Bipolar Disorder and Postpartum Psychosis Pregnancy Planning (PREP) Study: developing an interactive guide for women at high risk

Elen Medi Thomas

A Thesis Submitted for the Degree of Doctor of Philosophy

School of Medicine

Cardiff University

2021

Supervisors:

Professor Ian Jones

Dr Catrin Lewis

Dr Jess Heron

Acknowledgements

First and foremost, I would like to thank my supervisors Professor Ian Jones, Dr Catrin Lewis and Dr Jess Heron. I have learnt so much from you all in the last three years, I am very grateful to have had you as supervisors. Thank you for your continuous encouragement, support and belief in me. I would also like to extend my thanks to HCRW for funding this project.

Thank you to all past and present members of the NCMH team for their support. In particular, I would like to say a huge thank you to Catrin Hopkins for all her design work on the guide. I really enjoyed working with you on it, thank you for bringing the guide to life! Thank you also to Rita, Kate, Claudia and Jasmine for their assistance with the interview transcribing and coding. Also, thank you to Holly, Natalie, Danielle and Alice for their suggestions and thoughts on the guide. I am grateful to Mark and Claire who helped me to keep things running smoothly, especially over the last year. I would like to thank John Tredget for his support with recruitment and feedback on the guide. I would also like to thank Lowri for the discussions on qualitative analysis and for her support.

A very big thank you to Dr Clare Dolman from Bipolar UK for her help with recruitment and the invaluable advice on the guide, and project as a whole. A special thank you to everyone at APP for all their guidance and support with recruitment and the advisory group. I am extremely grateful and inspired by your work. Thank you to all the professional stakeholders for taking the time to share your expertise and opinions for the development of the guide.

A very special thank you to my family and friends, especially to Mam, Dad, Rhian and Rhys for supporting me in everything I do in so many ways. I cannot thank you enough. To Louis, thank you for your positivity, always believing in me and for keeping me going. I could not have done it without you. A heartfelt thank you to my close friends, thank you for being there and for reminding me that thesis writing is not forever! I am so lucky to have you all.

Finally, I would especially like to thank all of the women involved in the project for their willingness and commitment throughout the project. The project would not have been possible without everything you put into it, thank you.

Table of Contents

Summary

Women with bipolar disorder or previous postpartum psychosis have a high risk of experiencing severe mental illness during the perinatal period. Women have reported difficulty in obtaining the information they need when planning and making decisions relating to pregnancy.

The aim of this project was to develop a pregnancy planning guide for women with bipolar disorder and / or previous postpartum psychosis. The specific aims were to determine the following: the critical components of the guide, its acceptability, and the feasibility of a larger scale Randomised Controlled Trial (RCT) of the guide.

The process followed Medical Research Council (MRC) Guidance on developing and evaluating complex interventions (Craig et al. 2008). A review of online information available to women, along with qualitative interviews with women with lived experience of bipolar disorder and / or postpartum psychosis (n=8), and professionals involved in their care (n=14), informed the initial prototype of the guide. Qualitative interviews were analysed using a process of reflexive thematic analysis (Braun and Clarke 2006; Braun and Clarke 2019). The initial prototype of the guide was piloted twice (pilot one: 9 participants; pilot two: 8 participants) and refined based on qualitative and quantitative feedback.

The final prototype of the guide was an 88-page loose leaf guide with sections for women to personalise. Overall, the guide was acceptable to women. Decisional conflict scores were reduced (representing less uncertainty) after using the guide compared to before; participant data on depression and anxiety symptoms showed no clear direction in whether scores increased or decreased after using the guide. The guide appeared best suited to those who had received specialist professional input. For those without this input, at times the guide seemed overwhelming.

To conclude, I recommend that the current iteration of the guide could be used to complement care within specialist perinatal mental health contexts. Prior to conducting a larger scale RCT of its use, I recommend further development work. For example, this could involve further tailoring of the guide and trialling its use alongside input from professionals.

Contributions

The following describes my contributions to the work described in this thesis.

Study set up

I developed the protocol for this project and all relevant study documents. Study documents included: information sheets for participants (key stakeholders and women), consent forms, participant, General Practitioner (GP) letters to inform of participation in the study, consent to contact forms, questionnaires and assessments, and advertisement documents.

I was responsible for preparing and submitting the application for ethical approval for this project, including subsequent amendments. I attended the Wales Research Ethics Committee (REC) review meeting to answer questions about the project. I was also responsible for preparing the application for registration onto the Health and Care Research Wales (HCRW) Portfolio and setting up Cardiff & Vale University Health Board (CVUHB) as a research site.

Advisory group

I was responsible for establishing and keeping in contact with all advisory group members and previous participants throughout the project, sharing prototypes of the guide and recording and considering their feedback.

Review of online information

I was responsible for the design of the review of online information presented in Chapter 3 and conducted the search. I was responsible for inputting, coding and analysing all data.

Development of the guide

I was directly involved in advertising and recruitment for the project, involving conducting presentations at team meetings, conferences and public engagement events. The work in these chapters was based on novel data. For the development and piloting stages of the project, data collection involved assessments before using the guide, feedback interviews and questionnaire measures, which I was solely responsible for. I also transcribed over 20% of the qualitative interviews with the remaining interviews transcribed by members of the National Centre for Mental Health (NCMH) team and a commercial service. I coded and

analysed all qualitative interview and inputted, scored and analysed all quantitative questionnaire data.

I contributed to the graphic design of the guide prototypes using publication design software. I was responsible for the rewrites and refinement of all guide prototypes. I was the budget holder for the project and responsible for sourcing the physical materials and printing services for the professional printing of the guide.

Abbreviations

AMS (Altman Mania Scale)

APP (Action on Postpartum Psychosis)

BEPC (Bipolar Education Programme Cymru)

CVUHB (Cardiff & Vale University Health Board)

CMHT (Community Mental Health Team)

CBT (Cognitive Behavioural Therapy)

CUPS (Cardiff University Psychiatry Service)

DCS (Decisional Conflict Scale)

DSM (Diagnostic and Statistical Manual of Mental Disorders)

DSM-5 (Diagnostic and Statistical Manual of Mental Disorders 5th edition)

ECT (Electroconvulsive therapy)

FK grade level formula (Flesch Kincaid grade level formula)

FRE (Flesch Reading Ease)

GP (General Practitioner)

HADS (Hospital Anxiety and Depression Scale)

HSE (Health and Safety Executive)

ICD (International Classification of Diseases)

JAMA (Journal of the American Medical Association)

MBU (Mother and Baby Unit)

MMHA (Maternal Mental Health Alliance)

MS (Multiple sclerosis)

NCMH (National Centre for Mental Health)

NHS (National Health Service)

NICE (National Institute for Health and Care Excellence)

ONS (Office of National Statistics)

RCT (Randomised Controlled Trial)

REC (Research Ethics Committee)

SCIE (Social Care Institute for Excellence)

SD (Standard Deviation)

WHO (World Health Organization)

List of Tables and Figures

Chapter 4

Tables

Figures

Chapter 5

Tables

Figures

Chapter 6

Tables

Figures

Chapter 7

Tables

Chapter 1 Introduction

1.1 Overview

This introductory chapter will begin by providing a background on bipolar disorder and how childbirth acts as a significant trigger of mania and psychosis in women with bipolar disorder. This chapter will then describe factors that women at high risk of perinatal mental illnesses may need to consider in their planning and decision-making during the perinatal period. Following this, an overview of perinatal mental health care and treatment will be discussed, with a focus on women's information and support needs during the preconception and perinatal period. A rapid review of relevant literature will be conducted to identify studies looking into the development or evaluation of a pregnancy planning guide or decision tool for women with bipolar disorder or previous experience of postpartum psychosis. A brief overview of decision tools developed for other health conditions will follow. Finally, the aims of the project and the structure of this thesis will be outlined.

1.2 Bipolar disorder

Bipolar disorder is a chronic and recurrent mood disorder (American Psychiatric Association 2013). As the name suggests, bipolar disorder, formerly known as manic-depression, is characterised by episodes of high mood (mania) and low mood (depression), with the length, intensity and frequency of each episode differing widely between individuals (Grande et al. 2016). Mania is considered the hallmark mood state of bipolar disorder, which involves elevated mood, euphoria, or irritability in addition to symptoms such as overactivity, a decreased need for sleep, and pressured speech (Belmaker 2004). Acute episodes of mania may also include experiences of psychosis, such as delusions or hallucinations (American Psychiatric Association 2013). Individuals may experience hypomanic episodes, which consist of similar symptoms to a manic episode, but are less severe and last for a shorter amount of time (American Psychiatric Association 2013). Episodes of mania and hypomania can include behaviours which are out of character for the individual, such as disinhibited and flirtatious behaviour, poor self-regulation, spending money inappropriately and making excessively grandiose plans (Mitchell et al. 2006).

The lifetime prevalence of bipolar spectrum disorder is around 2 - 3%, depending on how it is defined and measured (Merikangas et al. 2011). The average age of onset for bipolar disorder is 22.2 years (Goodwin and Jamison 2007). The World Health Organization (WHO)

World Mental Health survey showed that bipolar disorder had the second greatest impact on the number of days out of role (being unable to work or carry out normal activities due to physical health, mental health or use of alcohol or drugs) (Alonso et al. 2011). Bipolar disorder has also been ranked within the top 20 most disabling illnesses as a result of loss of income and decreased quality of life (World Health Organisation 2008). Individuals with bipolar disorder have a high risk of death by suicide, being more than 20 times greater than the general population (Pompili et al. 2013).

As described in a biographical account of mania by Professor Kay Redfield Jamison, a clinical psychologist with personal experience of bipolar disorder, "When you're high it's tremendous. The ideas and feelings are fast and frequent like shooting stars, and you follow them until you find better and brighter ones" (Jamison 1997). Individuals can often view episodes of mania as a positive experience, a time where creativity and productivity are at their best (Jamison 1997). Indeed, a number of studies have documented the over-representation of bipolar disorder among those who have achieved fame within creative disciplines (Johnson et al. 2015). Manic episodes can however, be destructive and overpowering, as described by Professor Jamison, "the fast ideas are far too fast, and there are far too many; overwhelming confusion replaces clarity" (Jamison 1997).

The two most commonly used diagnostic classification systems are the International Classification of Diseases (ICD) (World Health Organisation 2018), and the Diagnostic and Statistical Manual of Mental Disorders (DSM) (American Psychiatric Association 2013). The 11th edition of the ICD is the latest to be published and focuses on physical and mental illnesses. The DSM, currently in its 5th edition, solely focuses on mental disorders (American Psychiatric Association 2013; World Health Organisation 2018). Mania is defined in the DSM 5th edition (DSM-5) as "a distinct period of abnormally and persistently elevated, expansive, or irritable mood and abnormally and persistently increased goal-directed activity or energy" together with symptoms such as an inflated self-esteem, grandiosity and a decreased need for sleep (American Psychiatric Association 2013). To meet criteria for an episode of mania, symptoms must be present for most of the day, nearly every day for at least one week, or require hospitalisation. Hypomania is defined in the DSM-5 in the same way as mania, however, only needs to last four consecutive days to meet criteria. Episodes which cause marked impairment in social or occupational functioning, or require hospitalisation, are classified as mania. If an individual presents with psychotic symptoms, an episode automatically meets criteria for mania (American Psychiatric Association 2013).

Symptoms of a major depressive episode are also common in bipolar disorder, as well as in other mood disorders, such as unipolar depression. Criteria for a major depressive episode is presented in Table 1.1 below. As shown, it is necessary to meet at least five of the criteria defined, within a 2-week period, with at least one of the symptoms being (1) depressed mood most of the day, nearly every day; or (2) loss of interest or pleasure in all, or almost all, activities most of the day, nearly every day (American Psychiatric Association 2013). Although major depressive episodes are not required for a diagnosis of bipolar disorder I, depression is often the predominant feature of the illness (Judd et al. 2002; Post 2005; American Psychiatric Association 2013). In fact, individuals with bipolar disorder spend as much as three times longer experiencing depressive symptoms compared to mania or hypomania (Post et al. 2003; Baldessarini et al. 2010). Bipolar depression is also associated with greater impairment in work, social and family life compared to mania (Post 2005). While depressive symptoms are a prominent feature of bipolar disorder for many, it is the manic episodes that define bipolar disorder.

The DSM-5 identifies bipolar disorder as a spectrum, with the major subtypes being bipolar I disorder and bipolar II disorder, as well as specific specifiers that can be applied to an episode, such as "rapid cycling" and "mixed features" (American Psychiatric Association 2013). For a diagnosis of bipolar disorder I, an individual needs to present with at least one manic episode, and for a diagnosis of bipolar disorder II, an individual needs to present with at least one hypomanic episode and one major depressive episode (American Psychiatric Association 2013). The "mixed features" specifier can be applied to any bipolar disorder diagnosis. For example, the "mixed features" specifier could refer to an episode of mania / hypomania with depressive features present, or an episode of depression with feature of mania / hypomania present). The "rapid cycling" specifier involves experiencing at least four episodes (meeting criteria for mania, hypomania or major depression) during a 12-month period.

The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) Criteria for Bipolar Disorder
Manic episode criteria *For a diagnosis of Bipolar I, it is necessary to meet the following criteria for a manic episode.* A.   A distinct period of abnormally and persistently elevated, expansive, or irritable mood and abnormally and persistently goal-directed behaviour or energy, lasting at least 1 week and present most of the day, nearly every day (or any duration if hospitalization is necessary) B.   During the period of mood disturbance and increased energy or activity, three (or more) of the following symptoms have persisted (four if the mood is only irritable) are present to a significant degree and represent a noticeable change from usual behaviour: 1.   Inflated self esteem or grandiosity

2. Decreased need for sleep
3. More talkative than usually or pressure to keep talking
4. Flight of ideas or subjective experience that thoughts are racing
5. distractibility (i.e., attention too easily drawn to unimportant or irrelevant external stimuli), as reported or observed
6. Increase in goal directed activity (either socially, at work or school, or sexually) or psychomotor agitation
7. *Excessive involvement in activities that have high potential for painful consequences (e.g., engaging in unrestrained buying sprees, sexual indiscretions, or foolish business investments).*

The mood disturbance is sufficiently severe to cause marked impairment in social or occupational functioning or to necessitate hospitalization to prevent harm to self or others, or there are psychotic features.

The episode is not attributable to the direct physiological effects of a substance (e.g., a drug of abuse, a medication, or other treatment) or another medical condition.

Hypomanic episode criteria

For a diagnosis of Bipolar II, it is necessary to meet the following criteria for a hypomanic episode, and at least one major depressive episode.

A. A distinct period of abnormally and persistently elevated, expansive, or irritable mood and abnormally and persistently increased activity or energy, lasting at least 4 consecutive days and present most of the day, nearly every day.
B. Same as criteria for manic episode.
C. The episode is not severe enough to cause marked impairment in social or occupational functioning or to necessitate hospitalization. If there are psychotic features, the episode is, by definition, manic.
D. The episode is not attributable to the physiological effects of a substance (e.g., a drug of abuse, a medication or other treatment).

Major depressive episode criteria

Minor or major depressive episodes are often present in Bipolar I. For a diagnosis of Bipolar II, it is necessary to meet criteria for a hypomanic episode, and at least one major depressive episode.

A. The diagnosis of a major depressive episode requires five or more of the following symptoms to be present within a 2-week period; at least one of the symptoms should be either (1) depressed mood or (2) loss of interest or pleasure.
   1. Depressed mood most of the day, nearly every day.
   2. Markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day.
   3. Significant weight loss when not dieting or weight gain, or decrease or increase in appetite nearly every day.
   4. Insomnia or hypersomnia nearly every day.
   5. Psychomotor agitation or retardation nearly every day (observable by others, not merely subjective feelings of restlessness or being slowed down).
   6. Fatigue or loss of energy nearly every day.
   7. Feelings of worthlessness or excessive or inappropriate guilt nearly every day.
   8. Diminished ability to think or concentrate, or indecisiveness, nearly every day.
   9. Recurrent thoughts of death, recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide.
B. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.
C. The episode is not attributable to the physiological effects of a substance or to another medical condition.

Table 1.1 DSM-5 Criteria for manic episode, hypomanic episode and major depressive episode

1.3 Gender differences in bipolar disorder

Similar rates of bipolar disorder occur in women and men, however women experience longer and more frequent depressive episodes, as well as there being a greater prevalence of bipolar II disorder, rapid cycling and mixed episodes in women compared to men (Diflorio and Jones 2010; Saunders et al. 2014). A key difference in the experience of bipolar disorder between men and women, is the impact of reproductive life events (Freeman and Gelenberg 2005; Jones and Cantwell 2010). Women with bipolar disorder are vulnerable to the impact that reproductive life events such as menarche, the menstrual cycle, childbirth and menopause, can have on their mental health (Freeman and Gelenberg 2005; Di Florio et al. 2013a; Teatero et al. 2014; Perich et al. 2017; Rosso et al. 2020). However, the relationship between bipolar disorder and childbirth is particularly strong and is discussed in more detail below.

1.4 Perinatal mental illness

Mental health problems are common during pregnancy and within the first year of giving birth (the perinatal period), affecting more than 1 in 10 women (Casanova Dias and Jones 2016). Conditions during the perinatal period include antenatal and postpartum depression, obsessive compulsive disorder, post-traumatic stress disorder (PTSD) and postpartum psychosis. These problems can develop suddenly and range from mild to moderate, to extremely severe, requiring different kinds of care and treatment (Casanova Dias and Jones 2016). As discussed, an episode of perinatal mental illness may be the first instance of mental illness for some women, while for others, it may follow experience of a pre-existing mental health condition which persists, deteriorates or reoccurs during pregnancy or after the birth of a baby (Jones et al. 2014). As described above, for women with bipolar disorder, the perinatal period represents a particularly high risk of recurrence of an episode of mental illness (Di Florio et al. 2018).

Perinatal mental illnesses are a significant concern, with suicide being a leading cause of maternal death (Cantwell et al. 2011). If perinatal mental illnesses go untreated, they can have long-term implications for the well-being of women, their babies and families. Illness can influence bonding with the baby and relationships can suffer (Jones et al. 2014). As well as the significant impact on women and their families, it is estimated that the UK cost for perinatal mental health problems in each one-year cohort of births is £8.1 billion, with the cost mainly relating to the impact that maternal mental health has on the child. This can

include adverse effects on the child's emotional, cognitive and sometimes physical development (Bauer et al. 2014).

Postpartum mood episodes or disturbances are most commonly classified into the following three categories: postpartum blues / baby blues, postpartum depression and postpartum psychosis, all of which vary in their presentation, prevalence and management (Doucet et al. 2009). It is important to differentiate between postpartum depression and postpartum psychosis which are mood disorders requiring assessment and treatment, from the baby blues which is a normal reaction to having a baby and does not require treatment (Lee and Chung 2007).

1.4.1 Postpartum blues / baby blues

The postpartum blues or baby blues is a minor mood disturbance during the postpartum period and is common following childbirth, affecting 30-80% of women (Jones and Shakespeare 2014). Symptoms of baby blues can include dysphoric mood, crying, anxiety, insomnia, loss of appetite, and irritability (O'Hara et al. 1991). The baby blues typically occur within two to three days following childbirth and importantly, symptoms resolve within 10 to 12 days postpartum without requiring treatment, unless the episode develops into postpartum depression (Jones and Shakespeare 2014; O'Hara and Wisner 2014). Twenty percent of women with this presentation go on to develop postpartum depression within the first year following childbirth, who then require treatment (O'Hara et al. 1991).

1.4.2 Postpartum depression

Postpartum depression is a mood disorder that, depending on how it is defined, affects around 10-15% of new mothers (Gaynes and Gavin 2005). Depressive disorders during the perinatal period are similar to symptoms of depression presenting at other times in a woman's life. They include symptoms of depressed mood and loss of interest or pleasure lasting at least two weeks (American Psychiatric Association 2013). Postpartum depression with an onset within four weeks postpartum, meets the DSM-5 diagnostic criteria of major depressive disorder category with the specifier "with peripartum onset" (American Psychiatric Association 2013).

A range of treatment approaches are recommended to treat postpartum depression, including psychological and psychosocial interventions, antidepressants and electro-convulsive therapy (Dennis and Hodnett 2007; Fitelson et al. 2011; National Institute for

Health and Care Excellence 2014b). Having psychological and psychosocial interventions as options are particularly important during the perinatal period, considering the potential concerns about teratogenic effects of pharmacological treatments (Howard et al. 2014). In a Cochrane review, both psychosocial (for example, peer support and non-directive counselling) and psychological (for example, cognitive behavioural therapy (CBT) and interpersonal psychotherapy) interventions were found to be effective in reducing depression symptoms during the postpartum period (up to one year) (Dennis and Hodnett 2007). For a woman with moderate or severe depression in pregnancy or the postnatal period, The National Institute for Health and Care Excellence (NICE) guidelines (2014a) recommend a high-intensity psychological intervention such as CBT. The choice of treatment depends on the severity of the episode and individual choice. The NICE guidelines (2014a) recommend the use of antidepressant medication to treat postpartum depression, particularly if symptoms are severe and symptoms do not respond to psychological treatment alone.

1.4.3 Postpartum psychosis

Postpartum psychosis, is a severe mental illness occurring after birth, usually characterised by symptoms of mania, severe psychotic depression, or mixed episodes with features of both high and low mood (Di Florio et al. 2013b; Bergink et al. 2016). Postpartum psychosis affects 1-2 in every 1000 deliveries and is one of the most severe forms of postpartum mental illness (Rai et al. 2015; Meltzer-brody et al. 2018). Postpartum psychosis occurs suddenly, often within a few days of giving birth and usually lasts between 2-12 weeks (Heron et al. 2012). Women may also experience depression, anxiety and low confidence in the months following an episode of postpartum psychosis (Heron et al. 2008). Despite the acute onset and severity of postpartum psychosis, prognosis is good and most women make a full recovery (Jones et al. 2014).

Despite the term 'postpartum psychosis' being used widely clinically and by the leading third sector organisation in this area ('Action on Postpartum Psychosis'), postpartum psychosis is not recognised as a distinct diagnosis in DSM-5 (American Psychiatric Association 2013) and although present in ICD-11, clinicians are told not to use the diagnosis unless other diagnoses are not possible (World Health Organisation 2018).

In DSM-5, women presenting with postpartum psychosis may receive a diagnosis of a depressive, manic or hypomanic episode including the 'with peripartum onset' specifier,

within the 'depressive or bipolar disorder and related disorders' category. The lack of a distinct diagnosis for postpartum psychosis has created confusion around how best to conceptualise these episodes within research and clinical settings (Jones 2020; Perry et al. 2021). Additionally, to use the 'with peripartum onset' specifier, the onset of the episode must occur within four weeks following childbirth. Considering that postpartum psychosis may occur beyond the four-week postpartum window, this makes the use of this specifier problematic (Rai et al. 2015). Despite this, qualitative research has shown that women find the term "postpartum psychosis" useful (Dolman et al. 2013).

An episode of postpartum psychosis should be considered as a psychiatric emergency, requiring immediate intervention and in most cases, inpatient psychiatric treatment (Jones et al. 2014; Meltzer-brody et al. 2018). A Mother and Baby Unit (MBU) is an inpatient mental health service for women who are experiencing severe perinatal mental illnesses. National guidelines recommend that women who require in-patient care for a mental health problem during late pregnancy up to 12 months postpartum should be admitted to a specialised MBU (National Institute for Health and Care Excellence 2014a). Despite this, many women in the UK are not receiving the care they need to recover from severe perinatal mental health episodes (Witcombe-Hayes et al. 2018; Smith et al. 2019). MBUs offer the benefit of avoiding the separation of mother and baby and therefore promote the attachment relationship (Kenny et al. 2013). They also provide an opportunity to educate women and their families about the postpartum illness (Jones et al. 2014).

1.5 Bipolar disorder and childbirth

Childbirth is a significant trigger of mania and psychosis in women with bipolar disorder, which further increases the distinction of the impact of bipolar disorder on women compared to men (Jones and Craddock 2005; Diflorio and Jones 2010; Di Florio et al. 2013a). In a Danish national register study examining over 600,000 pregnancies, it was found that women were over 23 times more likely to be admitted to a psychiatric hospital with an episode of bipolar disorder in the month following childbirth than at any other time in their life (Munk-Olsen et al. 2006).

Previous history of mental illness can help to identify those who are at high risk of experiencing severe mental illness during the perinatal period. In Jones et al's (2014) review, a history of bipolar disorder or previous severe-postpartum episode is described as the "strongest and best-established risk factor for susceptibility to post-partum psychosis". A

retrospective study of 1212 parous women (women who had given birth at least once) found that 1 in 5 women with bipolar disorder had experienced an episode of postpartum psychosis (Di Florio et al. 2013a). A meta-analysis conducted by Wesseloo et al (2016) found that women with either a history of postpartum psychosis or bipolar disorder had an overall relapse risk (of experiencing an episode of perinatal mental illness) of 35% in the postpartum period. Specifically, women with bipolar disorder had a relapse risk of 17%, and women's previous experience of postpartum psychosis a relapse risk of 29% in the postpartum period (Wesseloo et al. 2016).

A cohort study of 887 parous women explored the role of previous perinatal episodes on risk of subsequent episodes of mental illness (Di Florio et al. 2018). It was found that the risk of developing severe episodes of mental illness after birth differed depending on a woman's previous perinatal psychiatric history and current mental health diagnosis. Women with a diagnosis of bipolar I disorder had a particularly high risk of experiencing severe mental illness, specifically mania or psychosis, during subsequent perinatal periods (42.7%). This study also found that for women with bipolar disorder, the risk of experiencing a perinatal mental health episode (mania, psychosis or depression) in a second pregnancy was greater for those who already had experience of a perinatal mental health episode (55%), compared to those who did not (31%). Women with a previous history of perinatal mental illness (depression, mania or psychosis) and a diagnosis of bipolar I disorder or bipolar II disorder had a similar high risk of developing perinatal illnesses, i.e. mania, psychosis or non-psychotic depression (55% and 56%, respectively).

For women with bipolar disorder, a family history of postpartum psychosis can raise their risk of experiencing postpartum psychosis further (Jones and Craddock 2001). It is however episodes of non-psychotic depression during the perinatal period that are most commonly experienced by women with bipolar disorder. It has also been found that women who have experienced a previous episode of postpartum psychosis are at a very high risk of experiencing it again, over 1 in 2 (Bergink et al. 2012). It is also important to note that most instances of postpartum psychosis (over 50%) occur in women with no previous experience of psychiatric illness (Jones and Smith 2009; Bergink et al. 2012).

1.6 Management and prevention

Being informed on individual risk of becoming unwell during the perinatal period provides an opportunity for women and their clinicians to plan ahead and work towards preventing

an episode of illness. However, it is also important to consider that many pregnancies are unplanned, particularly among women with bipolar disorder, with one study finding that women with bipolar disorder experienced more unplanned pregnancies (37.7%) and fewer planned pregnancies (32.8%) compared to a control group (9.6% unplanned pregnancies, 78.1% planned pregnancies) (Marengo et al. 2015). This emphasises the importance of including discussions on family planning as routine for all women of reproductive age.

