NHS Digital, 2019, 2021a). This poses risks to both mother and child, trebling the risk of perinatal mortality (late fetal loss, stillbirths and neonatal deaths) (Centre for Maternal and Child Enquiries [CMACE], 2011), quadrupling the risk of congenital anomalies (Balsells *et al*., 2009; Bell *et al*., 2012) and increasing fivefold the risk of stillbirth, premature delivery and being large for gestational age (Macintosh *et al*., 2006; CMACE, 2011; Tennant *et al*., 2015).

Pre-pregnancy preparation can minimise risks, which involves taking high dose peri-conception folate, optimising blood glucose control and stopping any medication that may harm the developing baby (Forde, Patelarou and Forbes, 2016; Earle *et al*., 2017; NICE, 2015a). However, research suggests approximately 50% of women with diabetes seek support from healthcare services to prepare for pregnancy, even after experiencing an adverse outcome (Holing *et al*., 1998; NHS Digital, 2019; Murphy *et al*., 2010a; Tennant *et al*., 2015;). The reasons for this are complex and not fully understood but are explored in this thesis.

Women with diabetes and their partners who have experienced baby loss comprise a unique group who require individualised, specialist care in future pregnancies (Caelli, Downie and Letendre, 2002; Ellis *et al*., 2016; Fockler *et al*., 2017; Meredith *et al*., 2017). Such care differs, both clinically and psychosocially, from that offered to either women with diabetes who have not experienced loss, or women without diabetes who have experienced loss, as their situation and medical needs are particularly complex and preconception care needs to be sensitive to this group's needs (Earle *et al*., 2017; Forde, Patelarou and Forbes, 2016).

There is a gap in understanding how best to support women with diabetes who have experienced a baby loss to prepare for a subsequent pregnancy. This qualitative research project helps address this knowledge gap by shedding light on women with diabetes' experiences of the inter-pregnancy interval – the time between baby loss and a subsequent pregnancy – and the perspectives of healthcare professionals providing care for this group.

1.2 Overview of thesis

This thesis starts with a literature review of current understandings of baby loss, diabetes and preparing for pregnancy after a baby loss (Chapter 2). Chapter Three makes explicit the philosophical assumptions and theories underpinning this qualitative research including how stigma can affect women with diabetes from all angles. Chapter Four provides an overview and rationale for the chosen study design and methods. Details about the qualitative methods used to recruit, sample and conduct interviews and data analysis processes are provided followed by concluding researcher reflections on the methodology.

The findings from the analysis are presented in three layers across Chapters Five to Seven. Chapter Five presents the three descriptive themes, capturing some of the barriers faced by women with diabetes in the inter-pregnancy interval: (1) Decisions around becoming pregnant after a baby loss; (2) The triple burdens of baby loss, diabetes and planning for pregnancy; (3) Discontinuities and constraints in care in the inter-pregnancy interval. An interpretation and discussion of these findings in relation to existing literature follow the findings from the descriptive themes.

Chapter Six presents the three explanatory themes, where theory was used to interpret the data further: (1) Lost without a map: liminality in the inter-pregnancy interval; (2) Biomedicaliasation in the inter-pregnancy interval and stigmatised 'sub-optimal' pregnancy; and (3) Neoliberal strategies of responsibilisation.

In place of a traditional "discussion chapter", Chapter Seven presents a synthesis of the above descriptive and explanatory themes using a stigma syndemic framework to shed light on the tensions between experiencing a baby loss, living with diabetes and preparing for a subsequent pregnancy. Mapping out the findings in this novel way helped to make explicit the complexity faced by women with diabetes in a way that is useful for the practical application of the findings.

Chapter Eight presents the summary and conclusions from the analysis, followed by the implications of the research, strengths, limitations and areas for future research. The thesis concludes with recommendations to improve care for women with diabetes in the inter-pregnancy interval.

1.2.1 Thesis statement

In this thesis, I argue that:

a) The care and support currently available in the inter-pregnancy interval are inadequate to help women with diabetes grieve for their loss and prepare for a subsequent pregnancy. There is too much focus on individualistic factors and solutions for many women to manage, the implications of which makes it harder for women to meet the expectation to be 'optimally prepared' for pregnancy. The liminal inter-pregnancy interval is not a time for empowerment or to rely on additional levels of agency. Both the women with diabetes and healthcare professional participants' accounts of these experiences suggest that women with diabetes need support that is more visible, easier to access, and based on shared decision making. Change is required, as set out in my recommendations to improve care in Chapter Eight (section 8.4).

b) Bereavement support needs to consider the context of diabetes and link with support for subsequent pregnancies. A timely and sensitive discussion of pregnancy plans between healthcare professionals and women with diabetes in the inter-pregnancy interval is required to help support women with diabetes to prepare for subsequent pregnancy and signpost them to specialist services where this is welcomed.

c) Women with diabetes are disproportionately affected by various stigmas in the inter-pregnancy interval, which, when experienced simultaneously, have a synergistically negative effect. The stigmatising self-recrimination that women with diabetes may feel at the intersection of baby loss and diabetes poses a particular challenge.

Chapter 2. Literature Review

2.1 Introduction

Despite women with diabetes being at an increased risk of baby loss, much existing literature focuses on the separate issues of baby loss, diabetes, and pregnancy after loss. As a result, women with diabetes are a subset of the population on the margins of all three areas, so they are at risk of falling into gaps in care where healthcare services do not meet up. This literature review draws the separate bodies of literature together and considers how these distinct topics culminate to form a particularly complex situation for women with diabetes in the inter-pregnancy interval after a baby loss.

The chapter concludes by summarising the gaps in knowledge that call for further inquiry. This includes the need to better understand the decision-making process, support requirements and challenges that women with diabetes face in the inter-pregnancy interval, along with how bereavement services can be addressed to integrate better with pregnancy preparation services to improve outcomes for this group. The insights from this chapter inform the theoretical and methodological approach to this thesis. Unpacking some of the sociological issues will help broaden understandings of preparing for pregnancy after a baby loss for women with diabetes beyond the currently dominant biomedical approach.

2.2 Baby loss

Baby loss is an umbrella term that includes miscarriage, stillbirth, neonatal death and termination of wanted pregnancy for medical reasons, as fully described in the Glossary of Terms (pp. xvii-xviii). In the general population, one in four pregnancies in the UK is estimated to end in loss during pregnancy or birth (Tommy's, 2022), and baby loss rates have continued to rise over the past ten years (Nath, Hardelid and Zylbersztejn, 2021). Considering how many women are affected by baby loss compared with the relatively small amount of research in this area, many authors argue that baby loss is a neglected area of public health research (Darmstadt, 2011; Ellis *et al*., 2016; Scott, 2011), which could be attributed in part to the gender bias in research, where the study of women's health issues are underfunded (Holdcroft, 2007). Nowadays, baby loss is recognised as having a significant and far-reaching impact in terms of both tangible (monetary) and intangible (mental health) costs (Campbell *et al*., 2017; Mistry *et al*., 2013; Ogwulu *et al*., 2015).

Numerous studies have investigated parents' experiences of baby loss, consistently highlighting the profound and long-term negative impact of loss on women and their families, as well as healthcare systems and communities (Burden *et al*., 2016; Ellis *et al*., 2016; Fockler *et al*., 2017; Lamb, 2002). However, it was not until the 1970s and 1980s that research into the lived experience and grief processes of baby loss started to gain momentum (Lamb, 2002; Frost *et al*., 2007). Interest seemed to wane during the mid to late 1990s, and the focus was usually on stillbirths and neonatal deaths, with little focus on miscarriages (Lamb, 2002). Until the mid 1990s, baby loss was widely regarded as an 'invisible death' and neglected as an issue of importance to public health, society and policymakers (Ogwulu *et al*., 2015).

Over the past 20 years, the majority of baby loss research has predominantly focused on stillbirths and miscarriages (Jones *et al*., 2017) including the personal, social and economic costs of such losses (Boyle *et al*., 1996; Burden *et al*., 2016; Heazell *et al*., 2016; Murphy and Cacciatore, 2017). *The Lancet* published two series on stillbirths in 2011 and 2016; in 2021 it published a three-part series on miscarriage, which is the first time the journal has focused on miscarriage in its 200-year history. Parental experiences of having a termination of wanted pregnancy for medical reasons has received relatively little attention, despite advances in screening and diagnostic technology, that mean more parents are faced with difficult decisions (Carlsson *et al*., 2016; Hodgson *et al*., 2016; Hunt *et al*., 2009; Jones *et al*., 2017; Lafarge, Mitchell and Fox, 2014). Likewise, despite neonatal deaths being on the rise in the UK (Nath, Hardelid and Zylbersztejn, 2021), relatively few studies look at the lived experience of such loss (Redshaw, Henderson and Bevan, 2021).

2.2.1 Societal understandings of the complicated grief surrounding baby loss

There is growing recognition and research interest into the psychological and emotional burden on bereaved parents following a baby loss (Burden *et al*., 2016). Grief is widely accepted as a natural and expected response to bereavement, such as a baby loss (Hutti, Armstrong and Myers, 2013; Kalich and Brabent, 2006; Shear, 2012). The intensity and types of emotions associated with grief are acknowledged as unique to the individual and are expected to vary over time (Hutti *et al*., 2017; Kalich and Brabent, 2006). Although all and any emotions are, in theory, considered permissible in grief, not all emotions are viewed as appropriate due to the strong social norms about grief (Kalich and Brabent, 2006; Robson and Walter, 2013). The traditional and dominant medical/psychological model of grief encourages the bereaved to find closure by working through and experiencing all their emotions (Kalich and Brabent, 2006; Pearce and Komaromy, 2020). However, this perspective emphasises the individual's deficiency concerning how they handle grief and their grief work (Kalich and Brabent, 2006). Those who deviate from this linear model may experience added stress due to failing to behave and recover in the socially expected way and timeframe (Kalich and Brabent, 2006). Relatedly, from a clinical perspective, grief may be seen as a psychological process that can be completed 'successfully' in a linear way (Pearce and Komaromy, 2020), whereby the bereaved feel a deep connection with the deceased, but are also able to imagine a satisfying future without them (Shear, 2012). It is possible that the medicalised ideal that grief work can be completed plays into assumptions about when is a good time to embark on considering a subsequent pregnancy.

The grief associated with baby loss creates a particular kind of grief that can be difficult to describe and unique to those who experience it (Kersting and Wagner, 2012). Women process their grief in diverse ways and on different timescales, but grief has been found to be profound and long lasting (Schott and Henley, 2010). The significance of baby loss and the legitimacy of the associated grief has not always been acknowledged by society compared to other deaths (Kirkley-Best and Kellner, 1982; O'leary and Warland, 2013; Scott, 2011). Baby loss was for a long time a "quiet tragedy" that was seldom acknowledged (Kirkley-Best and Kellner, 1982, p. 420). Although attitudes have changed regarding the validity of grief, baby loss continues to be shrouded in silence and secrecy and remains a somewhat taboo subject in Western culture (Scott, 2011). Baby loss remains an uncomfortable subject for many and a great deal of social trepidation remains about how to respond when baby loss occurs.

2.2.2 The 'hierarchy' of baby loss

As a concept in thanatology (the scientific study of death), the 'hierarchy of loss' was intended to capture the varying grief reactions and social norms about which relationships were worth grieving and who could legitimately grieve (Robson and Walter, 2013). As a tool, it was intended to show how societal expectations around grief should not be viewed as a binary of either allowed or disallowed (Robson and Walter, 2013). However, numerous authors note how the 'hierarchy of loss' concept is often applied to baby loss, whereby the earlier the gestation, the lesser the loss (Lovell, 1983). When applied to baby loss, the impact or significance of a baby's loss is assumed to correlate with the type of loss, with later losses being afforded more social legitimacy (Kofod and Brinkmann, 2017; Middlemiss and Kilshaw, 2023). The impact of early miscarriage, for example, can be underestimated by society and healthcare professionals, which may partly be because of the ontological position that a pregnancy ending in the first 12 weeks of gestation is not a 'real' baby (Middlemiss and Kilshaw, 2023), or notions that 'it was not meant to be' (Layne, 1997; Tommy's, 2021a). The hierarchies of loss concept may have contributed to the low level of research into experiences of miscarriage through the 1970s-1990s and to the way healthcare resource allocation tends to be skewed towards later losses, despite there being limited support for this hierarchical model of grief for baby loss (Moulder, 1998).

2.2.3 Disenfranchised grief

The hierarchy of baby loss can be a precursor for disenfranchised grief, especially when the perceived hierarchy places mothers into what they feel is the wrong position on the scale of grief expectation (Robson and Walter, 2013). The concept of 'disenfranchised grief' and accompanying 'grief rules' were introduced by Doka in 1989 and have become well-established concepts within baby loss research and practice (Doka, 1989, 2002). 'Grieving rules', or the "who, when, where, how, how long, and for whom people should grieve" (Doka, 1989, p.4), draws upon research in the sociology of emotions by Durkheim (1915) and Hochschild (1983), and show how grief is experienced within a social context (Doka, 1989; Robson and Walter, 2013). How an individual is expected to behave in grief is defined socially, and such grief expectations vary across cultures (Robson and Walter, 2013). Nevertheless, it has attracted some criticism for two main reasons. Firstly, it suggests grief is a binary concept whereby grief is either enfranchised or disenfranchised, rather than as a spectrum (Robson and Walter, 2013). Secondly, and relatedly, the terminology of 'disenfranchisement' implies that this type of grief is bad or wrong, owing to the negative connotations within Western democracies, with moral and political overtones implying second-class status and subjugation (Robson and Walter, 2013).

However, disenfranchised grief remains a useful and relevant concept for this research. For example, when a mother's grief expression is dismissed, perceived societally as inappropriate in relation to the loss, or lacks a social ritual, such as a funeral, they may experience 'disenfranchisement' (Robson and Walter, 2013). Disenfranchised grief describes a lack of social acknowledgement of the loss or the relationship to the deceased (Doka, 1989; Robson and Walter, 2013) and occurs when the loss incurred is not, or cannot, be "openly acknowledged, publicly mourned, or socially supported" (Doka, 1989, p. 4), and may pose a challenge to the bereaved in the inter-pregnancy interval.

2.2.4 Complicated grief and problematic social emotions in grief

As well as being disenfranchised, where there is a conflict between the emotional experience of grief and the socially accepted way of expressing grief (Middlemiss and Kilshaw, 2023), the grief associated with baby loss and diabetes can be referred to as 'complicated' (Kersting *et al*., 2011; Kersting and Wagner, 2012) because it is different from 'normal' grief (Shear, 2012). Baby loss goes against the natural order of things, and mothers are grieving for the loss of a future possibility, something intangible that, societally speaking, did not fully exist, which can make it harder to heal (Shear, 2012). Complicated grief can be accompanied by relentless painful emotions such as anger, guilt, shame, hopelessness and envy (Shear, 2012), which have been described as 'problematic social emotions' in relation to maternal grief (Barr and Cacciatore, 2008). It is estimated that 25-30% women who experience a baby loss may experience complicated grief reactions, which may negatively affect women's psychological wellbeing (Heazell *et al*., 2016; Hutti *et al*., 2017; Kersting *et al*., 2011; Kersting and Wagner, 2012) and leave women feeling "deeply troubled" (Barr and Cacciatore, 2008, p. 331). As such, women who experience complicated grief need the appropriate clinical support (Hutti *et al*., 2018; Shear, 2012), as complicated grief is more likely to occur when there is a lack of social support (Kersting *et al*., 2011; Kersting and Wagner, 2012).

Diabetes, too, has been linked with these 'problematic emotions' which interestingly also closely align with the feelings associated with self-stigma (Browne *et al*., 2013; Seo and Song, 2019), and discussed in more detail in Chapter Three (section 3.8). When considered together, it is reasonable to assume that women with diabetes who have experienced a baby loss may be at a higher risk of experiencing complicated grief and the accompanying ‘problematic social emotions’ in the inter-pregnancy interval. It is worth noting that self-blame has been reported as prolonging the grieving process (Kersting and Wagner, 2012), which is pertinent to this research in the context of the *biomedicalisation of diabetes and pregnancy* (Chapter Three, Section 3.6), and *neoliberal strategies of responsibilisation* (Chapter 3, Section 3.7) where women with diabetes are individually responsible for ‘optimally preparing’ for pregnancy, as discussed in section 2.3.6.

2.2.5 Support following a baby loss

Considering the potential for women with diabetes to experience disenfranchised and complicated grief, providing the right type and amount of support for bereaved women is important; inadequate or inappropriate care can worsen the experience of baby loss (Hutti *et al*., 2017; O’Leary and Warland, 2013). Care for bereaved parents has been found to be inconsistent across services (Ellis *et al*., 2016; Mills *et al*., 2016; Murphy and Merrell, 2009; Robson and Leader, 2010), with limited evidence supporting specific bereavement interventions (Flenady and Wilson, 2008; Harvey, Snowdon and Elbourne, 2008; Kersting and Wagner, 2012) and a lack of structured procedures and hospital protocols create barriers to providing holistic and individualised care (Ellis *et al*., 2016).

There has been a growing awareness and understanding of the bereavement process following a baby loss, with guidance available to support subsequent pregnancies (Henley and Schott, 2008; Sands, 2022a) and calls for improvements in care for bereaved families (Ellis *et al*., 2016; Froen *et al*., 2016). Advances have been made in better understanding how to support those who are bereaved and the additional support required during a subsequent pregnancy, which can be a time of heightened anxiety and stress (Bhat and Byatt, 2016; Cuenca, 2023; Ellis *et al*., 2016; Gower *et al*., 2023; Hunter, Tussis and MacBeth, 2017; Hutti *et al*., 2015; Meredith *et al*., 2017).

The stillbirth and neonatal death charity, ‘Sands’, has developed good practice guidelines for care after a fetal or neonatal death (Henley and Schott, 2008; Sands, 2022a). These guidelines emphasise the importance of sensitive and informed postnatal follow up appointments, bereavement training for healthcare professionals, and the need for additional support for parents during subsequent pregnancies. However, specific discussion of planning and preparing for pregnancy after loss in the context of diabetes is lacking, with little consideration of how postnatal bereavement support should consider this issue.

2.2.6 Caring for bereaved parents: the National Bereavement Care Pathway

Caring for bereaved parents is difficult, stressful and emotionally challenging for midwives (Favrod *et al*., 2018; Fockler *et al*., 2017; Gardner, 1999; Oe *et al*., 2018). Training for healthcare professionals may be inadequate (Heazell *et al*., 2012; Nuzum, Meaney and O'Donoghue, 2014; Robertson, Aldridge and Curley, 2011), with many midwives and obstetricians receiving little or no training (Fenwick *et al*., 2007; McKenna and Rolls, 2011; Nuzum, Meaney and O'Donoghue, 2014), despite findings that prolonged psychological problems are less likely to develop where professional support is given (Burden *et al*., 2016; Flenady *et al*., 2014; Forrest, Standish and Baum, 1982; Hughes and Riches, 2003; Mills *et al*., 2014). NHS guidance for diabetes in pregnancy does not mention bereavement care after a baby loss (National Institute for Health and Care Excellence [NICE], 2015a), even though this group is more likely to experience a baby loss (Macintosh *et al*., 2006; Tennant *et al*., 2015).

In 2017, the National Bereavement Care Pathway (NBCP) was launched to improve the quality and consistency of bereavement care received by parents in NHS trusts after a baby loss (NBCP, 2023). The NBCP project was developed in response to the regional variations that were found to exist in the bereavement care received by parents across England (Donaldson, 2018a, 2018b, 2019; Sands, 2022a) with the objective of developing a high standard of parent-centred, safe and empathetic care that is consistent across the country (Sands, 2022a). The pathway is led by Sands and works closely with a core group of baby loss charities and professional organisations, and it aims to equip healthcare professionals to provide the best possible bereavement care to parents and families after a baby loss (NBCP, 2023). However, the pathway is non-clinical as it does not incorporate specific care for health conditions like diabetes.

The evaluation reports from an independent evaluation of the NBCP highlighted some of the challenges faced, such as difficulty engaging with senior management who may not appreciate the value of the pathway as there was no increase in resources to help with embedding the pathway, and some staff felt they were already working at capacity (Donaldson, 2018a). However, the final report indicates consistently positive responses from both parents and professionals, demonstrating that the pathway has been well-received and beneficial in raising the profile of bereavement care (Donaldson, 2019). Parents overwhelmingly agreed that communication was sensitive to their needs, they were treated with respect, and the hospital environment was caring and supportive (Donaldson, 2019). The NBCP has now been successfully rolled out across England, with 84% National Health England Trusts committed to adapting the NBCP standards,which is a positive step towards ensuring quality care regardless of postcode (NBCP, 2023).

2.2.7 Deciding about and becoming pregnant after a baby loss

There is an ongoing debate about the optimal length of the inter-pregnancy interval following a baby loss, as it has long been identified as a modifiable risk factor for adverse pregnancy outcome in subsequent pregnancy (Love *et al*., 2010; Fockler *et al*., 2017; Gold, Leon and Chames, 2010; Kangatharan, Labram and Bhattacharya, 2017; Klebanoff, 2019; Regan *et al*., 2019, 2020; Sundermann *et al*., 2017). Although UK guidance does not specify a waiting period, historically, it was thought that short inter-pregnancy intervals after baby loss were associated with adverse pregnancy outcomes (Bhattacharya *et al*., 2008; Kangatharan, Labram and Bhattacharya, 2017). More recent studies have shown that a short inter-pregnancy interval may not increase risks for adverse pregnancy outcomes in high-income countries (Klebanoff, 2019). However, it is possible that some healthcare professionals may hold outdated views that continue to inform practice today.

Little has been published about parents' experiences of the inter-pregnancy interval and becoming pregnant again after a baby loss. To try and address this gap, I conducted a systematic review of qualitative literature on deciding about and preparing for pregnancy after perinatal death for my MSc dissertation, which was published in BMJ Open in January 2019 (Dyer *et al.,* 2019) (Appendix A). Although the focus of my systematic review was not on diabetes, the findings are likely to be largely transferrable and suggest that parents experience a range of unique and personal reactions to loss, and many parents think about becoming pregnant again very soon after experiencing a baby loss (Dyer *et al*., 2019). This is in keeping with the literature, which suggests that many women experience an overwhelming urge to become pregnant again as soon as possible (Burden *et al*., 2016; Carlsson *et al*., 2016; Forrest, Standish and Baum, 1982;

Meaney *et al*., 2017) as many as 80% of women doing so within 18 months of baby loss (Cuisinier *et al*., 1996; DeBackere, Hill and Kavanaugh, 2008; Forrest, Standish and Baum, 1982; Lee, McKenzie-McHarg and Horsch, 2013; Mills *et al*., 2014). This is no different for women with diabetes – who are exposed to many of the same social norms surrounding parenthood as the general population.

Another salient finding from the 2019 systematic review by Dyer *et al*. was that healthcare professionals should anticipate the need to facilitate conversations from the very earliest point during the postnatal period whilst being mindful of the patient's individual preference for the amount and type of advice that they want or need, so as not to pressurise parents to unnecessarily prioritise or delay conception (Burden *et al*., 2016; Dyer *et al*., 2019; McHaffie, Laing and Llloyd, 2001). Rather than provide parents with prescriptive advice or specific recommendations (Burden *et al*., 2016; Lee, McKenzie-McHarg and Horsch, 2013; Stephansson, Dickman and Cnattingius, 2003), healthcare professionals should provide parents with information about the timing of a subsequent pregnancy, and they should be able to access information at a time of their choosing when they feel ready (Dyer *et al*., 2019). However, providing personalised and flexible support may be challenging for healthcare professionals working within healthcare systems that may not easily adapt to differing needs (Dyer *et al*., 2019).

It is essential to consider how a prior loss impacts a subsequent pregnancy, as baby loss has a pervasive, profound and long-term negative impact on women and their families, as well as healthcare systems and communities (Burden *et al*., 2016; Ellis *et al*., 2016; Fockler *et al*., 2017; Lamb, 2002). The enduring nature of grief, anxiety, depression and stress after baby loss often impacts subsequent pregnancy (Bhat and Byatt, 2016; Burden *et al*., 2016; Cuenca, 2023; DeBackere, Hill and Kavanagh, 2008; Gower *et al*., 2023; Hunter, Tussis and MacBeth, 2017; Hutti *et al*., 2015; Maconochie *et al*., 2007; Meaney *et al*., 2017; Mills *et al*., 2014), which is thought to increase further the risk of future loss or other adverse reproductive outcomes, such as low birth weight and preterm labour and delivery (Côté-Arsenault and Marshall, 2000; Maconochie *et al*., 2007; Sugiura-Ogasawara *et al*., 2002; Wang *et al*., 2021). Services have been developed to respond to parents' need for increased support during pregnancy following a loss. However, the process of conceiving the subsequent pregnancy is not discussed in these reports (Cŏté-Arsenault and Mahlangu, 1999; Côté-Arsenault and Marshall, 2000; Côté-Arsenault and Morrison-Beedy, 2001; Office for National Statistics [ONS], 2015).

Whilst the motives surrounding the decision to become pregnant again remain unclear, the findings from Dyer *et al*. (2019) suggest that this reaction to baby loss may reflect a strong desire to leave the liminal phase that parents experience following the death of a baby, whereby the nebulous identity of becoming non-pregnant leaves parents stranded between the recognised states of being pregnant and parenthood. Advanced maternal age (>35 years) is a growing trend in high income countries (Lean *et al*., 2021) and for the first time since records began, recent ONS statistics show that women in the UK are delaying starting a family until their mid-thirties (ONS, 2022). Advanced maternal age is associated with declining fertility levels, and an increased risk of baby loss (Lean *et al*., 2017, 2021; Sauer, 2015). Together, this creates what has been described as a “biological clock”, which can leave women who experience a baby loss with an urgency to become pregnant again as soon as possible (Sauer, 2015, p. 1141).

2.2.8 Summary of baby loss section

Baby loss literature consistently highlights a profound negative psychosocial impact on parents. The disenfranchised and complicated grief associated with societal reactions to baby loss can make it particularly difficult to grieve. The NBCP has improved the bereavement care offering for women who have experienced a baby loss within the majority of NHS Trusts, but as a non-clinical pathway, there is a gap in understanding of how the needs of women with diabetes who have experienced a baby loss might differ.

2.3 Diabetes and pregnancy

More people are living with type 1 and type 2 diabetes than ever before (Diabetes UK, 2023c). Diagnoses have doubled over the past 15 years (British Medical Journal [BMJ], 2021), with over 4.3 million people diagnosed in the UK (Diabetes UK, 2023c). The number of people being diagnosed with diabetes is growing; by 2030, it is estimated there will be 5.5 million people in the UK affected by the condition (BMJ, 2021), which equates to around one in 10 UK adults and over 2.4 million women (BMJ, 2021).

However, these dramatic headline figures do not tell the full story. It is worth noting that the diagnostic criteria changed in 2011 following a World Health Organisation (WHO) consultation (WHO, 2011). Diabetes used to be diagnosed using a fasting blood glucose test, which took a long time to administer and only provided an indication of the blood glucose levels at a given point in time (Sherwani *et al*., 2016). A HbA1c test (see glossary of terms, pp. xvii-xviii) is now the main blood test used to diagnose diabetes, which provides a marker for the average blood glucose levels over the previous two to three months (Diabetes UK, 2023b), and is a more convenient test to administer and evaluate than a fasting glucose test (Sherwani *et al*., 2016). Diabetes is diagnosed when the HbA1c level is 48mmol/mol or above (Diabetes UK, 2023b). People are considered to be at risk of developing type 2 diabetes (also known as pre-diabetes) if the HbA1c level is between 42-48 mmol/mol (Diabetes UK, 2023b).

It is likely, then, that the change in diagnostic criteria coupled with the ease of screening at-risk groups, has contributed to increase in the doubling of diagnoses over the past 15 years. Nevertheless, the dramatic increase in diabetes diagnoses in the UK has often been attributed to growing rates of overweight and obesity, perpetuating stigmatising attitudes towards people living with diabetes (see Chapter Three, section 3.8). Weight gain and body mass are related to the onset of both type 1 and type 2 diabetes (Al-Goblan, Al-Alfi and Khan, 2014), however, the frequent portrayal of diabetes as obesity's 'twin epidemic' seems to be facilitating moral panic in health discourse (Foley, McNaughton and Ward, 2020), and the relationship between obesity and diabetes is portrayed so frequently that diabetes is almost synonymous with having an overweight or obese body. As such, people with diabetes can be stereotyped as living with overweight and obesity and vice versa.

2.3.1 Aetiological classification of diabetes

The two main types of diabetes, type 1 and type 2, account for 98% of all cases of diabetes (Diabetes UK, 2023c, 2023d; NHS, 2023a). Both type 1 and type 2 diabetes are complex, serious and progressive diseases which cause complications affecting nearly every system in the body (Diabetes UK, 2023d, 2023e; Forouhi and Wareham, 2014; IDF, 2023a). Although the pathophysiology and aetiology of the conditions are distinct (Chiang *et al*., 2014; Owens *et al*., 2015), both conditions result in hyperglycaemia (high blood glucose/sugar levels). The long-term effects of hyperglycaemia can lead to complications and serious damage to other parts of the body, such as the eyes, heart and feet, which can result in amputation and organ failure (Diabetes UK, 2023d, 2023e; IDF, 2023a).

Type 1 and type 2 diabetes are the focus of this research as they are associated with similar rates of baby loss (Balsells *et al.*, 2009; Macintosh *et al*., 2006; NHS Digital, 2019, 2021a), they are managed medically, in a similar way, before and during pregnancy (NICE, 2015a), and they are often compared directly in analyses (Owens *et al*., 2015). Whilst the decision to include both type 1 and type 2 diabetes in this research posed a challenge in terms of the conditions being very different, it was also an opportunity to explore how the inter-pregnancy interval was experienced by participants, and offered the potential to highlight differences in healthcare delivery.

About 2% of people are diagnosed with other rarer forms of diabetes, for example, monogenic diabetes, cystic-fibrosis-related diabetes and gestational diabetes (Diabetes UK, 2023d). Gestational diabetes is caused by glucose intolerance and occurs, or is first detected, in pregnancy (International Diabetes Federation [IDF], 2023a; Plows *et al*., 2018). Gestational diabetes is not the focus of this study as it usually resolves after delivery (Plows *et al*., 2018); however, it is worth noting that in some cases, gestational diabetes is actually type 2 diabetes that has been undiagnosed until pregnancy (Plows *et al*., 2018). Women with gestational diabetes and their babies are at an increased risk of developing type 2 diabetes in later life (Plows *et al*., 2018; Rayanagouda *et al*., 2016) and as many as half of women with gestational diabetes go on to develop type 2 diabetes within five years of pregnancy (Bellamy *et al*., 2009; NICE, 2015a).

2.3.2 Type 1 diabetes

Type 1 diabetes accounts for approximately 8% of total cases of diabetes in the UK (Diabetes UK, 2023c, 2023d). The exact cause of type 1 diabetes remains unknown (IDF, 2023b; Korsgren *et al*., 2012). Type 1 diabetes is characterised by autoimmune destruction of the pancreatic β-cells of the islets of Langerhans (Chiang *et al*., 2014); essentially, the body attacks and damages the β-cells in the pancreas so that the body can no longer make the hormone insulin (Diabetes UK, 2023d; IDF, 2023b). Insulin is vital in allowing glucose to move from the bloodstream and into cells, and people need insulin to survive (Diabetes UK, 2023d). When people with type 1 diabetes eat and drink, their body breaks down carbohydrates into glucose (sugar); however, without insulin, the glucose stays in the bloodstream, causing high blood glucose levels (Diabetes UK, 2023d). Without insulin, death from ketoacidosis can happen rapidly, as the cells in their bodies cannot access the glucose needed to fuel the body (Diabetes UK, 2023f; NHS, 2023b) (see glossary of terms, pp. xvii-xviii).

The onset of type 1 diabetes is usually acute, and it most commonly occurs in children and adolescents (birth to 14 years) but can develop at any time and is more likely to affect those who are white and middle class (Forouhi and Wareham, 2014; IDF, 2023b). People with type 1 diabetes are required to either inject themselves with insulin several times a day manually, with a needle or insulin pen, or by using an insulin pump, which is attached to the body via a cannula, in order to maintain and control their blood glucose levels (Chiang *et al*., 2014; Diabetes UK, 2023a; IDF, 2023b). There have been several advances in recent years in the development of technology to help people with diabetes gain tighter control of their blood glucose levels, as discussed in more detail in Chapter Six (section 6.3.3) and outlined in the Glossary of Terms (pp. xvii-xviii). Generally, individuals manage their condition with the support of a diabetes team. As type 1 diabetes is usually diagnosed at an earlier age than type 2 diabetes, women with type 1 diabetes are more likely to have had conversations about pregnancy with healthcare professionals and receive structured education about how preparing for pregnancy can reduce risks of adverse pregnancy outcomes (Forde, Patelarou and Forbes, 2016; Klein *et al*., 2017; Spence *et al*., 2010; Tidy, 2022).

2.3.3 Type 2 diabetes

Type 2 diabetes is the most prevalent form of diabetes, accounting for approximately 90% of all cases (Diabetes UK, 2023c, 2023d; IDF, 2023c; NHS, 2023a). In type 2 diabetes, the pancreatic β-cells either produce an insufficient amount of insulin, or the insulin does not work correctly as the body becomes resistant to it and is not able to use it effectively, resulting in hyperglycaemia (Al-Goblan, Al-Alfi and Khan, 2014; Diabetes UK, 2023d, IDF, 2023; Reinehr, 2013). Most people with type 2 diabetes require medication and/or insulin to control blood glucose levels (IDF, 2023c).

The high prevalence of type 2 diabetes in the UK is strongly linked to modifiable risk factors, including overweight and obesity, having an unhealthy diet, physical inactivity and previous gestational diabetes (BMJ, 2021; Diabetes UK, 2023c; Holden *et al*., 2013; IDF, 2023c; NHS, 2023a). However, there is also a strong hereditary component to the disease (Reinehr, 2013) and women with type 2 diabetes are more likely to live in areas of socioeconomic deprivation (Candler *et al*., 2018; Klein *et al*., 2017; Macintosh *et al*., 2006; Murphy *et al*., 2011; NHS Digital, 2021a) and belong to black and Asian minority ethnic groups (Crawford, Mendoza-Vasconez and Larsen, 2015; Klein *et al*., 2017; Macintosh *et al*., 2006; Murphy *et al*., 2011; NHS Digital, 2021a, 2021b; Riste *et al.,*2001; Whincup *et al*., 2010). Compared with the general population, type 2 diabetes is around five times more likely to develop in Pakistani women, two and half times as likely in Indian women and four times more prevalent in Bangladeshi and Indian people as a population (Diabetes UK, 2023c; NHS, 2019). The higher rates are thought to be attributed to a higher incidence of abdominal adiposity in these groups (Crawford, Mendoza-Vasconez and Larsen, 2015), and these groups may face additional cultural, ethnic and financial barriers to accessing the healthcare they need (Klein *et al*., 2017).

Type 2 diabetes is more prevalent in adults 45-64 years as the risk of developing type 2 diabetes increases with age (Diabetes UK, 2023c; Forouhi and Wareham, 2014; IDF, 2023c). Indeed, type 2 diabetes was once referred to as ‘late onset diabetes’, as the condition is slow to develop and was almost exclusively only seen in middle or older age (Forouhi and Wareham, 2014; Wilmot and Idris, 2014). However, type 2 diabetes is frequently being diagnosed in younger overweight people, and even in children, due to the rise of childhood obesity, physical inactivity and poor diet (Candler *et al*., 2018; Forouhi and Wareham., 2014; Holden *et al*., 2013; Reinehr, 2013; Wilmot and Idris, 2014). Over the past 15 years, there has been a 90% increase in type 2 diabetes, with increasing numbers of younger women being diagnosed (Mackin *et al*., 2018). Women with type 2 diabetes are not always aware of the requirement to prepare for pregnancy (Williams *et al*., 2023). It was highlighted by Forde *et al*. (2020) that the standardised education programme ‘Desmond’ for type 2 diabetes does not include a pregnancy component, whereas it is included as part of the Dose Adjusted for Normal Eating and Exercise ‘DAFNE’ programme for women with type 1 diabetes (Tidy, 2022) (see glossary of terms pp. xvii-xviii for more information on structured education).

2.3.4 Diabetes and pregnancy

In 2020, there were 681,560 live births registered in the UK (ONS, 2021). It is estimated that 1-2% of pregnant women have pre-existing diabetes (RCM, 2022), which suggests that between 6,800-13,600 pregnancies annually in the UK are affected. The most recent National Pregnancy in Diabetes (NPID) Audit in 2020 recorded 4,540 pregnancies among 4,525 women with diabetes across 162 services (NHS Digital, 2021a). The NPID Audit shows women with type 2 diabetes made up more than half (54%) of pregnancies with diabetes in 2020, which is double the proportion (27%) in 2002 (27%) (Confidential Enquiry into Maternal and Child Health [CEMACH], 2005) and an 8% increase since 2015 (46%) (NHS Digital, 2016, 2021a, 2021b). Figure 2.1 provides an illustration of this trend. Type 1 diabetes accounted for 44% of pregnancies in 2020 (NHS Digital, 2021a), with the remaining 2% attributed to type not specified, Maturity Onset Diabetes of the Young (MODY) or 'other' diabetes type (NHS Digital, 2021a).

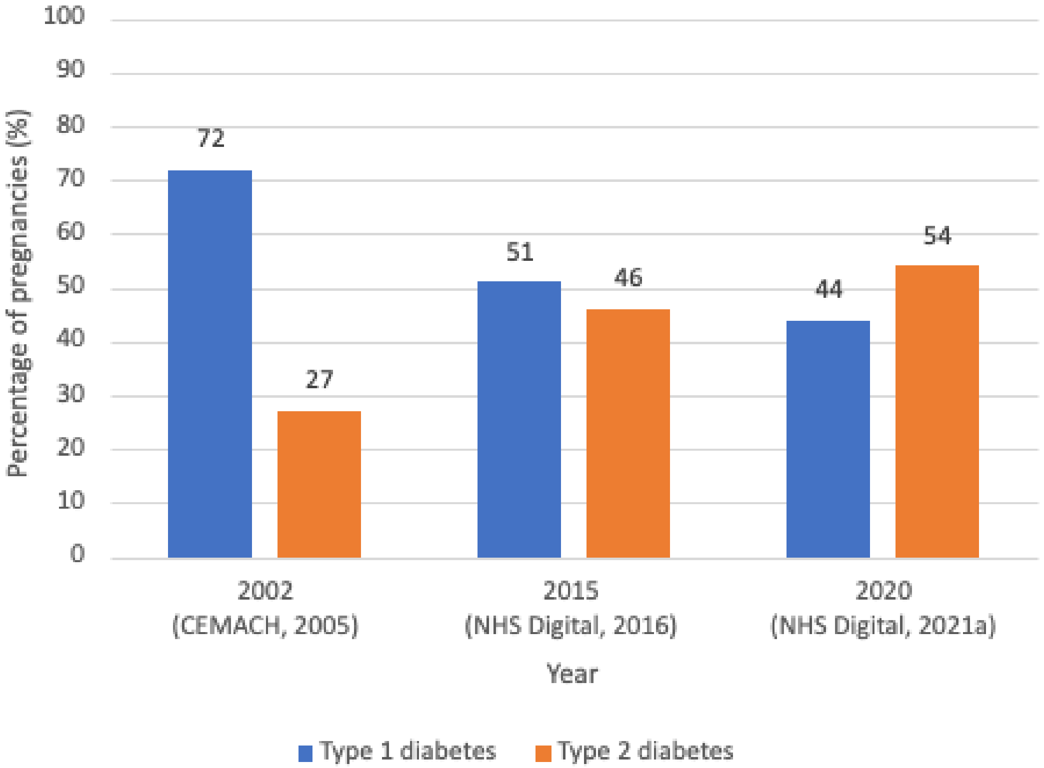


Figure 2.1: The trends for pregnancies associated with type 1 and type 2 diabetes 2002-2020

Hyperglycaemia (high blood glucose levels) caused by diabetes and commonly used teratogenic medications to treat the co-morbidities of diabetes (for example, statins used to treat high blood pressure) have been shown to have an adverse effect on pregnancy outcomes (Bell *et al*., 2008, 2012; Colstrup *et al*., 2013; Conway and Langer, 2000; Cooper *et al*., 2006; NICE, 2015a; NHS Digital, 2021a; Makda *et al*., 2013). Women with pre-existing type 1 and type 2 diabetes who become pregnant have a three- to four-fold increased risk of baby loss (Bell *et al*., 2012; Cundy *et al*., 2007; MacIntosh *et al*., 2006), and mother and baby are at a greater risk of developing complications, (Bell *et al*., 2008, 2012; Cooper *et al*., 2006; Dabelea *et al*., 2014), as outlined in Table 2.1.

Maternal complications	Fetal complications
• Pre-term birth • Hypertension • Pre-eclampsia • Perineal trauma • Maternal obstetric complications (haemorrhage, infection, thrombosis, admission to intensive care unit, incontinence) • Maternal diabetic complications (glycaemic control (glycosylated haemoglobin; HbA1c), hypoglycaemic episodes, diabetic ketoacidosis (DKA), retinopathy, nephropathy, macrovascular disease) • Operative delivery • Maternal death	• Baby loss • Congenital anomalies • Macrosomia, small for gestational age, low birthweight • Shoulder dystocia, birth trauma (bone fracture, nerve palsy) • Admission to intensive care, high dependency unit • Hypoglycaemia, respiratory distress, sepsis, transient heart failure, resuscitation, jaundice, hypocalcaemia, polycythaemia, hypoxic ischaemic encephalopathy, impairment of neurodevelopment

Table 2.1: Maternal and fetal complications related to diabetes in pregnancy (NICE, 2015b)

The high rate of baby loss among women with diabetes has been attributed to the pregnancy being affected by a congenital anomaly from ‘abnormal fetal development’ during organogenesis (Ornoy *et al*., 2021). Organogenesis is the critical period of embryonic development occurring at around four to ten weeks gestation – a time when the developing baby (fetus) is most sensitive to the maternal environment and possible harmful exposures (Korenbrot *et al*., 2002) before the occurrence of the first prenatal visit (Atrash *et al*., 2006; Department of Health, 2001; Earle *et al*., 2017; Forde, Patelarou and Forbes, 2016; Forde *et al., 2020*; Shannon *et al*., 2014), and before some women with diabetes are even aware they are pregnant (Shannon *et al*., 2014). Maintaining near-normal blood glucose levels before and around conception is a particularly important modifiable risk factor in reducing the chance of congenital anomalies and baby loss (Bell *et al*., 2012; Cundy *et al*., 2007; Colstrup *et al*., 2013; MacIntosh *et al*., 2006; Mackin *et al*., 2019; NICE, 2015a; Ornoy *et al*., 2021), and so women with diabetes are recommended to plan and prepare for pregnancy (Hammarberg *et al*., 2022; NICE, 2015a).

2.3.5 Planning pregnancy: a false dichotomy

All women are encouraged to plan their pregnancies to improve their chances of getting pregnant and having a healthy pregnancy (NHS, 2020b), but for women with diabetes, there is a convincing medical benefit for planning and preparing for pregnancy (Diabetes UK, 2022; Hammarberg *et al*., 2022; NICE, 2015a), as discussed above. Pregnancy is often viewed as binary of either planned or unplanned, and unintended pregnancies are used as a benchmark for measuring and improving women's reproductive health (Aiken *et al*., 2016). Planning a pregnancy is a widely promoted and pervasive ideal, where "women with or without their partners should follow a linear, rational, decision-making process in terms of when to plan a pregnancy" (Earle *et al*., 2017, p.89). Nevertheless, it is estimated that 45% of all pregnancies in England are unplanned (Public Health England, 2018), and approximately 50% of women with diabetes seek support from healthcare services to prepare for pregnancy (Holing *et al*., 1998; Murphy *et al*., 2010a; NHS Digital, 2019; Tennant *et al*., 2015). It should not be assumed, therefore, that women with diabetes give more prior consideration to becoming pregnant than that of the general population (Griffiths *et al*., 2008), despite the potential to improve pregnancy outcomes (Hammarberg *et al*., 2022).

Portraying pregnancy as a simplistic dichotomy of either 'planned' or 'unplanned' is problematic. It implies that unplanned pregnancies are unintended, unwanted, or in some cases irresponsible, and it also fails to capture the diverse experience and variation of pregnancy readiness, intention, personal reasons and emotions that lead to pregnancy (Aiken *et al*., 2016; Barrett and Wellings, 2002; Earle, 2004). Barrett and Wellings (2002) identified four key criteria to be met for a pregnancy to be 'planned': 1) pregnancy was intended, 2) contraception was stopped, 3) partners agreed, 4) optimum lifestyle/life stage. When these criteria are considered in combination with the NICE (2015a) NG3 guidelines, there is a lengthy list of things to consider for a pregnancy to be deemed 'planned'. While it may be true that some women do 'plan' their pregnancies, the "complex lived experiences of becoming pregnant [. . .] defy categorisation as planned or unplanned" (Earle *et al*., 2017, p.36), and so the notion that pregnancy is either planned or unplanned requires deconstructing.

Furthermore, despite planned pregnancies being idealised and encouraged by public health practitioners, the decisions surrounding planning a pregnancy are widely viewed as being in the private sphere; a private and intimate decision between partners (Stephenson *et al*., 2021). This is reflected by a lack of pregnancy advice services in the NHS (Tommy's, 2021b), which focuses primarily on sexually transmitted infections and contraception (NHS, 2022c), and is emblematic of the decline in priority placed on women's reproductive health. To counter the lack of pre-pregnancy care available to women, in 2018, the miscarriage charity Tommy's, launched a highly publicised nationwide '#areyouready' campaign (Tommy's, 2018). The aim of the campaign was to promote their free 'Planning for Pregnancy' digital tool and support women with information and resources alongside a drive to raise awareness of the importance of preconception health and planning for pregnancy to improve the chances of a safe and healthy pregnancy (Tommy's, 2018).

The Tommy's campaign was based mainly on the findings from a Tommy's survey with 750 women, which found that 67% of respondents spent three months or longer planning their summer holiday, compared to 20% of respondents who spent the same amount of time planning their pregnancy (McDougall *et al*., 2021). Most respondents were unaware they should do anything more than stop contraception in preparation for pregnancy; just under 40% stopped using contraception in the same week they decided to try for a baby, leaving little to no time to make any changes that may positively affect the pregnancy and health of the baby, for example, taking folic acid supplements, improving diet and exercise and achieving a healthy weight (McDougall *et al*., 2021). These important findings challenge the pervasive and idealistic notion that women should plan their pregnancies and highlight a pressing need for greater public health focus on preconception health for all women (McDougall *et al*., 2021).

While the Tommy's (2018) 'Planning for Pregnancy' digital tool is a helpful and accessible way for an individual to see ways to improve health before pregnancy, it perpetuates the inferred message that it is solely the mother's responsibility to plan and prepare for pregnancy - and thus, the mother's fault should pregnancy go awry. Paternal health is also a modifiable risk factor for adverse pregnancy outcomes (Carter *et al*., 2023; Fleming *et al*., 2018). The father's weight, diet and lifestyle before conception has been found to have profound implications for the safety of the pregnancy and the growth, development and long-term health of the child (Carter *et al*., 2023; Fleming *et al*., 2018). Nevertheless, much of the health literature, health policy, health communication and health service provision in this area continues to put the onus on the mother as being responsible for a healthy pregnancy (Caut *et al*., 2022; Carter *et al*., 2023).

2.3.6 Preparing for pregnancy for women with pre-existing diabetes

In 2015, NICE developed the 'NG3' preconception guidelines for women with diabetes (NICE, 2015a, 2015b) in response to strong evidence that carefully preparing for pregnancy could substantially reduce the risk of baby loss for women with diabetes (CEMACH, 2005, 2007; Hawthorne *et al.*, 1997; NICE, 2015a). Optimal pregnancy preparation includes taking 5mg/d folic acid, stopping any teratogenic medication and ensuring blood HbA1c levels are below 48mmol/mol (NICE, 2015a, 2015b) and has been shown to significantly reduce the risk factors for baby loss (Gardosi *et al*., 2013; NICE, 2015a; Monari and Facchinetti, 2010) and improve the outcome for both mother and child (McElvy *et al*., 2000; Murphy *et al*., 2010b; NHS Digital, 2021a; Wahabi *et al*., 2010; Wahabi, Alzeidan and Esmaeil, 2012). On paper, 'optimally preparing' for pregnancy seems reasonable, but in reality, it is difficult to do especially with regards to achieving tight control of blood glucose levels (NHS Digital, 2021a).

The 2020 NPID Audit Report reiterated the importance of optimising health before conception (NHS Digital, 2021a). The data from 2014-2020 show rates of serious adverse outcome (congenital anomaly, stillbirth and death in the first week after birth) were lowest in women who had an HbA1c of less than 48mmol/mol (6.9% in type 1 diabetes and 8.3%in type 2 diabetes) and highest in the women who had an HbA1c of more than 86mmol/mol in early pregnancy (14.2% in type 1 diabetes and 12.1% in type 2 diabetes) (NHS Digital, 2021a, 2021b). The 2020 NPID Audit reported that seven out of eight women with diabetes were considered 'sub-optimally' prepared for pregnancy compared to the NICE (2015a) guidelines (NHS Digital, 2021a), and there has been no improvement in pregnancy preparation over the past seven years (NHS Digital 2021a, 2021b).

There is a general lack of understanding as to why women with diabetes are unable to optimally prepare for pregnancy, given the risks to both mother and child. Pregnancy is often considered to be a 'teachable moment' (Locke, 2023; Phelan, 2010; Olander *et al*., 2016; Rockcliffe *et al*. 2021) defined by McBride, Emmons and Lipkus (2003, p. 156) as a "health event […] thought to motivate individuals to spontaneously adopt risk-reducing health behaviours". There seems to be an implicit assumption that the experience of baby loss will motivate women with diabetes to 'optimally prepare' for a subsequent pregnancy. However, the 'teachable moment' concept is under-theorised and there is little research to support that it actually improves positive behaviour change in relation to pregnancy (Rockcliffe *et al*., 2021); indeed, women with diabetes have been found to be no more likely to prepare for pregnancy after a baby loss, so are at risk of multiple losses (Holing *et al*., 1998; Murphy *et al*., 2010a; Tennant *et al*., 2015).

The 2020 NPID Audit Report supported the findings that women with diabetes are not more likely to prepare for a second or subsequent pregnancy, confirming the importance of this research. When pregnancy preparation for second or subsequent pregnancies (4,780) were compared with first pregnancies (3,305), there was no discernible improvement in 'optimal' levels of preparation for either type 1 or type 2 diabetes (NHS Digital, 2021a), as illustrated in Figure 2.2.

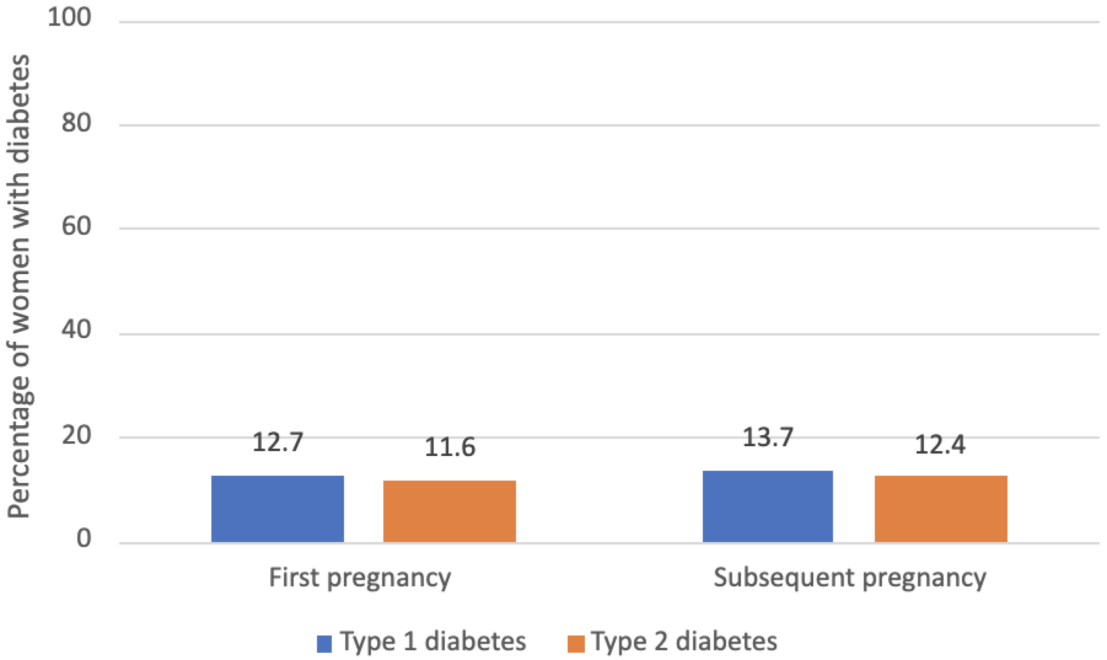


Figure 2.2: The percentage of women with diabetes considered to be 'optimally prepared' in first pregnancy compared with a subsequent pregnancy in 2020 (NHS Digital, 2021a)

There was a slight improvement in 5mg folic acid intake for both groups in subsequent pregnancy (type 1 diabetes = 50.6%, type 2 diabetes = 26.9%) compared to the first pregnancy (type 1 diabetes = 47.9%, type 2 diabetes = 23.4%) (NHS Digital, 2021a). Many women with diabetes struggle, in particular, to attain 'optimal' blood glucose targets (NHS Digital, 2021a). There was a minimal improvement of target HbA1c attainment for type 1 diabetes in a subsequent pregnancy (17.8%) compared to first pregnancy (17.2%) (NHS Digital, 2021b). For women with type 2 diabetes, target HbA1c attainment was found to be lower in subsequent pregnancy (35.2%) compared with first pregnancy (41.2%) (NHS Digital, 2021b).

These data evidence that current healthcare system approaches to pre-pregnancy care are not working for most women with pre-existing diabetes (NHS Digital, 2021a). Currently, neoliberal behaviour-change theories largely underpin solutions to manage or improve health, whereby the individual is viewed as responsible for their own health and wellbeing (Kara, 2017). To put this into context, women with diabetes are individually responsible for planning and preparing for pregnancy, and interventions to improve preparation for pregnancy tend to be individualistic in scope. For example, in terms of improving preparedness for pregnancy among women with diabetes, NICE (2015a) suggest barriers to achieving 'optimal' blood glucose levels include “health beliefs, a poor understanding of the importance of good blood glucose control, an inability to be able to comply with a demanding regimen of blood glucose testing up to 7 times a day, and the need to adjust insulin dosage” (NICE, 2015a, p. 42). These barriers are all individualistic in scope, point to a medicalised solution (i.e. technological help for women with diabetes to comply) and fail to mention any of the additional psychosocial and systemic challenges that this group may face, such as diabetes distress, financial struggles or access to and ability to afford healthful food.

Likewise, the 2020 NPID Audit Report recommendations are similarly medicalised and individualistic in character, with the ‘responsibility' ultimately lying with the woman, which indicates the importance of this research. As is so often the case, research and interventions focus on the individualistic factors at play – here, it is focussing on diabetes management. By neglecting the other factors, it is unlikely to solve the problem as the individual is only a small part of the problem. It is plausible that the more holistic approach of this research, which aims to better understan the social, psychological and emotional reasons behind suboptimal levels of preparation (Lauridsen, 2020), may help to inform healthcare delivery and improve the outcome for women with diabetes.

2.3.7 Pre-pregnancy care for women with diabetes

For women with diabetes, healthcare professional involvement in the decision to conceive is encouraged, and pre-pregnancy care (also referred to as preconception care), has been associated with improved preparation (CEMACH, 2005; Hopkins *et al*., 2023; Murphy *et al*., 2010b; Yamamoto *et al*., 2018) and significantly reduced risk of baby loss and other pregnancy complications for women with both type 1 and type 2 diabetes (Alexopoulos, Blair and Peters, 2019; August *et al*., 2011; Earle *et al*., 2017; Forde, Patelarou and Forbes, 2016; Hopkins *et al*., 2023; Monari and Facchinetti, 2010; Murphy *et al*., 2010b; Murphy *et al*., 2011; Wahabi *et al*., 2010; Wahabi, Alzeidan and Esmaeil, 2012). Definitions of pre-pregnancy care vary but generally consist of services that provide support and advice to elicit positive behaviour change in line with the NICE (2015a) NG3 preconception guidelines (Earle *et al*., 2017; Hopkins *et al*., 2023). Several different approaches to pre-pregnancy care for women with diabetes have been identified in the literature, including face-to-face clinics (Murphy *et al*., 2010a), opportunistic ‘brief intervention’ counselling in primary and secondary care (Shannon *et al*., 2014) and digital or web-based resources, such as smartphone applications (Nwolise, Carey and Shawe, 2017). All of these approaches may play an important role, depending on the needs and preferences of the women with diabetes.

Traditionally, pre-pregnancy care focused on women with type 1 diabetes (Forde, Patelarou and Forbes, 2016), as type 2 diabetes was not considered to affect women of childbearing age (Wilmot and Idris, 2014). Nowadays, type 2 diabetes affects over half (54%) of diabetes pregnancies (NHS Digital, 2021a) and carries additional obstetric risk factors (higher age, higher body mass index, previous pregnancies) (Yamamoto *et al*., 2018). Women with type 2 diabetes have similar levels of risk as type 1 diabetes pregnancies (Balsells *et al*., 2009; Forde, Patelarou and Forbes, 2016; MacIntosh *et al*., 2006; NHS Digital, 2021a; Owens *et al*., 2015) and so both forms require a similar intensity of pre-pregnancy care.

2.3.8 The uptake of pre-pregnancy care in women with diabetes

Women with diabetes are individually responsible for accessing pre-pregnancy care, and uptake of this care is poor (Murphy *et al*., 2010a; NHS Digital, 2021a; Tennant *et al*., 2015), especially among women with type 2 diabetes (Hopkins *et al*., 2023). Despite the well-established benefits of pre-pregnancy care, only around half of women with diabetes seek preconception advice (Glinianaia *et al*., 2014; Murphy *et al*., 2010a). The reasons for this are not fully understood and are complex.

The point at which pre-pregnancy care is accessed is crucial, and ideally, women with diabetes should start preparing for pregnancy before discontinuing contraception (McDougall *et al*., 2021; Murphy *et al*., 2010a). For this to work, women would have to know that they are planning a pregnancy and then take anticipatory action, highlighting how problematic it is for pre-pregnancy care to be based on the idealistic binary of un/planned pregnancy; pre-pregnancy care will only be relevant for half of the women with diabetes population when approximately 50% of women with diabetes seek support from healthcare services to prepare for pregnancy (Holing *et al*., 1998; Murphy *et al*., 2010a; Tennant *et al*., 2015). In general, many women only inform healthcare professionals once they have become pregnant (Lamb, 2002; Public Health England, 2018; Robson *et al*., 2009; Robson and Leader, 2010; Stephenson *et al*., 2021), reaffirming the suggestion that the consideration of conception is deemed a personal decision between partners (Meaney *et al*., 2017).

Women with diabetes may be more likely to experience what Earle (2004) referred to as 'recalcitrant' pregnancies; that is, despite less-than-ideal circumstances, they may experience a strong desire to become pregnant but feel like they might be discouraged by healthcare professionals (Earle, 2004; Murphy *et al*., 2010a). This has implications for women with diabetes as they may not actively be 'planning' a pregnancy, so they may not see the need to 'prepare'. Alternatively, failing to involve healthcare professionals may be partly due to an attempt to self-protect through disengagement (Mills *et al*., 2014) or potentially through insufficient awareness about the importance of appropriate pregnancy planning (Chuang, Velott and Weisman, 2010). For example, women with type 2 diabetes are less aware and less likely than women with type 1 diabetes to access pre-pregnancy care (Hopkins *et al*., 2023; Murphy *et al*., 2010a; Mustafa *et al*., 2012; NHS Digital, 2021a; Yamamoto *et al*., 2018). A meta-synthesis by Forde, Patelarou and Forbes (2016), whilst limited by the small number of included studies (n=7), highlighted multifactorial reasons for low uptake of pre-pregnancy care in women with type 2 diabetes and exposed some of the complexities involved in providing effective pre-pregnancy care for this group. Both patients and healthcare professionals reported a failure to recognise the risk to type 2 diabetes women, as well as limitations in delivering pre-pregnancy care by healthcare professionals, such as inconsistencies and a lack of integration in the system (Forde, Patelarou and Forbes, 2016).

Women with diabetes may have had negative experiences from attending pre-pregnancy care. Indeed, pre-pregnancy care can also have unintended consequences, as Griffiths *et al*. (2008) highlighted in their exploration of the perspectives of type 1 diabetes women living with the condition. Three of the 15 predominantly white British women with type 1 diabetes in this small study conducted in the West Midlands recalled negative pre-pregnancy care experiences, including increased anxiety levels and being 'filled with dread' (Griffiths *et al*., 2008). This created an additional burden for these women and put them off attending pre-pregnancy care for future pregnancies (Griffiths *et al*., 2008). Whilst this finding was based on the recalled experiences of only three women, this previously undocumented finding is still pertinent as much of the literature recommending pre-pregnancy care fails to consider the women's psychological well-being (Griffiths *et al.* 2008), highlighting the complexity of this area.

Similarly, in Murphy *et al.* (2010a), a study of 29 women with type 1 diabetes (n=21) and type 2 diabetes (n=8) from white British (n=23) and Asian (n=6) backgrounds, some did not attend pre-pregnancy care because information about diabetes and pregnancy was deemed too 'alarmist' and 'risk-focused' with too many 'horror stories' and a heavy emphasis on the potential for an adverse outcome. Two of the women recalled how they purposefully waited until their pregnancy was further advanced before seeking care, as they had previously been advised by healthcare professionals to terminate their pregnancy, which was against their beliefs (Murphy *et al*., 2010a).

A Health Technology Assessment report by Earle *et al*. (2017) explored the facilitators and barriers to the uptake of pre-pregnancy care by women with diabetes through a systematic review of 18 qualitative studies and 12 interviews conducted with British and Pakistani women (Earle *et al*., 2017). While limited by the relatively small sample size, the findings revealed four key issues which might help to explain the failure to make progress: Firstly, there is a lack of clarity about what pre-pregnancy care should consist of; secondly, there may be a lack of expertise in delivering the core elements of pre-pregnancy care (namely, pregnancy planning, fertility and contraception). Thirdly, it is not clear who is responsible for providing pre-pregnancy care to women with diabetes. Lastly, care needs to focus on enabling women to make positive changes rather than treating them as "women at risk of failure" (Earle *et al*., 2017, p.93). The systematic review element of the Health Technology Assessment report suggests that pre-pregnancy care best meets women with diabetes' needs when healthcare providers can communicate effectively with the women in their care (Earle *et al*., 2017). However, "communication was often perceived as authoritarian and paternalistic, and women sometimes felt judged, guilty, scared and pressurised rather than empowered and supported" (Earle *et al*., 2017, p.60). Earle *et al*.'s (2017) systematic review showed how pre-pregnancy care advice often focused too heavily on potential negative outcomes, scaring women by emphasising the risks rather than the positive changes that women might make when planning a pregnancy (Earle *et al*., 2017). Focusing more on the latter might encourage some women to engage more with the support offered (Earle *et al*., 2017).

A poignant finding from the meta-synthesis by Forde, Patelarou and Forbes (2016) was how some women were deterred from engaging in pre-pregnancy care as they wanted a 'normal' pregnancy experience where their diabetes did not take precedence. This was echoed in the systematic review by Earle *et al*. (2017), which suggested that women with diabetes want to be acknowledged as a 'whole person', an individual with a real life and aspirations, not 'just' a 'diabetic' or pregnant woman, highlighting the role stigma may play for this group (see Chapter Three, section 3.8). These women still wanted to experience the excitement and joy of pregnancy, but overly focusing on the medical management of their condition detracted from their capacity to enjoy the experience (Earle *et al*., 2017). This is in keeping with the 2010 study by Lavender *et al*., where all 22 participants felt that their pregnancy was overshadowed by diabetes management (Lavender *et al*., 2010). One participant felt 'labelled', and another struggled to enjoy the pregnancy as it was so medicalised (Lavender *et al*., 2010). This desire to normalise pregnancy was cited by Murphy *et al*. (2010a) in their qualitative study of women with type 1 diabetes (n=21) and type 2 diabetes (n=8) as one of the reasons they did not engage in pre-pregnancy care before becoming pregnant. It is understandably a challenge, therefore, for healthcare professionals to normalise the experience of pregnancy and the need to balance patient safety with enjoyment (Lavender *et al*., 2010; Woolley *et al*., 2015).

A key finding from the 2020 NPID Audit was how women with type 2 diabetes are frequently unprepared for pregnancy, with reduced use of insulin and folic acid before pregnancy and higher rates of perinatal deaths across all HbA1c categories (43-80mmol/mol) (NHS Digital, 2021a), which is likely related to the additional healthcare inequalities they face (Hopkins *et al*., 2023; NHS Digital, 2021a). Despite the various medical advances and the medicalisation of pregnancy, it is possible that some healthcare professionals may fail to recognise the risks for women with type 2 diabetes as they may still consider type 2 diabetes to be a 'disease of the elderly' and therefore not always associate it with pregnancy (Forde, Patelarou and Forbes, 2016; Klein *et al*., 2017; Murphy *et al*., 2011), so women may miss out on reproductive care unless they declare their pregnancy intention (Forde, Patelarou and Forbes, 2016). This is problematic, not only considering type 2 diabetes accounts for more than half (54%) of diabetic pregnancies (NHS Digital, 2021a) but the rising prevalence of type 2 diabetes among women of childbearing age (15-45 years) (Bell *et al*., 2008; Dabelea *et al*., 2014; ONS, 2022) means there are an unprecedented number of pregnancies affected by diabetes (NHS Digital, 2021a) and the actual scale of the problem is still unclear.

Overall, there is a general a lack of systematic consideration as to what pre-pregnancy care approaches work best for women with diabetes, as highlighted in a recent realist review by Hopper *et al*., (2022). Continuity of care, a personalised partnership approach, peer networks, access to psychological support and shared pre-pregnancy care guidelines that were integrated across specialties and services were recommended as the most important approaches and principles for pre-pregnancy care for people with chronic health conditions like diabetes.

2.3.9 Limitations of pre-pregnancy service provision

Pre-pregnancy care programmes have been criticised in the past for attracting primarily well-motivated women with higher socio-economic status, thus fail to focus resource on those who need it most (Gregory and Tattersall, 1992; Holing, 2000). In a (now dated) comparison of attendees and non-attendees at a pre-pregnancy care clinic in Edinburgh, Steel *et al.* (1990) found that non-attendees were significantly younger, more likely to smoke, less likely to be married and of lower economic class (Steel *et al*., 1990). The recent NPID Audit data support this criticism, and these data show how pregnancy preparation rates decrease in line with deprivation, and that the rates were lowest in women from the most deprived communities (NHS Digital, 2021a, 2021b). When compared against the NICE (2015a) NG3 guidelines, only 6.5% of women with type 1 diabetes and 9% of women with type 2 diabetes who lived in the most deprived quintile were ‘optimally’ prepared for pregnancy, compared with 21% of women with type 1 diabetes and 22% women with type 2 diabetes in the least deprived quintile (NHS Digital, 2021b).

The 2016 systematic review by Forde, Patelarou and Forbes, although small, with only seven included studies, explored the experiences of pre-pregnancy care for women with type 2 diabetes (n=28) and healthcare professionals (n=83). It brought to light how unconscious prejudices, biases and assumptions may exist about the reproductive readiness of women with diabetes, which may in turn affect the quality of advice provided by healthcare professionals (Forde, Patelarou and Forbes, 2016). For example, the systematic review reported how some women felt that healthcare professionals did not fully consider their reproductive needs or provide support to access pre-pregnancy care due to biased views about their age or weight and blood glucose control (Forde, Patelarou and Forbes, 2016). It was acknowledged by some healthcare professionals, although it was not clear how many, that women with type 2 diabetes were not routinely considered in terms of their reproductive potential, and may, in some cases hold negative views, particularly in relation to weight, and thus, pre-pregnancy care was not always incorporated into care for these women (Forde, Patelarou and Forbes, 2016; Spence *et al*., 2010). These findings were replicated in Forde *et al*.'s 2020 qualitative study involving semi-structured interviews with 30 women with type 2 diabetes and 22 healthcare professions. The women who participated were mostly obese, of black or Asian ethnicity (80%) and from areas of high deprivation (70%) (Forde *et al*., 2020). Both groups had negative perceptions of type 2 diabetes, lacked pre-pregnancy awareness, and communication between the groups was found to be unhelpful in eliciting reproductive intentions (Forde *et al*., 2020). Forde *et al*. (2020) identified the limited capacity for healthcare professionals in primary care to provide pre-pregnancy care, and overall, a lack of systemic processes meant that the reproductive healthcare needs of this group were not found to be embedded into their mainstream diabetes management.

In an attempt to increase uptake rates, and in recognition that most women do not 'plan' their pregnancies (Tommy's, 2018), Stephenson *et al*., (2021) suggest that preconception advice should be proffered to every woman of childbearing age with diabetes at every opportunity. This pragmatic view recognises that women, especially those with type 2 diabetes, may only spend a few hours in contact with healthcare professionals each year (Department of Health, 2001). Some women may be receptive to discussions about pregnancy planning when raised by the healthcare professional. Findings from a focus group by Chaung *et al*. (2010) involving 16 self-reported participants with diabetes recruited from a small community in Pennsylvania, USA, reported that some women found it hard to raise the issue of pregnancy planning. However, it is not transparent how many women felt this way and the generalisability of these findings is limited by the small sample. Conversely, receiving untimely advice that is deemed irrelevant may be a disincentive to women accessing pre-pregnancy care (Earle *et al*., 2017). Treating all women with diabetes as 'potentially pregnant' (Forde, Patelarou and Forbes, 2016) and routinely broaching the subject without prior consideration of women's individual needs may not be the most effective approach (Earle *et al*., 2017).

A further limitation of pre-pregnancy care provision is the inconsistencies in care provision across providers and barriers to access. In the UK, women with diabetes receive care across both primary and secondary care settings; there is a particular challenge to ensure entry points to pre-pregnancy care are easy to access and care is delivered collaboratively across professional services (Earle *et al*., 2017; Forde *et al*., 2020). Most pre-pregnancy care is located in specialist diabetic centres, and so services are more likely to be integrated with type 1 diabetes services (Forde, Patelarou and Forbes, 2016). In contrast, most routine type 2 diabetes care is delivered in primary care (Forde, Patelarou and Forbes, 2016; Forde *et al*., 2020). Such a disassociation may impact the accessibility of pre-pregnancy care to women with type 2 diabetes and may restrict their access to healthcare professionals with the appropriate expertise, as not all healthcare professionals are aware of the specific issues surrounding type 2 diabetes and pregnancy (Forde, Patelarou and Forbes, 2016; Klein *et al*., 2017; Murphy *et al*., 2011). Furthermore, women with type 2 diabetes may face an additional barrier to accessing pre-pregnancy care, as a result of resource constraints and either implicit or explicit care rationing (Earle *et al*., 2017).

There was a perception among some healthcare professionals in the study of type 2 diabetes women by Forde, Patelarou and Forbes (2016) that it was a waste of resources to refer a woman with type 2 diabetes to a specialist pre-pregnancy care clinic if they were not actively planning pregnancy, with some healthcare professionals unaware type 2 diabetes required pre-pregnancy care and with some falsely believing that care should only be optimised once pregnant. This highlights the pervasive false dichotomy that pregnancy is either planned or unplanned (Earle, 2004). At the end of the day, care systems are not orientated to providing preventative care, such as pre-pregnancy care, and there are inherent difficulties in trying to incorporate a pre-pregnancy care strategy within a care system that is already over-burdened (Forde, Patelarou and Forbes, 2016). This may have been further intensified by the effect of austerity and the fracturing of reproductive health clinics.

Yamamoto *et al*. (2018) have recently developed, implemented and evaluated the first community-based pre-pregnancy care programmes for women with diabetes, with a focus on engaging primary-care teams. This intervention was limited by the short duration (17 months) of the study and relatively small cohort (n=842 total; n=502 before pre-pregnancy care and n=340 after pre-pregnancy care), which meant it was unable to detect differences in adverse pregnancy outcomes. However, improvements in pregnancy preparation after the intervention for women with type 2 diabetes were significant, with a threefold improvement of pregnancy preparation among women with type 2 diabetes, almost 60% of whom reached the target HbA1c at conception and 50% were taking folic acid, and women with type 1 diabetes presented earlier for antenatal care (Yamamoto *et al*., 2018). Overall, the number of women considered to be 'optimally prepared' for pregnancy as per the NICE (2015a) guidelines doubled, from one in fourteen women to one in seven women (Yamamoto *et al*., 2018). As this pre-pregnancy care intervention was multi-faceted (it included pre-pregnancy care leaflets, electronic preconception care templates, online education modules and resources, and regional meetings and educational events), it was not possible to identify the most effective component of the programme, and there was a lack of information on important confounders, such as diabetes duration, smoking and social disadvantage (Yamamoto *et al*., 2018). Notwithstanding, complex problems need multi-faceted solutions (Hopkins *et al*., 2023), and this relatively simple and inexpensive intervention, with an estimated intervention cost of £49,476 per annum, has the potential to be reproduced in other regions. It offers evidence that such interventions offer a good financial return on the investment required, with the cost of delivering the programme less than the excess cost of managing adverse pregnancy outcomes (Egan *et al*., 2016; Yamamoto *et al*., 2018). This is an important finding because until recently, the unknown economic benefits of providing pre-pregnancy care had been a barrier to health care providers establishing a service (Egan *et al*., 2016).

In summary, care systems are not orientated to providing preventative care, such as pre-pregnancy care, and there are inherent difficulties in trying to incorporate a pre-pregnancy care strategy within a care system that is already over-burdened (Forde, Patelarou and Forbes, 2016). Fundamental to improving the service to women with diabetes is local services (diabetes, maternity, primary care, public health and commissioning teams) working collaboratively to create coordinated national initiatives (NHS Digital, 2021a). Furthermore, improving pregnancy preparation requires recognition that over half of women with diabetes have type 2 diabetes, over half are of non-white ethnicity and a high proportion are from areas of social deprivation. Therefore, specific initiatives to provide information, education and support to overcome social, cultural and economic barriers are needed, whilst recognising sociocultural differences and remaining sensitive to women's desires to have a family alongside optimising the health outcome for both mother and child (Hopkins *et al*., 2023; NHS Digital, 2019; Earl *et al*., 2017). There is a need for a blended and collaborative care approach, whereby women are provided with reliable, consistent information across services regardless of which healthcare professional is giving the message (Forde, Patelarou and Forbes, 2016; Hopkins *et al*., 2023).

2.3.10 The inter-pregnancy interval: the focus of this research

Many women with diabetes who experience baby loss will become pregnant again soon afterwards, with a median inter-pregnancy interval of only 12 months (Tennant *et al*., 2015). The short inter-pregnancy interval means there is only a small window of opportunity to support women to grieve for their baby and 'prepare' for their next pregnancy.

Both bereavement support and pre-pregnancy care have the potential to play a key role in supporting women with diabetes to grieve for their loss and prepare for subsequent pregnancy. Women with diabetes have specific needs concerning the disenfranchised and complicated nature of their grief and the additional burden of being required to 'prepare' for a subsequent 'risky' pregnancy within a small timeframe, indicating that this group may benefit from more specialised care in the inter-pregnancy interval.