1.6.1 Perinatal mental health care

In the UK, women with perinatal mental illnesses may receive care from specialist perinatal mental health teams, which include psychiatrists, psychologists, occupational therapist, mental health nurses, social workers, nursery nurses and a specialist pharmacist. However not all women with perinatal mental illness require specialist care; some women can be managed in primary care settings. Perinatal mental health teams offer interventions such as psychological therapies, medication, care planning and support relating to the relationship between mother and infant (Howard and Khalifeh 2020). Research on the effectiveness of perinatal mental health teams in caring for women with perinatal mental illnesses is currently in progress (Howard and Khalifeh 2020). Perinatal mental health teams in England support women from pre-conception up to two years after birth (NHS England. 2019a; NHS England. 2019b).

In recent years, efforts have been made to increase the number of specialist perinatal mental health services available. In 2016, the UK Prime Minister announced that over £290 million would be invested into new specialist perinatal mental health services, with additional funding being promised since (GOV.UK 2016; Howard and Khalifeh 2020). The Welsh Government also announced a £1.5 million annual recurring investment in 2016 for the provision of community perinatal mental health services across each of the health boards areas in Wales (Welsh Government 2016). Whilst improvements have been made, there is still work to do to ensure all women are able to access the specialist perinatal mental health services they require.

1.6.1.1 PRECONCEPTION

A qualitative study conducted by Dolman and colleagues (2016) explored women with bipolar disorder's experience of decision-making in relation to pregnancy. Twenty-one qualitative semi-structured interviews were conducted with women with lived experience of

bipolar disorder who were considering pregnancy, pregnant or previously pregnant. This was supplemented by comments obtained from the third sector organisation Bipolar UK's online forum. They found that women at risk of severe mental illness during the perinatal period highly valued the opportunity of receiving specialist preconception advice, whilst those not referred to a specialist service were disappointed with the information they received (Dolman et al. 2016). Preconception mental health care is becoming more of a focus within perinatal community mental health services in England (Catalao et al. 2020). In these services, preconception advice is being offered to all women referred with moderate to severe mental illnesses who are planning a pregnancy (Catalao et al. 2020). The NICE guidelines (2014a) recommends that all women of reproductive age with experience of mental illness should be offered preconception counselling, although currently this is not always the case. Not all women have access to a specialist perinatal mental health team, however the effectiveness of preconception advice from general services compared to more specialist services is unknown.

1.6.1.2 INPATIENT TREATMENT

Women with severe episodes of perinatal mental illness, such as psychotic disorders, mania, or severe depression, during pregnancy or after birth, require specialist perinatal mental health care, often within inpatient services tailored to their needs (Jones et al. 2014; Brockington et al. 2017). As referred to in '1.4.3 Postpartum psychosis', MBUs provide the opportunity for women to be admitted with their baby, meaning that mother-infant separation is avoided and women can receive support on bonding and breastfeeding. This also provides the opportunity for women and their partners to be educated on the illness (Jones et al. 2014). Qualitative research on women's information and support needs during recovery found that women value the specialist care that MBUs offer (Heron et al. 2012). While MBUs are considered best practice in the UK, there is a lack of evidence on their effectiveness in improving outcomes for women and their babies. A study to examine the effectiveness of mother and baby units compared with generic inpatient services is currently in progress (Trevillion et al. 2019).

1.6.2 Medication

For most people with bipolar disorder, alongside psychosocial aspects of management, medication is a key aspect of their treatment (Bodén et al. 2012). Women at risk of severe mental illness face difficult decisions when weighing up the benefits of taking medication to

keep well, against the potentially damaging effects of medication on the foetus (Dolman et al. 2016). These include stopping, switching or continuing medications, with all these options having potential risks and benefits (Bodén et al. 2012). Other considerations when making decisions around medication relate to breastfeeding and the impact of any side effects, such as sedation on their ability to care for their child (Jones et al. 2014).

Individuals with bipolar disorder not only take medication to treat episodes of low or high mood, but also when well to reduce the chances of a severe recurrence of illness. Many medications are used in the treatment and prophylaxis of bipolar disorder and a detailed consideration of their reproductive safety are beyond the scope of this introductory chapter. However, one particular medication is associated with a high risk of harm to the foetus and is a particular issue for women with bipolar disorder considering pregnancy. Sodium valproate is an anticonvulsant medication which is used as a mood stabiliser to treat bipolar disorder (Cipriani et al. 2013). Sodium valproate is not recommended for use in women of childbearing age due to both a significant teratogenic risk and also an impact on the cognitive development of babies exposed in utero, unless alternative treatments are unsuitable and the terms of the pregnancy prevention programme are met (Royal College of Psychiatrists 2018; Baldwin and Amaro 2020). Other anticonvulsant mood stabilisers, such as carbamazepine and lamotrigine may also be associated with teratogenic risks, however the risk appears to be considerably less than for sodium valproate (Jones et al. 2014). Studies do not suggest that antipsychotics in general are associated with increased teratogenicity, however research considering certain antipsychotics individually is limited (Huybrechts et al. 2016; Mcallister-Williams et al. 2017). While research on the association between lithium and teratogenic effects is uncertain, recent research suggests that the risk of lithium is much lower than earlier studies have suggested (Nora et al. 1974; Di Florio et al. 2017; Poels et al. 2018). For women with bipolar disorder who find themselves pregnant while taking medication, the foetus may already have been exposed to the effects of medication. Due to the risk of relapsing during pregnancy, abrupt discontinuation of the medication is usually discouraged (Jones et al. 2014).

It is considered best practice for women to undertake an individualised risk-benefit analysis with their clinicians around taking medication. In this analysis, the risk of relapse should be balanced with the reproductive safety of each medication choice (Jones et al. 2014; National Institute for Health and Care Excellence 2014b). The risk of becoming unwell during the perinatal period appears to be higher for women who discontinue their medication

(Wesseloo et al. 2016; Stevens et al. 2019), with one study demonstrating a doubling of risk for women with bipolar disorder who stopped taking their mood stabiliser treatment (Viguera et al. 2007). In a meta-analysis conducted by Wesseloo et al (2016), the relapse rate for women who had discontinued mood stabilisers was 66%, compared to a significantly lower relapse rate of 23% for women who continued with their medication during pregnancy (Wesseloo et al. 2016).

Women must consider the benefits of medication alongside the risk of untreated illness for herself and the baby. However, there is still much that is unknown, with research on the reproductive safety of medications for bipolar disorder during the perinatal period limited. Additionally, little research has been done on how medication may reduce the likelihood of becoming unwell, and the potential benefits of this on maternal mental health and infant outcomes. This makes it difficult for women to make informed choices during this time. More research is needed to allow women to make informed risk-benefit analyses regarding medication (Jones et al. 2014).

In Dolman et al's (2016) qualitative study, it was suggested that it would be useful to deliver information on medication in a comprehensible, jargon-free way, while taking into account the anxieties associated with making decisions on treatment during the perinatal period (Dolman et al. 2016). The authors of this study also discussed the usefulness of a decision aid for women with bipolar disorder to use when considering pregnancy, which has already been developed for women making decisions relating to antidepressant use during pregnancy (Dolman et al. 2016; Vigod et al. 2016b).

1.7 Information and support needs of women planning a high risk pregnancy

Deciding to have a child is a significant decision for any person or couple, however for women with an increased risk of severe mental illness, there are additional, complex decisions to make. As discussed by Anke et al (2019), a qualitative study on women with bipolar disorder's concerns and preparations, women may need to balance two identities – being a woman with bipolar disorder and becoming a mother. This section will discuss the information and support needs of women planning a high risk pregnancy, with a focus on women's own views described within the qualitative literature. Women feel that they need to allow enough time for medication changes when planning for a pregnancy, as well as preparing mentally and physically for having a baby (Dolman et al. 2016).

Jones et al (2014) states that "sensitively providing understandable information while acknowledging the many areas of uncertainty is critical to optimal care" for women with severe mental illness in their reproductive years. Qualitative research on women's opinions on perinatal mental health care convey their dissatisfaction with the lack of specialist advice available to them during this time (Dolman et al. 2013; Dolman et al. 2016; Anke et al. 2019). Women offered pre-conception counselling within primary care settings viewed this as "unsatisfactory" and felt counselling from a psychiatrist within specialist mental health services was needed (Anke et al. 2019). Qualitative research also highlights the key role of having a strong support network. Partner's involvement during the planning and decision-making period was considered critical, as well as family support postnatally, which was important for both married / cohabiting and single women (Heron et al. 2012; Dolman et al. 2016).

Many studies have highlighted the fear women feel when considering their risk of a severe episode of mental illness during the perinatal period (Dolman et al. 2016; Anke et al. 2019). This fear can be exasperated by thoughts of having to stop or change their medication (Dolman et al. 2016). Women also worried about the impact of medication (including effects on the foetus and on their decision to breastfeed), the heritability of bipolar disorder and the fear that social services may take their baby away if they became unwell (Dolman et al. 2013; Dolman et al. 2016). Other worries related to being a "bad parent" and the impact that becoming unwell postpartum may have on their relationship with a partner (Dolman et al. 2016). A major theme discussed within the literature however is women's strong desire to have a child, which often outweighs the undoubted worries they experience (Dolman et al. 2013; Dolman et al. 2016).

Despite the recognised importance and need for information and specialised care during this time, qualitative research has shown that women at high risk of experiencing postpartum psychosis have great difficulty in obtaining the information they need when planning for pregnancy (Dolman et al. 2016). Women have emphasised the need for a central depository of reliable information (Heron et al. 2012). Qualitative studies on women's information needs and decision making have found that women consult the internet for information relating to pregnancy and recovery from a severe episode of perinatal mental illness (Heron et al. 2012; Dolman et al. 2016). Women also report finding information on perinatal mental illness online which they found "alarming" and anxiety-inducing (Dolman et al. 2016). Women have expressed the importance of considering how advice is delivered, with women

viewing the term "high risk" as being unhelpful and exasperating feelings of fear and anxiety (Dolman et al. 2016). A qualitative study on perinatal decision making from women's perspectives showed that women would value having "some kind of guide or booklet for women", which was "not forbiddingly medical … and "doomy and gloomy"" (Dolman et al. 2016).

1.8 Shared decision making and decision aids

As conveyed in Dolman et al (2016), women need reliable information to aid them in working with their clinicians to make decisions about pregnancy and postpartum. In recent years, individuals have become more involved in their healthcare decisions. The literature on decision making discusses three main models in healthcare decision making: the paternalistic model, the informed model and shared decision making (Charles et al. 2013). The paternalistic model involves the patient adopting the most passive, dependent role, whereas the healthcare professional adopts an expert role. This differs from the informed model of decision making, which involves the sharing of information relating to treatment, but not necessarily a sharing of the decision making process (Charles et al. 1997). In this model, a healthcare professional's role is limited to sharing the technical or scientific knowledge required to make decisions, while the patient then, once equipped with this knowledge, makes a decision autonomously. While in each of these models, either the healthcare professional or the patient takes the lead in making a decision, shared decision making benefits from the expertise of both the healthcare professional and the patient. In shared decision making, the healthcare professional can be seen as the expert in empirical evidence relating to risks and benefits of the options available, while the patient is the expert of their own values and preferences. Shared decision making is described as "an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences" (Elwyn et al. 2010). Shared decision making is key to the delivery of patient-centred care (Barry and Edgman-Levitan 2012) and has been recognised in key policy documents in the UK, including the NHS Long Term Plan (NHS England 2019).

Decision aids can facilitate shared decision making and are described by the International Patient Decision Aids Standards (IPDAS) Collaboration as evidence-based tools that support individuals with making choices in the face of a number of different treatment options (IPDAS 2005; Elwyn et al. 2006; Joseph-Williams et al. 2014). Decision aids can support the process of shared decision making by complementing, rather than replacing, a clinicians' counselling

about the options available. The IPDAS describe that generally, a decision aid will: "1) explicitly state the decision being considered; 2) provide evidence-based information about a health condition, the options, associated benefits, harms, probabilities, and scientific uncertainties; and 3) help patients to recognize the values-sensitive nature of the decision and to clarify, either implicitly or explicitly, the value they place on the benefits and harms. (To accomplish this, patient decision aids may describe the options in enough detail that clients can imagine what it is like to experience the physical, emotional, and social effects, or they may guide clients to consider which benefits and harms are most important to them.)" In their guidelines on shared decision making, NICE recommends that healthcare professionals use patient decision aids to support shared decision making, alongside discussions on the risks and benefits of treatments available, within the context of what matters to them as an individual (National Institute for Health and Care Excellence 2021).

Decision aids appear to be effective in many different healthcare settings. Stacey et al (2017) conducted a Cochrane review of 105 randomised controlled trials (RCT) (31,043 participants) of the use of patient decision aids compared with usual care, published between 1983-2013. The review found that patient decision aid use was associated with a greater knowledge of options (70%) compared with usual care (57%). Significantly higher levels of accurate risk perceptions were made by patients who used a decision aid, compared with those who received usual care. Based on data from 17 studies (5096 participants), the ratio of accurate risk perceptions in those using a decision aid was 565 patients per 1000, compared with a ratio of 269 patients per 1000 in those receiving usual care. A greater likelihood of patients making decisions in line with their values was also found, with the ratio being 595 patients per 1000 in the decision aid group, compared with 289 patients per 1000 in the usual care group (based on 10 studies, totalling 4626 participants). Decision aid use was also found to decrease scores of decisional conflict relating to feeling uninformed and indecision about personal values. Additionally, of the patients using decision aids, less decisions were made by clinicians without patient participation (a ratio of 155 patients per 1000) compared with patients receiving usual care (a ratio of 228 patients per 1000), based on 16 studies totalling 3180 participants. Adverse effects such as anxiety or depression did not differ between groups.

1.8.1 Pregnancy decision aids

Studies that have developed and evaluated the use of decision aids in women with various health conditions (e.g. epilepsy, multiple sclerosis (MS) and rheumatoid arthritis) have had

promising results (Prunty et al. 2008; Meade et al. 2013; Meade et al. 2015; McGrath et al. 2017). Examples of decision aids relating to pregnancy in other medical contexts may be helpful to consider when developing a pregnancy planning guide for this project. In line with concerns that women at risk of perinatal mental illness have, these decision aids included information on medication, genetic risk and accessing support (Prunty et al. 2008; Meade et al. 2013; Meade et al. 2015; McGrath et al. 2017).

Prunty et al (2008) conducted a RCT of a decision aid designed for women with MS deciding whether to start or enlarge their families. One hundred and ninety-four women with MS were randomised to receive the decision aid or not. Participants were posted a copy of the decision aid and asked to use it for two weeks. A telephone interview after using the decision aid, as well as pre and post decision aid questionnaires, were used to measure women's views on having children, decisional conflict, self-efficacy, knowledge and mood symptoms. Scores of decisional conflict showed a significant decrease (signifying less uncertainty) after using the decision aid. There did not appear to be a difference in the direction of the decision on whether to have a child or not, suggesting that the decision aid was not biased towards a certain decision. Scores of knowledge and self-efficacy increased in those using the decision aid compared to the control group. Scores of anxiety and depression did not increase following the use of the decision aid, suggesting it did not cause distress.

In a similar study, Meade et al (2015) evaluated the use of an electronic decision aid for women with rheumatoid arthritis who were considering having children. As part of the RCT, 144 women were allocated to the intervention or a control group. Women were asked to use the decision aid for two weeks and complete pre and post intervention measures relating to decisional conflict, self-efficacy and knowledge on rheumatoid arthritis, pregnancy and parenting. Measures of mood were also taken before and after using the decision aid. As found in Prunty et al (2008), those using the decision aid showed an increase in relevant knowledge scores and a decrease in decisional conflict scores, compared to the control group. The decision aid was not associated with any increases in anxiety and depression scores, as in Prunty et al (2008).

A RCT of a decision aid for women with epilepsy who were considering having a child (McGrath et al. 2017), also found similar results to Prunty et al (2008) and Meade et al (2015) in relation to decision conflict, knowledge and depression and anxiety scores. The decision aid focused on the decision for women with epilepsy to start or enlarge their families. Seventy-nine participants were randomised to receive the decision aid (PDF booklet) or not,

and complete questionnaire measures pre and post intervention. Those receiving the decision aid showed greater improvements in knowledge about pregnancy and epilepsy, and reduced levels of decisional conflict compared to the control group. Decisions on having a child were not biased towards having a child, or not, and no adverse effects on depression or anxiety were found. Additionally, all participants who received the decision aid stated that they would recommend it to other women with epilepsy.

1.8.2 Perinatal mental health decision aids

One of the complex decisions that women at risk of severe mental illness make when considering having a child is whether or not to take medication during pregnancy. Broughton et al (2021) conducted a systematic review of decision aid use in women considering medication for a mental illness who were either pregnant or considering pregnancy. The review identified three eligible studies, including two RCTs involving women considering antidepressant use during pregnancy, and one non-randomised study involving women considering medication for the treatment of opioid use disorder (Guille et al. 2019; Khalifeh et al. 2019; Vigod et al. 2019). The decision aid in each of the three studies demonstrated good acceptability from participants (Guille et al. 2019; Khalifeh et al. 2019; Vigod et al. 2019).

The two RCTs also investigated participant knowledge, decisional conflict and depression and anxiety in participants (Khalifeh et al. 2019; Vigod et al. 2019). Vigod et al (2019) conducted a pilot RCT evaluating the use of an interactive web-based decision aid on antidepressant use in pregnancy. Participants were 96 women who had major depressive disorder, were planning a pregnancy or currently pregnant and had moderate to high levels of decisional conflict. Participants were recruited from a specialist setting (clinical care delivered by a psychiatrist specialising in the treatment of depression in pregnancy) (n=51) and a non-specialist setting (routine preconception care delivered by primary care / obstetrical providers) (n=45) and randomly allocated to receive the decision aid or an online information sheet including publicly available informational resources for four weeks. Decisional conflict levels were reduced in both the intervention and control group (signifying less uncertainty). There was a significant difference between decisional conflict scores found in the intervention and control group, however only for women recruited from a non-specialist setting. Decisional conflict scores were significantly reduced after four weeks in women receiving non-specialist care, but for women receiving care from a psychiatrist specialising in the treatment of depression in pregnancy, there was no significant difference. The decision

aid did not negatively affect anxiety and depression scores. Both those receiving the decision aid and the control intervention showed small, statistically significant increases in knowledge. Women viewed the decision aid positively, and the trial demonstrated the feasibility of a clinical trial protocol in terms of recruitment, acceptability and outcomes.

Khalifeh et al (2019) conducted a UK based pilot of Vigod et al's (2019) study, using an adapted version of the decision aid. Fifty-one women who were recommended an antidepressant for depression by their clinician, and were uncertain about antidepressant use while pregnant, were recruited via clinician or self-referral. Small increases in knowledge were found in the group using the decision aid, however this increase did not differ significantly from scores in the control group. Decreased levels of decisional conflict were found in both groups. There was a trend towards a larger reduction in decisional conflict scores in the intervention group compared to control, however as in Vigod et al (2019), there was no significant different between the groups. Supporting the results of Vigod et al (2019), the decision aid did not negatively affect anxiety and depression scores.

Patient acceptability and feasibility were primary outcomes in both Khalifeh et al (2019) and Vigod et al (2019). Acceptability in both studies were measured using an acceptability questionnaire comprising of qualitative and quantitative questions. Both studies had good acceptance rates, with 100% of participants finding the decision aid useful in Khalife et al (2019), and 82% in Vigod et al (2019). Both studies concluded that the study protocol was feasible, with successful methods of recruitment, high follow-up rates and acceptance, signifying the feasibility of conducting a larger scale trial.

1.8.3 Shared decision making, decision aids and equitable access to care

The literature presented on decision aids represents bias towards recruiting white, highly educated samples (Stacey et al. 2017b; Khalifeh et al. 2019; Vigod et al. 2019). It therefore leaves questions relating to how helpful decision aids may be in providing equitable care to all individuals. Vigod et al's (2019) study found that individuals without access to a psychiatrist specialising in depression treatment during pregnancy care appeared to benefit the most from using a decision aid, which represents a vast majority of women in many countries. Previous research has suggested that shared decision making interventions such as decision aids may help reduce health inequalities (Durand et al. 2014). For example, Durand et al (2014) conducted a systematic review and meta-analysis of 19 studies assessing the effect of shared decision making interventions on disadvantaged groups and / or health

inequalities. Overall, it was found that shared decision making interventions appeared to benefit individuals from disadvantaged groups (lower levels of literacy, education and socioeconomic status), compared to more privileged groups. The disparities between these groups before using the shared decision making interventions (i.e. lower levels of knowledge and self-efficacy, and higher levels of decisional conflict found in disadvantaged groups), narrowed post-intervention. Given the small sample sizes included in this study however, further research should seek to investigate this impact further. Additionally, given that an inclusion criterion for studies was that at least 50% of people from disadvantaged group were included, it may be that the interventions included had been specifically designed with the needs of disadvantaged patients in mind, which may not be representative of other shared decision making interventions in the literature.

1.9 Rapid review of the literature

As discussed above, women need better access to information that is tailored to their needs when planning a pregnancy. There is considerable disparity in the perinatal mental health services offered across the UK. The lack of access to mental health services during the perinatal period has been described as a "significant public health concern" in the UK (Smith et al. 2019). It therefore appears that women would benefit from accessible information to assist with planning and decision making during the pre-conception period and pregnancy.

To identify any studies that developed or evaluated the use of a planning or decision making guide, tool, aid or resource designed for women with bipolar disorder or previous postpartum psychosis to use when making plans or decisions during the perinatal period, a rapid literature review was conducted. The rapid review followed guidance from the Cochrane Rapid Reviews Methods Group (Garritty et al. 2020).

The Cochrane Rapid Reviews Methods Group define a rapid review as "A form of knowledge synthesis that accelerates the process of conducting a traditional systematic review through streamlining or omitting specific methods to produce evidence for stakeholders in a resource-efficient manner" (Garritty et al. 2020).

1.9.1 Selection criteria

The review aimed to include RCTs or pilot studies aimed at developing or evaluating a guide, tool, aid or resource designed to help women with bipolar disorder and / or previous postpartum psychosis with decision-making during the preconception and perinatal period.

This review aimed to consider studies of interventions that addressed whether to have a child or further children, and / or decisions relating to medication. Participants were required to have a diagnosis of bipolar disorder and / or a previous postpartum psychosis and be over 16 years old. The review did not include any exclusion criteria.

1.9.2 Search strategy

The databases Embase and Medline were searched from inception to 19 August 2021 using the search terms "mixed mania and depression" or bipolar mania or mania, hypomania, mania*.mp., puerperal psychosis, ((perinatal or postpartum or puerperal) adj2 psychosis).mp., exp pregnancy, pregnan*.mp., preconception.mp. or maternal care or prepregnancy care, motherhood.mp. or mother, perinatal.mp. or perinatal care or perinatal period, decision making.mp., (decision adj3 (patient or support or aid* or tool* or making or resource or guide*)).mp., exp Family Planning Services or planning.mp. or Health Planning (Appendix A). Potentially eligible studies were reviewed by the researcher. A specialist academic librarian at the School of Medicine, Cardiff University was consulted regarding the search strategy, which was deemed rigorous. The researcher did not restrict the search by language or publication status.

1.9.3 Results

The search identified 427 unique records and all titles and abstracts were reviewed. Figure 1.1 presents a flow diagram for study selection. All 427 records were excluded based on the inclusion criteria detailed above.
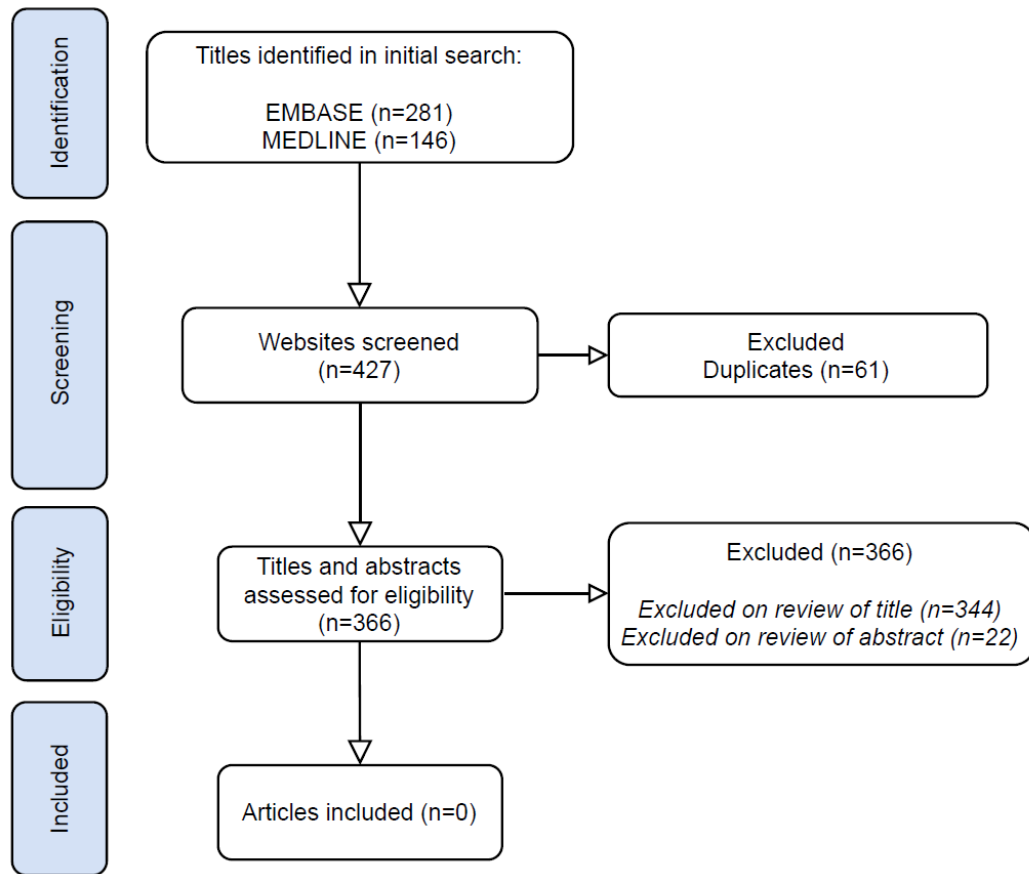
Figure 1.1 Flow diagram for study selection

As a result of the search not identifying any studies consistent with the criteria described above, it was decided that a review of freely available online information relating to bipolar disorder and pregnancy, and postpartum psychosis would be conducted. This was to develop an understanding of the online information currently available to women at risk of severe perinatal mental illness, presented in Chapter 2. This review also aimed to establish a basis for information to consider when developing the initial prototype of the guide, and to establish relevant, high-quality sources of information that the guide could signpost women to.