The inter-pregnancy interval is an opportune time to target pre-pregnancy care at a group who largely have pregnancy intentions, to help ensure they are supported to prepare for pregnancy the best they can, given the circumstances, and to reduce the risks of baby loss and pregnancy complications. It is possible that women who experience a baby loss are more likely to be aware of pre-pregnancy care services (Richmond, 2009). However, awareness does not necessarily increase the likelihood of attending (Lavender, 2010; Murphy *et al*., 2010b). Indeed, pregnancy preparation was found to be no more likely in the subsequent pregnancy after a baby loss (NHS Digital, 2021a; Tennant *et al*., 2015). A better understanding of what it is like to experience the inter-pregnancy interval might help unpack some of the barriers to the uptake of pre-pregnancy care.

2.3.11 Summary of diabetes and pregnancy section

Type 1 and type 2 diabetes are distinct and different conditions, but both are associated with a similar level of baby loss (Macintosh *et al*., 2006). The risk of baby loss can be reduced if pregnancy is carefully planned and prepared (NICE, 2015a), but around half of pregnancies among women with diabetes are unplanned (Holing *et al*., 1998; Murphy *et al*., 2010a; Tennant *et al*., 2015), which suggests that 'planning and preparing' for pregnancy is an idealist assumption and not in keeping with the social norms.

Optimal preparation, as outlined in the NICE (2015a) NG3 preconception guidelines, includes managing blood glucose levels, taking a high dose of folic acid and stopping any teratogenic medication that might harm the developing fetus. However, preparing for pregnancy is not easy for women with diabetes. The 2020 NPID Audit data shows that only one in eight women with diabetes is considered 'optimally prepared' for pregnancy (NHS Digital, 2021a, 2021b), suggesting the knowledge base for how to manage diabetes ahead of pregnancy is not as stable and coherent as assumed. Suggestions to improve pregnancy preparation among women with diabetes tend to be individualistic in scope and point to 'more of the same', perhaps with a 'better pre-pregnancy service', instead of rethinking why the current approach is not working. A systems approach, that considers how discussions of contraception and pregnancy can be embedded into routine care to better reach women with diabetes who may not be 'planning' a pregnancy, may be more effective.

Pre-pregnancy care has been shown to improve pregnancy preparation, but uptake of care is poor even after a baby loss. There is a gap in understanding why women with diabetes do not access pre-pregnancy care in the inter-pregnancy interval and do not prepare for pregnancy, given the strength of evidence that shows that pre-pregnancy care can reduce the risk of baby loss.

2.4 Summary of the literature review

Many women with diabetes will go on to have a subsequent pregnancy shortly after baby loss. It is, therefore, crucial that reproductive health, diabetes and baby loss are not considered in isolation. By drawing together the literature surrounding baby loss, diabetes and pregnancy after loss, this chapter has highlighted how women with diabetes who have experienced a baby loss are subjected to and required to manage many tensions in the inter-pregnancy interval. These include the potential to experience grief compounded by disenfranchisement and complicated by stigmatising ‘problematic social emotions’, and the moralistic and idealistic judgements surrounding the requirement to plan and prepare for pregnancy. There is a general lack of pre-pregnancy care for women, but this impacts women with diabetes hardest because they have the most to gain from it.

Women with diabetes who have experienced a baby loss currently fall into a gap in the inter-pregnancy interval, as their needs are not being met by existing guidance, which has severe implications for subsequent pregnancy preparation. Existing preconception guidance fails to cross-reference the specific needs of women with diabetes who have experienced a baby loss, even though this group is much more likely to experience a baby loss. There has been a growing awareness and understanding of the bereavement process following a baby loss, with guidance available to support subsequent pregnancies (Henley and Schott, 2008; Sands, 2022a). There is also guidance available to women with diabetes about preparing for pregnancy (NICE, 2015a; Diabetes UK, 2022), but neither guidance cross-references the specific needs of women with diabetes who have experienced a baby loss, even though this group is much more likely to experience an adverse pregnancy outcome.

There is an urgent need to better understand the decision-making process, support requirements and challenges that women with diabetes face in the inter-pregnancy interval. Women with diabetes are not a homogenous group, and the determinants of their poor pregnancy outcomes are complex. There is a need to tease out some of the reasons women with diabetes are not able to achieve ‘optimal’ preparation for pregnancy using a different approach to the current biomedical and individualistic ways of thinking.

2.4.1 The gap in understanding and rationale for study

Even though women with diabetes are at a higher risk of experiencing a baby loss, little is known about women with diabetes’ decisions around and experiences of becoming pregnant again after baby loss and their support requirements. Improving pregnancy outcomes for women with diabetes is a priority area for research and improving pregnancy preparation is a key part of the solution (Schaefer-Graf *et al.*, 2018). The 2020 NPID Audit Report evidenced that current healthcare system approaches to pre-pregnancy care are not working for most women with pre-existing diabetes (NHS Digital, 2021a). There is an urgent need to address the gap in understanding why women with diabetes do not access pre-pregnancy care in the inter-pregnancy interval and do not prepare for pregnancy, considering it can reduce the risk of baby loss. To my knowledge, no studies currently focus on the lived experience of the inter-pregnancy interval among women with diabetes and how these experiences impact the uptake of pre-pregnancy care. There is also a gap in understanding of how postnatal bereavement support should consider the context of diabetes and link with support for preparation for a subsequent pregnancy and the best approach to support women to prepare for pregnancy in the inter-pregnancy interval. There is a clear need to address these gaps in knowledge to understand and better address the needs of follow-up care for women with diabetes who experience baby loss and how bereavement services can be addressed to integrate better with pregnancy preparation services.

2.5 Research Questions

The research question asks: how can more women with diabetes be supported to prepare for pregnancy after a baby loss?

2.5.1 Research sub-questions:

- How should postnatal bereavement support consider the context of diabetes and link with support for subsequent pregnancies?
- Do women with diabetes have specific and different needs in the inter-pregnancy interval that are not currently being met by existing guidance?
- How could care provision be changed to enhance health outcomes?

2.6 Research Aims

This PhD project aims:

(1) To explore and better understand the holistic experiences of preparing for pregnancy after baby loss among women with pre-existing diabetes.

(2) To explore and better understand healthcare professionals' perspectives (for example, diabetes specialist nurses and midwives, obstetricians, diabetes physicians, and primary care staff) on providing pre-pregnancy care to women with pre-existing diabetes who have experienced a baby loss.

2.7 Research Objectives

The research objectives are:

1) To explore and analyse the views and experiences of women with diabetes who have experienced baby loss and successfully completed a subsequent pregnancy.

2) To explore and analyse the views and experiences of healthcare professionals responsible for caring for pregnant women with diabetes relating to postnatal care for pregnancies ending in baby loss and preparation for a subsequent pregnancy.

3) To develop recommendations to improve the support provided after a baby loss to help women with diabetes improve preparation for future pregnancies.

It was essential to engage with women with diabetes to explore the lived experience of preparing for pregnancy after a baby loss in the context of diabetes and to better understand the needs of this group. Interviews with healthcare professionals were also crucial for better understanding the professional perspectives of providing care for women with diabetes after a baby loss. Their views are analytically underdeveloped in the literature (Dyer *et al*., 2019).

By exploring these different dimensions, the findings from this study have identified several gaps in research relating to the experiences and care provided in the inter-pregnancy interval after a baby loss for women with diabetes. The findings shed light on some of the challenges women with diabetes faced when preparing for a subsequent pregnancy after baby loss, which in turn, helped to highlight where changes could be made to improve care for this group.

Chapter 3. Philosophical assumptions and theoretical frameworks

3.1 Introduction

This chapter demonstrates how I considered the research design to ensure the elements (project aims, purpose, philosophical, theoretical and methodological assumptions) fitted together to provide “conceptual coherence” (Braun and Clarke, 2013; 2022, p. 167). Locating myself in this way, being aware of the philosophical and theoretical assumptions that informed my research helped ensure theory and practice aligned, and in doing so, conferred “methodological integrity”, analytic power and analytic validity (Braun and Clarke, 2022, p. 167).

I found it helpful, like Guba and Lincoln (1994), Crotty (1998), Creswell (2012) and Braun and Clarke (2022), to view the philosophical assumptions underpinning my research as connected - ontological positions (the theories of reality, see section 3.2.1) tend to give rise to certain epistemological (theories of knowledge, see section 3.2.2) and axiological positions (theories of values, see section 3.2.3) (Braun and Clarke, 2022; Creswell, 2012; Crotty, 1998; Guba and Lincoln, 1994). These, in turn, guided the choice of interpretive and theoretical frameworks (see sections 3.3 and 3.4) and informed and influenced the methodology and methods used in the research process (Chapter Four) (Creswell, 2012). In practice, research is not linear in this way but iterative. Nonetheless, Figure 3.1 illustrates this ‘order of influence’ (Guba and Lincoln, 1994).

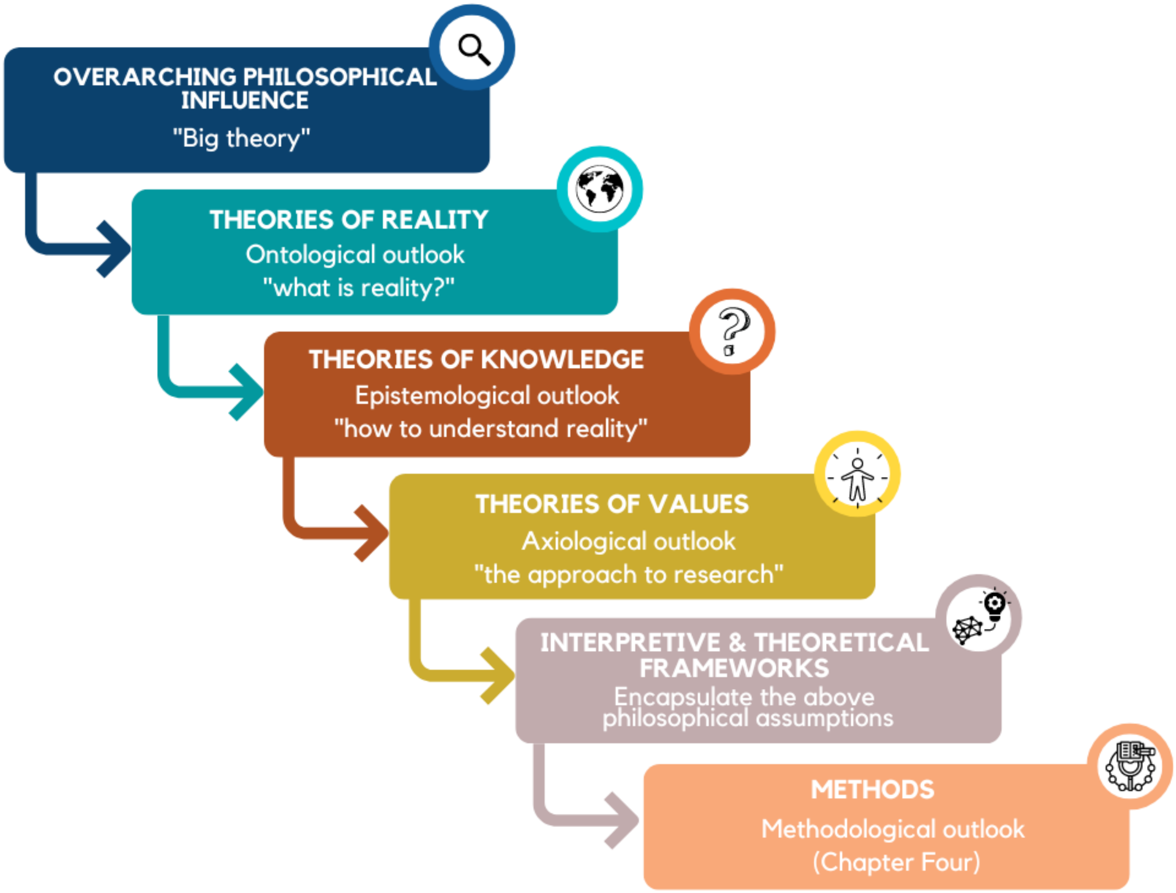


Figure 3.1: The ‘order of influence’ used to structure the theory chapter (Braun and Clarke, 2022; Creswell, 2012; Crotty, 1998; Guba and Lincoln, 1994).

The ‘order of influence’ (Guba and Lincoln, 1994), illustrated in Figure 3.1, was also used to structure this chapter. The chapter begins by defining my beliefs and philosophical assumptions, showing why and how they were incorporated into this research and how they, in turn, informed my choice of theoretical frameworks that guided my research (Creswell, 2012). I go on to introduce the overarching interpretive framework of social constructionism. Following this, the theoretical frameworks which helped to facilitate part two of data analysis and address the research problems are identified: *liminality*; *the biomedicalisation of diabetes and pregnancy; neoliberal strategies of responsibilisation*; and *stigma syndemics*.

3.2 Overarching philosophical assumptions or ‘Big Theory’

Simply put, philosophy involves using abstract beliefs and ideas to inform our research (Creswell, 2012). Our beliefs and philosophical assumptions are inherent and instilled in us over our lifetimes; through our experiences, training, and the communities we live in (Creswell, 2012). As succinctly put by Creswell (2012, p. 15):

> *"Whether we are aware of it or not, we always bring certain beliefs and philosophical assumptions to our research. Sometimes these are deeply ingrained views about the types of problems that we need to study, what research questions to ask, or how we go about gathering data"* (Creswell, 2012, p. 15).

Philosophical assumptions, therefore, are present at the conception of a research idea (Creswell, 2012) and form the foundations for our research (Braun and Clarke, 2022). However, it can be notoriously difficult to lay bare our beliefs and assumptions when they are so deeply ingrained and abstract that it is hard to pinpoint them. Braun and Clarke (2022) liken philosophical assumptions to "the oxygen for our research", which surrounds and permeates our practice, even if one does not want to think about it (Braun and Clarke, 2022, p. 156). Research cannot take place in a vacuum. Even if researchers fail to acknowledge their theoretical assumptions about reality and what constitutes meaningful knowledge, it still exists, and ignoring it constitutes poor practice (Braun and Clarke, 2022).

I took a qualitative approach to this research. In the broadest sense, I was interested in "process and meaning over cause and effect" (Braun and Clarke, 2022, p. 7). More specifically, I sought to understand situated meanings to generate contextualised knowledge (Braun and Clarke, 2022). This contrasts with the purpose of research in a quantitative paradigm, which seeks to record and understand a singular truth (Braun and Clarke, 2022); the 'when', 'what' and 'where' questions rather than 'how' and 'why' (Creswell, 2012). Qualitative research has no interest in "the idea of a singular universal truth to be discovered" (Braun and Clarke, 2022, p. 7), which can mean it continues to "earn its place" in academia (Morse, 2020, p.1). However, qualitative approaches have become increasingly valued in health research for the rich, nuanced insight and interpretation of lived experience they provide for policy and practice (Renjith *et al.*, 2021).

A qualitative, experiential approach was appropriate as I sought to explore and develop an understanding of how care in the inter-pregnancy interval could be improved for women with diabetes. I was interested in exploring the subjective experiences and perspectives of women living with diabetes and the healthcare professionals supporting this group. I sought to better understand the participants' inner worlds and their constructions of reality, to provide a platform for their voices (Braun and Clarke, 2022). My desire for understanding was "about nuance, complexity and even contradiction, rather than finding a nice tidy explanation" (Braun and Clarke, 2022, p.7).

In conducting a qualitative research project, I agreed with the following four philosophical assumptions, as outlined, in turn, in the following sections: *ontology*, *epistemology*, *axiology* and *methodology*. These four philosophical assumptions are deeply connected to research practice as they inform: what is ideal; what is permissible; and what does not make sense (Braun and Clarke, 2022).

3.2.1 Theories of reality: ontological outlook

Ontology, the 'study of being' (Gray, 2018; Pilgrim, 2020), refers to the nature of reality and its characteristics (Creswell, 2012). In other words, ontology relates to how the world is known (Kara, 2017; Ormston *et al*., 2014) or what exists or is 'real' (Braun and Clarke, 2022). In its simplest form, "ontology is about what it is that we think we can know" (Braun and Clarke, 2022, p.166). Essentially, this boils down to the question: can we assume (or theorise) that a separate, definable reality (or truth) exists (Braun and Clarke, 2022)?

In qualitative research, reality is only ever partially knowable, and any meaning or interpretation of reality is situated in practice (Braun and Clarke, 2022). This contrasts with quantitative (post/positivist) research, where reality is known through "systematic observation and experimentation" (Braun and Clarke, 2022, p.6). As a qualitative, experiential researcher, my ontological position was one of relativism, whereby I embraced the idea of multiple, subjective realities (Creswell, 2012). These multiple realities are a product of human action, constructed through lived experience and interaction with others (Braun and Clarke, 2022; Creswell, 2012). Braun and Clarke explain this simply:

> *"with relativism, we cannot assume anything beyond, beneath or behind that which we're seeking to understand"* (Braun and Clarke, 2022, p.174)

This is in contrast to realism, whereby ontologically, reality is conceptualised as a "singular reality that exists *independent* of human practices" (Braun and Clarke, 2022, p.174), and our understanding of it (Pilgrim, 2020). There are two common critiques of relativism, that are centred around morality and materiality; if you adopt a relativist position, you lose any basis for morality and essentially deny that a material world exists (Braun and Clarke, 2022). However, adopting ontological relativism is different from moral or material relativism (Burr, 2003). Ontological relativism relates to how we imagine the world around us and, fundamentally, what we can justifiably claim as knowledge (Braun and Clarke, 2022), which leads us to epistemology.

3.2.2 Theories of knowledge: epistemological outlook

Epistemology, the 'study of knowledge,' (Pilgrim, 2020) refers to how knowledge of reality is learned or is possible to study (Kara, 2017; Ormston *et al*., 2014). In other words, epistemology is a way of understanding and explaining *how* we think it is possible to know what we know and the best methods to attempt to know it (Braun and Clarke, 2022; Creswell, 2012).

As a qualitative and experiential researcher, my epistemological position was one of constructionism, which aligned with my ontological position of relativism (Braun and Clarke, 2022). Constructionism is a commonly utilised epistemology in qualitative research across the social and health sciences and is founded on the premise that research practices produce, not reveal, evidence (Braun and Clarke, 2022; Rogers and Pilgrim, 2021). With constructionism, meaningful and valid knowledge is known through the subjective experiences of the individual participants (Braun and Clarke, 2022), which was the central aim of this research. This requires the researcher to try and get as close to the participants as possible (Creswell, 2012), as it is not possible to access reality outside of human practice (Braun and Clarke, 2022). The researcher can be likened to an artist or storyteller:

> *"Creating 'something' with her tools and techniques, skills and cultural resources. But what this 'something' might be is bounded and has to 'make sense' within existing systems of meaning"* (Braun and Clarke, 2022, p.179).

Constructionism rejects the notion of any anchor for knowledge that determines its ultimate truth (Braun and Clarke, 2022).

With constructionism, what we ‘know’ a particular thing *is*, does not reflect its true nature but is constructed by humans located within a cultural and historical context (Braun and Clarke, 2022). As with relativism, there are concerns about the denial of a material world – but constructionism is not about denying that a physical world exists (Braun and Clarke, 2022):

> *“This doesn’t mean that we don’t ‘live’ as if things like sex, eating and reproduction aren’t real – of course we do! It means that we cannot ‘find’ - and therefore there cannot ‘be’ – any ‘reality’ of sex, eating or reproduction outside of human practices, which give rise to the meanings and understandings we work with, and act in relation to* (Braun and Clarke, 2022, p.183).

Instead, constructionism is about discourse and how the physical world is meaningless until we name it (Efran *et al*., 2014). Section 3.3 provides a more detailed description of how my constructionist outlook translated into social constructionism, the overarching interpretive framework used in this research.

3.2.3 Theories of values: axiological outlook

This section concerns the role of values in research (Creswell, 2012). Qualitative research is characterised by the axiological assumption that the qualitative researcher will honour their individual values and biases (Creswell, 2012). The qualitative researcher is not a “neutral conduit of information” (Braun and Clarke, 2022, pp. 14-15). Subjectivity is at the heart of qualitative research; the qualitative researcher embraces how knowledge comes from a position and admits to the value-laden nature of the data that are collected (Braun and Clarke, 2022; Creswell, 2012).

In this project, I adopted a reflexive approach to research whereby knowledge was treated as situated and shaped by the researcher (Braun and Clarke, 2022). This was a helpful approach when exploring this research topic, as qualitative approaches can be criticised for lacking transparency (Burr, 2003). In order to answer the research question, it was important to reflect on how my deeply embedded values, experiences, and taken-for-granted assumptions inevitably and inescapably shaped and informed my research practice. In doing so, I was able to explicitly ‘position’ myself in relation to the context and setting (Braun and Clarke, 2022; Burr, 2003; Creswell, 2012). Aspects of positionality included my social position (gender, age, race, for example), personal identity, experiences, values, and any relevant professional and political beliefs (Berger, 2015; Braun and Clarke, 2022). Locating oneself in this way shows how one's values have contextualised and shaped the research and analysis (Braun and Clarke, 2022).

3.3 Overarching interpretive framework: social constructionism

Interpretive frameworks encapsulate the above philosophical assumptions and offer a practical guide to conducting research (Creswell, 2012).

3.3.1 Social constructionism

The approach to this research used a social constructionist interpretive framework to look at and make sense of the world (Kara, 2017). Social constructionism is a school of thought within the field of social theory whereby the researcher seeks out the complexity of views directly from participants (Creswell, 2012). Broadly speaking, knowledge is understood as historically and culturally constituted; it is situated and bound to human practices and so is 'socially constructed' (Braun and Clarke, 2022, p.182). Nearly everything is viewed as a social construct, so it can be deconstructed – including science, technology, reproduction, food, eating, and physical activity (Braun and Clarke, 2022). As an influential theoretical position in the sociology of health and illness since the 1980s (Rogers and Pilgrim, 2021), social constructionism is recognised as a well-established approach to qualitative health research (Nettleton, 2013; Rogers and Pilgrim, 2021).

Ontologically, social constructionists believe a subjective world exists, and people *construct* facts and phenomena (Kara, 2017). In other words, no stable and objective reality is waiting to be discovered, but reality is a product, a *construct*, of human activity (Rogers and Pilgrim, 2021). Epistemologically, reality is co-constructed between the researcher and the participants, and the meaning of experiences is shaped and interpreted by individuals (Creswell, 2012; Kara, 2017). Social constructionism can sometimes be set in opposition to critical realism, which differs ontologically in the view that there is an independent reality (Rogers and Pilgrim, 2021) whilst still ascribing to epistemological relativism (Pilgrim, 2020). However, as Rogers and Pilgrim (2021, p. 20) assert, "it is not reality that is socially constructed but our theories of realities", a distinction that some can overlook. In some ways, critical realism can be considered as a form of social constructionism. As such, a social constructionist approach, which underpins the sociology of health and illness, was deemed an appropriate approach for this research as it offered a way to question the objectivity and ‘factualness’ of medical knowledge (White, 2002).

3.3.2 Social constructionist approach used in this research

As discussed in section 3.2.2, my epistemological position on diabetes and baby loss was shaped by constructionism, in that I viewed these phenomena as different for different people, and people’s actions and decisions necessarily affect how they create meaning from their experiences (Alderson, 1998; Kara, 2017). As such, social constructionism was a particularly appropriate interpretive framework for this research project to explore the experiences of diabetes and baby loss which had multiple social, psychological and physiological factors (Conrad and Barker, 2010). A social constructionist approach allowed me to capture a diverse set of experiences, which helped to provide a nuanced understanding of this complex research topic.

Social constructionism is a broad church; there are multiple ways in which to interpret it and conduct research. Burr (2003) argues that the most important aspect of a social constructionist approach is the way it informs the way data is interpreted, rather than swearing allegiance with a specific method or methodology. Nevertheless, this section briefly summarises my approach used in this research, which is drawn from Brown (1995), who identified three main strands within a social constructionist approach. The approach taken here had a ‘social problems emphasis’ whereby reality is not rejected outright, but is problematised to some degree (Brown, 1995). For example, researching diabetes and baby loss required me to acknowledge the factual status of death and the reality of the healthcare services that exist to treat women with diabetes. The social actors of interest, and therefore the focus of the research was on the lived experiences of women with diabetes and healthcare professionals. Rogers and Pilgrim (2021) note three central themes common to all three strands identified by Brown (1995). Firstly, reality is always problematised to some degree; secondly, it is important to view reality as a product of human activity (whether in whole or part) either through cognitive (thought and talk) aspects, or through the actions of individuals and collectives; thirdly, power relationships are inextricably bound with the definition of reality. The latter political dimension refers to the power to define, influence, or advance some interests at the expense of others (Rogers and Pilgrim, 2021).

This social constructionist approach allowed me to capture complexities and a range of experiential voices, and subjective meanings; aspects missed by a positivist approach (Alderson, 1998; Conrad and Barker, 2010; Walsh and Evans, 2014). Diabetes and baby loss mean different things to different people, including researchers and healthcare professionals. Diabetes and baby loss are socially constructed at the experiential level, but also, medical knowledge about these ‘conditions’ is constructed and developed by claims-makers and other interested parties, such as service commissioners (Conrad and Barker, 2010). Using a social constructionist approach allowed me to explore how deeply embedded cultural meanings shape the way society responds to women with diabetes who have experienced a baby loss.

Social constructionism embraces subjectivity; researchers are encouraged to explicitly acknowledge their positioning and biases, and consider how their values may influence the research process and findings (Alderson, 1998; Lincoln, Lynham and Guba, 2011). This research presents my interpretation of the data; the findings should be understood as a co-construction generated from my interactions with the research participants, my supervisors, and the literature. Rather than trying to claim objectivity and mitigate my values and biases, I embraced the importance of reflexivity, by acknowledging my personal positioning and relevant values (Burr, 2003) as discussed in more detail in Chapter Four (section 4.7). However, this can be seen as a limitation by those with more positivist leanings, who query the validity and utility and even legitimacy of findings that have no claim to an objective truth (Burr, 2003), as discussed in more detail in section 4.7. This is an ongoing debate in health research; while qualitative research is valued more than ever, there can still be a tendency to put positivism with its claims to an objective truth on a pedestal (Alderson, 2008).

On balance, social constructionism was deemed the most appropriate approach for this research as it allowed me to challenge the dominant medicalised discourse and individualistic rhetoric surrounding diabetes and baby loss by recognising how individual problems are actually rooted in problems stemming from aspects of society (Conrad and Barker, 2010; Rogers and Pilgrim, 2021; White, 2002). This helped me to contextualise the findings and was particularly helpful in exploring the dominant discourses surrounding ‘optimally preparing’ for pregnancy, and interrogating the underlying power structures, inequalities and stigma within the inter-pregnancy interval.

3.4 Overarching theoretical frameworks

Research does not occur in a vacuum; underlying theories always lead the researcher's gaze and inform data analysis (Braun and Clarke, 2022). Theoretical frameworks are essentially another way to enact the above-mentioned philosophical assumptions (ontology, epistemology, axiology) and methodology embedded within the research (Creswell, 2012). Therefore, theories can be thought of as a tool in the 'thinking toolbox' from which only relevant tools are selected for a specific use or analytic potential (Collins and Stockton, 2018).

Existing theories provide the researcher with a lens through which to view the data, helping researchers to interpret and make meaning from their findings (Creswell, 2012). Using existing theories as a lens helped me to see meaning embedded within the data (Kivunja, 2018). These lenses helped magnify the contents to reveal interconnections between abstract and concrete elements, helping to make meaning from the data and address the research problem (Kivunja (2018).

The selection of theory is highly contested. It is not unusual to find a vast variety of conflicting theories, all trying to explain the same phenomena, all of which are subject to debate, development and change (Braun and Clarke, 2022). Indeed, several potentially useful sociological theories were considered during the very early days of data analysis, including 'Reproductive Citizenship' (Lupton, 2012; Salmon, 2011), 'A Sociology of Nothing' (Scott, 2018), and 'The Risk Society' (Beck, 1992; Lupton, 2006, 2013; Mythen and Walklate, 2006), any of which would have proved interesting lines of inquiry. This goes to show how there is no *best* approach, only an appropriate approach (Braun and Clarke, 2022; Collins and Stockton, 2018; Pryke, Rose and Whatmore, 2003). The following blend of theories was identified over the course of data analysis. They were selected for their analytic potential to help deconstruct the inter-pregnancy interval to understand the research problem better and demonstrate how and why women with diabetes face so many points of tension.

The following four sections discuss the theoretical tools used in this research: *liminality* (section 3.5)*; the biomedicalisation of diabetes and pregnancy* (section 3.6)*; neoliberal strategies of responsibilisation* (section 3.7); and *stigma* (section 3.8). Using this combination of theoretical concepts enabled me to frame the research in such a way as to make more sense of something that has not been fully understood before: why do around half of the women with diabetes not prepare for pregnancy, even after a baby loss?

3.5 Liminality and the inter-pregnancy interval as a liminal phase

The concept of liminality originated from the French ethnographer Arnold van Gennep in his 1909 seminal work *Les Rites de Passage*, translated into English in 1960. Van Gennep used the term ‘liminaire’ (liminal) from ‘limen’, Latin for ‘threshold’ (Reiheld, 2015), to illustrate how rites of passage require one to traverse a threshold of ‘in-betweenness’ as they transition from one social position to another (van Gennep, 1960; Wagoner and Zittoun, 2021).

In *Les Rites de Passage,* van Gennep (1960) skillfully assembled all the available anthropological and historical data from across the world in multiple languages to show how ceremonies and life events follow a distinctive three-phase ‘rites of passage’ pattern, as depicted in Figure 3.2:

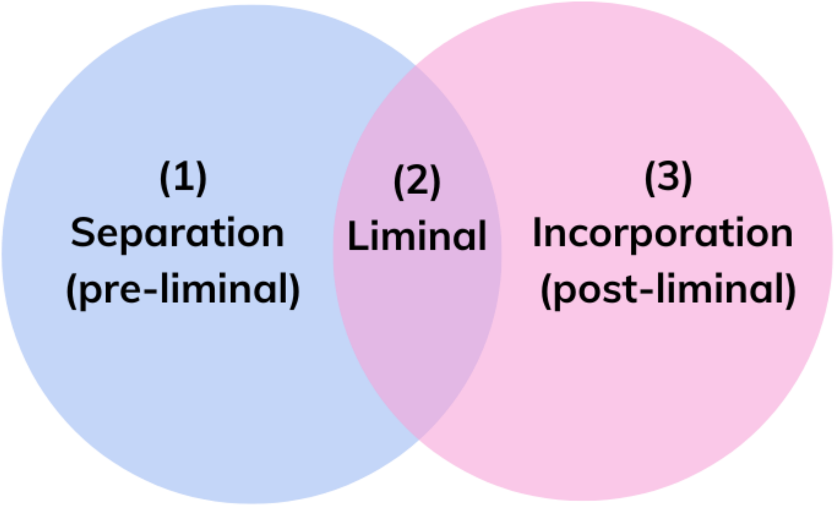


Figure 3.2: The three phases in the rites of passage

(1) pre-liminal rites (rites of separation), where people are no longer who they were but not yet whom they will become, move from their previous way of life towards the liminal state (Dowling and Pontin, 2017; Madge and O’Connor, 2005). The pre-liminal stage offers the possibility to move to a new structure or return to the old (Jackson, 2005).

(2) liminal rites (rites of transition) where the person transitions from one social role into another, crossing the limen (threshold) to leave one world behind as they enter a new one (Madge and O'Connor, 2005; Reiheld, 2015; Stenner, 2021).

(3) post-liminal rites (rites of incorporation), where the person is incorporated into a new social role and re-assimilated into society, usually in a different social state (Turner, 1969).

Together, the rites of passage symbolise the experience of 'going through' a transition (Stenner, 2021). The concept of liminality is both embodied and expressed during ceremonies and rituals, for example, the tying of hands in marriage or the burying of the dead (Stenner, 2021; van Gennep, 1960; Turner, 1969). The extent and significance that each part plays differs depending on the ceremony. For example, rites of separation are more prominent in funeral ceremonies, while the rites of transition may play a more important part in pregnancy (van Gennep, 1960). It is important, however, to note that this is more complicated than simply moving from A to B, but a process of transformation and really *becoming* something different (Stenner, 2021).

Although van Gennep is acknowledged as the originator of the concept of liminality, his work focuses on the rituals of rites of passage as a whole (Dowling and Pontin, 2017). It was not until 1963 that the British cultural anthropologist, Victor Turner, rediscovered and expanded the study of the liminal phase (Reiheld, 2015; Thomassen, 2014) when researching Ndembu triabal rituals. Turner focused on this 'betwixt and between' stage (Turner, 1969), which is characterised by a time of transition, indefiniteness and ambiguity (Wagoner and Zittoun, 2021).

Today, the concept of liminality is experiencing a revival (Thomassen, 2014). A growing number of publications across a diverse range of social sciences (psychology, anthropology, disability studies, geography, religious studies, political science, and history, to name but a few) use the concept of liminality to address those social aspects of human experience that fall outside of ordered structures (Horvath, Thomassen & Wydra, 2018; Stenner, 2021). Liminality has been applied to various health issues, including the sick role, living with chronic pain (Jackson, 2005), and fertility treatment (Allen, 2007). Managing chronic conditions like type 1 diabetes have also been likened to a state of liminality, where the pursuit of optimal management is ongoing and often feels unattainable (Sanders *et al*., 2019).

This research, therefore, draws more on recent theorisations and perhaps more fluid interpretations of liminality. These build on the works of Turner (1969), and include work by Thomassen (2014), Stenner (2021) and Wagoner and Zittoun (2021). Liminality has been recognised as a powerful tool of analysis – a prism through which to explore and better understand those in-between situations and conditions that are characterised by dislocated structure, change in social role and uncertainty about the future (Horvath, Thomassen and Wydra, 2018; Wagoner and Zittoun, 2021). As such, liminality is an indispensable concept to describe states of transition between social roles.

3.5.1 Using liminality as a frame to understand the inter-pregnancy interval

The inter-pregnancy interval encapsulates and embodies what it means to be in a liminal state, illustrated in Figure 3.3.

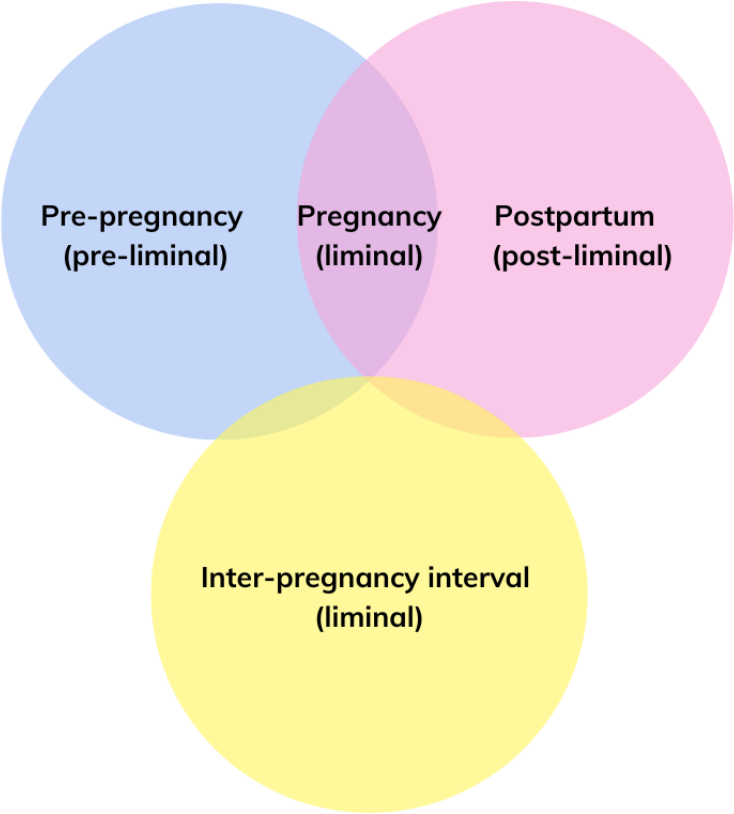


Figure 3.3: The Inter-pregnancy interval as a liminal phase

In the inter-pregnancy interval, mothers are symbolically detached from the social status of pregnancy, but the new social status of postpartum parenthood does not apply (Reiheld, 2015).

Mothers find themselves stranded, ‘betwixt and between’ (Turner, 1969). Here, the inter-pregnancy interval is constructed as a liminal experience of ‘becoming’ that is like a world within and between worlds (Stenner, 2021), as pregnancy is, in itself, a liminal and transitional phase.

Inter-pregnant mothers are neither here nor there; they are no longer who or what they were, but not yet who they are to become (Dowling and Pontin, 2017). This loss of self-identity is replaced by a nebulous identity of being non-pregnant (Bansen and Stevens, 1992), and as such, the liminal state suggests danger and threat (Navon and Morag, 2004). The previous identity is replaced by an ambiguous and unsettling situation of separation; a limbo (Carson, 2002; Thomassen, 2014). The inter-pregnancy interval is “declassification without reclassification" (Navon and Morag, 2004, p. 2338) and can be a time of “deep anxiety and suffering” (Szakolczai, 2018, p.34).

As a theoretical concept, there is little in the way of scientific literature or discussion on the topic, with only a handful of scholars applying liminality theory to miscarriage (Browne, 2022, 2023; Layne, 2003a; Reiheld, 2015), and so this research will move the topic forward. I considered using the *Sociology of Nothing* to illuminate the inter-pregnancy interval and the intangible nature of baby loss to reveal “how much nothing matters” when the focus of sociological enquiry is so often on social ‘things’ (Scott, 2018, p. 3). However, this approach did not strike a chord in the same way as liminality, a concept I came across during my MSc, which continued to intrigue me. Viewing the inter-pregnancy interval after baby loss through the lens of liminality was helpful as it revealed the complexity that women with diabetes faced in terms of the potentially unsettling transitoriness of the inter-pregnancy interval (Thomassen, 2014), which was overlooked by existing approaches in healthcare delivery, where baby loss is framed as a ‘failed’ pregnancy (see section 3.6). As a liminal phase, the inter-pregnancy interval can be described as follows:

> *“A peculiar kind of unsettling situation in which nothing really matters, in which hierarchies and standing norms disappear... in which authority in any form is questioned, taken apart and subverted; in which, as Shakespeare said, ‘degree is shaken’. Human experiences of freedom and anxiety (they do belong together) are condensed in liminal moments. Nothing really matters, and yet,*

> *deeply paradoxically, meaning often becomes over-determined"* (Thomassen, 2014, p. 1).

To summarise, liminality was identified as a useful theoretical resource for this research as the inter-pregnancy interval encapsulated the concept of liminality; a threshold the women with diabetes participants were required to cross in becoming pregnant subsequent to baby loss.

3.6 The biomedicalisation of diabetes and pregnancy

The biomedical model has dominated modern Western medicine for over two hundred years and constitutes of five key assumptions: (1) the mind and body can be treated separately (mind-body dualism); (2) the body can be repaired like a machine; (3) the merits of technological interventions are sometimes overplayed; (4) biomedicine is 'reductionist' in that diseases are explained by biological changes and neglect social and psychological factors; (5) reductionism is accentuated by the 'doctrine of specific aetiology' whereby a specific and identifiable agent causes all diseases (Nettleton, 2013, p. 2). Until the nineteenth century, illness, infections and disease were mysterious matters, generally understood as 'invading curses' with little or no rational treatment (Rocca and Anjum, 2020). Advances in biological knowledge, such as the germ theory of disease, had a revolutionary impact on medical thinking and allowed for a better understanding and explanation of illness and disease (Rocca and Anjum, 2020). For example, the first accurate description of type 1 diabetes dates back to the 2nd Century (Karamanou *et al*., 2016). However, type 1 diabetes was a fatal condition until the discovery of insulin in the mid-twentieth century (Karamanou *et al*., 2016), and so pregnancy with the condition was very rare (Löwy, 2014). Before the discovery of insulin, women with type 1 diabetes who became pregnant would nearly always enter a coma, and half of all pregnancies resulted in baby loss (Dunn, 2003). There is little doubt, therefore, that scientific advances and medical knowledge have changed the course of human history and saved many millions of lives (Rocca and Anjum, 2020).

However, over the past sixty years, medicine has claimed expertise in areas of life that had not previously been regarded as medical matters (Nettleton, 2013). For example, the human condition of pregnancy has been constructed as a medical problem to be treated almost as if it were an illness, rather than a normal life event (Conrad, 2007; Nettleton, 2013). When pregnancy is defined as a 'medical problem', it is conceptualised in terms of clinical risk, leading women to have their pregnancies monitored and babies delivered in hospitals (Nettleton, 2013). To put this into context, the biomedical model perpetuates the belief that reproduction can be controlled to ensure a positive outcome (Layne, 2003b). When pregnancy is viewed biomedically, a baby loss is conceptualised as a 'failed' pregnancy, overlooking the other aspects of such a complex social phenomenon, such as questions of life and death, illness, suffering, embodiment and personhood (Frost *et al*., 2007; van der Sijpt, 2010). The prioritisation of pregnancy is reflected by service provision, whereby there is a general lack of support for women who have experienced a baby loss (NHS Improving Quality, 2014), as discussed in Chapter Two (section 2.2.5).

Therefore, the concept of biomedicalisation is a key debate within sociology. It is indirectly linked to social constructionism by how it challenges the application of medical knowledge rather than the basis of medical knowledge (Conrad, 2007; Nettleton, 2013). Resultingly, rather than being viewed as a useful analytical model, from a sociological point of view, the biomedical model is often conceptualised as an "object to be attacked" (Gabe, Bury and Elston, 2004, p. 125). From a sociological point of view, the biomedical model and approach to medicine is limited as it overlooks the social and material causes of disease, fails to contextualise the body within its social environment, isolates the body from the person and neglects the subjective interpretation and meaning of health and illness (Nettleton, 2013; White, 2002). The biomedical approach offers a positivist account of disease whereby disease is presented as a 'fact', and defined as an entity or condition that deviates from the norm (White, 2002). The biological model has been criticised for failing to see illness as a condition of the whole person (Rocca and Anjum, 2020). Instead, the 'failed' body parts are treated separately to alleviate symptoms, but not the actual cause of the problem (Rocca and Anjum, 2020; White, 2002). Another criticism of the biomedical model relates to the tendency to 'objectify' the patient and reduce them to the target of therapy, rather than view people as active agents in their healing (Roca and Anjum, 2020).

Considering diabetes and baby loss are part of the human experience, the aim in this project is to explore these areas without the overriding judgement that these experiences should be eliminated (Cooper, 2010). By using a social constructionist approach, I sought to problematise some of the dominant 'taken for granted' biomedical assumptions. In doing so, I demonstrated how the hegemonic role of biomedical discourses are "inextricably linked with judgements of a moral and ethical nature" (White, 2002, p. 18), which may contribute to stigmatising processes for women with diabetes in the inter-pregnancy interval. While the impact of the biomedical model on pregnancy has been previously explored and criticised by feminist scholars, such as Oakley (1980), Davis-Floyd (1994) and Neiterman (2013), to my knowledge, the biomedicalisation of diabetes and pregnancy has not been used as a frame to comprehensively explore the difficulties faced by women with diabetes in the inter-pregnancy interval.

3.7 Neoliberal strategies of individual responsibilisation

Neoliberalism, the dominant ideology of the era (Navarro, 2007), is a complex and expansive topic with multiple definitions; the term is interpreted and employed in varying ways across contemporary social scientific literature (Bell and Green, 2016; Monaghan, Bombak and Rich, 2018). As such, "there is no pure or paradigmatic version of neoliberalism" (Springer, Birch and MacLeavy, 2016, p.2) and neoliberalism, like social constructionism, is best understood as an umbrella term within health research (Monaghan, Bombak and Rich, 2018). Neoliberalism commonly refers to a political and economic doctrine favouring market expansion and intensification with minimal government or state intervention (Ayo, 2012; Monaghan, Bombak and Rich, 2018; Navarro, 2007). However, neoliberalism is more than an economic or political term; it is "inherently social and moral in its philosophy" (Ayo, 2012, p. 101). At the individual level, neoliberalism may promote self-efficacy and self-reliance, but the ideology has been linked to poorer collective health and well-being (Card and Hepburn, 2023) and a substantial widening of health inequalities (Navarro, 2007). Neoliberalism is an ideology that that champions personal responsibility to be as healthy as possible (Broom and Whittaker, 2004; Monaghan, Bombak and Rich, 2018) rather than as a policy, programme or hegemonic project, which are expensive and time-consuming to deliver (Bell and Green, 2016).

In the context of diabetes and baby loss, neoliberal strategies of responsibilsation capture the zeitgeist of medical management today, whereby individuals are responsible for their own health and lifestyle choices, thereby bypassing critical reflection on the lack of resources in health care as a contributory factor. In the neoliberal society, the high rate of baby loss in women with diabetes is normalised as a dire outcome for those who choose to assert their right in a medical setting (Browne, 2023) by becoming pregnant before they are 'optimally prepared'. Women with diabetes are expected to be compliant, or at least able to be willing to 'optimally prepare' for pregnancy to reduce their risk of subsequent baby loss. The issues here surrounding agency and structure are contested from a social constructionist perspective (White, 2002). While neoliberal beliefs and policies may benefit those who have the ‘wherewithal’ to prioritise ‘optimal’ health, this essentially, “supports the ableist theory of the individual as independent actor, who can overcome any obstacle and achieve any dream if she only sets her mind to it and works hard enough” (Card and Hepburn, 2023, p. 364). In essence, this means that those who are able to afford to prioritise their health may benefit, which contributes to widening health inequalities between the rich and poor (Navarro, 2007), where those who are poor and disadvantaged suffer disproportionately more (Rose, 2019).

Here, I draw on the Foucauldian concept of governmentality, or ‘governing from a distance’ (Ayo, 2012; Bell and Green, 2016; Monaghan, Bombak and Rich 2018). Foucault saw governmentality as a method of social and political rule (Ayo, 2012; Lupton, 1999) and was interested in how humans engage in self-constituting practices (Ayo, 2012). Key to Foucault’s concept of governmentality is that social control is not overtly coercive or forceful, but individuals operate autonomously and willfully to regulate themselves in the state's best interest (Ayo, 2012; Lupton, 2013). Essentially, this is how much health promotion works; health-promoting agencies often rely on the autonomous desire of the individual to follow health advice, thus being personally accountable and responsible for their behavior, as implementing social or structural changes that would help the population as a whole are costly (Ayo, 2012).

As with biomedicalisation, neoliberal strategies of responsibilisation rely on individuals to proactively engage in health-seeking behaviours, and women who fail to ‘optimally prepare’ for pregnancy can be unfairly stereotyped as lacking willpower, rather than recognising how a woman’s ability to ‘optimally prepare’ for pregnancy is heavily influenced by the individual’s complex social life, which is further impacted by each individual's unique psychosocial, socioeconomic, cultural and lived experience (Annandale, 2014; Lauridsen, 2020). In contemporary biomedical diabetes management, there is tendency for there to be a heavy emphasis on *controlling* diabetes self-management, in terms of controlling blood glucose levels and food consumption (Broom and Whittaker, 2004). As a result, women with diabetes are subjected to potentially stigmatising processes of surveillance and discipline. Those who do not obey the required regimens, or who have difficulty achieving ‘optimal control’ are considered deviant or non-compliant and implies moral failing (Broom and Whittaker, 2004; Monaghan, 2022; Scambler, 2018), as discussed in more detail in section 3.8. As a result, neoliberalism is a concept that generates a great deal of concern and debate in health research due to how the moralistic overtones required to willfully and obediently prepare for pregnancy (Ayo, 2012), can negatively impact those living with diabetes and experience of baby loss. Ultimately, women with diabetes are individually responsible for 'optimally preparing' for pregnancy, contributing to maternal blame and self-blame when the pregnancy journey goes awry (Layne, 2003b).

In summary, neoliberal strategies of responsibilisation draw on individualistic reasons and solutions to manage. Efforts to improve pregnancy preparation among women with diabetes that focus solely on the individual's responsibility to prepare for pregnancy leaves much unaddressed (Monaghan, 2022), as this fails to fully account for the complexity of social lives and can lead to stereotyping suggestions that women do not prepare for pregnancy after a baby loss because they lack willpower, as discussed in more depth in the following section on stigma.

3.8 Stigma and stigma syndemics framework

Stigma has a long history as a key concept in the social sciences as it is widespread across most societies, making it a "culturally enduring phenomenon" (Rogers and Pilgrim, 2021, p. 188). It is also a widely applied term within the sociology of health and illness (Rogers and Pilgrim, 2021). There are few people who would consider themselves to be without any discrediting attributes (Gabe, Bury and Elston, 2014).

> *"Stigma is one of those odd things that is difficult to define, yet somehow easy to spot, feel, or know. Like other related forms of social and structural oppression, stigma can be overt and explicit, but most often it emerges in implicit and ambiguous ways that make it not only hard to define but difficult to identify, bound and uproot."* (Kessler, 2022, p. x)

Stigma operates on many levels and takes many forms, from Goffman's 1963 seminal work *Stigma: notes on the management of spoiled identity* to more recent theorisations, for example, the concepts of 'structural stigma' (Hannem, 2022; Hatzenbuehler, 2016, Link and Phelan, 2001; Scambler, 2018), health-related stigma (Scambler, 2009; Weiss, Ramakrishna and Somma, 2006), and ‘stigma power’ (Hannem, 2022; Link and Phelan, 2014; Tyler, 2018, 2020). The range and scope of sociological debates around stigma have created a vast and contested field to navigate. As Scambler succinctly describes:

> *“Stigma can be experienced or anticipated, characterised by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgement about person or group”* (Scambler, 2009, p. 441).

As such, stigma can be a poorly defined and taken-for-granted concept that is rarely problematised, which can blunt its analytical and explanatory potential (Gabe, Bury and Elston, 2004; Hannem, 2022). Nevertheless, stigma is widely understood as “standing at the centre of a downward spiral” (Brossard and Chandler, 2022, p. 78), where stigma begets stigma through lower self-esteem (Marcussen, Gallagher and Ritter, 2018) and a reduction in health-seeking behaviours (Prior, 2012; Wright, Jorm and Mackinnon, 2011).

Stigma was identified early on in the analytic process in this project, as a recurring and ubiquitous code in the data that I could not ignore. Therefore, in this instance I did not seek an alternative theory, but instead thought about how best to use the theory in this research. The following sections provide an outline of the relevant aspects of stigma that were applied in this research, which underpin the analysis of this thesis, followed by a section on stigma syndemics, which outlines my approach to utilising the concept in this research.

3.8.1 Goffman’s theory of social stigma

The study of stigma is grounded in interactionist sociology (Scambler, 2009), where Goffman’s pioneering 1963 study *Stigma: notes on the management of spoiled identity* continues to have an ongoing influence on sociological and healthcare research today (Hannem, 2022; Monaghan, 2022; Scambler, 2004; Weiss, Ramakrishna and Somma, 2006), inspiring research and stimulating theoretical debate (Monaghan, 2022).

Goffman defined stigma as an attribute, behaviour or reputation that threatens an individual’s social identity, reducing them from a whole ‘normal’ person to a ‘discounted’ person (Goffman, 1963). Goffman identified three distinct types of stigma: stigma of the body (visible blemish or deformity); stigma of the character (for example, mental illness or criminal behaviour); and tribal stigma of race, nation and religion (Goffman, 1963; Tyler, 2018). While stigma might be experienced as arising from the body of the stigmatised, Goffman actually intended stigma to describe a relation between the 'normal' and stigmatised persons as well as the relation of self to self (Goffman, 1963; Tyler, 2018). In other words, people acquire stigma through their exchanges and interactions with others - be it a glance, a comment, a reaction (Goffman, 1963; Tyler, 2018). Stigma, then, is produced in social settings and "pivots on the existence of a social consensus about 'what is normal'" (Tyler, 2018, p. 750). Society, Goffman argues, functions on the basis that the members in that society accept the norms in operation in any given context (Goffman, 1963; Tyler, 2018). People are expected not only to support a particular norm, but they are expected to conform to it (Goffman, 1963; Tyler, 2018). Therefore, stigma describes the negative social relation, as it emerges, when an individual fails to realise a particular norm, and people judge themselves by the ways they fall short of the norm (Goffman, 1963; Tyler, 2018).

Stigma, then, may or may not be visible, but confers 'deviant' status as it clashes with the stereotype of how the individual should be or behave (Goffman, 1963), as the stigmatisable attributes or behaviour results in the 'deviation from the norm' (Rogers and Pilgrim, 2021). This conceptualisation of stigma is relevant to both diabetes and baby loss, as both are potentially stigmatisable, as will be discussed in section 3.8.2. For Goffman (1963), stigma is a product and an outcome of human interaction. Once a person's identity is spoiled through stigma, this becomes the master status which is difficult to escape (Goffman, 1963). For example, the original infraction of being diagnosed with diabetes is seen as the 'primary deviance', which leads to a 'spoiled identity' as a response to the social reaction (labelling) from members of the public and/or healthcare professionals, which then leads to 'secondary deviance' which is the individual's response to the negative social reaction.

Goffman focused on how individuals experienced stigma differently and was concerned with the presentation of the self (Gabe, Bury and Elston, 2004; Goffman, 1963). A distinction was made between the 'discredited' - the stigma is clearly known and/or visible - and 'discreditable' - the stigma is unknown and concealable (Goffman, 1963). This is a relevant notion for my research in that the onset of type 1 diabetes is not generally linked to behavioural factors but is linked to a combination of environmental and genetic factors (IDF, 2023b). Consequently, people with type 1 diabetes are not ‘blamed’ or deemed responsible for their condition but are ‘discreditable’ should they fail to manage their condition appropriately. The onset of type 2 diabetes, on the other hand, is linked more strongly to individualistic factors, as well as overweight and obesity (NICE, 2015a; Teixeira and Budd, 2010). Consequently, people with type 2 diabetes may be considered ‘at blame’ or ‘discredited’ or shamed for their condition (Browne *et al.*, 2013; Cooper, 2010; Teixeira and Budd, 2010).

Central to Goffmanian stigma, therefore, is the emotional impact, for example, feelings of shame and hopelessness (Rogers and Pilgrim, 2021), and its potential to disrupt social interactions (Scheff, 2006, p. 56) through being ‘socially unacceptable’ or ‘inferior’ (Goffman, 1963). Of relevance here, is Scambler’s reframing of stigma, where he makes an analytical distinction between the related concepts of stigma and deviance, which are sometimes treated as synonymous (Scambler, 2009, 2018). Deviance invokes blame, denoting a ‘moral deficit’ from non-compliance, while stigma invokes shame, an ‘ontological deficit’ from non-conformance (Scambler, 2009, 2018). To put this into context, women with type 2 diabetes might be stereotyped as having acted in deviant ways with regards to their lifestyle choices, and so are (unfairly) blamed for causing the onset of their condition. Women with type 1 diabetes, who are not blamed for their condition, are still stigmatised for their spoiled identity for having diabetes.

Scambler (2009) notes how cultural norms of shame and blame are embedded within social structures and are variable and ever-changing. The relationship between stigma and deviance interacts as a political act which impacts large segments of society (Scambler, 2018). Also, chronic conditions co-exist in a society where cultural, structural, political and economic factors intermingle and play a role in the stigmatisation of individuals (Scambler, 2018). This reframing is far removed from the notion that chronic illness is a shameful personal tragedy (Scambler, 2018).

There are limits to Goffman’s concept of stigma. In Goffmanian terms, the process of stigmatisation is facilitated by the reactions of other ‘normal’ people (Goffman, 1963). Goffman problematically refers to stigmatised individuals as “not quite human” and inferior (Goffman, 1963, p. 15) and invites the reader to join him in his authorial position as a ‘normal’. ‘We normals’ is employed numerous times throughout the text as a way of designating the stigmatised person as inferior to the author and reader. It is not until the penultimate chapter that Goffman asserts that “the normal and the stigmatised are not persons but perspectives” (Goffman, 1963, pp. 163-164). Unsurprisingly, shame and victimisation become a central possibility for stigmatised individuals who may try to correct the “basis of his [sic] failing” (Goffman, 1963, p. 19). However, even where such a repair is possible, the individual is still denied a fully ‘normal’ status, discrediting them for having a tainted record (Goffman, 1963). Goffman postulates that stigmatised people should not question social norms, but just accept them, and ‘get on’ with life (Goffman, 1963). Goffman goes on to propose ways in which one might manage living with stigma, which boils down to tolerating the stigma, and *playing the part* society has assigned to them (Goffman, 1959, p. 28; Tyler, 2018), by using strategies of ‘passing and covering’ to “minimise the discomfort of the ‘normals’” (Goffman, 1963, p. 130). This failure to imagine systemic ways to prevent the discrimination that stigmatised persons face, whilst a product of its time, means that it is essential that we go beyond the reading of Goffman to find ways to understand the power and processes of stigma, and find ways to mitigate its effect.

Building on the work of Goffman (1963), research by Scambler and Hopkins (1986) showed that anticipation of experiencing stigma or discredit could affect an individual’s presentation of self. Scambler and Hopkins (1986) usefully differentiated between ‘felt’ stigma and ‘enacted’ stigma in describing an individual’s awareness of stigma. With felt-stigma, individuals may act defensively in anticipation of rejection (Hannem, 2022; Scambler and Hopkins, 1986). With enacted-stigma, individuals actually experience a negative social interaction, rejection, or overt discrimination on the basis of their being a ‘discounted’ person (Hannem, 2022; Scambler and Hopkins, 1986).

While Goffman points to how stigma is generated in a social situation, the ‘spoiled identity’ caused by stigma is society’s reaction to the deviation from the social norm (Goffman, 1963; Rogers and Pilgrim, 2021). However, Goffman’s social stigma research is limited in that it is overly individualistic in scope with a micro-focus on interactions and stigma self-management that overlooks the cultural norms and individual choices that underpin social structure (Gabe, Bury and Elston, 2004; Hannem, 2022; Scambler, 2009; Tyler, 2018). This distracts from the external and structural antecedents of stigma and fails to address stigma that is deeply embedded within social structures and institutions (Hannem, 2022).

The main critique of Goffman's work comes from disability studies, which questions the focus on stigma as either a "shameful personal tragedy" perspective or the problematic assumption that chronically ill and disabled people are 'deviants', makes this type of research inherently flawed (Thomas, 2007, p. 173; Scambler, 2004, 2018). While Goffman acknowledged that stigma could function "as a means of social control" (Goffman, 1963, p. 139), his understanding of normal-stigma relations is somewhat divorced from the macro-level structural power relations (Tyler, 2018), for example, the power inflicted through neoliberal policies. Failure to position stigma in the wider social and structural contexts (Scambler, 2009) and representing individuals in this way perpetuates the notion that chronic illness, such as diabetes, are characterised as a socially stigmatisable state of being that requires "individual management in the interactional order" (Thomas, 2007, p. 173), which as a result links stigmatisation with neoliberal notions of governmentality. Subsequent work in the field of stigma has developed Goffman's concept, thereby sharpening its analytical and explanatory potential, as discussed in the following section.

3.8.2 Beyond Goffman: stigma in the context of diabetes and baby loss

Social stigma has a particular effect on the biological and structural dimensions of health, and can drive many deleterious health interactions (Singer, Lerman and Ostrach, 2017). Research shows that people living with both type 1 and 2 diabetes are encumbered by stigma (Browne *et al*., 2013; Davidsen *et al*., 2022; Liu *et al*., 2017). Diabetes-related stigma has received a moderate amount of attention over the years, with most existing studies focusing on stigma related to type 2 diabetes (Browne *et al*., 2013; Liu *et al*., 2017; Teixeira and Budd, 2010) and less on stigma related to type 1 diabetes (Balfe *et al*., 2013; Browne *et al*., 2013; Liu *et al*., 2017). A recent large-scale (n=12,000) mixed-method self-reported survey of people living with diabetes in America by Liu *et al*. (2017) showed that 76% people with type 1 diabetes and 52% of people with type 2 diabetes reported diabetes-related stigma. In this study, regardless of the type of diabetes, the most widely reported experience of stigma (81%), was the perception of having a character flaw or feeling like they had failed to take personal responsibility for managing their condition (Liu *et al*., 2017). An interesting finding from Liu *et al*., (2017) was how some women with type 1 diabetes wanted the condition to be renamed, to disassociate it from type 2 diabetes, pointing to the stigma associated with having type 2 diabetes (Balfe *et al.*, 2013; Liu *et al*., 2017). The findings are pertinent to this research as they found a higher prevalence of stigma among women, and stigma was found to disproportionately affect those with a higher body mass index, higher blood glucose levels and poorer self-reported blood glucose control, which suggests that those who need the most help are also the most affected by stigma (Liu *et al*., 2017).

Stigma is not, however, an inevitable outcome of an illness but is socially produced (Brossard and Chandler, 2022) and the product of societally defined value judgements (Hannem, 2022). Stigma "feeds upon, strengthens and reproduces existing inequalities" (Parker and Aggleton, 2003, p. 13). This thesis draws on Link and Phelan's (2006) conceptualisation of stigma which goes beyond Goffman's predominantly unidirectional and individualised conceptualisation of stigma with a focus on the uniform application of a label and the impact of the prejudicial actions of one party on another (Rogers and Pilgrim, 2021). In contrast, stigma is recognised as a social process made up of five interrelated core components, as discussed in the next sub-sections in relation to the research topic: labelling, stereotyping, separation, status loss and discrimination (Link and Phelan, 2006).

Link and Phelan's (2006) reconceptualisation of stigma proved a useful way to think about stigma in this research topic, as it helped to identify the elements of stigma that may be present in the inter-pregnancy interval, and was useful in considering stigma-related outcomes (Link and Hatzenbuehler, 2016). Link and Phelan (2006) present stigma as a dynamic and interactive socially embedded process involving multiple aspects and which is contingent on economic and political power. Here, the stigmatisation process begins when a dominant group, or 'the normals' in Goffmanian terminology, identify a 'salient' difference based on deviance from the social norm (Link and Phelan, 1995, 2001, 2006; Rogers and Pilgrim, 2021). The process of stigma continues for as long as the difference remains and culminates into the construction of stereotypes and the individual being labelled to set 'them' apart from 'us' (Davidsen *et al.,* 2022; Link and Phelan, 2001, 2006; Rogers and Pilgrim, 2021). The end-point of discrimination as an outcome of stigma processes helps highlight the potential for stigma to affect the outcomes of many, not just the individual (Link and Hatzenbuehler, 2016).

3.8.3 Modified Labelling Theory

Central to labelling theory, which was developed and popularised by Becker in his 1963 book *Outsiders*, and and formalised by Scheff (1966) in his famous work on *Being Mentally Ill*, is a simple idea: what makes something deviant is the way that it is labelled by other, more powerful people; a consequence of which is stigmatisation, which in turn reinforces stigmatising behaviour (Goffman, 1963). Labelling remains important because “people live through how they name things” (Brossard and Chandler, 2022, p. 64). The increase in biomedical diagnoses of type 1 and type 2 diabetes (Diabetes UK, 2023c), as discussed in section 2.3, mean that more people are being labelled as a result, signaling, “a belonging to the realm of the pathological” (Brossard and Chandler, 2022, p. 72). However, labels alone do not qualify a diagnosis; they contribute to the production of the condition, and to the worlds that people inhibit (Brossard and Chandler, 2022).

While labelling theory is an important and enduring social theory, it is limited as it describes deviancy in individual terms and fails to recognise the broader social context. There are also disagreements as to the extent of power, how such labels operate and what they do, and the theory is criticised for failing to consider the disorder around biosocial networks (Link and Phelan, 2014). The modified labelling theory recognises that labelling is not uniform but a dynamic and social process. As such, this makes it a valuable framework for this research to better understand how categorising both diabetes as a chronic condition and pregnancy as ‘risky’ means they are both stigmatisable aspects, co-occurring in a particular set of individuals.

Link and Phelan (1995) argue that there are potential benefits, or “transformative potential” (Brossard and Chandler, 2022, p. 64) of labelling an individual, for example, by ‘empowering’ individuals to get access to the required support or treatments (Rogers and Pilgrim, 2021). Link and Phelan (1995) found that regardless of good practice, stigma persists as it is embedded in social processes in the community. Therefore, in Link and Phelan’s (1995) reconceptualisation, labelling was largely demonstrated as having a negative impact, causing a disvalued social status leading to various forms of disapproval, exclusion, rejection and discrimination, and ultimately, could lead stigmatised people to become isolated, demoralised and develop a ‘spoiled identity’ (Rogers and Pilgrim, 2021). This modified labelling theory is conceptualised as an interactive process based upon shared cultural assumptions, that results in social rejection (Link and Phelan, 1995; Rogers and Pilgrim, 2021).

The social production of labels is inextricably linked to an individual’s socio-historical context and, therefore, unstable and subject to change (Brossard and Chandler, 2022). Brossard and Chandler

(2022, p. 79) asserted that labelling has a “generative power”, whereby classification in itself could help identify disadvantage and inequality, but might also be part of the problem. Although Brossard and Chandler were referring to mental illness, there is relevancy here to the research topic, whereby the classification systems we use to identify chronic conditions, like diabetes, or types of baby loss, might be masking much deeper inequalities, thereby by reinforcing some of the problems in broader social structures without necessarily meaning to (Brossard and Chandler, 2022). In other words, we know from the 2020 NPID Audit data the scale of the problem, but not the mechanisms behind the data (NHS Digital, 2021a, 2021b). As such, a criticism of labelling a condition or an issue as stigmatising is that it can contribute to the interpretation that we are merely identifying a problem of social relations; it is still an issue that the stigmatised person must navigate rather than identifying or implicating the so-called ‘normals’ as perpetrators of stigma, or highlighting the issues of structural stigma as one that must be ameliorated (Hannem, 2022). This has recently been brought to light by the ‘Language Matters’ campaign, which has sought to change the way healthcare professionals talk about and communicate with people living with diabetes in an attempt to reduce stigma (Cooper *et al*., 2018; Lloyd *et al*., 2018; NHS England, 2018). For example, labelling a person as a ‘diabetic’ can be perceived as stigmatising, and so has widely been replaced in health literature with person-first language, as it has here, for example, ‘living with diabetes’ as this is potentially less stigmatising. However, this is a contested area, as person-first language is most frequently used to refer to people with stigmatisatiable conditions or disabilities than people without, and so person-first language may actually “accentuate stigma rather than attenuate it” (Gernsbacher, 2017, p. 859).

3.8.4 Stereotyping

Stereotyping is a micro-sociological phenomenon where individuals or groups are associated with often negative, narrow or misleading attributes according to other people’s expectations (Link and Phelan, 2001; Rogers and Pilgrim, 2021). Stereotyping, a form of social typing, ignores individual variations in social groups and can lead to stigmatisation (Rogers and Pilgrim, 2021). There is a tendency to construct stereotypes for women with diabetes, whereby fixed and common characteristics are attributed to the whole social group (Rogers and Pilgrim, 2021). However, solutions to treat and manage diabetes are typically individualistic and behavioural in scope, such as maintaining a healthy lifestyle, including increased physical activity and a healthy diet (IDF, 2023b, 2023c; Taylor, 2019; Youngson *et al*., 2015).

Women with diabetes may experience stigma as the result of interpersonal or structural discrimination, but it can also result from psychosocial mechanisms, whereby the stigmatised person perceives self-stigma (Davidsen *et al*., 2022; Earnshaw and Chaudoir, 2009; Link and Phelan, 2001). For example, stigma can be internalised when exposure to stigmatising stereotypes is absorbed and believed by the individual (Earnshaw and Chaudoir, 2009). Scambler (2004, 2009) refers to this as 'felt-stigma', where individuals feel the need to hide their condition, thereby internalising a sense of shame, for fear of encountering 'enacted' stigma, where overt discrimination is experienced on the grounds of 'being imperfect' or acting immorally (Scambler, 2004, 2009). Interestingly, felt-stigma (the lived experience of shame and fear of enacted-stigma) was typically found to be more disruptive than actual enacted-stigma (Scambler, 2009).

Much empirical research in other fields of study, for example, mental health, fat studies, and epilepsy, have demonstrated how stigmatised individuals are aware of expected social norms and so sometimes pre-emptively act to mitigate anticipated stigma (Corrigan and Watson, 2002; Hannem, 2022; Scambler and Hopkins, 1986; Thedinga, Zehl and Thiel, 2021). The notion that felt-stigma can lead to defensive actions, and self-exclusion even when overt discrimination is absent (Hannem, 2022; Thedinga, Zehl and Thiel, 2021) is relevant here, as it could help in understanding why women with diabetes may sometimes not engage in healthcare services in the inter-pregnancy interval, as they may anticipate feeling shamed, berated or stigmatised for falling short of the expected norm of 'preparing for pregnancy'.

This notion of self-derogation due to self-stigma has been shown to inhibit help-seeking behaviours and can harm social connections, self-esteem and mental health (Brossard and Chandler, 2022; Marcussen, Gallagher and Ritter, 2018; Prior, 2012; Wright, Jorm and Mackinnon, 2011). However, felt-stigma can mask and redirect our attention from the social context (Hannem, 2022; Link and Phelan, 2014; Tyler, 2020), and it is crucial to focus on the social processes that create stigma to which the individual is reacting, and not only on the individual and their behaviour (Hannem, 2022). As Tyler (2020) argued, locating the external source of these struggles might be more productive, for example, from the institutions offering support and social relationships. In other words, individuals do not stigmatise themselves; they may experience stigma and internalise feelings of shame and self-degradation in varying degrees *in response to* external social norms and interactional messages about their stigmatised category (Hannem, 2022).

3.8.5 Separation and status loss

Separation occurs when there is an 'us' and 'them' type distinction (Davidsen *et al*., 2022; Link and Phelan, 2001, 2006; Rogers and Pilgrim, 2021). Research on the differences between lay and professional perspectives (Rogers and Pilgrim, 2021) has shown how healthcare professionals and others without diabetes may not recognise diabetes as a stigmatised condition (Schabert *et al*., 2013). When such a lack of shared assumptions occurs in social interactions, Rogers and Pilgrim note how this can lead to a "disruption in confidence", which creates what they refer to as a "self-fulfilling prophecy" whereby "the patient keeps their distance, and the [healthcare] professional expects and lets this happen", which as a result creates a "vicious circle of social isolation" (Rogers and Pilgrim, 2021, p. 190).

As such, individuals can be stigmatised for, "failing to conform to the expectations of their category", but not all categories of people are subject to the same expectations (Hannem, 2022, p. 52). To put this into context, it is necessary to unpack the norms surrounding the expectations of planning and preparing for pregnancy discussed previously (see sections 2.3.5 and 2.3.6). Women with diabetes are placed into a different category to 'normal' women, whereby although they may share normative expectations about what is deemed 'normal' and expected for 'normal' women when preparing for pregnancy, is different to what is expected for women with diabetes. For example, all women are loosely recommended to plan and prepare for pregnancy (NHS, 2020b), whereas there is an expectation that women with diabetes should, and are expected to, plan and prepare for pregnancy. Although well intentioned to reduce risk, this creates a 'us' and 'them' separation between 'normal' women and women labelled with diabetes, and perpetuates the idealised assumption that women with diabetes should know about the requirement to plan and prepare, and be proactive in purposely planning and preparing for pregnancy, even though the social norm is for around half of pregnancies to be unplanned (Public Health England, 2018). When it comes to preparing for pregnancy, women with diabetes who do not ‘optimally prepare’ are seen as deviant and can be stigmatised for their moral failing to act in the expected way.

The separation between ‘us’ and ‘them’ may lead to status loss both in society and in the healthcare system (Davidsen *et al*., 2022), which may cause the individual to go downward in the social hierarchy (Link and Phelan, 2001), which can lead to discrimination (Earnshaw and Chaudoir, 2009). Parallels can be drawn between status loss and Goffman’s concept of spoiled identity. Both concepts are pertinent to women with diabetes who experience baby loss. Not only do they lose their social status of being pregnant, but women labelled with diabetes may face stigma for either failing to regain their pregnant social status or failing to manage their spoiled identity by behaving in ways to try and “correct” their “failing” (Goffman, 1963, p. 19), such as planning and preparing for their subsequent pregnancy. So, it can be seen how such separation and status loss culminates in a ‘discounting’ – or a ‘mattering less’ of women with diabetes who experience baby loss (Link and Hatzenbuehler, 2016).

3.8.6 Discrimination

The discrimination resulting from stigma pertains to negative treatment experiences and also oppressive structures (Link and Phelan, 2001). De-stigmatisation campaigns to reduce discrimination are challenging as they can have unexpected consequences (Gabe, Bury and Elston, 2004). For example, Navon’s (1996) campaign in Thailand to destigmatise leprosy found that educating the public about leprosy actually increased the risk of stigmatisation; the explicit message to “not be afraid” of leprosy implicitly suggests that most people are still afraid (Navon, 1996, p, 271). Therefore, information alone about diabetes and baby loss stigma and attempting to reverse public ignorance is not self-evidently likely to change stigmatising attitudes (Rogers and Pilgrim, 2021).

Attempts to tackle or reduce stigma generally involve individualistic and biomedical interventions focusing on health promotion and education (Scambler, 2009, 2018). However, information alone has been found to be unlikely to result in large changes of behaviour with most long-term conditions (Rogers and Pilgrim, 2021). Attempting to ameliorate stigma for a group (in this case, women with diabetes who have experienced a baby loss), solely at the individual level is of questionable value as it may well fail to address the structural disadvantages faced by the group

(Rogers and Pilgrim, 2021). For example, data from the 2020 NPID Audit demonstrated that women with diabetes who experienced baby loss were more likely to live in areas of deprivation or be from a minority ethnic background and, therefore, may face multiple disadvantages, and stigma may culminate from many angles. Such attempts to reduce stigma by 'empowering' the individual are likely to be ineffective as they do so from a 'top-down' basis and do not address the complex social structures, cultures and institutions that perpetuate stigmatisation (Scambler, 2009, 2018). Stigma processes, therefore, may play an unrecognised role on health, and health policies and healthcare delivery may "enact stigma processes, mitigate them, or ignore them" (Link and Hatzenbuehler, 2016, p. 653), so it is important that the role of stigma is not ignored.

3.8.7 Summary of stigma

Stigma is an often overlooked and under-recognised factor in health research (Link and Hatzenbuehler, 2016), but was identified as a valuable concept for this research. Both diabetes and baby loss are stigmatisable aspects of bodily health (Ostrach, Lerman and Singer, 2017), suggesting the inter-pregnancy interval provides fertile ground for numerous stigmatising processes. Goffman's ideas and arguments readily translate into social studies on the lived experience of diabetes and baby loss. Goffman's concepts and Goffmanian terms continue to "buttress contemporary sociological thinking" (Tyler, 2018, p. 747) and have relevancy in the stigma syndemics theory applied in this research (section 3.8.8). This thesis goes beyond Goffman and an individualistic analysis of stigma by drawing on Link and Phelan's (2001, 2006) conceptualisation of stigma, and the assertion that the components must coexist in a power situation that allows them to unfold.

3.8.8 Stigma syndemics

To use Brossard and Chandler's (2022, p. 79) metaphor, stigma is like an iceberg; the stigma that is obvious and can be seen is just the tip, and there is a great deal more hiding deep under the surface that needs to be considered. This section outlines how the concept of stigma was utilised in this research by using a stigma syndemics framework in an attempt to more adequately assess the structural forces that impact stigma under the surface (Gabe, Bury, Elston, 2004; Hannem, 2022; Link and Phelan, 2014; Scambler, 2018).

A syndemic, or synergistic epidemic (The Lancet, 2017) is where two or more interrelated biological or social factors work together to threaten health (Everson and Ostrach, 2017; Ostrach, Lerman and Singer, 2017). A stigma syndemic framework was chosen as it goes beyond co-morbidity or co-occurrence, and aims to illuminate and describe the complex overlapping and intersecting health risk interactions in the data (Ostrach, Lerman and Singer, 2017). At first, I considered using an intersectional approach, as per Link and Hatzenbuehler (2016) in their exploration of the intersection of stigma and policy. However, I felt that intersectionality was not quite the right fit for this particular research project. Race, gender and inequalities tend to be core elements of intersectional analyses (Sangaramoorthy and Benton, 2022), and the small, homogenous sample size meant it was not possible to frame the research in this way. Instead, a stigma syndemics framework seemed to offer a more appropriate approach in this instance.

As a relatively new concept proposed by Singer (1996), the theory of syndemics has received increasing attention in clinical medicine (Mendenhall *et al*., 2022). While there is not yet an extensive critique of this approach, criticisms include the oversimplification of complex social and health issues, and no empirical studies have yet validated the theory (Tsai, 2018). As a new concept, there is still a degree of conceptual ambiguity, whereby a clear and consistent approach is lacking, resulting in researchers using the approach differently, which could lead to confusion and limit the potential for broader application and development (Ouafik, Buret and Scholtes, 2022). While it is important to acknowledge such criticisms, they nevertheless, do not discount the importance and value of a stigma syndemic approach in studying marginalised groups in a more holistic way (Ouafik, Buret and Scholtes, 2022).

The theory of syndemics, which combines different aspects of well-known social science and medical theories offers the potential to map out the clustering of stigma in the inter-pregnancy interval. In place of a traditional “discussion chapter” at the end of this thesis, I used the stigma syndemics framework to synthesise and further discuss the research findings to better understand where stigma intersected in the inter-pregnancy interval. I was able to pay attention to stigma as the key driving structural or social factor that intersects and interacts with diabetes, baby loss and biomedicalised pregnancy, and how this affects health through stigmatised identities of the sufferers and stigmatisation of diabetes and baby loss. The stigma syndemics framework helped me to disentangle and explain the layering of diabetes, baby loss and stigma.

The stigma syndemics framework allowed me to consider how the social condition of stigma is converted into a ‘damaging force’ in physical and/or mental health (Ostrach, Lerman and Singer, 2017).

Distilling the complexity in this way provides a useful heuristic device that can be used by policymakers and programme implementers (Tsai, 2018) to mitigate and address the factors that give rise to stigma in the inter-pregnancy interval (The Lancet, 2017), which in turn, may improve healthcare and health outcomes for women with diabetes. To my knowledge, stigma syndemics has not been used to analyse work in this field before, hence the findings extend sociological, diabetes, and pregnancy research, and the syndemic framework in a new and, importantly, more socially conscious direction (The Lancet, 2017).

In summary, a stigma syndemic framework was considered to have analytic purpose in this study, helping to shed light on how stigma, as a key driving structural or social factor, intersected and interacted with diabetes and stigmatised pregnancy. Using stigma syndemics as a theoretical framework helped me assess the role(s) stigma played in the provision and uptake of pre-pregnancy care for women with diabetes after a baby loss. Exploring the findings in this way helped demonstrate both the nature and extent of stigma syndemic interactions that impact the stigmatisation of diabetes and baby loss and how this could affect health through stigmatised identities of the sufferers, which further complicates the access and provision of care for this group.

3.9 Chapter Summary

This chapter outlined my own broad philosophical assumptions (ontology, epistemology and axiology) and positioning in relation to the research, followed by the main theoretical approaches used to help make meaning from the data: *liminality; biomedicalisation; neoliberal strategies of responsibilisation;* and *stigma*. When layered together, these theories helped to paint a clearer and more in-depth picture of the inter-pregnancy interval landscape. Other avenues of inquiry were considered, but rejected in favour of the aforementioned approaches. The chosen blend of conceptual tools helped to demonstrate how and why there are so many points of tension for women with diabetes in the inter-pregnancy interval and the myriad ways in which stigma processes operate at simultaneously individual and structural levels (Hannem, 2012, 2022).

The individualistic predilections of both biomedicalisation and neoliberal strategies of responsibilisation, which dominate the healthcare received by women with diabetes who have experienced a baby loss, mean that there can be the perception that women with diabetes are responsible for individual disease-related risks and behaviours and, ultimately, can potentially be blamed for the baby loss (Davidsen *et al*., 2022). This research aimed to contribute to the body of literature on liminality and stigma syndemics, in particular, by examining the data using these concepts as lenses and thinking about what can be learned from this to help improve inter-pregnancy care for women with diabetes.

The following methods chapter, which is underpinned by the philosophical and theoretical approaches outlined in this chapter, explains and justifies the research design and methodological approach to this study.

Chapter 4. Study design, methods and methodology

4.1 Introduction

This chapter provides an overview and rationale for the chosen methodology. The qualitative approach taken in the interview and data analysis process is discussed. Details are provided about the methods used to recruit, sample and conduct interviews, followed by the methods of data analysis and researcher reflections. The main research question, as set out in the introduction (Chapter Two, section 2.5), asks: why do women with diabetes not prepare for pregnancy after a baby loss?

4.2 Explanation of study design

This qualitative research study comprised two main components: interviews with women with diabetes and interviews with healthcare professionals involved in caring for women with diabetes. There were five interrelated and iterative phases to this study (Figure 4.1), which allowed me to achieve the research aims and objectives set out in section 2.5.

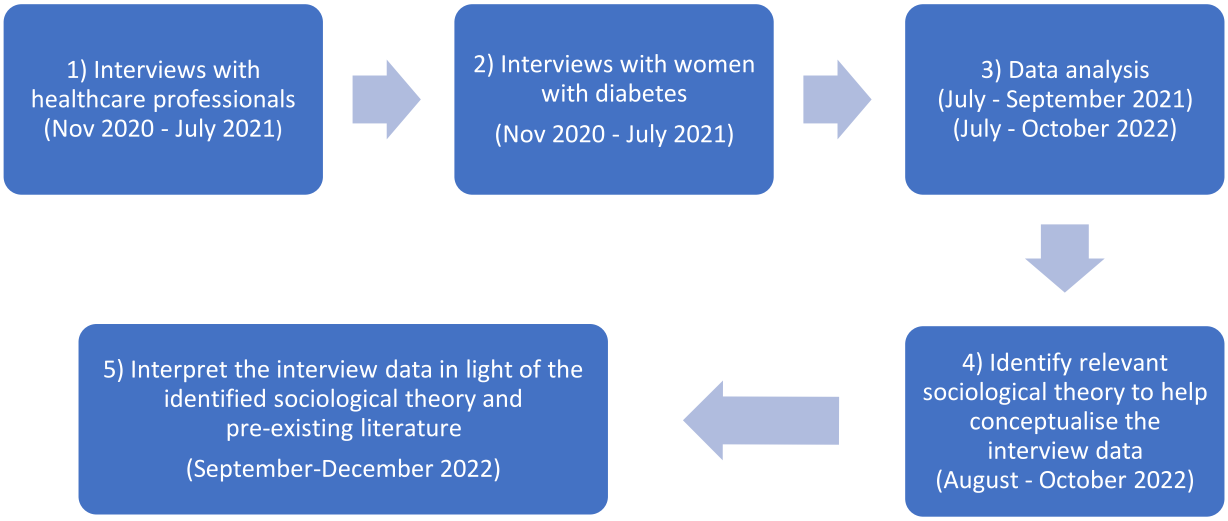


Figure 4.1: The five iterative phases of the research project

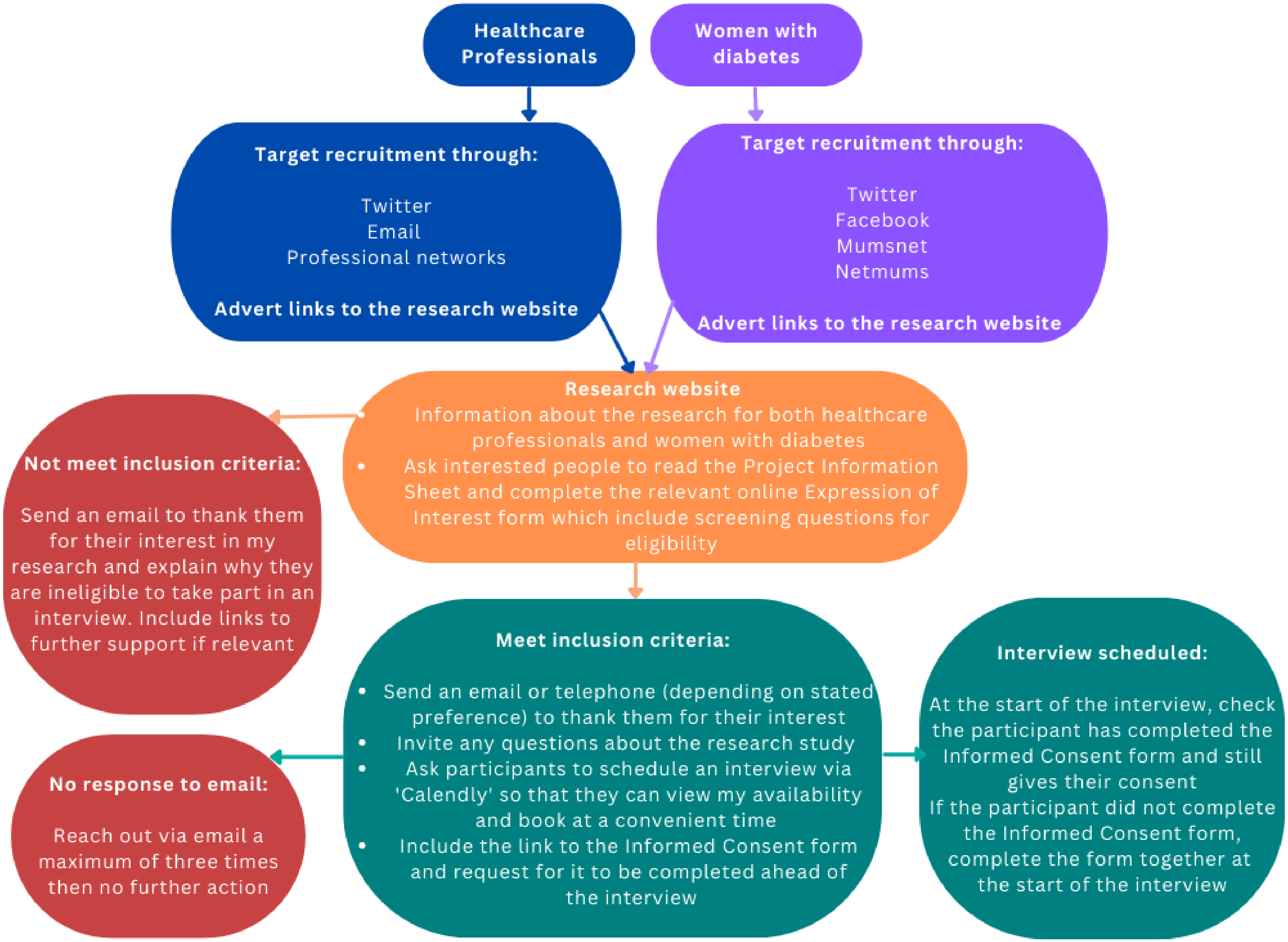
4.2.1 COVID-19 restrictions: remote research design

The strict lockdown measures enforced from 23rd March 2020 meant that the Health Research Authority froze all ethical applications for non-COVID educational projects.

Consequently, recruiting healthcare professionals through the NHS or conducting face-to-face interviews was not possible. The study was therefore designed so that participants could be recruited and interviewed online. To facilitate the remote methods, a research website was created using 'Wix' as a platform to direct potential participants (https://edyer24.wixsite.com/ella-dyer) (Appendix B), so they could find out more about the study, access the study documents, such as the Project Information Sheet (Appendix C) and submit an expression of interest form (Appendix D).

4.3 Recruitment and sampling

Recruitment began in late October 2020 and finished at the end of June 2021. Twenty-nine expression of interest forms were received from healthcare professionals and 23 from women with diabetes. Various social media platforms (Twitter, Facebook, Diabetes UK, Netmums and Mumsnet) and professional networks were used to identify and reach potential research participants. As illustrated in Figure 4.2, the recruitment strategy was guided by a pragmatic principle of yielding a sufficient and suitable sample of participants within the short timescale dictated by a three-year PhD project.



Healthcare Professionals

Target recruitment through:

Twitter
Email
Professional networks

Advert links to the research website

Women with diabetes

Target recruitment through:

Twitter
Facebook
Mumsnet
Netmums

Advert links to the research website

Research website

- Information about the research for both healthcare professionals and women with diabetes
- Ask interested people to read the Project Information Sheet and complete the relevant online Expression of Interest form which include screening questions for eligibility

Not meet inclusion criteria:

Send an email to thank them for their interest in my research and explain why they are ineligible to take part in an interview. Include links to further support if relevant

Meet inclusion criteria:

- Send an email or telephone (depending on stated preference) to thank them for their interest
- Invite any questions about the research study
- Ask participants to schedule an interview via 'Calendly' so that they can view my availability and book at a convenient time
- Include the link to the Informed Consent form and request for it to be completed ahead of the interview

No response to email:

Reach out via email a maximum of three times then no further action

Interview scheduled:

At the start of the interview, check the participant has completed the Informed Consent form and still gives their consent
If the participant did not complete the Informed Consent form, complete the form together at the start of the interview

Figure 4.2: Recruitment flowchart

Twitter was used to target both healthcare professionals and women with diabetes. My collaborators, the baby loss charity, Sands, tweeted about the research, which helped it to reach a bigger audience and helped to give the research credibility.

Facebook was used to target women with diabetes who had experienced baby loss, for example, diabetes support groups and baby loss charities. Nearly all of the Facebook groups were private groups for people living with diabetes or who had experience of baby loss. It was unethical to infiltrate the support groups, so a private message was sent to 26 Facebook group administrators to ask whether they would post about the research on my behalf (Appendix E). Confirmation was received that the research had been posted across 10 groups.

The appropriate permissions were sought to post an advert on the Diabetes UK website and online support platform (www.forum.diabetes.org.uk). An advert was also posted on the parenting forums, 'Netmums' and 'Mumsnet'.

Snowball sampling techniques were utilised to try and recruit additional participants by asking participants to share the research advert with anyone they thought might be interested.

The following professional networks assisted with recruitment by circulating an e-mail about the research study (Appendix F):

- Sands
- Diabetes UK
- National Diabetes Audit Quality Improvement Collaborative (QIC) for Pregnancy and Diabetes
- Northern England Diabetes and Pregnancy Steering Group
- Northern England Maternity and Perinatal Mental Health Network
- Maternity Voices Partnership

Table 4.1 provides an overview of where participants saw the research advert.

	Healthcare Professionals	Women with diabetes
Professional networks (e-mail)	4	
Diabetes UK professional conference	2	
Diabetes Support Forum	1	
Twitter	11	5
Sands Facebook group		3
4Louis Facebook group		3
Mumsnet		1
Total Interviews	**18**	**12**

Table 4.1: Summary of recruitment channels for those participating in an interview

Social media was chosen as the primary recruitment method for this study as it offered a largely accessible way of targeting both groups directly. Social media was an appropriate approach to recruiting participants, given that the interviews would also occur online (Hanna and Mwale, 2017). It was possible to reach a broad range of geographically dispersed participants (Hanna and Mwale, 2017; Gibson, 2017). Social media enabled me to connect with groups without being a member (Gibson, 2017) and allowed me to try different advertising methods (for example, images, videos, and hashtags) to see what worked best.

4.3.1 Approach to sampling

Individuals who responded to the study advert by completing an Expression of Interest (Appendix D) formed a purposive sample. Purposive sampling, often used in qualitative research where the researcher wants to gain detailed knowledge about a specific phenomenon rather than make statistical inferences (Braun and Clarke, 2013; Gray, 2018), was an appropriate approach given the limited time and resources. A purposive sample allowed me to identify and select information-rich cases, which enabled maximum variation in experience, allowing greater insight into the topic of interest by looking at it from as many angles as possible (Palinkas *et al.*, 2015).

The final sample size was determined when ‘meaning saturation’ was deemed to have been achieved (Hennink, Kaiser and Marconi, 2017). This decision was made during the later stages of data collection by iteratively reviewing the adequacy (richness, complexity) of the data for addressing the research question (Braun and Clarke, 2021a). This approach was appropriate considering the constraints of time and resources.

4.3.2 Screening process

Inclusion and exclusion criteria were used to facilitate sampling (Table 4.2). Screening questions were incorporated into the Expression of Interest form (Appendix D) so that individuals interested in participating were screened against the inclusion criteria at this point rather than after an interview had been arranged.

	Inclusion criteria	Exclusion criteria
Healthcare professionals	Experience in providing care for women with diabetes Healthcare professionals need not be diabetes specialists	Based outside of the United Kingdom[1]
Women with diabetes	Women who have pre-existing type 1 and type 2 diabetes with experience of pregnancy after a baby loss Women with diabetes who had subsequently completed a further pregnancy that resulted in a healthy infant who was alive and well at the time of the interview There was no limit on time elapsed since the baby loss	Below 18 years of age Gestational diabetes Unable to understand verbal English language Unable to provide consent Had not completed a further pregnancy Based outside of the United Kingdom

Table 4.2: Inclusion and exclusion criteria

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[1] I erroneously included a healthcare professional participant from Ireland. When checking the postcode provided on the Expression of Interest form, I thought the participant was located in Northern Ireland. It became apparent during the interview that an error had been made. After discussing with my supervisors, we decided it was unfair not to include this participant in the analysis as they had given up their time to participate.

As an exploratory study, this project focused on exploring an under-researched group with direct experience of the phenomenon in question. As such, the inclusion criteria were designed to be as inclusive as possible to try and encompass a breadth of experience of diabetes, baby loss and healthcare professional experience. A strict criterion for sociodemographic characteristics was not used as the research did not explicitly aim to contrast experiences of diabetes and baby loss by socio-economic status, gender, age or ethnicity. This would have required a much larger sample size than was practicably possible. Participants from outside of the UK were not eligible to take part, as the healthcare systems, services and provision vary considerably around the globe, so it would have been harder to interpret the findings and offer recommendations for good practice. Based on these guiding principles, the invitation to participate in the research was open to any consenting adult over 18 who had pre-existing diabetes and experience of pregnancy after baby loss.

Insight from a wide range of healthcare professionals from primary, secondary and community care sectors was sought. Women with diabetes encounter many different healthcare professionals, with and without specialist knowledge about diabetes and pregnancy, and healthcare professional insights were found to be lacking in the literature (Dyer *et al*., 2019).

Those who met the inclusion criteria were emailed with a link to the Consent Form (Appendix G). Potential participants could view the Project Information Sheet (Appendix C) again and ask any questions, either by e-mail or by submitting a question through the online form. Those who did not meet the eligibility criteria were thanked for their interest in the project and if appropriate, invited to take part in a pilot interview.

4.3.3 Response rate following an expression of interest

Women with diabetes were requested to self-report demographic information, their experience of pregnancy loss and their type of diabetes. The response rate for women with diabetes was 70%. Twenty-three women with diabetes expressed an interest in participating in an interview; six did not meet the inclusion criteria (still trying to conceive = 3, not based in UK = 2, experience of gestational diabetes and baby loss = 1) and five women did not reply to the e-mail inviting them to schedule an interview.

Healthcare professionals were asked about their job titles and location to ensure various professional experiences across the UK. The response rate for healthcare professionals was 64%. Twenty-nine healthcare professionals expressed an interest in participating in an interview. One participant was located in Pakistan so did not meet the inclusion criteria. Nine healthcare professionals did not reply to the e-mail inviting them to schedule an interview, and one healthcare professional did not attend the scheduled interview and did not respond to further correspondence.

4.3.4 Participant demographics and characteristics

A total of 30 participants took part in an interview between 26th November 2020 and 13th July 2021.

4.3.5 Women with diabetes overview

Twelve of the 30 participants were women with pre-gestational type 1 (n=9) and type 2 (n=3) diabetes with a range of baby loss experience between 2002-2018. There was no restriction on time elapsed since experience/s of baby loss. The majority of women with diabetes participants recalled events that had occurred within five (n=2) to 10 years (n=8) years prior to the interview. One woman recalled their experiences from 11 years previous, and one woman from 19 years previous. An overview of the women with diabetes demographics is provided in Table 4.3.

	Women with diabetes (n=12)
Type of diabetes	Type 1 = 9 Type 2 = 3
Age at the time of the interview	28-50 (median = 36) years
Age at diagnosis type 1 diabetes	7-28 (median = 11) years
Age at diagnosis type 2 diabetes	15-32 (mean = 26) years
Age at first pregnancy	23-35 (median = 29.5) years
Type of baby losses reported (please note, four participants reported multiple losses)	Early Miscarriage (<12 weeks pregnant) = 8 Late Miscarriage (12-24 weeks pregnant) = 5 Stillbirth (24+ weeks pregnant) = 2 Neonatal Death (death in the first month of life) = 3
Ethnic background	White = 11 Black/African = 1
Education level	Further education = 1 Undergraduate degree = 4 Postgraduate degree = 6 Undisclosed = 1
Relationship status at the time of the interview	Married = 8 Relationship = 2 Divorced = 1 Single = 1
Location during inter-pregnancy interval	London = 3 Northeast England = 3 West Midlands = 2 East Midlands = 1 Northwest England = 1 Yorkshire and Humber = 1 Southeast England = 1
Employment status at the time of the interview	Employed full-time = 11 Retired = 1

Table 4.3: Women with diabetes participant demographics

The median age of first pregnancy for all women with diabetes participants was 29.5 years old, which is in keeping with the average age women first become mothers in England and Wales

(ONS, 2022). Although some study participants had since moved areas, they resided throughout the UK during their experience of the inter-pregnancy interval.

Seven of the women with diabetes participants experienced baby loss in their first pregnancy. Five participants had older children before experiencing baby loss. The number of losses reported per participant ranged from one to five. Table 4.4 provides an overview of the decisions surrounding a subsequent pregnancy and actual inter-pregnancy interval alongside the type of baby loss.

	When started to try for subsequent pregnancy	Actual inter-pregnancy interval
Early miscarriage (<12 weeks pregnant) = 8	Straight away	2 months
	Straight away	4 months
	Straight away	6 months
	Straight away	7 months
	Waited 1 month	2 months
	Waited 2 months	4 months
	Waited 2 months	10 months
	Waited 3 months	6 months
Late miscarriage (12-24 weeks pregnant) = 5	Straight away	15 months
	Waited 3 months for test results	4 months
	Waited the advised 6 months	7 months
	Advised to wait 12 months	6 months
	Not discussed in the interview	Not discussed in the interview
Stillbirth (24+ weeks pregnant) = 2	Undisclosed	10 months
	Undisclosed	36 months
Neonatal Death (death in the first month of life) = 3	Straight away	9 months
	Waited 3 months	12 months
	Waited 60 months	66 months

Table 4.4: Decisions surrounding a subsequent pregnancy and actual inter-pregnancy interval

Four of the women with diabetes participants also worked in health care settings as a psychologist, a GP, a receptionist at a GP practice, and a midwife. As these participants signed up to take part in an interview as a woman living with diabetes, this was the focus during the interview.

4.3.6 Healthcare Professionals' Overview

Eighteen healthcare professionals participated in an interview from a wide range of professional perspectives, as summarised in Table 4.5.

	Healthcare Professionals (n=18)
Job Role	Diabetes consultant or endocrinologist = 4 Midwife = 3 Diabetes specialist midwife = 1 Baby loss specialist midwife = 1 Diabetes specialist nurses = 3 GP = 3 Obstetrician = 1 Clinical psychologist = 1 Diabetes dietician = 1
Years' experience	0-4 years = 4 5-9 years = 6 10-14 years = 3 11-15 years = 2 16-19 years = 2 20-24 years = 1
Types of diabetes treated	Type 1 and Type 2 = 12 Predominantly Type 1 = 5 Predominantly Type 2 = 1
Self-described gender	Female = 16 Male = 2
Ethnic background	White = 17 Asian/Asian British = 1
Location at time of interview	Northeast England = 9 London = 2 West Midlands = 1 East Midlands = 1 Yorkshire and Humber = 1 Southeast England = 1 Wales = 1 Northern Ireland = 1 Ireland = 1

Table 4.5: Healthcare professional participant overview

One healthcare professional disclosed personal experiences of baby loss, another had an experience of gestational diabetes in pregnancy, and one of the healthcare professionals had type 1 diabetes and disclosed personal experience of multiple baby losses. Although the interviews touched upon their personal experiences, the interview focused on their professional perspectives.

4.4 Ethics and consent

Ethical approval was granted by the Faculty of Medical Science Research Ethics Committee, part of Newcastle University's Research Ethics Committee, on 11th September 2020 (Appendix H).

4.4.1 Consent

The Newcastle University 'form builder' was used to create an online consent form (Appendix G). Compared to managing this process via e-mail, this proved to be a more efficient and secure way to handle the paperwork. A link to the online consent form was sent to participants when an interview was scheduled, and participants were requested to sign the consent form before the interview. The consent process involved answering a series of statements to which the participant had to give their consent. Participants gave their consent by completing and submitting the online form. A copy was automatically sent to the participant and the researcher after signing the form electronically. Participants were asked at the beginning of the interview whether they still gave their consent, which was audio recorded so it could be verified if required. Any participants who did not complete the consent form before the interview were required to go through the form with the researcher at the start of the interview.

The aim of gaining explicit consent to participate in an interview was to guard against inadvertent coercion and ensure participants were well-informed about the project aims and what was involved in participating. The Project Information Sheet (Appendix C) and Consent Form (Appendix G) made it clear that participation was voluntary, and participants could withdraw from the research at any time until analysis was complete, without giving a reason.

4.4.2 Privacy

Participant data were handled in compliance with the General Data Protection Regulations (GDPR) and treated with full confidentiality and anonymity - discussed in detail in the Data Management Plan (Appendix I). Particular attention was paid to ensuring data were kept securely, for example, data were stored on university drives with restricted access, and any files containing personal information were password-protected.

4.4.3 Harm and distress

It was sometimes a challenge to balance the need to provide key information about the research whilst retaining accessibility. I used a more formal approach to recruiting healthcare professionals, with more medicalised language. I used the university backdrop on the recruitment video to set a professional tone (link to recruitment video for Diabetes Specialist Nurses).

I worked closely with my collaborator, Sands, to ensure all communications, including the Project Information Sheet (Appendix C), recruitment materials (Appendices J and K), topic guides (Appendix L) and debriefing e-mails (Appendix M), were worded appropriately to minimise the risk of offending women with diabetes. For example, Sands suggested their users preferred the term ‘baby loss’ to ‘pregnancy loss’ or ‘perinatal death’. The more academic and formal approach may have been off-putting or even alienating for women with diabetes, so I made a more relaxed video with basic animations with the hope of being perceived as more approachable (link to recruitment video for women with diabetes).

To reduce the potential of causing undue distress, only women who had gone on to have a subsequent successful pregnancy were invited to take part. This was to mitigate the risk of further traumatising a participant who was currently trying to become pregnant after a baby loss - a time that can be filled with anxiety (Côté-Arsenault and Marshall, 2000; Hunter, Tussis and MacBeth, 2017; Wang *et al*., 2021). The semi-structured interview design meant the participant retained control over the topics they chose to discuss and the direction of the interview, which was an important aspect considering the sensitive nature of the research topic (DeJonckheere and Vaughn, 2019). At the start of the interview, the participant was reminded that they did not have to answer all of the questions if they preferred not to. A Sands representative suggested that interviews with women with diabetes should always begin by asking the participant to say a little about themselves and their experience of baby loss. Although my research focused on the inter-pregnancy interval and not on the experiences surrounding the baby loss, it was still important to acknowledge their baby.

I made every effort to ensure the interview process was as stress-free as possible and interviewed gently and sensitively. On two occasions, the participants became upset and cried during the interview. When this happened, I asked whether they wanted to pause the interview and return later or end the interview. On both occasions, the participant wished to continue, and I gave them the time and space that they needed. As a researcher, I was not able to counsel or provide advice. However, I ensured the debriefing email included a list of relevant organisations where the participant could receive further support (Appendix M).

I was also aware of the potential for the interview process to cause harm and distress to the researcher. Asking participants to reveal their most intimate and distressing experiences, whilst on the one hand can help researchers to gain an enhanced understanding of the research topic (Valentine, 2007), can take a heavy toll on the researcher (Corbin and Morse, 2003; Dickson-Swift *et al*., 2008) leaving them vulnerable to stress (Elmir *et al*., 2011; Dempsey *et al*., 2016). Researching baby loss presented a real risk of triggering 'vicarious traumatisation'. This is where the interviewer develops feelings of grief, fear and intrusive thoughts due to engaging empathetically with traumatised participants (Dunkley and Whelan, 2006). I was aware of this possibility and took steps to manage my emotional well-being and disengage physically and psychologically after the interviews. I established processes to facilitate self-care, such as scheduling time after the interview to decompress, restricting the number of interviews to two a day to allow time for reflection, keeping a research diary to process thoughts, and talking to a supervisor or supportive colleague after any difficult interviews (without compromising anonymity). Whilst at the time I was strongly committed to carrying out the research, in retrospect, I would not choose to conduct interviews on this subject again whilst also pregnant, as some of the stories I heard were deeply harrowing.

4.5 Data Collection: semi-structured interview

Participants were invited to take part in a one-off 45-60 minute semi-structured interview via remote methods (Zoom, Teams, Telephone), depending on the participant's preference. 'Calendly' was used to manage the sign-up of participants – this allowed the participant to view my availability and book an interview directly into my calendar.

Data were collected between 26th November 2020 and 13th July 2021. Interviews took place via the participants' preferred remote method, namely Zoom (n=10), Teams (n=11), Telephone (n=8) and Skype (n=1). Healthcare professionals tended to prefer Teams, whereas women with diabetes preferred Zoom, as outlined in Table 4.6. This suggested it is essential to offer participants a choice of the online platform.

Data Collection Method	*Healthcare professionals*	*Women with diabetes*
Zoom	3	7
Teams	11	0
Phone	4	4
Skype	0	1

Table 4.6: Overview of preferred interview method

The focus of both interview groups was on the inter-pregnancy interval, namely, the period between: (i) the postnatal review appointment following the loss of the baby and (ii) the first antenatal appointment in the subsequent pregnancy. Key aspects covered in the interviews included the impact of complex emotional events on satisfaction with care, interpretations of the reasons for the baby loss, and how best to support parents making decisions about a subsequent pregnancy.

Interviews with healthcare professionals ranged from 46 to 60 minutes in length, with an average length of 56 minutes across all interviews. Interviews with women with diabetes ranged from 44 to 65 minutes in length, with an average length of 59 minutes across all interviews. This length allowed for in-depth, nuanced and rich data.

During the interviews, a topic guide (Appendix L) was used as a prompt and aide-mémoire rather than a rigid schedule. I wanted to 'give voice' to the participants and ensure they had ultimate control over the topics discussed. In Goffmanian terminology, I saw my researcher's role as a "wise listener", showing solidarity and empathy (Goffman, 1963, p. 41). I was conscious of the power dynamic between myself and the interviewee and how intimidating it may have been for women with diabetes. However, using remote methods was arguably a more empowering experience for the interviewee, as they did not have to invite an 'expert' researcher into their home and could end the interview at a click of a button (Hanna and Mwale, 2017). The topic guides differed for healthcare professionals and women with diabetes. The focus of the research remained the same throughout data collection. The interviews with both groups were mainly conducted concurrently with the intention that the findings from each group could be used to inform future interviews and for the topic guides to evolve as the study progressed, in terms of prompts used in response to themes and questions of interest that came to light during the data collection process, which was in keeping with the social constructionist underpinnings of my research and the belief that knowledge creation is a co-construction (Creswell, 2012) (Appendix N).

4.5.1 Research design: remote semi-structured interviews

Interviews are a widely used data collection method in health services research and there exists a wealth of information about conducting effective interviews (DeJonckheere and Vaughn, 2019; Pope and Mays, 2020). The semi-structured approach used in this research allowed the freedom to explore the topic in detail whilst maintaining the flexibility to discuss pertinent aspects and tailor questions to the context of each interviewee (DeJonckheere and Vaughn, 2019). Due to the sensitive nature of the research topic, semi-structured interviews were chosen as the most appropriate method of data collection, as opposed to a more structured approach, where there is potentially less opportunity to build rapport or explore emergent topics (DeJonckheere and Vaughn, 2019).

Although not a replica of a face-to-face interview, remote semi-structured interviews were the closest approximation of live in-person interviewing feasible in the circumstances. They drew on the same approach and principles of qualitative interviewing more generally. As participants were recruited online, it was appropriate to collect the data online (Hanna and Mwale, 2017). Participants commented on the convenience of participating online and found it easy to reschedule if required. This was a particularly important benefit for healthcare professional participants, who were sometimes required to reschedule due to work commitments and helped to ensure a good response rate.

Remote interviews have been criticised for lacking the intersubjective 'feel' and rapport gained from being in the same room as the interviewee (Hanna and Mwale, 2017; Roberts *et al*., 2021). However, not only was there no choice at the time, but I do not think this was a detriment to this research. Remote interviews are conducted simultaneously in 'private' and 'public' spaces, which allows participants a degree of distance from the researcher while maintaining the intimacy of a face-to-face interview (Hanna and Mwale, 2017). As such, remote methods may be particularly effective for covering sensitive and deeply personal topics, such as baby loss, that could be difficult or awkward to discuss in person (Hanna and Mwale, 2017; Sy *et al*., 2020).

4.6 Data Analysis

The lead researcher (ED) transcribed the first five interview recordings verbatim into a word document. A clerical officer did the initial transcription of the remaining interviews, which were then checked by the lead researcher, ensuring the lead researcher remained engaged with the data. The lead researcher anonymised all the documents, whereby names, locations and other identifying information were removed. The anonymised transcripts of the qualitative online interviews formed the data for the analysis. The iterative approach to data analysis, which occurred concurrently with data collection, meant data from both women with diabetes and healthcare professionals were analysed in tandem rather than separately. This approach to analysis, which subsequently influenced the presentation of the data (section 4.6.2), offered the opportunity to draw together the experiences of both groups, demonstrating tensions and nuances in the inter-pregnancy interval that may have been missed by analysing and presenting the data separately.

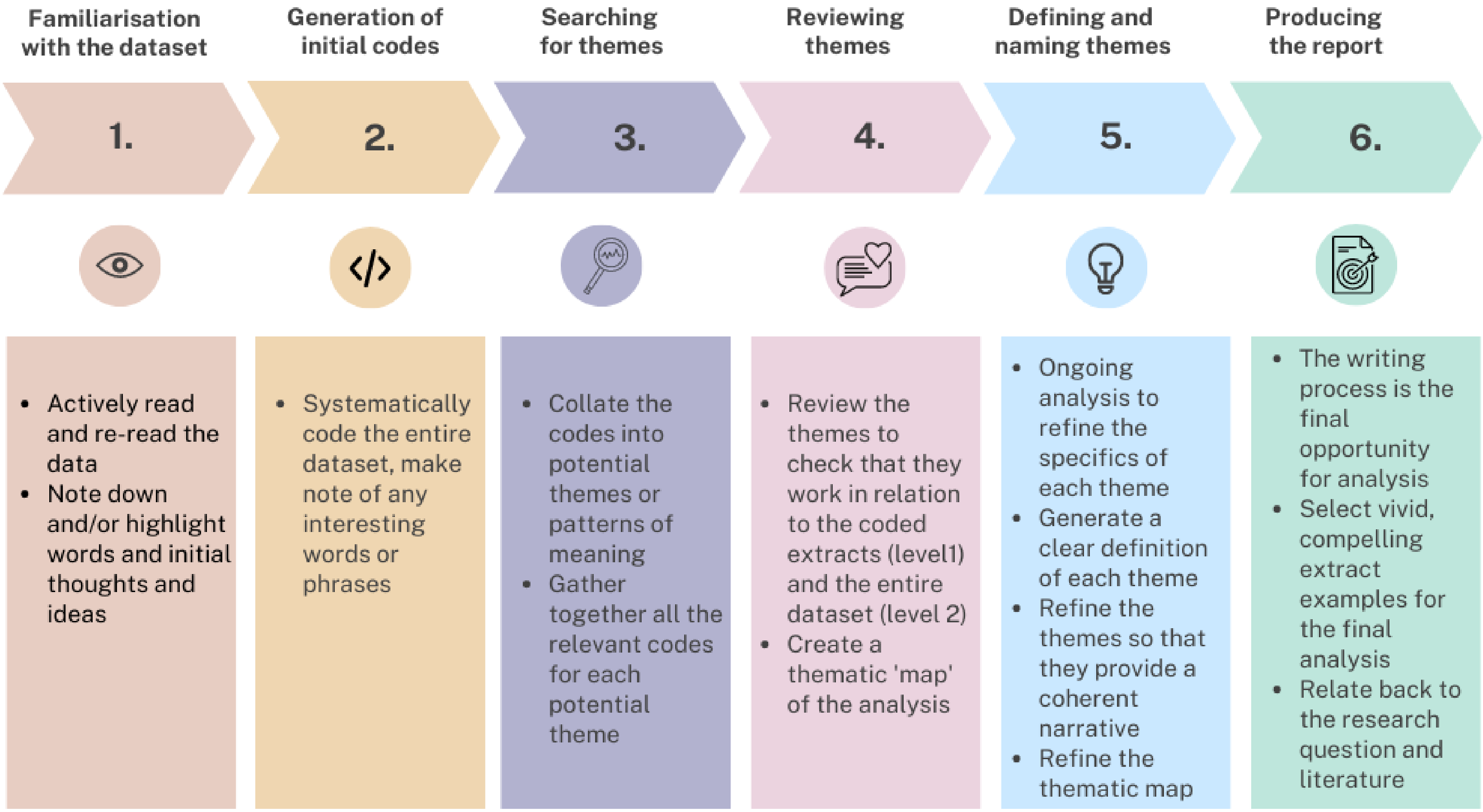
4.6.1 Approach to data analysis: reflexive thematic analysis

The data analysis was informed by social constructionism, as discussed in Chapter Three (sections 3.3.1 and 3.3.2). A central tenet to social constructionism is reflexivity and the researcher's role in analysis (Burr, 2003). Researchers using this approach are encouraged to acknowledge the influence of their subjective position and biases on the research findings and engage in critical self-reflection to ensure the findings were as transparent as possible (Burr, 2003). To achieve this, Braun and Clarke's (2019) Reflexive Thematic Analysis (RTA) was identified as a particularly suitable approach to data analysis.

RTA was recently developed in response to the critique that Braun and Clarke's earlier Thematic Analysis approach (2006) was incompletely defined, poorly understood and open to interpretation (Byrne, 2021). Although RTA follows the same iterative process as Thematic Analysis more generally, the RTA approach is more explicit about how data analysis should be implemented and understood (Braun and Clarke, 2019), and is designed for conducting thematic analysis within a fully qualitative paradigm (Morgan, 2022). Unsurprisingly, criticisms of an RTA approach are similar to criticisms leveraged at qualitative approaches more generally, whereby it is not possible to meet the ideals of more positivistic scientific enquiry, where quantitative methods are deemed more reliable (Morgan, 2022). For example, the subjective nature of RTA means it is not possible to replicate the study, and the findings are vulnerable to researcher bias, which affects the validity, rigour, or 'trustworthiness' of the findings (Roberts, Dowell and Nie, 2019).

In contrast, RTA requires a reflexive researcher, who endeavours to reflect on their assumptions and the impact such assumptions have on their analysis (Braun and Clarke, 2021b, 2021c), which is in keeping with the constructionist approach used in this research, as discussed in Chapter Three (section 3.3.2). Indeed, a defining feature of RTA is that it emphasises and embraces the researcher's active role and subjectivity in knowledge production (Braun and Clarke, 2019, 2021b, 2021c; Byrne, 2021) rather than viewing it as a threat to knowledge production (Braun and Clarke, 2019, 2021c). RTA acknowledges that themes are generated by "considerable analytic and interpretive work on the part of the researcher" (Braun and Clarke, 2021b, p. 39) through an engagement with the dataset that is mediated by the researcher's values, skills, training, and experience (Braun and Clarke, 2021a). As such, RTA was an appropriate method of data analysis for this research, as it combined influences from both the interpretive paradigm and pragmatism, whilst remaining ‘theoretically flexible’ regarding the theory that framed the research (Braun and Clarke, 2019, 2021a, 2021c; Byrne, 2021), and so fitted well with social constructionist approach, whereby subjectivity and reflexivity were embraced (Alderson, 1998; Lincoln, Lynham and Guba, 2011).

Responses from the open-ended interviews were coded and analysed using Braun and Clarke’s (2019) RTA approach, which builds on the six, iterative steps used in Thematic Analysis (Braun and Clarke, 2006) summarised in Figure 4.3 and discussed in further detail below.



1. Familiarisation with the dataset

- Actively read and re-read the data
- Note down and/or highlight words and initial thoughts and ideas

2. Generation of initial codes

- Systematically code the entire dataset, make note of any interesting words or phrases

3. Searching for themes

- Collate the codes into potential themes or patterns of meaning
- Gather together all the relevant codes for each potential theme

4. Reviewing themes

- Review the themes to check that they work in relation to the coded extracts (level1) and the entire dataset (level 2)
- Create a thematic 'map' of the analysis

5. Defining and naming themes

- Ongoing analysis to refine the specifics of each theme
- Generate a clear definition of each theme
- Refine the themes so that they provide a coherent narrative
- Refine the thematic map

6. Producing the report

- The writing process is the final opportunity for analysis
- Select vivid, compelling extract examples for the final analysis
- Relate back to the research question and literature

Figure 4.3: Summary of Braun and Clarke's (2006) six-step phases of thematic analysis

Stage 1 of data analysis, familiarisation with the dataset, took place concurrently with data collection (November 2020-July 2021). This allowed me to explore emergent ideas as and when they arose and incorporate them into the ever-evolving topic guide (Creswell, 2012; Dicicco-Bloom and Crabtree, 2006). Conducting ongoing analysis in this way enabled me to identify when 'meaning saturation' was reached (Hennink, Kaiser, and Marconi, 2017), signalling the end of the recruitment phase.

Stages 2 and 3, generating codes and searching for themes, took place between July-September 2021. The entire dataset was coded by the lead researcher (ED) using the qualitative data analysis software, Quirkos – a relatively new software package designed to facilitate the analysis of qualitative data (Quirkos 2.4.2, 2021). Although not without their criticisms, such as concerns about researchers being distanced from the data, or straightjacketed by the functionality of the software (St John and Johnson, 2000), software designed for qualitative data analysis (for example, NVIvo, Atlas.ti, Quirkos) are helpful systems for managing and exploring large amounts of data (Gray, 2018; St John and Johnson, 2000). With Quirkos, the coded data were represented as 'bubbles' on the screen (Appendix O). The 'bubbles' increase in size in line with the frequency of the codes that appear in the data. The colour of the bubbles can be changed, and the researcher can 'play' with data by moving the bubbles around to see how the codes might fit together to form themes. I found the interface flexible and intuitive to use, and it allowed me to fully immerse myself in the data, facilitating the formation of the themes.

Codes, both semantic (explicit, overt) and latent (implicit, underlying) were used to represent my interpretations of patterns of meaning across the dataset (Braun and Clarke, 2021b, 2021c; Byrne, 2021). The codes were collated to identify initial themes, which can be thought of as 'analytic outputs' from the coding process (Braun and Clarke, 2019). Themes do not passively emerge from the data, as if they were waiting to be found by the researcher (Braun and Clarke, 2019). Instead, themes are actively generated by the researcher and require considerable analytic work and reflection (Braun and Clarke, 2019). The themes were presented to my supervisors and discussed at four data meetings (1st February 2021, 30th April 2021, 19th August 2021 and 10th September 2021). Appendix P contains some photographs from the early stages of thematic development.

Stages 4-5, reviewing and defining themes, took place between July-October 2022 (I was on maternity leave September 2021-June 2022). The wording of the themes and the thematic map were collectively agreed upon by the lead researcher, three supervisors and a representative from Sands at a data meeting on 18th October 2022.

Stage 6, producing the report, took place between November 2022 and July 2023.

4.6.2 Presentation of the analysis

The complexity of the topic meant that the data generated a complicated range of themes. To help unravel the complexity, three levels of analysis are presented:

1) Analysis part one: three descriptive themes that represent the semantic, or explicit codes from the data, and capture the barriers faced by women with diabetes in the inter-pregnancy interval.

2) Analysis part two: three explanatory themes, that represent the latent codes, where theory (liminality, biomedicalisation and neoliberal strategies of responsibilisation) was used to help further interpret the data.

3) Analysis part three: a synthesis of the data using a stigma syndemics framework to shed light on the many tensions that lie between experiencing a baby loss, living with diabetes and preparing for a subsequent pregnancy.

Using the stigma syndemic framework to synthesise and further discuss the themes from the first two stages of analysis ensured the findings were both inductive and deductive, as I wanted the findings to be driven by the data, not just theory-driven. This is in keeping with the analytical approach of RTA, whereby the aim is to “produce insights into the meaning of the data that go beyond the obvious or surface-level content of the data to notice patterns or meaning that link to broader psychological, social or theoretical concerns” (Braun and Clarke, 2013, p. 204).

When the three layers of analysis are viewed, layered together, it can be seen how women with diabetes face the perfect storm when they are involuntarily thrust into the inter-pregnancy interval after a baby loss.

4.6.3 Presentation of the data

It was important to incorporate the participants' own words into my research, both to 'give voice' to the participants and illustrate my own thinking behind the interpretation of the data (Morgan, 2022). To protect the participants' identities, names and demographic information were omitted from quotes. Instead, quotes were provided alongside a code and general information about the type of diabetes and experience of baby loss (for example, WWD1 type 1 diabetes early miscarriage) or healthcare professional role (for example, HCP1 Diabetes Consultant) (Appendix Q).

Participant quotes are provided in most parts verbatim, although any unnecessary verbal 'tics', such as "like", "you know", "erm", or words or phrases that might compromise the location of the participant were removed. Quotes presented with ellipses within square brackets […] indicate that part of the quote has been redacted, in the most part to shorten the quote and improve the flow and readability, for example, if the participant drifted off-topic or repeated words. Quotes presented with words within square brackets indicate that the word has been changed or added by the researcher, either to protect the participants' anonymity, improve the readability of the quote, or provide context.

4.7 Methodological approach to data collection and analysis

Qualitative research tends to be characterised by its inductive nature, emerging organically, and being shaped and influenced by the researcher's subjective experience during data collection and analysis (Creswell, 2012; Morgan, 2022). Broadly speaking, qualitative research involves collecting textual and textural data, such as words, pictures, or sounds (Kara, 2017). It is a particularly valuable method for exploring patients' experiences of gain and gaining insight from healthcare professionals regarding events and behaviours (Pope and Mays, 2020). I aimed to obtain a rich and holistic understanding of the inter-pregnancy interval by interpreting and contextualising the data to gain in-depth insights into the specific phenomena (Gray, 2018). Given the limited existing research on the inter-pregnancy interval and the experiential perspectives of women with pre-existing diabetes and healthcare professionals who care for this group, a qualitative approach was deemed the most appropriate method to address the research questions and fill the knowledge gaps.

Despite the widespread use of qualitative research in health research, there is a persistent critique that the findings fail to have demonstrable impact on practice (Sandelowski and Leeman, 2012). This may be in part because the knowledge generated through qualitative research is considered less valid and reliable than quantitative methods by some due to its departure from a more traditional scientific or 'positivist' methodology, representing a different philosophical standpoint (Gray, 2018; Kara, 2017). Qualitative methods are criticised for their inability to claim objectivity, truth, or reality, which are central tenets of traditional scientific enquiry (Gray, 2018). However, as both qualitative and quantitative methods rely on similar epistemological underpinnings, there is an ongoing debate in the social science methods literature that argues for an 'end to the paradigm wars' (Bryman, 2008) because there is a 'false divide' between the two broad approaches (Bryman, 1984; Goertz and Mahoney, 2013).

Nevertheless, qualitative research offers a powerful analytical approach, and aligns with the social constructionist theoretical approach used in this research, as discussed in Chapter Three (section 3.3). Rather than seeking to discover an objective reality or truth, this research aimed to explore and gain a better understanding of how the inter-pregnancy interval was experienced by different individuals, embracing the notion of multiple, subjective, socially constructed realities shaped by personal lives and lived experience (Conrad and Barker, 2010). This qualitative research was grounded in the firsthand accounts of the participants, enabling knowledge to be constructed from the ground up (Creswell, 2012). Establishing a rapport with the participant was crucial during the interviews as it encouraged free communication and facilitated a deeper understanding of the topic, which was essential for addressing the research questions (Dicicco-Bloom and Crabtree, 2006; DeJonckheere and Vaughn, 2019). Semi-structured interviews allowed me to explore the multiple realities and perspectives of both women with diabetes and healthcare professionals. The rich data generated through these interviews aligned with the philosophical assumptions and theoretical framework as discussed in Chapter Three, and complemented the chosen method of data analysis (reflexive thematic analysis) to provide "conceptual coherence" (Braun and Clarke, 2013; 2022, p. 167).

A social constructionist approach allowed me to interrogate some of the 'taken for granted' assumptions (Burr, 2003; Conrad and Barker, 2010) surrounding diabetes, baby loss and preparing for subsequent pregnancy. As a result, the research findings illuminated how diabetes, baby loss and the inter-pregnancy interval have been constructed by biomedicalised and neoliberal ideologies, in three main areas, as outlined by Conrad and Barker (2010). Firstly, a social constructionist approach highlighted how diabetes and baby loss are not purely biological processes, but imbued with cultural meaning that arise from social processes which can lead to stigmatising processes. Secondly, the experience of diabetes and baby loss are socially constructed by the individuals. They are not passive actors but are actively engaged in their illness and construct their lives around their experiences actors. Thirdly, the generation of medical knowledge can exacerbate existing social systems of inequality. For example, a recent research finding demonstrated that type 2 diabetes can potentially be reversed by following a strict calorie-controlled diet, as discussed in Chapter Seven (section 7.6.3).

In summary, the flexible and reflexive approach employed in this research allowed the research questions and topic guide to evolve throughout the data collection process, resulting in an increasingly detailed and nuanced knowledge of the topic during data analysis (Dicicco-Bloom and Crabtree, 2006; Creswell, 2012). The following sub-sections provide my reflections as the researcher on the approach employed in this research.

4.7.1 Researcher reflections

As touched upon already, reflection was an important aspect of the research design. Keeping a research diary throughout recruitment and interviewing helped me to process my thoughts and captured some of the challenges that I faced along the way. For example, the excerpts from my recruitment diary presented in Appendix R highlight how I overcame some of the issues I faced early on during the recruitment stage.

By reflecting on my role as researcher, and considering how my individual circumstances, background, assumptions and experiences shaped and influenced the research and its findings allowed me to be more transparent about the interpretation of the findings (Braun and Clarke, 2019, 2021b, 2021c; Byrne, 2021; Pope and Mays, 2020). As a mother of a young child, and pregnant with my second child throughout the majority of the interview process, I could easily identify with the parents that I interviewed, in terms of what it might mean to experience a baby loss. I also live with an incurable and 'serious chronic disorder' (although not diabetes), which meant my pregnancy was considered 'high risk'. It could be argued that there was a risk for researcher projection, where my own experience affected the findings (Berger, 2015). However, although I had some insight into personally experiencing a highly medicalised pregnancy and the additional anxiety and vulnerability this provoked for myself, on reflection, my personal experiences were not comparable to those of the participants, so I do not think there was risk of over-identification in this research (Berger, 2015).

As suggested by Braun and Clarke (2013) I considered my strategy of personal disclosure ahead of the interview process. It felt unfair to ask participants to share their most intimate experiences without sharing anything about myself in return (Oakley, 1981), so I answered any questions honestly. I chose not to disclose my pregnancy to participants. The remote methods of data collection meant that my burgeoning pregnancy was not immediately obvious to participants, and I chose not to make this explicit as I did not want participants to censor their responses for fear of upsetting me.

I found it interesting that some participants assumed that I was only carrying out this research because I had personal experience with the research topic. Goffman refers to this as being a 'native', someone "who really knows" what it is like for the group (Goffman, 1963, p. 36). Some participants seemed disappointed when they discovered this was not the case. This made me feel somehow guilty, or a fraud, that I did not have personal experience of diabetes and my pregnancy experiences had not been as traumatic as those of the participants. However, my philosophical stance would suggest this did not mean that my interpretation of the data was any less valid as I sought to explore a variety of views from a range of individuals, rather than claim that the findings constituted a universal truth (Alderson, 1998). Even had I personally experienced living with diabetes and baby loss, then my experience and subjective reality would be different from the participants' experiences. In many respects, this meant I was able to view the data without having to disentangle my personal experiences, and so it was possible to offer a complementary perspective and understanding.

As a novice researcher, I was conscious of my inexperience in conducting interviews and worried about asking the 'wrong' questions or inadvertently offending someone. I took five key steps to improve my confidence and help overcome some of my worries. Firstly, I sought feedback on my topic guides from my collaborators, Sands. This was a helpful process in terms of questioning my prior assumptions (for example, about preparing for pregnancy), the order of questions and the wording. Secondly, I attended online bereavement training through Sands which helped me to prepare mentally and practically for handling the difficult and sensitive topic of baby loss. Thirdly, I piloted my interview topic guides with two friends – one a GP and another who had experienced a miscarriage a year earlier. I further piloted my topic guide with two women with diabetes who did not meet the inclusion criteria (they lived outside of the UK) and a healthcare professional who did not want to take part in an interview but was keen to discuss my research. The pilot interviews allowed me to test out and familiarise myself with the topic guides, ensuring I was comfortable navigating them during the interview process (DeJonckheere and Vaughn, 2019; Sampson, 2004). Fourthly, I reflected in my research diary at the end of each interview, using the following prompts: general reflection; what I think I did well; what I think I could do better; first thoughts; and actions. Reflecting in this way improved both my confidence and interview technique over the course of the interviews and proved a useful tool for recording my reactions and changing interpretations from what I witnessed during the interviews (Pope & Mays, 2020). Lastly, I strategically planned for the first interviews to be with healthcare professionals, who were less likely to become distressed. I went on to conduct interviews with both groups in parallel which allowed me to incorporate themes and questions into the topic guide as I went along (Dicicco-Bloom and Crabtree, 2006; Creswell, 2012).

4.7.2 Reflections on recruiting and collecting data remotely

Although remote methods have slowly gained traction in social science and health research, they were considered a novel approach when this research was conducted, and much of the discourse surrounding remote methods of data collection has retained a tone of compromise whereby they are viewed as inferior version of face-to-face approaches (Keen, Lomeli-Rodriguez and Joffe, 2022). The nationwide lockdowns enforced in response to the COVID-19 pandemic resulted in what has been described as a 'digital revolution' in research (Hantrais *et al*., 2021) with video calls becoming an accepted norm for communication, practically overnight, both for healthcare professionals and women with diabetes. The pandemic meant that people were more accustomed to using video conferencing platforms. This has necessarily altered the nature of health services research as remote interviews as a data collection method have since been rapidly adopted (Nind, Coverdale and Meckin, 2021). The high response rate suggests that recruiting and conducting online was successful. Remote methods of data collection will undoubtedly become a conventional method for health services research going forward. The following sub-sections consider the strengths and weaknesses of remote data collection.

4.7.3 Strengths of remote data collection

Collecting data using remote methods had numerous benefits for the whole data collection process, as I reflect upon in this sub-section:

1. **In terms of recruitment:** a significant benefit of using the internet to recruit and interview participants was that the sample was not geographically restricted (Deakin and Wakefield 2013; Keen, Lomeli-Rodriguez and Joffe, 2022). The sampling frame was broad and included all of the UK and Ireland. This proved a fruitful strategy in providing a variety of willing participants with a wide range of experience and expertise.

   I could strategically target specific groups. For example, I could adapt the recruitment videos to target a particular group of healthcare professionals and make sure my message was clear and relevant to the target group.

2. **In terms of scheduling interviews:** It was straightforward to sign-up and schedule an interview, and the remote methods facilitated a streamlined 'paper trail'. All participants commented on how easy they found the process, reflected by the high response rate.

   Remote methods offered greater flexibility in conducting interviews outside of standard work hours using a platform of the participants' choosing (Deakin and Wakefield, 2013; Keen, Lomeli-Rodriguez and Joffe, 2022). The ability to conduct interviews in the evening seemed particularly beneficial for the women with diabetes participants, whereas healthcare professionals tended to prefer a lunchtime slot.

   Remote methods made it extremely easy to schedule and *re-schedule* interviews (Keen, Lomeli-Rodriguez and Joffe, 2022). Participants were invited to select their preferred method and a convenient time. Re-scheduling interviews caused minimal disruption as I had not travelled (Deakin and Wakefield, 2013). This was a key benefit with regard to interviewing healthcare professionals, as they were sometimes required to cancel at the last minute.

3. **In terms of conducting interviews safely**: Collecting data remotely allowed me to overcome some inherent challenges of organising and conducting face-to-face interviews in terms of identifying a mutually convenient and safe place to conduct the research, which would also have taken a lot of time to plan and organise.

   Remote methods meant that I did not have to worry about my personal safety as I would have had to do with in-person interviews, for example, when conducting interviews in people's homes (Deakin and Wakefield, 2013; Keen, Lomeli-Rodriguez and Joffe, 2022). It was easy to withhold my number when making phone calls and make myself safely discoverable online. Participants could partake in interviews from the comfort of their homes, but without the potential discomfort of inviting a researcher into their home. Interviewing in a 'private' space was a specific benefit for the women with diabetes[2] who were discussing an extremely sensitive topic with an unfamiliar researcher. Video calls, in particular, provided a space that was simultaneously 'private' and 'public' and had the potential to lessen any feelings of intimidation and maintained a certain level of privacy (Hanna and Mwale, 2017). Conducting remote interviews allowed me to maintain a level of 'empathetic distance' whilst engaging with participants (Valentine, 2007), which can be more difficult in a face-to-face setting (Elmir *et al*., 2011).

   Remote methods provided greater control for the participant, as I gave them a choice regarding the preferred platform. This may have helped participants to feel more comfortable responding to the questions in the interview. Arguably, the participant had more control over their participation than in a face-to-face interview, as they could have terminated the interview at the click of a mouse without feeling the same amount of

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[2] It is important to acknowledge that whilst home is a safe and private place for many women, not all women live in 'safe' spaces. As such, interviewing remotely from home might not be a specific benefit to all women, for example, those who live in the context of domestic violence.

pressure and obligation they may have felt from sitting opposite a researcher (Hanna and Mwale, 2017).

Remote methods also provided ease of data capture in terms of being able to discreetly record the interview, which may have helped to reduce any intimidation from having the recording equipment on show, as with in-person interviews (Hanna and Mwale, 2017).

4. **In terms of resources**: Remote methods were more resource efficient in terms of time and money by not having to travel nationwide to conduct face-to-face interviews (Deakin and Wakefield, 2013; Keen, Lomeli-Rodriguez and Joffe, 2022). In hindsight, I would have struggled to travel extensively as I had a toddler at home, so I would have been unable to travel for extended periods and would have found it challenging to frequently be away from home.

4.7.4 Limitations of remote data collection

There are inherent limitations to any research method but here, the main limitations pertained to issues surrounding digital exclusion, technical issues, and engaging with the participants, as reflected in this sub-section.

The most significant limitation was related to issues surrounding digital exclusion or the 'digital divide' (Blank and Lutz, 2017; Roberts *et al*., 2021; Sy *et al*., 2020), whereby only those who had access to the internet and could afford the necessary equipment and internet connection could access and be included in this research, a concern generated about the internet more generally (Hargittai and Jennrich, 2016; Keen, Lomeli-Rodriguez and Joffe, 2022). This can create a sampling bias, whereby online research tends to attract those more technologically literate and is not representative of the broader population (Blank and Lutz, 2017; Hargittai and Jennrich, 2016). Even though I tried to recruit across a variety of platforms, this could have played a part in my ability to recruit women with type 2 diabetes, as women from "underrepresented racial and ethnic groups, and those of lower socioeconomic status tend to contribute to online conversations at lower levels" (Hargiatti and Jennrich, 2016, pp. 207-208). Interestingly, there were numerous Facebook groups for women with type 1 diabetes who had experienced baby loss, but none for women with type 2 diabetes who had experienced baby loss. This may reflect how women with type 2 diabetes have had less time to integrate into or develop a social network linked to their diabetes status, or could potentially have self-stigmatising connotations linked to self-exclusion.

Regarding technical issues, remote interviews were only effective with a stable internet or phone connection (Roberts *et al*., 2021). A poor connection affects the quality of data collection and can be frustrating for both parties as it can impede the flow of conversation. I mitigated this by discussing potential issues at the start of the interview, and there was a plan in place should the connection fail. For example, we agreed to try logging off and on again, and there was a backup plan to use an alternative method if required.

Another limitation of remote interviews is that building rapport can be more challenging, especially as it can be harder to accurately read body language via video call than in person and near impossible on the telephone. I sometimes found it difficult to read when the participant had finished talking, so there were occasions when we spoke over each other. A poor rapport can affect the data, as participants may feel less willing to speak freely (Keen, Lomeli-Rodriguez and Joffe, 2022). However, generally, I did not struggle to build a rapport with participants. Remote methods might make it harder to comfort participants should they become distressed during the interview (Keen, Lomeli-Rodriguez and Joffe, 2022), however, I did not personally find this to be the case in this research.

In summary, much of the discourse surrounding remote methods of data collection has retained a tone of compromise (Keen, Lomeli-Rodriguez and Joffe, 2022), however, in this research, given the context, the strengths of remote data collection far outweighed the limitations. There is scope for remote, digitalised methods to become a routine form of data collection in health services research (Keen, Lomeli-Rodriguez and Joffe, 2022), and not just an alternative or secondary choice for when face-to-face interviews cannot be achieved (Deakin and Wakefield, 2013). However, digital exclusion poses a particular challenge to researchers conducting research online.

4.8 Chapter summary

This chapter explained and justified the research design and methodological approach to this study. I provided details of the qualitative approach to data collection and analysis with a discussion of the strengths and limitations of this study design. Thirty participants, 18 healthcare professionals and 12 women with diabetes contributed over approximately nine months. Through conducting these interviews and the subsequent reflexive thematic analysis, I have constructed a rich and nuanced picture of how the participants experienced the inter-pregnancy interval from both a lived experience and a professional perspective. I have incorporated a reflexive account by considering my position as a researcher and how my personal experiences influenced the findings. I considered and addressed ethical concerns at each stage of the research process. I presented the strengths and weaknesses of the remote data collection method. The high response rate suggested that recruiting and conducting online was a successful approach and will undoubtedly become a conventional method for future health services research.

The next chapter is the first of three findings chapters that present and discuss the descriptive themes generated from data analysis.

Chapter 5. Analysis Part One - 'The inter-pregnancy predicament': descriptive findings and discussion from the thematic analysis

5.1 Introduction

The findings from the thematic analysis are presented across three layers (descriptive themes, explanatory themes and synthesis of themes) as set out in Chapter Four, section 4.6.2). This chapter (part one) presents the descriptive findings and discussion of the thematic analysis. There are three main descriptive themes: (1) Decisions around becoming pregnant after a baby loss; (2) The triple burden of baby loss, diabetes and preparing for pregnancy; and (3) Discontinuities and constraints in inter-pregnancy care.

5.1.1 An overview of the descriptive themes – the 'inter-pregnancy predicament'

The findings from each theme are presented in turn, followed by a discussion section to conclude the chapter. Figure 5.1 provides a visual overview of the descriptive themes and subthemes. All themes and subthemes reflect the voices of both women with diabetes and healthcare professionals from across the dataset. Quotes are used throughout to illustrate the findings. The arrows in Figure 5.1 demonstrate how the themes interact with each other, contributing to the complexity of the situation for women with diabetes in the inter-pregnancy interval after baby loss and before subsequent pregnancy.

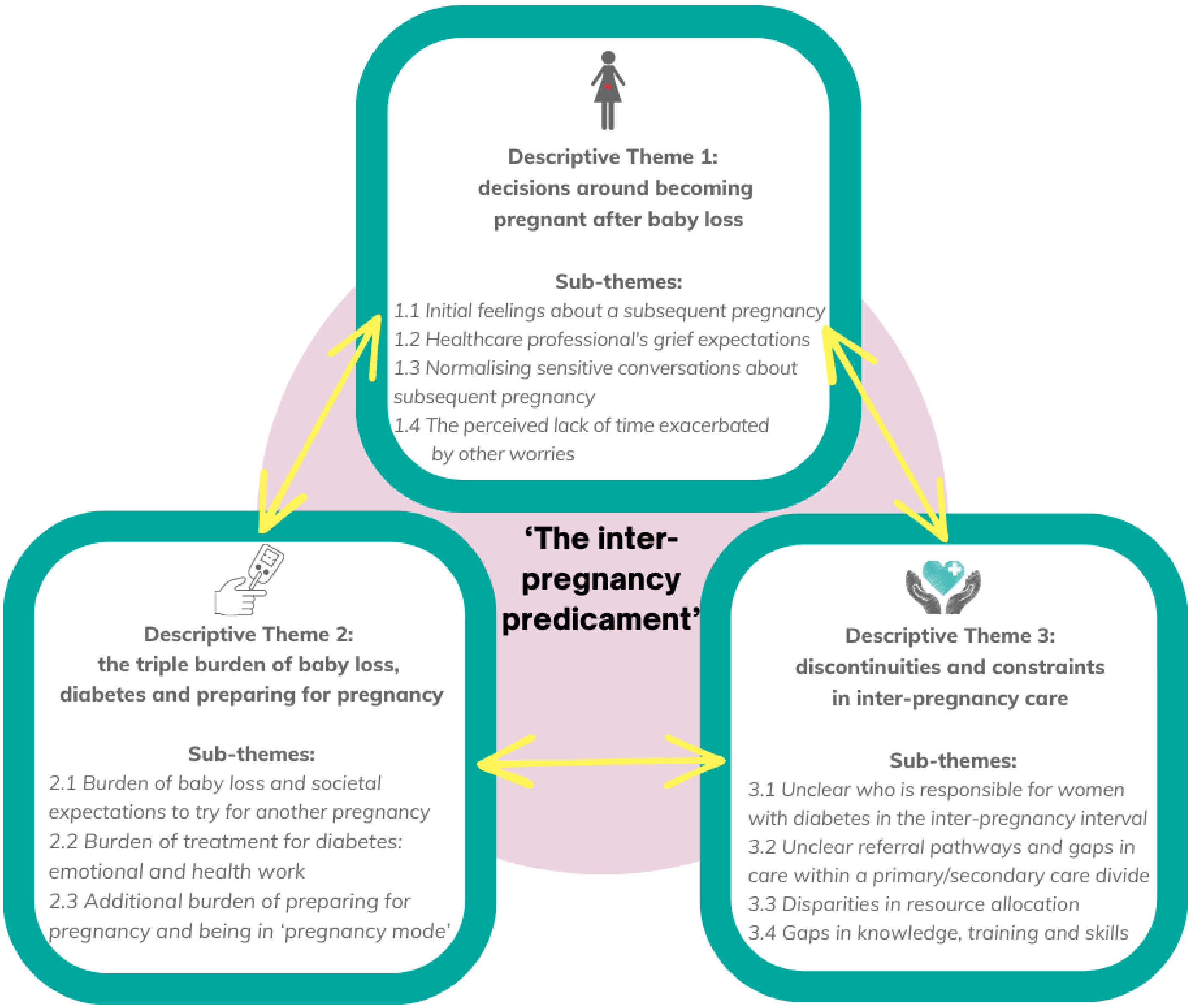

Figure 5.1: Visual overview of the descriptive themes and subthemes

The findings from the thematic analysis shine a light on the inter-pregnancy interval after a baby loss, an otherwise overshadowed part of a pregnancy journey. Navigating what participants report as being the bleak terrain of the inter-pregnancy interval is a challenge for women with diabetes and healthcare professionals alike. Women with diabetes, who already have individualised and sometimes complex healthcare needs, can face multiple, often hidden, obstacles to becoming pregnant after a baby loss. Gaps in knowledge, training and skills coupled with the discontinuities and constraints in healthcare and bereavement provision and a lack of referral pathways culminate in an inter-pregnancy interval that is experienced as precarious and challenging.

5.2 Descriptive theme 1: decisions around becoming pregnant after baby loss

The first descriptive theme represents participants' accounts of the time point directly after baby loss, prior to actively planning the timing of a subsequent pregnancy. This theme aims to reflect the initial thoughts about pregnancy after loss and the point at which pregnancy planning emerges in that context. During the interviews, healthcare professionals were asked to think about the care they provided to women who were in the inter-pregnancy interval and women with diabetes were asked to reflect on their experience of being in the inter-pregnancy interval.

5.2.1 Subtheme 1.1: Initial feelings about a subsequent pregnancy

All 12 women with diabetes interviewed knew straight away that they wanted to try for another baby at some point in the future. Ten of the 12 women with diabetes participants started trying for subsequent pregnancy within six months of all their baby losses. One woman with diabetes, who experienced a miscarriage and stillbirth with twins[3], waited one month after the miscarriage and 36 months after the stillbirths. One woman with diabetes waited about 60 months after a neonatal death before trying for a subsequent pregnancy. The actual inter-pregnancy interval between baby loss and subsequent pregnancies ranged from two to 66 months, with a median of seven months. However, of the 17 subsequent pregnancies after baby loss discussed, 14 had an inter-pregnancy interval of 12 months or less, and of these, eight inter-pregnancy intervals were

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[3] This participant was pregnant with triplets. Two of the babies were stillborn, and the third baby survived.

six months or less, as illustrated in Figure 5.2.

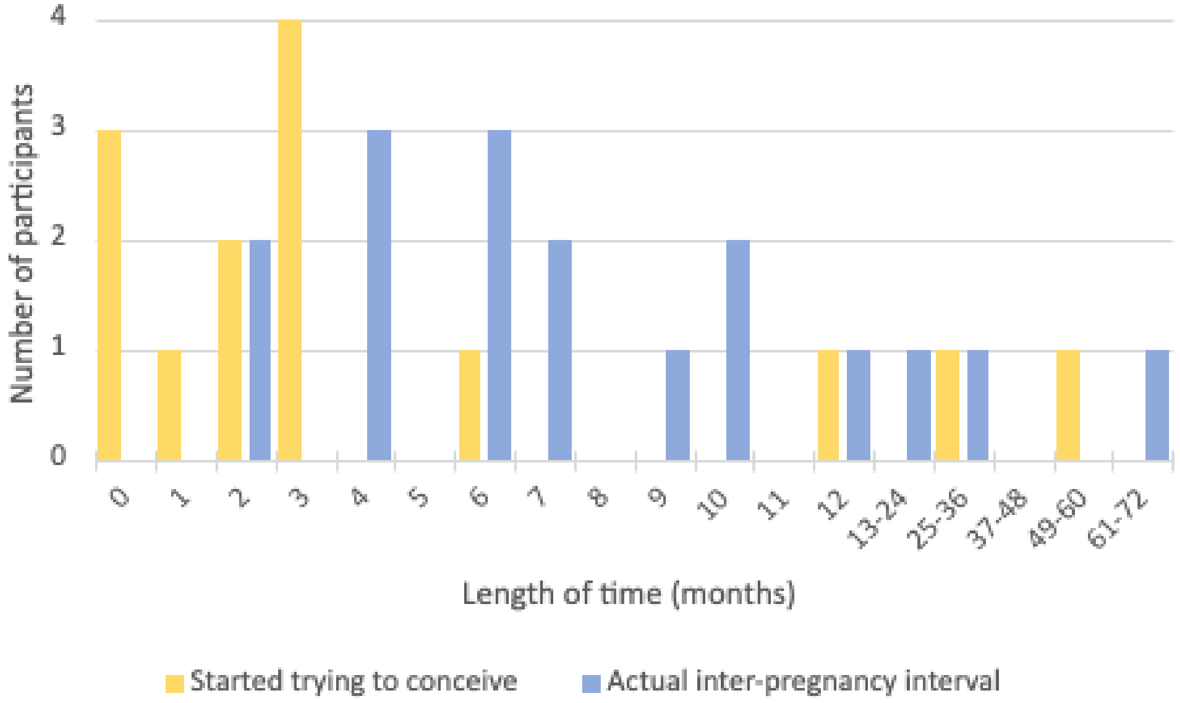

Figure 5.2: The length of time in months that women with diabetes started trying to conceive alongside actual inter-pregnancy intervals.

In terms of facilitating a conversation about a subsequent pregnancy, some healthcare professionals noted how following discharge from the hospital, there were not many routine opportunities for them to speak to women with diabetes after a baby loss, especially earlier losses. The six-week postnatal check-up was suggested by HCP5 and WWD4 as an opportunity to speak to women who had experienced a stillbirth or neonatal death.

5.2.2 Subtheme 1.2: Healthcare professional's grief expectations

In direct contrast to the finding that the women with diabetes participants knew straight away that they wanted to become pregnant again in the future, some healthcare professionals expected women with diabetes would need time and space to grieve before they could contemplate a subsequent pregnancy.

> *"I didn't ever bring [subsequent pregnancy] up and looking back I don't really know why, I guess I probably assumed that they wouldn't even be thinking about that yet."* HCP5 Midwife

> *"[Some women] are too busy […] dealing with the grief of that loss, and they have not got room in their heads for anything, even thinking about another baby."* HCP2 Midwife

Some women with diabetes were advised by healthcare professionals to wait a specified period of time before trying to conceive, to allow themselves time to grieve, heal emotionally and physically and also to allow time for post-mortem results. There were mixed reactions from the women with diabetes who were advised to wait, and even those who could see the benefits of waiting found it upsetting.

> *"I was quite upset about it at the time […] I didn't want to wait. I think I'd just got my head around the waiting thing and then found out I was pregnant again, so it was a roller coaster of emotions […] it's kind of like, 'who are you to tell me what I can do with my body and my future'."* WWD5 Type 1 Diabetes, Late Miscarriage

> *"We didn't know why he died so we had a full post-mortem which obviously took a while […] All I wanted was to bring a baby home, I'm not gonna lie to you. [The healthcare professional] said wait six months […] wait until we get the post-mortem reports back find out what caused this, to see if there's […] something what's happened […] that they can help prevent in future pregnancy. Or if there's something that I need to do before I get pregnant again."* WWD4 Type 2 Diabetes, Late Miscarriage

> *"I just thought oh I'm just going to carry on because I don't have time to wait six months before my HbA1c is down to whatever, I just need to get on with it, which is probably not a very good attitude but that's how I felt at the time."* WWD3 Type 1 Diabetes, Multiple Early and Late Miscarriages

A recurring theme was how hard it was to balance grief with the "yearning to have a baby" (WWD7) with medical advice to wait for a subsequent pregnancy.

> *"It was incredibly difficult [balancing the urge to be pregnant with allowing time to grieve] and I did think […] at some points that we might never be ready as a couple or a family to try that again or go through that."* WWD7 Type 2 Diabetes, Neonatal Death

5.2.3 Subtheme 1.3: Normalising sensitive conversations about subsequent pregnancy

Healthcare professional participants unanimously reported receiving little to no formal training on how to deal with sensitive situations and negotiate difficult conversations about pregnancy after loss – they learnt these skills on the job and hoped that they handled the situations well. As such, not all healthcare professionals felt comfortable discussing the baby loss and handling sensitive conversations about a subsequent pregnancy.

> *"I feel a bit better about it now because I've just got that bit more experience […] but when I first qualified and I was a community midwife I definitely wouldn't have felt comfortable having those discussions and I think actually […] I really wouldn't have known what to say. I definitely didn't have training on it and I think I would have probably found the whole thing quite awkward which probably sort of feeds in to the fact that I didn't bring it up."* HCP5 Midwife

> *"I would ask [about a subsequent pregnancy] because although you can't remove the possibility of it happening again you can get that woman's health optimised. So, I feel quite strongly that it shouldn't be ignored and we should be asking, and I'll probably say something like […] 'that must have been a very difficult time for you and this isn't easy to discuss, and you may not be ready to think about it yet, but do you feel able to talk about planning another pregnancy in the future?', something like that."* HCP11 Endocrinologist

There was a variation in response as to whether healthcare professionals knew about a prior baby loss, and it depended on which area the healthcare professionals worked and what systems were used. Some healthcare professionals had no way of knowing about a prior loss and would rely upon the women with diabetes bringing it up in a consultation.