1.10 Summary

This chapter provided an overview of bipolar disorder, with a particular focus on the strong association between bipolar disorder and mental illness in relation to childbirth. Following this, a discussion on the management and prevention of relapse during the perinatal period was included, focusing on perinatal mental health care, and decision-making relating to medication. This chapter also provided an overview on current mental health care available

to women with severe perinatal mental illnesses. The chapter then described the information and support needs of women and concerns they have when planning a pregnancy, informed by qualitative studies within the literature. Finally, a rapid review of the literature was conducted, finding no studies on the development or evaluation of a guide, tool, aid or resource, designed to help women with bipolar disorder or previous postpartum psychosis with planning and decision making during the perinatal period. As a result, a review of online information was conducted and presented in Chapter 2.

1.11 Aims and structure of thesis

As discussed in this chapter, women with a diagnosis of bipolar disorder or previous postpartum psychosis are at high risk of experiencing severe mental illness relating to childbirth. As a result, these women face difficult decisions during this period. Previous research has shown that women at high risk of severe perinatal mental illness have great difficulty in obtaining the information they need relating to pregnancy and the postpartum period (Heron et al. 2012; Dolman et al. 2016). As described in this chapter, a rapid review of the literature found no studies investigating the development or use of a decision-making guide or aid for women with bipolar disorder or previous experience of postpartum psychosis to use when planning a pregnancy. This suggested the need for new research to inform the development of a pregnancy planning guide for women to use during the perinatal period.

This research had the following broad and specific aims:

Overarching aim:

To develop and test a pregnancy planning guide for women at risk of severe mental illness during the perinatal period.

Specific aims:

1. To determine the critical components of a pregnancy planning guide for women with lived experience of bipolar disorder and / or postpartum psychosis who are at high risk of severe perinatal mental illness.
2. To establish whether the guide is acceptable to women with lived experience of bipolar disorder and / or postpartum psychosis at high risk of severe perinatal mental illness.
3. To determine whether a further phase 2 RCT of the guide would be feasible.

This research involved co-producing a pregnancy planning guide for women at risk of severe mental illness during the perinatal period and women with lived experience of postpartum psychosis. Professional stakeholders with experience of working with women at risk of severe mental illness during childbirth were also included in the production of the guide. This involved the development and initial piloting of a guide, as outlined by the Medical Research Council (MRC) on developing and evaluating complex intervention (Craig et al. 2008) (see Chapter 3). As suggested by the MRC guidelines, these aims were addressed using a combination of qualitative and quantitative methods.

The critical components of a pregnancy planning guide for women with lived experience of bipolar disorder or postpartum psychosis were informed by the following: (i) An evaluation of freely available online resources for women at risk of severe mental illness surrounding childbirth (Chapter 2); (ii) Qualitative analysis of interview data from women with lived experience of bipolar disorder and / or postpartum psychosis who had experience of considering or planning a pregnancy and professional stakeholders within healthcare, research and perinatal settings (Chapter 4); (iii) Qualitative and quantitative feedback on a guide prototype during two pilot studies to refine the guide (Chapters 5 and 6). Further details on the procedure followed to inform the critical components of each guide prototype and the final version are included in Chapter 3.

Acceptability of the guide was investigated in the following ways: (i) Qualitative interview data from participants relating to their use of the guide during pilot one and pilot two (Chapters 5 and 6); (ii) Quantitative data from a bespoke acceptability measure completed by each participant after using the guide (see Chapter 3 for information on the development and contents of this measure); (iii) Information on attrition and participant flow during each pilot (Chapters 5 and 6).

The feasibility of conducting this research on a larger scale as part of a phase 2 RCT of the guide was assessed in the following ways:

(i)   Information on whether recruitment targets were met in each stage of the project (development, pilot one and pilot two)

(ii)   Information on the sampling strategy and whether this was successful in reaching its aims relating to having representation from women with varying diagnoses, lived experiences, age, ethnicity and level of education (sampling strategy discussed in Chapter 3).

(iii)   Information on attrition and patient flow during each pilot to inform a larger scale project (Chapters 5 and 6, with further discussion in Chapter 7). Specifically, this looked at women who consented, but did not take part, exploring possible reasons for this. This also looked at missing data resulting from drop-out at the stage of completing post-guide outcome measures.

(iv)   Information on the acceptability of the guide, assessed by the qualitative and quantitative measures, as described below. The optimal outcome was that the guide was acceptable to women in terms of its contents, presentation and format and that women found it helpful, signified by qualitative interview responses and quantitative findings from the bespoke acceptability measure.

Chapter 2 Evaluation of online information

2.1 Overview

The internet has become an increasingly accessible source of information for individuals seeking health information. As discussed in Chapter 1, previous qualitative research has highlighted the importance of the internet as a source of information for women at risk of severe perinatal mental illness (Heron et al. 2012; Dolman et al. 2016). However there is little research in the area evaluating the availability, content and quality of online information available to these women. An evaluation of online information relating to bipolar disorder, pregnancy and postpartum psychosis was conducted as part of the development stage of this project. The decision was made to conduct a review of online information available to women due the lack of academic evidence to inform the development of the guide. The specific objectives for this evaluation were: (i) to develop an understanding of the online information currently available to women; (ii) to establish a basis for information to consider when developing the initial prototype of the guide; and (iii) to establish relevant, high-quality sources of information that the guide could signpost women to.

This chapter begins by providing a background on the internet as a resource for health information and relevant research conducted in the field. This will be followed by a description of the methodology used in this chapter, and the results and discussion of the evaluation of online information.

2.2 Introduction

2.2.1 The internet as a source for health information

With continual access to the internet via smartphones and other devices, consulting the internet for health information has become easier than ever before. The Office for National Statistics report on internet usage in the UK (Office for National Statistics 2019) found that the proportion of adults looking for health-related information grew from 54% in 2018 to 63% in 2019. Using the internet as a health information resource is empowering, helping individuals to take a more active role in decision making and planning with their healthcare professionals (Synnot et al. 2016). Individuals are sourcing their own information on the internet alongside their healthcare appointments (Higgins et al. 2011; Tan and Goonawardene 2017). In many cases, health information sought online by patients is not intended to replace advice from healthcare professionals, but rather, to support it. In a

qualitative study on patients' views of the effect of the Internet on their relationship with doctors, the internet was seen as a supplementary source of information that supported the therapeutic relationship and also a way of expanding on information sought from healthcare appointments (Stevenson et al. 2007). Other reasons for consulting the internet include preparing for appointments and facilitating discussions with the healthcare professional (Ybarra and Suman 2008; Riel et al. 2017).

Studies show that women use the internet to access health information more frequently than men (Andreassen et al. 2007; Bidmon and Terlutter 2015). In line with these findings, UK data shows that women are more likely than men to look for online health-related information, with 68% of women reporting to have looked for information online, compared with 59% of men (Office for National Statistics, 2019).

2.2.2 Barriers to accessing specialist perinatal mental health care

As described in Chapter 1, the lack of access to mental health services during the perinatal period has been described as a 'significant public health concern' in the UK (Smith et al. 2019). Considering this, the option of consulting online information is likely to be one of the very few, if not only option for many women at risk of severe mental illness when considering pregnancy. While investment in specialist services and public health interventions have been made recently (GOV.UK 2016; Welsh Government 2016), there is still more to be done to reduce the 'postcode lottery' of services across the UK (Fernandez Turienzo et al. 2021). The internet provides a convenient and accessible way to access health information for many people, regardless of geographical location.

Additionally, women may not ask for the help or treatment they need due to the fear of their baby being taken away. In 2014, it was reported that 30% of women reported never having told a health professional that they felt unwell with their mental health due to the fear that their baby would be taken away (Boots Family Trust. 2013, cited in Bauer et al. 2014). Qualitative studies describe how some women waited until crisis point before disclosing their struggles with mental illness as a result of this fear and stigma associated with diagnostic labels (Hall 2006; Patel et al. 2013). The internet therefore, may provide women with easily accessible sources of information, while also retaining their anonymity.

2.2.3 Online information for women at risk of severe mental illness

A systematic review and meta-synthesis of qualitative literature examining experiences of motherhood and support for women with severe mental illness found that women have great difficulty in getting the information they need during the pre-conception and perinatal period (Heron et al. 2012; Dolman et al. 2013; Dolman et al. 2016). Qualitative studies on women's information needs and decision making have found that women consult the internet for information relating to pregnancy and recovery from a severe episode of perinatal mental illness (Heron et al. 2012; Dolman et al. 2016). However, this also comes with the risk of accessing unreliable, low-quality information. In some cases, online information has been described by women as being 'alarming' (Dolman et al. 2016). Previous research found that women encounter inaccurate accounts when searching for information on stopping or changing medication while pregnant, which has added to their fear and anxiety (Dolman et al. 2016). According to Heron et al (2012), women who had searched for information on postpartum psychosis following their own experience had come across unhelpful information, including tragic real-life stories relating to divorce, suicide and infanticide. Women expressed that they wanted "censored and sanitised information aimed specifically at recovering women" (Heron et al. 2012).

Previous research has evaluated online information relating specifically to postnatal depression (Summers and Logsdon 2005) and postnatal anxiety (Heringhausen and Montgomery 2002; Kirby et al. 2018). Kirby et al (2018) conducted a search of websites including information on perinatal anxiety and evaluated their quality, usability and readability. They found that the 20 websites included in the analysis had highly variable reading level scores, with only two websites falling within the recommended reading grade level for health information (Hutchinson et al. 2016). Scores also indicated poor usability and quality, with websites missing key indicators of quality, such as, clearly presented dates of publication and the sources of information. Moore and Ayers (2011) conducted a review of online information on postnatal mental illnesses more broadly, conducting a search on the following terms using four search engines: "postnatal depression", "postnatal illness", "postpartum depression" and "postpartum illness". This study found that over 75% of websites reported nine or more symptoms, with the most frequently mentioned being depressive symptoms, tearfulness and sleep disturbances. The study reported that there were markedly fewer instances of postpartum psychosis symptoms mentioned (Moore and Ayers 2011). As discussed in Chapter 1, women with bipolar disorder or previous postpartum

psychosis are at high risk of experiencing severe mental illness such as postpartum psychosis during the perinatal period. It is unclear whether internet searches more tailored to women with bipolar disorder and / or previous postpartum psychosis may have resulted in additional information relevant to severe perinatal mental illnesses.

Given the lack of research in evaluating online information relating to severe perinatal mental illness, along with the importance of the internet as a resource for women with bipolar disorder, this chapter aims evaluate the content, quality and readability of online information freely available to women at risk of severe mental illness.

2.3 Method

2.3.1 Data collection

The methodology was chosen to replicate the way individuals search for online health information. The majority of people (65%) begin their search for online health information using a search engine, compared to 27% who begin their search using a health-related website (Fox 2006). Google is the most popular search engine in the UK, having 93.42% of the search engine market share between May 2020 and May 2021 (Statcounter Global Stats 2021). In line with previous research where short and specific search term phrases were used (Moore and Ayers 2011; Lindley et al. 2012), "bipolar and pregnancy" and "postpartum psychosis" were searched for, using Google search engine. Two searches ("bipolar and pregnancy" and "postpartum psychosis") were initially conducted on the 5th December 2019. An updated search was conducted on 14th April 2021.

The first 30 websites identified in both searches were selected for screening (n=60). Inclusion and exclusion criteria were applied to each website. Websites in the analysis included content relating to bipolar disorder and pregnancy, and / or perinatal mental health illnesses. The evaluation excluded any websites that were directed at healthcare professionals. Advertisements (for example, for products or research projects), online retailers, academic journals, videos, newspaper or magazine articles and national guidelines were excluded. Webpages including less than 300 words were also excluded (an example of this would be a page with a single definition). For each website included in the evaluation, the webpage returned in the search result, along with a maximum of three internal links included on the webpage, were analysed. Internal links were selected according to their relevancy to the topics "bipolar and pregnancy" or "postpartum psychosis". Duplicate websites were

excluded, unless the search engine returned unique webpages for each search return (for example, a large website such as the NHS may appear twice in the results, but include unique webpages). For each website, information was collected on the type of organisation (public sector, private, or non-profit organisation) and country of origin.

2.3.2 Data analysis

Descriptive statistics such as frequency, mean and standard deviation were calculated using Microsoft Office Excel (for Microsoft 365) for data on website content, quality and readability.

2.3.2.1 CONTENT ANALYSIS

Content analysis is a method used frequently for studying public health communication (Kreps and Maibach 2008). Content analysis methodology has been used previously to assess the content and availability of online health information available to the general public and healthcare professionals (Friedman et al. 2006; Friedman et al. 2008; Moore and Ayers 2011; Lindley et al. 2012; Kirby et al. 2018). Content analysis provides a systematic, rigorous approach to analysing online health information and is flexible in that it can be applied qualitatively or quantitatively (White and Marsh 2006).

This evaluation adopted a quantitative, deductive approach by developing a coding checklist prior to analysis (Appendix B). Rourke and Anderson (2004) define quantitative content analysis as a methodology where researchers "systematically identify, categorize, and count the objective elements of communication and provide audiences with a summary of this data". A bespoke coding checklist was devised to assess each website for content relating to planning a pregnancy for women at high risk of postpartum psychosis. The coding checklist followed a similar structure to that included in previous research (Moore and Ayers 2011). The coding checklist was devised based on a review of relevant literature and discussions with the project supervisory team (Jones et al. 2014; Dolman et al. 2016). The coding checklist was applied to each website, with the goal of quantifying the frequency of occurrences of each code within the search results. The presence of each code was counted once per search result. The coding checklist included seven general topics: (1) Signs and symptoms, (2) Risk (for example, previous experience of mental illness), (3) Medication, (4) Treatment, (5) Support, (6) Other and (7) Additional information. Each topic included a number of specific codes, totalling 29.

Website quality was assessed using the Journal of the American Medical Association (JAMA) benchmarks, a quality assessment tool designed to evaluate basic quality standards of online healthcare information (Silberg et al. 1997). The JAMA benchmarks has been used to assess the quality of online health information in several other areas, including breast cancer, child anxiety and lupus erythematosus (Nghiem et al. 2016; Reynolds et al. 2018; Murray et al. 2019). The tool uses four key features to evaluate websites: (1) Authorship, (2) Attributions, (3) Disclosure, and (4) Currency. To be awarded a point for each feature, a website must (1) state who the authors and contributors of the information are, including any affiliations and qualifications (Authorship); (2) clearly reference content included (Attribution); (3) clearly present any potential conflict of interest, for example, relating to sponsorship, advertising or website ownership (Disclosure); and (4) include dates of when content was uploaded or updated (Currency).The JAMA benchmarks are scored between 0-4 points, involving a point being awarded for each key feature clearly visible in a website, with 0 representing a poor quality website, and 4 representing a high quality website.

2.3.2.3 READING LEVEL

Reading difficulty level of websites was assessed using the readability measuring tools Flesch Reading Ease (FRE) Scale and Flesch-Kincaid (FK) grade level formula (Flesch 1948; Kincaid et al. 1975). The FRE and FK grade level formula are validated and commonly used readability tools used to assess the readability of health content in previous research (Lindley et al. 2012; Kirby et al. 2018). Previous research evaluating health information have found the FK grade level tool to be reliable and valid (Wang et al. 2013). The recommended level that health information should be written at is US school grade 6-8 reading level, equivalent to school year 7-9 in the UK (Hutchinson et al. 2016).

The FRE ranges from 100 (very easy to read) to 0 (very difficult) and considers the relationship of average sentence length compared to the average number of syllables per word or syllables per 100 words. The FK grade level is a modified version of the FRE, which generates reading grade level based on word and sentence length. The result is a number that corresponds with a US education grade level. Table 2.1 presents FRE and FK grade level score, including the UK age and school year equivalent for each readability level (very easy – very difficult). FRE and FK grade level scores were generated using Microsoft Word (for Microsoft

365). Readability scores were based on formulas that account for average sentence length and average syllables per word.

Reading difficulty	Flesch reading ease (FRE) score	Flesch-Kincaid (FK) grade level score	UK equivalent age / school year
Very easy	90-100	5	10-11 (Year 6)
Easy	80-90	6	11-12 (Year 7)
Fairly easy	70-80	7	12-13 (Year 8)
Standard	60-70	8 – 9	13-15 (Year 9/10)
Fairly difficult	50-60	10 – 12	15-18 (Year 11/13)
Difficult	30-50	13 – 16	University
Very difficult	0-30	≥College graduate	≥University graduate

Table 2.1 Flesch reading ease (FRE) and Flesch-Kincaid (FK) grade level scores

2.4 Results

Sixty websites were identified using "bipolar pregnancy" and "postpartum psychosis" as search terms on Google search engine. As presented in Figure 2.1, after applying exclusion criteria, a total of 36 websites were included for analysis. Websites excluded were academic journals (n=9), newspaper or online magazine articles (n=6), duplicates (n=4), resources aimed at healthcare professionals (n=3), national guidelines (n=1) and a webpage including non-relevant content (n=1). Figure 2.1 presents a flow diagram for websites selected for analysis.

The NHS website was identified in the search results three times, however each entry provided different webpages (and associated webpages). As the aim of the analysis was to assess the content and availability of information for women when planning a pregnancy, rather than evaluating individual websites, all webpages were included in the analysis.
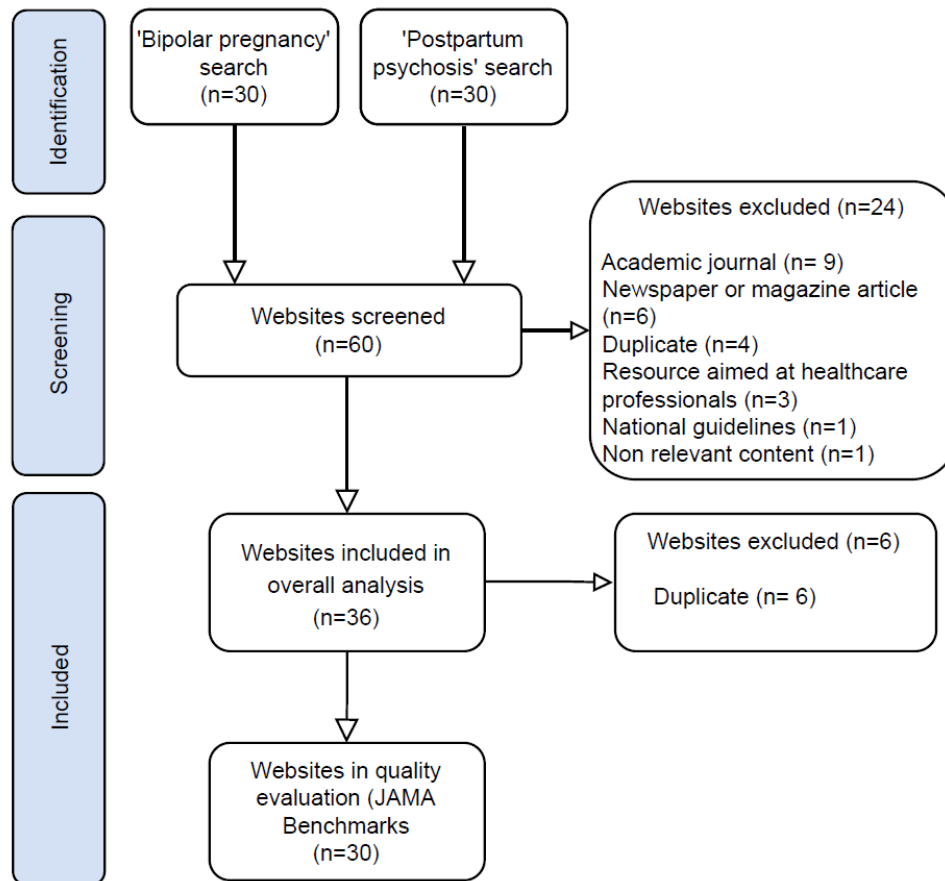
Figure 2.1 Study flow diagram

2.4.1 Website characteristics

Of the 36 websites included in the analysis, 50.0% (18/36) originated in the UK. Of the 50.0% originating outside of the UK, 33.3% (12/36) originated in the USA, 11.1% (4/36) in Australia, 2.8% (1/36) in Spain and 2.8% (1/36) in the Republic of Ireland. The majority of websites were non-profit organisations (41.7% / 15/36), followed by public sector (38.9% / 14/36) and commercial or private organisations (19.4% / 7/36).

2.4.2 Content analysis

Websites were coded for information presented on topics falling within the following categories: (1) Signs and symptoms, (2) Risk (for example, previous experience of mental health), (3) Medication, (4) Treatment, (5) Support, (6) Other and (7) Additional information. The additional category included codes not defined by their content. Table 2.2 below presents the percentage of websites that mention each topic included in the coding checklist. The number and percentage of websites including information on each topic is presented for

all websites (n=36), and for each affiliation: public sector (n=14), non-profit (n=15), and private (n=7).

Category	Topic	Total (n=36) (%)	Public sector (n=14) (%)	Non-profit (n=15) (%)	Private (n=7) (%)
			Affiliation		
Signs and symptoms	Postpartum psychosis	25 (69.44%)	9 (64.29%)	10 (66.67%)	6 (85.71%)
	Postnatal depression / baby blues / high moods	22 (61.11%)	8 (57.14%)	10 (66.67%)	4 (57.14%)
Individualised risk	Risk factors for postpartum psychosis	23 (63.89%)	8 (88.89%)	11 (73.33%)	4 (57.14%)
	Risk factors for other perinatal mental health episodes	16 (44.44%)	8 (88.89%)	6 (40.00%)	2 (28.75%)
	Individualised risk of becoming unwell	20 (55.56%)	4 (28.57%)	9 (60.00%)	7 (100.00%)
Medication	Stopping / switching medication when trying for a baby or when becoming pregnant	19 (52.78%)	7 (50.00%)	8 (53.33%)	4 (57.14%)
	Taking medication during pregnancy	19 (52.78%)	6 (42.86%)	10 (66.67%)	3 (42.86%)
	Medication and breastfeeding	20 (55.56%)	7 (50.00%)	9 (60.00%)	4 (57.14%)
	Medication in the postpartum period	20 (55.56%)	7 (50.00%)	10 (66.67%)	3 (42.86%)
	Uncertainty surrounding evidence on medication and pregnancy	8 (22.22%)	4 (28.57%)	2 (13.33%)	2 (28.57%)
	Teratogenic effects	19 (52.78%)	6 (42.86%)	8 (53.33%)	5 (71.43%)
	Risk of stopping medication	18 (50.00%)	6 (42.86%)	9 (60.00%)	3 (42.86%)
Treatment	Mother and Baby Unit (MBU)	16 (44.44%)	5 (35.71%)	9 (60.00%)	2 (28.57%)

		All	Public	Non-profit	Private
	Psychological treatment	16 (44.44%)	5 (35.71%)	8 (53.33%)	3 (42.86%)
	Electroconvulsive therapy (ECT)	13 (36.11%)	5 (35.71%)	4 (26.67%)	4 (57.14%)
	General inpatient admission	8 (22.22%)	2 (14.29%)	5 (33.33%)	1 (14.29%)
Support	Seeking professional help (e.g. encouraging women to do this, emphasising the importance of this)	28 (77.78%)	13 (92.86%)	12 (80.00%)	4 (57.14%)
	How to seek professional specialist perinatal support	25 (69.44%)	10 (71.43%)	12 (80.00%)	3 (42.86%)
	Support network	19 (52.78%)	5 (35.71%)	12 (80.00%)	2 (28.57%)
	Social services	8 (22.22%)	1 (7.14%)	6 (40.00%)	1 (14.29%)
Other	Self-management and lifestyle	16 (44.44%)	6 (42.86%)	9 (60.00%)	1 (14.29%)
	Sleep	14 (38.89%)	4 (28.57%)	8 (53.33%)	2 (28.57%)
	Genetic risk of bipolar	13 (36.11%)	5 (35.71%)	5 (33.33%)	3 (42.86%)
	Recovery from postpartum psychosis / perinatal mental health	12 (33.33%)	4 (28.57%)	5 (33.33%)	3 (42.86%)
	Parenting with bipolar disorder	4 (11.11%)	0 (0.00%)	3 (20.00%)	1 (14.29%)
	Making plans for perinatal period e.g. care plans, forward directives	17 (47.22%)	7 (50.00%)	8 (53.33%)	2 (28.57%)

Table 2.2 Website content included in all websites, and according to affiliation (public sector, non-profit and private)

The most common topic included in the evaluation related to postpartum psychosis symptoms (69.44%) (Appendix C). Information for symptoms for other perinatal mental

illnesses or the baby blues was the second most common topic (61.11%). Following these topics, information relating to the individualised risk of becoming unwell (55.56%) and information relating to taking medication during the perinatal period (52.78-55.56%) were the most common. Of the websites that included information relating to medication, the majority also covered the risk of teratogenic effects (52.78%), and the risk that stopping medication may have on the mother and child (50%). Considerably fewer websites referred to uncertain evidence relating to medication and pregnancy (22.22%). Information on Mother and Baby Units (MBU) was covered in less than half of the websites (44.44%), and general inpatient admissions, and social services, were covered in less than a quarter (22.22% for both topics). The topic covered in the least number of websites was parenting for women with bipolar disorder, which was only covered in 11.11% of websites.

The evaluation also coded each website for the inclusion of stories from women with lived experience of bipolar disorder / postpartum psychosis; information for partners, family, friends and carers; and signposting to other relevant information (presented in Table 2.3). Stories from women with lived experience was included in 27.78% (10/36) of websites, with the prevalence being the highest in non-profit organisation websites. Over half of all non-profit websites included stories from women with lived experience (8/15, 53.33%). Information for partners, family, friends and carers was poorly represented in the websites, only included in 19.44% (7/36) of the websites overall. Sixty percent (9/15) of non-profit websites signposted to other sources of information, which was the highest percentage amongst the three affiliations. Public sector websites included less signposting, with only one private websites out of seven (14.29%) including any signposting to other relevant information.

		Affiliation			
Additional information		Total (n=36) (%)	Public sector (n=14) (%)	Non-profit (n=15) (%)	Private (n=7) (%)
	Stories from women with lived experience of bipolar disorder / postpartum psychosis	10 (27.78%)	1 (7.14%)	8 (53.33%)	1 (14.29%)
	Information for partners, family, friends, carers	7 (19.44%)	4 (28.57%)	3 (20.00%)	0 (0.00%)

Signposting to other relevant information	16 (44.44%)	6 (42.86%)	9 (60.00%)	1 (14.29%)

Table 2.3 Additional information included in the evaluation of each website, according to total websites and each affiliation (public sector, non-profit and private)

The number of coding checklist items covered by each website varied considerably (see Table 2.4). The majority of websites included less than half of the topics (22/36), with eight websites scoring within the 0-24.99% range (percentage of codes included), and 14 websites within the 25.00-49.99% range. Fourteen websites coded for over 50% of topics, four of which for over 75% of topics. No website achieved higher than 83%.

Number of codes included (%)	Of total websites (n=36)
0-24.99%	8
25.00-49.99%	14
50.00-74.99%	10
75.00-100%	4

Table 2.4 Percentage (%) of codes included in each website

Websites mentioning over 75% of items from the coding checklist were: Royal College of Psychiatrists (24/29, 82.76%); Action on Postpartum Psychosis (APP) (24/29, 82.76%); Tommy's (23/29, 79.31%), and Bipolar UK (23/29, 79.31%). All those mentioning over 75% of codes were non-profit organisations, located in the UK. Those scoring less than 25% of codes were: Mayo clinic (5/29, 17.24%); Health and Safety Executive (HSE) (5/29, 17.24%); and NHS inform (6/29, 20.69%). These websites belonged to a non-profit organisation (n=1) located in America, and the public sector (n=2), based in Scotland, UK, and the Republic of Ireland.

2.4.3 Website readability

Reading difficulty level of websites was assessed using the FRE and FK grade level formula (Flesch 1948; Kincaid et al. 1975). As presented in Table 2.5, the average FRE score for all websites was 48 (SD = 13.3, range 14.3 – 73.5), reflecting an average "difficult" reading level and difficulty ranging from "fairly easy" to "very difficult" across websites. The average FK grade level score for all websites was 10.80 (SD = 2.5, range 6.5 – 18.2), reflecting an average "fairly difficult" reading level and difficulty ranging from "easy" to "very difficult".

	FRE mean	*FRE SD*	FK grade level mean	*FK grade level SD*
Total	48	*10.8*	13.3	*2.5*
Non-profit	49.7	*14.1*	10.5	*2.5*
Public sector	43.2	*14.8*	12.0	*3.1*
Private	48.5	*12.0*	10.4	*2.0*

Table 2.5 Flesch Reading Ease (FRE) Scale and Flesch-Kincaid (FK) grade level formula mean and standard deviation (SD) for all websites and according to affiliation (non-profit, public sector and private)

As discussed above, the recommended level for online health information is equivalent to school year 7-9 in the UK (Hutchinson et al. 2016). FRE scores within the recommended level for online health information would be between 60-90. Six websites (5 non-profit, 1 public sector) website scored within this range. FK grade level scores within the recommended level would be between 6-9. Ten websites (6 non-profit, 3 public sector, and 1 private) scored within this range. The website scoring as the most readable according to the FRE and FK grade level measure was the NHS inform website (Scottish health service), scoring within the "easy" (FK grade level score) and "fairly easy" (FRE score) ranges. The website scoring as the least readable on both the FRE and FK grade level measure was The Mental Elf website, scoring within the "very difficult" range for both measures.

2.4.4 Quality

An evaluation on quality was conducted on the 30 unique websites included in the study. Websites appearing more than once in the evaluation are not presented below, as the JAMA Benchmarks criteria assesses quality according to the website as a whole, rather than a sample of the website. Of the 30 websites included, five websites reached all four criteria of the JAMA benchmarks, eight reached three criteria, 12 reached two criteria, four reached one criterion, and one reached none of the four criteria (Appendix D). As shown in Table 2.6, the criterion 'Disclosure' was reached by the most websites (86.7% of websites), and 'Attribution' was reached by the least number of websites (36.7% of websites).

JAMA Benchmarks criteria	n	Percentage of Websites Adhering to Principle
Authorship	19	63.3%

Attribution	11	36.7%
Disclosure	26	86.7%
Currency	18	60.0%

Table 2.6 Journal of the American Medical Association (JAMA) Benchmarks criteria

As presented in Table 2.7, only five websites were awarded all four JAMA Benchmark criteria. The majority of websites scored two or less criterion (17/30), with one website scoring zero.

JAMA Benchmarks criteria: number of criteria awarded	Number of websites (n=30)
0	1
1	4
2	12
3	8
4	5

Table 2.7: Websites presented according to the number of Journal of the American Medical Association (JAMA) Benchmarks criteria awarded (0-4)

2.5 Discussion

The aim of this review was to evaluate the content, quality and readability level of online information freely available to women at risk of severe mental illness. A key strength of this research is that no studies have previously evaluated online information available, focusing specifically on severe perinatal mental health. It also offered an update on a previous study looking into the availability and quality of online information on perinatal mental health more generally (Moore and Ayers 2011).

The review identified and evaluated 36 websites for content, quality and readability. It was found that the number of topics covered, and the quality and readability level of each website varied greatly. Most websites had a reading level above the recommended level for health information meaning that many people may struggle to read the information provided (Hutchinson et al. 2016). In line with previous research, the most common topic covered by the websites were the symptoms of postpartum psychosis and of perinatal mental illness more generally (Moore and Ayers 2011). While many of the websites in this evaluation included information on a number of topics, some of which were of good quality, no one

website provided women with information on all of the topics included in the coding checklist.

Two websites that consistently scored within the top websites for quality, content and readability, were Tommy's (tommys.org) and The Royal College of Psychiatrists (rcpsych.ac.uk). Both of these websites included over 75% of the topics included in the coding checklist, scored on all four JAMA benchmark quality criteria and scored within the "standard" range for readability, within the recommended range for online information (Hutchinson et al. 2016). Non-profit organisation websites scored well overall in this review. Non-profit websites which generally scored well, but scored lower on the JAMA benchmark criteria (suggesting lower quality), were APP, Bipolar UK, and Mind. Reasons for scoring lower on the quality criteria was due to a lack of detail relating to the sources the content was based on, and a lack of dates for when the information was uploaded or updated on the website. The lack of references could however have been a conscious decision made by these organisations, in an effort to make the information as lay person friendly as possible. It could be argued that, considering that much of the content is likely to be based on research articles (for example, genetic risk of bipolar disorder), providing this level of information may be an information-overload for some women.

2.5.1 Strengths and limitations

One key limitation of this evaluation is that the internet and the contents of websites are constantly evolving, and the results of a Google search is likely to depend on numerous factors. For example, results could vary according to the date the search was conducted, the individual's location and search history. The internet is constantly evolving, meaning that the relevant websites may already have changed since conducting this evaluation. It is therefore likely that the search results presented in this chapter may differ from the results that a women may now find. Search terms used for this evaluation were specific and were based on similar search terms used in other studies (Friedman et al. 2006; Moore and Ayers 2011; Lindley et al. 2012). No studies, however, have investigated what search terms the public use when searching for information online. Future research could conduct a survey to determine what search terms are most likely to be used by women who are at risk of severe perinatal mental illness seeking online information. This may better reflect women's true online information search behaviour.

Excluding academic journals and resources aimed at healthcare professionals from the evaluation may be a limitation. The decision was made to exclude these as this study aimed to evaluate information aimed at women, however it may be that some women do indeed access information from these sources. Another limitation was that although the final analysis included 36 websites, it is likely that there are others with information on severe perinatal mental illness that were not evaluated. Additionally, only a sample of webpages were coded using the coding checklist for each website, rather than the website as a whole. It is therefore possible that further exploration into the website may have resulted in additional topics being coded. This method was used as way to conduct a more realistic replication of how women at high risk of severe perinatal mental illness may search for online information. It was felt that women who use search engines, rather than beginning their search with a specific website in mind, would be likely to look at relevant webpages from several different websites.

A strength of the search engine method used was that the majority of people conduct a search in this way when searching for online health information (Fox 2006). However considering that 27% of individuals begin their search using a specific health-related website when looking for online health information, this study did not account for this (Fox 2006). The search was conducted on just one search engine (Google), but it is the most popular search engine in the UK and this procedure is in line with other studies who have only included search results from Google (Cerminara et al. 2014; Reynolds et al. 2015; Kirby et al. 2018). Fifty percent of websites (18/36) in this project originated in the UK, which may have been biased by the search terms used. For example, individuals in other countries may be more inclined to use different terms for "postpartum psychosis", such as "puerperal psychosis" or "postnatal psychosis". Another limitation was that all coding and quality ratings were conducted by one researcher. To increase reliability, a proportion of the results could have been coded by another research, and coding compared for reliability purposes.

2.6 Conclusions

This study provides the first evaluation of online information for women with bipolar disorder and / or previous postpartum psychosis who are considering a pregnancy or currently pregnant. The 36 websites included were found to vary greatly in their level of quality, reading difficulty and the number topics covered according to the coding checklist developed for this project. While some websites scored consistently well across measures, no websites included information on all topics included in the coding checklist. This highlights

a need for a high-quality, accessible resource for women with all of the information they need in one place.

These findings highlighted key resources currently available for women with bipolar disorder and / or previous postpartum psychosis who are considering or planning a pregnancy. This chapter helped to identify informative and trustworthy resources that were used to assist with the development of the initial prototype of the guide prior to piloting. A number of websites identified in this evaluation were informative, of high quality, and written in accessible language, which provided this project with a number of resources to signpost women to in the pregnancy planning guide developed as part of this project.

Chapter 3 Method

3.1 Overview

As described in Chapter 1, the broad aim of this project was to develop and pilot test a pregnancy planning guide for women at risk of severe mental illness during the perinatal period. The specific aims of the project were 1) to determine the critical components of the guide; 2) to determine its acceptability to women; and 3) to determine the feasibility of carrying out a phase 2 randomised controlled trial (RCT) of the guide.

The procedure followed Medical Research Council (MRC) Guidance on developing and evaluating complex interventions (Craig et al. 2008). This chapter will firstly summarise the MRC guidance on developing and evaluating a complex intervention and demonstrate how it was incorporated into this project. It will then provide information on the overall procedure, providing information on recruitment, sampling strategy and data analysis used in the project overall. Finally, information specific to each stage (development, pilot one and pilot two, summarised in Figure 3.2) will be discussed in turn. Information on sample characteristics and participant flow specific to each stage of the project, is described in subsequent results chapters (Chapters 5 and 6).

3.2 MRC guidance for the development of a complex intervention

The MRC guidance on developing and evaluating complex interventions includes advice on developing, piloting, evaluating, reporting, and implementing a complex intervention. The MRC describes complex interventions as interventions with several interacting components, which can have a variety of outcomes (Craig et al. 2008). An intervention can be considered 'complex' if a variety of outcomes are expected, and the use of the intervention requires a degree of flexibility (Craig et al. 2008). The framework was first published in 2000, and later updated in 2008 to reflect developments in methodological techniques and to address limitations.

Feasibility / Piloting
1 Testing procedures
2 Estimating recruitment / retention

Development
1 Identifying the evidence base
2 Identifying / developing theory
3 Modelling process and outcomes

Evaluation
1 Assessing effectiveness
2 Understanding change process

Implementation
1 Dissemination
2 Surveillance and monitoring
3 Long term follow-up
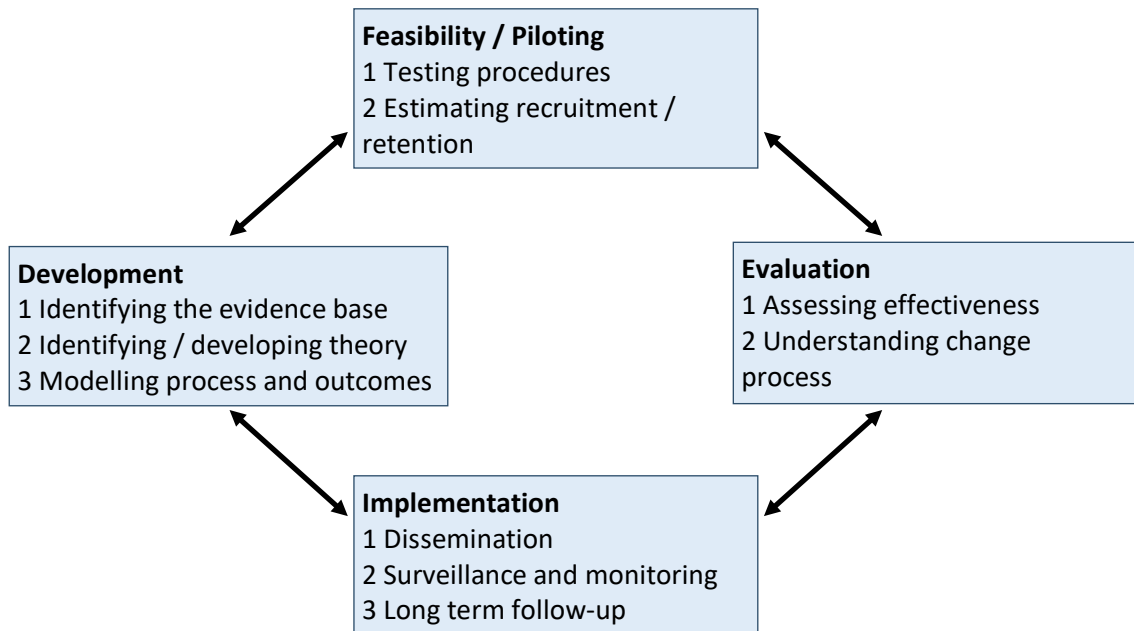
Figure 3.1 The MRC framework (Craig et al. 2008) for development of a complex intervention, detailing the four key stages for developing and evaluating an intervention. The arrows indicate the main interactions between each phase.

As shown in the framework in Figure 3.1, there are four stages included in the MRC framework: Development, Feasibility / Piloting, Evaluation and Implementation. When developing a complex intervention, the MRC strongly recommends that initial development and piloting work is conducted before a larger scale RCT. This project therefore carried out the steps outlined within the initial key elements 'Development' and 'Feasibility / Piloting', with the aim of informing a later RCT of the guide.

3.2.1 Development

Once an idea for a complex intervention has been identified, the MRC framework states that the steps outlined within the development phase should be carried out before formal pilot testing of the intervention begins. The steps involved in the development phase are outlined below, including information on their incorporation into this project.

3.2.1.1 IDENTIFYING THE EVIDENCE BASE

The initial step within the development phase is to identify the relevant, existing evidence base, ideally by conducting a systematic review. For this project, a rapid review of the literature was undertaken to identify and examine studies looking into the development or use of a pregnancy planning guide or decision tool for women with bipolar disorder or

previous postpartum psychosis. The search strategy implemented for the rapid review identified no studies looking into the development or evaluation of a guide or decision aid of this kind.

Qualitative studies on the decision making and information needs of women with bipolar disorder have found that women consult the internet for information relating to pregnancy and recovery from a severe episode of perinatal mental illness (Heron et al. 2012; Dolman et al. 2016). Due to the lack of academic evidence to inform the development of the guide, the decision was made to conduct a review of online information available to women planning a high risk pregnancy (Chapter 2). This investigated the content, quality and readability level of the online information currently available, which informed the development of the initial prototype of the guide.

3.2.1.2 IDENTIFYING / DEVELOPING APPROPRIATE THEORY

The development stage of the MRC framework suggests drawing on existing evidence and theory relating to the proposed intervention being developed (Craig et al. 2008). This can also be supplemented with novel research, such as qualitative interviews with 'stakeholders', i.e. those who may be targeted by the intervention or involved in its development or delivery (Craig et al. 2008). In addition to providing valuable input on specific elements of the initial prototype, the MRC recognises the inclusion of qualitative research as a beneficial way of involving individuals whom the intervention would target (Craig et al. 2008).

An advisory group of women with lived experience of bipolar disorder or postpartum psychosis was also formed to provide additional consultancy relating to the development of the guide, which is discussed in more detail below. The piloting phase which followed the development stage and how the MRC guidelines were implemented, is also discussed below (Craig et al. 2008).

3.2.2 Piloting and assessing feasibility

The MRC highlights the importance of piloting the intervention to gather feedback from participants, test acceptability and assess the feasibility of conducting a large-scale evaluation (Craig et al. 2008). Piloting provides the opportunity to examine the use of measures, procedures, rates of recruitment and retention of participants, all of which can help determine sample size and expected rates of recruitment and retention in future trials. A mixture of qualitative and quantitative methods is recommended to understand the

strengths and weaknesses of the intervention and any barriers to participating in trials or in using the intervention (Craig et al. 2008).

The key factors outlined in the piloting stage by the MRC guidelines are reflected in the specific aims of this project. These were to determine the critical components of the guide, to establish whether the guide is acceptable to women, and to determine whether a phase 2 RCT of the guide is feasible (discussed in Chapter 1).

This study involved two pilot studies, described in more detail later in this chapter. Feedback from participants via qualitative interviews and quantitative questionnaire measures during pilot one and pilot two informed refinements made to the guide prototype. Qualitative interviews and a bespoke acceptability measure provided information on the acceptability of the guide. The feasibility of conducting a larger scale study as part of a phase 2 RCT was assessed using information on recruitment, participant flow, attrition rates and qualitative responses from pilot one and pilot two. Information on the procedure followed for pilot one and pilot two are discussed in more detail later in this chapter.

3.3 Ethical Approval

The Wales Research Ethics Committee (REC) granted ethical approval for the study (19/WA/0142). The study had local Research and Development approval in Cardiff and Vale University Health Board (CVUHB) and was registered on the Health and Care Research Wales Portfolio.

3.4 Procedure overview

This study involved three stages: development, pilot one and pilot two (summarised in Figure 3.2). Data collected from women and professional stakeholders during the review of online information freely available to women (Chapter 2), were used to inform the content and presentation of the initial prototype of the guide that will be tested during pilot one.

Development stage

A review of online information available to women with lived experience of bipolar disorder and / or postpartum psychosis was conducted and informed the initial prototype of the guide (presented in Chapter 2).

Qualitative data from interviews with women with lived experience of bipolar disorder and / or postpartum psychosis and professional stakeholders involved in their care, during and after pregnancy further informed the initial prototype of the guide (presented in Chapter 4).

↓

Prototype one of the guide developed based on information collected during the Development stage (extracts presented in Chapter 4).

↓

Pilot one

Pilot one involved 8-12 women who were planning a pregnancy or currently pregnant, testing prototype one of the guide (inclusion criteria presented below). Brief assessment completed before testing the guide and a qualitative interview after testing the guide. Questionnaire measures were also completed before and after testing the guide.

Qualitative and quantitative results from pilot one were analysed and used to inform further refinement of the guide.

↓

Prototype two of the guide developed based on information collected during pilot one (extracts presented in Chapter 5).

↓

Pilot two

Pilot two followed the same procedure as pilot one.

Qualitative and quantitative results from pilot two were analysed and used to inform further refinement of the guide.

↓

Final prototype of the guide developed based on information collected during pilot two (Appendix O).

Figure 3.2 Flowchart summary of overall procedure of study

3.4.1 Recruitment

Approaches to identify and recruit women to take part in the three stages of the study included the following:

1. Via Action on Postpartum Psychosis (APP), a third sector patient support organisation collaborating in this current project.
   a. Via advertisements in their newsletter and social media (Appendix E). Approaches also included APP coordinators approaching those providing or receiving peer support within the organisation.
2. Via National Centre for Mental Health (NCMH), a Welsh Government funded Research Centre focusing on mental health, operated by Cardiff University, Swansea University and Bangor University, in collaboration with NHS Health Boards across Wales and NHS Trusts in England. The NCMH is an ongoing study of which Professor Ian Jones, the lead supervisor of this project, is the Director.
   a. Via advertisements on social media.
   b. Participants from a recent COVID study who met the inclusion criteria for this project were contacted via email and telephone.
3. Via Bipolar UK, a third sector patient support organisation collaborating in this current project.
   a. Information on the project provided to women during a break-out session 'Pregnancy and bipolar' held at the Bipolar UK conference 2019 and a webinar 'Bipolar, Pregnancy and Childbirth' (November 2020) held in collaboration with NCMH.
4. Via the Bipolar Education Programme Cymru (BEPC), a psychoeducation programme available to people diagnosed with bipolar disorder, over the age of 18 and living in Wales
   a. Information on the project provided to members of a BEPC course and flyers handed out (Appendix F).
   b. Via an advertisement in their newsletter.
5. Through CVUHB of NHS Wales.
   a. Via a clinical service offering pre-conception counselling to women with severe mental illness. Professor Ian Jones, lead supervisor of this project, is an Honorary Consultant Psychiatrist in CVUHB and clinical lead for the Cardiff University Psychiatry Service (CUPS) which offers this service.

      b.   I presented the project at the CVUHB perinatal community mental health team.

Participants identified via newsletters or social media were directed to a landing page (www.ncmh.info/prep) to fill out a brief online form asking for their name and contact details or were provided with my email address to contact directly. Participants identified in all other approaches listed were asked by a member of the research team or APP for their permission to be contacted with more information.

Participants were emailed with brief information about the project and asked for a convenient time for a telephone call to discuss the study in more detail and have an opportunity to ask any questions. Following this, I provided participants with an information sheet and consent form by post to provide written consent. For the development stage information sheet and consent form, see Appendix G and H, respectively. For the pilot study information sheet and consent form, see Appendix I and J, respectively.

In August 2020, during the COVID-19 pandemic, I obtained ethical approval to offer the option of consenting to the study remotely during a telephone / video call. This involved sending the information sheet and consent to participants via email. To obtain informed consent, I contacted the participant via telephone / video call and read each consent statement out verbatim and asked to participant to respond 'yes' or 'no' aloud. I then completed an electronic copy of the consent form as the participant responded. The conversation was audio recorded on an encrypted device and transcribed. A copy of the completed electronic consent form was sent to participants via email.

Professional stakeholders were recruited via word of mouth, including contacts known to the research team or to the professional stakeholders participating in the research. A snowball sampling strategy was also adopted, involving professional stakeholders identifying other individuals to take part in the project (Lewis-Beck et al. 2012). Professional stakeholders were provided with an information sheet and consent form prior to taking part in the research (Appendix K and L, respectively).

3.4.2 Sampling strategy

Sample size target ranges were guided by the 'Information power' concept (Malterud et al. 2016; Braun and Clarke 2021b). The Information power concept argues that an approximate sample size range can be determined beforehand. The Information power concept

recognises that determining an approximate range as a sample target is necessary when planning qualitative projects and suggests the final sample size can be continuously evaluated during the research process. To determine a final sample size, I considered factors such as the aim of the study, sample specificity and quality of the dialogue throughout the research process (Malterud et al. 2016).

A provisional target of 8-12 women with lived experience of bipolar disorder and / or previous postpartum psychosis and 8-12 professional stakeholders was agreed for the development stage. In deciding on the provision target range, I considered what was realistic in terms of the time frame for the project, in addition to the number of different diagnoses and personal experiences needed to be explored in the interviews. For pilot one and pilot two, a sample of 8-12 women for each was agreed. Final sample sizes were reviewed during the process of data collection and determined by the richness and adequacy of the data for addressing the research aims of determine the acceptability of the guide and the critical components of the guide (Malterud et al. 2016; Braun and Clarke 2021b). Attempts were made to include representation from women with different diagnoses, varying experiences of planning a pregnancy, for example, first / second child and varying demographics, age, ethnicity and level of education. Following feedback from each stage, recruitment was re-evaluated to target specific areas of interest in relation to the development of the guide, for example, seeking perspective of a single woman planning a pregnancy.

Efforts were made to include representation from different settings in which professional stakeholders work with women, for example, primary care, secondary care mental health services and specialist perinatal mental health services.

3.4.3 Advisory group

An advisory group was set up for additional feedback and guidance with developing guide prototypes, to supplement the qualitative data collected and provide advisory support. This involved voluntary peer supporters and employed team members from APP and a woman with lived experience and a Trustee of APP. All individuals had their own personal experience of bipolar disorder and / or perinatal mental health conditions and had already experienced planning a high risk pregnancy. Six women were initially invited to join the group. One individual had experienced postpartum psychosis 32 years ago and did not feel her input would be helpful. This individual was reassured of the value of her input; however, she chose not to join the group, which resulted in five women included in the Advisory group.

Discussions took place via a Facebook group and via email. A Facebook group was set up to include women from APP. It was decided that a platform where advisory group members could discuss with each other would be helpful. Google Docs was also considered; however, a Facebook group was decided on for ease of use and familiarity due to previous APP groups being coordinated via a Facebook group. One individual did not wish to become part of the Facebook group, but continued to provide feedback on guide prototypes via email. Screenshots were shared on the group and discussed, as well as discussion of feedback and ideas for content and presentation based on this. PDF and Microsoft Word (for Microsoft 365) section drafts were shared with group members via email. Participants provided feedback via Facebook comments and email. Women were invited to provide feedback in a format that suited them. Feedback was received in the following formats: bullet point summaries via email, annotated guide drafts using Microsoft Word (for Microsoft 365) tracked changes, email discussions and group discussions in the Facebook group.

3.4.4 Qualitative data analysis

Qualitative research is recognised for its ability to produce rich, detailed information within a range of social and healthcare contexts (Ritchie et al. 2013). A number of different options were considered before deciding that conducting a reflexive thematic analysis would be the most appropriate analytical approach to address the key aims of this project. A reflexive thematic analysis was conducted using an inductive approach, with code and theme development being directed by the content of the data (Braun and Clarke 2006; Braun and Clarke 2019). Reflexive thematic analysis is an approach used to identify patterns of meaning within qualitative data that address a given research question (Braun and Clarke 2006; Braun and Clarke 2019). The approach involves a rigorous process of identifying, analysing, organising, describing, and reporting themes found within a data set (Braun and Clarke 2006).

Braun and Clarke describe thematic analysis as a spectrum of methods, identifying three main thematic analysis approaches: 'coding reliability', 'codebook' and 'reflexive' (Braun and Clarke 2019; Braun and Clarke 2021a). 'Coding reliability' thematic analysis (Guest et al. 2012) involves multiple coders and the use of a codebook to ensure accurate and reliable coding. Coding quality is usually measured by inter-rater reliability exercises. Themes are often developed early in analytical process, sometimes prior to the analysis, meaning that the analysis is more deductive. 'Codebook' thematic analysis also uses a structured coding framework for analysis, with initial themes developed early on (Cassell et al. 2017). This

approach is iterative to some extent, allowing the modification of the codebook throughout the analytical process. However, similarly to a 'coding reliability' thematic analysis, 'codebook' adopts a structured approach to coding and themes that can be determined in advance of full analysis, often during early stages of familiarisation with the data (Braun et al. 2018). 'Codebook' approaches allow multiple coders to work through the different parts of the data independently. Each approach was considered in turn in terms of its suitability to the research project.

Reflexive thematic analysis is a popular method across a number of varying disciplines and fields. Braun and Clarke initially outlined the approach in their 2006 paper 'Using thematic analysis in psychology' (Braun and Clarke 2006), which to date, has been cited over 100,000 times. The authors have recently clarified their approach further and renaming it from 'thematic analysis' to '*reflexive* thematic analysis' to capture what is distinctive about their approach and to reflect the importance of the researcher's subjectivity and reflexive engagement with data and interpretation (Braun and Clarke 2019). Reflexive thematic analysis is considered theoretically flexible and can be used in a variety of research approaches, including inductive or deductive.

Of these approaches, reflexive thematic analysis is considered the most iterative, with themes developing much later in the analytical process compared to the other approaches outlined above. Considering this, a reflexive thematic analysis approach was decided upon for this project. An inductive approach was adopted, with coding and theme development directed by the content of the data rather than being dictated by existing theory and prior research. A deductive approach was initially considered, where themes would be predetermined on areas considered of most interest, based on the review of the literature and review of online information (presented in Chapter 1 and Chapter 2). However, a 'data-led' inductive approach seemed most appropriate, given the benefits of capturing novel opinions and ideas at this early stage in developing the guide. Since all elements of the guide were yet to be decided upon (for example, contents, presentation, form and use), it was felt that an inductive approach provided the best way to fully explore unique opinions and ideas during the qualitative interviews.