> *"I wouldn't know unless they tell me cos their pregnancy notes are different from the normal notes we use. […] So, it depends on the patient, some patients would bring it up others wouldn't."* HCP8 Diabetes Consultant

> *"It's not obvious on their diabetes record unless it's been specifically put in there […] The short answer is, no, you've got no way of knowing they've had a previous pregnancy loss."* HCP11 Endocrinologist

There were inconsistencies across the different types of losses. For example, HCP7, a GP, would be informed about a later loss, such as stillbirth or neonatal death, but was unlikely to know about earlier losses, such as miscarriage, and commented on the potential this had to damage the doctor-patient relationship:

> *"If a woman came in and has a reasonable assumption that one part of the health service talks to another and they […] make reference to [the miscarriage] […] And you look at their notes and then look at them a bit blankly because you haven't got a clue because there's nothing. Their assumption that you knew […] it damages their faith in the health service a little bit when something like that can be so unimportant that one part of the health service hasn't bothered to inform another about it."* HCP7 GP

The healthcare professionals largely found asking women with diabetes about a subsequent pregnancy to be a difficult conversation to negotiate as there was the potential to offend, and so in some cases, tended to wait for the women to initiate the conversation.

> *"I think you have to put it in their court. You can't suddenly go, 'ooh what about the next one? Let's just say goodbye about that one', and all those horrible sayings, 'oh it was never meant to be', or, ' it will happen again.' All those things are just insensitive, this woman is broken."* HCP16 Diabetes Specialist Midwife

The women with diabetes participants in this research tended to welcome the opportunity for a sensitive conversation about future pregnancy plans, but they would not always feel comfortable initiating that conversation themselves, as it felt "a bit odd" telling healthcare professionals about their intention for a subsequent pregnancy (WWD9).

> *"I'm not really superstitious but do you want to tempt fate by talking to somebody saying, 'I want to get pregnant' […] 'this is what I want to do,' or do you just think, 'let's just go for it and just see what happens.' Again, could just be me, but the idea of having that conversation with my GP, it would never have happened, never. I'm not a very good patient in that respect."* WWD3
> Type 1 Diabetes, Multiple Early and Late Miscarriages

Likewise, some healthcare professionals found their patients were "remarkably receptive" (HCP12) to talking about a subsequent pregnancy.

> *"Quite often […] they come back to that appointment pregnant so usually that's what they're thinking about, and that's really interesting."*
> HCP12 Obstetrician

A number of women with diabetes spoke about how they would have appreciated it if a trusted healthcare professional could have "taken the lead" (WWD4) to reach out just to ask, "how are you doing?" (WWD4). That the simple act of opening-up the conversation to see whether there was any additional support that could be offered would have been helpful.

As evident in subtheme one, the women with diabetes participants knew soon after the baby loss that they wanted to try for another pregnancy. So, for the conversation to be timely, it may be required shortly after the baby loss. However, participants reported that conversations about subsequent pregnancies were not normalised and were not necessarily initiated by healthcare professionals.

> *"The consultant had said, 'I hope to see you in future pregnancies' […] Thinking about it now [the next pregnancy] should have been [mentioned] but at the*

> *time it wasn't [and] maybe it should have been."* WWD6 Type 1 Diabetes, Late Miscarriage

WWD6 was not provided with any advice or information about a subsequent pregnancy during the inter-pregnancy interval and the conversation was closed rather than left open. Preparing for pregnancy was not mentioned, and WWD6 was advised that only when they were actually pregnant would they be able to access support.

There were examples of good practice, for example, HCP18 commended how the consultant they worked with handled difficult conversations about pregnancies:

> "*One of our consultants does it quite nicely cos he'll say to women, 'where are you in your life journey?' and then that sort of opens the conversation as to where they are and what we're thinking of."* HCP18 Diabetes Specialist Nurse

Other healthcare professionals tried not to "put women on the spot" (HCP11) by trying to frame questions about pregnancy unobtrusively:

> *"So as not to put any pressure on the woman […] I'm trying not to put them on the spot […] [I] do a lead in that says, 'I ask everyone this question, you don't have to share anything with me if you don't want to, but I just want to check for the record, are you on any contraception, or are you thinking about having a family?' So that's normally how I do it."* HCP11 Endocrinologist

> *"So, I say right at the very beginning of that follow up […] 'my plan [today] is to discuss what happened in the pregnancy and your test results and then what we do would do in future pregnancies'. And so, if they didn't want to discuss that, then […] they can say, 'well, actually, I don't want to discuss the future yet', and so I tend to do that as a kind of opening gambit to structure the consultation right at the very beginning."* HCP12 Obstetrician

A strong theme for both women with diabetes and healthcare professional participants was how a trusting relationship made it easier to have a sensitive discussion of pregnancy plans after a baby loss, especially in the context of high-risk pregnancies. Healthcare professionals spoke about continuity of care with such passion that it was clear that they cared deeply about their work and looking after their patients.

> *"I think that consistency of advice and that one person to talk to and that continuity really, really helped."* HCP12 Obstetrician

> *"I think women need it […] when there's a higher risk they need somebody that they've got a point of contact with and that they can have that continuity with. I think that's really important."* HCP16 Diabetes Specialist Midwife

> *"Probably the most useful thing we have there again is continuity and trust and the hope that […] they'll see us as friendly forces and be a bit more open to engaging with health care services."* HCP7 GP

Women with diabetes also tended to see the benefit of continuity of care.

> *"I really saw the benefit of [continuity of care] just seeing one person and they know your history and it's easy, she used to remember me. So, I didn't really have to go and explain everything."* WWD9 Type 1 Diabetes, Stillbirth

> *"I had the number of the diabetes midwife […] she was amazing, […] I dealt with her in both my pregnancies plus the in-between period. She was really great and I had her number on my phone."* WWD10 Type 1 Diabetes, Early Miscarriage

Some healthcare professional participants talked about how women with diabetes were more likely to talk candidly about their pregnancy intentions when there was a rapport between them, thus enabling them to proactively help women with diabetes "with some of the practicalities" (HCP11) of preparing for pregnancy:

> *"I'll start them on their full dose folic acid and organise a prescription even if it's well, even if their plans are well ahead, I try and do that pro-actively."* HCP11 Endocrinologist

However, HCP6 highlighted how not all women with diabetes may want to see the same healthcare professional after experiencing a baby loss.

> *"Who that conversation is with depends on the person and their relationship with those healthcare professionals and what happened last time. Because if they saw a whole pregnancy through with a midwife they might be keen to talk to her because they might be very close to her or that might be too traumatic because seeing that midwife is just a reminder of the baby that they lost. So, you know, it's really variable."* HCP6 GP

HCP12 spoke about trying to forge a doctor-patient relationship as "a partnership" where everyone is "working together for the same outcome" (HCP12).

> *"Quite a lot of women get quite anxious coming to clinic, and that they're […] going to get told off […] I reframe that in that what would we do differently next time, actually what would we do as a team […] how would we get you into the optimal position to be pregnant again."* HCP12 Obstetrician

5.2.4 Subtheme 1.4: The perceived lack of time exacerbated by other worries

The decision to try to become pregnant again was further complicated for many of the women with diabetes who had other considerations on top of their diabetes. Increasing age was a recurring theme and made women with diabetes feel like they did not have much time to conceive, so they were apprehensive about waiting. For example, WWD2 felt like there was a "ticking clock" and worried that they would become too old to conceive or that their condition would only get worse:

> *"We were trying pretty much straight away. I'm 35 now, I'm 36 this year which feels like ancient in child-rearing age. I just feel like I've got a deadline, like a ticking clock. I feel like if I get past forty it's not gonna happen and obviously because I'm diabetic, I feel like it'll progressively get worse as I go on."* WWD2 Type 2 Diabetes, Neonatal Death

> *"Age is a factor as well. I was 32, then 35, then 38 when I had my children, so by the time you get to 35 and everyone's saying, 'oh it's a geriatric pregnancy', you're like, 'thanks'. It's not the most flattering term when you're only in your mid-thirties."* WWD12 Type 1 Diabetes, Early Miscarriage

As described by WWD1, other co-occurring fertility issues may add an additional layer of pressure on women with diabetes to try and become pregnant again as soon as possible:

> *"When we first found out we had some fertility issues, they were mostly on my husband's side […] but on my side, they said that my egg reserve was that of a 42-year-old, even though I was 31, so I was just constantly being like, 'oh my god, we have to hurry up!'. So, for me, if I could have been pregnant the day after I had a miscarriage, I would have been."* WWD1 Type 1 Diabetes, Early Miscarriage

Not knowing how long it would take to conceive or whether the subsequent pregnancy would be 'successful' made some women try sooner than they might otherwise have.

> *"We were not expecting for it to happen so quickly. The first one took a year and a half, and the second one was really quick, but who knows what's going to happen next time, it could be the same again or it could be even longer, so let's start now."* WWD12 Type 1 Diabetes, Early Miscarriage

For some participants, the decision to become pregnant again was compounded by a need to be pregnant again. For example, some of the women with diabetes spoke of being "obsessed" (WWD1) and "desperate" (WWD3) to be pregnant again.

> *"I really wanted to get pregnant from the day my milk came in […] As soon as my milk came in I was like, 'I need a baby, my body needs a baby.'"* WWD9 Type 1 Diabetes, Stillbirth

WWD3 described how she had no intentions to start a family, as she enjoyed her busy and sociable life. However, when she became unexpectedly pregnant, and that pregnancy ended in miscarriage, she described feeling a strong urge to become pregnant again.

> *"It was a surprise pregnancy but it was very interesting in the way it made me feel that, well I didn't know I wanted to be pregnant but now I was and now I'm not I'd like to be pregnant again."* WWD3 Type 1 Diabetes, Early Miscarriage

For some, having a baby was felt to be the only way to heal their pain, and the overwhelming urge to become pregnant again was stronger than the urge to be mentally or physically ready.

> *"I don't believe I grieved for [baby's name] in those ten months. I was grieving, but I hadn't come to terms with it […] All I needed was another baby to be growing inside of [me], and I thought this other baby is going to take all this away. This baby is going to fix my heart […] This will make it right, and I can stop the pain if I know I'm pregnant."* WWD8 Type 1 Diabetes, Neonatal Death

Some healthcare professionals were conscious that women with diabetes might feel an overwhelming urge to be pregnant again, which made it difficult to take the time to prepare:

> *"I do often say to them, 'I appreciate that nothing is going to make it better until you've got a live baby in your arms'"* HCP1 Diabetes Consultant

Some healthcare professionals thought that women with diabetes might underestimate how long it might take to be 'optimally' prepared, as discussed by HCP14:

> *"Sometimes their expectations can be a bit misled […] If their HbA1c is quite high […] that's obviously our real indicator of outcome […] When we ask them, 'when are you thinking about trying?' and if they say, 'I want to try in three months,' then we have to be realistic and explain to them that that's probably not an ideal time based on where their diabetes management is and we would explain to them why that is. This just reinforces why it's really important to have these conversations with them earlier."* HCP14 Diabetes Specialist Dietician

A recurring motif from the women with diabetes was how, at the time, the inter-pregnancy interval felt like an interminable amount of time, even though, in hindsight, it was not. This is captured by WWD10, who, when asked about how they felt at the time about the interval of time between their miscarriage and becoming pregnant again, replied:

> *"It was grim. Objectively […] it was four months and feels like it was years […] I remember at the time being like, 'something is definitely wrong with me, like, I can't get pregnant' [...] There was only two months of trying before I then got pregnant again, but that to me felt like absolutely aeons of time […] and objectively it really was not."* WWD10 Type 1 Diabetes, Early Miscarriage

There was a contradiction here that women with diabetes reported feeling like they did not have enough time whilst simultaneously feeling like it was taking too much time to become pregnant again, as explored further in part 2 of the analysis (liminality).

5.2.5 Summary of descriptive theme 1: decisions around becoming pregnant after baby loss

These findings are important as they highlight that decisions around pregnancy intention may happen sooner than healthcare professionals might assume. Women with diabetes may start trying for a subsequent pregnancy shortly after baby loss. The median inter-pregnancy interval was seven months. Asking about subsequent pregnancy can be a difficult conversation for healthcare professionals to initiate, especially when little formal training is provided. Continuity of care was widely accepted as beneficial in facilitating sensitive conversations, but it may not be practicably feasible to deliver that continuity all of the time.

Women with diabetes lead complex lives, and diabetes is only one part of the picture. For example, some women with diabetes felt their age added an additional level of complexity and pressure to become pregnant again sooner, as not only does the risk of baby loss become higher with age, but fertility levels decline. Not knowing how long it would take to conceive or whether the subsequent pregnancy would be 'successful' compounded the pressure to become pregnant again as soon as possible.

5.3. Descriptive theme 2: The triple burden of baby loss, diabetes and preparing for pregnancy

The second descriptive theme illustrates how, for women with diabetes, the inter-pregnancy interval intersects with multiple burdens. During the interviews, healthcare professionals were asked to think about how easy or hard it was for women with diabetes to plan and prepare for pregnancy after a baby loss. Women with diabetes were asked to reflect on what it was like to live with diabetes, specifically about their experience managing their condition in the inter-pregnancy interval. Women with diabetes spoke of busy lives, with work and family commitments to manage. Some also looked after older children or relatives.

5.3.1 Subtheme 2.1: Burden of baby loss and societal expectations to try for another pregnancy

Generally, healthcare professionals saw their role as supporting women with diabetes from a physical diabetes point of view. Women with diabetes participants were not routinely referred to counselling services to help them process their loss. Many women with diabetes and healthcare professionals commented that it tended to be left up to the women to initiate conversations about additional help and support. Some healthcare professionals were able to signpost women to other bereavement or psychological services or involve other members of their multi-disciplinary team (if available), but this varied tremendously.

Some women with diabetes participants described how good-intentioned societal expectations to ‘just try again’ were unhelpful, as it was not that straightforward with diabetes. WWD7 (who was also a GP) spoke about how people would say things out of awkwardness, and the following example stuck with her:

> *“I felt like there was a pressure from society and […] people are incredibly blunt […] and just say ridiculous things about having babies and I’m aware of that from my job, as well, how often that can be distressing to women […] People would say, ‘you are going to have another one, aren’t you? You’re not going to let this beat you?’ And I […] found that a really incredibly odd thing to say because […] what does that mean? It doesn’t mean anything! […] I found it really hard being on maternity leave and seeing other people with babies.”*
> WWD7 Type 2 Diabetes, Neonatal Death

One participant spoke about how the burden of loss meant she hid her subsequent pregnancy from everyone except close friends and family for as long as possible as a protective measure:

> *"I don't think I got as excited about my pregnancy or felt as comfortable [...] it's sad that I never took a photo of my bump until three days before I had [my baby]. I didn't tell anyone apart from my close family and friends because I'd been through that, where I'd shared all the scans, and I'd had to go back and retract all that, and I didn't want to go through that again. So, I was very guarded. The only people at work that knew I was pregnant was [...] the managers [...] When I went back to work after maternity, no one knew I'd been pregnant."* WWD5 Type 1 Diabetes, Late Miscarriage

5.3.2 Subtheme 2.2: Burden of treatment for diabetes: emotional and health work

Both women with diabetes and healthcare professional participants commented on the burden of living with a chronic condition like diabetes. HCP11 and HCP18 likened it to a "full-time job" for their patients. WWD1, who had type 1 diabetes, spoke of how maintaining tight control of her diabetes required constant effort and planning, especially around work commitments.

> *"Just, 'what am I going to eat?' took a lot of effort […] the more effort I put in, the better the results are, so it's not something that just runs smoothly, and it's fine, and I can just ignore it […] If I do that, the then levels always end up being slightly higher than I would like them to be."* WWD1 Type 1 Diabetes, Early Miscarriage

HCP13, a clinical psychologist, talked about how diabetes seemed to "intrude into all aspects" of a woman's life:

> *"People with type 1 have to make, on average, 180 additional decisions every single day. So, whether it's thinking about food and carb content or planning for what you're going to do later that day, or organising prescriptions, everything else, it's so, so intrusive. I think it's very common for people to just feel exhausted and completely burnt out by it. The natural reaction when people are*

> *trying to [control] diabetes when it's too intrusive, too stressful, is to just try and minimise it, to push it away."* HCP13 Clinical Psychologist

For some women with diabetes, despite considering healthcare professionals to be empathetic, they did not feel like they understood what it was like to live with their condition, especially as each individual uniquely experienced diabetes.

> *"It's a hard disease to understand if you don't have it because it's something that the people who have it live with every minute of every day, so I think it's really hard to understand it. But I have to say especially the nurses, they have a lot of empathy, and they really try their best."* WWD1 Type 1 Diabetes, Early Miscarriage

Some women with diabetes commented that psychological support in the inter-pregnancy interval was beneficial in better understanding the emotional work required in managing their condition and acknowledging that preparing for pregnancy after a baby loss was more challenging for women with diabetes.

> *"The thing that helped with the diabetes [was the diabetes psychologist] because he specialised in diabetes. He was working at the clinic, he knew a fair amount about diabetes in pregnancy and was like, 'you're right that this is going to be really hard, you're right that probably you do need to be really controlled, it's not you being over the top about it', that sort of thing, which really helps."* WWD10 Type 1 Diabetes, Early Miscarriage

Both healthcare professionals and women with diabetes were conscious that it was primarily the women with diabetes' responsibility to manage their condition themselves in the inter-pregnancy interval with little additional support. Recent technologies, such as 'Libre' sensors and Continuous Glucose Monitoring pumps (see glossary of terms, pp. xvii-xviii), were mostly seen by both women with type 1 diabetes and healthcare professional participants as beneficial for helping women to tightly manage their blood glucose levels without further increasing the burden.

> “*There’s a huge amount of fixation on blood sugars and trying to get it right. I would say that that has got much easier since we’ve got a bit more diabetes technology cos where these women would have to, you know prick their fingers eight to ten times a day they’re now wearing sensors and they can understand a little bit more about what’s happening.”* HCP14 Diabetes Specialist Dietician

5.3.3 Subtheme 2.3: Additional burden of preparing for pregnancy and being in ‘pregnancy mode’

All women with diabetes participants were aware and knowledgeable about the NICE NG3 preconception guidelines during the interview. However, some participants only became aware of the benefits of preparing for pregnancy after they had experienced a baby loss. The majority of women with diabetes participants commented on how being ‘optimally prepared’ for pregnancy was not straightforward and took a great deal of effort.

All women interviewed took the responsibility of preparing for pregnancy themselves. However, most would have appreciated more holistic support in the inter-pregnancy interval, as it was a challenging time mentally and physically for all participants. For women with type 2 diabetes, preparing for pregnancy may involve managing their condition in a completely new way and they may not be aware of what is required if they are reviewed infrequently.

> *“Some of them may not even be checking their own blood glucose at all, some of them may not have needed to in the past. So, sometimes it really is starting from scratch and explaining that […] we do need to […] keep a much tighter eye on it. So, yeah, sometimes it is quite a lot of input from us initially getting them up and running with checking their blood sugars and knowing what to look for.”*
> HCP6 GP

> *“I think sometimes some patients don’t know what their diabetes management is actually like. So, they may not have engaged with the GP or they may not know what their HbA1c is, they might not know how well they’re doing because they maybe are not getting those regular reviews.”* HCP14 Diabetes Specialist Dietician

HCP14, a Diabetes Specialist Dietician, went on to say that it was not as simple as just providing women with T2DM with technology to monitor their blood glucose levels, but that the technology needed to be provided with support. HCP14, reflected on the “intense psychological burden” women with type 2 diabetes face in the inter-pregnancy interval when trying to become ‘optimally’ prepared for pregnancy with little help and support:

> *“Women [with type 2 diabetes] should get monthly support because […] you’re expecting them to monitor and to make these really close adjustments. But you’re leaving them to try and work out how to make this better and how to interpret all this information that they’re now getting about their glucose levels and their diet. And actually, if we spoke to them monthly we could talk through what’s happening, why the highs and lows are happening, and make small adjustments. Whereas we’re just not seeing them as often to do that.”* HCP14 Diabetes Specialist Dietician

Furthermore, some healthcare professional participants highlighted how women with type 2 diabetes may still have access to the blood glucose monitor they were issued in pregnancy, but might not be able to access the testing strips in the inter-pregnancy interval because they were not always prescribed by GPs outside of pregnancy.

> *“The challenge for them sometimes is actually getting the disposables, the testing strips and the lance on repeat prescription from their GP when they’re not pregnant anymore. […] the number of conversations where women have really struggled to get repeat prescriptions for testing lances and strips, even something that simple, even in pregnancy, because we get them to test so much and so they’re pretty much going for a pot of strips you know almost on a fortnightly basis […] because if it’s not on your repeat prescription and it’s difficult to do and you have to make an appointment to go and see a GP and you have to go, so if it becomes difficult to do then your motivation has to be even higher to actually carry on doing it.”* HCP12 Obstetrician

In an attempt to help women with diabetes to be better prepared for a subsequent pregnancy, some healthcare professionals would recommend that women with diabetes “go back on folic acid straight away” (HCP17), regardless of whether pregnancy intentions had been discussed.

> *“The folic acid won’t do you any harm but it’ll definitely do your baby some good’.”* HCP17 Bereavement Midwife

> *“You could certainly put someone on folic acid as a fall back and minimise risk that way, but they still need a proper review just to look at the preconception side of things.”* HCP18 Diabetes Specialist Nurse

In contrast, some healthcare professionals may think that prescribing folic acid so soon after a baby loss would give women with diabetes “the green light” (HCP2) to become pregnant. HCP2 had conflicted feelings about prescribing folic acid to all women with diabetes.

> *“After a conversation with the diabetic nurses and the diabetic consultant, I’m actually coming more to their thinking [that] if we give women folic acid, we worry that that’s then like a green light […] you know, if you do get pregnant then that’s alright because you’ve got the folic acid. I do think maybe it’s a good idea, and wouldn’t it be better that they had something over nothing?”* HPC2 Midwife

Some healthcare professional participants reported that, from experience, they would recommend that women with diabetes allowed six months to become ‘optimally prepared’ for pregnancy, illustrating how being ‘optimally prepared’ is not quick and easy to achieve.

> *“It can take [six months], sometimes it’s quicker, sometimes it takes longer it depends on the individual how they’re managing their diabetes how they feel about their diabetes as well and along with what other commitments they have. ‘Cos if they’ve got family, working full time, they’ve lots of other commitments on their time and it’s not an easy thing to do. Especially in type 1, where you’re juggling different insulins, different doses, monitoring regularly. It’s a big bit of work we’re asking women to do”* HCP18 Diabetes Specialist Nurse

A powerful theme generated from the analysis was how being ‘optimally prepared’ for pregnancy, as per the NICE NG3 guidelines, equated to being in, what WWD1 termed “pregnancy mode” - essentially acting as if they were pregnant, which the women with diabetes found really hard to sustain, especially when not actually pregnant. The burden of being in ‘pregnancy mode’ meant that the women with diabetes participants did not want to be preparing for pregnancy “for longer than I have to” (WWD10) owing to the amount of effort it took to try and meet the NICE NG3 preconception targets.

> *“I essentially had to convince myself every month that it was very possible that I was pregnant […] I had to believe that until I got my period and then be like okay I’m not […] I found that really challenging and I feel very, very lucky that although the pregnancies happened quite quickly for me cos I think if I was in that cycle for a year or something I just don’t know that I could keep it up.”* WWD10 Type 1 Diabetes, Early Miscarriage

In order to try and achieve the blood glucose levels recommended in the NG3 preconception guidelines, WWD1 commented on how preparing for pregnancy with type 1 diabetes, “takes over your life” (WWD1) and likened the level of control required to having an eating disorder, because blood glucose levels were the “one thing I can control” (WWD1). Similarly, WWD10 described the “really frequent testing” and "very rigid behaviours around food” required for her to be optimally prepared for pregnancy.

For these participants, the burden of preparing for pregnancy and being in ‘pregnancy mode’ meant that it was not realistic for them to be ‘pregnancy ready’ on the off-chance that they fall pregnant. WWD10 described being in pregnancy mode could, at times, feel like, “an exercise in futility”, whereas her friends did not face this burden when trying for a baby.

> *“You’re putting so much effort into something, and chances are that it doesn’t matter cos chances are you aren’t pregnant. […] Just setting your alarm every night right to wake up at two in the morning and test your blood. […] The reality is if I’m doing that, we are trying [to get pregnant] […] it felt like much more of a kind of on and off switch […] we’re either trying or we’re not trying […]. I certainly have friends who are like […] ‘I’ve just decided to come off that pill and*

> *we'd see what happens', which just feels like such a luxury imagine that?"* WWD10 Type 1 Diabetes, Early Miscarriage

The majority of healthcare professional participants recognised some of the difficulties that women with diabetes faced in order to meet the NICE NG3 guidelines and sympathised about how hard it could be, which is why some services offer pre-pregnancy care to assist women with diabetes in preparing for pregnancy.

> *"It's only with experience I think that you start to understand that this isn't just them not trying hard enough this is an entirely difficult, different challenge for them. And yeah you have some people who are more engaged than others but actually they're trying to manage something that they've never managed before […] and they're frightened."* HCP12 Obstetrician

Some healthcare professionals thought that the preconception guidelines for women with diabetes set unrealistic HbA1c targets.

> *"We ask them unrealistic goals and set unrealistic targets. It's not unusual when we tell them the targets someone will say, 'but that's impossible, I'm not going to be on that all the time'. And they are right, it's impossible for someone with diabetes who doesn't have an absolutely boring, nothing in their life, to keep like those simple targets."* HCP8 Diabetes Consultant

Not all services offer a pre-pregnancy clinic to help women with diabetes prepare for pregnancy, and some healthcare professionals worried that asking women to attend another clinic could be seen as an additional hoop to jump through when they are already overburdened, they may be unwilling to take additional time off work, and worried about potentially facing discrimination.

> *"Having lots of appointments is hard enough as it is, let alone add on, sort of, double that, or if not more, to come and make sure your diabetes is well controlled [in preparation for pregnancy]."* HCP3 Diabetes Specialist Nurse

> *"One of the things that people said to me, was that you don't want to be taking time off work, you certainly don't want a clinic letter that says 'preconception'*

> *and […] we've got enough appointments in our lives with diabetes, and I think if I start taking more time off, our bosses will start to get suspicious that we're planning pregnancy."* HCP1 Diabetes Consultant

Some healthcare professionals reported that they were unable to predict whether a woman with diabetes would accept pre-pregnancy care when offered to them in the inter-pregnancy interval.

> *"We've got some people that are very keen and some people that will say I'm not interested, not thinking about it now, and then the next we know is that they're pregnant. So, it's a mixture and there's not anybody you could really pick out and say they will have preconception they won't."* HCP18 Diabetes Specialist Nurse

Some women with diabetes participants did not find pre-pregnancy care told them anything they did not already know about the need to prepare for pregnancy, physically, from a diabetes point of view. Others welcomed pre-pregnancy care as it allowed them to gain access to technology to help them better manage their condition, so found it more useful.

> *"Nothing much really changes, except with the Libre […] You're still only seen every six months and you get advice on what they can see. I'm like, 'okay I was already doing that, I'm already aware of the folic acid."* WWD9 Type 1 Diabetes, Stillbirth

These findings suggest that pre-pregnancy care does not always meet the needs of women with diabetes and could be an additional burden to bear.

5.3.4 Summary of descriptive theme 2: The triple burden of baby loss, diabetes and preparing for pregnancy

Women with diabetes may face multiple burdens in the inter-pregnancy interval, with the burden of managing their condition on top of the burden of baby loss and societal expectations to become pregnant again. Preparing for pregnancy may add an additional burden to an already overburdened group. Women with diabetes may feel overwhelmed or distressed by the prospect of being in 'pregnancy mode' for any longer than necessary. These findings suggest that being ‘optimally prepared’ for pregnancy was difficult to sustain, especially when there was little or no support in the inter-pregnancy interval.

5.4. Descriptive theme 3: Discontinuities and constraints in inter-pregnancy care

The third descriptive theme illuminates how healthcare professionals and women with diabetes found the provision of care in the inter-pregnancy interval to be disconnected, constrained, and inconsistent across services. This made it more difficult for healthcare professionals to refer women with diabetes to care in a timely manner, and burdensome for women with diabetes to access to the care or support they needed. This section lays bare the disparities between the accessibility and provision of care for women with type 2 diabetes compared to type 1 diabetes.

5.4.1 Subtheme 3.1: Unclear who is responsible for women with diabetes in the inter-pregnancy interval

During the inter-pregnancy interval, women with diabetes reported finding themselves at the intersectional margins of baby loss, diabetes and (preparing for) pregnancy. Without wholly belonging to any one group, there was no one healthcare area that had an overarching responsibility to care for the needs of this group.

> *“You have to reach out to [the healthcare professionals] that’s the thing. I think they just, the hospital thought right [the local charity] is dealing with her, and there was absolutely nothing after [my daughter died], which really, I really needed.”* WWD8 Type 1 Diabetes, Neonatal Death

This seemed to be the case for type 2 diabetes in particular, where both women with diabetes and healthcare professionals commented on how practitioners in primary care tended to assume that women with diabetes were being offered support in secondary care and vice versa.

> “*I mean whose responsibility is it to have that conversation with the patient? is it the GP? is it the practice nurse? What about if you’ve got a patient […] that’s just diet controlled and not taking any medication so therefore they don’t really go and see the GP, they don’t have their regular blood test?”* HCP14 Diabetes Specialist Dietician

WWD2, for example, was told by her doctor that someone from the hospital "should be in touch with you about [therapy]", but no-one got in touch. When WWD2 brought it up with the doctor again, the only support that was offered was for a general 'talking therapies' service. A recurring theme from both healthcare professional and women with diabetes participants was the inappropriateness of a "beating the blues" (WWD7) type service, aimed at general mental health and not for those who had experienced a bereavement or trauma complicated by a long term health condition, like diabetes.

> *"You would be able to access counselling through your GP as part of, you know, I think they're called IAPT services like talking therapies but that would be the same sort of counsellor that you'd see if you, you know, had anxiety or depression and you know, you were a man in your fifties or a woman in her, you know forties it would be same sort of counsellors they wouldn't be specific, you know, reproductive health counsellors."* HCP5 Midwife

On the whole, women with diabetes participants did not find it straightforward to access pre-pregnancy care that was equipped to support them both physically, mentally or emotionally. A recurring theme for women with diabetes was how services were not geared up to meet their needs. For example, women with diabetes participants talked about how bereavement or grief support was unequipped to consider the context of diabetes, physical diabetes support unable to support the psychological side of diabetes and psychological support was not always geared up to support women living with long term conditions such as diabetes.

> *"The bereavement midwife was brilliant. But she wasn't specialised in diabetes […] it's very, very much about you've lost a baby but they don't deal with the fact that you've lost a baby and your health condition could be that reason"* WWD5 Type 1 Diabetes, Late Miscarriage

WWD6 recalled how she missed out on pre-pregnancy care in the inter-pregnancy interval

> *"He did say I should be under a team [and] that was literally how it was left as. But it wasn't something that was massively like pushed or anything […] thinking*

> *about it now it could have been. […] [when] I found out I was pregnant […] [I made] a phone call back to the diabetic nurse saying, 'look, I'm pregnant like what do I do?'"* WWD6 Type 1 Diabetes, Late Miscarriage

Not knowing who was responsible seemed to result in women with diabetes falling into gaps in care provision, experiencing inconsistencies in advice, or receiving care in an inappropriate space. Sometimes the pre-pregnancy clinic was held in the same location as the antenatal clinic, which may make sense in terms of service provision but was found to be distressing for some of the women with diabetes participants.

> *"It's within the antenatal clinic, it's run on an antenatal clinic day. There are four slots, so they'll come and see us within that clinic […] It can be a delicate area […] around ladies there that are pregnant."* HCP3 Diabetes Specialist Nurse

There was a consensus among healthcare professionals that primary care and community services would be well-placed to be able to support the varied needs of women with diabetes in the inter-pregnancy interval, but that services required improvement. A number of healthcare professionals commented on the time pressures faced by GPs, and questioned whether asking women with diabetes about pregnancy intentions was high on the priority list.

> "*We normally have between 10 to 20 minutes per patient and we need to go through glucose, blood pressure treatment, if they're on a pump, we need to download all the pump and see how things are going. We go through social as well, and then the other bloods they may have like cholesterol, cardio-vascular risk, so it's a lot of things you need to go through. If you run out of time discussing contraception or a pregnancy […] you need to cut off on other items like cardio-vascular risk."* HCP8 Diabetes Consultant

5.4.2 Subtheme 3.2: Unclear referral pathways and gaps in care within a primary/secondary care divide

After experiencing a baby loss, the care of the women with diabetes in this study was transferred back to whatever pre-pregnancy care they had prior to the pregnancy. Generally, the women with type 1 diabetes were predominantly managed in secondary care and type 2 diabetes in primary care with support from specialist services, although healthcare professionals reported how this could differ depending on the model of care used by their specific service. The unclear referral pathways were described by both women with diabetes and healthcare professionals as gaps into which women with diabetes could fall.

> *"The minute they get pregnant they start getting passed around services and so it's very easy for people to fall between gaps because they might have shifted from being maternity DSN back in to normal DSN clinics."* HCP13 Clinical Psychologist

WWD10 described their experience of being in the inter-pregnancy interval as:

> *"This period when you're trying, but not pregnant, or don't know whether you're pregnant, where you still technically fall under your normal diabetes team, but they don't really […] think of the pregnancy stuff […] that's not really something that they're set up to deal with, and the obstetricians aren't set up to deal with you until you're actually pregnant. So, I think there's a little gap in that pathway."* WWD10 Type 1 Diabetes, Early Miscarriage

HCP13 went on to describe how the change in frequency of clinics between 'normal' and 'pregnancy' clinics and healthcare professionals made it "very easy for women to drop out of the system completely and just be completely ignored" (HCP13).

> *"You might have […] been having weekly or fortnightly clinic appointments to monitor your progress [in pregnancy]. But then when you get shifted back into generic adult type 1 services it might be six months or even a year between your appointments."* HCP13 Clinical Psychologist

There was a great deal of variation in the types and availability of services reported by both women with diabetes and healthcare professionals. In general, women with diabetes spoke about being required to be responsible for proactively seeking out their own referrals from their GP or Diabetes Specialist Nurse to another service, for example, for bereavement, mental health, or, pre-pregnancy support.

> *"It went back to […] the yearly appointments where they check your feet and do the HbA1c check and everything like that […] When I spoke to the doctor and said 'I'd like to get pregnant, what can I do about my diabetes?' So that was me asking, no-one specifically spoke to me about that."* WWD2 Type 2 Diabetes, Neonatal Death

Women with type 2 diabetes, in particular, seemed to find themselves in the "middle ground" (HCP8) between primary and secondary care.

> *"In some ways our women with type 1 are slightly luckier than primary care because they get regular reviews and somebody is asking them the question [about pregnancy] whereas in primary care, I'm not sure […] are they falling pregnant on lots of […] medications that they shouldn't be taking?"* HCP14 Diabetes Specialist Dietitian

Women with type 2 diabetes were reported to be more reliant on being referred to pre-pregnancy care and specialist diabetes services by their GP. This was a recurring theme among healthcare professional participants working in secondary care, who commented on how they saw few women with type 2 diabetes pre-pregnancy.

> "*Most of type 2 diabetes isn't followed up in hospital. So, I think there's a huge amount of work to be done in how we can embed strategies in primary care to improve sign-posting to preconception care and access of preconception care. Because usually, the cases I see with the high HbA1c's, that statistically, the biggest likelihood of significant anomaly, are women with type 2 diabetes looked after in primary care without any preconception care."* HCP11 Endocrinologist

Some healthcare professional participants worked in services that women with diabetes could self-refer themselves into, which made it easier for women with diabetes to access pre-pregnancy care, but as acknowledged by HCP10, an open access pre-pregnancy care services can be difficult to set up where there is a primary-secondary divide.

> *"It would be set up, in an ideal world, open access so patients could self-refer in, but it's having the systems within a secondary care, primary care divide to allow that to happen easily."* HCP10 Diabetes Consultant

Many healthcare professionals felt that women with diabetes were being let down by the system. Healthcare professionals described how they did their best to use the referral pathways that were available to them. However, they felt there was a lack of consistency regarding how a woman with diabetes should be supported in the inter-pregnancy interval after a baby loss.

> "*I refer them back into the general diabetes service because that's the pathway I have available to me. What I have no control over is what they do with them and how often they see those women, I only have control over how often I can see them when they're pregnant. But I do give them that caveat that they can always come back to me."* HCP12 Obstetrician

To counter the unclear referral pathways and lack of "robust signposting" (HCP11) and clarity over who was responsible for this group in the inter-pregnancy interval, healthcare professionals and women with diabetes relied on their own informal and professional networks and third-sector charities for support in the inter-pregnancy interval.

> *"I can do [referrals] but I fell into that by accident […] I don't even know if the clinical psychologist I use is someone who's even meant to be providing this service. […] I have used her with a couple of my patients with long-term conditions with a psychological element to that and a burden and I've used her and she's done amazing things […] while I focus on the hormone numbers […] that's something I'm hoping to use more but […] I don't think there's a formal service in place."* HCP11 Endocrinologist

> *"I felt like, services-wise, I was able to access semi-professional support from friends. I didn't feel particularly supported by the diabetic and obstetric team that I'd been under for the care of my pregnancy, and I did feel frustrated by all of that. But I was able to push and access support that might not have been readily available for other people, and in a wider sense, I felt like I had a small group of friends who really supported me and were really helpful."* WWD7 Type 2 Diabetes, Neonatal Death

5.4.3 Subtheme 3.3: Disparities in resource allocation

Healthcare professional participants described how there were differences in the allocation of resources depending on the type of diabetes and type of baby loss, and it was apparent from the responses that resource allocation also differed across services. For example, healthcare professional participants considered blood glucose monitoring technology a helpful tool for enabling women with diabetes to gain tighter control of their blood glucose levels, but it was not widely available to women with type 2 diabetes.

> *"If they're not on insulin they don't even get offered blood glucose monitors, so how are they supposed to monitor how they're doing? […] Our type 1's […] get so much more insight into what's happening. Whereas the type 2's, they don't get that insight do they, because they're relying on HbA1c, which is going to be done every three months, so how do they know? […] Just because they feel fine it doesn't mean that their sugars aren't running at a 15."* HCP14 Diabetes Specialist Dietician

Some healthcare professionals spoke about how they were able to use their discretion to give women with diabetes access to resources, such as blood glucose monitoring technology and insulin pumps, outside of pregnancy.

> *"We use [technology] before pregnancy when I can, for example, an insulin pump, I try to do it before pregnancy because it has a learning curve. It works much better if the lady knows how to manage the pump before they get pregnant."* HCP8 Diabetes Consultant

It became apparent through the interview process that healthcare professionals and women with diabetes had different experiences around the availability of bereavement midwives, counselling services and support and advice about diet and lifestyle.

> *"I know one hospital where if you've had a miscarriage they can offer you counselling support because they have counselling attached to their unit. But I mean, that's very, very rare. In the vast majority of cases you wouldn't be getting any counselling."* HCP5 Midwife

Some trusts had a diabetes specialist, nutritionist or dietician. In contrast, other healthcare professionals spoke about how there were no services to refer women with diabetes to, only basic healthy eating advice from the GP, as described by HCP7:

> *"There is nothing commissioned between me telling them, basically you need to cut down on the carbs, you need to move a bit more, and watch your calorie intake, and the next step after that is a jump straight up to referral to bariatric service."* HCP7 GP

Judging by how participants spoke about their experiences of accessing or delivering pre-pregnancy care, it was evident that there was a great deal of variation in the way pre-pregnancy care services were set up. For example, it varied from no separate service whatsoever, to a preconception clinic with few slots resulting in a four-month waiting list to access, to pre-pregnancy care clinics that women with diabetes could self-refer themselves into and be seen within days.

5.4.4 Subtheme 3.4: Gaps in knowledge, training and skills

Women with diabetes may come into contact with a range of healthcare professionals throughout their childbearing years. Gaps in knowledge, training and skills, both for healthcare professional and women with diabetes, have the potential to jeopardise women with diabetes' ability to prepare for pregnancy in the inter-pregnancy interval.

The healthcare professionals who participated in an interview were generally interested in the research topic and, therefore, had good knowledge of the NICE NG3 preconception guidelines and available services in their area. There was a feeling among healthcare professionals based in secondary care, in particular, that not all primary and community care professionals were knowledgeable about the need for women with diabetes to prepare for pregnancy.

> *"I think it's GPs, so a lot of the time they don't realise that we would advise preconception, so they don't even realise planning pregnancy is important. So, when they're under GP care, that's one of the things [preventing type 2 diabetes from getting preconception care]."* HCP18 Diabetes Specialist Nurse

> *"We need to upscale all healthcare professionals who may come into contact with somebody with diabetes who may wish to be pregnant so that whomever she chooses to have that conversation with can give the right advice."* HCP6 GP

> *"It's an interesting group to think about because probably we are missing a lot of this in general practice […] particularly type 2 diabetes, we're more involved with initiating and monitoring medication and blood levels […] I think even sometimes we may not be aware of people who have diabetes. We see them about other things and perhaps haven't made that link between the two problems."* HCP9 GP

Healthcare professionals frequently commented on how many more women with type 2 diabetes were becoming pregnant. They were concerned that some healthcare professionals might not associate type 2 diabetes with the possibility of pregnancy, as the condition was historically associated with older people no longer in their childbearing years.

Several healthcare professionals proposed that upskilling all healthcare professionals who interact with women with diabetes to have a basic understanding of diabetes and pregnancy would improve their ability to provide ad-hoc pre-pregnancy counselling as needed.

> *"I don't think it matters who the woman has a conversation with, whether it's their GP, practice nurse, a midwife, somebody from secondary care. I just think it is important that they have that conversation with someone, and if all healthcare professionals have the same basic level of knowledge where we can*

> *give them the basic advice, they know where to seek more advice if they will accept that."* HCP6 GP

Some healthcare professionals were reliant on the women with diabetes being knowledgeable about the need to prepare for pregnancy, willing to initiate the conversation, as well as be direct about the support they required.

> "*Unless the patient was quite direct about what they were wanting I don't necessarily think that would get picked up in general practice. Not to say it shouldn't but I think with the time constraints in an appointment we often tend to focus in on what their main concern is, and although ideally, it would be good to radiate around the issues […], it might be hugely overlooked."* HCP9 GP

Not all the women with diabetes participants were 'educated' about the risks in pregnancy when they were diagnosed. For example, pregnancy was not mentioned to WWD2 when she was diagnosed with type 2 diabetes one year before her first pregnancy, and only found out that preparing for pregnancy could reduce the risk of baby loss after she experienced a neonatal death.

> *"It wasn't really until I was pregnant that I realised how much it could affect it."* WWD2 Type 2 Diabetes, Neonatal Death

An important finding from this research was that preparing for pregnancy was reported as not featuring on the nationally delivered 'Desmond' structured education course offered to women with type 2 diabetes. However, pre-pregnancy was reported as being included in the equivalent 'DAFNE' course for type 1 diabetes, which could put women with type 2 diabetes at a further disadvantage.

> *"It isn't in there as part of the curriculum and we're having more women of child bearing age diagnosed with type 2 diabetes, the numbers are climbing massively. So, if it's not in structured education then that's not then passed on at that point, so it's patchy […] [but] for type 1 pregnancy and preconception is in DAFNE."* HCP18 Diabetes Specialist Nurse

Many of the healthcare professionals participants reported that little training was provided on how to deal with sensitive topics, such as discussing pregnancy after a loss, or conducting a bereavement follow-up.

> *"Medical and healthcare professionals […] should be acknowledged as well in the fact that actually it is tough and […] maybe tools to help us and train us to do it better. Because you get very little training as an obstetrician and you don't do those bereavement follow ups until you're a consultant because it needs to be the most senior person. But that means that the first time you do it you are the most senior person doing it. So, I wonder, if actually, there is something about helping us be better at it and help facilitate those difficult conversations."*
> HCP12 Obstetrician

5.4.5 Summary of descriptive theme 3: discontinuities in inter-pregnancy care

It was unclear who had overall responsibility for women with diabetes in the inter-pregnancy interval. This group were found to be on the intersectional margins of baby loss, diabetes and preparing for pregnancy. As a result, there was no one service where women with diabetes could be wholly supported in the inter-pregnancy interval, and sometimes services assumed that women with diabetes would receive care from a different area. Unclear referral pathways and gaps in care put women further at risk of missing out on the support needed. Care in the interpregnancy interval was reported as disconnected and inconsistent. Healthcare professionals found it difficult to refer women to services and women with diabetes found it difficult to know who to turn to, or found the care to be burdensome to access.

Women with diabetes may come into contact with various healthcare professionals during the inter-pregnancy interval. Not all healthcare professionals were aware of the need for women with diabetes to prepare for pregnancy. Healthcare professionals in primary or community care settings may not associate type 2 diabetes with an increased risk in pregnancy. Knowledge about the topic and asking about pregnancy was not necessarily considered to be in the remit for all of these healthcare professionals, and conversations about subsequent pregnancy after a baby loss were not normalised.

There may be a missed opportunity to educate women with type 2 diabetes about pregnancy preparation. Not all women with diabetes knew that preparing for pregnancy could reduce the risk of baby loss. Women with type 2 diabetes might not be informed about the risks in pregnancy at diagnosis, and it was reported that the nationally-delivered structured education course, ‘Desmond,’ does not cover pregnancy and preparation.

Discontinuities and constraints within and between service provisions further compounded these issues. The disparities between the provision of services and support for type 1 diabetes compared to type 2 diabetes were laid bare women with type 2 diabetes were reported as facing additional barriers to accessing support and resources to prepare for pregnancy in the interpregnancy interval.

5.5 Discussion of the descriptive themes

5.5.1 Introduction

This discussion aims to explore the key findings from the descriptive themes in relation to the literature review and the research questions, aims and objectives, highlighting the implications for existing understanding and care provision in the inter-pregnancy interval.

5.5.2 Discussion of descriptive theme 1: decisions around becoming pregnant after baby loss

This section captured the participants’ experiences of deciding about becoming pregnant again after the baby loss. The findings suggest that women with diabetes may welcome a conversation about subsequent pregnancy sooner than is currently assumed. Some healthcare professionals might assume that women with diabetes need time and space after experiencing a baby loss to come to terms with the loss before they would be ready to consider a subsequent pregnancy. In contrast, all the women with diabetes who participated in this research knew straight away that they wanted to become pregnant again after the baby loss at some point in the future. While it is possible that the participants were a self-selected group, this finding is noteworthy as it suggests that there might be a discrepancy between women with diabetes' needs and readiness to discuss a subsequent pregnancy and what the healthcare professionals feel might be appropriate to raise and when.

Participants experienced grief differently, and women with diabetes may want and need different levels of support. Recognising grief and responding in the most appropriate way was reported as a challenge for healthcare professionals. These data demonstrate the influential role healthcare professionals may play in normalising and validating women with diabetes' experiences, especially during the inter-pregnancy interval. This is in keeping with the baby loss literature, which suggests that parents experience a range of unique and personal reactions to loss (Dyer *et al*., 2019). However, whilst the literature points to the importance of providing the right type and amount of support for bereaved women (Hutti *et al*., 2017; O'Leary and Warland, 2013), a single intervention is rarely enough (Alqassim *et al*., 2022), and a lack of structured procedures and hospital protocols create barriers to providing holistic and individualised care (Ellis *et al*., 2016). The literature also points to how caring for bereaved parents is difficult, stressful and emotionally challenging (Favrod *et al*., 2018; Fockler *et al*., 2017; Gardner, 1999; Oe *et al*., 2018). It is essential to acknowledge that healthcare professionals have complex roles, with sometimes little or no additional training to handle sensitive and emotionally difficult topics. It is a challenge for healthcare professionals to support women with diabetes and their complex needs in a healthcare system prioritising physical health. Training for healthcare professionals to support bereaved parents has been described as inadequate (Heazell *et al*., 2012; Fenwick *et al*., 2007; McKenna and Rolls, 2011; Nuzum, Meaney and O'Donoghue, 2014; Robertson, Aldridge and Curley, 2011), despite findings that prolonged psychological problems are less likely to develop where professional support is given (Burden *et al*., 2016; Flenady *et al*., 2014; Forrest, Standish and Baum, 1982; Hughes and Riches, 2003; Mills *et al*., 2014).

A recurring theme in the women with diabetes' accounts was the tension they felt in balancing the yearning for a baby with medical advice or a felt expectation to wait for a subsequent pregnancy. Some of the women reported that having another baby was the only way for them to heal. This is in keeping with the literature, which suggests that many women experience an overwhelming urge to become pregnant again as soon as possible after loss (Burden *et al*., 2016; Carlsson *et al*., 2016; Forrest, Standish and Baum, 1982; Meaney *et al*., 2017). Some of the women with diabetes participants talked about the added internal and external pressures to conceive again as quickly as possible. For example, societal expectations to 'try again,' not knowing how long it might take to become pregnant, or whether the pregnancy would be ‘successful’, and other fertility issues all contributed to this group's desire to become pregnant again as soon as possible. The notion that ‘time is of the essence’ can be seen in other baby loss research (Hughes, Turton and Evans, 1999; Meaney *et al*., 2017) and may become further impacted by the trend for women to delay starting a family until their mid-thirties (ONS, 2022), as advanced maternal age (>35 years) is associated with declining fertility levels, and an increased risk of baby loss (Lean *et al*., 2017, 2021; Sauer, 2015). Together, this creates what has been described as a “biological clock”, which can leave women who experience a baby loss with an urgency to become pregnant again as soon as possible (Sauer, 2015, p. 1141). Considering the unforgiving timeline for women with diabetes, whose median age was in the late thirties, becoming pregnant again as soon as possible was not necessarily an unreasonable response to baby loss. It is plausible that a perceived lack of time to conceive may contribute to the low uptake of pre-pregnancy care support and services. However, these findings suggest that it may be more complex than just wanting to be pregnant again as soon as possible, and will be discussed further in Chapter Six (section 6.5.2).

It is crucial to consider the impact of a short inter-pregnancy interval, specifically in the context of diabetes. In this research, the median inter-pregnancy interval for women with diabetes was short, at seven months. Whilst this research only included participants who went on to pursue a subsequent pregnancy, it is in keeping with research that indicates a short inter-pregnancy interval after a baby loss (Tennant *et al*., 2015). This finding is important for three main reasons. Firstly, it emphasises the small window of opportunity in the inter-pregnancy interval to refer women with diabetes to other services to support them in grieving the loss of their baby and preparing for a subsequent pregnancy. Medical involvement in pregnancy preparation is encouraged for women with diabetes (Hopkins *et al*., 2023; Murphy *et al*., 2010b; Yamamoto *et al*., 2018). However, most of the women with diabetes who participated in this research recalled having little contact with healthcare professionals in the inter-pregnancy interval. This finding may be especially pertinent for women with type 2 diabetes, who were reported as being transferred back to primary care services, which might involve infrequent or even annual appointments. Women with type 2 diabetes may have little or no opportunity to speak with a healthcare professional in the inter-pregnancy interval. As a result, they may miss out on the opportunity to receive timely pre-pregnancy care, bereavement support and support for preparing for pregnancy. This is echoed in the diabetes and pregnancy literature, which has highlighted how the reproductive needs of women with type 2 diabetes can be overlooked, in part because this group is predominantly cared for in primary care, where a lack of systemic processes meant that the reproductive healthcare needs of women with type 2 diabetes were not embedded into mainstream diabetes management (Forde *et al*., 2020).

Secondly, it highlights how important it is for all healthcare professionals who come into contact with women with diabetes to know the benefits and requirements of preparing for pregnancy, as there might not be many opportunities to discuss pregnancy. In light of these findings, to ensure all women with diabetes have the opportunity to discuss pregnancy plans with a healthcare professional, conversations about pregnancy may need to be embedded into routine appointments. This is especially important for women with type 2 diabetes who are overseen mainly in primary care or those who have experienced a miscarriage that they managed at home, as they may not have as many 'touch points' with healthcare professionals in the inter-pregnancy interval, and so may miss the opportunity for timely pre-pregnancy care advice or the chance to be referred to pre-pregnancy care services. The participants in this research were predominantly white, British and well-educated. However, I speculate that the disparities in access to resources and support for women with type 2 reported here reflect a more significant problem societally. It is likely that the unequal access to resources and support contributes to and exacerbates the widening health inequalities and disparities faced by women from ethnically minoritised groups and socioeconomically deprived areas, as these groups are more likely to be diagnosed with type 2 diabetes at an earlier age (Diabetes UK, 2023c).

Thirdly, healthcare professionals could initiate a sensitive discussion about subsequent pregnancy earlier than they might assume. Initiating this conversation as soon as possible represents an opportunity to link women with diabetes with support and services ahead of a subsequent pregnancy. The findings showed that conversations about subsequent pregnancy were not normalised. Some healthcare professionals feared initiating a conversation about pregnancy soon after a baby loss would be insensitive or offensive, so they avoided the conversation altogether. Instead, they would wait for the patient to instigate the conversation or assume it would be had with another healthcare professional later. However, for those women who participated in the study, a sensitive conversation about future pregnancy plans initiated by healthcare professionals would have been welcomed sooner after the baby loss so that there was an opportunity to discuss how they might be more prepared for pregnancy and, if welcomed, get a timely referral to specialist pre-pregnancy services. However, there was no agreement among participants about when might be the best time to facilitate a conversation about subsequent pregnancy, and it is important to note that not everyone welcomed medical input in the inter-pregnancy interval, reinforcing the need to be receptive to the needs of each individual. The six-week check-up after a stillbirth or neonatal death was suggested as an opportunity to speak to women with diabetes about pregnancy plans. However, this check-up would not routinely be offered to women with diabetes who experience a miscarriage. Indeed, the findings suggest that not all healthcare professionals were made aware when a woman with diabetes experienced a baby loss, especially a miscarriage. For some healthcare professionals, the lack of transparency about previous baby loss contributed toward a reluctance to initiate a conversation about pregnancy in general for fear of whom it may offend, so they avoided asking the question altogether.

There is literature to support the notion that healthcare professionals should anticipate the need to facilitate conversations from the very earliest point during the postnatal period, whilst being mindful of the patient's individual preference for the amount and type of advice that they want or need (Burden *et al*., 2016; Dyer *et al*., 2019; McHaffie *et al*., 2001). However, relatively little has been published about women's experiences of the inter-pregnancy interval and becoming pregnant again after a baby loss, so it is unclear from the literature whether there are existing prompts or guidance regarding preparing for the next pregnancy (with or without diabetes). Despite being considered an important part of care practice, there is a lack of guidance as to how to conduct meaningful follow-up conversations, and so healthcare professionals end up 'learning on the job' and relying on their own opinions and experience (van Kempen, Kochen and Kars, 2022). The goals and content are rarely explicated, and it is unclear how parents experience conversations about pregnancy after a baby loss (van Kempen, Kochen and Kars, 2022). As a result, healthcare professionals may not routinely bring up the topic of subsequent pregnancy. The hesitancy to avoid a conversation about a subsequent pregnancy may be well -intentioned; it may be partly due to avoiding the implication that it is possible to 'replace' the deceased baby, which may be inferred as undermining the parent's grief (Grout and Romanoff, 2000). However, the hesitation to talk about subsequent pregnancy may imply an expectation that a woman's reaction to baby loss should always be “devastating grief” (Browne, 2023, p. 87), and talking about a subsequent pregnancy would be offensive. In contrast, these findings highlight how important it is to set assumptions aside to give women with diabetes the opportunity to talk about if and when they might like to try for another baby.

In summary, women with diabetes may welcome a sensitive conversation about subsequent pregnancy sooner than healthcare professionals currently assume. Healthcare professionals should initiate conversations early and embed them in routine appointments to ensure timely referrals and support. This is especially important for women with type 2 diabetes who have limited contact with healthcare professionals in the inter-pregnancy interval.

5.5.3 Discussion of descriptive theme 2: The triple burden of baby loss, diabetes and preparing for pregnancy

This section highlights how women with diabetes may face multiple burdens in the inter-pregnancy interval: the burden of baby loss; the burden of diabetes; and the additional burden of planning and preparing for a subsequent pregnancy. The collective impact of this triple burden has received little attention.

In terms of the burden of baby loss, some women with diabetes described how good-intentioned societal expectations to ‘just try again’ were unhelpful, as it was not that straightforward with diabetes. Many of the women described how their physical health was prioritised over their mental health. Most of the women with diabetes participants were not routinely referred to counselling services to help them process their loss, but would have welcomed more support in the way of specialised counselling. Women tended to be required to proactively initiate conversations about additional help and support, which was described as burdensome. Some healthcare professionals were able to signpost women to other bereavement or psychological services or involve other members of their multi-disciplinary team (if available), but this varied tremendously. On the whole, the women with diabetes participants largely described being left to endure their grief alone. Baby loss remains an uncomfortable topic in Western society (Scott, 2011). Societal awkwardness may be perpetuated by the common unspoken rule that many women choose not to tell anyone before 12 weeks of pregnancy (Stephenson *et al*., 2021), seemingly to protect the discomfort of others in case pregnancy ‘goes awry’. While the silence and taboo surrounding baby loss is beginning to change, largely through the work of baby loss charities, such as Tommy's and Sands, women with diabetes may experience disenfranchised and complicated grief which is thought to require medical support to process (DeBackere, Hill and Kavanagh, 2008; Shear, 2012).

The notion that diabetes can be notoriously burdensome to manage, and the unpredictable nature of the condition can cause distress is widely supported in the literature (Adu *et al*., 2019; German *et al*., 2023; Khan and Choudhary, 2018; Pandit *et al*., 2014; Singh *et al.,* 2019). Diabetes distress is the emotional response to living with diabetes, the burden of relentless daily self-management (Pandit *et al*., 2014; Schmidt *et al.,* 2019) and the prospect of potential long-term complications (Hendrieckx *et al*., 2019). Although diabetes distress and depression partly overlap, they are separate constructs and are not interchangeable phenomenon (Snoek, Bremmer and Hermanns, 2015). Diabetes distress is known to affect those with both type 1 and type 2 diabetes (German *et al*., 2023; Khan and Choudhary, 2018; Tschirhart *et al*., 2023; Wardian *et al*., 2018). However, the conditions manifest differently and so have different challenges. Diabetes distress has been found to be significantly associated with poorer glycaemic control (Fisher *et al*., 2008) which exacerbates feelings of anxiety, guilt, depression and despair (Balfe *et al*., 2013; Fisher *et al*., 2008; Peyrot *et al*., 2005), and was found to be a significant predictor of adverse pregnancy outcome, albeit in women with gestational diabetes (Schmidt *et al*., 2019). Further research is warranted as to whether diabetes distress is associated with adverse pregnancy outcomes in women with type 1 and type 2 diabetes. Psychological support has been shown to help women with diabetes manage diabetes distress (Peyrot *et al*., 2005). However, women with diabetes may not routinely be able to access psychological help when they need it (Britneff and Winkley, 2013; Peyrot *et al*., 2005), and the women who participated in this research generally found psychological support to be lacking in the inter-pregnancy interval.

Women with diabetes described how preparing for a pregnancy after a baby loss was not straightforward and took a great deal of effort. For many of the women with diabetes participants, attending pre-pregnancy care services was seen as an additional hoop to jump through. In the context of the inter-pregnancy interval, the requirement, or expectation to be 'optimally prepared' for pregnancy essentially meant acting as if they were pregnant but with less support. WWD1 termed this as being in "pregnancy mode," which was a strong theme generated by the analysis. Being in ‘pregnancy mode’ may be a considerable burden for women with diabetes who are grieving. The findings suggest that the women with diabetes participants found it exhausting and unsustainable to maintain ‘pregnancy mode’.

For women with diabetes, becoming pregnant again after a baby loss is further complicated by the requirement of being ‘optimally prepared’ before they become pregnant again. There seemed to be competing and multi-layered understandings of what ‘optimally prepared’ meant. The dominant focus was biological readiness, with an emphasis on blood glucose levels, which is reductionist in scope. The findings suggested that women with diabetes and healthcare professionals considered the blood glucose targets for women with diabetes to be ‘optimally prepared’ were difficult to reach and maintain. Some healthcare professionals commented that it might take around six months to get control of the condition, which may be an off-putting thought for women with diabetes in the inter-pregnancy interval, especially if they are yearning for another pregnancy. Whereas, if ‘optimally prepared’ was understood in a more holistic context, with more flexibility for individuals, perhaps being ‘optimally prepared’ would be less ‘unrealistic’.

It is largely acknowledged that managing diabetes during pregnancy is challenging, which is reflected in the level of support available antenatally (NICE, 2015a). Improving the quality of maternity care has been a priority over the past few decades, however, improvements in preconception care have lagged behind (Stephenson *et al*., 2021). While the literature points to a low uptake of pre-pregnancy care (Earle *et al*., 2017; Forde, Patelarou and Forbes, 2016; Murphy et al., 2010a, 2010b; NHS Digital, 2021a), there is a general lack of recognition that being ‘optimally prepared’ for preparing for pregnancy is a burden in itself. As such, the view that preparing for pregnancy is an additional burden for women with diabetes is not explicitly documented in the diabetes literature, so the notion of ‘pregnancy mode’ is a salient finding, as is the potential for ‘pregnancy mode’ to require women with diabetes to manage their condition as if they had an eating disorder. While the literature has highlighted the potential for the management of diabetes to exacerbate or cause eating disorders or disordered eating (Gagnon, Aimé and Bélanger, 2017; Toni *et al*., 2017), there is to my knowledge, no literature linking these issues to the requirements of being optimally prepared for pregnancy.

The triple burden faced by women with diabetes in the inter-pregnancy interval may not be obvious to healthcare professionals, so how do they know how best to support women unless their needs are communicated to them? It is possible that continuity of care and trusting relationships may be one way to understand the lives and challenges faced by women with diabetes (National Maternity Review, 2016; NICE, 2015a), and have been linked with positive outcomes for women and their babies (Wallace and Stulz, 2020). However, healthcare professionals will only ever have an incomplete picture of their patients. There is simply not enough time or touchpoints to know the ever-changing lives of their patients or to account for all the varying circumstances that may affect women with diabetes in their lives. What is not clear is whether it is possible to share the burden. For example, even the simple act of taking folic acid could add to the burden. There is a paradox here whereby pregnancy decisions are primarily considered a private, 'unmedicalised' matter, yet women with diabetes are required to have medical involvement so they can get a prescription for folic acid. Would proactively, offering women with diabetes a high-dose folic acid prescription after a baby loss help to reduce the burden on women and prophylactically improve subsequent pregnancy preparation? Some healthcare professionals may worry that this would give women with diabetes the "green light" for pregnancy (HCP2). However, it would also provide some benefit to them if they were to find themselves pregnant, which is especially important considering many pregnancies are not 'planned'. Indeed, the inter-pregnancy interval after a baby loss provides an opportunity to target this group, as most will have a subsequent pregnancy within a year (Tennant *et al*., 2015). In some respects, this group is largely pre-pregnant.

In summary, women with diabetes may face a triple burden in the inter-pregnancy interval, and the collective impact of this triple burden and the interplay of the different factors has received little attention. These findings suggest that being 'optimally prepared' for pregnancy was difficult to sustain, especially when there was little or no support in the inter-pregnancy interval.

5.5.4 Discussion of descriptive theme 3: discontinuities in inter-pregnancy care

This theme described inconsistencies in care provision and the way women were handled after a baby loss across services. It was unclear who was responsible for looking after the interests of this group. Women with diabetes may not be routinely followed up after discharge from antenatal services, and there was variation between services as to whether women with diabetes would have automatic access to bereavement and counselling services; later losses were more likely to involve a package of care.

Most women with diabetes participants did not find it straightforward to access the support they required during the inter-pregnancy interval, especially regarding emotional or psychological support. The findings suggested that GPs were able to refer women with diabetes to general 'talking therapies' type services, but these are not necessarily geared up to helping the specific needs of women with diabetes who have experienced baby loss, and the literature points to long waiting lists for psychological support (Punton, Dodd and McNeil, 2022), which is not helpful if women with diabetes feel like they are under time pressure to conceive. In the inter-pregnancy interval, women with diabetes may benefit from more targeted support in terms of the additional psychological impact of the burden of diabetes and the additional distress it can cause, the potential for them to blame themselves for the baby loss (Bhat and Byatt, 2016; Burden *et al*., 2016; Frost *et al*., 2007; Hale, 2007), whilst also managing the additional burden of preparing for pregnancy while potentially experiencing complicated and disenfranchised grief (Kersting *et al*., 2011; Kersting and Wagner, 2012). Third-sector support groups may well be helpful for women with diabetes. However, they are unlikely to be able to cater for the additional and specific needs of women with diabetes surrounding the additional burdens they face in managing their condition and the individual responsibilisation to prepare for pregnancy and thus be 'blamable' for the baby loss. Women with diabetes seeking support in the inter-pregnancy interval may be looking for something more than what is offered by third-sector charities. They may require support with their diet and lifestyle, for example, or psychosocial support with managing the diabetes distress that can be intensified by the 'pregnancy mode' requirements.

The findings showed that not all women with diabetes and healthcare professionals knew that preparing for pregnancy could help reduce the risk of baby loss. The duration of the condition may have an impact on women with diabetes' ability to understand the condition. For example, some women with type 2 diabetes, in particular, were newly diagnosed but felt like healthcare professionals assumed they should be experts in their condition. This suggests that conversations about pregnancy are not always routinely embedded into healthcare services, which is in keeping with the findings from Forde, Patelarou and Forbes (2016) and Stephenson *et al*., (2021). It is vital for pregnancy to be mentioned at or around the time of diagnosis, especially as preconception and pregnancy were reported as not being included in the 'Desmond' structured education curriculum for type 2 diabetes, which was also a finding by Forde *et al*. (2020). It is unclear from the literature why pregnancy might not be mentioned at diagnosis - whether through lack of knowledge on the healthcare professionals' part (Klein *et al*., 2017; Murphy *et al*., 2011; Spence *et al*., 2010), not wanting to overwhelm the women with diabetes at the time of diagnosis, or assuming that pregnancy was not on the women with diabetes' agenda. The latter of which may be related to stereotypical assumptions about reproductive potential among this group, who are likely to be older and more likely to live with overweight and obesity (Forde, Patelarou and Forbes, 2016; Spence *et al*., 2010). Furthermore, women with type 2 diabetes tend to live in areas with higher deprivation and may be further disadvantaged as research shows that poorer people are treated differently by healthcare professionals and receive worse service (D'Anna *et al*., 2018).

The diabetes and pregnancy literature also point to how healthcare professionals are not always aware of the risks, especially for women with type 2 diabetes (Forde, Patelarou and Forbes, 2016; Klein *et al*., 2017; Murphy *et al*., 2011), and the systematic review by Earle *et al*. reported a perception that some pre-pregnancy care healthcare professionals lack the required skills and resources to deliver pre-pregnancy care effectively (Earle *et al*., 2017). Training and upskilling primary and community care practitioners, such as doctors, nurses and pharmacists, so that they know about the need to prepare for pregnancy, and can offer ad-hoc pre-pregnancy advice, prescribe high-dose folic acid and review medications, may be one of the ways to ensure women with diabetes, and those with type 2 diabetes in particular, receive the timely care they need, and has been suggested in the literature as a way to improve preconception care in general (Stephenson, *et al*., 2021). However, Forde et al., (2020) cautioned that healthcare professionals in primary care have limited capacity to provide pre-pregnancy care, and few UK practices have a written policy on delivering pre-pregnancy care (Shannon *et al*., 2014). Furthermore, there is a risk that this approach could perpetuate some of the issues highlighted by Earle *et al*., (2017), such as a lack of clarity about what pre-pregnancy care should consist of, a lack of expertise in delivering the core elements, and it would still remain unclear who was responsible for the needs of this group.

Regarding accessing support to prepare for a subsequent pregnancy, participants' responses highlighted that not all services had a dedicated pre-pregnancy care service to refer women with diabetes into. Where pre-pregnancy care services did exist, some healthcare professionals and women with diabetes suggested that the referral process to pre-pregnancy care services was not straightforward and, in some areas, could take a long time, which may also contribute to poor uptake, as women with diabetes in the inter-pregnancy interval might not feel like they have much time. The referral pathways for women with type 2 diabetes were reported to be particularly unclear, and this group can be more easily overlooked as they have less routine contact with healthcare professionals, especially diabetes specialists, which creates an even more significant gap in inter-pregnancy care provision and patchy referral pathways. The delivery of pre-pregnancy care has been described as fractured in the literature, and healthcare professionals have described a lack of agreement about who should provide pre-pregnancy care and the best way to deliver it (Earle *et al*., 2017). As highlighted by Murphy et al., (2010) and Hopkins *et al.* (2023), this can disproportionately affect vulnerable and ethnic minority groups, who may lack the communication, self-efficacy and self-management skills required to access the care they need.

Part of the problem here may be how maternity services are set up and funded by tariffs. Pregnancy is funded by a tariff, but preconception care is not. Therefore, the lack of pre-pregnancy care is partly a consequence of structural issues, as it is not clear who funds the care and appointments. If medical knowledge is produced by and reflects the society that it is formed in (White, 2002), has society decided that pre-pregnancy care is not worth spending money on? It is not clear whether specialist diabetes services have the capacity and set-up for primary care to refer women with type 2 diabetes into their services. While there is undoubtedly value in pre-pregnancy care services (for example, dedicated time and space), it risks being another burden for women with diabetes if it is not easy to access in a timely way.

Fundamental to improving the service to women with diabetes is local services (diabetes, maternity, primary care, public health and commissioning teams) working collaboratively to create coordinated national initiatives (Klein *et al*., 2017). Cross-cultural communications, services and pathways need to be developed to ensure that all women with diabetes, irrespective of social or cultural barriers, understand the importance of preparing for pregnancy, and locally commissioned diabetes education programmes include information about contraception and pregnancy preparation. This could include embedded prompts within all electronic patient records to support the uptake of safe and effective contraception as well as current and future pregnancy plans with all women in childbearing years (Yamamoto *et al*., 2018).

In summary, it was unclear who was responsible for looking after the interests of women with diabetes in the inter-pregnancy interval. There were no reports of clear, standardised referral pathways within the healthcare system for providing bereaved women with diabetes information and support around a subsequent pregnancy during the inter-pregnancy interval. However, the complex and individualised needs reported suggest that offering a standardised care pathway would be challenging.

5.6 Summary of descriptive thematic analysis

The descriptive findings exposed how women with diabetes may find themselves in a predicament in the inter-pregnancy interval, owing to the number of barriers they may face in terms of being ‘optimally prepared’ for a subsequent pregnancy.

There was a disconnect between healthcare professional assumptions and women’s needs in the inter-pregnancy interval. All women with diabetes knew straight away that they wanted to try for another pregnancy at some point, but healthcare professionals may be wary of initiating discussions about subsequent pregnancy. The potentially short inter-pregnancy interval means that there were reduced opportunities for contact with healthcare professionals, limiting the time period for supporting women with diabetes to prepare for a subsequent pregnancy.

Preparing for pregnancy is not easy and takes time. The requirement to be ‘optimally prepared’ for pregnancy generates additional burdens to an already over-burdened group. Women with diabetes may feel overwhelmed or distressed by the prospect of preparing for pregnancy for lengthy periods as being in ‘pregnancy mode’ was difficult to sustain. In addition, it is unclear who has responsibility for ensuring this group’s needs are met during the inter-pregnancy interval, imposing an unfair burden on women with diabetes to be highly proactive in seeking advice.

Unclear referral pathways compounded the problem, as healthcare professionals found it difficult to refer women to services, and women with diabetes found it challenging to know whom to turn to or found accessing care burdensome. Healthcare professionals were frustrated by the lack of funding in this area, often relying on informal networks and third-sector charities to plug perceived gaps in provision.

These findings support existing research that highlight the structural issues in services, challenges in funding pre-pregnancy services and resulting disconnected and inconsistent care. The findings laid bare some of the disparities between type 1 diabetes and type 2 diabetes care provision, which is supported by the literature. The findings present a more nuanced framing of the inter-pregnancy interval, whereby ‘poor preparation’ for subsequent pregnancy in the inter-pregnancy interval is less a moral failing of the individual, but rather something that could be attributed to these structural issues and discontinuities in care.

The next chapter, part two of the analysis, presents the explanatory thematic findings and discussion. The theoretical frameworks set out in Chapter Three (sections 3.5-3.8) helped to explore some of the underpinning structural forces at play in the inter-pregnancy interval.

Chapter 6. Analysis Part Two: Explanatory findings and discussion from the thematic analysis

6.1 Introduction

The findings from the thematic analysis have been split into three broad parts (descriptive themes, explanatory themes followed by a synthesis and further discussion of the themes using a stigma syndemics framework) as set out in Chapter Four, section 4.6.2). This chapter (part two) focuses on the explanatory findings from the thematic analysis and uses the theoretical frameworks discussed in Chapter Three (sections 3.5-3.8) to interpret the data further and build on the descriptive findings from part one. Together, these findings help paint a picture of the landscape in which women with diabetes find themselves in the inter-pregnancy interval. There are three main explanatory themes: (1) Lost without a map: liminality and stigma in the inter-pregnancy interval; (2) Biomedicalisation in the inter-pregnancy interval and stigmatised pregnancy; and (3) Neoliberal strategies of responsibilisation. Figure 6.1 provides a visual depiction of the explanatory themes and subthemes.

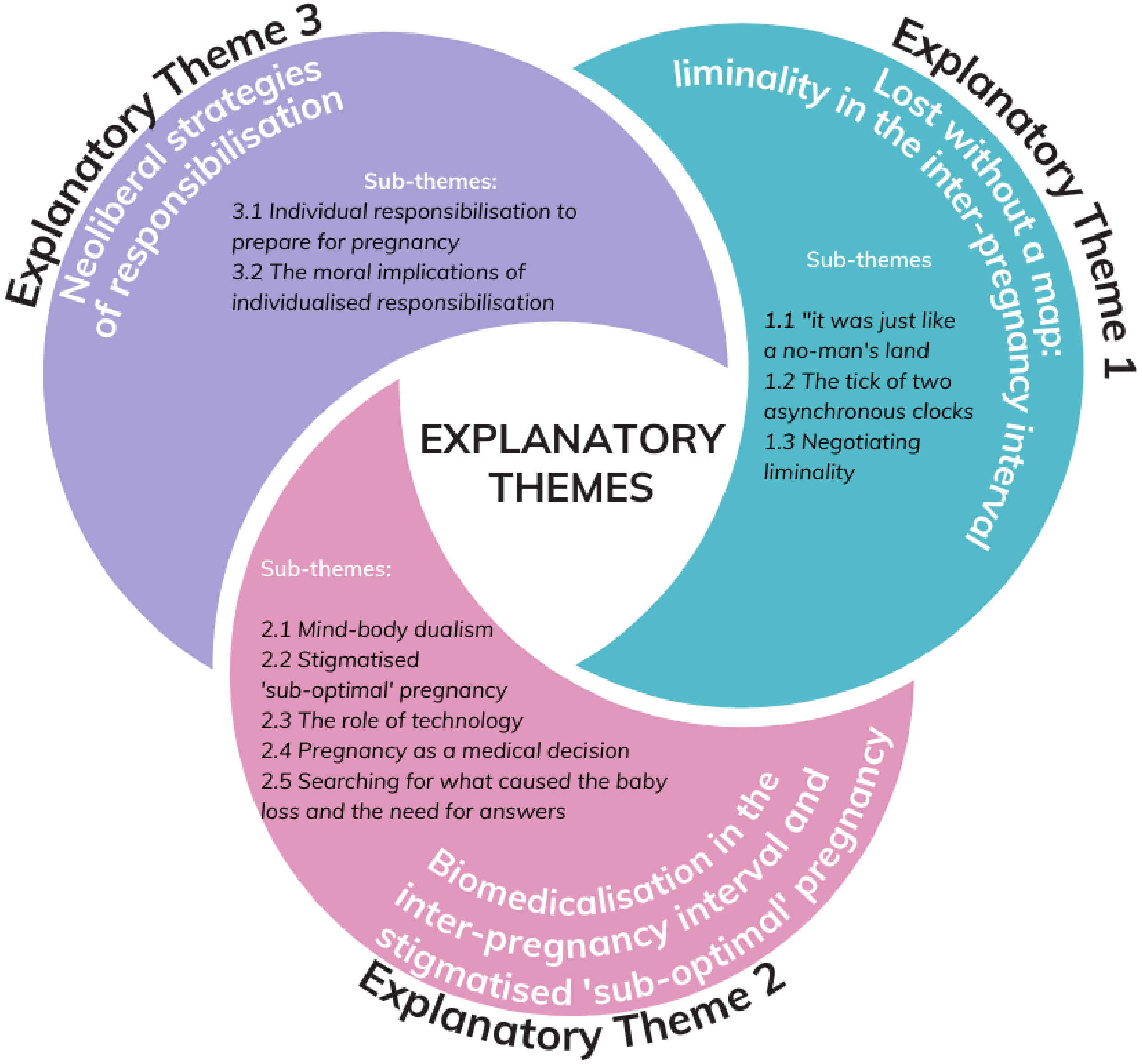

Figure 6.1: Thematic map overview of the explanatory themes and subthemes

6.2 Explanatory theme 1: Lost without a map: liminality in the inter-pregnancy interval

The inter-pregnancy interval encapsulates and embodies the concept of liminality. After a baby loss, mothers are symbolically detached from the social status of both pregnancy and parenthood (Reiheld, 2015). The nebulous and spoiled identity of being non-pregnant (Bansen and Stevens, 1992) has the potential to make women with diabetes feel stigmatised and othered.

To become pregnant again, women with diabetes must cross the 'threshold' of the inter-pregnancy interval. As explored through the descriptive themes (Chapter Five) crossing this threshold is not easy. Women with diabetes face complex burdens which obfuscate their journey to becoming pregnant again. The gaps in knowledge, training, and skills, coupled with unclear referral pathways, culminate into a precarious inter-pregnancy interval that is challenging to navigate. There is neither a map nor a clear path for women with diabetes to traverse the liminal landscape of the inter-pregnancy interval.

6.2.1 Subtheme 1.1: "It was just like a no-man's land," being 'in limbo' in the liminal inter-pregnancy interval

The women with diabetes participants spoke of difficulty managing the yearning for a subsequent pregnancy and the need to recover mentally and physically. When viewed through the lens of liminality, the inter-pregnancy interval can be seen as a 'limbo', or as WWD10 described it, a "no man's land".

The sudden detachment from their prior social status was mirrored in the care provision. Women with diabetes were ejected from their pregnant identity when they were taken off one list and put on another, leaving them "abandoned" (HCP16) as they did not feel like they belonged on either list, for example:

> *"I think in the hospital, it's a little bit like, either you're pregnant, or you're not. If you're pregnant, then you're on this list for these appointments […] and if you're not pregnant, then you're on this list for [these] appointments […] you were either one or the other."* WWD1 Type 1 Diabetes, Early Miscarriage

Any feelings of ambiguity, loneliness and unbelonging seemed to be perpetuated by the lack of structured medical support in the inter-pregnancy interval, as discussed in Chapter Five (section 5.4.1). This disconnection in referral pathways led to perceived gaps in care where women with diabetes were left on their own during the inter-pregnancy interval

> *"I think some sort of a de-brief after the miscarriage before the next attempt would probably have been useful but was never offered. I got this very much from talking to the diabetic midwife, but there was no pathway for that. It was just […] like a no man's land in terms of, well like, if you're worried you can call us, but there's nothing structured there"* WWD10 Type 1 Diabetes, Early Miscarriage

There was potentially a subconscious element of knowing that at least when they became pregnant again, they would have support and, therefore, a sense of belonging.

> *"I was thankful to actually have diabetes because it meant I was monitored, you know, more closely, physically anyway."* WWD4 Type 2 Diabetes, Early and Late Miscarriages

Some women with diabetes turned to online support communities and bereavement groups for support and a sense of solidarity and understanding. Some healthcare professionals noted peer support as offering the potential to be helpful to women with diabetes as they faced unique challenges. One participant spoke about feeling guilty about attending a baby loss group when they already had an older child and did not feel like she fitted in with the other parents who were yet to carry a baby to term. One participant reflected on how the bereavement support did not encompass the additional layers of complexity when diabetes was added to the equation. For example, she did not feel the bereavement care was well suited to managing the complexity that women with diabetes faced, especially surrounding the additional layer of guilt resulting from the implied mismanagement of diabetes as potentially being the cause for the baby loss.

> *"[It would have been helpful to have] even a phone conversation with someone who had some background knowledge of long-term health conditions and pregnancy loss. Not even necessarily diabetes, but complication that you deal*

> *with on a daily basis that could cause that problem. It wouldn't necessarily have to be someone who has a diabetes background but just someone that understands the complexity of the medical conditions behind the baby loss, rather than just baby loss."* WWD5 Type 1 Diabetes, Late Miscarriage

6.2.2 Subtheme 1.2: The tick of two asynchronous clocks

In Chapter Five (section 5.2.4), subtheme 1.4 described how women with diabetes reported how they perceived a time pressure to become pregnant again, including fears about their fertility levels decreasing with age and societal expectations to try again for another pregnancy. Women with diabetes also reflected on how, at the time, the inter-pregnancy interval felt like a long time, although objectively, it was not.

> *"Now [looking back], that year seems like nothing at all, but when you're trying every month, it just felt like the longest time ever."* WWD2 Type 2 Diabetes, Neonatal death

Whilst inhabiting inter-pregnancy interval, months may feel like years or even a "lifetime" (WWD8). It is only from the vantage point of having a subsequent baby that women with diabetes could see that, objectively, the time they were 'trapped' in limbo was not as interminable as it felt at the time.

Healthcare professionals may have a different frame of reference to women with diabetes and may not be aware of how differently time is perceived during the liminal inter-pregnancy interval.

> *"I see women who have a loss and then fall pregnant again very quickly afterwards, and they're still in the same situation as they were before. And the risk is still really high."* HCP18 Diabetes Specialist Nurse

6.2.3 Subtheme 1.3: Negotiating liminality – re-incorporating women with diabetes by filling the gaps in care

The women with diabetes participants were usually referred back to their 'normal' care, whether with the diabetes service or back into the community setting. However, the participants in this research knew they wanted to be pregnant again at some point and some viewed the baby loss and inter-pregnancy interval as a part of the pregnancy journey.

> *"My losses, they've always been a […] part of the next pregnancy."* WWD4 Type 2 Diabetes, Early and Late miscarriages

HCP17, a bereavement midwife, recognised how most of her women with diabetes patients went on to become pregnant again within a year and recommended that women with diabetes continue taking folic acid.

> *"I always tell the mums who have […] lost a baby to go back on folic acid straight away. I always say […] a lot of these babies won't be planned, and I know you think at this minute in time leaving this hospital that you're not going to have another baby. But […] from experience […] nine times out of ten you have another baby within a year, and these babies aren't planned, and the folic acid won't do you any harm, but it will definitely do your baby some good."*
> HCP17 Bereavement Midwife

HCP15 spoke of how women with diabetes who had experienced loss were routinely offered an appointment in the preconception clinic six weeks after the baby loss.

> "*We [automatically refer women] straight back [into preconception care after a loss] because there was a breakdown in so many angles, like the GP might think the consultant was seeing her, and the consultant might think the GP was seeing her […] I know the flaws in the system [and] I don't want them to be part of the flaw […] I say, 'this is my number, I would like you to come to our preconception clinic where we go through everything that has happened to you and right the wrongs that you're feeling at the minute, but we're going to give you time […] we want you to come back to us in six weeks, have your questions ready.'"* HCP15 Midwife

HCP15 emphasised that the women were not pressured to attend the pre-pregnancy service, and it was possible to defer or cancel the appointment. HCP15 remarked that the women seemed to appreciate the automatic referral.

6.2.4 Summary of explanatory theme 1: lost without a map: liminality and stigma in the inter-pregnancy interval

Viewing the inter-pregnancy interval through the frame of liminality and seeing baby loss as an uncomfortable extension of the pregnancy journey helps to interpret and clarify the meaning of the data. The asynchrony of wanting to be pregnant again clashes with perceptions of the interminable and excruciatingly slow passage of time in the liminal inter-pregnancy interval.

6.3 Explanatory theme 2: Biomedicalisation in the inter-pregnancy interval and stigmatised 'sub-optimal' pregnancy

Underpinning the liminal inter-pregnancy interval is the biomedical model of chronic illness, a strand that fits into both the liminal and neoliberal themes. Pregnancy is conceptualised as 'high risk' for women with diabetes, which requires women with diabetes to be heavily monitored during pregnancy and their babies delivered in hospitals (Nettleton, 2013).

It is not possible to escape the fact that women with diabetes who experience baby loss do so in a medicalised healthcare system. The aim here is not to challenge the basis of medical knowledge or to suggest that pregnancy should not be medicalised for women with diabetes, but to contextualise how the liminal inter-pregnancy interval is experienced within a medicalised system, and how having a chronic illness, like diabetes, contributes to the stigmatisation of pregnancy. To explore this further, Nettleton's (2013, p. 2) five key assumptions of the biomedical model was used as a framework to organise the themes. Table 6.1 shows how the inductive themes generated from the thematic analysis mapped onto Nettleton's framework.

	Nettleton’s five key assumptions	Subtheme title
1.	The mind and body can be treated separately (mind-body dualism)	Mind-body dualism in the inter-pregnancy interval
2	The body can be repaired like a machine	Stigmatised ‘sub-optimal’ pregnancy
3.	The merits of technological interventions are sometimes overplayed	The role of technology in the inter-pregnancy interval
4.	Biomedicine is ‘reductionist’ in that diseases are explained by biological changes and neglect social and psychological factors	Pregnancy is a medical decision, no longer a choice
5.	Reductionism is accentuated by the ‘doctrine of specific aetiology’ whereby a specific and identifiable agent causes all diseases	Searching for what caused the baby loss and the need for answers

Table 6.1: The five key assumptions of the biomedical model (Nettleton, 2013)

6.3.1 Subtheme 2.1: Mind-body dualism in the inter-pregnancy interval

Many of the women participants reported how they did not feel holistically cared for during the inter-pregnancy interval. They spoke of how their physical health and diabetes management was the focus of healthcare in the inter-pregnancy interval. The ‘disease focus’ meant that women with diabetes’s ‘pregnant’ identities were overlooked, as was their need for holistic, emotional and psychological support for managing the multiple burdens they may experience after a baby loss, as explored in Chapter Five (section 5.3).

> *“I think my medical care while I was pregnant was brilliant, but the mental side of it wasn’t so supportive.”* WWD5 Type 1 Diabetes, Late Miscarriage

Women with diabetes spoke about how they would have appreciated it if a trusted healthcare professional could have “taken the lead” (WWD4) to reach out just to ask, “how are you doing?” (WWD4) and would have welcomed more follow-up (WWD5):

> *"I could have picked the phone up, but I wasn't in the right place to think. Maybe there should have been just a little more follow-up. I don't think one visit from a bereavement midwife after you've come home cuts it, and I get that they're overwhelmed with people they've got to deal with. But they could pick up the phone as much as I can."* WWD5 Type 1 Diabetes, Late Miscarriage

The simple act of opening up the conversation to see whether additional support could be offered would have been more helpful than giving women with diabetes a pile of leaflets to read.

> *"Is there anything we can do from this side to help you? Are you still going to your counselling? Is there any other support you need? Is there anyone we can contact for you? That probably would have been the most helpful. But no, [the phone numbers] were in the leaflets, and yeah, I never really bothered reading them. They'll still be lying around somewhere."* WWD4 Type 2 Diabetes, Early and Late Miscarriages

Nevertheless, this is still a difficult conversation to navigate and requires clear referral pathways, which may not be in place. HCP18 spoke about how difficult it was to navigate these types of conversations in practice, especially over the phone.

> *"Over the phone, it's very difficult, but I'm looking for cues that they've had enough speaking to me, that they're trying to get off the phone or that they want to keep talking. Then I'll work out with them what they want. It's difficult [for us to tell] when somebody [says] that they want to be left alone, that they're doing okay, that they don't need anything, but actually they're not [ok]."* HCP18 Diabetes Specialist Nurse

6.3.2 Subtheme 2.2: Stigmatised 'sub-optimal' pregnancy

Another tenet of the medical model is the notion that the body can be repaired as if it were a machine. A number of women with diabetes spoke of how they felt judged by healthcare professionals when their blood glucose levels were 'sub-optimal' for pregnancy.

> *"[The healthcare professional] opens the book, looks at the numbers and makes you feel very guilty and hate diabetes. And I don't want to hate diabetes. […] My sugars are not going to be perfect at all times [..] they didn't like the low sugars […] and they didn't like the eight and nines. Look, I don't know how to make it perfect all the time."* WWD9 Type 1 Diabetes, Stillbirth.

Maintaining tight control of blood glucose levels was reported as being the most challenging aspect of being 'optimally prepared' for pregnancy by both healthcare professionals and women with diabetes.

> *"I think the HbA1c targets, I know why they are what they are, I think that's probably the most challenging. You know we can put them on folic acid we can try and make sure they've had retinol screening within a few months before they conceive we can check their blood pressure. But I think the hardest bit for most women is getting that HbA1c."* HCP11 Endocrinologist

Women with diabetes were required to attain the HbA1c targets with minimal support. For example, both women with diabetes and healthcare professionals spoke of how suboptimal funding levels meant that the testing strips and lances used with blood glucose monitors were not freely available on prescription outside of pregnancy for both type 1 diabetes and especially women with type 2 diabetes.

> *"The GP did not like the fact I was checking my sugar a lot. I had to get a few letters from [the diabetes consultant] and give them to the GP because they were not giving [me enough] test strips. […] They were giving me fifty strips at a time, and I'm like, 'What will fifty do? Fifty is [enough] for five days 'cos I used to test myself ten times a day […] I know it's a bit on the extreme side, but […] another person is relying on me. I really need to make sure my sugar is the best it can be."* WWD9 Type 1 Diabetes, Stillbirth

> *"We get them to test so much, and so they're pretty much going for a pot of strips, you know, almost on a fortnightly basis. And actually, primary care can sometimes be very difficult about that. […] we issue them [with a monitor]*

> *when they're initially pregnant. And we do that for all women, so they've still got the monitor, but they do need the disposables on a repeat prescription from the GP."* HCP12 Obstetrician

6.3.3 Subtheme 2.3: The role of technology in the inter-pregnancy interval

Technology was widely regarded by both women with diabetes and healthcare professionals as being instrumental in helping women with diabetes become prepared for pregnancy, as it provided a way for women with diabetes to have tighter control of their blood glucose levels.

WWD9 described how being granted access to a 'Libre' sensor in the inter-pregnancy interval made a big difference to her ability to prepare for a subsequent pregnancy, as it gave her a sense of control and ownership of her condition, whereas she previously had to rely on infrequent diabetes appointments:

> *"Nothing much really changed, except with the Libre […] You're still only seen every six months and you get advice on what they can see […] I used to ask the GP for folic acid but I wasn't telling my diabetic clinic [about my pregnancy plans."* WWD9 Type 1 Diabetes, Stillbirth

At the time of interview, women with diabetes were not technically eligible to access diabetes technology, when 'not pregnant', although it seemed like healthcare professionals tended to turn a blind eye to this, as they could see the benefit of how technology was a helpful tool for women with diabetes. However, there was an obvious divide between type 1 and type 2 diabetes, which was reported by the majority of the healthcare professional participants.

> *"If you think somebody is going to scan really regularly and get some benefit there is a way to make sure that they have one […] our type 1's yes but for the type 2's no, they don't get offered this do they, so you know and if they're not on insulin they don't even get offered blood glucose monitors."* HCP14 Diabetes Specialist Dietician

> *"So, type 1's get the CGM but type 2's don't […] in fact, the flash [Libre], they won't get that either. Some of them will pay for it, but they won't get it as routine."* HCP16 Diabetes Specialist Midwife

Although the merits of technology were acknowledged, some healthcare professionals recogonised that technology could fuel a "fixation on blood sugars" (HCP14) for both healthcare professionals and women with diabetes alike, which had the potential to contribute to stigma and feelings of guilt if the technology evidenced 'sub-optimal' blood glucose levels.

6.3.4 Subtheme 2.4: Pregnancy as a medicalised decision, no longer a 'normal' life choice

For some of the women with diabetes participants, the construct of a 'normal' pregnancy was no longer an option as their diabetes was so heavily medicalised.

> *"People don't want to think that this could cause many problems they just want to have a baby like their friends are having babies and they just want to get on with it and not have to medicalise it."* HCP6 GP

For some, medicalisation posed a challenge in terms of becoming pregnant again, for example, WWD10 described being denied the "luxury" of just deciding to "come off the pill" to "see what happens" (WWD10). Instead, pregnancy was constructed as medically 'high risk', and subsequently choosing to become pregnant became a medical decision.

> *"It's trying to sell preconception care […] planting that seed that if we can get your diabetes as tightly managed as possible, the risks are reduced. But sometimes the desire for a baby is so strong that nothing else matters, so you just have to work with the situation we're in, give as much support as we can to get things controlled and keep fingers crossed."* HCP18 Diabetes Specialist Nurse

Some women with diabetes participants felt that the choice to become pregnant was a personal one, and they did not see the benefit of consulting healthcare professional involvement in the 'thinking stage'. For example,

> *“How do you ring somebody and be like, ‘I’m thinking about this. What do I need?’ It’s just like it happens or it doesn’t, [that] was how we were thinking about it.”* WWD6 Type 1 Diabetes, Late Miscarriage

The resulting silence around becoming pregnant entrenches the idea that it is a private matter.

> *"We don’t talk about the reproductive system because ‘that’s not for us to discuss’, but we need to get over that. […] People get pregnant, and we need to do it safely. Yeah [it’s awkward], but it’s the need. The risks are so high we need to almost get over that a little bit.”* HCP18 Diabetes Specialist Nurse

Instead of discussing pregnancy, healthcare professionals tended to focus on and emphasise contraception, although a number of healthcare participants commented on how women with diabetes were not always receptive to discussing contraception and pregnancy planning.

> *“They’ve said, ‘no, I’m not planning’ […] and then two months later they turn up in antenatal clinic! So, you know, that is just very frustrating.”* HCP1 Diabetes Consultant

> *“They don’t like [talking about contraception] normally at all, at all. They either say ‘there’s not a problem, I’m not thinking about it, I don’t want contraception’. They get like a little bit tense. Most of the others are like, ‘yeah I’m on contraception, don’t worry.’ […] I think it’s because it’s something very intimate it’s about their personal life it’s not about how you doing with the sugars, how’s work and everything like that. It’s about their own sexual activity and that’s always difficult.”* HCP8 Diabetes Consultant

HCP1 reported a tendency for women to only seek out healthcare professional involvement when they struggled to conceive, rather than to ask for support in preparing for pregnancy.

> *“One of our main sources of referral [to the pre-pregnancy clinic] is overweight women going to their GPs to say they are struggling to get pregnant.”* HCP1 Diabetes Consultant

HCP6, a GP, reported how oftentimes women with type 2 diabetes would deny pregnancy intentions or not want to talk about a potential pregnancy, but would then become pregnant soon afterwards.

> *"We need to bear in mind many, many pregnancies […] are actually not planned at all […] that's when it's really hard to provide any kind of preconception care because you know, we've had women who've been to their appointments, and said 'no, not thinking about pregnancy' and then, eight weeks later come in 'oh I'm pregnant!' Which is great and they're happy and that's lovely but you just, your heart is sinking a little bit because you know they've got a Hb1c of ninety and BMI of forty and you know they've not been taking folic acid. […] I think that's the group that's it's important to target with all of this advice even if they're not trying for a baby actively at that time."*
> HCP6 GP

6.3.5 Subtheme 2.5: Searching for what caused the baby loss and the need for answers

Not knowing why the baby loss happened was reported as difficult for women with diabetes:

> *"I am really fortunate to have gotten answers from mine. Because my biggest fear was sending him off for a post-mortem and then it coming back with there was nothing, like nothing wrong, nothing."* WWD4 Type 2 Diabetes, Early and Late Miscarriages

> *"In terms of becoming pregnant again after miscarriage my experience was that it was kind of slightly dismissed […] especially as I had had a successful pregnancy before […]it was very much like, well, you know, one in three, four women miscarry [you] just have to wait and try again. There was nothing, there was no medical advice or thinking around it. It was very much just one of those things that happens. Which, in a way, is good, but I'm the sort of person that likes to know why things happen, so it was kind of frustrating for me."* WWD1 Type 1 Diabetes, Early Miscarriage

All the women with diabetes who had post-mortem tests carried out on their babies waited for the results before becoming pregnant again, which suggests how important it was to get answers.

Participants were not clear on how to best manage conversations about the cause of baby loss in the context of diabetes. Some healthcare professional respondents tried to mitigate against feelings of blame by handling conversations "tactfully" (HCP18) – even though they could not rule it out as a cause, they would try and underplay the role of diabetes:

> *"If they have had a [baby loss] and they had high HbA1c, it's just tactful telling them it's not your fault it happens."* HCP18 Diabetes Specialist Nurse

It is essential to acknowledge how hard it must be for healthcare professionals to negotiate such conversations. For example, HCP14, a Diabetes Specialist Dietician, found it "heart-breaking" when asked by a patient whether they thought the baby loss was caused by diabetes management. HCP12, an obstetrician specialising in diabetes, reflected on how even though they had conducted post-mortem follow-up appointments for many years, they found the appointments with women with diabetes "one of the most difficult", to conduct, in part due to carefully treading the line between providing answers and avoiding ascribing any blame.

> *"I think there's a lot that we could do about that non-judgemental support, and I don't know how. I need very clever psychologist to kind of help with that. […*] *Quite often, what you're telling women is that the diabetes is the source of the problem [sighs] […] I do bereavement follow-ups for other problems in pregnancy, and quite often, we don't find a recurring reason for the loss. Which I think as it happens, we can feel quite guilty about and the fact that we can't tell them why this happened and what the pathology is. But actually, it gives them the reassurance that there isn't an underlying process that's going to recur. With women with pre-existing diabetes, I can't give them that*

> *reassurance […] They can reduce their risks, but this is going to be an issue that's going to recur with every pregnancy they have."* HCP12 Obstetrician

6.3.6 Summary of explanatory theme 2: Biomedicalisation in the inter-pregnancy interval and stigmatised pregnancy

Using Nettleton's (2013, p. 2) five assumptions of the biomedical model as a framework, this section explored how the underpinning medical model of chronic illness contributed to socially stigmatised pregnancy for women with diabetes in the inter-pregnancy interval. Women with diabetes who became pregnant again before being 'optimally' prepared faced being stigmatised should anything go wrong in the pregnancy. Accounts from both healthcare professionals and women with diabetes suggest that care focused on the physical aspects of diabetes management, and there appeared to be less emphasis on the psychological and mental well-being aspect. Many women would have welcomed more emotional and psychological support in the inter-pregnancy interval. Technology may play a role in ensuring that women with diabetes are prepared for pregnancy, but accessibility is a barrier.

6.4 Explanatory theme 3: Neoliberal strategies of responsibilisation

Neoliberal strategies of responsibilisation capture the zeitgeist of medical management today, whereby individuals are responsible for their own health and lifestyle choices (see Chapter Three, section 3.7). In the neoliberal society, women with diabetes must be compliant, or at least 'able to be willing' to 'optimally prepare' for pregnancy to reduce their risk of subsequent baby loss.

6.4.1 Subtheme 3.1: Individual responsibilisation to prepare for pregnancy

During the inter-pregnancy interval, the women with diabetes participants reported a lack of support in working how the NICE (2015) preconception guidelines translated into what they needed to do on the day-to-day to 'optimally prepare' for pregnancy:

> *"It's easy enough to say, 'Oh, your blood sugar needs to be really tightly controlled'. But then the reality of the ways that you can achieve that, especially without CGM at the time, well, that requires a huge amount of work*

> *that you're kind of just left on your own to deal with."* WWD10 Type 1 Diabetes, Early Miscarriage

> *"I had to start reading slightly random books […] by a controversial American guy to actually get me to the levels I wanted to be at. I found that the guidance is clear in terms of, 'This is the level we recommend you be at to safely have a pregnancy.' Got it. That's clear. But, for me, how do I get there was actually something that I had basically no advice on. The only advice that I received for me didn't work at all."* WWD1 Type 1 Diabetes, Early Miscarriage

Some women approached this challenge by viewing the inter-pregnancy interval as an extension of their pregnancy, termed "pregnancy mode" by WWD1. Essentially, this required the women with diabetes to manage their diabetes as if they were pregnant but without the support in formal healthcare that is available during pregnancy. This required a great deal of agency and responsibility:

> *"You're expecting them to monitor and to make these really close adjustments. But you know then you're leaving them to try and work out how to make this better and how to interpret all this information that they're now getting about their glucose levels and their diet. And actually, if we spoke to them monthly, we could talk through what's happening, why the highs and lows are happening and make small adjustments. Whereas we're just not seeing them as often to do that, and so the psychological burden of this is very intense."* HCP14 Diabetes Specialist Dietician

Many of the women with diabetes participants reported that suggestions to improve care or solutions to manage their condition drew on individualised actions, such as eating 'healthier' food and exercising more. WWD2, for example, who was diagnosed with type 2 diabetes one year before she became pregnant with her first baby, who died shortly after birth, was actively trying to prepare for pregnancy after she "heard that if you have high blood sugars when you conceive, that can cause problems with the baby." WWD2 actively sought out advice from the local diabetes clinic, which "Didn't tell me anything I didn't know already" and just said, "Keep on doing what you're doing." WWD2 was "So desperate to do something" that she took matters into her own hands and tried her hardest to lose weight and manage her diabetes by herself with no support and ended up injuring herself and experiencing hypoglycemia as a result:

> *"I needed to do something about my diabetes, so I tried to lose loads of weight, and I was doing this […] five hundred calorie diet. […] basically, you could reverse your diabetes, and I […] lost like a couple of stone, but it's really hard to maintain. It's horrible. […] The stress I was doing to my body in terms of trying to lose weight but obviously the desperation of trying to get pregnant again in that time and just trying to manage my diabetes […] it was all going well until I broke my ankle and then I slowed down […] I was just doing too much, I think, to try and get my body ready for pregnancy again."* WWD2 Type 2 Diabetes, Neonatal Death

This example encapsulates what is expected when women with diabetes are individually responsible for preparing for pregnancy after a baby loss and touches on the stress it may cause for women with diabetes who are left responsible for preparing by themselves. In some ways, WWD2 did precisely what was expected of her. After her baby died, she took ownership of her condition to ensure she was prepared for a subsequent pregnancy – but with dangerous consequences. The potential for there to be a "fixation on blood sugar levels" (HCP14) to try and make them perfect can result in behaviour not unlike an "eating disorder" (WWD1).

> *"It's probably similar to some extent to an eating disorder, in the sense where like […] there's a sense of control, right? […] I can't control if I have a miscarriage or not, but the one thing I can control is my blood sugar, so [….] I'm going to try and control that as much as I can."* WWD1 Type 1 Diabetes, Early Miscarriage

> *"It's like you have to act as if you are pregnant all the time, and most of the time you're not […]. I'm taking my folic acid. I'm keeping my blood sugars super tightly controlled, which for me requires quite a lot of work to keep them super tightly controlled and then this feeling of like, well, it's for nothing. [It's] incredibly challenging [and] I found it even more challenging after having had*

> *the miscarriage, and there seems to be no acknowledgement of that."* WWD10 Type 1 Diabetes, Early Miscarriage

The more affluent individuals are, the more able they are to conform to a 'healthy' lifestyle and the ideals of pregnancy preparation, and so the impact of neoliberal policies falls the hardest upon the poorest, perpetuating health inequalities.

> *"Our poorest patients don't have the resources in terms of ability to buy better food and cook it. In terms of space to actually exercise or in terms of ability to simply have the time to look after themselves because a lot of our patients are in low-end jobs where they don't get paid if they don't turn up to work, and while the hours are long and possibly longer than the hours that they're actually getting paid for. And where they're essentially, you'll forgive my language, eating crap because they are just too tired when they get in from work to do anything other than that before they fall asleep and get up again for another long grind of a day."* HCP7 GP

6.4.2 Subtheme 3.2: The moral implications of individual responsibilisation

Baby loss can be framed as an individual tragedy that can be prevented. WWD1, for example, questioned whether she was responsible for the miscarriage:

> *"In the back of my mind, I was like, 'did I miscarry because my diabetes wasn't as well controlled?'[…] especially having had the miscarriage, I was like, oh well, I have to try even harder to have my diabetes be perfect, so actually, my HbA1c was even lower [for the next pregnancy] I was just like, 'I'm not taking any chances with this.'"* WWD1 Type 1 Diabetes, Early Miscarriage

This can leave women with diabetes feeling morally reprehensible for their actions pre-pregnancy, which many women with diabetes are painfully aware of after suffering a baby loss.

> *"I think you get it drummed into you so much before you become pregnant that high blood sugars cause pregnancy loss and cause big babies and all these sorts of problems. But I became absolutely petrified of eating and drinking the wrong*

> *thing and how each thing that I did was going to affect my diabetes control […] I was petrified of my blood sugars getting slightly out of range because I thought if they did, I'd cause harm to my baby."* WWD5 Type 1 Diabetes, Late Miscarriage

Generally, information was seen as 'empowering' for women. For example,

> *"Information needs to be made available to them […] education is very empowering isn't it? And diabetes is all about self-management, and I think it should be for every woman of childbearing age who's diabetic. Somebody should be asking or making sure they're having this conversation with them. Because it's their body, it's their health. It's their mental health afterwards."* HCP14 Diabetes Specialist Dietitian

Not everyone has easy access to the internet and a high level of health literacy, as brought to light by HCP7, a GP in a deprived area in the North East of England:

> *"Does [the information] exist? Yes, yes, it exists, but you've got to have the resources to find it. So the Diabetes UK site and the NHS Choices website, these are good. These are really good sources of information […] But again, a lot of this is resource dependant […] they're great if you have decent internet access and, importantly, can read. […] Quite a lot of our patients, certainly high double figures, are essentially either illiterate or very, very close to it. And we're not talking about people who don't have English as their first language. We're talking about native English speakers who are simply hugely undereducated and have a learning disability or both."* HCP7 GP

6.4.3 Summary of explanatory theme 3 - Neoliberal strategies of responsibilisation

Women with diabetes are at an increased risk of baby loss. Rather than seeing this risk as evidence of the need to develop better standards of care in the inter-pregnancy interval, neoliberal strategies of responsibilisation mean that women with diabetes are responsible for their health and lifestyle choices to ensure they are 'optimally prepared' for pregnancy. However, women with diabetes may not have as much choice and autonomy as assumed, and access to such opportunities is affected by social contexts.

6.5 Discussion of the explanatory themes

6.5.1 Introduction

This chapter focused on the explanatory findings from the thematic analysis and used the theoretical frameworks discussed in Chapter Three (sections 3.5-3.8) to interpret the data further and build on the descriptive findings from part one. There were three main explanatory themes: (1) Lost without a map: liminality and stigma in the inter-pregnancy interval; (2) Biomedicalisation in the inter-pregnancy interval and stigmatised pregnancy; and (3) Neoliberal strategies of responsibilisation.

This discussion aims to explore the key findings from the explanatory themes in relation to the existing literature and the research questions, aims and objectives, highlighting the implications for enhancing understanding and care provision in the inter-pregnancy interval.

6.5.2 Discussion of explanatory theme 1: lost without a map: liminality and stigma in the inter-pregnancy interval

This section discusses the first explanatory theme, where the inter-pregnancy interval is conceptualised as a liminal threshold that women with diabetes had to cross to become pregnant again. The women with diabetes participants found themselves thrust and suspended in an ambiguous state that eluded classification (Turner, 1979). Women with diabetes were no longer who or what they were (pregnant), but not yet who they were to become (a mother) (Dowling and Pontin, 2017); they were “undefinable” (Douglas, 1966, p. 119), and “suspended, or ‘stuck’ within an arrested journey that never arrived at its destination” (Browne, 2023, p.102).

Peer through the lens of liminality, and you see what it might mean to grieve when in ‘limbo’. As discussed in Chapter Five (section 5.2.2), healthcare professionals had varying ‘grief expectations’ about women with diabetes needing time to grieve before wanting to talk about a subsequent pregnancy. From a liminal perspective, being in limbo may intensify the pain, discomfort and suffering caused by grief, so leaving the limbo is one step closer to healing. The women participants knew straight away that they wanted to try for another baby at some point. For most women participants, there was a sense of urgency to become pregnant again, as if there was a "ticking clock" (WWD2). The literature on liminal states suggests danger, threat, and unease (Douglas, 1966; Navon and Morag, 2004; Thomassen, 2014). Being 'in limbo' is a disorienting and unsettling experience whereby the previous social identity of being pregnant is replaced by ambiguity and separation (Carson, 2002; Thomassen, 2014; Wagoner and Zittoun, 2021). It is therefore plausible that the yearning to be pregnant again was a reaction to not wanting to be in limbo – becoming pregnant again was one such way to leave the uncertain limbo of the inter-pregnancy interval and access a place of belonging and repair their spoiled identity (Goffman, 1963).

As mentioned in Chapter Five (section 5.5.2), previous baby loss research has pointed to the notion of the "ticking clock" (WWD2) and how a perceived lack of time might be a contributing factor in a short inter-pregnancy interval (Hughes, Turton and Evans, 1999; Meaney et al., 2017). Using liminal theory to explore the findings from subtheme 1.2, 'The tick of two asynchronous clocks,' (section 6.2.2) enabled me to capture a novel insight about a perceived duality of time, a recurring theme for many of the women with diabetes participants who described how at the time, the inter-pregnancy interval felt like an interminable amount of time, even though, in hindsight, it was not. For example, when in the liminal state of limbo, women with diabetes are stranded in a 'world between worlds' (Stenner, 2021). The whole concept of time may enter a new dimension when simultaneously trying to manage the tension of grieving alongside a yearning to be pregnant again. I propose that the desire to be pregnant and leave the liminal inter-pregnancy interval creates a new measuring system of time – almost like a time warp. The discomfort and unease of being in limbo mean that time seems to move slowly whilst, at the same time, there is a feeling of not having much time, as the external and internal pressures to become pregnant again as soon as possible remain (for example, increasing age, fertility concerns, of not knowing how long the journey will take, or whether the journey will lead to the desired destination). This sense of timelessness and ticking time meant that there were simultaneously "aeons of time" (WWD10) and 'not a lot of time' whilst trying to become pregnant again.

This perceived ‘duality of time’, which to my knowledge, has not been presented in other baby loss research, could help explain why women with diabetes may not want to extend the discomfort of being in limbo for any longer for two main reasons. Firstly, because ‘preparing’ for pregnancy may be burdensome, as discussed in Chapter Five (section 5.3). Secondly, because waiting too long risks women being trapped in limbo if they are no longer able to become pregnant. In this context, a ‘sub-optimal’ pregnancy may be considered preferable to the risk of no pregnancy. Becoming pregnant again is one step closer to gaining mother status and exiting the interminable limbo of the inter-pregnancy interval. It is as though a ‘time dilation’ occurs (May, 2021), whereby women with diabetes perceive time to slow down compared with healthcare professionals, who perceive women with diabetes become pregnant again quicker than they anticipate they should. This may go some way to explain why women with diabetes might feel the need to become pregnant again as soon as possible and could help healthcare professionals understand why women with diabetes would enter a subsequent pregnancy without preparing.

To recap, in *Les Rites de Passage,* van Gennep (1960) showed how life events, such as pregnancy, follow a distinctive three-phase ‘rites of passage’ pattern: (1) pre-liminal rites (the rites of separation) where one moves from the previous way of life towards the liminal phase (Dowling and Ponting, 2017; Madge and O’Connor, 2005); (2) liminal rites (the rites of transition) where one crosses the liminal threshold and leaves the old world behind (Madge and O’Connor, 2005; Reiheld, 2015; Stenner, 2021); and, (3) post-liminal rites (the rites of re-incorporation) where one is incorporated into the new social role and reassimilated into society, usually in a different social state (Turner, 1969). In terms of the re-incorporation phase and the healthcare delivery in the inter-pregnancy interval, the women with diabetes’s accounts suggest that they feel they are transferred back to the first ‘pre-liminal’ phase in the rite of passage, together with the responsibility to seek out pre-pregnancy care or vocalise their pregnancy plans proactively. This may be acceptable for someone who knows that they do not want to try for another pregnancy or those who know that they would like to wait for longer before trying. However, the participants in this research knew they wanted to be pregnant again and, as I have argued, may feel trapped ‘in limbo’ in the liminal phase. This juxtaposition of healthcare being in one phase and the women with diabetes being in another may help explain why uptake of pre-pregnancy care in the inter-pregnancy interval is so low. Currently, the lack of joined-up care in the inter-pregnancy interval intensifies the ambiguous nature of being in liminality - of being not quite one thing or another. Essentially, there is a conflict whereby healthcare services are aimed at a pre-liminal group; a 'not-pregnant' group. In contrast, the women with diabetes' accounts suggest that pregnancy may be viewed differently since experiencing baby loss; they are an almost 'un-pregnant' group who are already on their pregnancy journey.

By reframing the inter-pregnancy interval as a part of the pregnancy journey, a liminal phase, where a baby loss is no longer a 'failed pregnancy' but an extension of the pregnancy journey, healthcare professionals may understand the value of initiating a sensitive conversation about pregnancy plans at the earliest appropriate opportunity. The option for women to automatically refer themselves into pre-pregnancy care would allow the women with diabetes to be *re-incorporated* back into healthcare services that better reflected the stage that they were at in their pregnancy journey; it was potentially a steppingstone closer to *regaining the social status* of being pregnant and could be one way to help close one of the gaps in the referral pathway for women with diabetes in the inter-pregnancy interval. One healthcare professional participant (HCP15) suggested automatically referring women back into pre-pregnancy care services. Although this may be deemed controversial, it may help to prevent some women from falling into gaps in care provision and could help improve access to pregnancy preparation support in subsequent pregnancies.

While the concept of liminality seems to have gained traction in recent years, there is little literature or discussion on the topic, with only a handful of scholars applying the concept to miscarriage (Browne, 2022, 2023; Layne, 2003a; Reiheld, 2015). The notion that baby loss should be recognised as part of the pregnancy journey has been echoed in baby loss research, but not healthcare delivery, for some time (Browne, 2022; Côté-Arsenault and Marshall, 2000).

In summary, I argue that the low uptake of pre-pregnancy care following loss could be attributed in part to the complexity involved in 'planning' and 'preparing' pregnancy whilst at the same time existing in the unsettling limbo of the inter-pregnancy interval, which in turn has the potential to lead to conflicted and ambivalent feelings about their condition (Earle *et al*. 2017). To my knowledge, the concept has not been applied to the inter-pregnancy interval in this context in prior research, and may have particular value in unpacking and in understanding some of the unseen challenges faced by women with diabetes in the inter-pregnancy interval.

6.5.3 Discussion of explanatory theme 2 – The biomedical model in the inter-pregnancy interval and stigmatised sub-optimal pregnancy

Women with diabetes who experience baby loss do so in a powerful biomedicalised healthcare system that conceptualises pregnancy as 'high risk', which can contribute to stigmatising processes for women with diabetes. This discussion section of the second explanatory theme explores how women with diabetes and healthcare professionals experienced the inter-pregnancy interval using Nettleton's (2013, p. 2) five key assumptions of the biomedical model as a framework to organise the inductive themes.

The first key assumption of the biomedical model is the tendency to treat the body and mind as separate entities. This mind-body dualism has long been criticised for failing to view the mind and body as one holistic being (Rocca and Anjum, 2020). This was also the case for the women with diabetes; many reported how they did not feel holistically cared for during the inter-pregnancy interval. They spoke of how their physical health and diabetes management was the focus of healthcare in the inter-pregnancy interval. The 'disease focus' meant that women with diabetes's 'pregnant' identities were overlooked, as was their need for holistic, emotional and psychological support for managing the multiple burdens they may experience after a baby loss, as explored in Chapter Five (section 5.3). The 'disease focus' can lead to a preoccupation in trying to ensure diabetes management is optimised before a subsequent pregnancy, which fails to take into account the complexities that women with diabetes face in the inter-pregnancy, nor does it appreciate the physical and emotional toll of being in the liminal inter-pregnancy interval. This can potentially lead to tension in managing the differing priorities, where the healthcare professional may focus on managing the illness, and women with diabetes may be focused on becoming pregnant. Another consequence of mind-body dualism is that grief can be viewed as a purely psychological problem that the mind must work through linearly (Pearce and Komaromy, 2020). That grief, like the body, can and should be fixed, like a machine, before becoming pregnant again. However, perinatal mental health services, in general, are lacking (Donaldson, 2019; National Maternity Review, 2016; Punton, Dodd and McNeil, 2022; The Lullaby Trust, 2019) and this was no different for the participants in this research, who described a lack of referral pathways for healthcare professionals to use.

The second key assumption of the biomedical model is that the body can be repaired like a machine. In this subtheme, women with diabetes felt an expectation that they should, 'optimally prepare' for pregnancy like a primed machine. Maintaining tightly controlled blood glucose levels was widely considered the most challenging aspect of preparing for pregnancy by women with diabetes and healthcare professionals. What seemed particularly unfair to participants was the expectation for women with diabetes to be 'optimally prepared' but with a suboptimal level of support, thereby imposing an agentic role on women to manage their own care. This approach can potentially disadvantage those who might find such a role more challenging to enact, for example, those less affluent or where English is not the first spoken language, or those with reduced access to material resources. The preoccupation with 'optimal preparation' meant those considered 'sub-optimally prepared' for pregnancy were left vulnerable to stigmatising processes. For example, entering pregnancy in a 'sub-optimal' state is not 'best practice'. It implies that women with diabetes choose to risk their pregnancy in favour of 'self-sacrificing' their own needs by remaining in the liminal inter-pregnancy interval for longer.

Women with diabetes face a unique challenge in the inter-pregnancy interval, whereby they face being stigmatised for 'sub-optimal preparation' for pregnancy that may leave them morally responsible for any adverse pregnancy outcome. Unlike many other stigmatised pregnancies, such as where alcohol or drugs are knowingly used in pre-pregnancy, here it comes down to the everyday and essential acts of eating and lifestyle. This links back to recognising that the mind and body are connected (Rocca and Anjum, 2020), and being healthy in mind and spirit may help women with diabetes, in turn, better manage their diabetes. For example, people eat for many more reasons than sustenance alone. People eat, and even crave, less nutritious foods that are inadvisable for diabetes when tired and stressed (Cortes *et al*., 2021; Tryon *et al*., 2012; Ulrich-Lai *et al*., 2015). Food is not the only factor to affect blood glucose levels; stress, hormones, and exercise also contribute (Davies, 2004; Wong *et al*., 2019), so even if someone consumed precisely the same thing every day, blood glucose levels would still vary. This demonstrates how hard it can be for women with diabetes to manage their blood glucose levels tightly, especially if material resources are limited.

The third assumption of the biomedical model relates to the merits of technological intervention, which can sometimes be overplayed. The participants in this research tended to welcome technology as a tool to help women with diabetes to self-manage their condition. In this research, healthcare professionals tended to use their discretion to allow women with type 1 diabetes to continue using CGM technology during the inter-pregnancy interval. Research has shown how technology can help to reduce some of the burdens of self-management (Adu *et al*., 2019; Iyengar *et al*., 2106), ending the requirement to manually test their blood glucose levels "six to eight" (HCP18) times a day (NICE, 2015a). Following the findings from the 'CONCEPTT' multicentre, international, randomised control trial involving 325 women with type 1 diabetes (Feig *et al*., 2017), CGM technology has recently been approved for use by women with type 1 diabetes in pregnancy. The CONCEPTT trial demonstrated the positive impact CGM technology had on keeping blood glucose levels in a safer range for longer throughout the day, which subsequently improved neonatal outcomes (Feig *et al*., 2017). However, despite the importance of preconception glucose levels (NHS Digital, 2021a; NICE, 2015a), the role of CGM technology in the inter-pregnancy interval is somewhat shaded; technically, women should not have access when no longer pregnant, and so not all women with type 1 diabetes can access technology during the inter-pregnancy interval. For example, there can be economical or cultural constraints in service provision, such as when planning a pregnancy is seen as a private decision between couples, so healthcare professionals are unaware of pregnancy intentions. A recent announcement by the *British Medical Journal* (2023) suggested that women with type 1 diabetes who are pregnant or planning pregnancy should be eligible to access the newest hybrid 'closed loop' systems (also referred to as an artificial pancreas) subject to NHS England negotiating a cost-effective price with industry. The hybrid 'closed loop' systems involve users wearing a CGM sensor that transmits data to an insulin pump which automatically delivers the correct dose of insulin (BMJ, 2023). This demonstrates that attitudes may be beginning to change with regards to the importance of pre-pregnancy on pregnancy outcomes.

Women with type 2 diabetes are not generally eligible to use 'Libre' or 'CGM' technology, even though women with type 2 diabetes face similar challenges controlling blood glucose levels and many would benefit (Daly and Horvorka, 2021). During pregnancy, women with type 2 diabetes may start testing their blood glucose using older 'finger prick' technology, using a blood glucose monitor and testing strips. Again, outside of pregnancy, women with type 2 diabetes may no longer be eligible to continue using the blood glucose monitor, and women can face issues with getting a prescription for the testing strips and lances. Instead, women with type 2 diabetes often have to rely on monthly (or even less frequent) HbA1c readings, usually carried out at the doctor's surgery, to get an indication of their diabetes control over the last one-three months. I argue that this is insufficient in the inter-pregnancy interval when women may feel time pressured to become pregnant again as soon as possible. Relying on HbA1c measurements not only has the potential to perpetuate individual blame, but it also fails to capture how specific foods, drinks, and exercise affect blood glucose levels, along with multiple complex factors at play that can affect glycaemic control, such as stress and hormones (Davies, 2004; Wong *et al*., 2019). The lack of access to technology for women with type 2 diabetes undoubtedly reflects funding issues, but there is also an element of discrimination at play; is there an implicit judgement that women with type 2 diabetes are undeserving candidates because they are stereotypically deemed individually responsible for developing type 2 diabetes in the first place? Do women with type 1 diabetes have more unrestricted access to technology because individualistic factors did not cause their condition, so they are more deserving than women with type 2 diabetes?

Furthermore, there may be issues around how such provision is funded, especially in primary care. Women ineligible for a free prescription for ‘Libre’ or ‘CGM’ technology may be able to self-fund. However, diabetes technology is expensive; both ‘Libre’ and ‘CGM’ sensors cost around £50 every two weeks in the UK, with additional costs associated with purchasing the compatible equipment to read the sensors (Diabetes UK, 2023a, 2023g). The newest hybrid ‘closed loop’ systems, which are designed predominantly for people with type 1 diabetes, are estimated to cost an average of £5744 per year, which is a higher cost than NICE usually considers to be effective use of NHS resource (BMJ, 2023). This puts women with type 2 diabetes, in particular, at a disadvantage, as there are higher levels of deprivation among this group. Furthermore, new technologies enter the market all the time, so there is the risk of the technology becoming obsolescent or not supported by the healthcare team (Diabetes UK, 2023a, 2023g).

Diabetes technology is a double-edged sword. While technology may enable healthcare professionals to better support and advise women with diabetes with their glycaemic control, this medicalised technology can exacerbate a fixation on trying to perfect and control the ‘numbers’, potentially contributing to feelings of blame for the baby loss. CGM and ‘Libre’ technology also acts as a surveillance mechanism for healthcare professionals by giving them almost unlimited access to blood glucose readings, which means women with diabetes are subjected to an around-the-clock medical gaze and are left vulnerable to stigmatising judgement should they fail to manage their diabetes are tightly as required. This raises questions about power as it positions healthcare professionals as having the expertise to interpret the data and gives them the power to “monitor, intervene and pass judgement” (Nettleton, 2013, p. 25) on women with diabetes. Although technology assists with more accurately measuring blood glucose levels, it does not play a role in reducing blood glucose – this still comes down to the individual efforts of women with diabetes. Some women with diabetes may struggle to understand the overwhelming quantity of data or find the sensors uncomfortable to wear (Diabetes UK, 2023a, 2023g). There is also a ‘learning curve’ for getting used to the technology (Danesi et al., 2021)) - a convincing argument for initiating pre-pregnancy rather than during pregnancy.

The fourth key assumption relates to how biomedicine is ‘reductionist’ in its approach. Here, the construction of pregnancy as ‘high risk’ meant pregnancy was seen as a medical decision that failed to consider the other factors that may influence a woman’s decision and time scale to become pregnant again. This was captured in some of the healthcare professional responses, where the strong desire for a baby was acknowledged but it was implied that this desire was irrational or not ideal; in other words, the women who yearned for a baby and became pregnant before ‘optimally prepared’ were considered to be non-compliant with medical advice. Some women participants described the challenge they faced in the inter-pregnancy interval, whereby their condition was already medicalised, so the construct of a ‘normal’ pregnancy was no longer an option. This is in keeping with some of the literature on the uptake of pre-pregnancy care, which suggested women with diabetes wanted a ‘normal’ pregnancy (Forde, Paterlarou and Forbes, 2016; Murphy *et al*., 2010a), to be acknowledged as a ‘whole’ person, and allowed to the experience the excitement and joy of pregnancy (Earle *et al*., 2017), without it being overshadowed by diabetes management (Lavender *et al*., 2010). The reductionist sentiment of medicalisation neglects the social and psychological factors experienced in the liminal inter-pregnancy interval that leads to women with diabetes wanting to become pregnant again after a baby loss before they are ‘optimally prepared’. Biological reductionism means pregnancy is seen simply as a biological phenomenon, neglecting any association with agency or conscious becoming (Browne, 2023). Pre-pregnancy, then, is taken for granted as a “pre-condition of existence, but deprived of existential significance itself” (Browne, 2023, p. 57). This links with the “undefinable” (Douglas, 1966, p. 199) nature of being in the liminal inter-pregnancy interval; although women with diabetes may feel like the inter-pregnancy interval is an extension of their pregnancy, it is not recognised as such by the medical model. As such, there is an idealised and normative judgement for women with diabetes who are labelled as ‘high risk’ that their pregnancies *should* be planned – even though half of such pregnancies are unplanned (NHS Digital, 2019; Tennant *et al*., 2015; Holing *et al*., 1998; Murphy et al., 2010a, 2010b).

In this contemporary era, pregnancy is highly regulated, especially ‘high-risk’ pregnancies. Although there is increasing interest and focus on the pre-pregnancy space as a medical concept, with informal networks and specialist interest developments, it remains a grey area regarding service and resource provision for women with diabetes, as explored in Chapter Five (section 5.5.4). Consequently, the inter-pregnancy interval becomes a grey area, whereby the decision to become pregnant after a baby loss was generally considered by women with diabetes and healthcare professionals as a private “intimate” (HCP8) matter between couples. Instead of discussing pregnancy, healthcare professionals tended to focus on and emphasise contraception – the resulting silence around becoming pregnant entrenches the idea that it is a private matter. Viewing pregnancy decisions as a private matter may be a way for medicine to distance itself from eugenic debates of the ‘right sort of pregnancy'. Eugenic ideals have long tainted the maternal advice and care that people with chronic conditions, such as diabetes, receive (Tuchman, 2015). Framing pregnancy in this way also perpetuate the neoliberal ideal of providing a private solution to a public health problem (Löwy, 2014). However, despite claims that pregnancy was deemed a private decision, there is a moral imperative that women with diabetes ‘optimally prepare’ for pregnancy, which requires medical involvement, which could be inferred as “taking action to influence procreation” (Brown, Brown and Schippers, 2019, p. 121). For example, women with diabetes need a prescription for high-dose folic acid, whereas, in contrast, women without diabetes can easily buy folic acid at a supermarket, pharmacy, or online. The contradiction is that, as a private space, there is not much support to do so, therefore requiring women with diabetes to essentially self-medicalise and potentially self-fund their pre-pregnancy.

This paradox, whereby pregnancy decisions are deemed a private, ‘unmedical’ choice, yet making it so that women with diabetes have to have medical involvement so that they can prepare, is problematic for two main reasons: firstly, the lack of pre-pregnancy care hits women with diabetes the hardest because they have the most to gain from it; and, secondly, it leads to women with diabetes being morally responsible should the pregnancy go awry, whereby women with diabetes are still judged retrospectively for becoming pregnant before being ’optimally’ prepared. This paradox raises questions about power, control, responsibility and choice. For example, it was revealed in the interviews that one of the healthcare professionals worked with a colleague who withheld access to folic acid for fear of giving women with diabetes the “green light” for pregnancy. WWD5 spoke of how she and her partner “got told off” when she became pregnant sooner than the 12 months that she was advised to wait by her healthcare professional. Such paternalistic actions work on the basis that patients comply with medical advice and can do more harm than good to women with diabetes, who may feel unheard and judged and disengage with medical advice and treatment (Earle *et al*., 2017; Morgan, 2018). A shared decision-making model may be more appropriate in this context, as the women are ultimately responsible for implementing any decisions that are made (Morgan, 2018), and was an approach used by some of the healthcare professional participants in this research.

The fifth and final biomedical assumption pertained to how reductionism was accentuated by the ‘doctrine of specific aetiology’ whereby a specific and identifiable agent causes all diseases. To put this in context, sometimes it is possible to carry out tests or a post-mortem to find out the cause of baby loss. In general, the literature shows that women in general often blame themselves for the baby loss (Bhat and Byatt, 2016; Burden *et al*., 2016; Frost *et al*., 2007; Hale, 2007). The results can reassure women that there was nothing they could have done to prevent the baby loss (Hale, 2007; Lamb, 2002), which may help women to decide about whether to pursue a subsequent pregnancy (Bhat and Byatt, 2016; Meaney *et al*., 2017), and may help to reduce anxiety in a subsequent pregnancy (Meaney *et al*., 2017). Often, the results are inconclusive, especially with earlier baby losses and unexplained stillbirth, which can be challenging for women not to know whether it could happen again (Gower *et al*., 2023; Hachem *et al*., 2017). However, considering women may already blame themselves for the baby loss, great care needs to be taken when citing diabetes as a causal factor for the baby loss. It may be seen as evidence that they are to blame, which could have a detrimental effect on women's mental health and well-being (Bhat and Byatt, 2016).

Considering how the medical model is criticised for failing to recognise a disease as the "product of multiple, yet identifiable, entwined biosocial processes" (Ostrach, Lerman and Singer, 2017, p. vii), it is not clear the extent to which diabetes is used as a convenient explanation for baby losses when there is likely a complex mix of multiple factors at play. Healthcare professionals reported how challenging it was to negotiate conversations around the cause of death, as they received little training and support to manage them. It was rarely possible to reassure women that diabetes did not play a role, which may leave women with diabetes feeling like they were to blame. The de-emphasis on the social structural issues, such as access to material resources, that impact diabetes and baby loss, perpetuates the over-emphasis on individual responsibility, thus fuelling stigma in the form of blame, shame and self-recrimination, as discussed further in the following section (section 6.5.4) and Chapter Seven (section 7.3)

Biomedicalisation has been a hotly debated topic for many decades in the sociology of health and illness, and the human condition of pregnancy has been constructed as a medical problem to be treated almost as if an illness rather than a normal life event (Conrad, 2007; Nettleton, 2013). Little has been published with regards to this specific research topic, and in terms of diabetes, biomedicalisation tends to be regarded favourably, and tends to focus on single aspects of Nettleton's (2013) core assumptions, rather than all five assumptions, as is the case here. For example, there is vast amount of literature pointing to the benefits of technology to improve diabetes management (Daly and Horvorka, 2021), with little critique on how technology can be a double-edged sword in terms of the potential for women to be exposed to constant surveillance and the medical gaze, and the opportunity for the data to be used as evidence that women did not 'optimally prepare' for pregnancy, and so are left subject to blame. As such, existing literature fails to capture the complexity of the issues faced by women with diabetes in the inter-pregnancy interval, and few studies have problematised the implicit assumptions and implications of the biomedical model in this context.

In summary, this second explanatory theme explored how women with diabetes who experience baby loss do so in a powerful bio-medicalised healthcare system that conceptualises pregnancy as ‘high risk’. As a result, women with diabetes may be exposed to stigmatising processes whereby the ‘disease-focus’ and preoccupation with being ‘optimally prepared’ for pregnancy involves priming the risky body like a machine using medical technology and neglecting the other psycho-social factors at play in the decision to become pregnant again. The merits of technological intervention can be overplayed for women with diabetes. The fixation on blood glucose levels means that diabetes can be identified as a causal factor in baby loss, which can be detrimental to women with diabetes, who may be implicitly blamed or blame themselves for the baby loss and may have mental health consequences and impact their ability to grieve.

6.5.4 Discussion of explanatory theme 3: Neoliberal strategies of responsibilisation

Neoliberal strategies of responsibilisation (see Chapter Three, section 3.7) capture the zeitgeist of medical management today in the UK. This discussion section explores how the underpinning neoliberal strategies of responsibilsation affect women with diabetes in the inter-pregnancy interval in two main ways: first, women are required to individually take responsibility for being ‘optimally prepared’ for pregnancy, with little support; second, how this individualistic, risk based framing has moral implications for women with diabetes.

The essence of this theme is that the increased risk of baby loss that women with diabetes face is not viewed as evidence of the need to develop better standards of care in the inter-pregnancy interval, but rather, the responsibility of the women with diabetes to reduce their own risk. Women with diabetes are expected to be knowledgeable about what they need to do to be ‘optimally prepared’ for pregnancy to reduce their own risk. A striking finding in this research was how being ‘optimally prepared’ for pregnancy required women to be in “pregnancy mode" (WWD1). Essentially, this required women to manage their diabetes as if they were pregnant but without the support available during pregnancy. This required a great deal of agency and responsibility. However, just because some women with diabetes can take on this responsibility, it does not mean everyone can or wants to take on the challenging burden of preparing for pregnancy alone. Rather than looking to the holistic networks within which women with diabetes operate, suggestions to improve care or solutions to manage the condition draw on individualised actions, such as eating ‘healthier’ food and exercising more. This misjudged but pervasive notion that women have ‘choice’ and ‘control’ over their lifestyle is damaging and stigmatising. Women with type 2 diabetes may be particularly impacted in the inter-pregnancy interval as they are more likely to live in areas of high deprivation (NHS Digital, 2021a) and face double stigma for being deemed responsible for causing their condition and then for being individually responsible for being ‘optimally prepared’ for pregnancy. Considering this group may face additional health inequalities and disparities, how much control and choice do they really have? How fair is it to require them to attend a monthly meeting to get HbA1c levels? How accessible is the doctor's surgery? How easy is it to get time off work? How affordable and accessible are healthful foods? For example, recent media coverage has demonized ‘ultra-processed foods’ as being particularly bad for people’s health (The Food Foundation, 2023). However, such food is cheap, and considering the current cost of living crisis, such foods are all some people can afford (The Food Foundation, 2023), so there is an illusion of choice in mitigating risks at the level of the individual.

The neoliberal strategies of responsibilisation require women with diabetes to be submissive to a medicalised view of their circumstances, and expects women with diabetes to be responsible for being ‘optimally prepared’ for pregnancy during an incredibly challenging time, with little or no support. I argue that owing to the challenges of being lost in a liminal ‘limbo’ during the inter-pregnancy interval, many women with diabetes have limited choice or autonomy, all within a time-sensitive dimension. The liminal inter-pregnancy interval is not a time to prioritise individual empowerment or to over rely on additional individualised forms of agency over structural mechanisms of support. Women with diabetes need more visible support, that is easier to access, and based on shared decision-making. It is unfair to expect women with diabetes to prepare for pregnancy by themselves – to assume they have the understanding, required skills and wherewithal to lose weight, exercise more and manage their blood glucose levels with little or no structural support in the inter-pregnancy interval. I speculate that the requirements of being ‘optimally prepared’ glorify risky behaviours, such as “very rigid behaviours around food” (WWD10) and exercise (for example, WWD4), which can be harmful to women, potentially causing hypoglycaemia or injury (Toni *et al*., 2017). The extreme ‘disordered eating’ measures that some women felt were necessary were disconcerting in the sense that obtaining tight blood glucose levels was seen as an appropriate rather than an alarming response to the medicalised ideal of an 'optimally prepared' pregnancy. As suggested by Neiterman (2012, p. 388), such observable lifestyle changes are often taken on extremely diligently by those who face 'stigmas' or 'deviant' pregnancy. Women with diabetes are under tremendous pressure to 'control themselves' and make 'good' choices at a time when they may not feel in control. When pregnancy preparation is framed as something that should be optimised and controlled through individual behaviour and lifestyle choices, those behaviour and choices are blamed when a pregnancy ends in baby loss, which can be perpetuated with the use of technology as a surveillance mechanism to monitor compliance.

There are moral implications of individual responsibilisation, where this individualistic framing means that the fate of the pregnancy is seen as being determined by the individual's lifestyle 'choices' (Browne, 2023), rather than, for example, reflecting on broader social factors, such as food policy, or income levels. Neoliberal strategies of responsibilisation, therefore, can have a troubling impact on women with diabetes, as it perpetuates a cycle of blame and shame whereby women with diabetes are left accountable should anything go wrong with the pregnancy. Women with diabetes have a moral responsibility to prepare for pregnancy; ergo, women with diabetes are irresponsible if they do not prepare for pregnancy.

There is also a cycle of blame and shame for those who are not knowledgeable about their condition, do not know about the need to 'prepare' for pregnancy, or do not comply with medical advice; it is the women with diabetes' responsibility to be educated to become an expert in managing their condition (Tidy, 2022). However, this does not consider the societal issues around deprivation, access to easily understandable, non-stigmatising information, or the risk of women with diabetes falling through gaps in services and support.

The majority of women with diabetes participants in this research had a high level of education – participants spoke of searching the internet and reading widely to understand better how to manage their condition. However, information can only be empowering if women with diabetes can access it and understand it, and it is helpful information that can offer actions that are practical and feasible in the context of everyday life. Great care needs to be taken when assuming that women with diabetes have the agency and ability to individually manage their condition, and also with regards to respecting women's decisions to become pregnant before 'optimally prepared'. Health information needs to be made available in a truly accessible way, and more could be done to acknowledge how stigmatising it is for women with diabetes to be individually responsible for preparing for pregnancy after a baby loss.

The neoliberal concept of putting the onus on the individual has long been contested from a sociological point of view (White, 2002). There is widespread recognition that neoliberal policies support ableist theories, and so benefit those who are able to afford to prioritise their health (Card and Hepburn, 2023), which contributes to widening health inequalities between the rich and poor (Navarro, 2007) where those who are poor and disadvantaged suffer disproportionately more (Rose, 2019). The findings from this research highlighted how this individualistic, risk-based framing has moral implications for women with diabetes, who may be blamed and blame themselves for the baby loss, the former of which is an uncomfortable finding that is not widely reported in the literature.

In summary, women are required to individually take responsibility for being 'optimally prepared' for pregnancy. However, more could be done to acknowledge how hard it is for women to be 'optimally prepared' for pregnancy, especially in the context of baby loss, where this individualistic framing means that the fate of the pregnancy is determined by the individual's lifestyle 'choices' (Browne, 2023), which means women are held responsible or feel responsible for the baby loss. In contrast, the broader social structures that constrain individual actions are left unchallenged. If women with diabetes are expected to bear the burden of being in 'pregnancy mode' to be 'optimally prepared' for pregnancy, I argue they should be supported to do so, by access to similar formal care options as in pregnancy.

6.6 Summary of the explanatory themes from the thematic analysis

Building on the descriptive analysis in Chapter Five these explanatory findings shed new light on how women with diabetes may experience the inter-pregnancy interval, illuminating an otherwise overshadowed part of the pregnancy journey and deepening understanding of why women with diabetes might not ‘optimally prepare’ for pregnancy after a baby loss.

Women with diabetes may find themselves trapped in an unsettling and precarious ‘limbo’ and face the invisible challenges of managing their condition, grieving and preparing for a subsequent pregnancy with added time-related pressures and stigmatising rhetoric. A key insight was how ‘optimally preparing’ for pregnancy may require women with diabetes to be in what one participant called “pregnancy mode” (WWD1) - essentially acting as though pregnant. To do this safely, women with diabetes need an appropriate level of support.

Accounts from healthcare professionals and women with diabetes suggest that care focuses on the physical aspects of diabetes management. Equitable access to technology may play a role in supporting women with diabetes to prepare for pregnancy. There appeared to be less emphasis on psychological and mental well-being aspects. Many women would have welcomed more emotional and psychological support in the inter-pregnancy interval.

By reframing the inter-pregnancy interval as a part of the pregnancy journey, a liminal phase, where a baby loss is no longer a ‘failed pregnancy’ but an extension of the pregnancy journey, healthcare professionals may understand the value of initiating a sensitive conversation about pregnancy plans at the earliest appropriate opportunity. Supporting women with diabetes as much as they would be in pregnancy may help reduce the high rate of baby loss in a subsequent pregnancy.

Chapter 7. Analysis Part Three: Synthesis and further discussion of the descriptive and explanatory themes – the syndemic of diabetes, baby loss, and stigma in the inter-pregnancy interval

7.1 Introduction

The findings from the thematic analysis are presented across three layers (descriptive themes, explanatory themes and synthesis of themes) as set out in Chapter Four, section 4.6.2). The analysis presented in this chapter (part three) synthesises the findings from the previous two chapters using a stigma syndemics framework, as discussed in Chapter Three (section 3.8.8). This approach seeks to explore and map out in depth how stigmatising processes are experienced and produced in the inter-pregnancy interval, and contextualise this mapping with reference to existing research in the field.

These findings show how women with diabetes may face unique and additional pressures in the inter-pregnancy interval compared with ‘normal’ women, due to the stigma syndemic pathways of interaction. There are three main themes which correlate with some of the ‘problematic social emotions’ associated with complicated grief (see Chapter Two, section 2.2.4) and align with the explanatory themes presented in Chapter Three: (1) Complicated feelings of self-blame and “future envisaged guilt” (2) Complicated feelings of failure and fear, and (3) Complicated feelings of shame and blame.

Providing this synthesis analysis offers a coherent but applied method to demonstrate how the inter-pregnancy interval was not only fertile ground for stigma but also the ‘problematic social emotions’ associated with complicated grief (see Chapter Two, section 2.2.4), and that together, these create a matrix of blame, shame, guilt, and hopelessness for women with diabetes after a baby loss.

This chapter takes the analysis forward in a novel way to enhance the accessibility and utilisation value of the findings for a diverse range of disciplines (Sandelowski and Leeman, 2012). Not only do these findings further the understanding of stigma processes from a sociological point of view, but they have relevance to a wide range of disciplines. They would readily translate into a usable interdisciplinary tool for the practical application of the findings. Figure 7.1 visually depicts the stigma syndemic synthesis themes and subthemes.

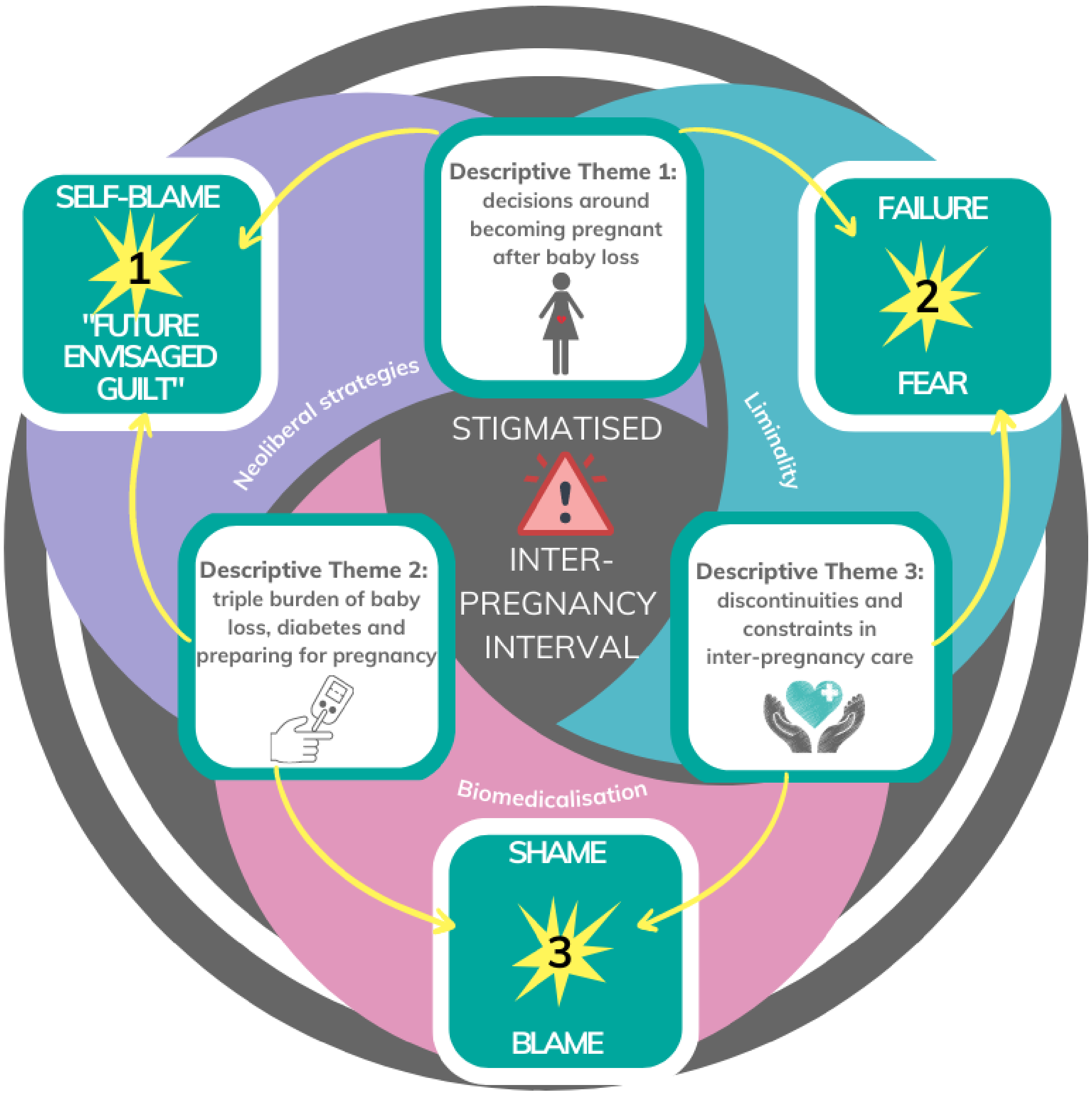

Figure 7.1: Stigma syndemic synthesis model of the inter-pregnancy interval

The intersecting themes are discussed in turn, followed by a discussion of how the findings relate to stigmatising processes in the disparate fields of baby loss, diabetes and inter-pregnancy care provision, topics that broadly align with the descriptive themes presented in Chapter Five.

7.2 Stigma syndemic framework

As presented in Chapter Three (section 3.8.8), a stigma syndemics framework was identified as a helpful tool with the analytic potential to interrogate the thematic findings and map out the complexities in an accessible and helpful way for a multidisciplinary audience. To recap, a syndemic is where two or more interrelated biological or social factors work together to threaten health (Ostrach, Lerman and Singer, 2017). The syndemic framework “goes beyond simple co-morbidity or co-occurrence and helps describe the complex overlapping and intersecting interactions” (Ostrach, Lerman and Singer, 2017, p. viii) in the data.

The synthesis used an adapted form of Ostrach and AbiSamra’s (2017) conceptualisation of stigma syndemics as a heuristic device to organise and explore the interactions between diabetes, baby loss and inter-pregnancy care in relation to each other. Ostrach and AbiSamra (2017) refer to separate social, biological and biomedical factors, which was too over-simplistic for this research. For example, diabetes is not a wholly biological factor but has complex biological, psychological, and sociological underpinnings. Instead, the descriptive and explanatory themes from the previous two chapters were used as a base for the synthesis.

7.3 Theme 1: Complicated feelings of self-blame and “future envisaged guilt” at the intersection of diabetes and baby loss

The stigma experienced separately through baby loss or diabetes is exacerbated where these factors intersect, culminating in a stigma syndemic which aligns with the issues discussed in Chapter Six (section 6.4) in the neoliberal strategies of responsibilisation theme (Figure 7.2). There is a matrix of guilt and a moralising turn from both healthcare professionals and oneself when a baby loss occurs, whereby women with diabetes may be, or feel, implicitly or explicitly blamed for the negative outcome, further compounding the social stigmatisation of baby loss.

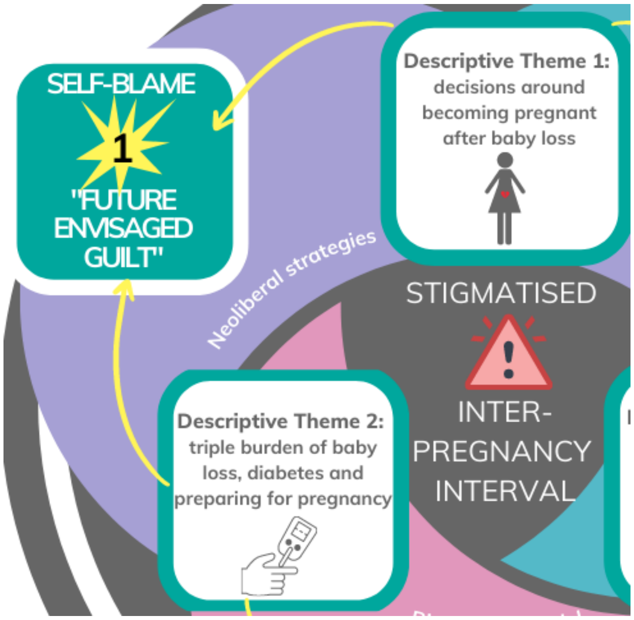

Figure 7.2: Illustration of Theme 1

7.3.1 Subtheme 1.1: Feelings of self-recrimination (blaming oneself and guilt)

This subtheme highlights the pervasive feelings of self-blame described by women with diabetes and witnessed by healthcare professional participants.

> *"I always had this question in my mind to the extent of which the diabetes had or had not contributed to the miscarriage."* WWD10 Type 1 diabetes, early miscarriage

Feelings of self-recrimination may run deep and were a strong theme in this research, touched upon by nearly all women with diabetes and healthcare professional participants. HCP16, a diabetes specialist midwife, commented that a woman with diabetes will "always blame herself, so it doesn't matter what you say." Similarly, HCP18, a diabetes specialist nurse, described, "There's an awful lot of guilt".

WWD5 was relieved when diabetes was not attributed to causing her baby loss in the post-mortem results, and questioned whether she could have coped as she considered her mental health to be fragile at the time:

> *"If they had said it was something to do with me, I don't think I would have coped, I don't. […] My mother-in-law walked out of the room, and she went, 'I'm really glad it wasn't diabetes. I don't think you would have lived with yourself' […] I think because of my diabetes control and stuff. My ultimate thought was always going to be it was my fault. I could have done more, I could have, but you can't."* WWD5 Type 1 Diabetes, Late Miscarriage

The women waiting for the results from the post-mortem delayed trying again for a subsequent pregnancy until the results came back. WWD8, who had type 1 diabetes and experienced a neonatal death, was told that diabetes was the cause:

> *"I felt as though it's there in black and white. It's my fault that I've basically killed him with my body and […] I still think like that to this day. […] the guilt, you know, people can say until they're blue in the face, but no, it's embedded in me." WWD8* Type 1 Diabetes, Neonatal Death

Some healthcare professional participants found it hard to reassure women about the cause of the baby loss as it was not possible to definitively rule out diabetes or diabetes management as potentially contributing to the baby loss.