A reflexive thematic analysis approach involves six steps: familiarisation; generating codes; generating themes; searching for themes, defining and naming themes; and producing a report (Braun and Clarke 2006; Braun and Clarke 2019). Braun and Clarke's (2006) six step

method, presented below, is an iterative and reflective process that involves constant moving back and forth between phases.

3.4.4.1 STAGE ONE: FAMILIARISATION

I conducted all interviews and audio-recorded using an encrypted dictaphone. Interviews were transcribed verbatim by me, members of the wider NCMH research team and a professional transcription service. Following this, transcripts were imported into NVivo 12 software for data management and analysis (QSR International Pty Ltd. 2018). All transcripts were read and re-read at least twice in order to become fully immersed in the data before coding. Notes on initial thoughts were taken following each interview and notes on ideas for coding were taken while reading and re-reading the interview transcripts.

3.4.4.2 STAGE TWO: GENERATING CODES

Generating codes is a process of identifying interesting aspects in the data items. A process of 'open coding' was used to systematically work through the data set. The use of NVivo 12 software aided the process of sorting and organising of data into codes. Once all the data had been initially coded, a comprehensive list of codes was devised.

An additional researcher coded approximately 10% of interviews during each stage of the project. The goal was not to reach a consensus between coders, but to encourage further reflective engagement and develop a richer understanding of the data through a process of collaborative coding (Braun and Clarke 2019). The process of collaborative coding involved both researchers coding the interview independently, before discussing their coding via Zoom. Prior to coding an interview, the additional researcher was informed of the aims of the project. Each researcher completed the coding using the tracked changes function on Microsoft Word (for Microsoft 365). The interview was discussed via a videocall. New ideas for codes arising from the discussion were added to the document and included in the following steps involved in the analysis.

3.4.4.3 STAGE THREE: GENERATING INITIAL THEMES

Originally termed 'searching for themes' by Braun and Clarke (2006), this step involved reviewing the comprehensive list of codes and grouping codes into broader groupings to develop the initial themes. Initial themes were not determined by the number of codes or responses, but on whether it depicted something important in relation to the primary aims

of the project (Braun and Clarke 2006). To aid the process of developing themes, thematic maps were created electronically using an online mind mapping application, 'Mindmup' (www.mindmup.com) (Attride-stirling 2001). Themes and subthemes were developed and formed into thematic maps to further examine the research and develop a richer analysis of the data. As recommended by Braun and Clarke (2006), a list of miscellaneous codes was kept to refer back to while reviewing themes.

3.4.4.4 STAGE FOUR: REVIEWING THEMES

Once initial themes had been devised, data extracts within each theme were carefully considered as to whether they supported the theme. Thematic maps and corresponding text segments were considered for each theme. Various changes were required during this refinement phase. This included merging themes, separating themes, inclusion of new themes and abandoning themes with some themes being merged, new themes inserted and existing themes being abandoned based on a lack of data supporting them. Once I was able to clearly define each theme and describe its contents and relation to other themes, this process was considered complete.

3.4.4.5 STAGE FIVE: DEFINING AND NAMING THEMES

A name and description for each theme was developed. Theme descriptions illustrated the relevance of the data within each theme. Difficulty in naming or describing any themes led to further consideration and refinement of the theme, revisiting previous steps in the process.

3.4.4.6 STAGE SIX: PRODUCING A REPORT

The final step in conducting an inductive reflexive thematic analysis was to describe the data set and the main findings in detail. Thematic maps were included in addition to written descriptions of the main findings. Data extracts were also included to illustrate important points within each theme. Participant numbers were used to label data extracts included in the report. For professional stakeholders, job titles were used to label data extracts. A report of the qualitative data from the development stage is presented in Chapter 4.

3.4.4.7 RESEARCHER REFLEXIVITY

Reflexivity can be considered as the researcher's awareness of how their own characteristics and experiences affects how information is interpreted (Finlay 2002). I had prior experience

of conducting in-depth research assessments relating to severe mental illness and perinatal mental illness, but had no prior experience in collecting and analysing qualitative data. PhD supervisors IJ, CL and JH supervised the research and have experience in conducting and supervising thematic analysis. I am a 28-year-old woman with no personal experience of bipolar disorder or planning a high risk pregnancy. Throughout the process of analysis, I acknowledged ways in which my own experiences and personal characteristics may have influenced the research process.

3.5 Development stage

3.5.1 Participants

Inclusion criteria for women included being female, having a diagnosis of bipolar disorder and / or lived experience of postpartum psychosis and being over 16 years old. Inclusion criteria for professional stakeholders included having experience of working with women with bipolar disorder and / or postpartum psychosis. Exclusion criteria included the inability to understand spoken and / or written English and the inability to provide valid informed consent. Participant demographics and participant flow specific to the development stage are presented in Chapter 4.

3.5.2 Semi-structured qualitative interviews

Women with lived experience of bipolar disorder and / or postpartum psychosis were asked to take part in a qualitative interview, lasting in the region of 60 to 120 minutes. Interviews were conducted face to face, via telephone call or video call. Women were given the option of completing the interview alone or inviting a partner or significant other to take part in the interview with them. No women decided to invite their partner to the interview.

Professional stakeholders were asked to take part in a focus group or interview, lasting in the region of 60 to 120 minutes. A small number of professional stakeholders were happy to take part in a focus group, however difficulty in aligning schedules meant that all professional stakeholders took part in separate qualitative interviews. Interviews were digitally recorded for later transcription.

Initial versions of the topic guides were developed for interviews with women and with professional stakeholders and then shared with the supervisory team and refined further to develop the version to be used during the interviews. The topic guides (see Figures 3.3 and

3.4) could be adapted following each interview to include any additional points of interest that were discussed in previous interviews. The topic guide, as the name suggests, was used as a guide as opposed to a script to be followed systematically. The order of questions could be changed, and new questions could be asked when appropriate.

The aim of the qualitative interviews was to explore the thoughts and opinions of individuals in relation to the contents, presentation and use of the guide. The following key questions provided the basis for the topic guide and were explored during qualitative interviews:

1. What are the critical components that should be included in a pregnancy planning guide for women at risk of postpartum psychosis?
2. What should a guide like this look like and how should the contents be presented?
3. In what way might women like to use a guide like this?

Topic Guide – Pilot one participants (women with lived experience of bipolar / postpartum psychosis)

This research project will involve designing a guide that aims to help women make decisions about pregnancy and the postpartum period.

By working with women with lived experience of bipolar disorder and / or postpartum psychosis (and their partners or significant others), we are hoping to learn about what information is needed when planning for a pregnancy and the postpartum period. You will be asked about the content and presentation of the guide, as well as given the opportunity to introduce your own topics for discussion. The guide will be in the form of a booklet for this research project, however other options may be considered in the future.

Interviews will be recorded. The audio recording of the interview will be kept until transcription is complete. Audio recordings will be destroyed immediately after transcription. All information collected during the research will be kept strictly confidential. We may use anonymous quotes from the interview in reports that we produce - you will not be identifiable from these quotes. We will not pass on any of the information we collect about you unless we have serious concerns about your mental or physical health or the care that you are receiving.

This interview will last in the region of 1-2 hours. We acknowledge that some people find it difficult or upsetting to answer questions related to mental health. You may skip any questions that you do not wish to answer, take a break or terminate the interview at any point.

Background and experience

Recap on previous phone call when the participant's experiences were discussed.

- What information was available to you when planning for a pregnancy? / What information on pregnancy planning is available to you?
  Prompts (if required):
  - *Where did you source the information that you needed? / Where will you source the information that you need?*
  - *What information did you find useful?*
  - *Did you feel you had enough information?*
- Looking back, what information do you feel would have been helpful during this time? / What information do you feel will be helpful for when planning a pregnancy?
  Prompts (if required):
  - *What would help with future episodes / What would you recommend?*

Content of guide

- What would be most useful to cover in a guide to help women with a *(tailor to specific situation of the woman: e.g. diagnosis of BP / a history of PP)* when considering / planning a pregnancy?
  Prompts (if required):
  - *Medication?*
  - *Risk factors? E.g. genetic factors, medication changes, sleep deprivation*
  - *Self-management strategies? E.g. mood monitoring*
  - *Lifestyle? E.g. exercise*
  - *Real life stories from women who have a history of BP / PP?*
  - *What episodes occur in relation to pregnancy and childbirth – symptoms of postpartum psychosis, postnatal depression, 'baby blues', high moods*
  - *Early warning signs*
  - *Forward directives – making a plan in the event of becoming unwell*
  - *Risk to offspring (will my children get bipolar?)*

  o *Advice regarding sleep*
  o *Managing expectations of friends and family during pregnancy and postpartum*
  o *General pregnancy / postpartum advice (i.e. physical health)*
  o *Parenting with bipolar disorder*

Presentation of guide
- What do you think the guide should be called?
  Prompts (if required):
   – *Guide / Tool?*
   – *'The collaborative guide'*
   – *'The PREP guide'*

Using the guide
- Would it be useful for the guide to be 'interactive'? To have sections to personalise and fill in yourself?
   – e.g. early warning signs and triggers, decision making exercises based on values.
- How do you imagine using the guide?
  Prompts (if required):
   – *Just for your personal use?*
   – *Something to share with partner or family member(s)? e.g. information on early warning signs and symptoms if you were to become unwell.*
   – *Should there be a section to fill out together with your clinician? E.g. to summarise discussions?*
   – *As a starting point for information?*
   – *Something to enhance your existing knowledge on the subject?*
   – *Something to use alongside other resources?*
- Would you use this guide during clinical appointments?
- How long would you want to use the guide for?
  Prompts (if required):
   – *Read through once when planning a pregnancy?*
   – *Something to refer to from the planning stage through to the postpartum period?*
- That's the end of the questions that I have. Is there anything else that you'd like to discuss that we haven't covered yet?

That's the end of the interview, thank you very much for taking the time to speak with me. In terms of what happens next, once all the interviews from stage 1 have been completed, we will develop the initial prototype of the guide. You will then be given the opportunity to provide feedback on the guide to help with its further development. Following this, we will test the guide during two pilot studies and refine the guide based on the results. You will be given the opportunity to provide feedback on the refined versions of the guide.

Figure 3.3 Topic guide for interviews with women during the development stage

Topic Guide – Pilot one professional stakeholders (focus groups / qualitative interviews)

This research project will involve designing a guide that aims to help women make decisions about pregnancy and the postpartum period. By working with women with lived experience of bipolar disorder and / or postpartum psychosis and professional stakeholders, we are hoping to learn about what information is needed when planning for a pregnancy and the postpartum period. You will be asked about the content and presentation of the guide, as well as being given the opportunity to introduce your own topics for discussion. Interviews will be recorded. The audio recording of the interview will be kept until transcription is complete. Audio recordings will be destroyed immediately after transcription. All information collected during the course of the research will be kept strictly confidential. We may use anonymous quotes from the focus group / interview in reports that we produce - you will not be identifiable from these quotes.

Content of guide
- What would be most useful to cover in a guide to help women with a history of BP or PP when considering / planning a pregnancy?
    - *Medication?*
    - *Risk factors?*
    - *Factors that individualise risk?*
    - *Self-management strategies?*
    - *Lifestyle?*
    - *Real life stories from women who have a history of BP / PP?*
    - *What episodes occur in relation to pregnancy and childbirth – symptoms of postpartum psychosis, postnatal depression, 'baby blues', high moods*
    - *Early warning signs*
    - *Forward directives – making a plan in the event of becoming unwell*
    - *What are your thoughts about including information on genetic risk in the guide? How do you think it should be presented?*
    - *Advice regarding sleep*
    - *General pregnancy / postpartum advice (i.e. physical health)*
    - *Parenting with bipolar disorder*
    - *Practical - Managing expectations of friends and family during pregnancy and postpartum*
    - *Social services – Women with bipolar sometimes worry about the involvement of social services. What are your thoughts about including information on social services? How do you think this should be presented?*

- How much detail should the guide provide on medication?
    - Should any medications be discussed in more depth?
- How much detail should be provided for each condition (postpartum blues, postpartum depression, postpartum psychosis, episodes during pregnancy)?

Presentation of guide
- What do you think the guide should be called?
    - *Guide / Tool?*
    - *'The collaborative guide'*
    - *'The PREP guide'*
- How should the guide be presented?
    - *As a physical copy, e.g. in the form of a booklet?*
    - *A webpage?*
    - (At the moment, it may not be feasible for us to develop an app for the guide, however this may be something that we consider in the long-term plan for the project)

- Do you think it would be useful for the guide to be 'interactive'? To have sections to personalise and fill in?
    - e.g. early warning signs and triggers, decision making exercises?
- *How would you feel about a woman bringing the guide into a consultation with you?*
- *What would you find it useful for it to cover*
- *Should there be a section to fill out together with clinicians – summarise discussions?*
- How do you imagine women would use the guide?
    - *Just for their personal use?*
    - *Something to share with their partner or family member(s)? e.g. information on early warning signs and symptoms if they were to become unwell.*
    - *Something to refer to during clinical appointments?*
    - *Something to use alongside other resources?*
    - *Something to enhance their existing knowledge on the subject?*
    - *As a starting point for information?*

- That's the end of the questions that I have. Is there anything else that you'd like to discuss that we haven't covered yet?

The end of the interview

That's the end of the interview, thank you very much for taking the time to speak with me. In terms of what happens next, once all of the focus groups and interviews from stage 1 have been completed, we will develop the initial prototype of the guide. You will then be given the opportunity to provide feedback on the guide to help with its further development. Following this, we will test the guide during two pilot studies and refine the guide based on the results. You will be given the opportunity to provide feedback on the refined versions of the guide.

Figure 3.4 Topic guide for interviews with professional stakeholders during the development stage

3.5.3 Prototype one

The first prototype of the guide was developed based on the qualitative analysis of professional stakeholder and participant interview data, an evaluation of freely available online information for women with bipolar disorder and / or postpartum psychosis when planning a pregnancy and reviewing example decision aids from other medical contexts. Key components of other decision aids were considered by reviewing descriptions included in studies detailing their development and evaluation (Prunty et al. 2008; Meade et al. 2013; Meade et al. 2015; McGrath et al. 2017). This allowed me to consider ways of practically incorporating the input from the development stage qualitative interviews, into the initial prototype of the guide. Two PDF electronic copies were obtained for decisions aids developed for women with rheumatoid arthritis and women with epilepsy to use when considering having children or further children (Meade et al. 2011; Meade et al. 2015; McGrath et al. 2017). Attention was paid to the information included in the decision aids,

their presentation and particularly, the content and presentation of interactive worksheets and exercises designed to assist women in the decision making process of having a baby. Further discussion and examples from the initial prototype of the guide can be found in Chapter 4.

3.6 Pilot studies

3.6.1 Participants

Recruitment for all stages is outlined in section 3.4 above. The inclusion criteria for pilot one and pilot two were the same as the development stage, with the addition of an inclusion criterion that women were either considering or planning a pregnancy, or were currently pregnant. Participant demographics and participant flow for pilot studies are presented in Chapters 5 and 6.

3.6.2 Initial brief assessment

An initial telephone call was arranged with participants to explain the aims of the project and what taking part would involve. This was also an opportunity for participants to ask any questions. Informed consent was obtained (written or verbally) and participants were asked to provide their General Practitioner's (GP) contact details. I then sent a letter to their GP to inform of participation in the project (Appendix M). Following this, a telephone or zoom call was arranged for participants to take part in a 30 to 60 minute assessment. This involved answering questions relating to demographic information, education, mental health diagnoses and treatment, physical health and perinatal specific questions about previous history of episodes and current pregnancy plans.

3.6.3 Guide delivery

Following the initial brief assessment, all participants received a paper copy of the guide by post. I instructed participants to use the guide over the next four weeks in any way that they liked. I explained to participants that the guide included information, as well as interactive exercises and spaces to write personal information or plans. It was made clear that the guide could be used alone or with others, for example, with significant others or healthcare professionals. I had no contact with the women between the initial assessment and the semi-structured interview after using the guide.

3.6.4 Qualitative data

Participants took part in a semi-structured interview after testing the guide. This was to hear their thoughts and opinion on the guide, and any ideas or suggestions that they had for improvements. All interviews took part via telephone or video call.

A topic guide developed for the piloting stage is presented in Figure 3.5 below. The initial version of the topic guide was developed in line with the initial prototype of the guide and finalised following discussions with the supervisory team. As in the development stage, the topic guide could be adapted following each interview to include any additional points of interest that were discussed in previous interviews. The topic guide was also adapted prior to pilot two to reflect any refinements made to the guide. The topic guide focused on questions relating to three main points: (1) the contents of the guide, (2) the presentation and layout of the guide, and (3) how women used the guide. A report of the qualitative data from pilot one is presented in Chapter 5.

Interview topic guide – Pilot one

I want to start by thanking you for your help with the project so far. I'm very grateful for your time today to speak with me about the guide. If it's ok with you, I will be recording the interview which will then be transcribed. The recording of the interview will be kept until transcription is complete and will be destroyed immediately after transcription. All information collected during the course of the research will be kept strictly confidential. We may use anonymous quotes from the interview in reports that we produce but you will not be identifiable from these quotes.

You have now spent a number of weeks testing the pregnancy planning guide and we are very interested in hearing how you've found it. Your honest opinions (both positive and negative) and any advice or ideas you have for us will be very helpful.

Overall
- What did you think of the guide?
  - o Did anything stand out to you as being particularly helpful?
  - o Was there anything you didn't find as helpful?
- Did the guide help you with any difficult decisions that you have been making?
  - o Has the COVID-19 pandemic affected any of your decisions or plans relating to planning a pregnancy / your pregnancy?
  - o Can you tell me a bit more about this?

Using the guide

Involvement with others
- Did you use the guide with others?
o Partner, family members or friends?
o Healthcare professionals?
o Do you think the current situations with the COVID-19 pandemic affected how you used the guide with others in any way?
o Has the care that you receive from professionals changed due to the COVID-19 pandemic?
- Did anyone other than you read the section 'What do partners, family and friends need to know?'
o What did they think?
- Was the guide helpful to aid discussions with others?
o Do you have any examples of when the guide was helpful to aid discussions?
- Is there anything else that would have been helpful to include in the guide for family, friends or partners?

Interactive sections
- How did you find the interactive sections?
o Did you fill them in?
o Were they helpful?
o Were they easy to follow?
- Would it have been helpful to include all the interactive elements in a separate section? Or a separate booklet?
- Did you share these sections with others? Was this helpful?
- Is there anything else that would be helpful to include?

Modules

What were your thoughts on each section of the guide?
- Using this guide
- About me: Questions about my history and lifestyle
- What mental health conditions might I experience?
- What do I need to think about when planning a pregnancy?
- What support will I receive during pregnancy and after having a baby?
- What do I need to know about medication and pregnancy?
- How can I help myself stay well?
- What do partners, family and friends need to know?
- Bringing it all together

Organisation
- What did you think about how the sections of the guide were ordered? *Do you have any other suggestions?*

Content
- Was there enough information in each section?
  - *Or was there too much information?*
- Is there anything else we could include in the guide?
- What did you think about the signposting that was included? *Was it helpful?*
- Did you feel there was any judgment or bias in how the information was included?

Knowledge
- Do you feel more knowledgeable or informed since reading the guide?
  - *About any topic in particular?*
- Do you feel more confident in how much you know since reading the guide?

Presentation
- What did you think about how the guide looks?
  - *What did you like?*
  - *Was there anything that you didn't like?*
  - *Did it look appealing?*
  - *Colours? Fonts? Photos? Icons?*
  - *Layout of pages?*
  - *Front cover? Title and photo? Including diagnoses on the front?*
- Is there anything you'd change about how the guide looks?

Conclusion

If planning a pregnancy
- During our initial phone call, you described yourself as currently planning a pregnancy / considering whether or not to have a baby. Did you feel the guide was helpful to have at this stage?
  - *Do you think it would also be helpful to use during pregnancy? Or would it be better to have two versions?*

If currently pregnant
- Do you feel that this guide is helpful to use during pregnancy?
  - *Would it have been more useful if you received it when thinking about pregnancy?*
  - *Do you think we should have two versions of the guide – one for the planning stage and one for pregnancy?*

- Overall, would you say that this guide is acceptable to you?
- Would you recommend this guide to other women with bipolar or previous postpartum psychosis who are planning a pregnancy / currently pregnant? If not, why not?
- Do you have any suggestions to help us improve the guide?
- **Before we finish, do you have any other thoughts or opinions on the guide?**

That's the end of the questions that I have for you. Thank you very much for your time today to share your thoughts and comments with me. It will be very useful when thinking about improvements we can make to the guide. If you have any further questions, comments or suggestions, please feel free to get in touch with me.

Figure 3.5 Topic guide for interviews with women during pilot one

3.6.5 Quantitative data

Before and after using the guide, participants were sent a questionnaire pack in the post to complete and return in the freepost envelope provided (Appendix N). Participants completed

the following measures before and after using the guide 1) Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith 1983); 2) Altman Mania Scale (AMS) (Altman et al. 1997); 3) Decisional Conflict Scale (DCS) (O'connor 1995); and 4) a bespoke acceptability measure. Further information on each questionnaire, including reasons for their use in this research, are described below. An overarching reason for including all measures in this research was to determine the feasibility of their use as part of a larger scale RCT in the future.

3.6.5.1 HOSPITAL ANXIETY AND DEPRESSION SCALE (HADS)

The Hospital Anxiety and Depression Scale (HADS) is a brief 14-item standardised self-rating questionnaire to detect the severity of anxiety (7 items) and depression (7 items) simultaneously (Zigmond and Snaith 1983). Participants respond using a 4-point Likert type scale, which are scored 0 to 3. A higher score represents greater severity of anxiety and depression. For each subscale, scores range from 0 to 21, with 0 to 7 indicating a Normal score (indicating no case of anxiety or depression), 8 to 10 a Borderline score, and 11 to 21 an Abnormal score (indicating a case of anxiety or depression). The HADS has been found to be a reliable and valid measure (Herrmann 1997).

The HADS was included in the research to assess whether the use of the guide could have a negative impact on women's mood and anxiety scores or whether episodes of mental illness may have occurred alongside the use of the guide, which may have influenced outcomes.

3.6.5.2 ALTMAN SELF-RATING MANIA SCALE (AMS)

The Altman self-rating Mania Scale (AMS) (Altman et al. 1997) is a 5-item self-administered measure, designed to assess the presence and / or severity of manic symptoms (elevated mood, increased self-esteem, less need for sleep, pressured speech and psychomotor agitation). The measure includes five questions relating to symptoms of mania, which are answered on a five-point scale to assess the presence and severity of manic or hypomanic symptoms (Altman et al. 1997). Each item is rated on a scale of 0 to 4, with total scores ranging from 0 to 20. Higher scores indicate greater severity of manic symptoms. Scores of 6 or higher indicate a high probability of mania or hypomania, based on a sensitivity rating of 85.5% sensitivity and a specificity rating of 87.3% (Altman et al. 1997).

As with the HADS, the AMS was included to assess whether the use of the guide could have a negative impact on women's mood scores or whether episodes of mental illness may have occurred alongside the use of the guide.

3.6.5.3 DECISIONAL CONFLICT SCALE (DCS)

The Decisional Conflict Scale (DCS) is used to measure decisional conflict and has been used widely in a wide range of studies (O'connor 1995). The traditional DCS presented in statement format was used, including 16 items and five response categories presented as a 5-point Likert response scale (strongly agree, agree, neither agree or disagree, disagree and strongly disagree) (O'Connor 2010). The DCS includes five subscales of decision making, which include 1) Informed, reflecting how informed a person feels about the options available to them and the associated benefits and risks of each option (3 items); 2) Values clarity, reflecting how clear an individual is on their personal values relating to potential risks and benefits (3 items); 3) Support, how supported a person feels in their decision making (3 items); 4) Uncertainty, how uncertain a person feels about the decision they are making (3 items); and 5) Effective Decision, relating to the level of perceived effectiveness or sense of personal satisfaction the person feels in relation to their decision (4 items). The DCS has been associated with a test-retest reliability coefficient of 0.81, with internal consistency coefficients ranging from 0.78 to 0.92 (O'connor 1995).

Participants completed two separate DCS relating to the following decisions: 1) Making a decision about whether or not to have a baby; and 2) Making decisions about medication during pregnancy. Participants were asked to state their current preferred option for each decision. The DCS was used to determine whether the guide had a positive impact on factors relating to decision making.

3.6.5.4 ACCEPTABILITY MEASURE (BESPOKE)

Participants completed an acceptability measure after using the guide. A bespoke acceptability measure was designed for the research. This measure was tailored specifically to the contents of the guide. This was beneficial in allowing me to learn about women's experiences of specific components included in the guide. Previous studies involving the development and testing of decision aids have also developed acceptability measures specifically for the study (Metcalfe et al. 2007; Vigod et al. 2019). Minor changes were made to the acceptability measure following the revision of the guide for pilot two, to accommodate any changes in the wording or the order that information was presented in the refined guide.

The bespoke acceptability measure was adapted from the Ottawa Decision Support Framework's Acceptability measure (O'Connor and Cranney 1996). The Ottawa Acceptability

tool has been devised for determining acceptability of decision aids. As this project involved developing a pregnancy planning guide rather than a decision tool, some items in the measure were not included and items related to content were tailored to this research.

The bespoke acceptability measure included questions relating to the guide layout and presentation, content, length and amount of information included, factors relating to using the guide and overall thoughts on the guide. Participants were asked to respond to statements relating to the topics above using one of the following options: 'strongly agree', 'agree', 'neutral', 'disagree' or 'strongly disagree'. Participants were asked to respond to questions relating to the helpfulness of content by circling a number between 1 and 5 (1= not at all, 2= slightly, 3= moderately, 4= very, 5= extremely). The measure was used to determine whether the guide was acceptable to women and to inform refinements made to guide prototypes, alongside the qualitative data collected.

Statistical analysis of results from a small sample of participants such as this would be inappropriate on the basis of insufficient power. Participant questionnaire data was therefore presented using line diagrams to plot each participant's scores on the measures described above. A report of the quantitative data from pilot one is presented in Chapter 5.

3.6.6 Refinement of guide prototypes

The second and third prototype of the guide was developed based on the qualitative and quantitative analysis of participant data, advisory group feedback and discussions with the supervisory team. Further discussion and examples from the second and third prototype of the guide can be found in Chapter 5 and Chapter 6.

3.7 Summary and conclusion

I developed the protocol for this research project to be consistent where possible with the MRC guidance for the development of a complex intervention. This involved identifying the existing evidence base, collecting and analysing qualitative data to develop a guide prototype during the development stage and conducting two pilots to test the guide.

The aim of the research project was to determine the critical components of a pregnancy planning guide for women with bipolar disorder and / or postpartum psychosis, to determine its acceptability to women, and determine the feasibility of a larger scale RCT of the guide.