> *"You're never quite sure if it's something that's happened because it happened or whether it was related to their diabetes, and I don't think the women ever really know, do they really? […] If their HbA1c is quite high, there may be an indication. But in truth, we don't really know why they lost their baby."* HCP14 Diabetes Specialist Dietician

WWD2, who was diagnosed with type 2 diabetes a year before she fell pregnant with her first baby, described how, despite being told by healthcare professionals that the diabetes was not thought to have contributed to the neonatal death, she still felt it might have, as her first pregnancy was unplanned, and so had not 'prepared' for that pregnancy.

> *"When I got pregnant […] apart from being on Metformin, I didn't do anything specifically for my diabetes […] I just fell pregnant, and this was it. Because I've*

> *had a loss, I was very conscious of that, and I genuinely thought, even though the doctors are saying, 'we don't think it's diabetes. You had really good management,' I felt like, well, it can't have helped."* WWD2 Type 2 Diabetes, Neonatal Death

7.3.2 Subtheme 1.2: "Future envisaged guilt."

An interesting finding was how women with diabetes may also experience what WWD10, who had type 1 diabetes and experienced miscarriage coined "future envisaged guilt", where the experience of baby loss and awareness that diabetes increases their risk of baby loss intersects, culminated in fear that "something will go wrong and it will be on [you]." This future envisaged guilt was used as self-motivation for some women with diabetes to prepare as best they could for subsequent pregnancy.

> *"That's why I worked so hard to get my HbA1c down cos I thought I can never, ever, ever let this happen again. And you know, when my waters broke at 24 weeks, I just thought, 'No!' I was like, 'I've done everything I possibly can!'"*
> WWD8 Type 1 Diabetes, Neonatal Death

There is the potential for healthcare professionals to harness this 'future envisaged guilt' as a justification for encouraging women with diabetes to try harder to manage their condition in a subsequent pregnancy. But in doing so, they effectively reaffirm neoliberal strategies of responsibilisation and implicitly suggest women with diabetes are morally responsible for reducing the risk of a subsequent baby loss, as captured in the below quote (with emphasis added):

> *"I think preparing them and then if [baby loss] does happen, you know, if the HbA1c was really good* ***and they did everything right****, then we can say to them it's very, very unlikely to be your diabetes, you know,* ***you did everything you could****."*
> HCP14 Diabetes Specialist Dietician

'Future envisaged guilt' may be a more powerful motivator to prepare for pregnancy than hope, but it was a significant burden for women with diabetes. WWD10 commented on how she was "working very hard all the time to avoid [future envisaged guilt]." WWD1 likened preparing for pregnancy to an eating disorder which required a great deal of control to meet the targets set out in the NICE (2015) preconception guidelines. WWD5 commented on how the pregnancy preparation requirements resulted in fear of eating.

> *"I think you get it drummed into you so much before you become pregnant that high blood sugars cause pregnancy loss and cause big babies and all these sorts of problems. But I became absolutely petrified of eating and drinking the wrong thing and how each thing that I did was going to affect my diabetes control […] I was petrified of my blood sugars getting slightly out of range because I thought if they did, I'd cause harm to my baby."* WWD5 Type 1 Diabetes, Late Miscarriage

Some women with diabetes participants sought support from baby loss groups and bereavement midwives. Whilst they widely reported that they found such support helpful in having a place to talk about their experiences of baby loss, some questioned how it was equipped to support women with a chronic condition like diabetes, that might have been a factor in the baby loss itself.

> *"Because of my diabetes control, my ultimate thought was always going to be it was my fault; I could have done more. […] The bereavement midwife was brilliant, but she wasn't specialised in diabetes […] it's very much about you've lost a baby, but they don't deal with the fact that you've lost a baby and your health condition could be that reason"* WWD5 Type 1 Diabetes, Late Miscarriage

7.3.3 Summary of Theme 1: Complicated feelings of guilt at the intersection of diabetes and baby loss

Feelings of self-recrimination may run deep and were a strong theme in this research, touched upon by nearly all women with diabetes and healthcare professional participants. An interesting finding was how some women with diabetes might also experience what WWD10 termed "future envisaged guilt", where there was a fear of being blamed for a future baby loss which motivated some women to prepare as best they could for a subsequent pregnancy. This syndemic pathway highlighted how women with diabetes might face unique and additional pressures in the inter-pregnancy interval compared with the 'normal' women, and aligned with some of the issues discussed in the neoliberal strategies of responsibilisation theme in Chapter Six (section 6.4).

7.4 Theme 2: Complicated feelings of failure and fear at the intersection of constrained inter-pregnancy care and baby loss

This subtheme captures the stigma in the intersection between baby loss and constrained inter-pregnancy care, culminating in a syndemic which aligns with the issues discussed in Chapter Six (section 6.2) in the liminality theme (Figure 7.3).

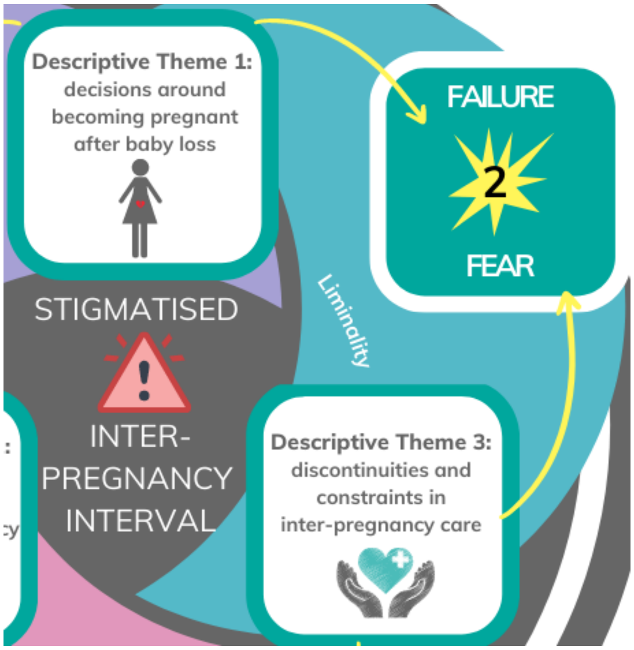

Figure 7.3: Illustration of Theme 2

7.4.1 Subtheme 2.1: Stigmatising feelings of failure

By falling short of the social expectation to 'successfully' complete pregnancy, women with diabetes may receive comments from people. WWD7, for example, whose second child died shortly after birth, found it "really hard being on maternity leave without a baby" and felt "there was a pressure from society" (WWD7) to become pregnant again, which emphasised social expectations to 'right the wrong' and become pregnant again:

> *"People would say, 'You are going to have another one, aren't you? You're not going to let this beat you?'"* WWD7 Type 2 Diabetes, Neonatal Death

After experiencing a late miscarriage with her twins, WWD3 spoke about being "almost desperate" to become pregnant again. This suggests the perception that the only way to avoid stigmatisation for having an 'incomplete' pregnancy and repairing their spoiled identity was to become pregnant again.

> "*To try and put it right because I'd lost two children, and I just wanted things to be better, and I felt that getting pregnant was the answer."* WWD3 Type 1 Diabetes, Multiple Early and Late Miscarriages

Some women described how societal reactions could facilitate stigmatising feelings, such as isolation and shame, due to social awkwardness and a reluctance to talk openly about baby loss.

> *"I think it's infrequent enough that people would rather not talk about it because it's just sad and it's difficult, and they don't know how to have these conversations, and I think it's more frequent than people realise because women feel unable to talk about it in public or are ashamed in some way."* WWD7 Type 2 Diabetes, Neonatal Death

7.4.2 Subtheme 2.2: Stigmatising feelings of fear

Many women with diabetes participants reported that they feared experiencing multiple baby losses. Some women described how the lack of answers about the baby loss made them more fearful that they would experience recurrent baby losses

Many healthcare professionals recognised that women were scared in the inter-pregnancy interval.

> *"There isn't always an answer as to why their baby died, so that doesn't help them. If you had a reason that your baby died, I think that's something that you*

> *can grip on to. But if you haven't, you've got that fear of, well, this could happen again. Why do I want to get pregnant? Why would I put myself and my partner and my family through that again?"* HCP16 Diabetes Specialist Midwife

There was the potential for medical terminology used when communicating the cause of death to be stigmatising and alienating for some women with diabetes. WWD4 described how they would have appreciated more opportunity for a follow-up afterwards, as there was a lot of information to take on board

> *"Getting post-mortem results is like a huge thing, and [in] that meeting, they give you all this information as well in one go […]. Telling you how your baby died, what they died of, [they] give you this report what's using all these medical terms […] I think maybe a little check-in after that would have been good to say, 'do you have any questions?' Because […] the information she gave me brought up more questions in my head once I got home."* WWD4 Type 2 Diabetes, Early and Late Miscarriages

Healthcare professionals advised some women to wait a period of time after the baby loss before becoming pregnant again. Some women with diabetes participants complied with advice to wait for fear of being blamed should there be an adverse outcome in the subsequent pregnancy, but others feared they might run out of time or their condition would progressively worsen if they waited.

> *"I wanted to make sure I'd waited the time that they'd recommended really just because if anything had happened in the next pregnancy, I would have blamed myself for not waiting the length of time that they'd recommended."* WWD4 Type 2 Diabetes, Early and Late Miscarriages

7.4.3 Summary of Theme 2: Complicated feelings of failure and fear at the intersection of constrained inter-pregnancy care and baby loss

This subtheme highlighted how women with diabetes might experience feelings of failure and fear at the intersection of constrained inter-pregnancy care and baby loss, which culminates into a syndemic that aligned with the issues discussed in the liminality theme in Chapter Six (section 6.2), such as feeling isolated and alone.

7.5 Theme 3: Complicated feelings of shame and blame at the intersection of diabetes and constrained inter-pregnancy care

The stigma experienced separately through diabetes and constrained inter-pregnancy care is exacerbated where these factors intersect, culminating in a stigma syndemic which aligns with the issues discussed in Chapter Six (section 6.3) in the biomedicalisation theme (Figure 7.4). There is potentially a combination of shame and blame from both the self and healthcare professionals when a baby loss occurs, especially when pregnancy preparation was deemed 'sub-optimal'.

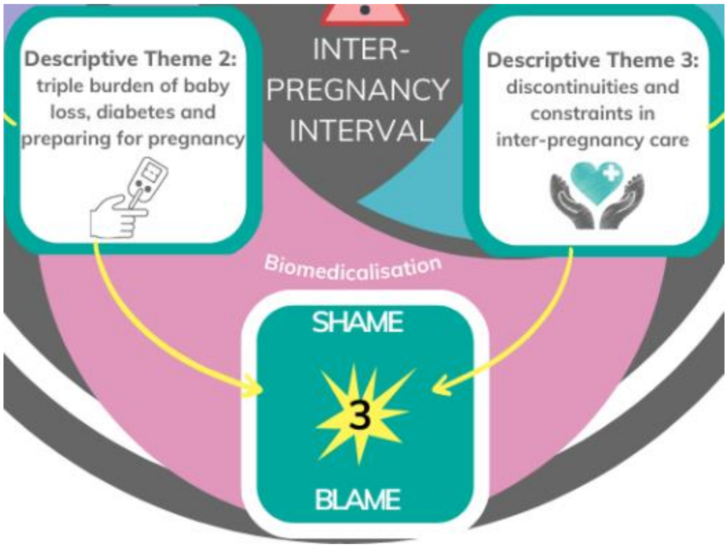

Figure 7.4: Illustration of Theme 3

7.5.1 Subtheme 3.1: Ideals of the 'optimal' pregnancy.

This subtheme shed light on how some women with diabetes felt stigmatised for having a 'sub-optimal' pregnancy. For example, WWD4 could see the value of being monitored but described how the prospect of pregnancy no longer felt ‘natural’ and touched on implicit notions of medical power and control when healthcare professionals passed judgement on her blood glucose levels.

> *“You come to the clinic, you wait for ages […] you speak to them, they tell you what you’ve been eating, what’s bad, look at your blood sugars, adjust your insulin, off you go home […] [Pregnancy] is made to feel not really a natural life event and more of a real medical thing.”* WWD4 Type 2 Diabetes, Early and Late Miscarriage

For example, WWD11, diagnosed with type 1 diabetes during pregnancy with her first child, described how she might not have attempted pregnancy at all had she been diagnosed before pregnancy.

> *“I probably wouldn’t have had children because everybody would have been so negative about it.”* WWD11 Type 1 Diabetes, Miscarriage

Being biomedically ‘optimally prepared’ for pregnancy required considerable effort, and meeting the strict HbA1c targets, for which the women with diabetes were largely individually responsible, was recognised by many healthcare professionals as the most challenging part of being optimally prepared for pregnancy, especially considering the syndemic of stigma and potential for blame and shame.

> *“I think for them preparing is very difficult cos we tend to blame them all the time and pre-pregnancy targets are very tight [...] they feel like there’s no way I’m doing this, it’s too much.”* HCP8 Diabetes Consultant

Some women with diabetes had access to technology in the inter-pregnancy interval, which was widely reported as a helpful tool for helping women with predominantly type 1 diabetes to achieve tight pre-pregnancy targets. However, using technology can be a double-edged sword; HCP11 cautioned how technology had the potential to contribute to driving stigmatising feelings of ‘future envisaged guilt’ if the technology evidenced ‘sub-optimal’ blood glucose levels.

> *“What I really dislike about it is this fascination on a number because I think then that drives the patient’s guilt if they don’t achieve it and something goes*

> *wrong. So, for very good reason, we need to get the glycaemic control as good as we can, but if something happens and they weren't there, there's like a black and white reason they think for the guilt."* HCP11 Endocrinologist

7.5.2 Summary of Theme 3: Complicated feelings of shame and blame at the intersection of diabetes and constrained inter-pregnancy care

This subtheme highlighted how women with diabetes might experience feelings of shame and blame when there is the potential for pregnancy to be 'sub-optimal'. The potential for stigmatising processes at the intersection of diabetes and inter-pregnancy care aligned with the issues discussed in Chapter Six (section 6.3) in the biomedicalisation theme.

7.6 Discussion of the synthesis analysis

7.6.1 Introduction

This chapter presented a synthesis of the research findings using a stigma syndemics framework to map the clustering of stigma in the inter-pregnancy interval. The three main themes presented correlated with some of the 'problematic social emotions' associated with complicated grief (see Chapter Two, section 2.2.4): (1) Complicated feelings of self-blame and 'future envisaged guilt'; (2) Complicated feelings of failure and fear; (3) Complicated feelings of shame and blame.

This discussion section relates the analysis from the stigma syndemics synthesis to the disparate fields of baby loss, diabetes and inter-pregnancy care provision, topics that broadly align with the descriptive themes presented in Chapter Five, and highlights how stigmatising processes culminate in the interpregnancy interval.

7.6.2 Discussion of baby loss related stigma

Pregnancy is a culturally celebrated liminal phase, often constructed as a joy-filled and natural experience (Andipatin, Naidoo and Roomaney, 2019), viewed as a "rite of passage" that culminates in the taken for granted and socially recognised 'rightful endpoint' of delivering a healthy baby (Andipatin, Naidoo and Roomaney, 2019; Browne, 2023, p. 102). Conversely, the inter-pregnancy interval following a baby loss is seen as a deviation from the expected trajectory of a pregnancy, a derailment of the pregnancy journey (Browne, 2022, 2023). This research frames the inter-pregnancy interval as a liminal threshold over which women with diabetes must cross (see Chapter Six, section 6.2).

Baby loss is biomedically constructed as a 'failed' pregnancy (Andipatin, Naidoo, and Roomaney, 2019; Browne, 2023; Frost *et al*., 2007). This biomedical framing filters through into society and structures and influences how baby losses are responded to (Andipatin, Naidoo, and Roomaney, 2019), as evidenced by the lack of a widely used word to describe someone whose baby has died; It is against the 'natural order'. Layne (1997) described this as 'cultural denial' whereby relatives, friends and co-workers can sometimes act as if nothing has happened. Women with diabetes may be stigmatised and othered for falling short of the social expectation to complete pregnancy (Frost *et al*., 2007). The culture of silence surrounding baby loss can give rise to a "proliferation of awkwardness, avoidance and silence" (Browne, 2023, p. 83). The discomfort surrounding baby loss may be derived from its 'death salience' within our Western culture (Reiheld, 2015) that, "avoids confronting the materiality of death, and indeed anything corporeally unpleasant" (Browne, 2023, p. 83). The resulting silence demotes women with diabetes from the public, socially acknowledged status of pregnancy to the private status of non-pregnant (Browne, 2023).

Research studies on baby loss, in general, point to an 'urge' to become pregnant again as soon as possible (Burden *et al*., 2016; Carlsson *et al*., 2016; Forrest, Standish and Baum, 1982; Meaney *et al*., 2017). What sets the inter-pregnancy interval apart for women with diabetes is the expectation of planning and preparing for pregnancy, which is not easy and can take a long time. Feelings of self-recrimination were a strong theme in this research and are a common finding from baby loss studies (Bhat and Byatt, 2016; Burden et al., 2016; Frost et al., 2007; Hale, 2007). Women often blame themselves for baby loss, despite the unknown cause of many baby losses (Bhat and Byatt, 2016; Burden *et al*., 2016; Frost *et al*., 2007; Hale, 2007). People may rush to reassure women that they could not have done anything to prevent the baby loss (Frost *et al*., 2007; Hale, 2007). However, even with the best care in the world, women with diabetes still face the fact that they feel as if they are to blame for a baby loss due to the individual responsibilisation for managing their condition. Bereavement support may not be equipped to fully support women with diabetes in the inter-pregnancy interval in terms of negotiating the matrix of complicated feelings of self-blame and ‘future envisaged guilt’ when faced with the burden of preparing for a subsequent pregnancy.

In summary, the biomedical framing of baby loss as a ‘failed pregnancy’ has far-reaching stigmatising implications, including a lack of inter-pregnancy support. Self-recrimination and guilt are common among women who have experienced a baby loss. However, women with diabetes may feel additional responsibility due to their condition requiring self-management. Standard bereavement care may not be equipped to offer support with negotiating the stigmatisable aspects that specifically affect women with diabetes who experience baby loss.

7.6.3 Discussion of diabetes related stigma

Women with diabetes reported experiences where healthcare professionals judged and scrutinised their blood glucose levels and, in some cases, openly told them off or failed to hide their frustration or irritation, which contributed to feelings of shame and stigma. However, being biomedically ‘optimally prepared’ for pregnancy required considerable effort, and participants described a lack of support in the inter-pregnancy interval. The added pressure of being in the liminal inter-pregnancy interval produced additional strain as there was a temporal element to consider, as well as potentially ‘complicated’ and ‘disenfranchised’ grieving process alongside discontinuities in a fragmented care offering within an economically constrained system.

Meeting the strict HbA1c targets, for which women with diabetes are mainly responsible, was reported by most participants as the most challenging part of being ‘optimally prepared’ for pregnancy. Some women with diabetes participants described experiencing what WWD10 coined ‘future envisaged guilt’ as motivation to ‘optimally prepare’ for pregnancy. However, some participants reported extreme measurements taken to achieve tight blood glucose levels, including rigid behaviours around food that could constitute an eating disorder, excessive exercise, and extreme calorie restriction. This response may have been a way to “exonerate themselves from blame” (Broom and Whittaker, 2004, p. 2378). The biomedical model of healthcare, which prioritises physical over mental health and promotes the notion that the body can be repaired like a machine, suggests that women with diabetes should make diabetes their top priority, regardless of their particular social circumstances. Those who do not comply may be deemed deviant and potentially unworthy of support and services (Broom and Whittaker, 2004).

However, as touched upon in Chapter Five (section 5.5.4), not all women with type 2 diabetes were aware of the risks in pregnancy and how preparing for pregnancy could help reduce the risks, which is in keeping with the findings from Forde *et al.* (2020). Some women with diabetes participants believed that high HbA1c levels meant they could not become pregnant, which was also a finding in Forde *et al*. (2020). This suggests that conversations about pregnancy are not always routinely embedded into healthcare, especially at diagnosis, and it was reported that the standardised, nationally-delivered 'Desmond' education programme for people with type 2 diabetes did not include a pregnancy component, which was also highlighted by Forde *et al*. (2020). Failing to provide information or structural support to facilitate a reduction in risks ahead of pregnancy for women with type 2 diabetes is an institutional practice that encapsulates structural discrimination.

Diabetes related stigma is widely reported in the literature. While there has recently been growing awareness of the importance of using non-stigmatising language in clinical encounters (LLoyd *et al*., 2018), this is the tip of the iceberg. Women with type 1 and type 2 diabetes may experience stigma across many life domains, for example, in the workplace, healthcare settings or in relationships (Broom and Whittaker, 2004; Browne *et al*., 2013; Schabert *et al*., 2013). In effect, women labelled as 'diabetics' are reduced from a whole 'normal' person to a 'discounted' person (Goffman, 1963). Diabetes-related stigma may negatively impact women with diabetes' psychological well-being and self-care, leading to sub-optimal clinical outcomes (Browne *et al*., 2013; Forde *et al*., 2020; Schabert *et al*., 2013). Stigma tends to fuel a 'damaging feedback loop' (Ostrach, Lerman and Singer, 2017), whereby the women with diabetes who feel most stigmatised for 'failing' to prepare for pregnancy might wait for longer before informing healthcare professionals about pregnancy intentions or not informing healthcare professionals until they are pregnant again for fear of being stigmatised for demonstrating risky behaviour. Stigma contributes to and is exacerbated by persistent myths and misconceptions about the ability and readiness to become pregnant (Forde *et al*., 2020).

In the inter-pregnancy interval, women with diabetes have a moral responsibility to plan and 'optimally prepare' for pregnancy. They may be stigmatised if they fail to comply by increasing the risk of their already biomedically high-risk pregnancy. As succinctly described by Hannem (2022, p. 60):

> *"Those who are labelled as risky and subject to control and intervention then subsequently experience symbolic stigma in interaction with those individuals who exercise control or over-see programmes of intervention. In these moments and interactions, the varnish of objective, categorical risk is lost, and we see that structural stigma and the language of risk offer cover to what remain deeply symbolic and moralistic judgements."*

Despite the social norm for half of the pregnancies in the UK to be unplanned (Public Health England, 2018), there is a moral imperative for women with diabetes to plan for their biomedically risky pregnancies to avoid being judged as morally irresponsible. Pregnancy is stigmatised for women with diabetes, thanks partly to deeply entrenched eugenicist ideals of the 'optimal' pregnancy (Tuchman, 2015). The perceived refusal of pre-pregnancy care or non-compliance with preparing for pregnancy may be interpreted as deviance or lacking knowledge, both of which are stigmatisable aspects, in terms of identity.

Women with both type 1 and type 2 diabetes are stigmatised groups but have different attributes about personal 'fault' from a biomedical viewpoint which may contribute to differential levels of personal acceptance and support (Rogers and Pilgrim, 2021). Women with type 1 diabetes are not generally blamed for causing their condition. In contrast, women with type 2 diabetes may be blamed as being 'responsible' for developing their condition, as it is associated with individual lifestyle choices, overweight and obesity (Browne *et al*., 2013); essentially, developing type 2 diabetes is deemed to occur as a result of morally deviant or unacceptable behaviour (Broom and Whittaker, 2004). Women with type 2 diabetes are, therefore, highly stigmatisable as they are exposed to an added layer of blame and shame (Browne *et al*., 2013) and may be disproportionately affected by stigmatisation due to neoliberal strategies of responsibilisation, as discussed in Chapter Six (section 6.4).

Type 2 diabetes stigma manifests within multiple levels of society: media; law and policy; institutions; communities; relationships between individuals; and within individuals themselves, as self-stigma (Browne *et al*., 2013; Davidsen *et al*., 2022; Earnshaw and Chaudoir, 2009; Link and Phelan, 2001). Recent ground-breaking and highly publicised research from Newcastle University has shown that in some cases, it is possible to 'cure' people with type 2 diabetes by 'reversing' the development of the condition or by putting it into 'remission' with medical intervention and calorie restriction (Taylor, 2019; Taylor *et al*., 2018, 2021). While undoubtedly a breakthrough in scientific discovery, as type 2 diabetes was considered incurable, irreversible and progressive, there is the potential for the media portrayal of type 2 diabetes to contribute to stigmatising attitudes and assumptions. For example, the media frequently and relentlessly portrays people with type 2 diabetes as 'lacking the willpower' to put their diabetes into remission, as encapsulated by the feverish Daily Mail headline "Worried you haven't got the willpower to lose weight? These three thought the same and walked away from Type 2 diabetes?", which simultaneously shames and blames those who have 'not tried hard enough' to cure themselves from the condition (Harris, 2021). Such negative stereotyping of type 2 diabetes is often unreasonable and, in this case, is unfair, as it is socially patterned and linked to inequality and ethnicity (Candler *et al*., 2018; Reinehr, 2013); nonetheless, it still occurs (Rogers and Pilgrim, 2021). When the prejudicial social typing is enlarged, such as with women with type 2 diabetes, it shifts from being a stereotype to being stigmatised (Rogers and Pilgrim, 2021).

While diet and lifestyle play a significant role in blood glucose management, blood glucose levels are also impacted by stress and hormones (Davies, 2004; Wong *et al*., 2019) and the environment people live in (The Food Foundation, 2023; Marmot *et al*., 2020). Neoliberal strategies of responsibilisation require women with diabetes to follow a 'healthy' lifestyle. However, it is far more complicated than that. There is a strong relationship between deprivation and obesity and areas of high deprivation are more likely to be 'obesogenic' environments where people face significant barriers to accessing affordable and healthy food and taking exercise (Holmes, 2021; Marmot *et al*., 2020; Swinburn, Egger and Raza, 1999), and more nutritious options are frequently more expensive than foods considered inappropriate for people living with diabetes (Jones *et al*., 2014). The recent influential 'Broken Plate' report by The Food Foundation (2023) demonstrated how 'healthy nutritious foods' (£10.00/1,000 kilocalories) were over twice as expensive as 'obesogenic unhealthy products' (£4.45/1,000 kilocalories).

Chapter Five discussed how people lead busy lives and face multiple burdens daily. Being unable to achieve 'optimal' blood glucose levels can result in stigmatising attitudes from society and sometimes even by healthcare professionals (Browne *et al*., 2013). Women with type 2 diabetes, in particular, are not well supported to find out the impact of diet and exercise on their blood glucose levels. HbA1c measurements provide a good measure of blood glucose over the past few months. However, it cannot provide specific information about what foods or actions cause the most significant spike in blood glucose levels. Especially given that lifestyle changes take time, there may not be much time in the inter-pregnancy interval nor timely access to nutritional advice. The inequitable access to support with managing blood glucose levels in the inter-pregnancy interval faced by women with type 2 diabetes constitutes structural discrimination as a result of stigma power (Link and Phelan, 2014) which results, essentially, in social exclusion, a process through which this group are excluded from the facilities, benefits and opportunities afforded to women with type 1 diabetes, their ‘betters’ (Link and Phelan, 2014; Tyler, 2018).

In summary, this section explored how stigma affected the lives of women with diabetes in the inter-pregnancy interval. Diabetes-related stigma may lead to psychological distress, inadequate self-care, and sub-optimal clinical outcomes. Planning for a stigmatised pregnancy becomes a moral responsibility, but lack of support and judgment from healthcare professionals contribute to shame and stigma. Women with type 2 diabetes face additional blame and shame due to societal perceptions of their condition. Stigma operates at multiple levels and perpetuates inequalities in access to resources, reinforcing social exclusion (Link and Phelan, 2014; Tyler, 2018).

7.6.4 Discussion of constrained inter-pregnancy care-related stigma

The constrained care experienced by women with diabetes in the inter-pregnancy interval may perpetuate stigmatisation processes for women in the inter-pregnancy interval.

The lack of structured support for women with diabetes in the inter-pregnancy interval, as discussed in Chapter Five (section 5.5.4), overtly signifies a disregard for acknowledging baby loss as a valid part of the pregnancy journey, implying baby loss is ‘wrong’ and shameful. The absence of a ‘rite of passage’ to ‘re-incorporate’ women with diabetes into regular social life after baby loss perpetuates the taboo surrounding this liminal phase. Along with scholars such as Linda Layne, Alison Reiheld and Victoria Browne, it is vitally important that we recognise the inter-pregnancy interval as a liminal event so that we can better understand its ‘taboo’ status and the potential for this to be a stigmatising and isolating experience. The lack of support in the inter-pregnancy interval reported by the women with diabetes participants could potentially constitute structural discrimination. More joined-up care and structured support are needed when the 'rite of passage' of pregnancy deviates from societal expectations. Women with diabetes should be appropriately reintegrated into pre-pregnancy care or diabetes services, depending on their individual needs. Healthcare professionals are essential in initiating a sensitive conversation about pregnancy plans at the earliest opportunity. Healthcare professionals may offer a rare chance to discuss subsequent pregnancy; when they do not initiate the conversation, it is plausible that there is potential for women with diabetes to feel ashamed for having thoughts 'too soon' about a subsequent pregnancy.

With baby loss being framed as a failure rather than a fairly normal part of the pregnancy journey, healthcare provision in the inter-pregnancy interval mainly focuses on the physical aspects of being a non-pregnant woman with diabetes. The mind-body dualism in biomedicine prioritises physical over mental health. As a result, healthcare professionals use informal networks and third-sector organisations and charities for bereavement and psychological support who may not have the resource or expertise to support women with health conditions like diabetes.

The potential for blame may motivate some women with diabetes to attend pre-pregnancy care for a subsequent pregnancy. However, it is also plausible that it prevents some women with diabetes from accessing pre-pregnancy care for a subsequent pregnancy for fear of being told off or judged for their diabetes management, or for going ahead with pregnancy in 'sub-optimal' circumstances. Women with diabetes who are non-compliant in attending pre-pregnancy care and not optimally prepared before pregnancy may be labelled 'difficult patients' and considered deviant. However, pre-pregnancy care services to support women with diabetes to prepare for pregnancy are inconsistent across providers. Some pre-pregnancy care services require a referral, and some may have long waiting lists. Some services do not have dedicated pre-pregnancy care at all. Even after a woman with diabetes has taken steps to prepare for a subsequent pregnancy, stigma contributes to delayed or denied pre-pregnancy care by the lack of services in some areas.

In summary, this section highlights some of the ways constrained inter-pregnancy care can perpetuate stigmatising processes in the inter-pregnancy interval. The absence of structural support during this period disregards the significance of the baby loss and contributes to the shame, silence and isolation surrounding the inter-pregnancy interval. Non-compliance with pre-pregnancy care can lead to labels of being ‘difficult patients’ while inconsistent availability of services and the fear of judgment may hinder access to care. Addressing stigma and providing comprehensive support are crucial in ensuring the well-being of women with diabetes in the inter-pregnancy interval.

7.7 Summary of the stigma syndemic synthesis

In this analysis chapter, the descriptive and explanatory themes were synthesised using a stigma syndemics framework to map out and scrutinise how stigma interacted and intersected in complex ways, drawing on the themes from the previous two chapters. This allowed for a more in-depth interrogation and analysis of the ways stigma is both experienced and produced, creating so many points of tension for this sub-group of women with diabetes. Three main synthesis themes correlated with some of the ‘problematic social emotions’ associated with complicated grief (see Chapter Two, section 2.2.4): (1) Complicated feelings of self-blame and “future envisaged guilt” (2) Complicated feelings of failure and fear (3) Complicated feelings of shame and blame.

The analysis in this chapter maps out the complexity in how stigma clusters in lived experiences of the inter-pregnancy interval. Concerning baby loss and becoming pregnant again, five main ways were identified by which women with diabetes may be exposed to stigmatising processes: firstly, a baby loss is biomedically framed as a ‘failed’ pregnancy; secondly, the spoiled identity of being neither pregnant nor non-pregnant; thirdly, conceiving again before the advised waiting period; fourthly, attempting to conceive before being ‘optimally prepared’ for pregnancy; and fifthly, the medical label of ‘diabetes’ can take precedence over and above that of the women’s liminal identity of being between pregnancies.

All women experiencing baby loss are exposed to stigmatisation in this liminal inter-pregnancy phase relating to processes one and two (Burden et al., 2016; Meaney et al., 2017). However, processes three, four and five are more likely to affect women with diabetes specifically. What sets it further apart for women with diabetes is that preparing for pregnancy is not easy and can take time and resources that they may not have. Crucially, women with diabetes may face stigmatisation regardless of their pregnancy status. If they decide to become pregnant again, they may face judgment and criticism if perceived as inadequately prepared. Conversely, if they choose not to pursue pregnancy, they may be stigmatised for failing to fulfil personal ambitions and societal expectations, and for having a spoiled identity. This dual burden of stigma further compounds the experiences of women with diabetes.

To summarise, stigma is recognised in the separate fields of baby loss, diabetes and healthcare provision. This synthesis takes the findings forward in a new way by using a stigma syndemics framework to make explicit how women with diabetes are faced with additional and complex forms of stigma where the fields intersect. A benefit of presenting the findings in this way is that it clearly shows how the three areas coalesce in the inter-pregnancy interval and helps avoid a potential hierarchy of harm, whereby one area is prioritised over another. Mapping the synthesis out in this way may provide a particularly useful way to understand and present the ways complicated grief manifests in the inter-pregnancy interval more holistically. Thus, the analysis generated with this stigma syndemic framework is important because it uses a different and new way to look at the complexity of experiences in inter-pregnancy interval, including women with diabetes' experiences and healthcare professional's perspectives. Such insight could be well placed to inform the development of an interdisciplinary tool for supporting women with diabetes who have experienced a baby loss, and the healthcare professionals who care for them. While it is too ambitious to expect these findings to "change the way people think" about stigma, like Link and Hatzenbuehler (2016), I would be very happy indeed if stigma processes were better recognised in the inter-pregnancy interval, so that actions to mitigate the damaging effects could "percolate in places where decisions are made" (Link and Hatzenbuehler, 2016, p. 669).

Chapter 8: Conclusions, implications and recommendations

8.1 Introduction

This concluding chapter starts by briefly summarising the research findings as a whole followed by the implications for existing understanding, and strengths and limitations of the study. Areas for future research are then suggested. The final section outlines how the complex findings from this research have addressed the research aims and objectives and questions, and concludes with four recommendations for good practice.

8.2 Summary of the analysis

Together, the findings from the analysis highlight how women with diabetes who have experienced baby loss are at the nexus of something extremely complicated regarding the many tensions they are subjected to and required to manage in the inter-pregnancy interval.

The descriptive findings of this study shed light on the challenging and precarious nature of the inter-pregnancy interval for women with diabetes who have experienced baby loss, a significant but often overlooked part of the pregnancy journey. Providing timely and appropriate care and support for women with diabetes in this interval is complex, given the unclear referral pathways, discontinuities, and constraints in inter-pregnancy care that healthcare professionals face. There is a disconnect between healthcare professionals' assumptions and the needs of women in the inter-pregnancy interval, as women may experience thoughts and feelings about subsequent pregnancy sooner than expected. The limited contact with healthcare professionals during this period poses a challenge in adequately supporting women with diabetes preparing for a subsequent pregnancy. Additionally, the pressure to be ‘optimally prepared’ for pregnancy adds an often unrealistic burden to those faced by women with diabetes, who already face multiple challenges and often lack sufficient support beyond their individual social capital.

The findings also highlighted the disparities in care provision between type 1 and type 2 diabetes, with women with type 2 diabetes potentially being overlooked due to gaps in healthcare professionals' knowledge and resource access. Women with diabetes may find themselves in a liminal and unsettling state during the inter-pregnancy interval, managing their condition, grieving, and preparing for a subsequent pregnancy, all while facing time-related pressures in terms of both everyday time and in terms of reproductive lifecycle opportunities in the life course. The stigmatisation surrounding baby loss and pregnancy further exacerbates their experiences. Reframing the inter-pregnancy interval as an integral part of the pregnancy journey and initiating sensitive conversations about pregnancy plans early on, and providing more consistent access to support, could help reduce the high rate of subsequent pregnancy loss.

The research findings emphasised the clustering of stigma in the inter-pregnancy interval and identified various ways women with diabetes may be exposed to stigmatising processes. This interdisciplinary analysis, employing a stigma syndemics framework, offers a comprehensive understanding of the complex ways in which stigma interacts and intersects in the lived experiences of women with diabetes, and those who provide care for them. By presenting the findings in this manner, the findings aimed to avoid prioritising one area over another and provided a holistic perspective on the manifestation of complicated grief in the inter-pregnancy interval. The insights gained from this study add depth to existing understandings of baby loss in women with diabetes and have the potential to inform the development of an interdisciplinary tool to support women with diabetes who have experienced baby loss in the inter-pregnancy interval.

8.3 What implications do the findings have for existing scholarship?

These findings support other literature that points to a short inter-pregnancy interval after a baby loss. This means there is not much time for healthcare professionals to support women with diabetes to prepare for pregnancy, so a sensitive discussion about subsequent pregnancy and ways to support should be initiated at the earliest opportunity, which may be sooner than is currently assumed.

A salient finding was the concept of ‘pregnancy mode’ for women with diabetes, that ‘optimally’ preparing for pregnancy as per the NICE (2015a) NG3 preconception guidelines required women with diabetes to act as if they were pregnant. Maintaining ‘pregnancy mode’ is not easy, especially regarding tight control of blood glucose levels. This means that women might not wish to prepare for pregnancy any longer than is strictly necessary. This has implications for policy as there is scope for improvement. Pre-pregnancy is not considered a part of the pregnancy journey, whereas ideally, it should be. If women with diabetes are expected to act as if they are pregnant, they should have as much support as they get during pregnancy.

These findings build on, and go beyond existing research in two main ways. First, by applying the theory of liminality to explore baby loss in the context of diabetes, and second, by using stigma syndemics as a framework to expose the multiple layers of stigma in the inter-pregnancy interval. These concepts have not, to my knowledge, been used to analyse lived experienced in this field before, thereby expanding both liminal and syndemic theory to include a view of how women with diabetes experience stigma from multiple angles in the inter-pregnancy interval. The findings from the stigma syndemics framework may be particularly transferable to practice and could form the basis of an interdisciplinary tool to support women with diabetes who have experienced a baby loss.

Existing research and narratives draw on very individualised reasons and solutions to manage diabetes. These findings point to a compelling case to promote a non-individualistic model of inter-pregnancy care based on relationships rather than responsibilising terms. Such inter-pregnancy care requires multiple layers of support and networks for this group, who have complex needs. Furthermore, women with diabetes face a stigma syndemic in the inter-pregnancy interval, where stigma operates in multi-directional pathways. Women with diabetes face stigma from every angle, not only for their condition but for the baby loss and being individually responsible for planning a pregnancy and entering a subsequent pregnancy in a biomedically 'optimised' state. To make pregnancy safer for women with diabetes, researchers, providers and policymakers all have a role in acknowledging stigma as a risk factor that intersects with multiple factors in the inter-pregnancy interval for women with diabetes.

8.3.1 Strengths of the research

This research focused on the inter-pregnancy interval, an under-researched area in both baby loss literature and diabetes literature, despite women with diabetes being around four times more likely to experience baby loss (CMACE, 2011). A key strength of this research was the qualitative, reflexive approach used to explore this area in depth, to problematise the 'taken for granted' assumptions about the research topic. The findings connect research areas seldom explored together, providing new insights into potential reasons why women with diabetes do not ‘optimally’ prepare for pregnancy after experiencing a baby loss and suggestions to improve inter-pregnancy care. This research adds to the literature by including women’s experiences and healthcare professionals' perspectives. Healthcare professional perspectives, in particular, were analytically underdeveloped in the literature, so this research adds to the body of literature.

The approach used to recruit and interview participants can be considered a strength. The research involved interviews with 30 participants, providing rich and nuanced data. The sample encompassed a range of baby losses, and the participants were distributed across the UK and Ireland, highlighting differences in healthcare services delivery. Women with diabetes may come into contact with a wide range of healthcare professionals in the inter-pregnancy interval. This research included a diverse range of diabetes specialist and non-specialist professional perspectives. Talking with many diverse groups brought many ideas and challenges to the paper. However, including diverse perspectives was a strength of this research because it highlighted how not all healthcare professionals who come into contact with women with diabetes have specialist knowledge about the needs of women with diabetes after loss. They may play an essential role in signposting women to support services.

Another strength of this research was working collaboratively with the baby loss charity Sands, who helped shape the research by providing feedback on the research resources and were instrumental in recruiting women with diabetes to participate. The collaboration with Sands also promises to enhance the findings' impact, knowledge transfer and communication to improve support for women with diabetes who have lost a baby during or shortly after pregnancy. For example, Sands facilitated my attendance at the All Party Parliamentary Group on Baby Loss during my MSc Dissertation project (Dyer *et al*., 2019) (see Appendix A), and I plan to re-engage with this group to share these findings.

8.3.2 Limitations of the research

Alongside the strengths, and despite meeting the research aims and objectives, there are limitations inherent with such a qualitative approach to research. Although the social constructionist approach was justified in Chapter Three (section 3.3), this approach means that the findings reflect the researcher’s subjective, and co-constructed interpretation of the data. While subjectivity is not deemed a limitation of this approach to research, it does limit some of the wider application of the findings in that the findings are not representative or generalisable to all women with diabetes who have experienced a baby loss.

The women with diabetes participants were predominantly women with type 1 diabetes (n=9), so the voices of women with type 2 diabetes (n=3) were underrepresented. Most parents I spoke to were white, well-educated, and heterosexual, which means minority groups and those from socioeconomically deprived areas are not represented in these findings. This relatively small and homogenous sample meant it was not possible to contrast the experience of diabetes and baby loss by socio-economic status, gender, age or ethnicity. There were no participants with experience of termination of pregnancy for medical reasons, although a pilot interview was conducted with a woman with type 1 diabetes who had lived experience of such a loss.

Recruiting and collecting the data online could have contributed to a sample bias, whereby only those who were more technologically literate were able to take part in the research, and so the sample was not representative of the broader population (Hargittai and Jennrich, 2016). The homogeneity of the women with diabetes sample could have occurred through digital exclusion, whereby only those who had access to the internet and could afford the necessary equipment and internet connection were able to access and be included in this research.

This research sought to include participants from across the UK so as to comment on a range of healthcare practice. However, around half of the healthcare professional participants were based in the North East of England, and the varied practices between hospital trusts, and devolved healthcare governance, likely had an impact on participants' experiences. Furthermore, there was no limit on time elapsed since the events women were reporting on, which could have impacted participant recollections, and care provision could have potentially since changed. This, although the findings will be useful to inform policy across the NHS, specific implementation of changes to practice are likely to require more thorough knowledge of the challenges that are specific to each region, or hospital trust.

8.3.3 Opportunities for future research

While this argument adds to existing research and knowledge on the topic, it does not constitute an exhaustive exploration of the issues. Future research in this area would be beneficial if women with diabetes are to be cared for and supported after experiencing the trauma of a baby loss. This concluding section proposes future research ideas based on answering some questions raised by this research and filling gaps in understanding that this research highlighted but could not address adequately.

Further research is required to determine the best way to handle conversations about baby loss and subsequent pregnancy when complicated by feelings of blame. There is an opportunity to conduct Patient and Public Involvement and Engagement (PPIE) work by working with Sands, healthcare professionals and women with diabetes to develop a framework to facilitate sensitive discussion of pregnancy plans between healthcare professionals and women with diabetes in the inter-pregnancy interval to help women with diabetes prepare for subsequent pregnancy.

More research with healthcare professionals and women with diabetes and their families is needed to understand how best to communicate the cause of the baby loss back to parents, especially in the context of diabetes, where there is the potential for blame and guilt. It is important to identify ways to mitigate some of the blame surrounding baby loss and diabetes and ensure that conversations around the cause of death do not contribute to the stigma.

The role and process of stigma is under-acknowledged and understudied in this area. Reducing the stigma that surrounds pregnancy and diabetes is vital. It may help to improve the chances that women with diabetes can be supported to prepare for pregnancy, thus reducing the risk of baby loss. There is a need to understand better how to address the multifaceted dimensions of stigma in the inter-pregnancy interval. Stigma is deeply ingrained in the fabric of our society. Addressing the multiple forms, and different levels of stigma that women with diabetes are exposed to in the inter-pregnancy interval, including attitudes, policy and care provision, is not an easy task. Nevertheless, more could be done to mitigate some of the stigmas experienced by this group, and it would be a worthwhile and fruitful topic to pursue in future research. It could also include additional intersecting elements, such as weight stigma and stigma surrounding groups more likely to experience type 2 diabetes, such as ethnically minoritised groups and people living in areas of high socio-economic deprivation. The stigma syndemic framework presented in Chapter Seven provides a useful starting point, but will require further development and evaluation for use in a healthcare setting.

Research to reduce health inequalities and disparities for women with diabetes is desperately required, and interacting with women with diabetes and marginalised groups not represented in this research is a priority. Women with type 2 diabetes who are from ethnically minoritised groups and socioeconomically deprived areas, are more likely to be diagnosed with diabetes at an earlier age, may face additional barriers to accessing health care, and are at a higher risk of experiencing baby loss and other adverse pregnancy outcomes.

More research is required to understand the experiences of women newly diagnosed with type 2 diabetes and how best to provide them with non-stigmatising information about preparing for pregnancy. The challenge, however, will be doing this in a culturally-appropriate, accessible, and non-stigmatising way. Great care needs to be taken not to alienate these groups and provide culturally-sensitive information preconception information that is specific to the group's needs and in the most accessible format. There is a need to be mindful of the 'health literacy' required to assimilate the quantity and complexity of information provided around the time of diagnosis, especially when English is not the first language or access to additional online resources is not possible. More must be done to support women who are not actively 'planning' a pregnancy but may have pregnancy intentions soon.

There is also scope for future research on the role of diet for women with diabetes in the inter-pregnancy interval and how this group can be better supported to meet tight blood glucose levels. This is particularly pertinent in terms of providing culturally-sensitive support for women with type 2 diabetes from ethnically minoritised groups and those women living on low income as a low carbohydrate diet, which might help to reduce blood glucose levels, has been shown to be more expensive.

8.4 Recommendations

The following recommendations were drawn from the research findings in answer to the sub-question: ***how could care provision be changed to enhance health outcomes?*** The recommendations suggest practicable ways to improve care provision and potentially enhance health outcomes for women with diabetes in the inter-pregnancy interval. Central to all recommendations is the aim of reducing health inequalities, disparities, and stigma.

8.4.1 Recommendation 1: improving the structure of inter-pregnancy care

The research findings suggest that pre-pregnancy is not considered part of the pregnancy journey, despite the importance of preparing for pregnancy for this group.
Pre-pregnancy care must be reframed as a vital part of the pregnancy journey and included as part of the high-risk pregnancy tariff. Being optimally prepared for pregnancy requires women to bear the burden of being in ‘pregnancy mode’, so it requires a level of support that mirrors this, with the same access to resources as in pregnancy. This is especially important for women with type 2 diabetes, who are likely to revert to infrequent appointments back in primary care after a baby loss.

These findings suggest that women with diabetes were ‘lost without a map’ in the inter-pregnancy interval. Currently, care provision and referral pathways are unclear. There is an over-reliance on informal networks and third-sector charities, which means care is inconsistent across services and women with diabetes’ needs can be unmet. There is a need for an inter-pregnancy pathway that allows clear choices and easy referral to various support services to mitigate some of the multiple burdens this group faces. The option to self-refer to services would be advantageous to women with diabetes by making it easier to access services in a timelier way without increasing the burden of gaining a referral. Inter-pregnancy care based on relationships rather than responsibilising terms could help reduce some of the stigma this group faces. Women with diabetes have complex needs, so ideally, all women who experience a baby loss should be routinely contacted within two months to be offered various types of support depending on need. Support could include bereavement support, access to counselling, specialist psychological support, specialist dietetic services, pre-pregnancy support along with more material forms of support to assist with managing the condition.

8.4.2 Recommendation 2: improving the content of inter-pregnancy care

The women in this research knew straight away that they wanted to become pregnant again at some point in the future. More could be done to follow up with women with diabetes who have experienced baby loss. Healthcare professionals should proactively initiate a sensitive conversation about subsequent pregnancy so that women with diabetes can access the appropriate support sooner after a baby loss, as the inter-pregnancy interval may not be long.

This would provide an opportunity to discuss prescribing a high-dose folic acid prescription, check medications and refer to pre-pregnancy services with that conversation already started.

All women with diabetes who want to try for a subsequent pregnancy should have access to technology in the inter-pregnancy interval. Women with type 2 diabetes need more support to gain tight control of their blood glucose levels. Relying on HbA1c measurements is insufficient for women with type 2 diabetes who are trying to prepare for pregnancy. At the least, women with type 2 diabetes should have easy access to blood glucose monitors and a prescription for testing strips and lances in the inter-pregnancy interval.

8.4.3 Recommendation 3: Improving awareness of preparing for pregnancy

Healthcare professionals may assume that women need time and space before thinking about a subsequent pregnancy. However, these findings showed that women knew straight away that they wanted to try for another pregnancy at ome point. Healthcare professionals should be aware that women might decide quickly about pregnancy after a baby loss.

These findings highlighted how not all healthcare professionals who came into contact with women with diabetes were aware of the risks for women with diabetes during pregnancy. More could be done to raise awareness among healthcare professionals and women with type 2 diabetes about the importance of preparing for pregnancy. A good start would be to ensure that the ‘Desmond’ structured education programme offered to women with type 2 diabetes shortly after diagnosis includes information on preparing for pregnancy.

All healthcare professionals who come into contact with women with diabetes should be aware of the importance of preparing for pregnancy and what this involves, as they are in a position where they can deliver a brief intervention to ensure women with diabetes know what they need to do and can easily gain a prescription for high dose folic acid and have their medication reviewed in a timely fashion. In particular, healthcare professionals working in primary and community care settings may not be aware that women with type 2 diabetes should prepare the same way as those with type 1 diabetes.

8.4.4 Recommendation 4: Improving communication skills

Initiating and normalising a sensitive conversation about subsequent pregnancy sooner than is currently happening could allow more opportunities to support women with diabetes in both grieving for their loss and preparing for pregnancy. Healthcare professionals reported that they received little training on handling sensitive conversations about baby loss and pregnancy after loss. Previous baby losses are not always well-documented and evident on notes across services. As a result, healthcare professionals might avoid conversations about pregnancy for fear of upsetting the patient.

Healthcare professionals must receive training on handling sensitive conversations and are equipped with the communication skills to be comfortable discussing baby loss and a subsequent pregnancy much earlier than might currently be happening, rather than assuming there will be a waiting period before deciding about a subsequent pregnancy. These findings suggest that healthcare professionals could initiate a sensitive conversation about pregnancy plans early after baby loss, offering an opportunity to refer women with diabetes to the most appropriate services in a timelier way.

The stigmatising self-recrimination that women with diabetes may feel at the intersection of baby loss and diabetes poses a particular challenge for women with diabetes and healthcare professionals alike. In some cases, women with diabetes may implicitly be blamed for the baby loss when diabetes and suboptimal diabetes management are identified as causing the baby loss. Great care must be taken in delivering this information to women with diabetes, and healthcare professionals could be better supported in managing such difficult conversations.

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Chapter 10. Appendices

Appendix A: Dyer E, Bell R, Graham R, Rankin, J (2019) Pregnancy decisions after fetal or perinatal death: systematic review of qualitative literature. BMJ Open. 2019;9:e029930

BMJ Open

Pregnancy decisions after fetal or perinatal death: systematic review of qualitative research

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ABSTRACT

Objectives To synthesise the findings of qualitative research exploring parents' experiences, views and decisions about becoming pregnant following a perinatal death or fetal loss.

Design Systematic review and meta-synthesis of qualitative research.

Data sources Medline, Web of Science, CINAHL, PsycINFO, ASSIA, Embase, PUBMED, Scopus and Google Scholar.

Eligibility criteria Nine electronic databases were searched using predefined search terms. Articles published in English, in peer-reviewed journals, using qualitative methods to explore the experiences and attitudes of bereaved parents following perinatal or fetal loss, were included.

Data extraction and synthesis Qualitative data relating to first-order and second-order constructs were extracted and synthesised across studies using a thematic analysis.

Results 15 studies were included. Four descriptive themes and 10 subthemes were identified. The descriptive themes were: deciding about subsequent pregnancy, diversity of reactions to the event, social network influences, and planning or timing of subsequent pregnancy. The decision to become pregnant after death is complex and varies between individuals and sometimes within couples. Decisions are often made quickly, in the immediate aftermath of a pregnancy loss, but may evolve over time. Bereaved parents may feel isolated from social networks.

Conclusions There is an opportunity to support parents to prepare for a pregnancy after a fetal or perinatal loss, and conversations may be welcomed at an early stage. Health professionals may play an important role providing support lacking from usual social networks.

PROSPERO registration number CRD42018112839

Strengths and limitations of this study

- This review synthesised qualitative data from primary studies describing the experiences of bereaved parents in their transition from perinatal death to pregnancy.
- We used standardised methods, including double blind screening, quality rating and data extraction.
- The themes identified were supported by evidence grounded in all included studies.
- Study participants were mainly mothers from high-income countries, with high levels of education and living with their partners, limiting the wider applicability of the findings.
- The review was limited to peer-reviewed journal articles published in English.

INTRODUCTION

Perinatal and fetal death remain common adverse pregnancy outcomes,[1,2] with a perinatal mortality rate of 5.40 per 1000 births in England and Wales,[3] and estimated miscarriage rate of 25%–43%.[4,5] Many parents who have experienced fetal or perinatal loss will have further pregnancies. Debate continues about recommendations concerning the optimum interpregnancy interval following such a death.[6–9] The WHO recommends couples wait at least 6 months before trying to conceive again,[10] based on evidence that shorter interpregnancy intervals are associated with adverse pregnancy outcome.[9,11–13] However, a recent meta-analysis found no clear evidence to support this recommendation,[9] and UK guidance does not specify a waiting period. An additional concern is allowing sufficient time to grieve and minimise the risk of trying to replace the deceased child, both of which have been associated with psychological and bonding issues.[14–16] Hence, parents may receive contradictory advice from health professionals.[17]

Many women experience an overwhelming urge to become pregnant as soon as possible after fetal or perinatal death[18–20]; 80% of women become pregnant within 18 months of the death.[20–24] The motives and processes involved in subsequent pregnancy decisions remain unclear. Health professional involvement in the decision to conceive is encouraged, and it is important for health professionals to listen to and support women where modifiable risks can be reduced to try and avert subsequent perinatal death.[25,26] However, many women only inform health professionals once they have become pregnant,[27–29] suggesting that the consideration

of conception is primarily a personal decision between partners.[19]

This systematic review aimed to identify, appraise and synthesise existing qualitative research reporting parents' experience of the decision-making process concerning becoming pregnant again after experiencing fetal or perinatal death.

METHODS

Search strategy

Qualitative research reporting bereaved parents' interpregnancy experiences pertaining to thinking about, planning or preparing for subsequent pregnancy following a perinatal death (miscarriage, stillbirth, termination of pregnancy for fetal anomaly or neonatal death) was eligible for inclusion, if published in English in a peer-reviewed journal article. Search terms were identified using the Sample, Phenomenon of Interest, Design, Evaluation, Research Type framework[30–32] (online supplementary appendix S1).

Electronic database searches (Medline, Web of Science, CINAHL, PsycINFO, ASSIA, Embase, PUBMED, Scopus and Google Scholar) were conducted between February and June 2018. Titles and abstracts were screened by ED using the web-based tool 'Rayyan'.[33] A 10% sample was blindly double screened, and any title highlighted as potentially relevant by either reviewer was included in the full-text review. There was very high agreement between screeners (97.2%) indicating a reduced risk of screening error. Two reviewers independently read all full text articles. Uncertainties about inclusion were resolved through discussion with a third reviewer. All included studies were also manually citation searched.[34–40] Fifteen studies were included in the final review (online supplementary appendix S2).

Quality appraisal

Study quality was assessed using the 2018 Critical Appraisal Skills Programme (CASP) checklist for qualitative research.[41] To help facilitate quality assessment, a scoring system was formulated so that numerical values were assigned to the three possible answers to the CASP questions (yes=2, can't tell=1, no=0), with a maximum possible score of 20. Studies were considered 'good quality' if the overall score was 16 or more. Two reviewers independently rated each study, and differences were resolved by discussion. The quality score was considered during data analysis to ensure that all themes were present in better quality studies. While there is a debate surrounding this approach, there is no 'gold standard' tool for critical appraisal.[42,43] As such, this pragmatic decision enabled the researchers to ascertain an indicative level of quality for all included papers which helped to mitigate the tension between reporting quality and relevance, an approach used successfully by other researchers.[44]

Data extraction and synthesis

Data including bibliographic information, aims, method, quality assessment and findings were extracted onto an Excel form separately by two researchers to ensure consensus was reached. Qualitative data relating to first-order (participants' quotes) and second-order constructs (author interpretations, assumptions, statements and ideas) were recorded and imported into QSR NVIVO V.12 for management and thematic analysis.

Thematic analysis techniques, adapted from Butler *et al*,[58] and Harden and Thomas,[45] were used primarily by ED to systematically analyse and synthesise qualitative data from the included studies in two iterative stages:

Stage 1—coding text: data from the primary studies were examined line by line for meaning and content, and within each study conceptual codes were systematically assigned allowing emerging concepts to be aggregated across the studies. Subsequent studies were coded into pre-existing concepts, and new concepts were created when deemed necessary.

Stage 2—development of descriptive themes: the list of codes was examined and re-analysed for meaning and organised into categories. Each category was examined and descriptive themes were organised to reveal relationships and link theoretically similar sub-themes together, thus offering thought-provoking new insights into the body of knowledge in this area of research.[46]

A priori themes of interest included parents' decisions about pregnancy subsequent to loss, experiences surrounding preconception preparation and conception in the context of perinatal death, and the role of health professionals. All themes were independently checked for accuracy and reviewed by a second researcher to ensure a consensus was reached.

Patient and public involvement

Patient and public views were not sought.

RESULTS

Included studies

Fifteen studies published between 1986 and 2017 and conducted in eight countries met the inclusion criteria (online supplementary appendix S2 and table S1). Sample sizes ranged from 4 to 122 participants, and fetal or perinatal deaths occurred across a range of gestations. Investigating subsequent pregnancy decisions was the main aim of five studies,[19,21,47–49] while 10 studies reported relevant findings from studies where this was not the main focus. Seven studies focused solely on women's experiences,[21,47,48,50–53] seven included both parents[15,16,19,49,54–56] and one included wider family members. Participants predominantly reported ethnicity as white,[15,16,21,49,52,56] relationship status as married or cohabiting[15,16,19,21,48–51,53,54] and had completed some form of post-secondary education.[16,48,49,54] Twelve studies were considered 'good quality', including details of ethical approval, participant recruitment, research design and evidence of researcher reflexivity (online supplementary table S2).

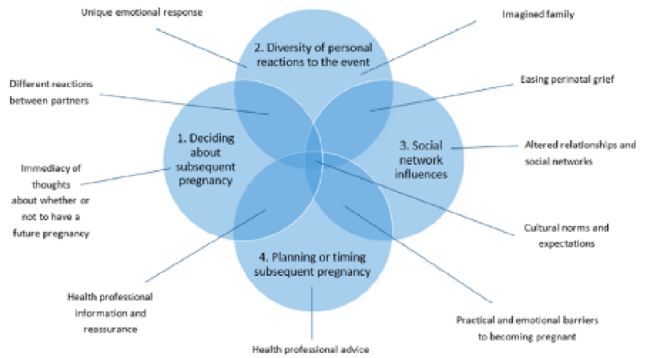

Figure 1 Themes and subthemes

Findings

There were four main descriptive themes: (1) deciding about subsequent pregnancy, (2) diversity of personal reactions; (3) social network influences; (4) planning or timing of subsequent pregnancy. Ten subthemes were identified which interacted with the four themes (figure 1). Themes and subthemes were tabulated according to the studies from which they arose (online supplementary table S3).

Theme 1: deciding about subsequent pregnancy

This theme captured findings relating to the immediate period after the loss, reflecting initial thoughts about subsequent pregnancies and the point at which pregnancy planning emerges as an idea. The subthemes highlight some of the complexity involved in decision making in the aftermath of perinatal death, especially when there is disagreement between partners.

Immediacy of thoughts

Eight studies reported data suggesting that parents form a clear idea about whether or not they wish to try to conceive again soon after the death of their baby.[19 21 47 49–51 53 55]

> Absolutely immediately…. Whilst we were waiting to be induced, we were talking about next time.[21]

Differences in reactions between partners

Six studies considered the experiences of both parents; four found that parents sometimes disagreed on the decision to try for another baby.[16 19 49 54] This was a key observation in one study where fathers were observed to be more reluctant to consider a future pregnancy.[19]

> My husband was saying he didn't want any more children. So I don't know if you count this much but someone who has lost a baby, for me I would have been pregnant coming out of the hospital again I wanted to be pregnant again that badly and then he was saying he didn't want any more at all and he wouldn't discuss it until after we got the results from the hospital.[19]

In three studies,[19 53 54] men were reported to carry a different burden to women, in particular taking on the role of 'protector' who needed to be emotionally strong,[19 53 54] and less likely to express their own fears.[19 53 54]

While there is insufficient data here to support the idea that all parents know straight away about subsequent pregnancy, this theme is noteworthy because it highlights that parents may not simultaneously feel ready, and so access to specialised care to decide what is best for them may be required soon after the event, or may be required later on. This is in keeping with the findings from Conway and Russell,[54] who emphasise the need to carry out more research into the most appropriate type and timing of intervention after loss.

Theme 2: diversity of personal reactions

The subthemes represent how the unique and individual experiences and reactions of parents to loss is intrinsically linked in decisions surrounding the timing of subsequent pregnancy which in turn influenced how each individual engaged with the concept of future pregnancy decisions.

Emotional response

Emotional responses to the death of a baby are unique to each parent, and varied from feelings of self-blame and guilt, loneliness and emptiness, anger, fear, failure and shame, to sadness and grief. In turn, the emotional response may not only influence, but also shape, understandings of the self and identity. In turn, these impact decisions about becoming pregnant after loss. In four

studies, participants described the death as a void that could only be filled by a subsequent pregnancy.[15 21 47 55]

> Emotionally everything had been geared towards having a baby and then there was a big hole, a baby-shaped hole which was much bigger than a baby.[21]

Imagined family

Findings from 11 studies highlighted how pregnancy and childbirth are conceptualised within individuals' life narratives, and how parents often have pre-existing expectations about their reproductive aspirations. Experiencing a perinatal death prompts parents to reconsider their life goals.[16 19 51]

> …but I was 29 when she was born, and I had this vision in my head that I was going to have all my kids by the time I was 30, and that wasn't working out, and so we better get on….[16]

Easing perinatal grief

Five studies[21 47 49 51 55] reported that, for some parents, a subsequent pregnancy was considered essential for their recovery, eased feelings of perinatal grief and gave hope for the future.

> I knew it was going to be a long process and it helped me recover because it made me focus on the future and I was more hopeful.[49]

However, not all parents were so certain that a subsequent pregnancy would aid recovery, and needed longer to overcome the grief and feel ready.[19 21 47 49] These framings set the scene for future pregnancy planning which emerged and developed with reference to how an individual has interpreted the meaning of the prior loss in relation to their sense of self.

This theme highlights just how individual and personal the decision to become pregnant is, and helps to make sense of why parents can react so differently to similar circumstances of loss. This necessarily colours the context in which questions about future pregnancy planning emerge, and develop, in ways that are highly dependent on how an individual has interpreted the meaning of the previous incidence of loss in relation to their sense of self.

Theme 3: social network influences

Future pregnancy planning decisions could be influenced by an individual's social network and the cultural norms and expectations within their social group. Comments and assumptions by others about future planning could be interpreted as supportive or distressing, depending on the context.

Altered relationships and social networks

Eight studies[16 19 48 50 52 55–57] highlighted how relationships and social networks changed after a perinatal death. In three studies, some parents reported much support thereby reinforcing bonds with their social network.[21 48 56] However, in five studies, parents felt that friends and family were not supportive, and relationships were profoundly altered following unhelpful attitudes and responses.[19 48 50 52 56] As a result, bereaved parents may withdraw or isolate themselves from friends, family and colleagues to avoid hurt,[19 48 50 52 56] and avoid discussing their loss to prevent their friends and family feeling uncomfortable.[56]

> Everything is okay with my friends, as long as I don't talk about my baby. When I do, they look away and change the subject. What am I supposed to do? I need to talk![56]
>
> [I] talked a lot about it with my boyfriend and friends. On the one hand it was fine, on the other hand not. None of my friends have experienced this, so it is quite difficult for them to understand. And then sometimes they said…well at least you know that you can become pregnant…I got that kind of remark.[48]

This subtheme highlights that the concept of subsequent pregnancy planning may be complicated by the comments and assumptions made by other within an individual's social network some of which could be interpreted as supportive, but in some circumstances, distressing.

Cultural norms and expectations

Nine studies discussed the impact of cultural norms on decisions about subsequent pregnancy.[16 19 48 50–53 55 56] Parents in four studies noted other people's discomfort, reporting that such uneasiness led to unsupportive reactions.[16 21 52 56]

In some cultures, while there are strong expectations for women to bear children, stillbirth is regarded as taboo and parents are not expected to see or to discuss their dead baby.[50 51] A striking finding was the guilt and sense of failure that was reported following a perinatal death in this environment.[50 51] This led some women to pursue pregnancy as soon as possible to undo the sense of wrongdoing associated with stillbirth[50] and fulfil the cultural expectations of being a successful mother.[51]

> I am trying to have a baby again. As long as I can have a baby, my mother-in-law can't look down on me. Also, failing to deliver a baby makes me feel that I am not a woman. Every woman should be able to deliver a baby—that's what makes a woman so different from a man.[50]

This theme highlights that the concept of subsequent pregnancy planning may be complicated by the comments and assumptions made by others within an individual's social network. Pregnancy and childbirth may be viewed by society as a natural and celebratory part of life, rather than the anxiety-filled prospect that bereaved parents now face. Some comments could be interpreted as supportive, but some parents may perceive the expectation for them to 'get over it' and 'get on with it' hard to tolerate, especially as some felt that a subsequent pregnancy could be dismissive of their deceased baby.

Theme 4: planning or timing subsequent pregnancy

Encapsulated in this theme is the notion that planning or timing of a subsequent pregnancy may be influenced by the advice, information and reassurance from health professionals which may differ depending on the emotional and medical barriers faced by bereaved parents after loss.

Eleven studies reported discussion of planning or timing a subsequent pregnancy.[16,19,21,47–49,52,54–57] In six studies, parents felt that the timing of a subsequent pregnancy should be based on personal reasons and individual experience, rather than the thoughts of others, including medical professionals.[19,21,47,49,52,56] Women spoke of listening to their body and trusting their own feelings.[21,47] Planning a subsequent pregnancy often involved overcoming barriers,[16,47,49,55,57] and sometimes conflicting messages from health professionals.[56]

Barriers: practical and emotional

In five studies, parents cited a range of emotional and medical challenges as barriers to conceiving after loss.[16,47,49,55,57] Parents faced a period of ambiguity and uncertainty when planning their next pregnancy,[16,19,21,48,49,55,57] and a loss of control associated with a long conception period.[48]

> The last time I was actually very impatient because after that last miscarriage it lasted a year and a half before we were pregnant again. So I thought it would take a year and a half again to become pregnant so we tried again a month after the miscarriage.[48]

Such an uncertainty was intensified by practical factors, such as the number of previous perinatal deaths experienced, advanced maternal age, financial strain, parent relationship status and fertility problems.[48,49,57] High levels of anxiety and fear were linked to the lack of reassurance that a subsequent pregnancy would end successfully.[16,19,52,54,55,57]

Such barriers may redefine decisions about how many children parents wish to have,[57] or how soon parents try to conceive, with some deciding to delay to make sure they felt emotionally and physically ready for pregnancy,[21,47–49,55] whereas others may try to become pregnant regardless of emotional or physical readiness for fear of not being able to conceive again.[16]

> Mother: I also had a real fear of not becoming pregnant again, I thought that maybe that was my once in a lifetime shot. So that was on my mind too, that maybe I wouldn't get pregnant. So after 6 months I was real anxious to get going because I thought it might take a while.
>
> Father: Well, we missed one month, and of course right away L. panicked and figured out she'd never become pregnant again.[16]

Health professional advice

Seven studies discussed the involvement of health professionals in the interpregnancy period. The amount and type of advice given varied, but included answering medical questions, providing information and advice about subsequent pregnancy and reassurance about the level of care that would be received for a subsequent pregnancy.[16,19,47–49,54,56]

One early study focused specifically on mothers' perceptions of medical advice about timing of a subsequent pregnancy.[47] Again, the advice varied; five women were advised to wait less than 6 months before trying to conceive, matching the women's expectations, as they felt an urgent need to get pregnant.[47] Fourteen were advised to wait at least 6 months, 11 of whom found this advice unacceptable mainly due to the strong desire to have a baby:

> [12 months] is an eternity…I had all this parenting energy and nowhere to direct it….[47]

Five women in this study received no *specific* advice about waiting. These women appreciated this both at the time and in hindsight, as it empowered them to make their own informed decision based on their individual needs. This was a consistent finding in other studies[21,47,49,56] and highlighted the importance of *appropriate* advice, rather than the amount or the content of the advice.

Health professional information and reassurance

Concerned parents sought reassurance and information from health professionals, for example, about the risks of another negative outcome and the type of specialised care and emotional support they might expect to receive in a future pregnancy.[16,19,21,47,49,52,55,56]

> …they basically told us that we had the same chance of it happening to us again as if it had never happened to us. The same as any couple walking down the street. But the only thing I kept saying was that it did happen to us you know so they can't give any reassurances.[19]

However, not all parents received such advice and support,[21] and although parents can be informed of level of risk, it was not possible to guarantee that there will not be another negative outcome in a future pregnancy.[19]

This theme highlights how bereaved parents may turn to health professionals for advice, information and reassurance regarding the timing of a subsequent pregnancy and overcoming barriers to conception.

DISCUSSION

This review analysed and synthesised qualitative data from primary studies, describing the experiences of bereaved parents in their transition from perinatal death to pregnancy, an area largely overlooked in the literature to date. The sample included a range of experiences from both parents, across eight countries, and included parents who had experienced different types of fetal or perinatal death. The themes identified were supported by evidence grounded in the primary studies. This systematic review followed the Enhancing Transparency in Reporting the Synthesis of Qualitative Research reporting structure (online supplementary appendix S3). To reduce the risk of bias, we used standardised and comprehensive methods, with explicit criteria, double blind screening, quality rating and data extraction. As researchers, not practitioners in the field, we have a particular interest in understanding both lay and professional experiences of healthcare provided in the context of distressing life events such as reproductive loss. It was therefore important to stay close to the data so as not to impart our own opinions or judgements on the findings.

Many parents decide whether or not they wanted to have another pregnancy shortly after the loss. However, parents sometimes disagreed with their partners and early decisions could evolve over time. A key theme was the range of unique and personal reactions to loss. These experiences were intrinsically linked to decisions surrounding the timing of subsequent pregnancy which in turn influenced how participants engaged with future pregnancy decision-making. Future pregnancy planning may be influenced by an individual's social network and the cultural norms that guide people within their social group. The taboo that surrounds perinatal death makes it a difficult subject to discuss, potentially leaving bereaved parents feeling isolated and lonely. A salient finding was the assertion that parents should be provided with information about timing subsequent pregnancy, rather than prescriptive advice or specific recommendations.[21,47,49,56] Health professionals need to be mindful of the patients' individual preference for the amount and type of advice that they want or need. Parents should be empowered to access information at a time of their choosing, when they feel ready.

Resource constraints limited the review to journal articles published in English. Relevant material was identified in other sources including abstracts and theses, and some themes may not have been identified owing to the large number of search results and the fact that relevant studies may report data as secondary findings, increasing the likelihood of screening error resulting in studies being missed. The majority of study participants were mothers; fathers' experiences may be underrepresented. All studies were undertaken in high-income countries, and participants were mainly educated and living with the father of the baby. This has implications for the wider applicability of the findings.

There are inherent limitations associated with systematically reviewing qualitative studies, since only data which has been selected for presentation within the study is available, rather than the totality of the data collected. The quality of a systematic review further depends on the quality of the studies it includes. While the majority of the included studies were rated as good quality, not all studies indicated the data analysis technique used or the retrospectivity of loss which may impact the reliability of findings. Care was taken to ensure that themes were represented across multiple studies, one study rated as average quality contributed to six of the ten subthemes and dominated the findings in the subtheme regarding health professional advice. Thus, caution should be exercised regarding the wider applicability of this theme.

The findings suggested that some parents develop a clear idea soon after perinatal death whether or not they wish to pursue a subsequent pregnancy. This reaction to pregnancy loss may reflect a strong desire to leave the liminal phase that parents experience following the death of a baby, whereby the nebulous identity of becoming non-pregnant leaves parents stranded between the stable states of being pregnant and parenthood.[56,58] Other explanations include the theory that mothers and fathers assume their role of parents early in pregnancy,[59] with psychological preparation for parenthood beginning before conception.[60] Jaffe and Diamond further suggest that people determine their own 'reproductive stories' as early as their own childhood; the perinatal death leaves this desire unfulfilled until a living child is born.[61] While there is insufficient data to conclude that all parents decided quickly about subsequent pregnancy, we suggest that some parents may welcome opportunities to discuss their plans earlier than health professionals may assume. Conway and Russell emphasise the need to understand the most appropriate type and timing of health professional intervention after loss.[54]

The data describe a range of reactions to loss, and highlight the personal and individual nature of timing a subsequent pregnancy. This is consistent with other studies.[18,62–64,64–68] Our findings suggest that parents may feel increased isolation after fetal or perinatal death, due to the taboo nature of the topic.[18,69,70] Social withdrawal has also been identified as an expression of grief following bereavement.[71,72]

The needs of bereaved parents during the period when they are contemplating becoming pregnant again has received substantially less interest than the need for additional support during subsequent pregnancy. Several studies have explored the experiences of parents during pregnancy following loss, and services have been developed to respond to their need for increased support. The process of conceiving the subsequent pregnancy is not discussed in these reports.[22,28,73–75] It is possible that health professionals do not consider involvement in such decisions as part of their role. However, there are a number of causes or risk factors for fetal and perinatal death which may be amenable to intervention in the interpregnancy interval, for example, diabetes, obesity or smoking.

This review highlights that the window of opportunity to influence these factors and support parents in reducing the risks in the next pregnancy may be relatively short. Health professionals may play an important role as a bridge between medical information and emotional support in the interpregnancy interval, but with a paucity of research looking specifically at the perspectives of health professionals it is not possible to establish why advice may differ between health professionals and whether they feel able to offer the individualised advice and support that bereaved parents require or seek.

CONCLUSION

Many parents think about becoming pregnant again very soon after experiencing a pregnancy loss, and health professionals should anticipate the need to facilitate conversations from the very earliest point. Providing personalised and flexible support may be challenging for health professionals working within healthcare systems which may not easily adapt to differing needs. Health professional perspectives are currently analytically underdeveloped in the literature, so should be an area for further development. Further research should also address the need to better understand the decision-making process, support requirements and challenges that parents face in the interpregnancy interval following pregnancy loss, and address how bereavement services can integrate better with pregnancy preparation services. This could be of particular benefit to those with medical conditions, such as pre-existing diabetes, where effective preparation for pregnancy and delayed conception have been shown to significantly improve outcomes.[76 77]

Contributors ED contributed to protocol development, performed the searches, reviewed the papers, conducted the thematic synthesis and wrote the first draft of the article. RB developed the idea for the study, contributed to protocol development, reviewed papers for inclusion, quality assessment and data extraction, and contributed to writing the final article. RG developed the idea for the study, contributed to protocol development, reviewed papers for inclusion, quality assessment and data extraction, supervised and reviewed the thematic synthesis, and contributed to writing the final article. JR developed the idea for the study, contributed to protocol development, reviewed papers for inclusion, quality assessment and data extraction, and contributed to writing the final article.

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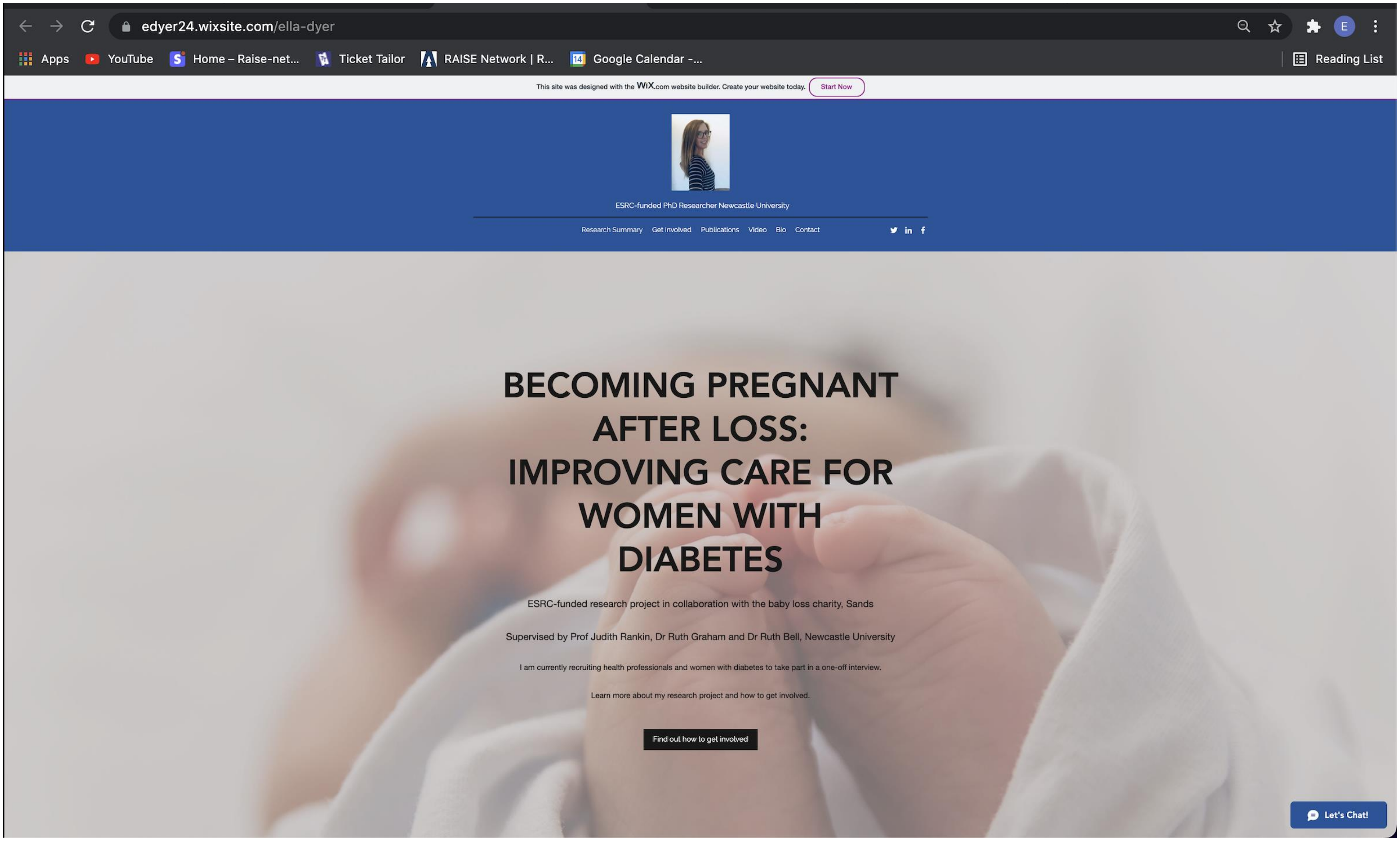
Appendix B: Screenshots from website



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ESRC-funded PhD Researcher Newcastle University

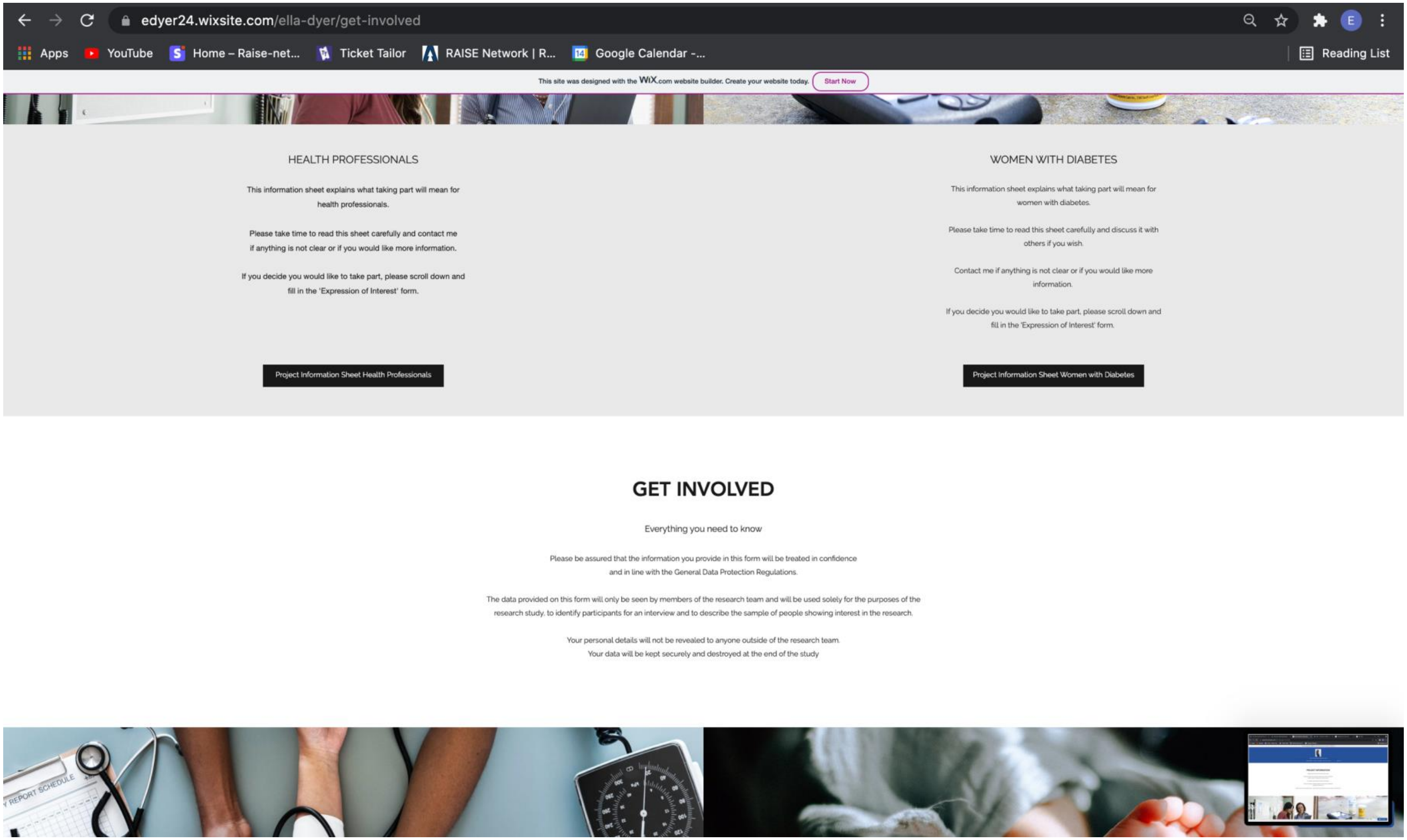
BECOMING PREGNANT AFTER LOSS: IMPROVING CARE FOR WOMEN WITH DIABETES

ESRC-funded research project in collaboration with the baby loss charity, Sands

Supervised by Prof Judith Rankin, Dr Ruth Graham and Dr Ruth Bell, Newcastle University

I am currently recruiting health professionals and women with diabetes to take part in a one-off interview.

Learn more about my research project and how to get involved.



HEALTH PROFESSIONALS

This information sheet explains what taking part will mean for health professionals.

Please take time to read this sheet carefully and contact me if anything is not clear or if you would like more information.

If you decide you would like to take part, please scroll down and fill in the 'Expression of Interest' form.

WOMEN WITH DIABETES

This information sheet explains what taking part will mean for women with diabetes.

Please take time to read this sheet carefully and discuss it with others if you wish.

Contact me if anything is not clear or if you would like more information.

If you decide you would like to take part, please scroll down and fill in the 'Expression of Interest' form.

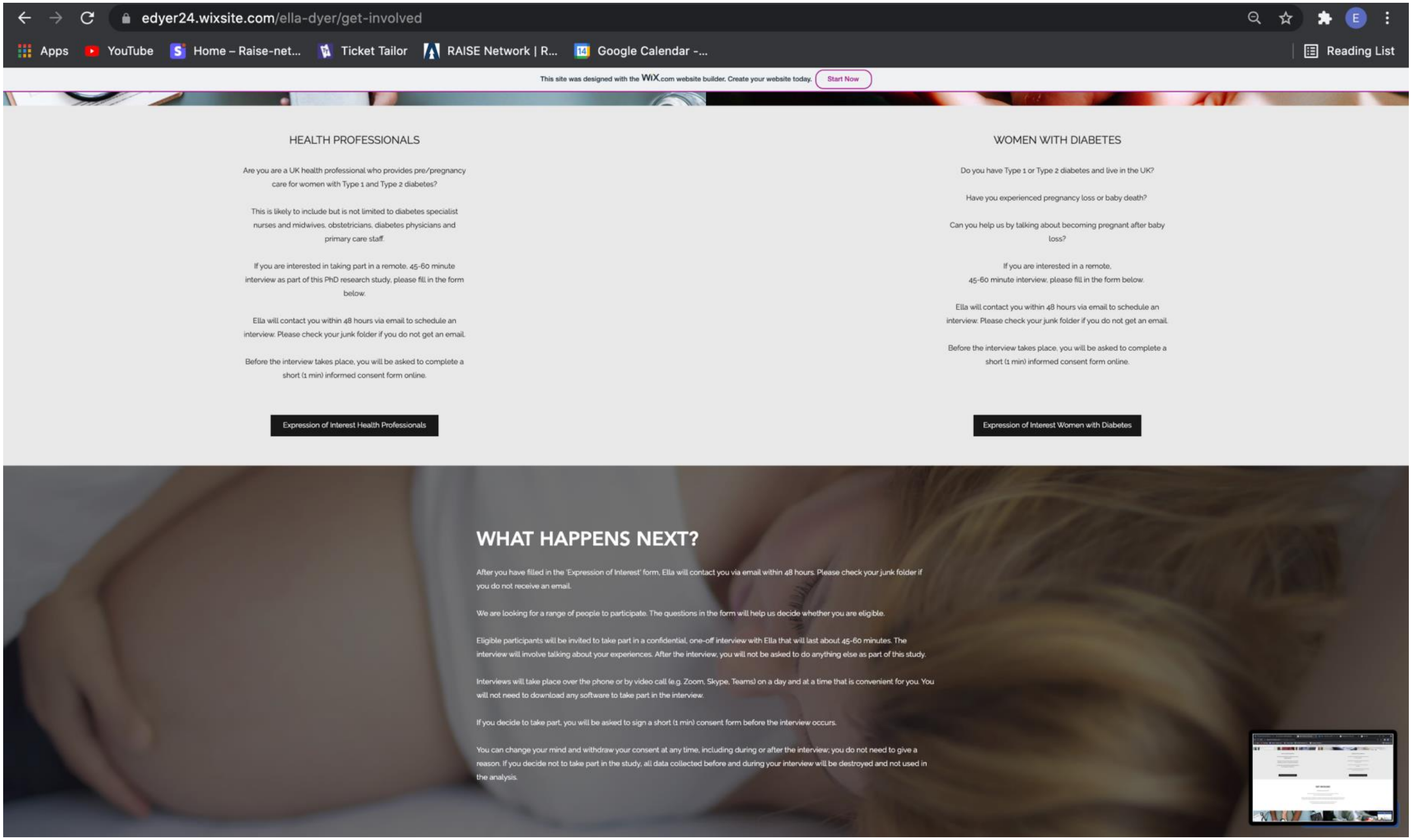
GET INVOLVED

Everything you need to know

Please be assured that the information you provide in this form will be treated in confidence and in line with the General Data Protection Regulations.

The data provided on this form will only be seen by members of the research team and will be used solely for the purposes of the research study, to identify participants for an interview and to describe the sample of people showing interest in the research.

Your personal details will not be revealed to anyone outside of the research team.
Your data will be kept securely and destroyed at the end of the study



HEALTH PROFESSIONALS

Are you are a UK health professional who provides pre/pregnancy care for women with Type 1 and Type 2 diabetes?

This is likely to include but is not limited to diabetes specialist nurses and midwives, obstetricians, diabetes physicians and primary care staff.

If you are interested in taking part in a remote, 45-60 minute interview as part of this PhD research study, please fill in the form below.

Ella will contact you within 48 hours via email to schedule an interview. Please check your junk folder if you do not get an email.

Before the interview takes place, you will be asked to complete a short (1 min) informed consent form online.

WOMEN WITH DIABETES

Do you have Type 1 or Type 2 diabetes and live in the UK?

Have you experienced pregnancy loss or baby death?

Can you help us by talking about becoming pregnant after baby loss?

If you are interested in a remote,
45-60 minute interview, please fill in the form below.

Ella will contact you within 48 hours via email to schedule an interview. Please check your junk folder if you do not get an email.

Before the interview takes place, you will be asked to complete a short (1 min) informed consent form online.

WHAT HAPPENS NEXT?

After you have filled in the 'Expression of Interest' form, Ella will contact you via email within 48 hours. Please check your junk folder if you do not receive an email.

We are looking for a range of people to participate. The questions in the form will help us decide whether you are eligible.

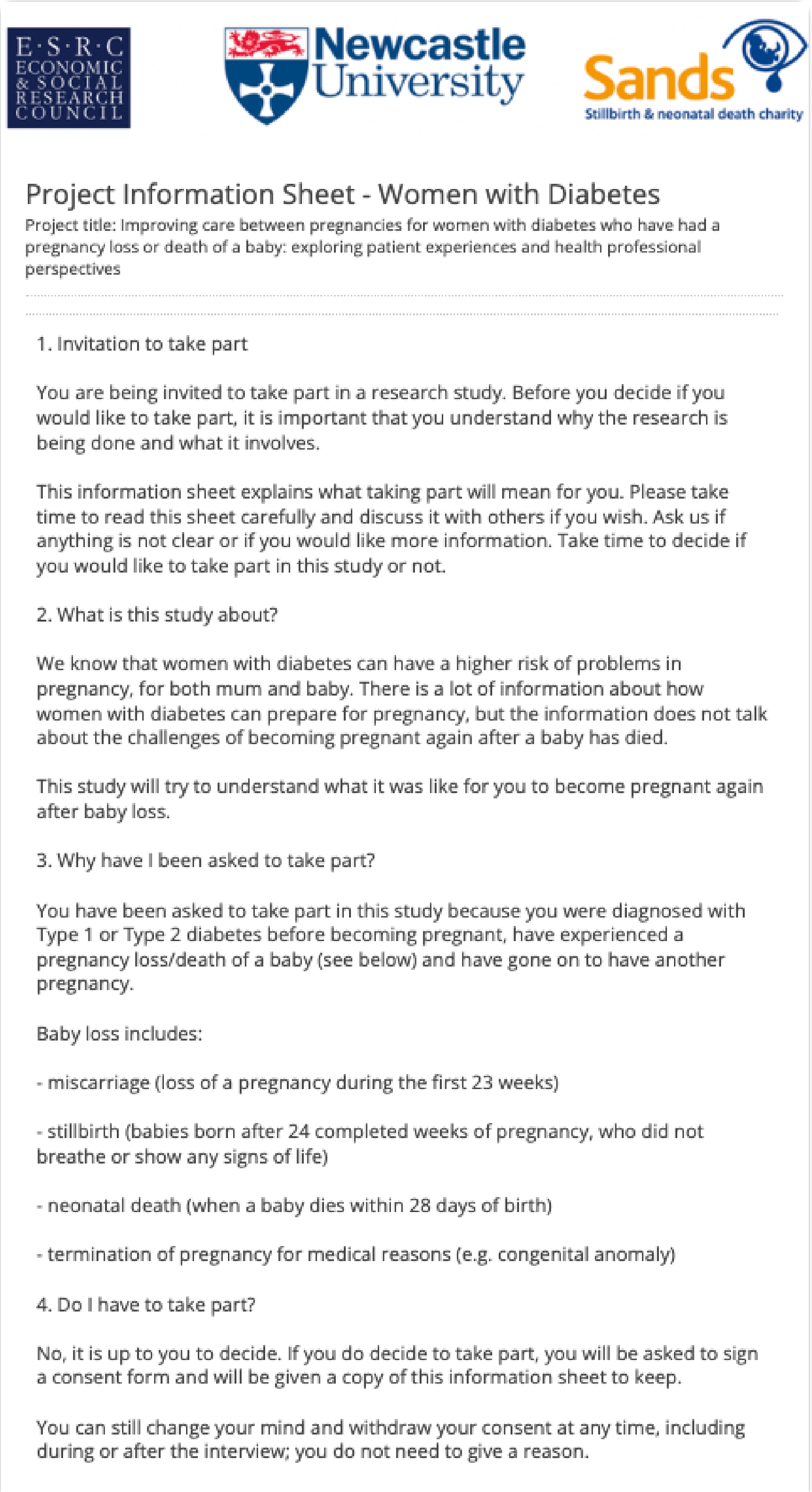
Eligible participants will be invited to take part in a confidential, one-off interview with Ella that will last about 45-60 minutes. The interview will involve talking about your experiences. After the interview, you will not be asked to do anything else as part of this study.

Interviews will take place over the phone or by video call (e.g. Zoom, Skype, Teams) on a day and at a time that is convenient for you. You will not need to download any software to take part in the interview.

If you decide to take part, you will be asked to sign a short (1 min) consent form before the interview occurs.

You can change your mind and withdraw your consent at any time, including during or after the interview; you do not need to give a reason. If you decide not to take part in the study, all data collected before and during your interview will be destroyed and not used in the analysis.

Appendix C: Project Information Sheets



E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL

Newcastle University

Sands
Stillbirth & neonatal death charity

Project Information Sheet - Women with Diabetes

Project title: Improving care between pregnancies for women with diabetes who have had a pregnancy loss or death of a baby: exploring patient experiences and health professional perspectives

1. Invitation to take part

You are being invited to take part in a research study. Before you decide if you would like to take part, it is important that you understand why the research is being done and what it involves.

This information sheet explains what taking part will mean for you. Please take time to read this sheet carefully and discuss it with others if you wish. Ask us if anything is not clear or if you would like more information. Take time to decide if you would like to take part in this study or not.

2. What is this study about?

We know that women with diabetes can have a higher risk of problems in pregnancy, for both mum and baby. There is a lot of information about how women with diabetes can prepare for pregnancy, but the information does not talk about the challenges of becoming pregnant again after a baby has died.

This study will try to understand what it was like for you to become pregnant again after baby loss.

3. Why have I been asked to take part?

You have been asked to take part in this study because you were diagnosed with Type 1 or Type 2 diabetes before becoming pregnant, have experienced a pregnancy loss/death of a baby (see below) and have gone on to have another pregnancy.

Baby loss includes:

- miscarriage (loss of a pregnancy during the first 23 weeks)

- stillbirth (babies born after 24 completed weeks of pregnancy, who did not breathe or show any signs of life)

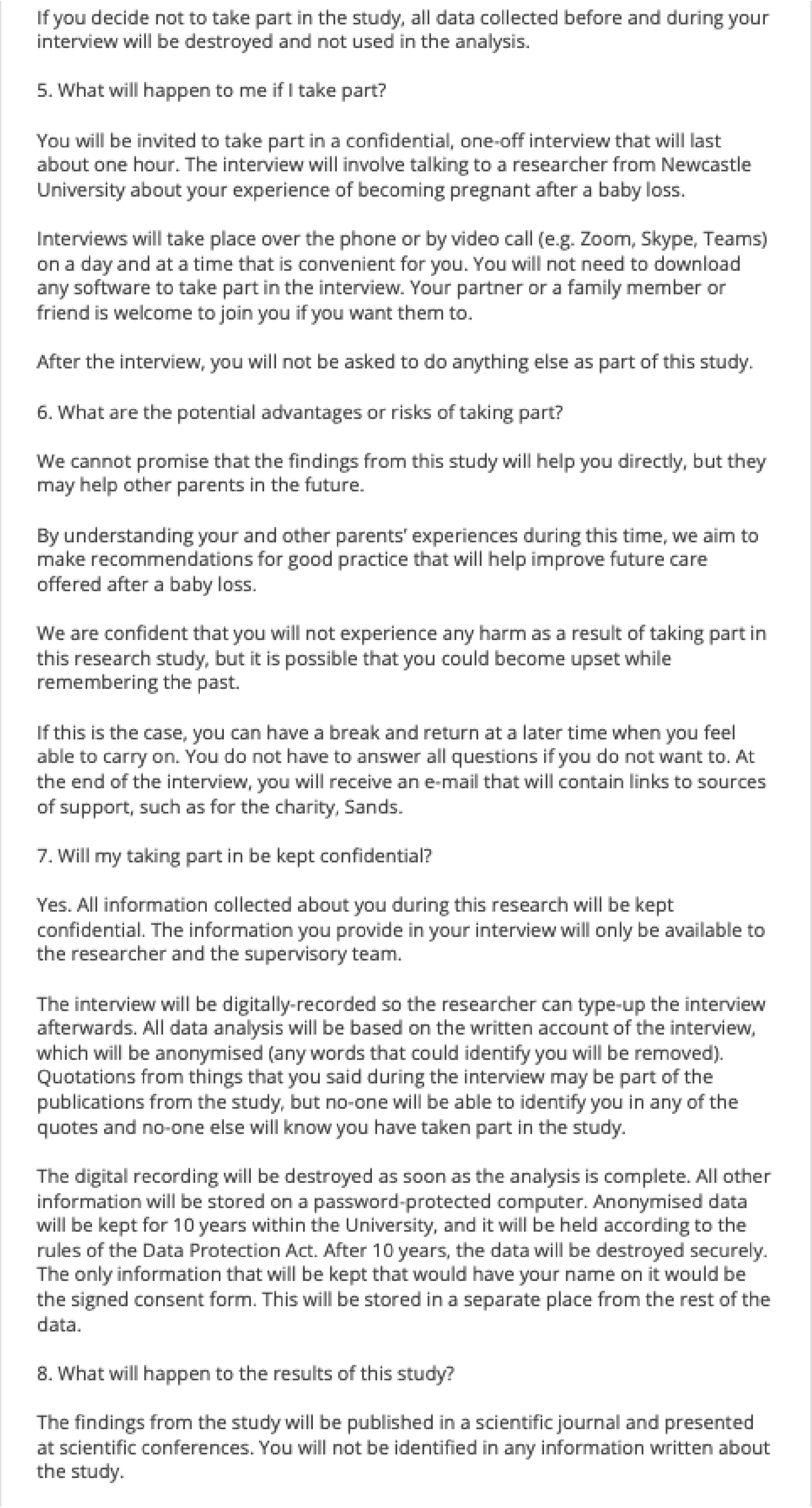
- neonatal death (when a baby dies within 28 days of birth)

- termination of pregnancy for medical reasons (e.g. congenital anomaly)

4. Do I have to take part?

No, it is up to you to decide. If you do decide to take part, you will be asked to sign a consent form and will be given a copy of this information sheet to keep.

You can still change your mind and withdraw your consent at any time, including during or after the interview; you do not need to give a reason.



If you decide not to take part in the study, all data collected before and during your interview will be destroyed and not used in the analysis.

5. What will happen to me if I take part?

You will be invited to take part in a confidential, one-off interview that will last about one hour. The interview will involve talking to a researcher from Newcastle University about your experience of becoming pregnant after a baby loss.

Interviews will take place over the phone or by video call (e.g. Zoom, Skype, Teams) on a day and at a time that is convenient for you. You will not need to download any software to take part in the interview. Your partner or a family member or friend is welcome to join you if you want them to.

After the interview, you will not be asked to do anything else as part of this study.

6. What are the potential advantages or risks of taking part?

We cannot promise that the findings from this study will help you directly, but they may help other parents in the future.

By understanding your and other parents' experiences during this time, we aim to make recommendations for good practice that will help improve future care offered after a baby loss.

We are confident that you will not experience any harm as a result of taking part in this research study, but it is possible that you could become upset while remembering the past.

If this is the case, you can have a break and return at a later time when you feel able to carry on. You do not have to answer all questions if you do not want to. At the end of the interview, you will receive an e-mail that will contain links to sources of support, such as for the charity, Sands.

7. Will my taking part in be kept confidential?

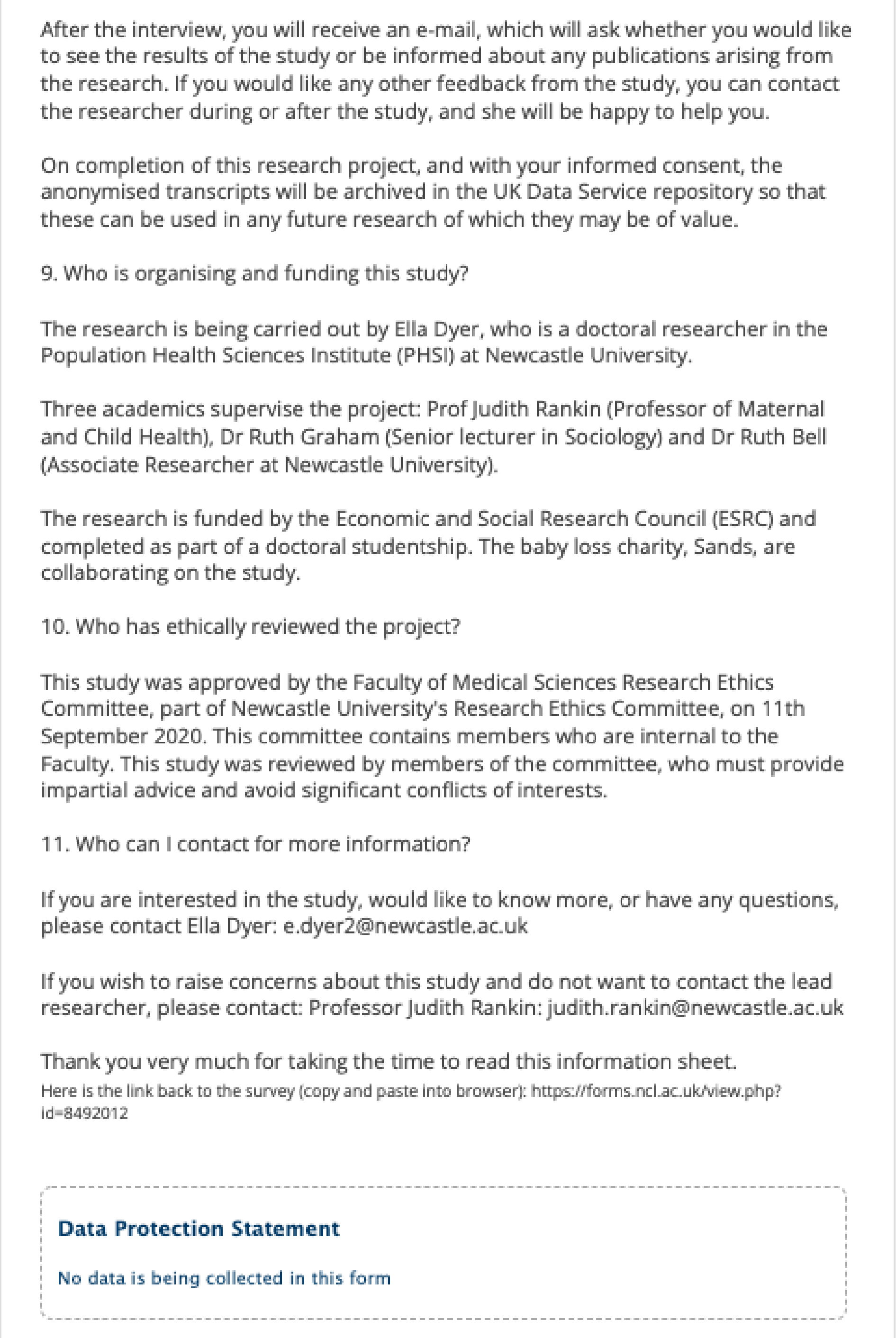
Yes. All information collected about you during this research will be kept confidential. The information you provide in your interview will only be available to the researcher and the supervisory team.

The interview will be digitally-recorded so the researcher can type-up the interview afterwards. All data analysis will be based on the written account of the interview, which will be anonymised (any words that could identify you will be removed). Quotations from things that you said during the interview may be part of the publications from the study, but no-one will be able to identify you in any of the quotes and no-one else will know you have taken part in the study.

The digital recording will be destroyed as soon as the analysis is complete. All other information will be stored on a password-protected computer. Anonymised data will be kept for 10 years within the University, and it will be held according to the rules of the Data Protection Act. After 10 years, the data will be destroyed securely. The only information that will be kept that would have your name on it would be the signed consent form. This will be stored in a separate place from the rest of the data.

8. What will happen to the results of this study?

The findings from the study will be published in a scientific journal and presented at scientific conferences. You will not be identified in any information written about the study.



After the interview, you will receive an e-mail, which will ask whether you would like to see the results of the study or be informed about any publications arising from the research. If you would like any other feedback from the study, you can contact the researcher during or after the study, and she will be happy to help you.

On completion of this research project, and with your informed consent, the anonymised transcripts will be archived in the UK Data Service repository so that these can be used in any future research of which they may be of value.

9. Who is organising and funding this study?

The research is being carried out by Ella Dyer, who is a doctoral researcher in the Population Health Sciences Institute (PHSI) at Newcastle University.

Three academics supervise the project: Prof Judith Rankin (Professor of Maternal and Child Health), Dr Ruth Graham (Senior lecturer in Sociology) and Dr Ruth Bell (Associate Researcher at Newcastle University).

The research is funded by the Economic and Social Research Council (ESRC) and completed as part of a doctoral studentship. The baby loss charity, Sands, are collaborating on the study.

10. Who has ethically reviewed the project?

This study was approved by the Faculty of Medical Sciences Research Ethics Committee, part of Newcastle University's Research Ethics Committee, on 11th September 2020. This committee contains members who are internal to the Faculty. This study was reviewed by members of the committee, who must provide impartial advice and avoid significant conflicts of interests.

11. Who can I contact for more information?

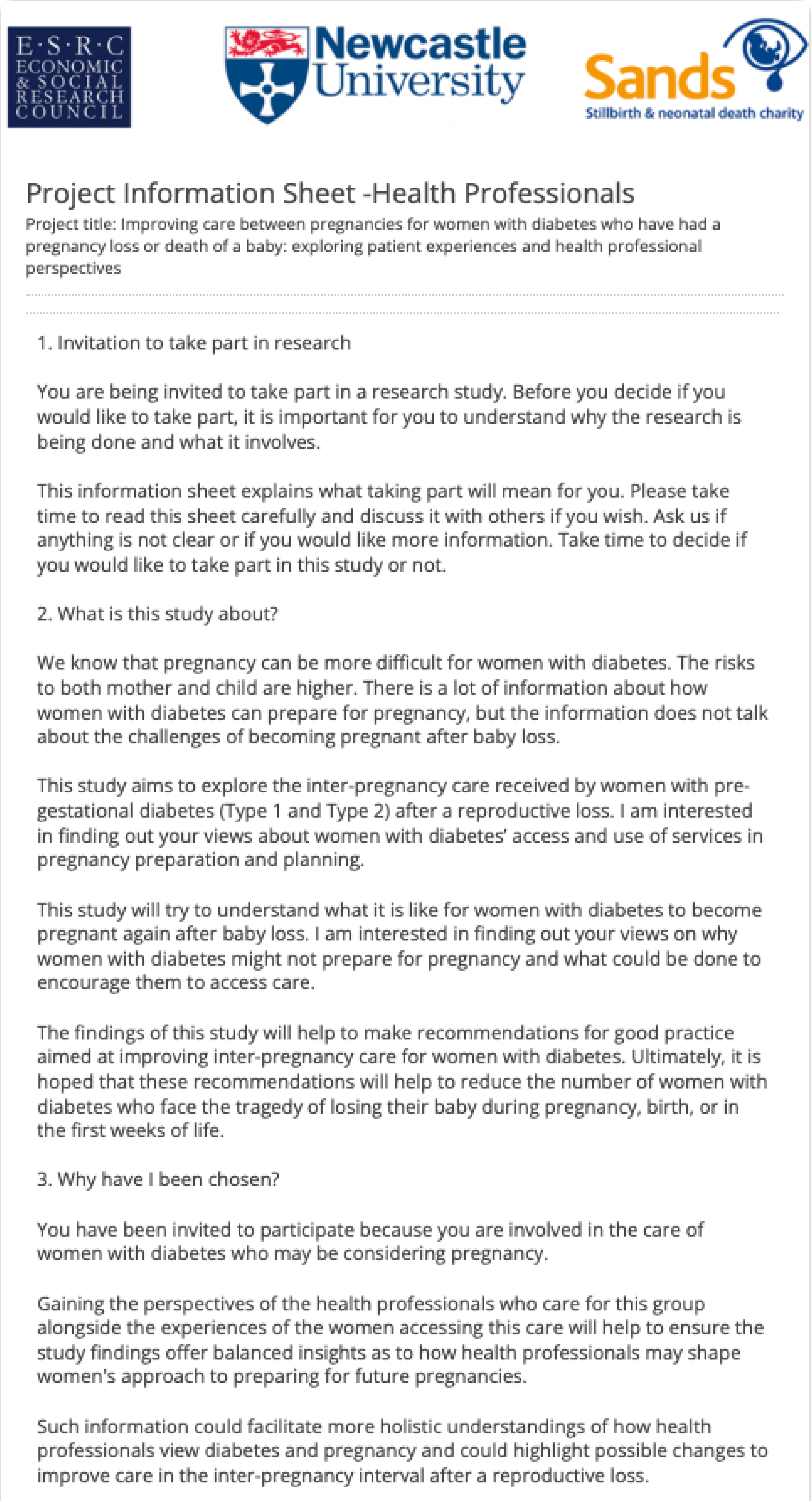
If you are interested in the study, would like to know more, or have any questions, please contact Ella Dyer: e.dyer2@newcastle.ac.uk

If you wish to raise concerns about this study and do not want to contact the lead researcher, please contact: Professor Judith Rankin: judith.rankin@newcastle.ac.uk

Thank you very much for taking the time to read this information sheet.
Here is the link back to the survey (copy and paste into browser): https://forms.ncl.ac.uk/view.php?id=8492012

Data Protection Statement

No data is being collected in this form



E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL

Newcastle University

Sands Stillbirth & neonatal death charity

Project Information Sheet -Health Professionals

Project title: Improving care between pregnancies for women with diabetes who have had a pregnancy loss or death of a baby: exploring patient experiences and health professional perspectives

1. Invitation to take part in research

You are being invited to take part in a research study. Before you decide if you would like to take part, it is important for you to understand why the research is being done and what it involves.

This information sheet explains what taking part will mean for you. Please take time to read this sheet carefully and discuss it with others if you wish. Ask us if anything is not clear or if you would like more information. Take time to decide if you would like to take part in this study or not.

2. What is this study about?

We know that pregnancy can be more difficult for women with diabetes. The risks to both mother and child are higher. There is a lot of information about how women with diabetes can prepare for pregnancy, but the information does not talk about the challenges of becoming pregnant after baby loss.

This study aims to explore the inter-pregnancy care received by women with pre-gestational diabetes (Type 1 and Type 2) after a reproductive loss. I am interested in finding out your views about women with diabetes' access and use of services in pregnancy preparation and planning.

This study will try to understand what it is like for women with diabetes to become pregnant again after baby loss. I am interested in finding out your views on why women with diabetes might not prepare for pregnancy and what could be done to encourage them to access care.

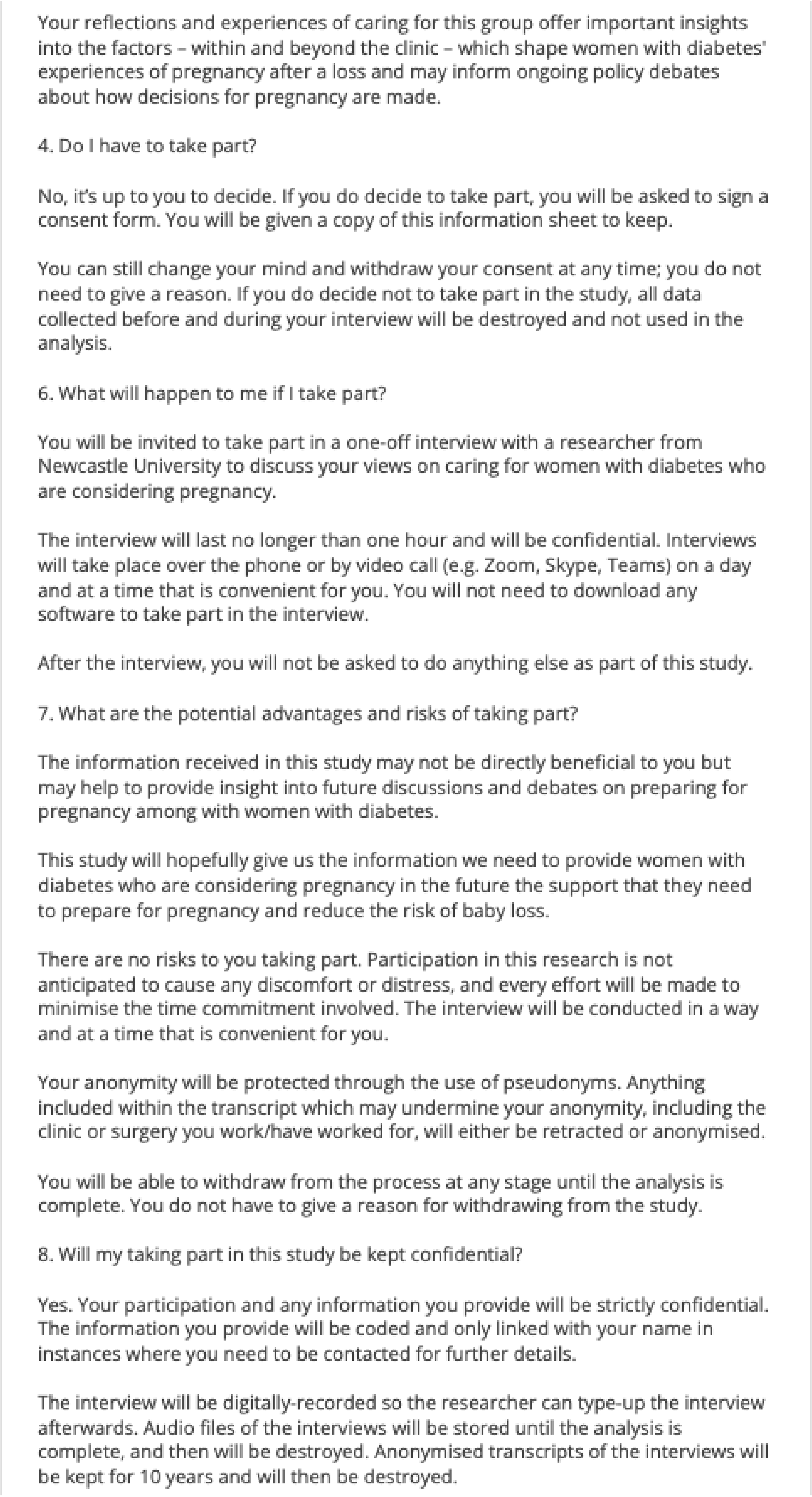
The findings of this study will help to make recommendations for good practice aimed at improving inter-pregnancy care for women with diabetes. Ultimately, it is hoped that these recommendations will help to reduce the number of women with diabetes who face the tragedy of losing their baby during pregnancy, birth, or in the first weeks of life.

3. Why have I been chosen?

You have been invited to participate because you are involved in the care of women with diabetes who may be considering pregnancy.

Gaining the perspectives of the health professionals who care for this group alongside the experiences of the women accessing this care will help to ensure the study findings offer balanced insights as to how health professionals may shape women's approach to preparing for future pregnancies.

Such information could facilitate more holistic understandings of how health professionals view diabetes and pregnancy and could highlight possible changes to improve care in the inter-pregnancy interval after a reproductive loss.



Your reflections and experiences of caring for this group offer important insights into the factors – within and beyond the clinic – which shape women with diabetes' experiences of pregnancy after a loss and may inform ongoing policy debates about how decisions for pregnancy are made.

4. Do I have to take part?

No, it's up to you to decide. If you do decide to take part, you will be asked to sign a consent form. You will be given a copy of this information sheet to keep.

You can still change your mind and withdraw your consent at any time; you do not need to give a reason. If you do decide not to take part in the study, all data collected before and during your interview will be destroyed and not used in the analysis.

6. What will happen to me if I take part?

You will be invited to take part in a one-off interview with a researcher from Newcastle University to discuss your views on caring for women with diabetes who are considering pregnancy.

The interview will last no longer than one hour and will be confidential. Interviews will take place over the phone or by video call (e.g. Zoom, Skype, Teams) on a day and at a time that is convenient for you. You will not need to download any software to take part in the interview.

After the interview, you will not be asked to do anything else as part of this study.

7. What are the potential advantages and risks of taking part?

The information received in this study may not be directly beneficial to you but may help to provide insight into future discussions and debates on preparing for pregnancy among with women with diabetes.

This study will hopefully give us the information we need to provide women with diabetes who are considering pregnancy in the future the support that they need to prepare for pregnancy and reduce the risk of baby loss.

There are no risks to you taking part. Participation in this research is not anticipated to cause any discomfort or distress, and every effort will be made to minimise the time commitment involved. The interview will be conducted in a way and at a time that is convenient for you.

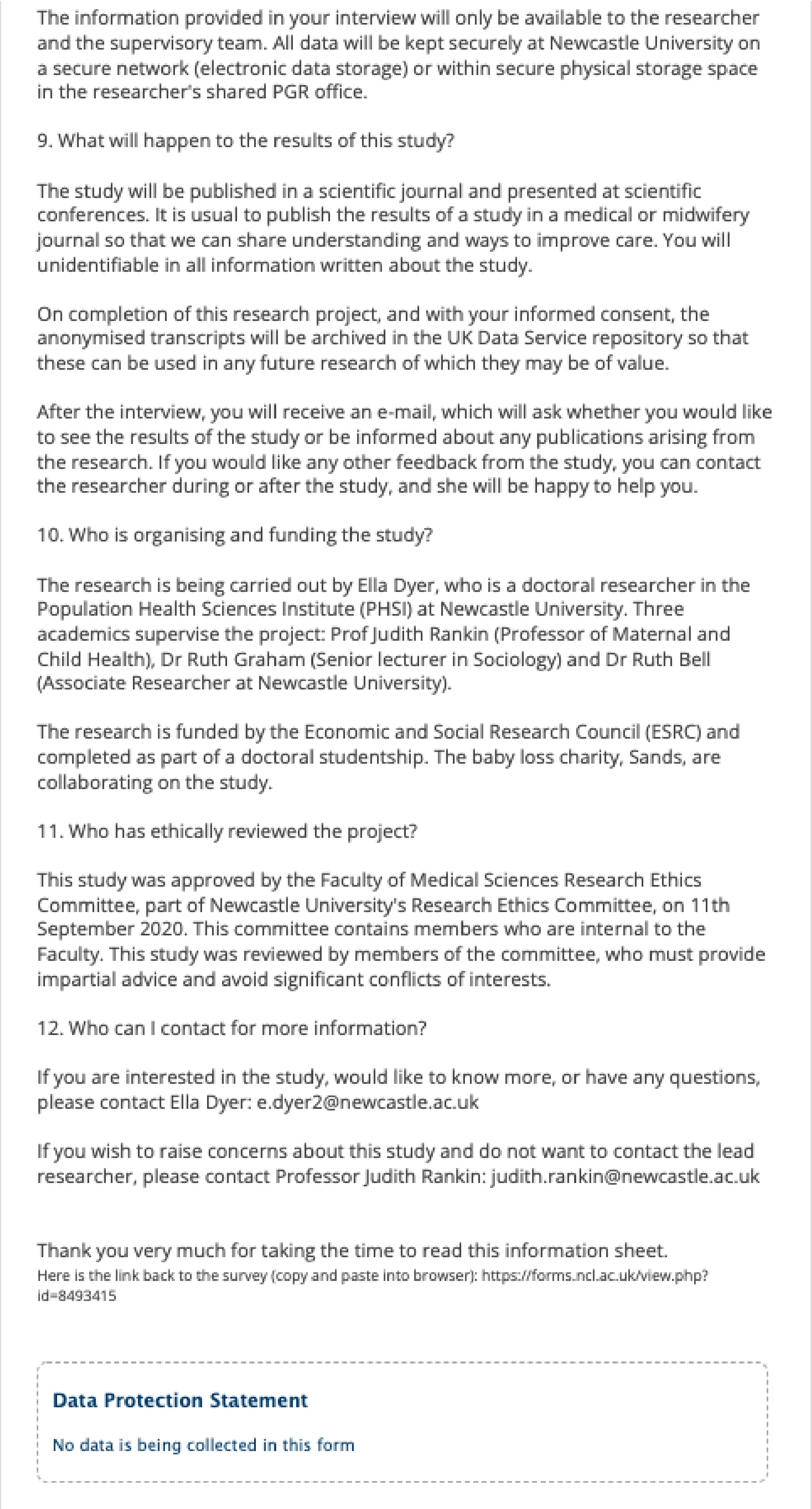
Your anonymity will be protected through the use of pseudonyms. Anything included within the transcript which may undermine your anonymity, including the clinic or surgery you work/have worked for, will either be retracted or anonymised.

You will be able to withdraw from the process at any stage until the analysis is complete. You do not have to give a reason for withdrawing from the study.

8. Will my taking part in this study be kept confidential?

Yes. Your participation and any information you provide will be strictly confidential. The information you provide will be coded and only linked with your name in instances where you need to be contacted for further details.

The interview will be digitally-recorded so the researcher can type-up the interview afterwards. Audio files of the interviews will be stored until the analysis is complete, and then will be destroyed. Anonymised transcripts of the interviews will be kept for 10 years and will then be destroyed.



The information provided in your interview will only be available to the researcher and the supervisory team. All data will be kept securely at Newcastle University on a secure network (electronic data storage) or within secure physical storage space in the researcher's shared PGR office.

9. What will happen to the results of this study?

The study will be published in a scientific journal and presented at scientific conferences. It is usual to publish the results of a study in a medical or midwifery journal so that we can share understanding and ways to improve care. You will unidentifiable in all information written about the study.

On completion of this research project, and with your informed consent, the anonymised transcripts will be archived in the UK Data Service repository so that these can be used in any future research of which they may be of value.

After the interview, you will receive an e-mail, which will ask whether you would like to see the results of the study or be informed about any publications arising from the research. If you would like any other feedback from the study, you can contact the researcher during or after the study, and she will be happy to help you.

10. Who is organising and funding the study?

The research is being carried out by Ella Dyer, who is a doctoral researcher in the Population Health Sciences Institute (PHSI) at Newcastle University. Three academics supervise the project: Prof Judith Rankin (Professor of Maternal and Child Health), Dr Ruth Graham (Senior lecturer in Sociology) and Dr Ruth Bell (Associate Researcher at Newcastle University).

The research is funded by the Economic and Social Research Council (ESRC) and completed as part of a doctoral studentship. The baby loss charity, Sands, are collaborating on the study.

11. Who has ethically reviewed the project?

This study was approved by the Faculty of Medical Sciences Research Ethics Committee, part of Newcastle University's Research Ethics Committee, on 11th September 2020. This committee contains members who are internal to the Faculty. This study was reviewed by members of the committee, who must provide impartial advice and avoid significant conflicts of interests.

12. Who can I contact for more information?

If you are interested in the study, would like to know more, or have any questions, please contact Ella Dyer: e.dyer2@newcastle.ac.uk

If you wish to raise concerns about this study and do not want to contact the lead researcher, please contact Professor Judith Rankin: judith.rankin@newcastle.ac.uk

Thank you very much for taking the time to read this information sheet.

Here is the link back to the survey (copy and paste into browser): https://forms.ncl.ac.uk/view.php?id=8493415

Data Protection Statement

No data is being collected in this form

Appendix D: Expression of Interest forms

Expression of Interest Form –Healthcare professionals

Thank you for your interest in participating in this study.

Project Title: Improving care between pregnancies for women with diabetes who have had a pregnancy loss or death of a baby: exploring patient experiences and healthcare professional perspectives

Name of researcher: Ella Dyer, a doctoral researcher at Newcastle University

If you have any questions about this study before you complete this form, please e-mail Ella directly at e.dyer2@newcastle.ac.uk

After completing this form, the researcher may contact you to schedule an interview.

1. Please download and read the Project Information Sheet before completing this survey (attached)

1. I confirm I have read and I understand the Project Information Sheet (attached above)

   ○ Yes

   ○ No

2. I am interested in finding out more and may wish to participate in this study

   ○ Yes

   ○ No

Screening Questions

There is a screening process for participating in this study. We are looking for a range of people to participate. To help us decide whether you are eligible, please answer these questions. If you have any questions, please use the box below to write a comment.

1. I am a Healthcare professional who provides care for women with diabetes.

   ○ Yes

   ○ No

   ○ Other (please specify)

- ○ Prefer not to say

2. What is your job title?

…………………………………………………………………………….

3. How long have you had this job for?

   ………………………………………………………………………………

4. Please can you briefly describe your involvement with women with diabetes who are considering pregnancy?

   ………
   ………
   ………

5. Age

   ………………………………………………………………………………

   - Prefer not to say

6. Gender

   ………………………………………………………………………………

   - Prefer not to say

7. Postcode

   ………………………………………………………………………………

   - Prefer not to say

8. How would you describe your ethnicity?

   ………………………………………………………………………………

   - Prefer not to say

9. Use this space if you have any questions or comments (Leaving this box blank will indicate you do not have any questions at the moment). You can ask questions about the study at any time by contacting e-mailing e.dyer@newcastle.ac.uk.

………
………
………

Contact Details

Please provide your contact details so the researcher can contact you to answer your questions and / or arrange an interview

1. Name

   …………………………………………………………………………………

2. Mobile / Telephone number

   …………………………………………………………………………………

3. E-mail

   …………………………………………………………………………………

4. What is your preferred method of contact?

   - ○ Phone
   - ○ E-mail

5. Please indicate your preferred day/time of contact (Leaving this box blank will indicate you are happy for the researcher to contact you any day mid-week during work hours)

   …………………………………………………………………………………

Thank you for your interest in taking part in this study

The lead researcher will be in touch shortly.

If you have any questions or wish to contact the researcher in the meantime, please send an e-mail to e.dyer2@newcastle.ac.uk

Data Protection Statement

Please be assured that the information you provide in this form will be treated in confidence and in line with the General Data Protection Regulations.

The data provided on this form will only be seen by members of the research team and will be used solely for the research study, to identify participants for an interview and to describe the sample of people taking part in the research.

Your personal details will not be revealed to anyone outside of the research team. Your data will be kept securely and destroyed at the end of the study.

Submission Confirmation

Thank you for your interest in taking part in this study.

Your submission has been successfully saved and you will receive an e-mail copy of this form.

Expression of Interest Survey – women with diabetes

Thank you for your interest in participating in this study.

Project Title: Improving care between pregnancies for women with diabetes who have had a pregnancy loss or death of a baby: exploring patient experiences and healthcare professional perspectives

Name of researcher: Ella Dyer, a doctoral researcher at Newcastle University

If you have any questions about this study before you complete this form, please e-mail Ella directly at e.dyer2@newcastle.ac.uk

After completing this form, the researcher may contact you to schedule an interview.

Please download and read the Project Information Sheet before completing this survey (attached)

1. I confirm I have read and I understand the Project Information Sheet (attached above)
    - ○ Yes
    - ○ No
2. I am interested in finding out more and may wish to participate in this study
    - ○ Yes
    - ○ No

Screening Questions

1. There is a screening process for participating in this study. We are looking for a range of people to participate. To help us decide whether you are eligible, please answer these questions. If you have any questions, please use the box below to write a comment.

2. What type of diabetes do you have?

   - ○ Type 1
   - ○ Type 2
   - ○ Other (please specify)

   …………………………………………………………………..

3. How long have you had diabetes

   ………………………………………………………………………………

4. I am sorry to hear you have experienced baby loss. How would you describe the type/s of loss?

   - ○ Miscarriage (my baby died in pregnancy before 24 weeks gestation)
   - ○ Stillbirth (my baby was born after 24 weeks but did not show any signs of life)
   - ○ Neonatal Death (my baby died in the first 28 days after birth)
   - ○ Termination of pregnancy for medical reasons (my pregnancy was ended after my baby was diagnosed with a life-limiting medical condition during a test or scan)
   - ○ Other / further comments
   - ○ Prefer not to say

   ……………………………………………………………………………….

5. When did this happen? (approximate date)

   ………………………………………………………………………………

   - Prefer not to say

6. After my baby loss, I went on to have another pregnancy that resulted in a healthy infant who is alive and well

- Yes
- No
- Prefer not to say
- Other (please specify)

7. Time/s between loss and pregnancy (months/years)

……………………………………………………………………………..

- Prefer not to say

8. Age

………………………………………………………………………………

- Prefer not to say

9. Marital Status

………………………………………………………………………………

- Prefer not to say

10. Employment Status

………………………………………………………………………………

- Prefer not to say

11. Occupation

………………………………………………………………………………

- Prefer not to say

12. How would you describe your ethnicity?

………………………………………………………………………………

- Prefer not to say

13. Highest educational level achieved?

…………………………………………………………………………….

- Prefer not to say

14. Postcode

…………………………………………………………………………….

- Prefer not to say

15. Use this space if you have any questions or comments (Leaving this box blank will indicate you do not have any questions at the moment). You can ask questions about the study at any time by contacting e.dyer@newcastle.ac.uk.

……

……

……

Contact Details

Please provide your contact details so the researcher can contact you to answer your questions and / or arrange an interview

16. Name

…………………………………………………………………………….

17. Mobile / Telephone number

…………………………………………………………………………….

18. E-mail

…………………………………………………………………………….

19. What is your preferred method of contact?

○ Phone

○ E-mail

20. Please indicate your preferred day/time of contact (Leaving this box blank will indicate you are happy for the researcher to contact you any day mid-week during work hours)

……………………………………………………………………………….

Thank you for your interest in taking part in this study

The lead researcher will be in touch shortly.

If you have any questions or wish to contact the researcher in the meantime, please send an e-mail to e.dyer2@newcastle.ac.uk

Data Protection Statement

Please be assured that the information you provide in this form will be treated in confidence and in line with the General Data Protection Regulations.

The data provided on this form will only be seen by members of the research team and will be used solely for the purposes of the research study, to identify participants for an interview and to describe the sample of people taking part in the research.

Your personal details will not be revealed to anyone outside of the research team. Your data will be kept securely and destroyed at the end of the study.

Submission Confirmation

Thank you for your interest in taking part in this study.

Your submission has been successfully saved and you will receive an e-mail copy of this form.

Appendix E: Example letter to approach group administrators on Facebook

Hi, my name is Ella, and I'm a researcher at Newcastle University.

My research, which collaborates with the Stillbirth and Neonatal Death charity, Sands, is about becoming pregnant after baby loss: improving care for women with diabetes.

I am currently recruiting women with diabetes to participate in a short, one-off interview via phone or video call.

Would you be able to post in your group on my behalf? I don't want to intrude in your group as I don't have diabetes myself. Still, I would appreciate your help in getting the word out about my research project to the people who matter.

My research aims to improve the care and support offered to women with diabetes after a pregnancy loss. In turn, I hope this will help reduce the number of women with diabetes who face the heartbreak of losing their baby in pregnancy, birth or the first weeks of life.

Let me know if this is something you can help with, or if you have any questions or concerns, please get in touch.

Many thanks in advance,

Ella.

I suggest something along the lines of, but I'm happy for you to reword:

A researcher at Newcastle University is looking to speak to women with diabetes about their experience of becoming pregnant after a baby loss.

If you have experienced pregnancy after loss, you could help improve future care by taking part in this research.

Here's a short video to explain a bit more: [Recruitment video for women with diabetes]

For more information and to sign up: https://edyer24.wixsite.com/ella-dyer

Appendix F: Invitation letter for circulation via email

Proposed wording for e-mails – healthcare professionals

Are you a healthcare professional that cares for women with type 1 or type 2 diabetes before pregnancy?

Might you be interested in taking part in a 45-60 minute remote interview as part of Ella Dyer's PhD research study?

Ella is a doctoral researcher at Newcastle University. Her PhD study, which is in collaboration with the baby loss charity, Sands, is a qualitative exploration of how to improve inter-pregnancy care for women with diabetes after a reproductive loss.

The attached participant information sheet provides details of what your participation in the study would involve. The study has approval from the Newcastle University Research Ethics Committee.

If you are interested in participating in the study, please review the participant information sheet and complete the expression of interest survey at https://forms.ncl.ac.uk/view.php?id=8493415.

Please also feel free to share this invitation with any colleagues who specialise in diabetes. If you have any questions, please do not hesitate to contact Ella by e-mail at e.dyer2@newcastle.ac.uk.

Appendix G: Informed consent form

Informed Consent Form

Please complete this form online at: https://forms.ncl.ac.uk/view.php?id=8449514

Thank you for your interest in participating in this research study.

Please use this form to confirm you wish to take part.

Project Title: Improving care between pregnancies for women with diabetes who have had a pregnancy loss or death of a baby: exploring patient experiences and health professional perspectives

Name of researcher: Ella Dyer, a doctoral researcher at Newcastle University

If you have any questions about this study before you complete this form, please e-mail Ella directly at e.dyer2@newcastle.ac.uk

Project Information Sheet

Please ensure you have read the project information sheet before filling in this consent form

(copy and paste the below link into a new browser).

Project information sheet for women with diabetes: https://forms.ncl.ac.uk/view.php?id=8933867

Project information sheet for health professionals: https://forms.ncl.ac.uk/view.php?id=8932831

1. I confirm I have read and I understand the Project Information Sheet (link above)
   - ☐ Yes
   - ☐ No

2. I have had the opportunity to consider the information, ask questions, and I am happy with the answers
   - ☐ Yes
   - ☐ No

3. I understand that my participation is voluntary and that I am free to withdraw from the research at any time, without giving any reason
   - ☐ Yes
   - ☐ No

4. I give my consent for the interview to be audio recorded.
   - ☐ Yes
   - ☐ No

5. I am aware that the researcher, Ella Dyer, will listen to and transcribe the audio recording
   - ☐ Yes
   - ☐ No

6. I understand the audio file will be deleted once the analysis is complete, but the anonymised transcripts will be kept in a secure location for 10 years (in accordance with the Data Protection Act).
   - ☐ Yes
   - ☐ No

7. I am aware the transcript will contain no identifiable features, such as name or place of work. Pseudonyms (e.g. participant 1) will be used to replace any names.
   - ☐ Yes
   - ☐ No

8. I permit the researcher to use direct quotes from the interview transcript in the reporting on or presentation of any research findings, as long as this is done anonymously using pseudonyms.
   - ☐ Yes
   - ☐ No

9. I agree that the anonymised transcripts can be put into the UK Data Service repository so that it can be used in any future research of which they may of value.
   - ☐ Yes
   - ☐ No

10. I agree to take part in the interview for this study.
    - ☐ Yes
    - ☐ No

11. I confirm that I am 18 years or older
    - ☐ Yes
    - ☐ No

12. My preferred method of interview
    - ☐ Zoom
    - ☐ Skype
    - ☐ Teams
    - ☐ Telephone
    - ☐ Other

Informed Consent Form

13. Name

……………………………………………………………………………

14. Date Today

……………………………………………………………………………

15. E-mail (please include your email so a copy of this consent form can be sent to you)

……………………………………………………………………………

16. Please check this box as a way of signing this form
    - ☐ I am signing this form
    - ☐ I do not wish to sign form

Data Protection Statement

Please be assured that the information you provide in this form will be treated in confidence and in line with the General Data Protection Regulations.

The data provided on this form will only be seen by members of the research team and will be used solely for the research study and gaining informed consent to take part in this study.

Your personal details will not be revealed to anyone outside of the research team.

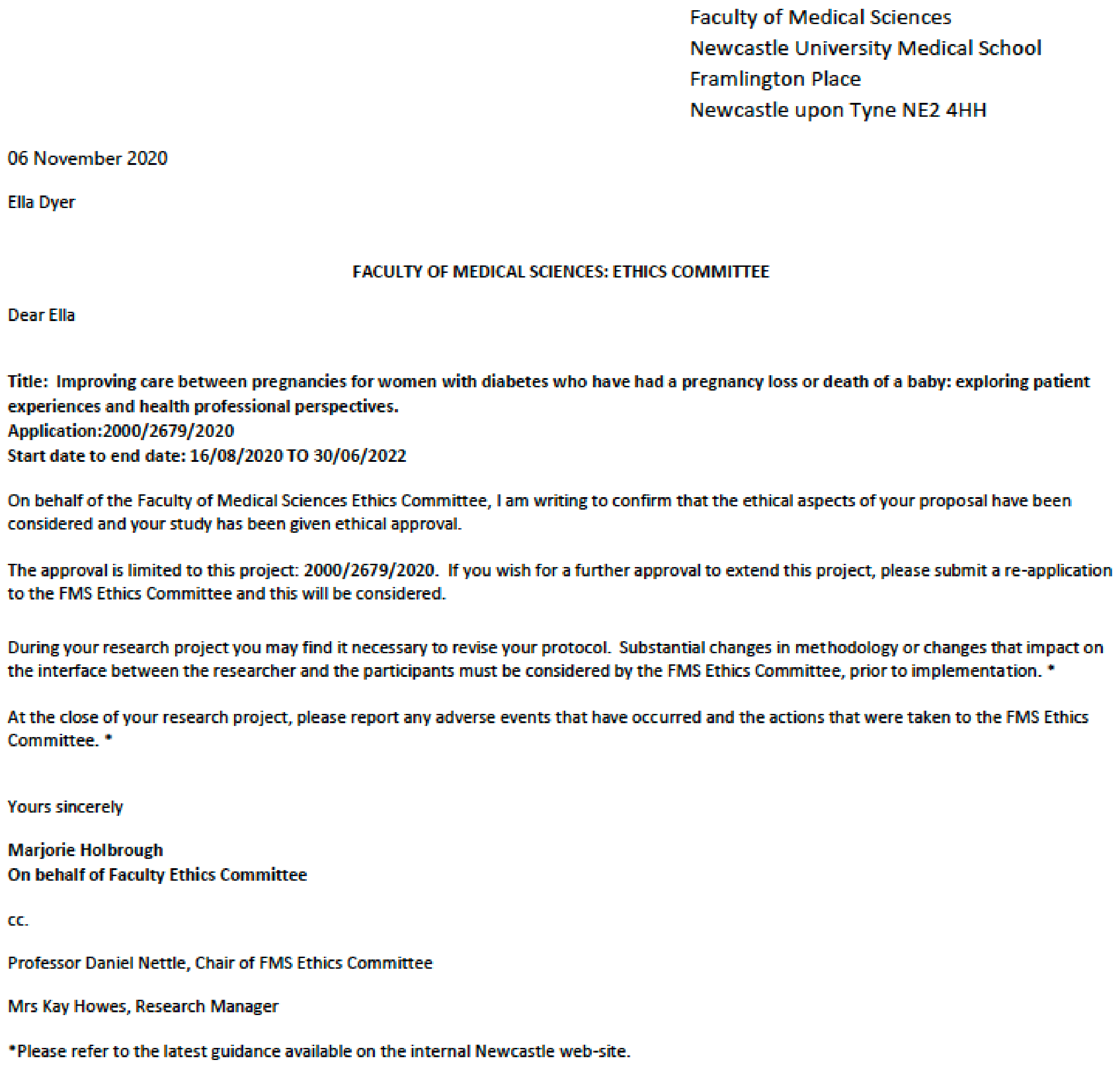
The data collected in this form will be kept securely for 10 years (in accordance with the Data Protection Act) and then destroyed.

Submission confirmation

Thank you. Your submission has been successfully saved. A copy of this form will be sent to the e-mail address provided and the lead researcher will be in touch shortly.

Meanwhile, if you have any questions about the research, please e-mail: e.dyer2@newcastle.ac.uk

Appendix H: Ethical approval



Faculty of Medical Sciences
Newcastle University Medical School
Framlington Place
Newcastle upon Tyne NE2 4HH

06 November 2020

Ella Dyer

FACULTY OF MEDICAL SCIENCES: ETHICS COMMITTEE

Dear Ella

Title: Improving care between pregnancies for women with diabetes who have had a pregnancy loss or death of a baby: exploring patient experiences and health professional perspectives.
Application:2000/2679/2020
Start date to end date: 16/08/2020 TO 30/06/2022

On behalf of the Faculty of Medical Sciences Ethics Committee, I am writing to confirm that the ethical aspects of your proposal have been considered and your study has been given ethical approval.

The approval is limited to this project: 2000/2679/2020. If you wish for a further approval to extend this project, please submit a re-application to the FMS Ethics Committee and this will be considered.

During your research project you may find it necessary to revise your protocol. Substantial changes in methodology or changes that impact on the interface between the researcher and the participants must be considered by the FMS Ethics Committee, prior to implementation. *

At the close of your research project, please report any adverse events that have occurred and the actions that were taken to the FMS Ethics Committee. *

Yours sincerely

Marjorie Holbrough
On behalf of Faculty Ethics Committee

cc.

Professor Daniel Nettle, Chair of FMS Ethics Committee

Mrs Kay Howes, Research Manager

*Please refer to the latest guidance available on the internal Newcastle web-site.

Appendix I: Data management plan

1. **Project title:** Improving care between pregnancies for women with diabetes who have had a pregnancy loss or death of a baby: exploring patient experiences and healthcare professional perspectives

2. **Assessment of existing data**

Achieving this project's research objectives requires generating qualitative data that is not available in existing archives. While some existing data has helped to contextualise the project and develop its central research questions, sociological research into the inter-pregnancy interval after a reproductive loss is limited and underdeveloped. In particular, there have been no studies exploring the lived experience of care received in the inter-pregnancy interval for both women with diabetes and the healthcare professionals that support them.

There is currently a gap in understanding of how postnatal bereavement support should consider the context of diabetes and link with support for subsequent pregnancy preparation. Conducting qualitative interviews with women with diabetes who have experienced reproductive loss as well as the healthcare professionals that care for them, will provide a more holistic insight into how to improve or promote inter-pregnancy care. These accounts will be different from those in existing data, which tend to view these groups separately rather than as interrelated phenomena.

3. **Information on new data**

This project will use the following types of data collection:

1. Qualitative interviews with healthcare professionals

2. Qualitative interviews with women with diabetes (and partners if desired)

3. Quantitative demographic data collected via the 'Expression of Interest' form will allow for purposive sampling of participants and reporting the sample demographics of

participants. Obtaining demographic data is an important way to help ensure the sample is as socially and culturally diverse as possible.

4. Data formats

4.1 Textual Data

4.1.1 'Expression of Interest' and 'Informed Consent' Forms

I will create these forms using the Newcastle University 'Form Builder'. Participants will follow a link to the form and will complete the forms online. I will securely export the responses using University systems into a Microsoft Excel document (.xls/ .xlsx). I will save all demographic data into separate Excel documents so that I can present it anonymously in tabular form.

The data provided on the Expression of Interest form will contain identifiable information from the screening questions (e.g. age, marital status, employment, type of diabetes, type of healthcare professional). Only members of the research team will be able to view this data. This data will only be used to identify participants for an interview and to describe the sample of people taking part in the research. This identifiable data will be kept separately and securely away from other data so the identity of participants is protected.

The Informed Consent form will only be seen by members of the research team. I will only use this data to show that I gained informed consent before the interviews took place. The only identifiable information in the consent form is the name of the participant. It will not contain any other identifiable information, such as date of birth, address, contact details or participant number. Consent forms will be stored separately from any other research documents for that participant.

4.1.2 Transcripts of Interviews

All transcripts will be in Microsoft Word. I will use qualitative analysis software to explore, organise and code the transcribed data (e.g. nVivo / Quirkos / MAXQDA).

To facilitate long-term reuse of the data collected in the interviews, I will convert the word documents into Rich Text Format (.rtf). Rich Text Format is an appropriate and long-lasting way to backup and archive data. This is because you can share and open Rich Text Format texts in a wide variety of software suites. They are relatively small in file-size and retain the same function and appearance as originally intended by the author.

2. **Audio data**

4.2.1 Audio Recordings

Interviews will take place in a private space, with closed doors. I will record interviews with a Dictaphone. Audio recordings will be stored in digital format for the duration of analysis (e.g. MP3).

5. **Data Storage**

Data will be predominantly electronic and will be stored on a password-protected computer on Newcastle University's password-protected secure network. Due to the current COVID-19 measures, any hard-copy data will be stored securely at home. I will transfer the data to University premises as soon as it is possible to do so. Here it will be stored within a locked filing cabinet in the researcher's share PGR office.

I will delete any data saved on the Form Builder platform as soon as recruitment is complete. Exported data from Form Builder (from Expression of Interest and Informed Consent forms) and anonymised interview transcripts will be kept for 10 years before they are securely destroyed. Audio files will be permanently destroyed as soon as data analysis is complete.

Data collected will be fully compliant with GDPR by following the 6 security and privacy principles outlined below:

1. Lawfulness, fairness and transparency

Lawful and transparent: Processing will meet the tests described in GDPR and the subject will be informed what data processing will be done.
Fair: What is processed must match up with how it has been described

2. Purpose limitations

Personal data can only be obtained for “specified, explicit and legitimate purposes.” Data can only be used for a specific processing purpose that the subject has been made aware of and no other, without further consent.

3. Data minimization

Data collected on a subject should be “adequate, relevant and limited to what is necessary in relation to the purposes for which they are processed.”

No more than the minimum amount of data should be kept for specific processing.

4. Accuracy

Data must be “accurate and where necessary kept up to date.”

5. Storage limitations

Personal data will be “kept in a form which permits identification of data subjects for no longer than necessary.” Data no longer required will be removed (anonymized, destroyed, etc.).

6. Integrity and confidentiality

All data will be handled “in a manner [ensuring] appropriate security of the personal data including protection against unlawful processing or accidental loss, destruction or damage.”

Before any research is conducted, all participants will be well informed of the purpose of the study and their risks in the Project Information Sheet before they sign the Informed Consent Form (privacy notice).

After data has been collected I will anonymise and/or pseudonymize the data and work with the de-identified data.

6. Data Sharing

The personal and sensitive nature of some of the data generated by this project could create some difficulties for data sharing. I will ensure it is possible to share data generated by this project safely, ethically and legally, while protecting the confidentiality and anonymity of participants.

Before participants can provide informed consent, they must read the Project Information Sheet so they are familiar with the details of the project. The Informed Consent form will ask for participants' explicit permission and consent to share and archive any data generated in the project under agreed terms and conditions.

Participation in the project and any information provided will remain confidential; I will use codes in file names so that I can link with participants' names only if it is necessary to contact them for further information. I will protect participants' anonymity by using pseudonyms. I will retract or anonymise any identifying information in the transcript that could undermine participants' anonymity, such as their name, location, or clinic they work/attend.

Only the researcher and the supervisory team and participant will have access to the anonymised data provided in interviews. I will use e-mail and password-protected files to share this data.

7. Data Archiving

On completion of this research project, and with the informed consent from participants (see Attachment 9), I will add anonymised transcripts into the UK Data Service repository so that these can be used in any future research of which they may be of value.

8. Documenting my data

It is crucial to document all data in a clear and accessible way. This metadata will ensure the long-term future re-use of any data shared. I will do this by describing, annotating and contextualising my data from the very beginning of the data collection process. I will use descriptive notes on textual data files and descriptive tags on audio files.

I will use cover sheets on interview transcripts to record relevant notes taken during the interview and provide contextual information about the interviewee (while protecting their anonymity). These may include:

- participant age (within a particular aggregate e.g. 20-25 to protect participant anonymity)
- participant gender
- participant occupation and/or diabetes or baby loss organisation they are affiliated with
- type of reproductive loss
- time elapsed since the reproductive loss
- region in which participant lives and works
- date of interview

I will use memos to facilitate the coding process. For example, I will make notes of the rationale or steps that helped me decide on a particular code or category.

I will ensure the data collection methods are explicit and full details of the inclusion and exclusion criteria will be included if data are shared. Details of any modifications made to data over time will also be given and kept up to date.

9. **Organising data**

Throughout the data collection process, I will be consistent and systematic in the way I organise and save data. I will use a numbering and scaling system to name data files, for example, 2020_09_12_HP_Interview_02/015. This filename includes the date the data was created, version number, as a well as a code to anonymously link the file to the correct participant and consent form.

I will keep all data files in folders named after each particular research stage (e.g. Healthcare professional Interviews). I will regularly review all files and folders to ensure they remain well organised and in date order.

10. Data volume

I do not yet know exactly how many participants will be involved, but I anticipate the need to recruit 15-20 participants in each of the healthcare professional and parents' study to achieve meaning saturation as described by Hennink, Kaiser, and Marconi (2017) in their article on 'Code Saturation Versus Meaning Saturation: How Many Interviews Are Enough?'.

The final sample size will be determined in-situ, and will be shaped by the adequacy (richness, complexity) of the data for addressing the research question (Braun and Clarke, 2019), but is not expected to exceed 20 participants per group. This iterative decision will be made by reviewing the data during the data collection process (Braun and Clarke, 2019) within the constraints of time, resources and accessibility.

I do not expect the data generated to exceed the 500GB of shared storage space provided by the university, but if necessary, I can request and purchase more space.

11. Quality assurance of data

Quality assurance and quality control of data will take place during data collection, data entry and digitisation, and data checking.

I will take measures to ensure all data collected and stored are of the richest and highest quality and accurately reflect facts, participant responses and researcher observations. These involve:

- Taking notes/memos throughout the interviewing, transcribing, coding and analysis process.
- Making written comments about the interview that may not be evident from written transcript alone, for example, comments about the interviewee's tone of voice, facial expressions or body language. This will help me to remember the interview as accurately as possible and will aid later analysis and interpretation.
- Using coding techniques throughout the analysis process. I will discuss each code with my supervisor/s as a way to refine codes and ensure I do not become so absorbed in the data that the accuracy of meaning is lost.

- Using the best possible equipment to record the interviews.
- Taking great care in the transcription process to ensure the authenticity and accuracy of the data.

12. Security and backup of data

All data (including personal and demographic data) generated by this project will be protected in line with the University's Research Data Management Policy Principles & Code of Good Practice, as well as with external General Data Protection Regulations.

In addition to the University's automatic backup, I will regularly manually back up data in Rich Text Format as I progress through the project.

13. Copyright and intellectual property ownership

I will cite any documents gathered as part of this research project in all research data outputs. The intellectual property rights (including copyright) to the data generated in this project belong to Newcastle University.

14. Responsibilities

As the researcher who is conducting the study, I will be responsible for overseeing the management of data, the production of metadata, the quality control of data and facilitating its archiving, sharing and reuse. To ensure I can meet these responsibilities adequately and in full, I will consult my supervisors (for help with reviewing my coding, analysis and transcription of data, to contribute to quality control and data authenticity) and my University's IT services (for additional advice relating to data storage, security and backup of data.

Appendix J: First iteration of recruitment adverts for social media

Proposed wording and image for social media posts – Healthcare professionals

Are you a healthcare professional specialising in #diabetes?

Do you provide care for women with #type1 #type2 #diabetes who may become pregnant?

Would you like to take part in a remote interview as part of a PhD research study?