The next chapter will present analysis relating to the development stage (Chapter 4) and the piloting stage (Chapter 5 and Chapter 6) of the research. Discussion on the results of the research will be considered in relation to the specific aims of the project in the Discussion (Chapter 7).

Chapter 4 Development stage results

4.1 Overview

This chapter presents the qualitative results of the development stage of this project, used to inform the initial prototype of the guide. The first step of the development stage was to identify and evaluate online information available to women with bipolar disorder and / or postpartum psychosis when planning a pregnancy. Following this review, questions remained as to what should be included in the guide. Medical Research Council (MRC) guidance on developing and evaluating complex interventions (Craig et al. 2008) suggests supplementing a review of existing evidence or information with qualitative interviews with those who may be targeted by the intervention, or involved in its development or delivery (Craig et al. 2008). Qualitative interviews were therefore conducted with women with lived experience of bipolar disorder and / or postpartum psychosis, researchers and healthcare professionals involved in their care. The aim of the qualitative interviews was to explore the thoughts and opinions of individuals in relation to the contents, presentation and potential use of the guide.

All participants took part in a semi-structured qualitative interview to explore their thoughts and opinions on what should be considered when developing a pregnancy planning guide for women with bipolar disorder and / or previous experience of postpartum psychosis. Interviews were conducted in person, via telephone or video call between August 2019 and November 2019. Interviews were digitally recorded for later transcription. The qualitative results in this chapter, along with the findings of the review of online information in Chapter 2, informed decisions relating to the development of the initial prototype of the guide. The initial prototype of the guide, including examples to illustrate, are discussed at the end of this chapter.

4.2 Participants

Sample size target ranges for women and professional stakeholders were guided by the 'information power' concept (Malterud et al. 2016; Braun and Clarke 2021b). In line with this concept, sample size ranges were determined beforehand. A sample range of 8-12 was decided upon for women. This would ensure representation from a diverse group of women with varying diagnoses; whether they were planning a further pregnancy, already had planned a high risk pregnancy, or were currently pregnant. A sample range of 8-12

professional stakeholders was also decided upon, to ensure representation from a range of different specialities. Final sample sizes were considered throughout the research process. Factors that influenced the final sample size was the richness of the interview data in answering the aims of the project, the quality of the dialogue and the range of experiences included in the samples.

4.2.1 Women with lived experience of bipolar disorder and / or postpartum psychosis

Inclusion criteria for women with lived experience included being female, having a diagnosis of bipolar disorder and / or lived experience of postpartum psychosis, and being over 16 years old. Exclusion criteria included the inability to understand spoken and / or written English and the inability to provide valid informed consent.

Eight women with lived experience of bipolar disorder and / or postpartum psychosis were included in the development stage qualitative interviews (see Table 4.1). Women were at various stages and had a range of different experiences in relation to perinatal mental health. These included experience of planning a second pregnancy following a perinatal episode, deciding not to have further children after a perinatal episode, and being currently pregnant. The women had a range of ages and included participants who had been previously pregnant, as well as those who were considering starting a family. The average interview time for women was 01:06:14 (hours, minutes, seconds), ranging between 00:24:01 to 01:31:37 (hours, minutes, seconds).

Characteristic	Frequency (N=8) (%)
Age	
20–30 years	0 (0%)
31–40 years	4 (50%)
>40 years	4 (50%)
Ethnicity	
White British	6 (75%)
Any other White background	2 (25%)
Employment status	
Employed, full time / part time	7 (87.5%)
Unable to work (including those receiving Disability Living Allowance (DLA))	1 (12.5%)
Level of education	

Graduate level or above	6 (75%)
Higher National Diploma (HND)	1 (12.5%)
Unknown	1 (12.5%)
Partner / Single	
Partner	8 (100%)
Single	0 (0%)
Diagnosis	
Bipolar disorder	2 (25%)
Bipolar disorder and Postpartum Psychosis	4 (50%)
Postpartum Psychosis	2 (25%)
Currently pregnant	
No	7 (87.5%)
Yes	1 (12.5%)
Currently planning	
No	6 (75%)
Yes	2 (25%)

Table 4.1 Development stage demographic information for women

4.2.2 Professional stakeholders

A number of health care professionals are involved in the care of women throughout the perinatal period. Inclusion criteria for professional stakeholders included having experience of working with women with bipolar disorder and / or postpartum psychosis. Efforts were made to include representation from different settings in which professional stakeholders work with women, for example, primary care, secondary care mental health services and specialist perinatal mental health services. Exclusion criteria included the inability to understand spoken and / or written English and the inability to provide valid informed consent.

A total of 14 professional stakeholders were included to ensure representation from all relevant groups including primary care, antenatal care, and mental health services (see Table 4.2). Additional professional stakeholders were required than originally anticipated to ensure representation from all different specialities involved in the care of women with a diagnosis of bipolar disorder or postpartum psychosis (Malterud et al. 2016). The number of professional stakeholders was guided by the content of earlier interviews. For example, a social worker was included for an additional perspective on parenting and social services, two topics which were particularly undecided upon for inclusion in the guide. Professional

stakeholders included a range of healthcare professionals working within different disciplines from primary care, social care, mental health and specialised perinatal mental health services. These included professionals who were the first point of contact for many women with bipolar disorder or previous postpartum psychosis experience, for example, a general practitioner (GP) in addition to mental health professionals including those who specialised in mental health care during the perinatal period. The average interview time for professional stakeholders was 44:33 (hours, minutes, seconds), ranging between 00:25:51 - 01:15:10 (hours, minutes, seconds).

Profession / Role of interest	Frequency (n=14)
Consultant perinatal psychiatrist	3
Perinatal psychiatrist and researcher	1
Clinical psychologist (Perinatal mental health team)	1
Midwife (Perinatal mental health team)	1
Community mental health nurse manager	1
Community mental health nurse	2
Midwife	1
Health visitor	1
Social worker	1
GP, Perinatal mental health champion	1
GP	1

Table 4.2 Development stage demographic information for professional stakeholder participants

4.3 Qualitative analysis

4.3.1 Overview of qualitative results

This section presents the qualitative results of semi-structured interviews conducted with 8 women with lived experience of bipolar disorder and / or postpartum psychosis and 14 professional stakeholders involved in the care of women with bipolar disorder and / or previous postpartum psychosis. A process of reflexive thematic analysis (Braun and Clarke 2006; Braun and Clarke 2019) was used to analyse the qualitative interviews.

Four overarching themes were identified and used as a framework for presenting the results: 1) Knowledge is power; 2) Planning and preparing; 3) Positivity and reassurance; and 4) Using the guide with others (see Figure 4.1).
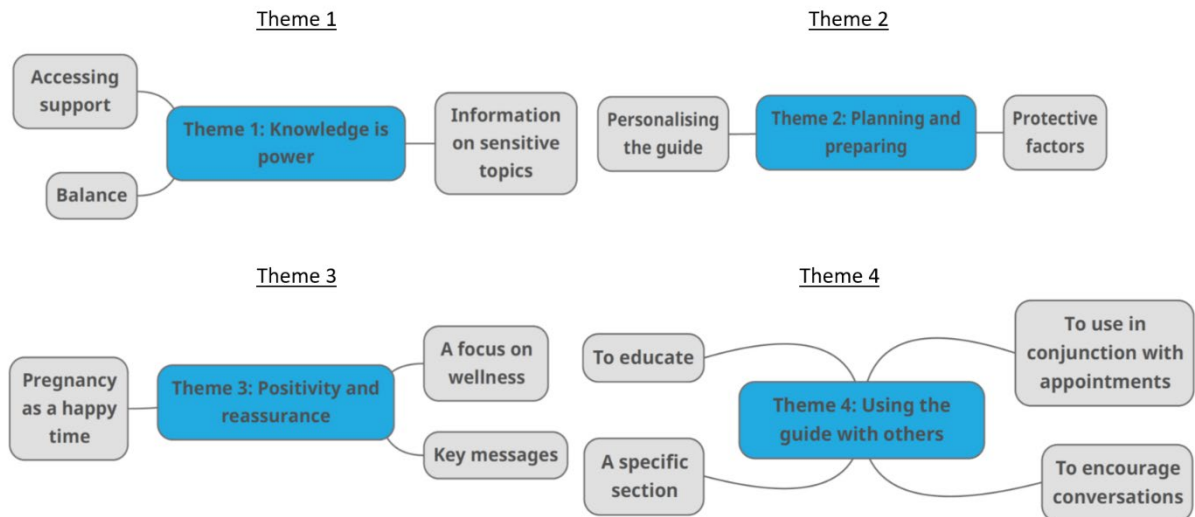
Figure 4.1 Four overarching themes identified and used as a framework for presenting development stage qualitative interview results

4.3.2 Overall impressions of participants

Participants (women and professional stakeholders) advocated the development of a pregnancy planning guide for women with bipolar disorder and / or previous postpartum psychosis and made suggestions for its content, presentation, and use. There was clear consensus between women with lived experience and professional stakeholders that the guide should attain a balance of being positive and hopeful, while also being informative. Participants felt it was important to cover topics such as individualised risk of becoming unwell, but for this to be balanced with a focus on remaining well. Differing views were obtained on the inclusion of some sensitive topics, such as the genetic risk of bipolar disorder, social services and parenting with bipolar disorder.

The guide was also discussed in the context of its potential use with others, such as with significant others and during appointments with healthcare professionals. Women and professional stakeholders made suggestions on how the guide could be incorporated into clinical care, including having sections to personalise, for example, to record information on previous episodes of illness. Suggestions also included having a section for partners, family or friends to read.

The amount of information included in the guide was a key discussion point, which again attracted differing views. Those involved in the care of women, for example healthcare

professionals and peer supporters (included in the group of women with lived experience of bipolar disorder and / or postpartum psychosis), raised concerns about the possibility of providing too much information, while some women felt more detailed information would be helpful. The challenges of developing a guide for women with differing diagnoses was also discussed.

Each theme and its subthemes are discussed below, including examples from the interviews to illustrate. Professional stakeholder quotes are labelled by their speciality, while women with lived experience of bipolar disorder and / or previous postpartum psychosis are labelled as participants. While participants in this stage were grouped as 'professional stakeholders' or 'women with lived experience', one professional stakeholder was also an expert by experience. Some women with lived experience of bipolar disorder and / or previous postpartum psychosis, were also able to contribute from their perspective as a peer supporter helping other women.

4.3.3 Theme 1: Knowledge is power
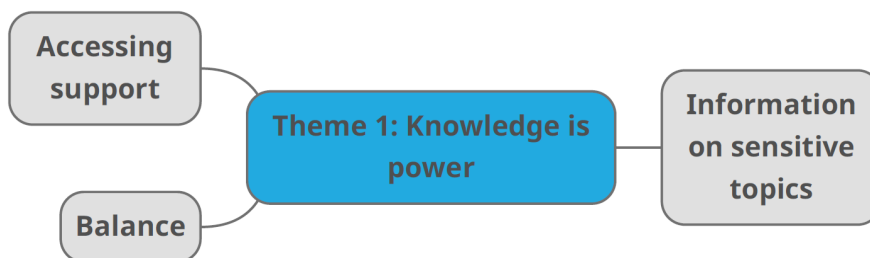
Figure 4.2 Thematic map for Theme 1: Knowledge is power

It was emphasised that being armed with knowledge for decisions and planning during the perinatal period was empowering. As presented in Figure 4.2, data relating to this theme was organised into the following three subthemes: accessing support; balance, and information on sensitive topics.

4.3.3.1 ACCESSING SUPPORT

Women and professional stakeholders believed all women should be able to access specialist perinatal mental health care from pre-conception onwards. However, they felt that women's needs were not always met. Participants acknowledged the lack of specialist mental health care nationally and the need for improvement within these services.

It was suggested that the guide should include information on the care that women may expect to receive during the perinatal period, particularly when seeking pre-conception support. Providing information on care and support was considered especially important for women who were under the care of their GP, rather than a community mental health team (CMHT) or a specialist perinatal CMHT.

> *"Yeah, I mean, there are probably, there probably will be women that have been discharged from the psychiatric service because they're doing well, they're on the right level of medication so then they probably will- the GP probably would be their first point of call, but even so, then they need to speak to the GP and say "I think … I've been advised to, yknow get referred to the perinatal team""*
>
> *Participant 3*

Women emphasised the need for women to discuss their plans with a perinatal specialist from the pre-conception period onwards. As perinatal mental health services vary regionally, professional stakeholders in this study described how non-perinatal healthcare professionals may not always be aware of the services offered by perinatal mental health services in their area. Encouraging women to find out what specialist care might be available to them locally was important.

> *"The sort of positives of the fact what services are out there, what input they can be provided with … it's getting better in Wales, but still now …I think GPs and even CMHTs aren't aware where these women can go, they're not completely fully [aware] of what the perinatal mental health teams do but erm with the, the patients … informed … at least they can erm ensure that they are sent to the correct team as well, erm so I think that would be helpful as well."*
>
> *Perinatal psychiatrist*

Participants felt that including this as a recommendation in the guide would provide women with the confidence that they can ask their healthcare professionals about support available. Suggestions on how to find out about specialist perinatal mental health support included asking a healthcare professional, such as a GP or a professional within a CMHT.

> *"I wish in my third pregnancy that I had kind of pushed a bit more for a bit more support. Not support in my pregnancy but just a bit more preparation for if things didn't go right … I think if the guide says yknow "you can speak to your midwife or you can speak to your GP or" yknow opens it up and lets people know who they can talk to about their different concerns I think that's important … if it's a tool that kind of gives women knowledge and kind of lets them know that they're going to be listened to as well, I think it's- that's really important."*
>
> *Participant 1*

4.3.3.2 BALANCE

When discussing the amount of information covered in the guide, participants felt a balanced approach was needed. They felt that the guide should be comprehensive and cover a wide range of topics, but also clear and accessible to all women. Women and other professional stakeholders in this study felt that it was important that information was not complicated or overly medical. Some expressed concern that including too much information could be overwhelming for women. Professionals and women who worked for third sector organisations, or volunteered as peer supporters, appeared particularly cautious about how much information should be included in the guide. Women in the study with experience of helping others spoke of this concern within the context of their work, rather than referring to their personal experience. A participant, with experience of supporting other women during the perinatal period, felt that in-depth knowledge was unnecessary, but enough information in an accessible way was helpful so that women were informed.

> *"Even when I'm seeing these mums now, I've got these guides from Action on Postpartum Psychosis to give them, but then I'm like 'I don't want to give them too much information that it freaks them out' but they need information that they're informed, so it's finding the balance isn't it."*
>
> *Participant 3*

By contrast, women who were considering their own personal experience, were less concerned about the issue of including too much information. One woman explained that she would like a guide with "lots and lots of detail", but also appreciated that she might not want what the "average person" would. Participant 4 explained her experience of receiving

conflicting advice from different professionals on medication and felt that extensive information about medication would be helpful.

> *"I think it would be really helpful to have all the information about the medication that is available"*
>
> *Participant 4*

Participants discussed the idea of there being two kinds of women who might read the guide: those who would like to know everything and appreciate thorough information, and those who may be seeking a more basic understanding. Some professionals felt that the guide should accommodate for women seeking detailed information, to ensure that the guide would be useful to them.

> *"I would probably put more in than less because I think you don't want your guide to be so simple that it's … not worth referring to … You have to cater to the you know really interested and intelligent as well don't you?"*
>
> *GP*

Suggestions on how the guide could accommodate women's differing information needs were including briefer, initial information in the guide, and signposting to more in-depth information.

> *"Some women will want just to have a quick little read through something; some women will want to know everything to the last dot"*
>
> *Participant 3*

Participants also felt that signposting to other sources of more detailed information on topics such as medication would be sensible, as otherwise they would require regular updating to correspond with new research findings and guidelines changing over time. A second suggestion on how the guide could accommodate all women was to include key messages, summaries and quotes for women who may not want to read section but may focus on key pieces of information.

> *"I think actually in the guide, yknow, on each page, if you had like a quote from different women, that would be nice, just- because sometimes,*

> *yknow you read these guides and things and you're like "oh there's so much to take in", but then you'd home in on something that was in speech marks or whatever and, and think "oh yeah" and then you'd probably read the rest of it but, you sometimes, I- well I do that I home in on something that's in bold or something and then I go "oh that sounds- that's telling it in a nutshell""*
>
> *Participant 3*

4.3.3.3 INFORMATION ON SENSITIVE TOPICS

Women also commented that reading information on certain topics, for example, on the individualised risk of becoming unwell, could be "scary". Despite this, women also felt it was important to be informed on topics such as this, and that the guide should not "skirt over" important information.

> *"I think if you've got a major mental health problem, it's not going to scare you to know a bit more. Yknow it is a scary thing to say you've maybe got a 50% chance of it happening again or … the statistics are high … but it's kind of like knowledge is power … it's empowering you if you know what might happen, and it lets you consider if you … want to have another pregnancy or … what type of medication you want to take … it's really important to let people know, there's no point in hiding it"*
>
> *Participant 1*

It was felt that sensitive topics should be covered in a way that was not too "alarming". Participants recognised the different information needs of women who were currently making decisions relating to having a child, compared to those who were already pregnant. Women questioned how helpful it would be to include information on more sensitive topics, such as the risk of bipolar disorder being passed on to their child, particularly if women were currently pregnant and had not thought of this before. Participants discussed how this information would be helpful for women in the pre-conception stage but recognised that for some women, information such as this would be difficult to read.

> *"It seems strange not to put it in just in case you hurt someone's feelings … I'd rather know about things, those statistics and the research … But yeah, if you're already pregnant it's really not that helpful"*
>
> *Participant 1*

Women and professional stakeholders felt strongly that social services, specifically children being taken into care, were a source of worry for many women. Participants discussed the benefits of including brief information on social services in the guide, and emphasising that mental illness alone is not a reason to be referred to social services:

> *"Yeah, just that one little bit of information yeah … It's not gonna be like "ohh this mother is mental health, this baby, this family is gonna need a lot more observation from social services" – no, not at all … I think … it's worth giving a nod to it and including it in your guide"*
>
> *Participant 5*

A perinatal psychiatrist suggested it would be helpful to include the fact that most women with bipolar disorder do not have their child removed from them.

> *"I think you should say something because most women are worried about it … and actually most women with bipolar disorder don't have their children taken away from them, but most people worry about it"*
>
> *Perinatal Psychiatrist*

Parenting was another topic that women and other professional stakeholders had varying views on. Women and other professional stakeholders expressed concern about including information on parenting with a diagnosis of bipolar disorder and how this could negatively impact women reading the guide. Women and professional stakeholders felt that information relating to parenting should be the same for everyone, regardless of diagnosis and that including it in a guide specifically for women with bipolar disorder or previous postpartum psychosis could appear to be stigmatising.

> *"I wouldn't, in my opinion… it would perhaps be wrong to segregate people as a parent that has bipolar or a parent who you know, has had previous*

episodes of psychosis. The parenting aspect of it is and should be the same

for everyone"

Social worker

While the majority of participants lent towards not including information relating to parenting, of those who advocated the usefulness of this information, one suggestion included signposting to general information about parenting (i.e. not specifically written for women with experience of mental illness). One woman described however that more long-term issues such as parenting were the "biggest factor that played overall in making my decision" and felt it would be helpful to hear how a mental illness could impact on parenting.

4.3.4 Theme 2: Planning and preparing
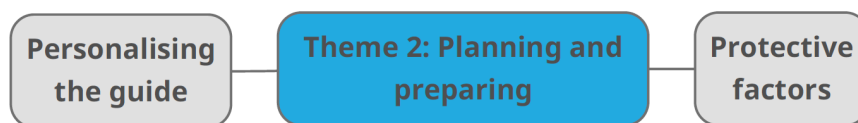
Figure 4.3 Thematic map for Theme 2: Planning and preparing

Developing individualised plans for pregnancy and the postpartum period was a key discussion point during the interviews. As presented in Figure 4.3, data relating to this theme was organised into the following two subthemes: personalising the guide and protective factors. Many felt the guide should encourage women to consider and write out plans to encourage a sense of control and empowerment. Professional stakeholders emphasised the importance of women being engaged in the process of planning and feeling in control of their situation.

4.3.4.1 PERSONALISING THE GUIDE

It was considered important for the guide to be something that the women held and had ownership over. Professionals and women in this study suggested that personalising the guide would advocate a sense of ownership over both the guide, and their experience of planning a pregnancy more generally.

"Certainly as a clinician I would find it really helpful if women and families

can have this sort of thing so that they are really engaged in the process

> *and empowered through this process rather than feeling daunted …*
> *although we should be doing collaborative care planning it's … really hard*
> *to get families and women to own their care because they're like what is*
> *a care plan so actually something from the start that um is owned by them*
> *is really important"*
>
> *Health visitor and public health specialist*

Professionals felt this would empower women through the process of planning and take an active role in planning and decision making.

> *"People engage with something like that, they've got ownership over it*
> *and they help create it, and it's not being told to do something but it's like*
> *taking that responsibility for their own health and wellbeing, you know*
> *mental health, and you'd expect them then to use it more and be more*
> *engaged and pull it together."*
>
> *Clinical psychologist*

Women in the study reflected on developing their own detailed plans before attending appointments and felt the guide should encourage women to make their own plans. As well as evoking a sense of control and empowerment, other benefits of personalising the guide and having a plan written down included: a way of sharing plans and preferences with others, encouraging communication between teams involved in the woman's care, preparing for appointments and also saving the women from repeating their previous mental health history during different appointments.

Making their own plans helped women to feel in control, even when things did not end up going to plan. Knowing that there was a plan in place helped women to feel less stressed in the lead up to the birth, reassuring them that they had done everything within their control.

Specific suggestions on what women could write in their plan in the guide included: information on previous mental health episodes, early warning signs and triggers, any preferences relating to support and care during the perinatal period and important contact numbers.

In addition to writing plans, other recommendations on how the guide could be personalised included providing space to write notes. This could be used to reflect on decisions, to write a summary of discussions with professionals or to write questions that they would like to ask during appointments with professionals.

> *"And I would put a section um, a section sorry, in which, what question I would ask to my doctor 'cause you want to empower them … So "what's my plan", you know like not all women, just some women want to know "where am I going if I'm sick", and it's like "show me"."*
>
> *Perinatal psychiatrist and researcher*

Responses suggested the importance of the guide not being too prescriptive and to allow for flexibility. Women and professionals in this study acknowledged that some women may read the guide but choose not to personalise the guide. Or women may choose to personalise the guide, but may not wish to share this with anyone.

4.3.4.2 PROTECTIVE FACTORS

When planning a pregnancy, women and professionals felt it would be helpful for the guide to have a focus on factors that can be controlled. It was felt that women needed to be aware of their individualised risk based on their diagnosis and previous mental health history, but for the guide to focus on what women could do to help lower the risk of becoming unwell.

> *"Protective factors 'cause I would, I would not necessarily go into things that you can't change … the DNA, you know you can't change that so it's not helpful information. It's helpful perhaps to target your risk but it's not 'cause we don't know enough … so actually I would focus on modifiable factors"*
>
> *Perinatal psychiatrist and researcher*

Women in the study felt that self-management and lifestyle strategies played an important role in helping them recover if they had become unwell or preventing them from becoming unwell in the first place.

> *I would absolutely include the lifestyle side of it because for me … that's been a huge element in terms of my sort of recovery"*

> *Participant 4*

One professional stated that information on protective factors such as lifestyle and self-management strategies should be covered in a way that did not evoke guilt in women if they did become unwell. It was important to clarify to women that even with the best effort to make plans to prevent an episode, sometimes becoming unwell was out of their control and impossible to prevent.

> *"Doing it in a way that doesn't make women feel that it's all down to them and what they do because that's something I've had to have a conversation with women sometimes … if they become ill sometimes it's just not their day and it's just bit of luck, a flip of a coin … it's not that somebody did something wrong … I think there's a lot of guilt in these situations and actually trying to dispel a bit of that"*
>
> *Consultant perinatal psychiatrist*

Participants had numerous suggestions on what might be helpful to include when discussing protective factors in the guide. This included seeking support from significant others, being aware of previous triggers and early warning signs and ensuring significant others were aware of the signs and had access to important contact details in case of emergency. Other suggestions included mood monitoring, exercise, such as yoga or short walks, taking time to relax, reducing stress (in the lead up to the birth and after) and thinking about sleep.

A practical suggestion that women and professionals in this study felt women should consider in advance was managing visitors after having the baby. Participants felt women should not feel pressure to have visitors until they were ready and feel able to prioritise their own needs. Participants felt that setting boundaries relating to visitors would help women to take the time they needed to recover, sleep and rest.

> *"That's like, the one bit of advice that I always try and give people, it's like it's such a major thing, yknow, you wouldn't- if you had a huge operation, you wouldn't be inviting loads of visitors, yknow you'd say "just give me a bit of time to recover" … so yeah, I think that's really important to kind of say "you don't have to have lots of visitors, and you can take time to rest""*
>
> *Participant 1*

Sleep was an important consideration when planning for late pregnancy and the postpartum period. Sleep was discussed as a potential trigger for becoming unwell and participants suggested numerous strategies to assist women with planning for sleep. This included acknowledging the impact of feeding on sleep when making decisions to breastfeed, bottle feed or combination feed. Other considerations included asking significant others to help with night feeds.

> *"I suppose just letting people know how important it is to sleep and look after yourself because you can't look after your baby unless you were ok so yeah, it is ok to stop or to yknow feed combination yknow, give them breastmilk and bottle feed if it's necessary, if it's what they've got to do. If you can't breastfeed because of medication then that's ok as well"*
>
> *Participant 1*

During the interviews, one woman reflected on her own experience of feeling selfish for needing to sleep after having her baby. She felt it was important for other women to know that prioritising sleep was not selfish, but important for her and her baby.

> *"Yeah or even just so that they know that it's not selfish, because I felt like I was being selfish when I was saying "look, I need to sleep" because I was like "well you had this baby, you wanted it, you need to look after it, you can't just say oh wait a minute, I need to sleep" but I think to let mums know that it's not selfish, it's important."*
>
> *Participant 1*

Although it is expected that sleep will be disrupted with a newborn baby, one woman felt that women should acknowledge their needs as a mother with a severe mental illness to ensure that they are getting enough sleep to reduce the risk of becoming unwell. Participants also raised that any suggestions relating to promoting sleep would need to be tailored to suit the postpartum period.

4.3.5 Theme 3: Positivity and reassurance
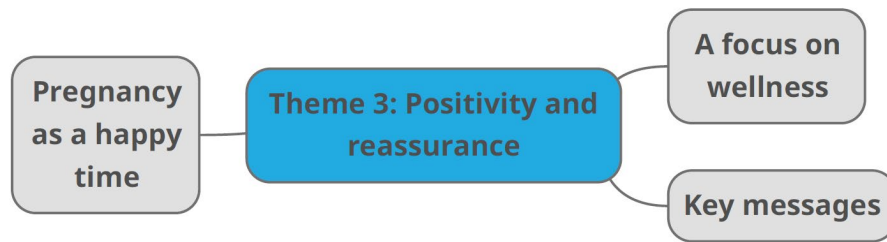
Figure 4.4 Thematic map for Theme 3: Positivity and reassurance

Participants felt the guide should adopt a positive and reassuring tone and suggested ways that this could be achieved through the content and presentation of the guide. As presented in Figure 4.4, data relating to this theme was organised into the following four subthemes: pregnancy as a happy time; a focus on wellness and key messages.