Express interest here: https://forms.ncl.ac.uk/view.php?id=8493415

Do you provide care for **women with diabetes** before **pregnancy?**

Can you tell us about your **professional experiences** of **diabetes** and **pregnancy care ?**

Newcastle University

This study is open to all **diabetes** specialists

This is likely to include, but is not limited to: **diabetes specialist nurses, midwives, obstetricians, physicians, GPs and dietitians**

For more information email

e.dyer2@ncl.ac.uk

You are not obliged to take part if you request more information.

This study is being carried out as part of a PhD thesis in collaboration with Sands at Newcastle University.

Proposed wording and image for social media posts – women with diabetes

Do you have #type1 or #type2 #diabetes and experience of #babyloss #stillbirth #miscarriage #neonataldeath #rainbowbaby?

Can you help us by talking about becoming pregnant after #babyloss?

If you are interested in an interview, please fill in this form:
https://forms.ncl.ac.uk/view.php?id=8492012

Do you have
type 1 or **type 2 diabetes?**
Did you experience a
baby loss before **becoming**
pregnant again?

Would you be willing
to **take part** in a
one-off interview?

over phone/zoom/skype (your preference)
at a time that is convenient for you?

Newcastle University

Your experiences may
help to **improve**
future care
and **the support**
women with diabetes
receive before pregnancy

For more information email

e.dyer2@ncl.ac.uk

You do not have to take part
if you request more information.

This study is being carried out as part of a PhD thesis in collaboration with Sands at Newcastle University.

Appendix K: Example scripts from recruitment videos

My name is Ella, and I am a doctoral researcher at Newcastle University.

If you are a midwife or a nurse, you might be interested in my research on diabetes and pregnancy.

If so, I would really like to hear from you.

The premise behind my research is that if you are a woman with T1 or T2 diabetes, your baby is around 4 times more likely to die during pregnancy, birth or in the first weeks of life compared with the general population.

It doesn't have to be this way.

The risks can be significantly reduced with careful pregnancy preparation, as set out in the NICE NG3 preconception guidelines.

I'm trying to find out how preconception care can be promoted or improved, or, how women with diabetes can be better supported to access this care given the positive influence it has on pregnancy outcomes.

This is where you come in.

I'd really like to hear your professional perspectives of providing care for this group, as WWD are likely to have already built a good relationship with you and may feel more comfortable talking to you about their plans to become pregnant again after a pregnancy loss or baby death.

All it involves is a one-off interview with myself, over the phone or video. It will last no longer than one hour.

It's really easy to sign-up. All the information is on my website on the 'get involved' page. The link to my website is in my bio.

If you'd like to find out more, or if you have any questions, please do get in touch with me by sending me a direct message, or by using the contact form on my website. Thank you.

Example script for recruitment video for women with type 1 diabetes

Hello, my name is Ella, and I am a PhD researcher at Newcastle University.

If you are woman with T1DM, you might be interested in my research on diabetes and pregnancy. If so, I would really like to hear from you.

Becoming pregnant can be a lot harder when you have T1DM. There are risks to both mum and baby. There is a higher risk that your baby will die in pregnancy, birth or in the first weeks of life.

These risks can be reduced, with careful pregnancy preparation, as set out in the NICE guidelines. BUT preparing for pregnancy is not easy and it takes time AND preparing for pregnancy can be especially difficult after your baby has died in pregnancy, birth or in the first weeks of life.

This is where you come in.

I'm trying to find out how women with type 1 diabetes can be better supported to access pre-pregnancy care

If you have type 1 diabetes and you have experienced a miscarriage, stillbirth, neonatal death or termination of a pregnancy for medical reasons, I'd really like to hear your personal experiences of becoming pregnant again after pregnancy loss or baby death.

Did you get pre-pregnancy care before you became pregnant again? Was it easy to access the support you needed? Or was there anything that could have been done better to help you become pregnant again?

All it involves is a one-off interview with myself, over the phone or video call. It will last no longer than one hour. It's really easy to sign-up. All the information is on my website on the 'get involved' page. There is a link in this post.

If you'd like to find out more, or if you have any questions, please do get in touch with me by sending me a direct message, or by using the contact form on my website. Thank you.

Appendix L: Interview topic guides at start of data collection

Topic Guide - Healthcare professionals

Introduction

- Thank you for seeing me today and offering to take part in this study.

- Confirm receipt of electronically signed informed consent formand project information sheet.

- Recap project information sheet and record verbal consent (this will be audio recorded so my supervisors can witness informed consent if needed).

- Feel free to ask questions at any stage during the interview

- **Topics / Prompts** (N.B. This is not a rigid interview schedule. This topic guide is intended as an aid memoir as a reminder of topics to talk about. I have included a list of prompts in the event they are needed, for example, if the participant does not say very much).

1. Can you tell me about your job and the sort of care you provide for women with diabetes?

2. Are there any specific guidelines you follow when providing care for women with diabetes who are considering pregnancy?
- How would you know whether someone with diabetes had previously lost their baby in pregnancy, birth or in first few weeks of life? (Would you rely on them to tell you? Would you bring it up?)

3. What are the current arrangements when providing care for women with diabetes who are considering pregnancy after a baby loss?
- do you do anything differently?
- do you ask the parents to do anything differently?

4. Do you feel you have received adequate training and/or support to cope with the emotionally difficult nature of providing care for bereaved parents?

5. Do you feel you have received adequate training and/or support to cope with providing medical care for bereaved parents?

6. Can you tell me about some of your experiences of consultations with parents in the inter-pregnancy period (the time after a baby loss and before next pregnancy)?
- Describe any interactions specific to diabetes and pregnancy.
- Did you feel that you could meet your patients' needs?
- Are there areas that require strategies to improve patient care?
- Do you have any examples of good practice?
- Do you have any lessons that can be learned/shared?

7. Are there are challenges or barriers to providing effective care?

- resources (e.g. funding, facilities, staffing, numbers, training, work environment)
- task/service demands (e.g. patient numbers; geographical coverage; performance targets)
- organisation and management of service delivery (e.g. care pathways, linked services, the network of providers; protocols and guidelines; continuity of care)
- knowledge and/or training

8. Anything else that the interviewee/interviewer feels has been missed / did not get a chance to discuss fully.

9. Do you have any questions or is there anything else you would like to talk to me about?

End of Interview

10. Thank you for taking the time to talk to me today and take part in my research
- Next steps (e.g. I will send you a debriefing e-mail)

Topic Guide - Women with Diabetes

Introduction

- Thank you for seeing me today and offering to take part in this study.
- Confirm receipt of signed informed consent formand project information sheet.
- Recap project information sheet and record verbal consent (this will be audio recorded so my supervisors can witness informed consent if needed).
- You do not have to answer all the questions if you do not want to.
- Let me know if you want to have a break or stop the interview at any point.
- Feel free to ask questions at any stage during the interview.

Topics / Prompts (N.B. This is not a rigid interview schedule. This topic guide is intended as an aid memoir as a reminder of topics to talk about. I have included a list of prompts in the event they are needed, for example, if the participant does not say very much).

1. I am so sorry to hear about the loss of your baby/your baby's death. Would you like to tell me a little about your baby? (What was their name? When did it happen? What happened? How did you feel at the time? How do you feel now?)

2. Thank you for sharing that with me. I will not be asking questions specifically about your pregnancy (or neonatal care) with your baby (insert name if applicable), but about the time after your baby died and before becoming pregnant again. However, please feel like you can talk about your baby or that pregnancy, if you want to, at any time during our interview.

3. Can you think back to the time between your baby dying and becoming pregnant again?

    - How long was the gap between your baby dying and becoming pregnant again?
    - How did you feel about this at the time? How do you feel about this in hindsight?
    - How did you feel about becoming pregnant again at the time? How do you feel about it now, looking back?

4. After your baby died, and before you became pregnant again, did you receive/were you offered any bereavement support?

If yes	If no
- What sort of care did you get? - Where did you get this care? How did you find out about it? - Do you feel it helped you in terms of feeling ready to become pregnant again? In what ways? - Did you feel your needs at the time were met or was there more that could have been done to help you (both at the time and in hindsight)?	- Did you want care, but it wasn't offered/you weren't able to access? - How did you feel about this at the time? - How do you feel about this in hindsight? - Is there anything that stopped you from getting bereavement care?

5. Can you tell me a bit about your diabetes?

  - What type of diabetes do you have?
  - How long have you had diabetes?
  - In what ways does it affect your life?

6. Thinking about the time between your previous pregnancy and the next pregnancy, did you receive any/were you offered any pre-pregnancy care or advice from healthcare professionals to help with becoming pregnant with diabetes?

If yes	If no
- What sort of care/advice? - From whom? - How long before pregnancy? - How did you feel about this at the time? - Did it mean more visits to the doctors/hospital? - How many different healthcare professionals did you speak to in the time between your previous pregnancy and the next pregnancy? - Can you tell me about some of the conversations/interactions you had with healthcare professionals? - Did you do anything differently when preparing for the next pregnancy? What sort of things? - How did you feel about these conversations/interactions? At the time? In hindsight? - What aspects worked well? Less well? - Did you feel your needs were met at the time or was there more that could have been done to help you? - What aspects worked well and what worked less well? - In what ways was your previous pregnancy acknowledged or taken into account?	- Did you want care, but it wasn't offered/able to access? - How did you feel about this at the time? - How do you feel about this in hindsight? - Did you look for any advice/ support from elsewhere? Can you tell me a little about what/where? - Is there anything that would have improved the likelihood of you attending PPC?

7. Overall, do you feel you were able to access the care and support that you needed before becoming pregnant again?

- Was there anything that could be done differently that would have helped you?
- Would you have liked more support? What type of support would have been helpful?
- Would you have liked more advice or information?
- What type of advice/information would have been helpful?
- Where is the best place for you to access this advice/information?
- (if relevant) Do you feel your ethnicity has affected the care you were able to access? What could be done to improve access for you?

9. Anything else that the interviewee/interviewer feels has been missed / did not get a chance to discuss fully.

10. Do you have any questions or is there anything else you would like to talk to me about?

End of interview

11. Thank you for taking the time to talk to me today and for taking part in my research.

    - Next steps (e.g. I will send you an e-mail with some helpful information and links)

Appendix M: Examples of debrief e-mails

De-briefing e-mail – healthcare professionals

Thank you very much for contributing your time for my PhD study.

Please forward this link onto any colleagues who might be interested in taking part so they can get in touch with me: https://forms.ncl.ac.uk/view.php?id=8493415

There is nothing more that you need to do, but:

- If you have any questions or would like to hear more about any findings or publications that arise from this research study
- If you would like the chance to review the transcript of your interview before I start the analysis process
- If you change your mind and no longer want your interview data to be used in this research study. You can withdraw your consent without reason until the analysis is complete.

Just let me know by replying to this e-mail.

With thanks and best wishes,

Ella.

De-briefing e-mail – women with diabetes

Thank you again for taking the time to share your personal experiences in the interview for my research study.

Please forward this link to anyone you think would like to take part so they can get in touch with me: https://forms.ncl.ac.uk/view.php?id=8492012

There is nothing more that you need to do, but:

- If you have any questions or would like to hear more about any findings or publications that arise from this research study
- If you would like the chance to review the transcript of your interview before I start the analysis process
- If you change your mind and no longer want your interview data to be used in this research study. You can withdraw your consent without reason until the analysis is complete.

Just let me know by replying to this e-mail.

Below is a selection of links for support and further information, should you feel you need someone to talk to (only relevant links to be included).

- Antenatal Results and Choices (ARC) - Support line 0845 077 2290 or 0207 713 7486 from a mobile; website https://www.arc-uk.org/
- Bliss (support for parents of babies born premature or sick) - e-mail hello@bliss.org.uk website https://www.bliss.org.uk/
- Child Bereavement UK - Support line 0800 028 8840; e-mail support@childbereavementuk.org website https://www.childbereavementuk.org/
- Miscarriage Association - Support line 0192 420 0799; e-mail info@miscarriageassociation.org.uk website https://www.miscarriageassociation.org.uk/

- Sands (stillbirth and neonatal death charity) - Support line 0808 164 3332; e-mail helpline@sands.org.uk website https://www.sands.org.uk/about-sands

- Twins Trust, formerly known as Tamba (the Twins and Multiple Births Association) - Twinline (which can direct you to the bereavement service) 0800 138 0509; e-mail bereavementsupport@twinstrust.org website https://twinstrust.org/

- Tommy's – Support line 0800 0147 800; website https://www.tommys.org/

- The Lullaby Trust (support for parents who experience the sudden loss of a baby) - Support line 0808 802 6868; e-mail support@lullabytrust.org.uk

With thanks and best wishes,

Ella.

Appendix N: Examples of how the topic guides evolved over course of interviews

Topic Guide - Healthcare professionals

Introduction

- Thank you for seeing me today and offering to take part in this study.
- How did you find signing up process?
- What to do if poor connectivity
- You should have received an email copy of your informed consent?
- Check you still give your informed consent to take part in this interview
- The premise behind this research study is that women with type 1 and type 2 diabetes are around 4 times more likely to suffer a reproductive loss.
- The risk can be reduced with careful pre-pregnancy preparation, but the NPID audit shows that only 1 in 8 women are optimally prepared for pregnancy.
- WWD are not more likely to prepare for pregnancy after a reproductive loss
- Becoming pregnant after a loss can be particularly challenging.
- This study aims to explore and better understand what it is like for women with diabetes to become pregnant again after pregnancy loss or the death of their baby.
- I am interested in finding out your views about women with diabetes' access and use of services in pregnancy preparation and planning, given the positive influence it can have on pregnancy outcomes.

----

1. You've been invited to participate because you are involved in the care of women with diabetes who may be considering pregnancy. Can you tell me a little bit about your job and the sort of care you provide for women with diabetes?

2. How frequently do you see your WWD patients?
- is that the same for T1DM and T2DM?
- how many WWD get referred to see you? Is it easy/timely to get a referral? Is this the same everywhere?
- Why do not all services not have a diabetes specialist dietician?
- do WWD get referred to you after a loss?
- do you refer WWD to PPC services if they mention pregnancy?

3. Would you know whether a WWD had experienced a previous reproductive loss?
- does loss/grief affect their ability to prepare for pregnancy?
- Would you rely on them to tell you?
- If it was in the notes, would you bring it up?

4. How often consultations involve talking about pregnancy?
- Do WWD come to see you because they want to become pregnant, or are there other reasons?
- in general, do WWD allow a lot of time to prepare for pregnancy, which could potentially involve a dramatic change diet/lifestyle?

- what are the typical challenges that WWD face after a pregnancy loss and preparing for pregnancy. Are the challenges different for T1DM and T2DM
- Is there generally a best approach/diet, or is it completely unique depending on the individual's needs?
- a few participants have likened preparing for pregnancy to having an eating disorder owing to how it has to become an obsession for them to gain control. Do you ever come across issues around eating disorders/disordered eating and preparing for pregnancy?
- what are your views about the role of technology for women with diabetes?
- how easy is it for WWD to access technology before pregnancy. Is this same T1DM and T2DM?
- what are the dangers of letting a WWD try and manage their diabetes themselves?

5. Found from my interviews so far that WWD are required to have a great deal of self-motivation and agency to access the care and services that they need after a baby loss. I.e. self-refer / ask specifically for things

In terms of Preparing for pregnancy
- How easy is it for WWD to speak to a dietician?
- How east is it for WWD to meet pre-pregnancy blood glucose targets?
- how beneficial is it for WWD to get a handle on their diets before pregnancy?
- how long does it take?

6. Found from my research that women with T2DM can feel stigmatised for having their condition – notion that "you've brought this on yourself". Is this something that you see?

7. Many of the HCPs that I have spoken to have mentioned the dramatic rise in WWD T2DM being diagnosed earlier and so now there, if not as many, there are more WW T2DM becoming pregnant.
- I wondered what your views are on this, in terms of what could/should be done to help reduce the number of women developing T2DM at an early age
- Is there enough support for WW T2DM, in particular, to change their lifestyles and diets?
- A couple of participants with T2DM mentioned how they did not feel like they were able to control their diabetes (because all they were asked to do was take a tablet and get sporadic HBA1C tests). Is this something you see?

8. From your professional point of view, why do you think women with diabetes don't prepare for pregnancy?
- Why are WWD no more likely to prepare for pregnancy after a baby loss?

9. What are the challenges or barriers of providing specialised diabetes dietician services across all health services?
- resources (e.g. funding, facilities, staffing, numbers, training, work environment)
  - task/service demands (e.g. patient numbers; geographical coverage; performance targets)
  - organisation and management of service delivery (e.g. care pathways, linked services, the network of providers; protocols and guidelines; continuity of care)
  - knowledge and/or training

10. How has COVID19 impacted your (PCC) services?
- Will there be lasting changes?

11. Anything else that the interviewee/interviewer feels has been missed / did not get a chance to discuss fully.

12. Do you have any questions or is there anything else you would like to talk to me about?

End of Interview

1. Thank you for taking the time to talk to me today and for taking part in my research
- Next steps (e.g., I will send you a debriefing e-mail)
- Would you like to be kept updated with the findings?
2. ***Please share the link to my research with anyone you think might be interested in taking part***

I'm particularly interested in speaking with some more diabetes specialist nurses

Topic Guide - Women with Diabetes

Introduction

- Thank you for seeing me today and offering to take part in this study.
- Where you saw this study advertised? / How find signing up process?
- What to do if poor connectivity
- You should have received an email copy of your informed consent?
- Please can I just check you still give your informed consent to take part in this interview (run through form) - you know your participation is voluntary and you can withdraw at any time without giving a reason...you're happy for this interview to be recorded so that it can be transcribed and used for analysis?
- I want this to feel more like a chat than a formal interview
- You do not have to answer all the questions if you do not want to.
- Let me know if you want to have a break or stop the interview at any point.
- Feel free to ask questions at any stage during the interview.

- The premise behind this research study is that pregnancy can be more difficult for women with diabetes, and there is a higher risk of baby loss
- The risk can be reduced with careful pre-pregnancy preparation, e..g NICE
- But preparing for pregnancy is not easy and the guidelines don't talk about the challenges of becoming pregnant again after a pregnancy loss or baby death.
- This research study aims to explore and better understand what it was like for women with diabetes to become pregnant again after a baby loss
- I am interested in finding out your experiences of the time between pregnancies &
- your views about the access and use of services in pregnancy preparation and planning

1. I am so sorry to hear about the loss of your baby/your baby's death. Would you like to tell me a little about your baby? (What was their name? When did it happen (date)/how long ago? What happened? How did you feel at the time? How do you feel now?)

2. Thank you for sharing that with me. I will not be asking questions specifically about your pregnancy (or neonatal care) with your baby (insert name if applicable), but about the time after your baby died and before becoming pregnant again. However, please feel like you can talk about your baby or that pregnancy, if you want to, at any time during our interview.

3. Can you think back to the time between your baby dying and becoming pregnant again?
    - How long was the gap between your baby dying and becoming pregnant again?
    - How did you feel about this at the time? How do you feel about this in hindsight?
    - How did you feel about becoming pregnant again at the time? How do you feel about it now, looking back?

4. After your baby died, and before you became pregnant again, did you receive/were you offered any bereavement support?

If yes	If no
- What sort of care did you get? - Where did you get this care? How did you find out about it? - Do you feel it helped you in terms of feeling ready to become pregnant again? In what ways? - Did you feel your needs at the time were met or was there more that could have been done to help you (both at the time and in hindsight)?	- Did you want care, but it wasn't offered/you weren't able to access? - How did you feel about this at the time? - How do you feel about this in hindsight? - Is there anything that stopped you from getting bereavement care?

5. Can you tell me a bit about your diabetes?
    - What type of diabetes do you have?
    - How long have you had diabetes?
    - In what ways does it affect your life?

6. Thinking about the time between your previous pregnancy and the next pregnancy, did you receive any/were you offered any pre-pregnancy care or advice from health professionals to help with becoming pregnant with diabetes?

If yes	If no
- What sort of care/advice? - From whom? - How long before pregnancy? - How did you feel about this at the time? - Did it mean more visits to the doctors/hospital? - How many different health professionals did you speak to in the time between your previous pregnancy and the next pregnancy? - Can you tell me about some of the conversations/interactions you had with health professionals? - Did you do anything differently when preparing for the next pregnancy? What sort of things? - How did you feel about these conversations/interactions? At the time? In hindsight? - What aspects worked well? Less well? - Did you feel your needs were met at the time or was there more that could have been done to help you? - What aspects worked well and what worked less well? - In what ways was your previous pregnancy acknowledged or taken into account?	- Did you want care, but it wasn't offered/able to access? - How did you feel about this at the time? - How do you feel about this in hindsight? - Did you look for any advice/ support from elsewhere? Can you tell me a little about what/where? - Is there anything that would have improved the likelihood of you attending PPC?

7. Overall, do you feel you were able to access the care and support that you needed before becoming pregnant again?

- was it easy to navigate the care system/ get the help you wanted?
- Was there anything that could be done differently that would have helped you?
- Would you have liked more support? What type of support would have been helpful?
- Would you have liked more advice or information?

- What type of advice/information would have been helpful?
- Where is the best place for you to access this advice/information?
- (if relevant) Do you feel your ethnicity has affected the care you were able to access? What could be done to improve access for you?

8. Were both pregnancies "planned"?
Is "preconception clinic" off-putting? What about "Woman's wellness" clinic?

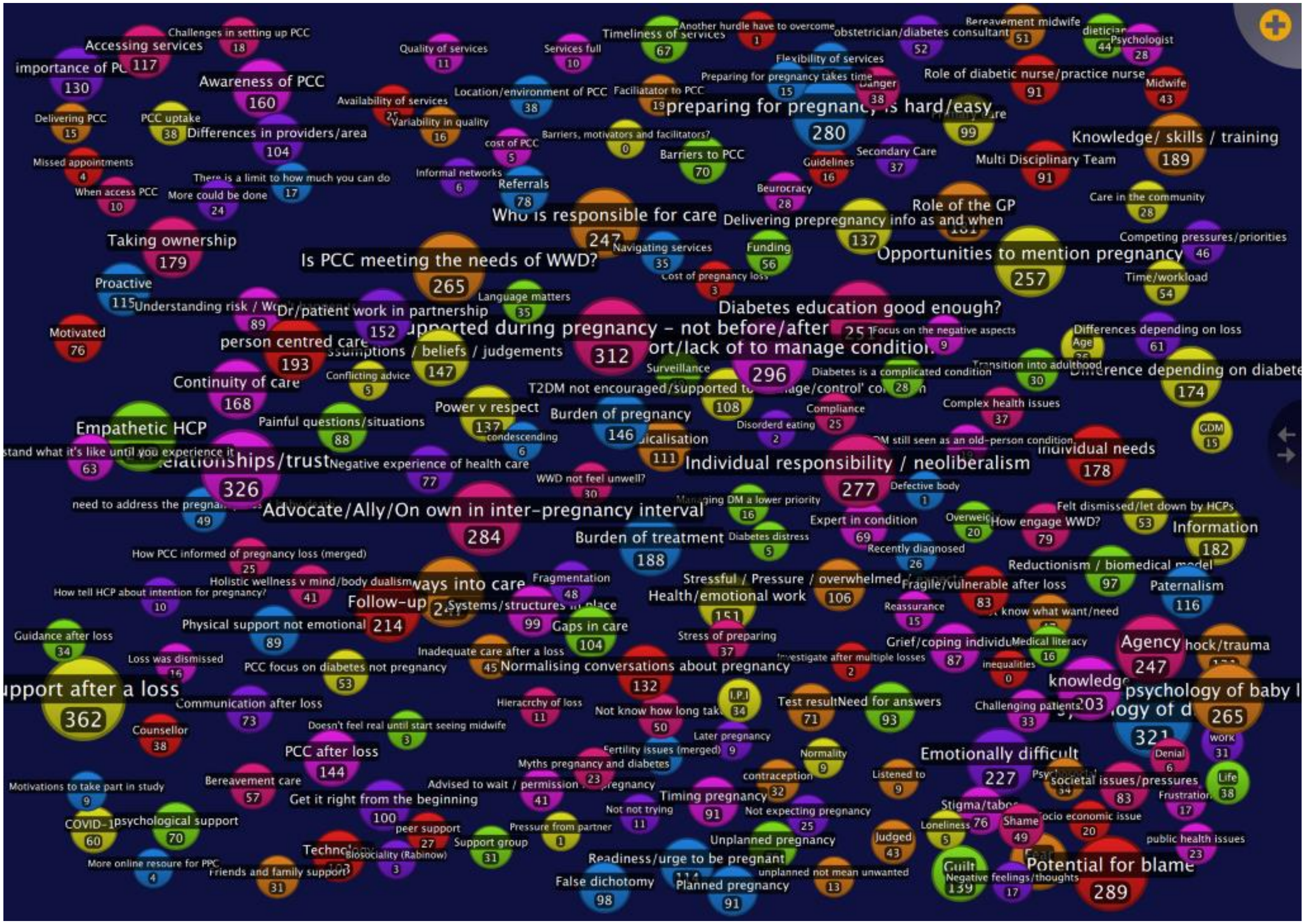
9. Anything else that the interviewee/interviewer feels has been missed / did not get a chance to discuss fully.

10. Do you have any questions or is there anything else you would like to talk to me about?

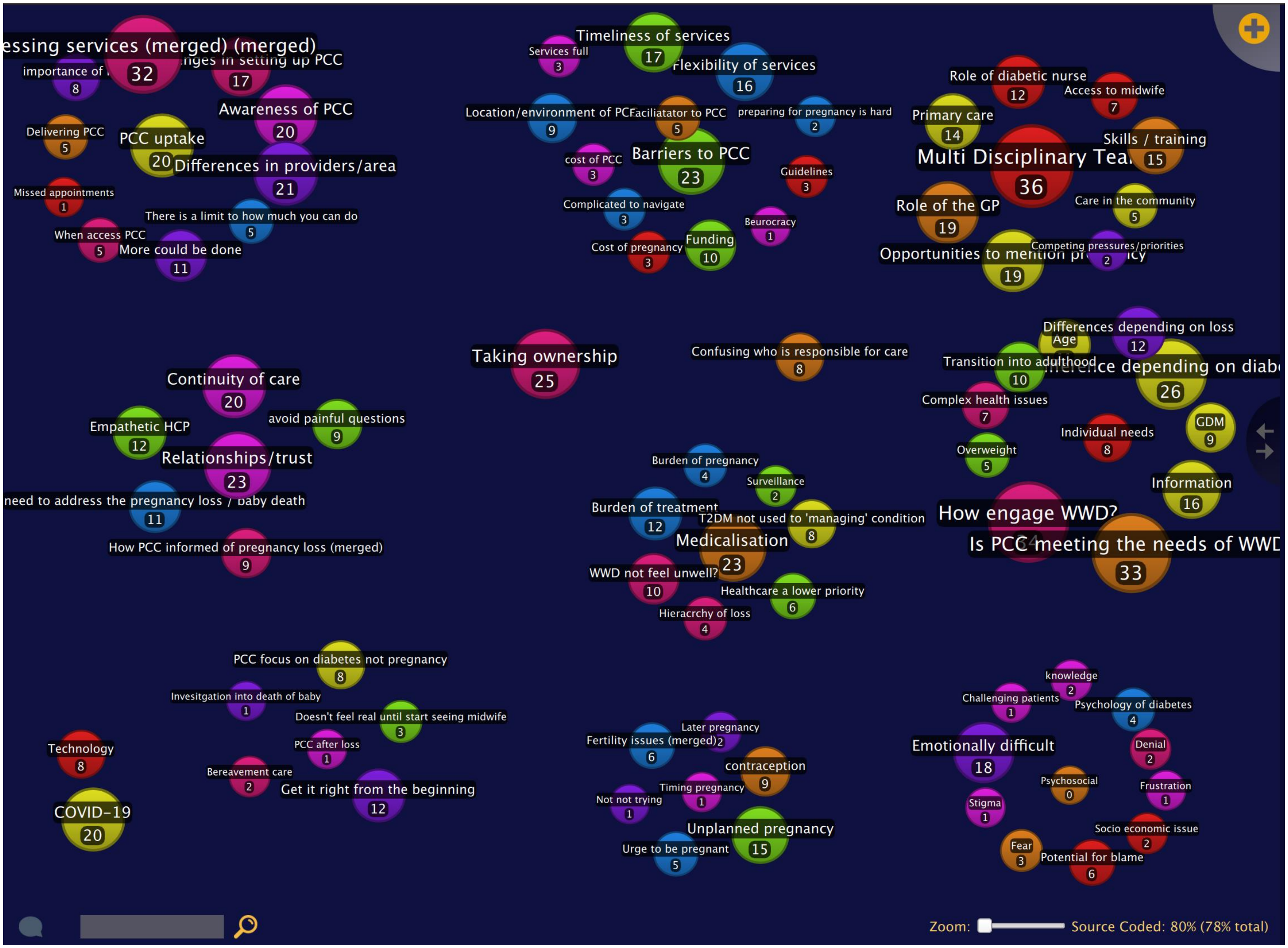
End of interview

11. Thank you for taking the time to talk to me today and for taking part in my research.
    - Next steps (e.g. I will send you an e-mail with some helpful information and links)
    - Would you like to be kept informed about any findings?

Appendix O: Using Quirkos to code the data and start developing themes



A screenshot of the very early stages of coding the data using Quirkos

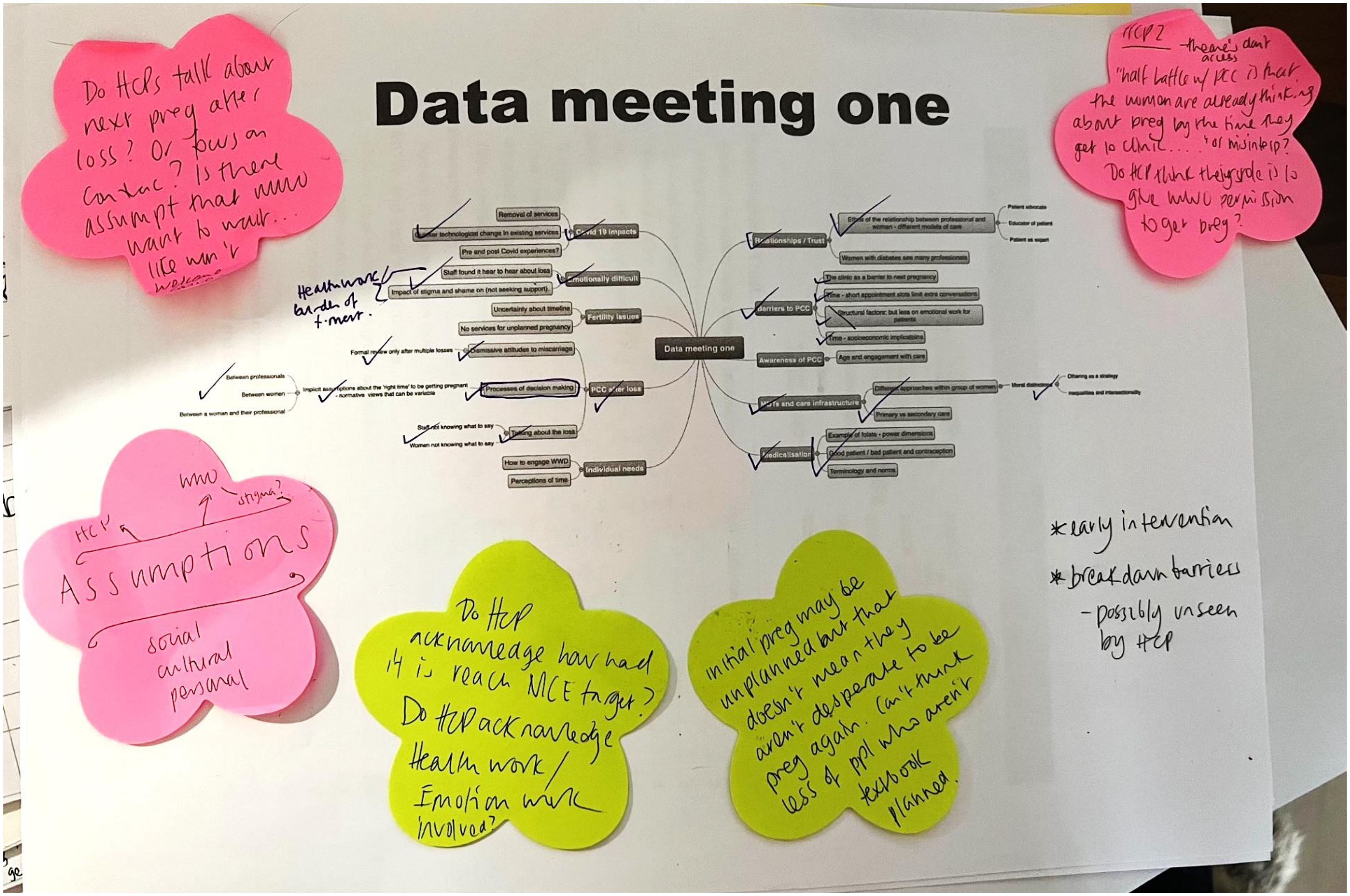


“Playing” with the codes in the early stages of thematic development

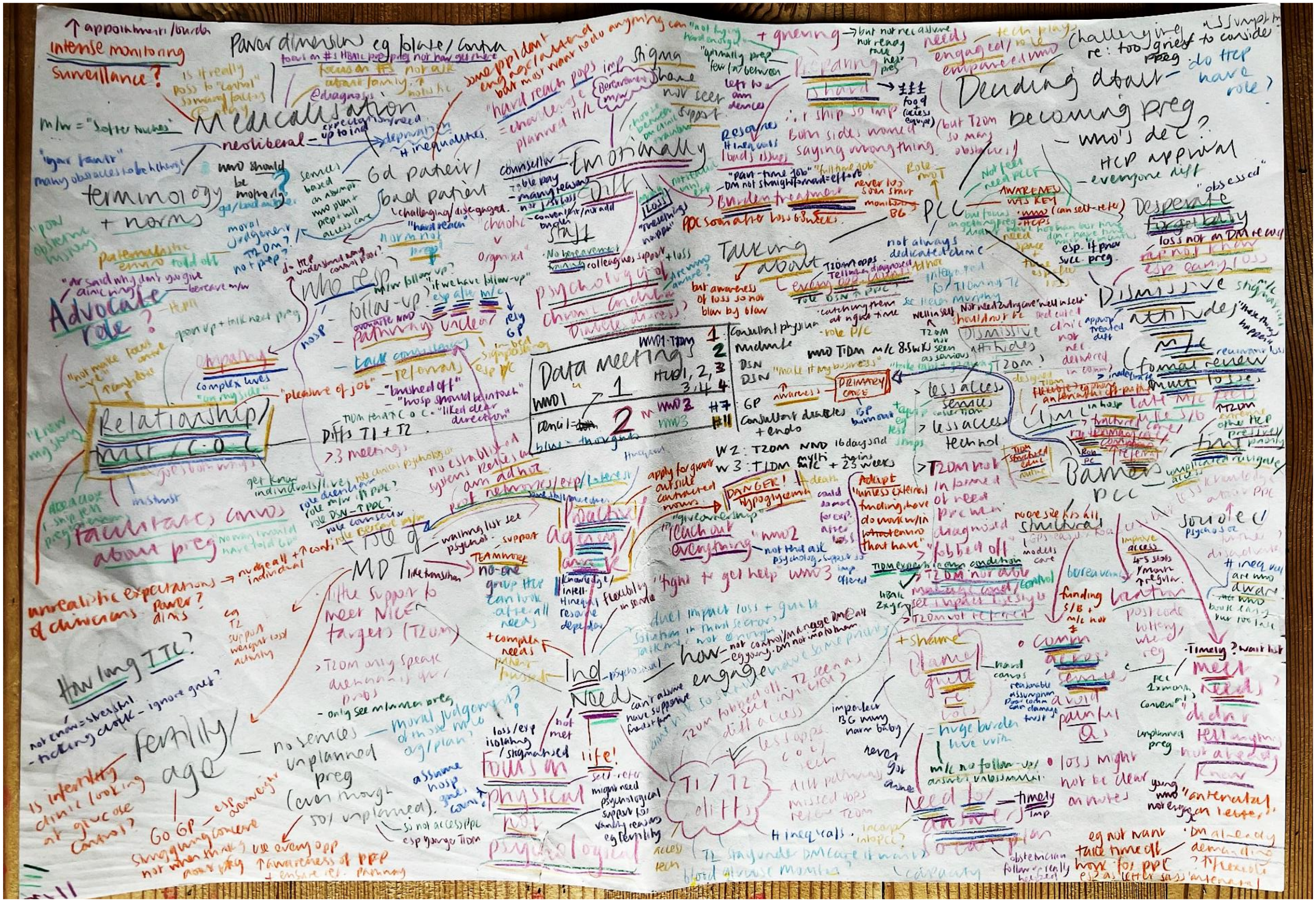
One of the functions on Quirkos allows you to put the codes in ascending order. I found this a useful way to help streamline the codes by merging similar codes and deleting unconvincing codes ahead of forming the themes. E.g. There were 10 slightly different codes for pre-pregnancy care.

Screenshot of Quirkos during the latter stages of code development

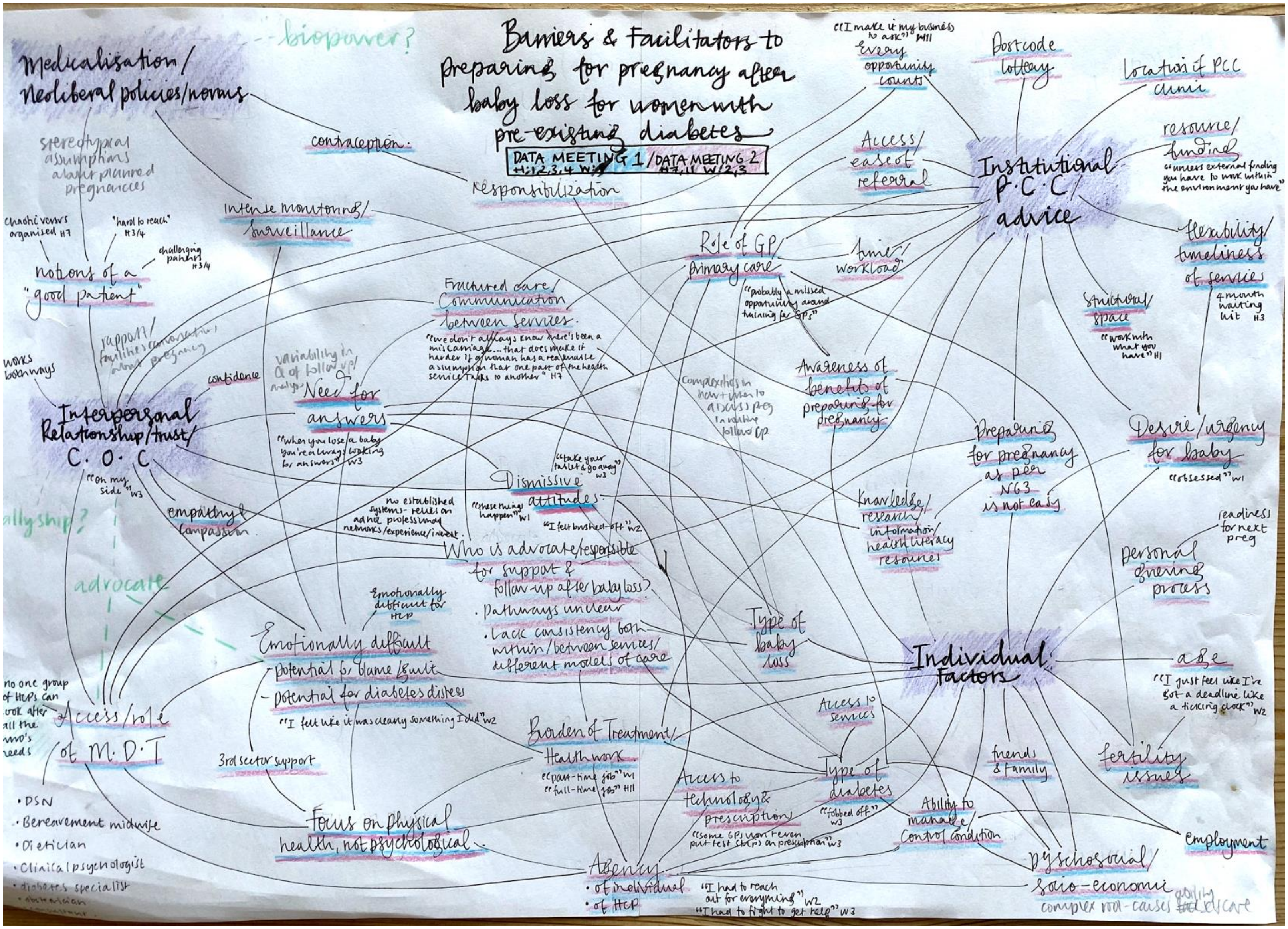
Appendix P: Images of thematic development during the analysis process



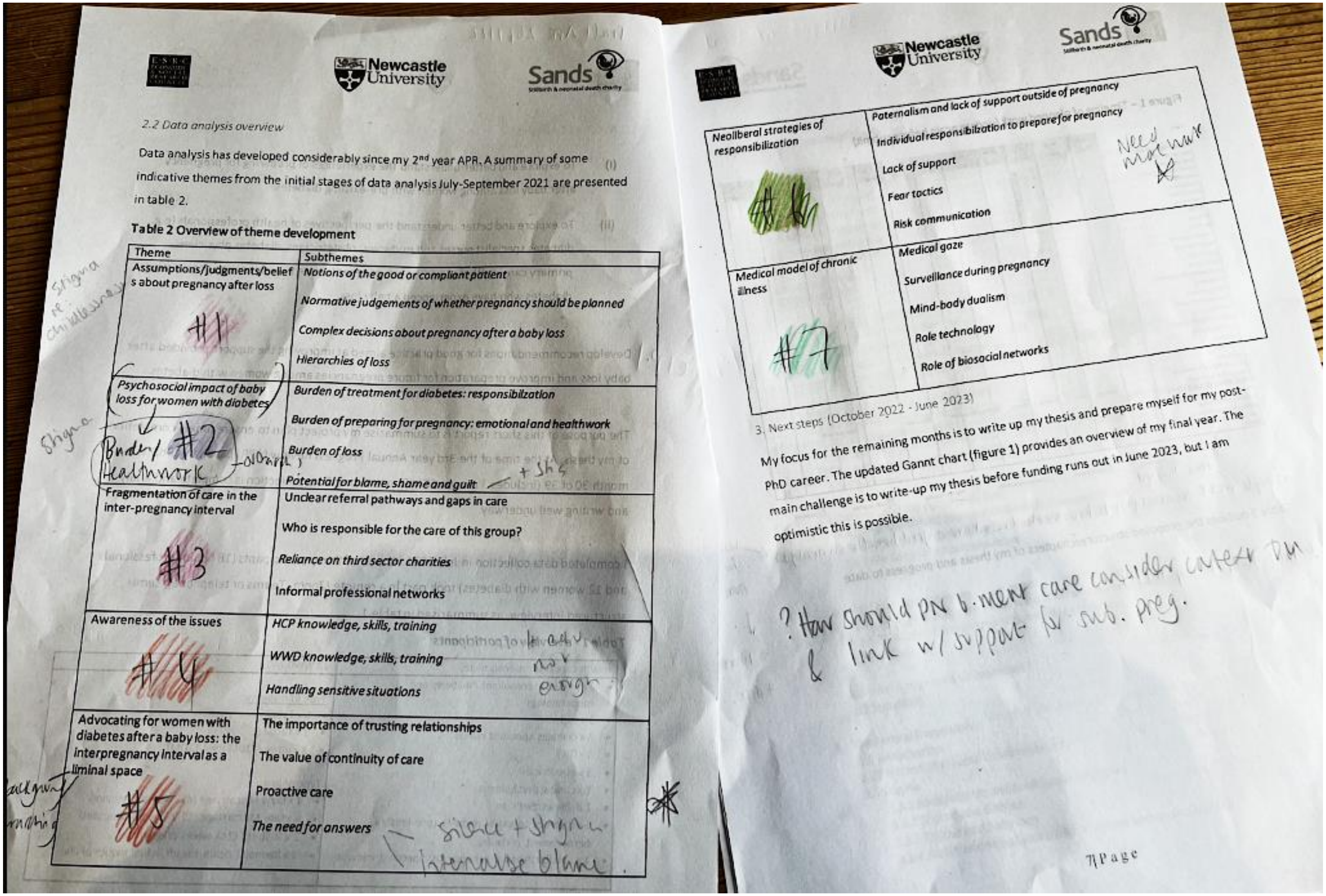
Notes from Data Meeting One (February 2021)



A photograph of a mind map from very early on in thematic development (April 2021)



A photograph of the first stages of thematic development (May 2021)



2.2 Data analysis overview

Data analysis has developed considerably since my 2nd year APR. A summary of some indicative themes from the initial stages of data analysis July-September 2021 are presented in table 2.

Table 2 Overview of theme development

Theme	Subthemes
Assumptions/judgments/beliefs about pregnancy after loss #1 Stigma re: childlessness	*Notions of the good or compliant patient* *Normative judgements of whether pregnancy should be planned* *Complex decisions about pregnancy after a baby loss* *Hierarchies of loss*
Psychosocial impact of baby loss for women with diabetes #2 Stigma Burden/ Healthwork - overall)	*Burden of treatment for diabetes: responsibilization* *Burden of preparing for pregnancy: emotional and healthwork* *Burden of loss* *Potential for blame, shame and guilt* + Sh's
Fragmentation of care in the inter-pregnancy interval #3	Unclear referral pathways and gaps in care Who is responsible for the care of this group? *Reliance on third sector charities* Informal professional networks
Awareness of the issues #4	*HCP knowledge, skills, training* *WWD knowledge, skills, training* *Handling sensitive situations* HCP not enough
Advocating for women with diabetes after a baby loss: the interpregnancy interval as a liminal space #5 background meaning	The importance of trusting relationships The value of continuity of care Proactive care *The need for answers* — silence + stigma internalise blame
Neoliberal strategies of responsibilization #6	*Paternalism and lack of support outside of pregnancy* *Individual responsibilization to prepare for pregnancy* *Lack of support* *Fear tactics* *Risk communication* Need more work
Medical model of chronic illness #7	*Medical gaze* *Surveillance during pregnancy* *Mind-body dualism* *Role technology* *Role of biosocial networks*

3. Next steps (October 2022 - June 2023)

My focus for the remaining months is to write up my thesis and prepare myself for my post-PhD career. The updated Gannt chart (figure 1) provides an overview of my final year. The main challenge is to write-up my thesis before funding runs out in June 2023, but I am optimistic this is possible.

? How should PN b.ment care consider context DM
& link w/ support for sub. preg.

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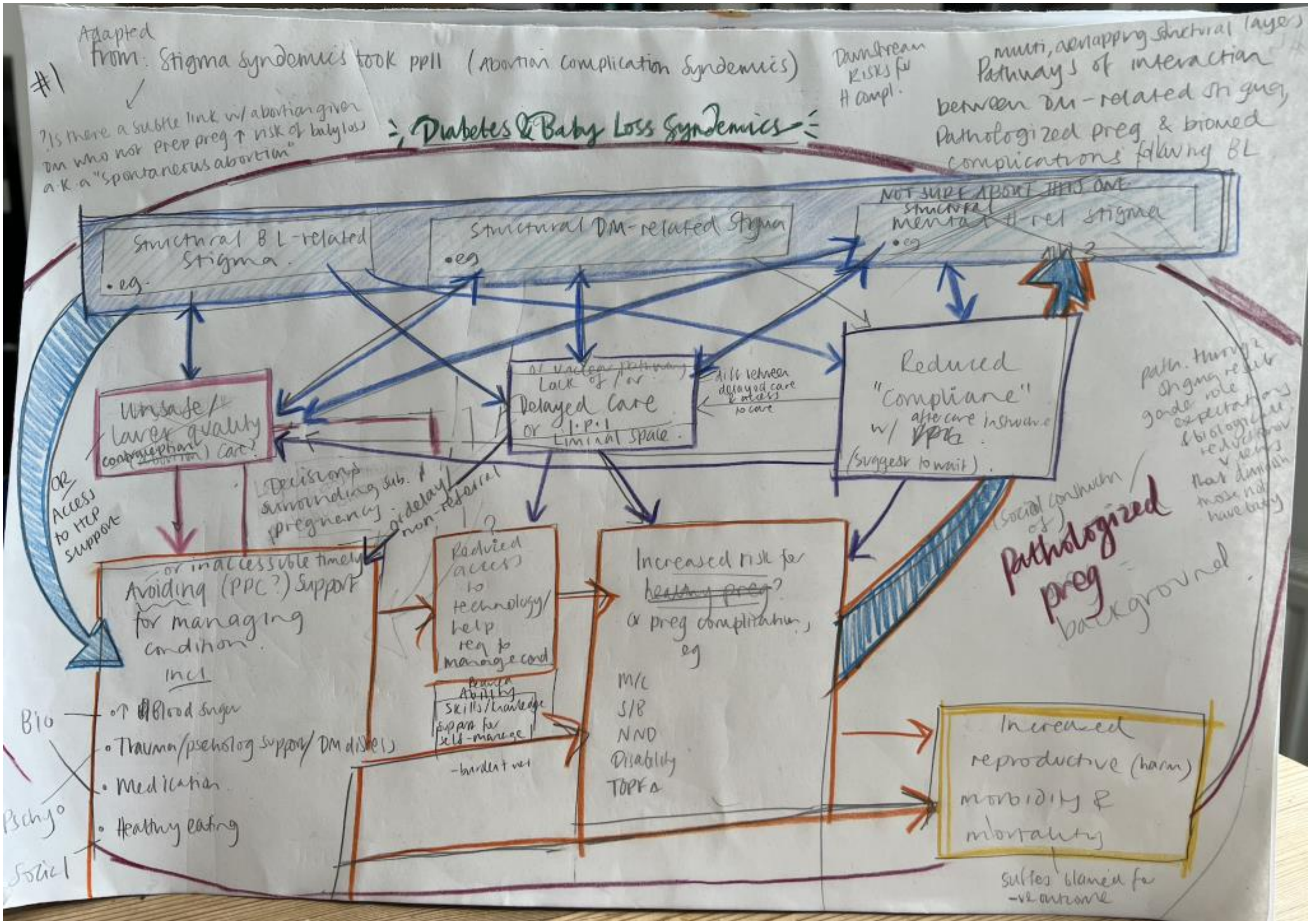
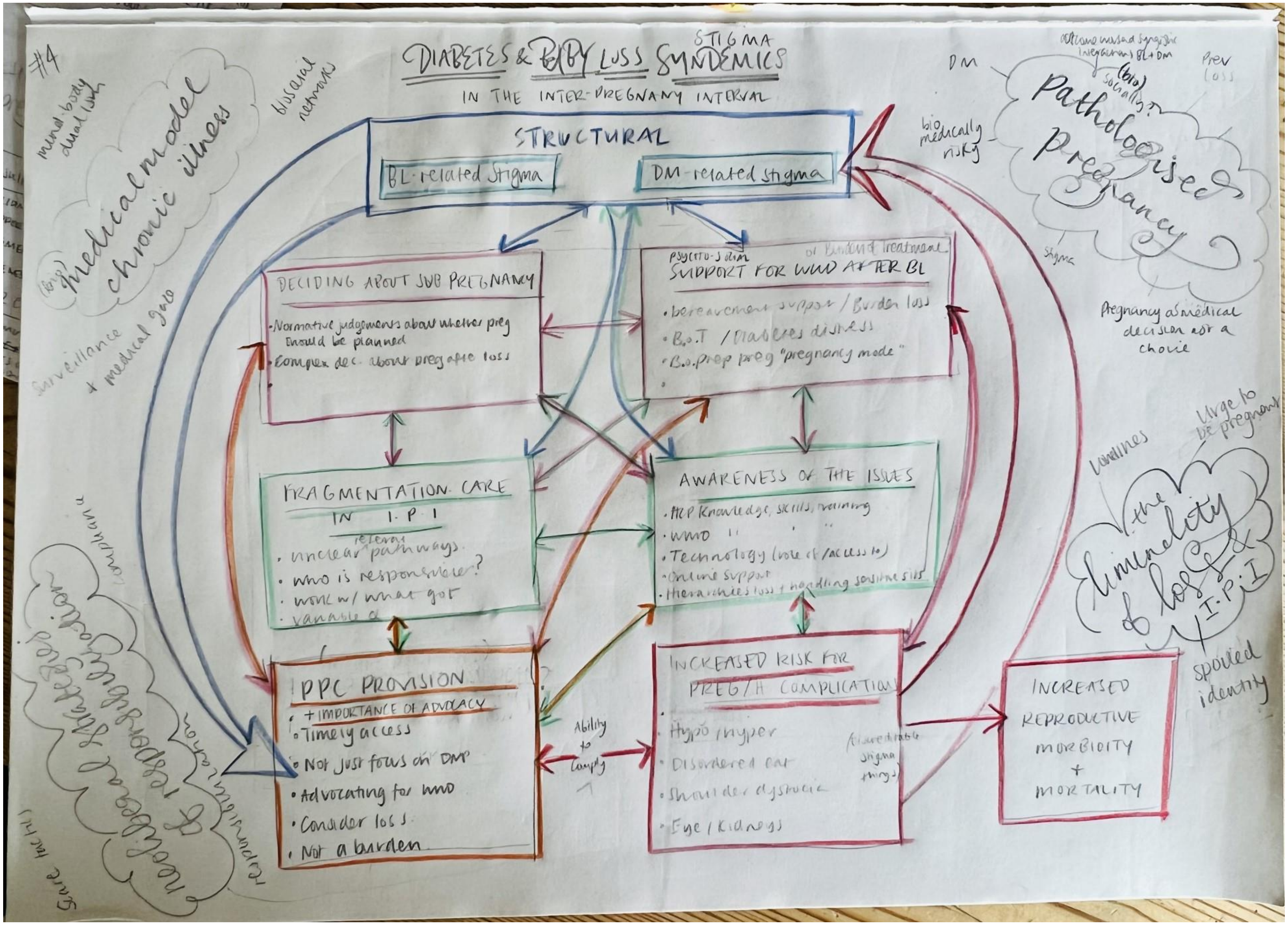
By August 2021 the themes and subssthemes had started to take shape ahead of my maternity leave, ready to pick up and present at my Annual Progression Review in September 2022

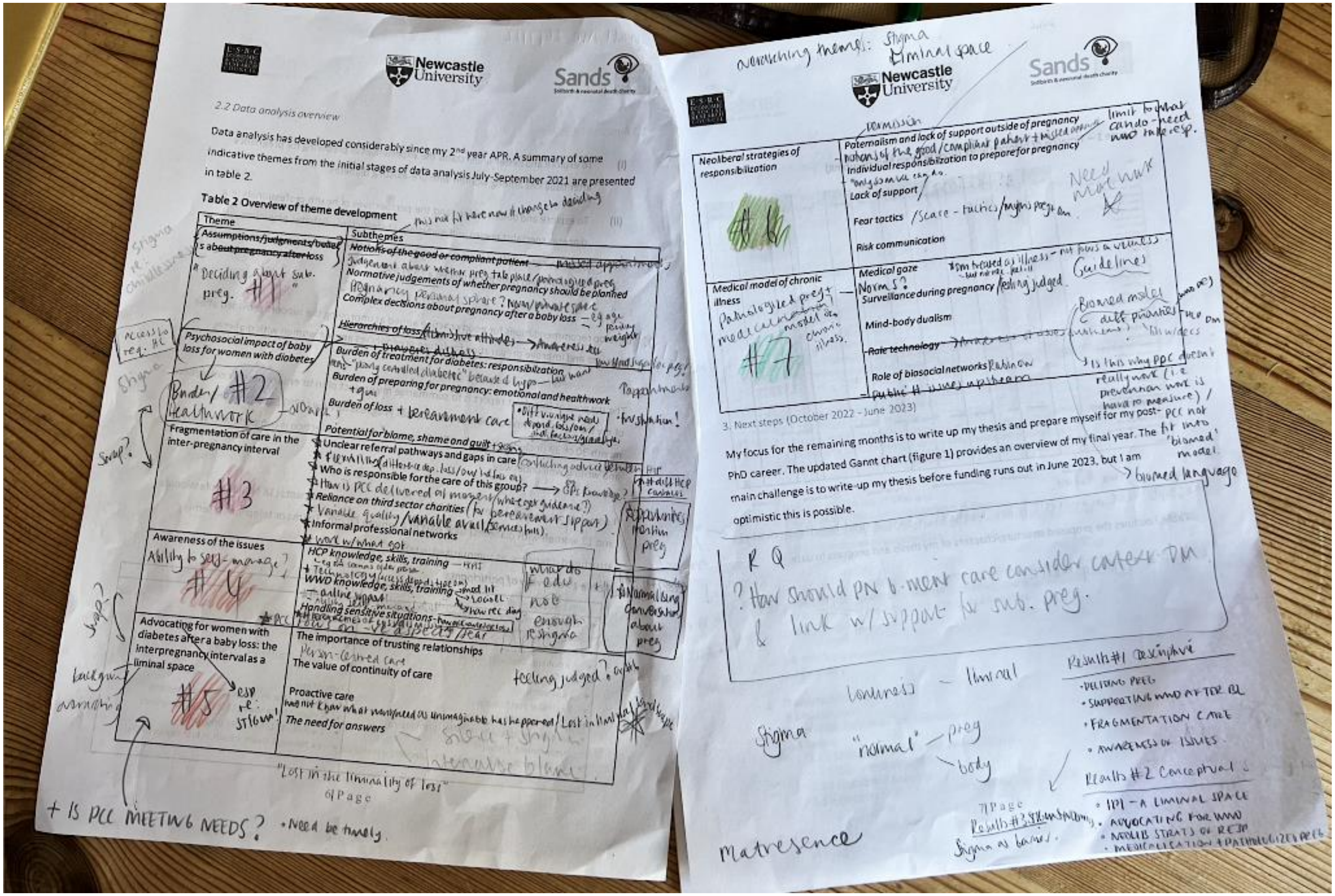


A photograph of an early iteration of using a stigma syndemics framework August 2022



A photograph of the developing stigma syndemic framework August 2022

An early sketch of how I envisaged the layering of themes for my 3rd year Annual Progression Review September 2022



2.2 Data analysis overview

Data analysis has developed considerably since my 2nd year APR. A summary of some indicative themes from the initial stages of data analysis July-September 2021 are presented in table 2.

Table 2 Overview of theme development

Theme	Subthemes
Assumptions/~~judgments/belief~~s about ~~pregnancy after~~ loss "Deciding about sub. preg. #1"	~~Notions of the good or compliant patient~~ — missed appointments Judgement about whether preg take place Normative judgements of whether pregnancy should be planned Pregnancy personal sphere? Now/private space Complex decisions about pregnancy after a baby loss — eg age, parity, weight ~~Hierarchies of loss~~
Psychosocial impact of baby loss for women with diabetes Burden/Healthwork #2	Burden of treatment for diabetes: responsibilization "poorly controlled diabetic" because of hypo Burden of preparing for pregnancy: emotional and healthwork + guilt Burden of loss + bereavement care Potential for blame, shame and guilt + stigma
Fragmentation of care in the inter-pregnancy interval #3	Unclear referral pathways and gaps in care — conflicting advice between HCP Who is responsible for the care of this group? → GPs knowledge? How is PCC delivered at moment (what are guidance?) Reliance on third sector charities (for bereavement support) Variable quality/variable avail (services/hubs) Informal professional networks work w/ what got
Awareness of the issues Ability to self-manage? #4	HCP knowledge, skills, training WWD knowledge, skills, training Handling sensitive situations PCC focus on -ve aspects/fear
Advocating for women with diabetes after a baby loss: the interpregnancy interval as a liminal space #5 esp re: stigma!	The importance of trusting relationships Person-centred care The value of continuity of care Proactive care The need for answers silence + stigma internalise blame

"Lost in the liminality of loss"

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+ IS PCC MEETING NEEDS? • Need be timely.

overarching themes: Stigma, Liminal space

Neoliberal strategies of responsibilization #6	Paternalism and lack of support outside of pregnancy notions of the good/compliant patient + missed appts Individual responsibilization to prepare for pregnancy Lack of support Fear tactics /Scare-tactics/myths preg + DM Risk communication Need more work
Medical model of chronic illness Pathologized preg + medicalisation model of chronic illness #7	Medical gaze Norms? Surveillance during pregnancy / feeling judged Guidelines Mind-body dualism Biomed model ~~Role technology~~ Role of biosocial networks

limit to what can do - need WWD take resp.

is this why PPC doesn't really work (i.e. prevention work is hard to measure) / PCC not fit into 'biomed' model

3. Next steps (October 2022 – June 2023)

My focus for the remaining months is to write up my thesis and prepare myself for my post-PhD career. The updated Gantt chart (figure 1) provides an overview of my final year. The main challenge is to write-up my thesis before funding runs out in June 2023, but I am optimistic this is possible.

→ biomed language

RQ

? How should PN b-ment care consider context DM & link w/ support for sub. preg.

loneliness — liminal

Stigma

"normal" — preg
— body

Results #1 Descriptive
- DECIDING PREG
- SUPPORTING WWD AFTER BL
- FRAGMENTATION CARE
- AWARENESS OF ISSUES

Results #2 Conceptual
- IPI – A LIMINAL SPACE
- ADVOCATING FOR WWD
- NEOLIB STRATS OF RESP
- MEDICALISATION + PATHOLOGIZED PREG

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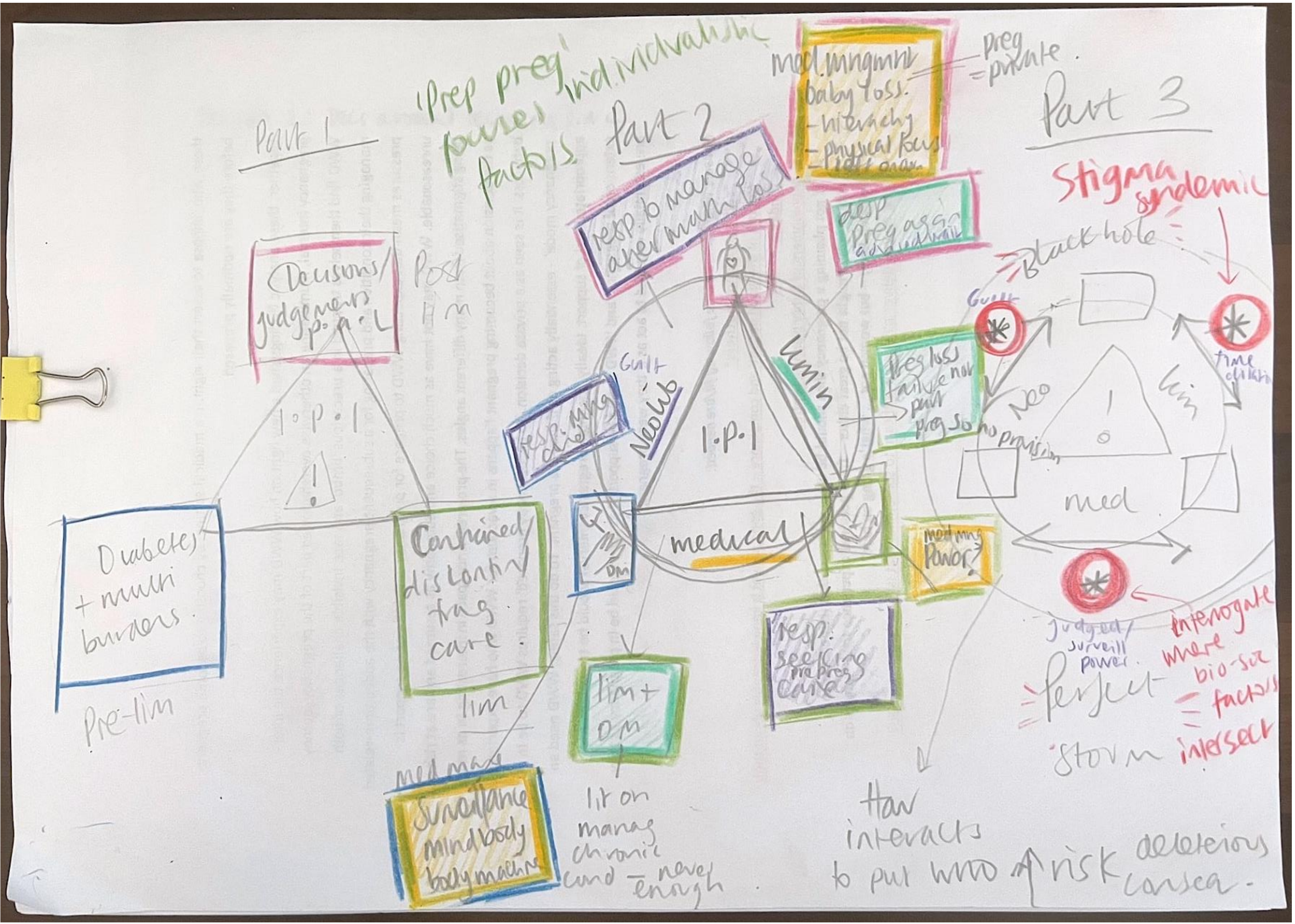
Results #3

Stigma as barrier.

Matresence

Preparing for the final data meeting October 2022



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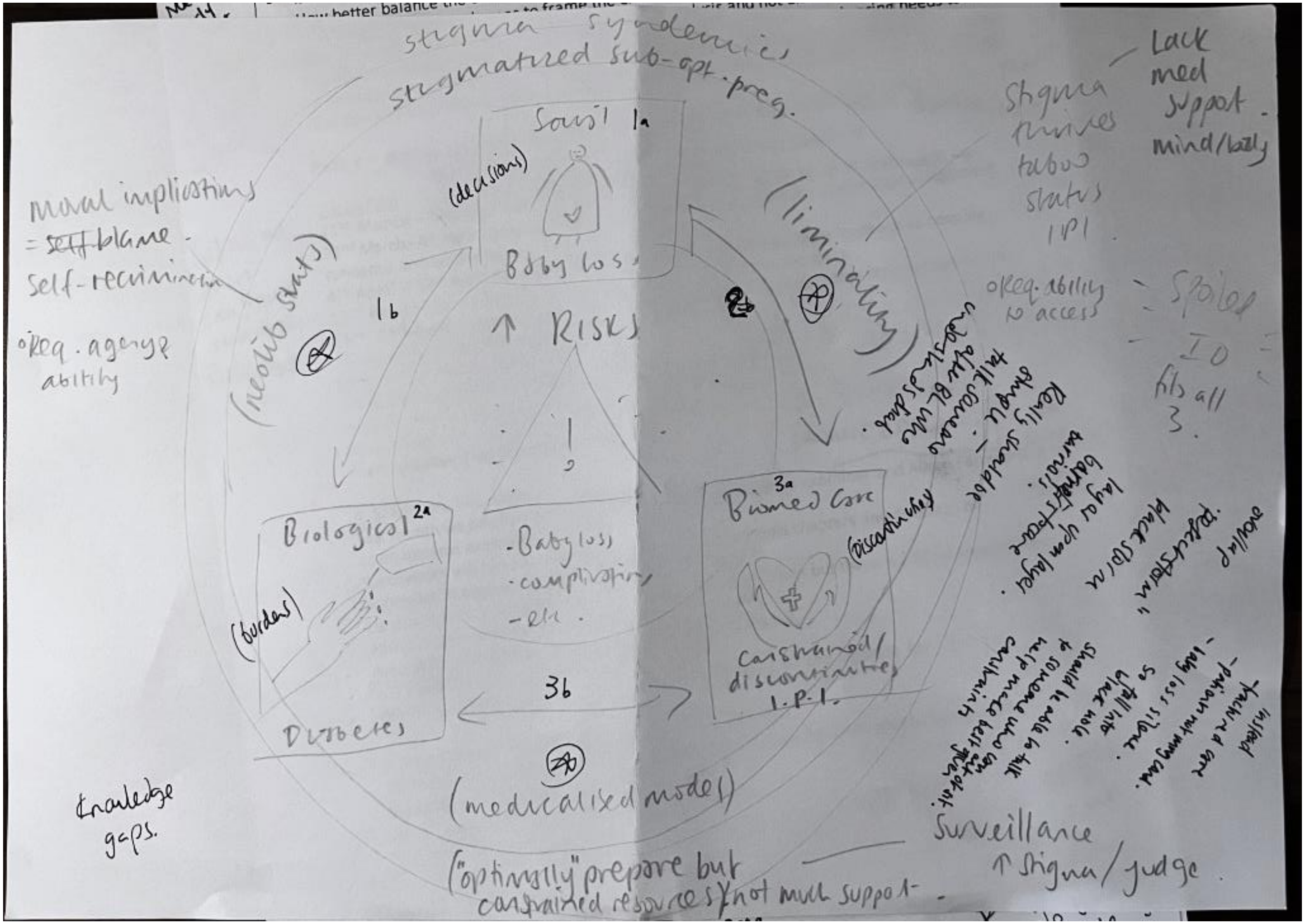
A sketch showing the development of the final thematic map (March 2023)



A rough sketch of the final thematic map (March 2023)

Appendix Q: Participant identifiers and brief overview

Healthcare professional identifier and job role		Women with diabetes identifier, type of diabetes and type of loss(es)	
HCP1	Diabetes Consultant	WWD1	Type 1 diabetes, early miscarriage
HCP2	Midwife	WWD2	Type 2 diabetes, neonatal death
HCP3	Diabetes Specialist Nurse	WWD3	Type 1 diabetes, 3 x early miscarriages, 1 x late miscarriage
HCP4	Diabetes Specialist Nurse	WWD4	Type 2 diabetes, early miscarriage, late miscarriage
HCP5	Midwife	WWD5	Type 1 diabetes, late miscarriage
HCP6	GP	WWD6	Type 1 diabetes, late miscarriage
HCP7	GP	WWD7	Type 2 diabetes, late miscarriage, neonatal death
HCP8	Endocrinologist	WWD8	Type 1 diabetes, neonatal death
HCP9	GP	WWD9	Type 1 diabetes, stillbirth
HCP10	Diabetes Consultant	WWD10	Type 1 diabetes, early miscarriage
HCP11	Endocrinologist	WWD11	Type 1 diabetes, early miscarriage
HCP12	Obstetrician	WWD12	Type 1 diabetes, early miscarriage, stillbirth
HCP13	Clinical Psychologist		
HCP14	Diabetes Specialist Dietician		
HCP15	Midwife		
HCP16	Diabetes Specialist Midwife		
HCP17	Bereavement Midwife		
HCP18	Diabetes Specialist Nurse		

Appendix R: Excerpts from my recruitment diary from early on in the recruitment process (November -December 2020)

4th November Sands tweeted my research for the first time today, but it clashed with the USA election day, so I'm worried it got lost amongst all of the noise.

9th November Two healthcare professionals completed and Expression of Interest form today but only one has scheduled an interview.

16th November I know it's only been a couple of weeks since the recruitment adverts went 'live' but it feels so anti-climactic and slow. I had, rather optimistically, expected to have received a little more interest than I have had. I wonder whether the Expression of Interest form is off-putting to potential participants? It's very wordy. I wonder whether a website might be a better platform to send people to as it will be more aesthetically pleasing and will help breakdown the information. I'll ask around and see if anyone has experience of setting up a website.

22nd November I designed and created a website this afternoon using Wix.

1st December I hit a bit of a low point today. When I say low point, I literally found myself crumpled on the floor in tears. I feel like I have put a lot of energy into recruitment, and it is disheartening that no-one seems to be 'taking the bait'. I feel so exhausted by it all, and at this rate, it is going to take me 30-40 months just to recruit – never mind analysing the data etc!

I had a long shower and had a long deep think to gain some perspective. Yes, I had spent a fair amount of time sending out a number of tweets, but they were obviously not reaching the intended participants, or if they were, my message was not clear, convincing, or persuasive enough. I was getting lost in the interminable feed of Twitter.

2nd December I listened to a podcast by the Thesis Whisperer whilst on a dog walk, and she was talking about the importance of specifically targeting communications to the group you are trying to reach. I wish I had listened to this about 8 months ago!

I have spent some time this week thinking about to boost recruitment. What I am currently doing is not working, so I need to try something different. I think I need to spend longer targeting people more specifically. I also need to be mindful about the timing of my tweets – I'm not sure when the ideal day/time is, but it is likely that posting early in the morning, in the evening or at the weekend will be best for targeting healthcare professionals

3rd December On my morning dog-walk, I suddenly had the realisation that by tweeting to all healthcare professionals, maybe I am not standing out to individual groups. Or, perhaps the individual groups don't really know that I am trying to get their attention. It would make more sense to directly target midwives, GPs, obstetricians, nurses etc so I can be explicit about why my research is of interest to them.

I also think that it would be a good plan to record some short videos to bring my research to life. Perhaps people would be more willing to sign up if they know who they are talking to? It seems like video dominates social media at the moment. But, if I am honest, I am nervous about recording videos and I don't relish the idea. I think this might be a 'blocker' for me - something that I need to do, but I am resisting it because the task is making me feel uncomfortable. But, I think it is worth a try.

It all feels a bit overwhelming, so so I am going to break it into bitesize chunks. Today, I will try targeting midwives. I think I can adapt the script that I used for my recent 3 Minute Thesis presentation to make a 2-minute video to target midwives. I tried recording on Teams, but the quality wasn't great, so I ended up recording it on Zoom and editing in iMovies, so I could chop the beginning and end off. I thought about using my phone, but I liked that I could use a background on Zoom so that no-one could see my messy house! I used the tips from Laura at Nifty Fox in an attempt to be engaging:

- Start with why (a story with no purpose = no point)
- Know your audience. Tailor you r message so the audience cares
- Decide on your 3 key points. Brevity = clarity = engagement
- Less words, more visuals
- Measure success. Track engagement and do what works

I scheduled my tweet for 7.30pm to try and catch midwives in the evening after work, and then thought nothing of it, and carried on with my day. I also looked on LinkedIn to find groups for midwives. These professional groups are usually closed, so I contacted the administrators of four groups to ask if I could post about my research (Nurse Innovation UK / Maternity, Midwifery and Baby Midwifery Exchange / Midwives and Research / Midwives Support Forum). Lisa Rickers from Nurse Innovation UK responded to my request, and also suggested a couple of Facebook groups. I posted my video in the Nurse Innovation group at 6.17pm (142 members) and on the corresponding Facebook page at 6.25pm (229 members).

At 7.30pm, my phone started to go crazy with notifications. My good friend, Jen, retweeted my video and tagged a midwife friend and the whole thing escalated! Within an hour, the tweet had about 1,000 'impressions' and several retweets and 'likes'. 18 people looked at my website and 2 people completed the E of I form. I am absolutely thrilled.

The insights, below, are from 8am the following morning, which is amazing compared to the 'seen by 22 and liked by 2' on the Nurse Innovation Facebook group (0 likes on LinkedIn).

ella dyer @ellabelladyer
I need #**midwife** participants for my PhD study on #**diabetes** & #**pregnancy** -please RT!

How can preconception care be promoted/improved?

How can women w/diabetes be better supported to access PCC given the positive influence on outcomes?

Sign up here 👉🏽 https://edyer24.wixsite.com/ella-dyer pic.twitter.com/oOBdS6cYN4

Impressions times people saw this Tweet on Twitter	3,344
Media views all views (autoplay and click) of your media are counted across videos, vines, gifs, and images	657
Total engagements times people interacted with this Tweet	182
Detail expands times people viewed the details about this Tweet	73
Media engagements number of clicks on your media counted across videos, vines, gifs, and images	35
Retweets times people retweeted this Tweet	22
Profile clicks number of clicks on your name, @handle, or profile photo	20
Link clicks clicks on a URL or Card in this Tweet	15
Likes times people liked this Tweet	13
Replies replies to this Tweet	4

Twitter insights from the first recruitment video (4th December 2022)