4.3.5.1 KEY MESSAGES

Key messages that professionals and women in the study referred to included "pregnancy is possible", "recovery is possible" and "prognosis is good". Women described how hearing from other women who have had children encouraging and provided hope that they could start a family.

> *"And seeing that over the last few years, hearing, even just one story like that like 'if they can [do] it I can do it'"*
>
> *Participant 8*

When considering times where women have become unwell during the perinatal period, participants felt it would be helpful to focus on the fact that women do recover, and that prognosis is good. Suggestions on how to portray these key messages involved including real-life stories from women who have been there themselves and have recovered well. Women commented how this would not only be helpful when planning a pregnancy, but also for women currently recovering from severe perinatal mental illness to know that it may take time to recover, but that things will get better.

> *"Oh definitely, even some of the work that we're involved in now in terms of Mother and Baby units in terms of really, really unwell women, who can't believe that- "you were here too?" "Yeah." And that is, it's almost*

> *that lightbulb moment, which is really, really important to offer that. That*
> *hope and that real possibility of it, cos when you're going through it you*
> *think you know your life's over, even when you're recovering you think*
> *your life's over because it can take that time to get back."*
>
> *Participant 6*

The need for a positive and hopeful tone was balanced with the need for an honest and a realistic outlook on the risk of becoming unwell. Participants emphasised the importance of also focusing on recovery when discussing women's individualised risks of becoming unwell. One participant, described below, suggested that including stories from women with lived experience of becoming unwell during the perinatal period, with a focus on their recovery, would be helpful.

> *"It's got to demonstrate to women that risks can be really high but actually*
> *the prognosis is quite good as well, um so maybe … recovery stories from*
> *other women would be helpful"*
>
> *Health visitor and public health specialist*

4.3.5.2 PREGNANCY AS A HAPPY TIME

Women in the study explained that when planning for a high risk pregnancy, the typical idea of it being a happy and exciting time was sometimes lost. Participant 6 described her experience of planning a pregnancy and striving to keep a balance between planning in the event of becoming unwell, but also recognising this as a "happy and exciting time" for her and her partner:

> *"I don't know to be honest, I think on some level it was a 'finding out what*
> *was helpful' but then not getting it as that being the overriding thing about*
> *thinking about having another baby is the only thing was(sic) you know*
> *becoming unwell again obviously it was a major factor of it but we tried to*
> *keep it very much balanced in terms of, you know all sorts of other things*
> *could've gone wrong sort of pregnancy related and I guess just that sort of*
> *not getting too, not getting too wound up or too anxious about one thing*
> *might happen and yes it was obviously it was a major thing that had*
> *happened before but actually it was really important in terms of trying not*

> *to let…what should be a really happy and exciting time be overshadowed by something I suppose."*
>
> *Participant 6*

Participant 3 pointed towards resources that she felt achieved a positive tone, such as the APP 'insider guides'. This participant felt that it was important to acknowledge pregnancy as an important life event and that this was celebrated. Despite the fact that women reading the guide would be at high risk of becoming unwell with their mental health, it was important that the guide did not only focus on becoming unwell. It was emphasised that the guide should not feel as if it was questioning women for their decisions to have a baby.

> *"In the APP booklets there's "congratulations on your pregnancy!" I think it just comes across really nice, just yknow, "oh … congratulations on planning the next part of your life" or something … just so it's not like, "the doom of this could make you ill" yknow "what are you doing?""*
>
> *Participant 3*

One woman felt that the colour scheme could also contribute towards making the guide appear positive and not overly medical, and provided specific colours that she felt would be calming, positive and happy. These were the colours blue, purple and yellow.

> *"If you're gonna put any colours on it, calming colours like erm you know blues or purples or yellows … yellows is normally positive and happy."*
>
> *Participant 2*

While professionals encouraged a sense of positivity in other ways, such as focusing on remaining well and protective factors, contrastingly to the responses from women, no professionals discussed the idea of viewing this time as a "happy" or "exciting" time for women.

4.3.5.3 A FOCUS ON WELLNESS

Participants expressed uncertainty when thinking of a suitable title for the guide. Women and professionals in the study considered it helpful for the title to make it clear who the

guide was for, for practical reasons. However, they were also apprehensive about including diagnoses on the front and felt that the front cover should focus on planning and wellness.

> *"Something simple like … 'my wellness plan' … this is around wellbeing it's not about illness and diagnosis"*
>
> *Health visitor and public health specialist*

Some women expressed that they would not choose to have their diagnosis on the front cover of a guide. Women provided clear examples of times when having diagnoses on the front cover of the guide would make them uncomfortable. Examples included reading the guide in public, or leaving it around the house where others could see it.

> *"I am a bit … closed off about being bipolar and I don't really talk about it much so if I had a book on my … coffee table that said "bipolar" on … that wouldn't be my preference"*
>
> *Participant 4*

Some suggestions for the title included having diagnoses presented on the front cover of the guide, but in a less conspicuous way. For example, participants suggested including diagnoses in smaller writing under the main title. One woman suggested having a more general title and then including more specific information such as "for pregnant women or people looking to have a baby … that have bipolar disorder and / or have had previous postpartum psychosis" in smaller text on the cover.

One woman expressed the difficulty in providing a guide that would appeal to women with varying diagnoses, explaining that some women with experience of postpartum psychosis, but without a diagnosis of bipolar disorder might be deterred from using the guide if it associated them with a diagnosis of bipolar disorder.

> *"I like, yeah, pregnancy planning guide make a lot of sense, pregnancy planning support … I don't know about including all the stuff about bipolar and … psychosis, but I suppose you do need to put that somewhere … because I'm not bipolar I find it really weird being associated with people with bipolar … "pregnancy planning guide for women and families*

susceptible to high risk conditions" … something like that you can make it a bit friendlier."

Participant 2

4.3.6 Theme 4: Using the guide with others
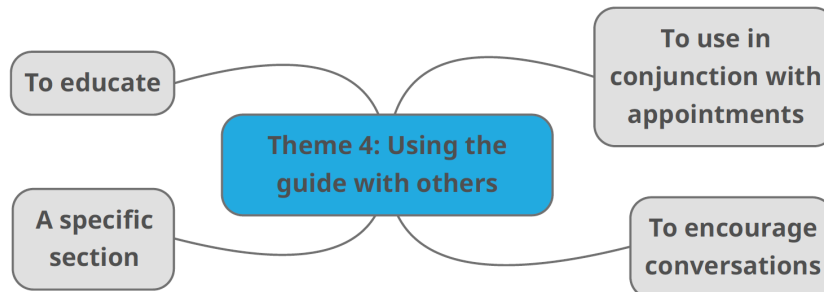
Figure 4.5 Thematic map for Theme 4: Using the guide with others

Women and other professional stakeholders suggested using the guide with others to achieve several different objectives. As presented in Figure 4.5, these were summarised into four subthemes, which were: to educate; to use in conjunction with appointments; a specific section; and to encourage conversations.

4.3.6.1 TO EDUCATE

Women reflected on their own experiences of becoming unwell or planning for a high risk pregnancy and the role that their partner played during this time. Many emphasised the importance of their partner knowing what early warning signs and symptoms to look out for as well as how to respond to this. Suggestions for the guide included having space to write down important contact numbers so that significant others can access support women need in a timely manner. One important reason to educate partners about individual early warning signs and symptoms was because partners may not have experienced the woman becoming unwell before.

"I think that the partner needs to be very involved throughout – and also the partner may never of seen the woman unwell before … so it might be that they need some kind of education"

Perinatal psychiatrist

Women and professionals envisaged the guide as something that could be used to prepare for appointments, and in some cases, during appointments. Women commented on how the guide could offer a central place for women to write notes following discussions with clinicians.

> *"Key spaces for information so that you can write down some of the notes from those key discussions like when you meet your perinatal psychiatrist, what are their suggestions of the things you need to remember"*
>
> *Participant 7*

Women and healthcare professionals felt it was important for the guide to be used in conjunction with healthcare appointments, to ensure that a tailored approach was adopted when needed and any further questions were answered. Some suggested the usefulness of not only using the guide alongside professional care, but during appointments:

> *"Yeah, I think something that you can maybe go through with your midwife that would make specific points and questions and let you fill in bits and work with a plan together … you can write bits in and your midwife can write bits in and everybody else involved"*
>
> *Participant 1*

However, some women in the study saw the guide as something that they would use at home when preparing for appointments, rather than something that they would take along with them. Some clinicians also felt that the guide may be better suited as something to work through at home and follow up on during appointments, particularly if appointments were short, such as a ten-minute GP appointment. For example, a GP saw the benefit of women using the guide prior to an appointment, having reflected on their thoughts surrounding issues relating to pregnancy, which could then be discussed during the appointment.

> *"No, I mean as a GP that would be helpful, erm if they brought something with then because you can see what their thinking and what their reading straight away and you can get to the, get to the sort of nitty gritty of it,*

> *rather than having to – err you having to help them break down the barriers and being able to talk about it."*
>
> *GP*

4.3.6.3 A SPECIFIC SECTION FOR SIGNIFICANT OTHERS

Women advocated the idea of including a specific section for significant others and had numerous ideas and opinions on how best to achieve this. Suggestions for this section included ways that a partner can support the new mother, information on symptoms and early warning signs that are personal to the woman.

> *"I think, from my experience my husband would have liked something that was specifically for him … So it might be that it's just one page or something that's just, yknow, "these are the signs you might need to … look out for in your partner""*
>
> *Participant 3*

Women and other professional stakeholders highlighted how this can be a difficult time for partners and significant others and felt strongly about including information on wellbeing and support available for partners and significant others during the perinatal period. Women and other professional stakeholders stressed the importance of ensuring inclusivity in this section, recognising that some women may have a partner that is female, may not have a partner or may rely on family members or friends as their main source of support.

4.3.6.4 TO ENCOURAGE CONVERSATIONS

As seen in the 'To use in conjunction with appointments' above, the guide was seen as something that could "break down barriers" when discussing sensitive topics. Women and professionals explained how a guide like this could act like and aid to help to initiate conversations with partners, family members and professionals.

> *"It's a good springboard to sort of talk about stuff"*
>
> *Community mental health nurse and researcher*

4.4 Prototype one

The analysis of the qualitative interviews presented in this chapter, alongside the review of online information, input from the advisory group and discussions with the supervisory team, informed the development of the initial prototype of the guide. This section describes the initial prototype, including illustrative examples from the guide.

4.4.1 Title, cover and presentation

The cover included the title 'Planning your pregnancy' and subtitle 'Information for women with bipolar disorder or previous postpartum psychosis, to read and personalise' (see Figure 4.6). The cover photo included a stock image of a woman at a desk, writing in a notepad with a coffee cup beside her. Advice gained from the development stage and the advisory group was that the majority of women reading this guide would not be pregnant, and therefore an image of a woman who was not obviously pregnant was chosen. The overall colour scheme for the guide was blue, yellow and grey. As discussed earlier in the chapter, women felt that the overall presentation and colour scheme should not have an overly medical feel. Colours suggested for this desired effect included blue and yellow which a woman with lived experience felt would be calming, positive and happy.

Figure 4.6 Cover page

4.4.2 'About me' pages

As discussed above, women and key stakeholders described the benefits of having the option of personalising the guide. A section to personalise was added in and termed 'About me' sections. Figure 4.7 presents the first page of the 'About me' section, including guidance and suggestions on using it. The majority of the 'About me' pages followed the initial introductory pages of the guide. This was a 14-page stand-alone 'About me' section. This section included space for women writing information on topics such as their previous episodes, early warning signs and triggers to becoming unwell. 'About me' pages also included interactive exercises to promote reflection on worries and concerns they may have.

About me

Questions about my history and lifestyle

This section includes boxes for you to fill in with information about yourself.

It is up to you who you share this document with. This can be shared with your partner, family, friends and healthcare professionals.

Writing down your information in one place may help you to prepare for appointments with healthcare professionals. It may help others to understand your decisions and know what you want to happen if you become unwell.

Personal details

Name: _____

Date of birth: _____

NHS number: _____

Estimated delivery date: _____

Elective C-section date (if applicable): _____

About me

Information about yourself, such as who you live with, any other children you have, whether this is your first pregnancy. You can also include information about you as a person – your personality, things you enjoy doing. *Please feel free to write in paragraphs or bullet points.*

_____
_____
_____
_____
_____
_____
_____
_____
_____

8

Figure 4.7 Cover page of the initial prototype of the guide

4.4.3 Using this guide

The initial pages of the guide were designed to give women an overview of what to expect, and ideas on how to use it. It also included a quote from a woman with lived experience of postpartum psychosis. This section also included suggestions on how to use the guide, based on feedback from the qualitative interviews and suggestions from the advisory group. It was emphasised that women could determine how to use the guide in a way that worked best for them, see Figure 4.8.

94

Some ways to use this guide

We have some suggestions below on how you can get the most out of this guide, however we suggest using the guide in a way that works best for you.

■ **It can be personalised**

You will see spaces to make your own notes and interactive exercises to help you prepare for appointments.

■ **It can be used to aid discussions with significant others**

You may find it useful to work through this guide with a partner, family member or friend. There are sections in this guide that are designed to be shared with others.

■ **It can be used to aid discussions with healthcare professionals**

It may help to use the guide at home while preparing for your appointments with healthcare professionals. You may want to let your healthcare professionals know you are using this guide – sharing the interactive sections in this guide with them may be helpful.

The importance of clinical care

This guide is not a replacement for your usual clinical care. Your healthcare professional or clinical team will be able to give you specialist, tailored advice.

The guide has been designed to complement the clinical care you are receiving and act as a starting point to getting the information and support you need.

5

Figure 4.8 Introductory page including suggestions on how to use the guide

4.4.4 Section 1: How could childbirth impact on my mental health?

This section included information on symptoms and treatment of mental health conditions that can occur during pregnancy and after birth. This included information on postpartum psychosis, postnatal depression and brief information on other conditions that may occur during this time, such as anxiety. Information was also included on the postnatal blues, with an emphasis of the importance of not mistaking this for serious mental illnesses, such as postnatal depression or postpartum psychosis. Information on the individualised risk of becoming unwell was also presented in this section as an infographic (see Figure 4.9).

Bipolar, postpartum psychosis and childbirth

What's the link?

0.1%

or 1 in 1000 women may experience postpartum psychosis

The likeihood of experiencing postnatal depression rises to 1.5 in 10 women

Women with bipolar or previous experience of postpartum psychosis or postnatal depression are at an increased risk of becoming unwell during the perinatal period.

There are some factors that can increase your chances of becoming unwell. These factors include a history of certain mental health conditions and a family history of becoming unwell.

2.5 in 10

If you have a diagnosis of bipolar, your chance of experiencing postnatal depression is 2.5 in 10 or 25%.

If you have a diagnosis of bipolar and your mother or sister has experienced postpartum psychosis, your chance of experiencing postpartum psychosis is 5 in 10 or 50%.

If you have experienced an episode of postpartum psychosis and have a diagnosis of bipolar, your chance of experiencing postpartum psychosis in a subsequent pregnancy may be as high as 7 in 10 or 70%.

If you have a diagnosis of bipolar and have experienced a previous perinatal episode of mental illness, your chance of experiencing an episode (mania, psychosis or depression) in this pregnancy is 5.5 in 10 or 55%.

3 in 10

If you have a diagnosis of bipolar and did not experience a perinatal episode of mental illness during your last pregnancy, your chance of experiencing an episode in this pregnancy is around 3 in 10 or 30%.

27

Figure 4.9 Information on the individualised risk of becoming unwell

4.4.5 Section 2: What do I need to think about when planning a pregnancy?

This section included information to consider when considering or planning a pregnancy. As shown in Figure 4.10, the first page included a quote from a woman describing her experience of planning a second pregnancy following postpartum psychosis. Following feedback from the interviews, women from the advisory group were asked to write quotes that they felt would be helpful for women receiving the guide to read. Reflective questions and interactive scales to complete included reflecting on reasons for having a baby and potential concerns. Questions included: "Why am I feeling positive about having a baby?" and "What are my concerns and worries about having a baby?" This section ended with a

five-point scale to circle on "How certain am I about whether or not to have a baby?", presented in Figure 4.11.

What do I need to think about when planning a pregnancy?

Deciding to have a child is an important decision for any woman. For a woman with bipolar or previous postpartum psychosis, this decision may be more complex.

This section has been designed to help you consider your choices when thinking about having a baby.

If you are already pregnant, you may decide to skip ahead to the next section.

The following questions are designed to provide you with a starting point to help you decide about whether or not to start a family or have another baby.

Spend some time noting down your thoughts for each question in the boxes.

You may find it helpful to work through these questions with your partner, family member or friend.

> *There were so many more things for us to consider when deciding to have our second child: Would I get ill again? If I did get ill again, how would it affect our firstborn? Would I want to take medication during pregnancy?*
>
> *While I was still in recovery from postpartum psychosis, I could never imagine wanting to take the risk of PP again. Yet when I began to feel more like myself again, I knew that I desperately wanted to give my son the joy of a sibling.*
>
> *So we found out everything we could about the risks of PP reoccurring and how it might be possible, with careful planning, to prevent another episode. In the end realising that there was a possibility of experiencing another episode of psychosis whether I had another pregnancy or not, cemented our decision.*
>
> *We decided to have another child, and weather whatever storm may come – except this time we would be fully prepared for the worst. Thankfully, though there were wobbles along the way, we prevented a second episode of PP with medication and a supportive perinatal team. We are now a family of four.*
>
> A woman who experienced postpartum psychosis with her first child

31

Figure 4.10 First page of Section 2 'What do I need to think about when planning a pregnancy?'

_____
_____
_____
_____
_____
_____
_____
_____

How certain am I about whether or not to have a baby?

Circle the scale below where best fits in with how you are feeling:

1   2   3   4   5

1 - Absolutely sure about not having a baby   3 - Unsure about having a baby
5 - Absolutely sure about having a baby

Key messages

- Having a baby is a big decision for anyone, but for women with a diagnosis of bipolar or previous postpartum psychosis, there is more to think about.

- It will be helpful to think about what your thoughts and preferences are about whether or not to have a baby.

- This is a section that you might revisit and consider over time. Your decision may change as you work through the information in this guide and with your healthcare professionals.

Remember it is ok to reconsider your decision over time.

38

Figure 4.11 Final page of Section 2 'What do I need to think about when planning a pregnancy?'

4.4.6 Section 3: What support may I receive during pregnancy and after having a baby?

This section included information on support that women may receive during the perinatal period. This included healthcare appointments, third sector organisation support and social services. It also included an 'Important contacts' sheet and interactive exercises relating to the 'pros and cons' of Mother and Baby Units (MBU).

4.4.7 Section 4: What do I need to know about medication and pregnancy?

This section included information on medication options to consider and factors to consider when making decisions relating to medication, as shown in Figure 4.11. This section also

included information on who women can discuss medication options with, and example questions that women could raise at appointments to discuss with a healthcare professional.

Who can I discuss my options with?

It is important to discuss medication plans with the doctors prescribing for you - your psychiatrist, or GP for example, ideally before you become pregnant.

A pharmacist may also be able to give you information.

If you have a perinatal mental health team in your area, they may be able to offer you an appointment even before you are pregnant to discuss your options.

Your healthcare professional will be able to offer you tailored advice but ultimately, it will be your decision whether you decide to continue, stop or change your medication.

The options to consider are summarised in the box below.

Your options with medication and pregnancy:

There are three broad options that you will need to consider with the professionals involved in your care: no change, switch or stop

- **No change** - continue your current medication through pregnancy and after birth
- **Switch** - stop your current medication and start another medication(s)
- **Stop** - come off your current medication

There are two options if stopping:
- To stop taking medication throughout the pregnancy and after the baby is born – restarting only if you become unwell

- To stop taking medication and then restart medication later in the pregnancy or after birth to help keep you as well as possible

53

Figure 4.12 Example page from Section 4 'What do I need to know about medication and pregnancy?'

4.4.8 Section 5: How can I help myself stay well?

This section included self-management strategies and suggestions on how others can support women to keep well during the perinatal period. Suggestions came from the development stage qualitative interviews and the advisory group. These were suggestions based on what women had found helpful when they had become unwell and what they felt helped them to remain well during a second pregnancy following previous experience of postpartum psychosis.

99

4.4.9 Section 6: What do partners, family and friends need to know?

This section included information for partners and significant others to read. A key messages box was included with recognition that this section was not only for partners, but for anyone who may be supporting women during this time (see Figure 4.13).

What do partners, family and friends need to know?

Although we use the term 'partner' in this section, this information will be helpful for everyone who plays a key part in the mother's life.

Families come in all shapes and sizes and this section is for anyone who wants to know more and be supportive during this time.

This section is for the partners, family and friends that want to know how they can support you.

It includes suggestions on how to help yourself keep well during pregnancy and after giving birth.

In this section we provide you with information about supporting your partner with decisions relating to pregnancy, during

pregnancy and if she becomes unwell. This section also aims to help you to think about your own wellbeing during this time.

While it is important to plan ahead in case your partner does become unwell, it is not inevitable that she will. Many women will remain well during pregnancy and after birth.

Some women will be more likely than others to become unwell.
Women with experience of bipolar, postpartum psychosis, or a family history of severe mental health conditions during pregnancy and birth are more likely to become ill during pregnancy or after birth.

You can find more information about the chances of becoming unwell during this time and what symptoms can look like in Section 2 of this guide.

Thinking about having a baby

Deciding on whether to have a baby is an important decision that can bring up a mixture of feelings for anyone.

For women with bipolar or those who have been unwell with their mental health during previous pregnancies, thinking about having a baby can bring up a lot of worries, for them and their partners.

Sharing your feelings and worries will help you to make an informed decision together – **there is no right or wrong answer.**

Remember that help with these decisions is available. You may be able to speak to a specialist such as a perinatal psychiatrist when planning for a pregnancy.

72

Figure 4.13 First page of Section 6 'What do partners, family and friends need to know?'

4.4.10 Section 7: Bringing it all together

This section included questions for women to reflect on their planning, considering what their plans so far and their next steps. Each question included half a page of writing space (see Figure 4.14).

Bringing it all together

Now that you have come to the end of the guide, you may be better placed to make some of the difficult decisions we have discussed.

Reading through the information may have answered some questions and made clear the questions that you still need to ask.

You may have made the decision to have a baby and are now looking to develop plans and discuss further with your healthcare professionals.

Or maybe you haven't decided yet – you may want to discuss your options in more detail with your healthcare professionals and third sector organisations.

Whether you have made your decision or not, this section is designed to help you plan what the next steps are for you.

Next steps
Consider each of these questions and use the boxes below to write down how you feel and any plans that you have related to each one.

How do I feel about how much I know?
Do I have enough information about mental health problems during the perinatal period?

eg I want to find out more about postpartum psychosis. Plan - ask my psychiatrist about this

81

Figure 4.14 Section 7 'Bringing it all together'

4.4.11 Format

The guide was presented in an A4 slimline ring binder folder. The ring binder design was chosen to offer women the flexibility of using the guide in different ways. This included removing personal information included in the 'About me' sections of the guide, to take to during appointments, and having the option of updating these pages.

4.4.12 Input from women with lived experience

Quotes from women with lived experience of bipolar disorder / postpartum psychosis were included throughout the guide. As discussed above, quotes were provided by members of the advisory group and from existing resources developed by the National Centre for Mental Health (NCMH) and Action on Postpartum Psychosis (APP).

4.5 Conclusion

This chapter presented the results from the development stage of this project which involved qualitative interviews focusing on the thoughts and opinions of women with lived experience and professional stakeholders on the content and presentation of a pregnancy planning guide. The initial prototype of the guide, developed based on the results from this chapter along with other sources described above, was tested as part of pilot one, presented in Chapter 5.

Chapter 5 Pilot one results

5.1 Overview

This project involved developing and testing a pregnancy planning guide for women with bipolar disorder or previous experience of postpartum psychosis to use when planning a pregnancy. The guide was developed following Medical Research Council (MRC) guidance for the development of a complex intervention (Craig et al. 2008). The aim of pilot one, presented in this chapter, was to test the initial prototype of the guide and to refine it based on feedback. The initial prototype of the guide was designed for women who were considering, planning or were currently pregnant. It was designed specifically for women who had a diagnosis of bipolar disorder or previous experience of postpartum psychosis. As explained in the introductory section of the initial guide prototype, the guide could also be useful for women with other diagnoses, for example, schizoaffective disorder and other mood and psychosis related experiences. The guide aimed to be helpful for women at varying stages of preconception and pregnancy, i.e. those who were yet to decide whether they would like to have a baby or not, those who were currently planning a pregnancy, or those who were already pregnant.

This chapter presents the qualitative and quantitative results from pilot one. Participants with lived experience of bipolar disorder and / or postpartum psychosis who were planning a pregnancy or currently pregnant tested the guide for approximately four weeks. Participants took part in a semi-structured qualitative interview with the researcher after testing the guide. The purpose of this interview was to hear women's thoughts and opinions on the guide, and any ideas or suggestions that they had for improvements. All interviews were conducted via phone or video call and were conducted between September 2020 and November 2020. Interviews were digitally recorded for later transcription. Participants also completed self-administered questionnaire measures before and after using the guide. The qualitative and quantitative results informed decisions relating to the refinements made to the prototype of the guide and provided insight into its acceptability. Changes made to the guide are discussed in this chapter, with examples from prototype two presented at the end.

5.1.1 Participants

Recruitment for this pilot study was guided by the 'Information power' concept (Malterud et al. 2016; Braun and Clarke 2021b). Ten women were selected. Of the ten selected, nine women were interviewed. For the one participant who withdrew, I asked by telephone her

reasons for not taking part. She reported that taking part would take too much of her time and that there appeared to be too much writing involved with the guide. The participant was in her 3rd trimester of pregnancy. Of the nine participants interviewed in pilot one, one did not send back her post-guide questionnaires (designed to be completed after using the guide).

The average interview time was 55 minutes, 33 seconds (range: 00:28:47 – 01:10:54). The average age of women who took part in the qualitative interviews was 36.4 (range 26–44, SD 5.55). Six women had been diagnosed with bipolar disorder (and had no experience of postpartum psychosis) (67%). One woman had a diagnosis of bipolar disorder and had experience of postpartum psychosis (11%). As presented in Table 5.1, two women had previous experience of postpartum psychosis, but did not have a diagnosis of bipolar disorder (22%). The sample consisted of women at different stages of the planning process. Five women were considering or planning their first pregnancy (56%) and two women were considering their second pregnancy (22%). Two women were pregnant at the time of interview (22%), for one of whom it was their first pregnancy.

Characteristic	Frequency (N=9) (%)
Age	
20–30 years	1 (11%)
31–40 years	5 (56%)
>40 years	3 (33%)
Ethnicity	
White British	6 (67%)
Any other White background	1 (11%)
Any other Asian background	1 (11%)
Mixed / Multiple ethnic background	1 (11%)
Employment status	
Employed, full time / part time	7 (78%)
Homemaker	1 (11%)
Out of work and looking for work	1 (11%)
Level of education	
Graduate level or above	7 (78%)
A Levels of NVQ qualifications	1 (11%)
5+ GCSEs or equivalent	1 (11%)
Partner / Single	

Partner	9 (100%)
Diagnosis	
Bipolar disorder	6 (67%)
Bipolar disorder and Postpartum psychosis	1 (11%)
Postpartum psychosis	2 (22%)
Pregnancy planning	
Considering or planning first pregnancy	5 (56%)
Considering or planning second pregnancy	2 (22%)
Currently pregnant (1st pregnancy)	1 (11%)
Currently pregnant (2nd pregnancy)	1 (11%)

Table 5.1 Sample characteristics for completers in pilot one

5.2 Qualitative results

5.2.1 Overview of qualitative results

This section presents the qualitative results of semi-structured interviews conducted with women with lived experience of bipolar disorder and / or postpartum psychosis who were considering or planning a pregnancy or were currently pregnant.

As presented in Figure 5.1, overarching themes were identified and used as a framework for presenting the results. These were: 1) Using the guide in different ways; 2) Using the guide with others; 3) Realistic and positive; and 4) Reflective planning and decision making.
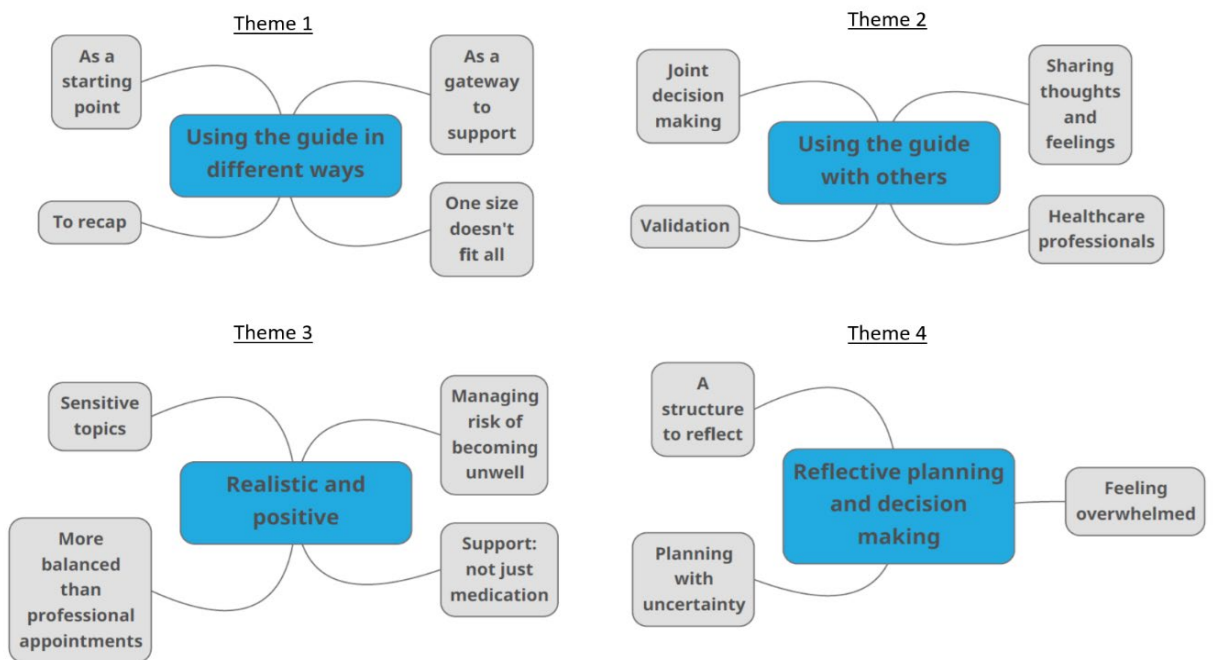
Figure 5.1 Four overarching themes identified and used as a framework for presenting pilot one qualitative interview results

5.2.2 Overall impressions of participants

Overall feedback was positive from women who took part in pilot one. All women taking part in the interviews found the guide helpful, with women earlier in their experience of planning finding it the most useful. The guide helped women to plan in a structured way and it was seen as something that could be shared with others and revisited more than once throughout the perinatal period.

The guide was seen as more than just an information source; it was used as a conversation prompt, a way to recap, and as a tool to validate their existing knowledge to others and also as reassurance to themselves. All women had specific recommendations and suggestions on how the guide could be improved, described in more detail below.

5.2.3 Theme 1: Using the guide in different ways
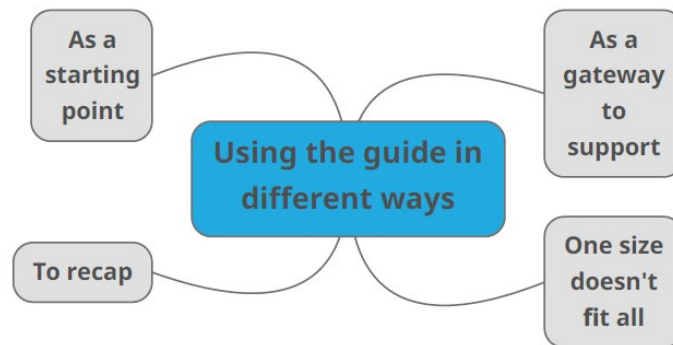
Figure 5.2 Thematic map for Theme 1: Using the guide in different ways

As presented in Figure 5.2, data relating to the theme 1 'Using the guide in different ways' was organised into the following four subthemes: as a starting point, as a gateway to support, to recap, and one size doesn't fit all. Some women made use of the whole guide, reading each section in order and completing the interactive sections. Other women, found it helpful to pick the most relevant sections to read, using the contents page to navigate their way through the guide.

Those most likely to utilise the whole guide were women earlier in their planning journey. Women who had considered pregnancy for a number of years, were under the care of a perinatal mental health team and / or were currently pregnant found some information sections and the interactive sections less relevant to them. This was because they were topics they had covered previously through their own research or during discussions with healthcare professionals.

5.2.3.1 AS A STARTING POINT

Women who had been considering a pregnancy for a number of years, or had lived experience of becoming unwell during pregnancy, felt that the guide was not particularly informative to them and more suited to women earlier in the planning process. Some women had done extensive research of their own before testing the guide and in some cases, had also received support from perinatal mental health specialists.

> *"It's definitely a guide that I would've loved to have received before planning, you know in the very early stages of planning a pregnancy."*
>
> *Participant 9*

Another woman found the guide helpful to consider during the stage of planning that she was at but commented that she would have appreciated more detail in some sections. Overall, she felt that the guide was helpful at an early stage and that further research would be required to further her plans.

> *"Maybe I would seek more information as I go but at the very early stage…*
> *I really found it helpful."*
>
> *Participant 1*

This person also found the signposting helpful. She commented that having the additional information that was signposted to included in the guide would be even more helpful but acknowledged that having such detailed information would not suit all women.

The guide included reflective exercises designed to help explore thoughts and feelings relating to the decision of whether to have a child. Predictably, women who were yet to decide whether to have a baby utilised these interactive sections the most. Women commented that the guide helped with decision making and that the reflective exercises played a key role in this.

> *"I used it I think this guide definitely helps you make a decision, so if you're*
> *not really decided what you want to do I definitely think that the guide*
> *helps you to feel more confident to plan a baby."*
>
> *Participant 7*

One woman explained that the guide as a whole had helped her and her partner to decide about whether to have a baby.

> *"It's really good preparation for me, the last time I spoke to you like I said*
> *to you we can't decide it's like one day we decide we'll have a baby, the*
> *next day we're not sure and now we've decided that we are going to go*
> *ahead. This is perfect timing for me as well."*
>
> *Participant 7*

For other women, the guide highlighted that there was more to think about when considering having a baby than they had initially thought. Using the guide made them realise that there was a great deal to reflect on before deciding whether to have a baby. Having a baby is a major life change for any women and is likely to be even more stressful for women at high risk of becoming unwell during the perinatal period. During the interviews, women discussed how making decisions about pregnancy could be a stressful experience and at times, had negatively impacted on their mental health. As a result, they realised it was important to focus on their own mental health before taking on a decision like this.

> *"Erm, actually it erm it made it very clear to me erm that erm maybe before making the decision I should focus on erm my … mental state and try to sort err things out … before making a decision like this. Erm so it – yeah, it made it maybe a bit clearer."*
>
> *Participant 1*

5.2.3.2 AS A GATEWAY TO SUPPORT

Women considered the guide to be helpful in identifying the first steps in accessing support when considering or planning a pregnancy. Additionally, women discussed how it also helped them to understand what to expect from appointments and how best to prepare.

> *"I actually now have an idea - where to consult, who to consult in the … next stages. I know what is available … I also have bit of idea what I should take to the consultation as well."*
>
> *Participant 1*

Overall, women mostly described the guide as having the right balance of information. It was felt that the guide was informative, with signposting to help keep the guide concise, but helpful to those who wanted to research more into certain topics.

Women who were considering their first pregnancy or planning a high risk pregnancy for the first time (for example, following a previous episode of postpartum psychosis), felt that the guide helped them to understand what professional support might be available to them. Reading the guide encouraged some participants to contact their general practitioner (GP) for advice or a referral to more specialist perinatal mental health services.

> *"Yeah [the guide has] definitely helped with realising that I need to call my GP and set up a support network here because I've just moved … so I don't have any teams in place whereas where I was, where I used to live I'd probably naturally go to the people who were looking after me before … but here I don't even know what's available so [the guide has] kind of got the ball rolling that I called the GP and see what perinatal services are in the area where I am now … it's good that [the guide has] got me you know putting plans in place and making decisions to find what's here and yeah basically get the ball rolling."*
>
> *Participant 7*

5.2.3.3 TO RECAP

Many women using the guide had been considering a pregnancy for a number of years and over this time, had gained an in-depth understanding of many issues relating to bipolar disorder, postpartum psychosis and pregnancy. Sources of information included, mental health and specialist perinatal mental health professionals, online resources, research articles, peer support services and attendance at webinars and conferences. Additionally, two of the women testing the guide were pregnant and under the care of a perinatal mental health team at the time.

Some women explained that they did not learn much new information from the guide due to the extensive research they had done already. It is likely that the way in which participants were recruited led the sample to include women who were more expert in these areas compared to most other women. It was interesting however that these women still found the guide useful as a way of recapping on what they already knew. This suggested that the guide was not only beneficial as an information tool, but also helpful for the planning process in other ways.

One woman, who was pregnant, explained how the guide was helpful not only because it provided her with information, but also because it reassured her that she had already reflected on and discussed many of the topics included in the guide. The discussion within Theme 2 'Using the guide with others' and Theme 4 'Reflective planning and decision making' also provided an insight into how women found it helpful in ways, other than increasing their own knowledge.

> *"It's given me a lot of reassurance as well because you know I obviously think a lot of the things we'd already thought about and talked about but there certainly been things that have come up because of the guide. Erm, and I think in terms of really making sure that I am prepared working through that has helped to reassure me a little bit more."*
>
> *Participant 2*

Women used the guide in different ways, depending on how much knowledge they had beforehand. Women who had more prior knowledge relating to planning a high risk pregnancy found it helpful to skip to the most relevant parts of the guide.

> *"I liked how you know that you have your contents and things that you could go to different parts when you wanted to because although I said that this guide is concise it is quite a lengthy guide, so it was good to have those sections, you could go back and forth through and I read it like all the way through and I went back and forth and it made just as much sense both ways really."*
>
> *Participant 9*

5.2.3.4 ONE SIZE DOESN'T FIT ALL

A key challenge discussed during the development stage and this current pilot was maintaining a balance between keeping the guide focused, but also relevant to women in varying situations with different previous experiences. Women suggested adding information on particular topics that played an important role in their personal experiences of decision making relating to pregnancy. For example, topics included fertility and c-section experience.

> *"The topic of fertility in general and kind of the difficulty of conception could have been covered, but also I do appreciate as a subject that's fairly easy to attain that information on the internet, or through a GP, or what have you anyway."*
>
> *Participant 3*

Suggestions on accommodating this information included signposting women to additional information online. This would allow women to further research a topic only if it were relevant to them, allowing the guide to remain as focused as possible. Similarly, a participant with experience of a c-section suggested this as being helpful to cover, but also appreciated that it may be difficult to include everything that may be relevant to women planning a pregnancy.

> *"See this is quite individual to me, but I don't know if it's something that you would add, but one of the factors, one of the issues that I has was that I had a C-section … now I've got experience of C-section so I know what questions to ask, but for someone who hadn't had a C-section, I didn't plan, I didn't have any information, or planning in place before I got sick so I dunno I mean again you could branch off into so many different subjects couldn't you to do with birth I mean there's so many things, that's just something that happened to me, so it just depends on how common it is and how it's a factor."*
>
> *Participant 7*

Another factor that affected a person's experience of the guide was the diagnosis that they had received. The difficult task of designing a guide for women with bipolar disorder and for women with experience of postpartum psychosis without a bipolar disorder diagnosis, was also discussed during the initial development stage and considered in the refinement of prototype one. Similar to the development stage, those who considered this to be a potential issue for the guide were women who had lived experience of postpartum psychosis and did not consider themselves to have a diagnosis of bipolar disorder.

Women without a diagnosis of bipolar disorder felt that some parts of the guide were less relevant to them. Examples included the 'About me' sections which invited the individual to complete a life chart. One participant felt this was less relevant to her as she had only experienced one episode of mental illness. Another example was an interactive section inviting women with bipolar disorder to consider self-management strategies that they had found helpful previously.

> *"I think it's a little bit tricky covering both bipolar and postpartum psychosis in the same guide in some ways … cos like page 70 is very much bipolar again, but that's I mean its fine I just sort of skip those ones"*
>
> *Participant 8*

Despite this, it was felt that sections such as these could be skipped by those who felt they were not relevant. However, following this feedback, one revision was made, which involved changing an interactive section from 'You may want to think about times when you have been at your most stable in your *bipolar'* to 'You may want to think about times when you have been at your most stable in your *mental health'*.

5.2.4 Theme 2: Using the guide with others
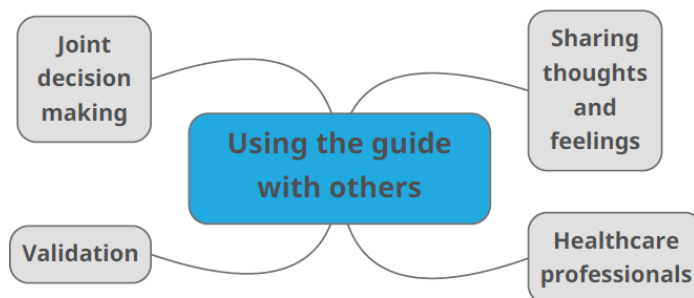
Figure 5.3 Thematic map for Theme 2: Using the guide with others

As presented in Figure 5.3, data relating to theme 2 'Using the guide with others' was organised into the following four subthemes: joint decision making; sharing thoughts and feelings; validation; and healthcare professionals.

'Using the guide with others' was a key discussion point and was also a theme during the initial development stage of the project. As a result, the initial guide prototype tested as part of pilot one aimed to encourage discussion and collaboration with others when making decisions and plans relating to pregnancy. It was therefore encouraging that women found it beneficial to use the guide with others in a variety of ways. Women mostly spoke about using the guide with a partner. Some women used the guide with other family members, or had intentions of doing so after the initial four weeks of testing the guide as part of this project.

With the guide being in a physical form, its potential for collaborative use may not have been

fully realised during this project due to social distancing restrictions associated with the COVID-19 pandemic. Women shared how the pandemic may have affected their likelihood to use the guide with others, including healthcare professionals that they were now seeing remotely. Women described their plans to use the guide more with family members once social distancing restrictions were eased. Women also discussed barriers to using the guide with others which were unrelated to the COVID-19 pandemic and corresponding restrictions. Women explained how limited time during appointments could also be a potential barrier to using the guide during healthcare appointments.

> *"I would definitely share it with health professionals if I had usual appointments as well where I actually see them in the flesh, obviously when you're on a telephone consultation you know … and cos I haven't even- I've spoken to a midwife on the phone and someone from the perinatal team, but I don't actually know what they look like or anything and … time is limited really, so I do feel it has been affected."*
>
> *Participant 9*

5.2.4.1 JOINT DECISION MAKING

The guide covered many decisions that women and their partner may face during the perinatal period. Examples included deciding on whether to have a child, the use of medication during the perinatal period, and managing visitors during the postpartum period. Many of the decisions that women reflected on during the interviews were considered as joint decisions between themselves and their partners.

Women felt that the guide portrayed decisions as something that the partner or the woman considered alone, rather than together. For example, Section 6 'What do partners, family and friends need to know?' included information for significant others to consider, including suggestions on how to manage visitors. As shown in the quote below, it was felt that this was portrayed as something that the partner would consider alone, without input from the woman.

> *"The one thing I would say, while were just talking about erm your partner erm kind of managing visitors for example … I felt like I would want it to be more explicit about that being like a joint decision … Because … it says*

> like 'managing visitors erm in the early days after giving birth you may want to manage the number of visitors you have to ensure your partner has enough time to rest and sleep' … in our relationship … I felt like that was a very joint thing that we'll do together … I felt like in our situation I'd want that to be more collaborative."
>
> *Participant 6*

Another participant commented on her partner's opinions on an interactive section designed to encourage women to reflect on their thoughts and feelings on the decision to have a baby. In this instance, it was felt that the guide covered this in a way that did not consider the partner's role in this decision. Similarly, it was felt that a decision such as this would be a joint decision and that the guide should reflect this.

> "I think he found it a little bit, sort of woman focused, well mother focused, like particularly sort of … reflecting on the decision to start a family or have another baby, was all quite focused on the woman rather than the couple … Yeah like the question like 'When is the right time for me to have a baby?' That sort of thing. Yeah then on page 38, 'it's how certain am I about whether or not to have a baby?', so I think he felt a bit excluded."
>
> *Participant 8*

As discussed during the initial development stage of the project, ensuring that the guide is inclusive to all, including individuals who may not have a partner, was an important consideration. Because of this, some sections mentioned by participants, for example, questions relating to the decision to have a child, remained as questions aimed at the woman. I felt that this alongside the acknowledgement of the important role that others may play (included in the introductory sentences) within the guide was the right balance.

All participants in pilot one had a partner. In pilot two, it was thought to be beneficial to specifically include women who were consider or planning a pregnancy without a partner in the sample. This allowed me to gain a perspective on the appropriateness of the language used throughout the guide when discussing decision making.

The guide was considered a helpful tool to initiate conversations that may be difficult or uncomfortable. Women felt that the guide was a helpful way of encouraging involvement from others in the planning process and prioritising important discussions in a timely way.

> *"It was quite timely in that it reminded me that it is still quite important for me and it, and it sort of re-prioritised itself on my kind of life-plan … rather than it be off the table, not talked about, feeling uncomfortable raising it with my partner, it was like actually no we do need to, we do need to think about this."*
>
> *Participant 3*

Using the guide provided women and their significant others an opportunity to discuss their thoughts and feelings on important decisions relating to pregnancy. It was also considered a way to make the partner feel involved in the process of decision making and planning.

> *"I mean he seems, yeah, I think this, it would be good to show him this section and make him feel quite involved and discuss how he feels about it."*
>
> *Participant 4*

5.2.4.3 VALIDATION

In addition to helping with decision making and providing a platform to share feelings, women explained how the guide provided them with validation of their existing knowledge when sharing this with others. For example, discussing information relating to the importance of sleep and self-management strategies in the guide helped reinforce to their partner how important these were. Similar to the development stage of the project, a point that was raised was that a partner may not have seen the woman unwell before. As a result of this, women felt that a partner may not appreciate the importance of planning ahead with important risk factors of becoming unwell in mind.

The guide was considered a tool that could raise awareness of important risk factors such as a lack of sleep and emphasise the importance of these to others.

116

> *"It started a conversation between us where I'd sort of said well they're your parents though and I feel like I would get more support from my parents … the visitor thing opened up an interesting conversation between us … and the sleep section as well erm, it's something he knows about because sleep was like a really big thing in my manic episodes so, it's something that I've talked about a lot but I think seeing it written down probably really kind of brings that home … because he wasn't around [when I was previously unwell] a part of me sometimes worries that he thinks that I'm just saying this to get out of night time feeds … having it like in black and white that actually you know this is a real risk factor erm, hopefully will make him erm, like more aware of that erm just means sort of prioritise me getting enough sleep more."*
>
> *Participant 2*

Women used the guide at home prior to appointments, which increased their confidence to bring up conversations and share their own views and concerns with their healthcare professionals. Examples include women who discussed preparing care plans with perinatal mental health teams and discussing medication with healthcare professionals involved in their care. One woman described a psychiatrist involved in her care as being "pro-medication" and valued having the guide as another source of information on medication. The guide included a section relating to medication which discussed the options available to women during the perinatal period, for example, stopping, switching, starting or continuing with or without medication. Responses suggested that the guide may have provided a more balanced view of these options compared to information received from some healthcare professionals. For this participant, the guide appeared to increase her confidence in raising her own concerns relating to taking medication. The participant explained that she felt less concerned about taking medication following the appointment, suggesting that voicing her concerns may have contributed to a valuable discussion with her healthcare professional about her specific needs and concerns.

> *"I'm not taking medication at the moment and I think the, this kind of will feed into when I … put together a care plan to make sort of my views known that I would like to … have medication as like a last resort really … I know my first appointment was with the psychiatrist they were quite pro*

> *medication and I came away feeling quite disconcerted about that because I haven't been on medication for such a long time. Erm but my second appointment was very different and I think this guide kind of helped me to think about voicing those concerns, that actually I was less concerned about erm [long pause], less concerned I suppose about erm medication now and taking it now but more about what will happen afterwards.*
>
> *Participant 2*

The information in the guide, particularly the medication section, provided women with the confidence to voice their own concerns. In this example, the participant initiated a conversation about her desire to continue medication during a future pregnancy with a GP, something that she was advised against previously. In both examples, initiating a conversation led to a discussion that participants felt was helpful and reassuring.

> *"This section is probably the most important to me because I'm taking Citalopram at the moment and in my first pregnancy I stopped taking Citalopram because the doctor said it can have an effect on babies heart, but now I don't wanna stop taking Citalopram so this is a very interesting section for me and I've already spoken to the GP and she's reassured me regarding Citalopram and pregnancy so yeah very, very helpful"*
>
> *Participant 1*

Providing women with the guide appears to have helped shift the power balance of knowledge when discussing medication with professionals. Providing women with this information appeared to encourage productive conversations where professionals were able to provide women with tailored advice on medication, while also considering the woman's own thoughts and feelings.

5.2.4.4 HEALTHCARE PROFESSIONALS

Some, but not all women, felt that they would use the guide with healthcare professionals in the future. Despite this, nobody used the guide with healthcare professionals during the current testing phase. Various reasons for not using the guide with professionals were discussed. Some women explained that the effect of the COVID-19 pandemic on their

healthcare appointments prevented any intentions they may have had to use the guide with healthcare professionals, particularly as healthcare appointments were being held remotely (as discussed above). Women also discussed hindrances generally, regardless of the pandemic, to using the guide with professionals. A lack of time during appointments was one reason that women felt that a guide like this may not be a practical addition to appointments. Women also expressed concerns about the sensitive personal information included throughout the guide, and their hesitancy in sharing this with all professionals involved in their care. Examples included the reflective exercises relating to deciding on whether to have a baby.

> *"I think sections of it would be erm, I would give to them, not the whole thing … some of it like you might not want to share with them … but yeah definitely things like erm, you know the contact details section erm things around medication preferences and stuff like that, definitely."*
>
> *Participant 6*

One woman, who was pregnant, and felt that much of the planning and decisions had already been done, but could see the benefit of using the guide with healthcare professionals for someone earlier in their pregnancy.

> *"I think again, if it was earlier in my pregnancy I would've probably – yeah, I think it would have been really useful to take parts of it to erm medical appointments, definitely."*
>
> *Participant 6*

5.2.5 Theme 3: Realistic and positive
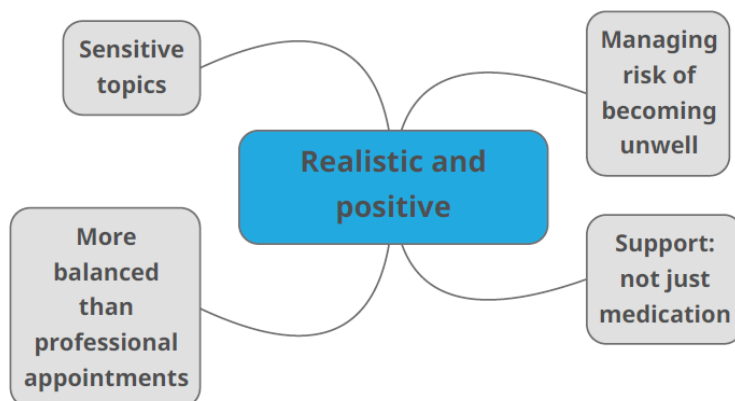
Figure 5.4 Thematic map for Theme 3: Realistic and positive

As presented in Figure 5.4, data relating to theme 3 'Realistic and positive' was organised into the following four subthemes: sensitive topics; managing risk of becoming unwell; more balanced than professional appointments; and support: not just medication. A topic discussed during the initial development phase of the project and pilot one was the importance of getting the balance right with the tone of the guide. It was felt that the guide needed to be realistic and informative, but also provide a sense of hope for women. Overall, women felt that the content in the guide was portrayed positively, and this was something that they valued. Women felt that the inclusion of quotes from women with lived experience helped to instil a sense of positivity and suggested including additional quotes in the guide. Three additional quotes were added to the guide following this feedback. An example is provided at the end of this chapter.

5.2.5.1 SENSITIVE TOPICS

Achieving a realistic and positive tone was particularly important when discussing topics that many women worried about, for example social services and the genetic risk of bipolar disorder being passed on to their children. The inclusion of information on these topics were debated during the initial development phase. Responses from the pilot one provided support for the inclusion of these topics. Women described the inclusion of this information and how it was presented as "positive" and "helpful".

> *"There was a part in there about kind of genetics of bipolar and there's a bit you know that says that I've got bipolar will my children have bipolar*

and I found that section quite reassuring … I thought that was quite a nice thing to put because I think it's something that people do worry about erm, and it was quite positive it wasn't completely damming that this was going to be a problem, erm I think that was helpful."

Participant 2

Participants recognised that genetic risk and the possible involvement of social services were issues that women did think about and therefore including information about them in a helpful way was beneficial. It was felt that the information on social services emphasised the supportive role that social services can offer to women and their families, rather than reinforcing their pre-existing negative views of social services.

"One other bit I thought was quite good in terms of the section page 46 Will I be referred to social services? You know I think … it did emphasise enough that that's more of a support cos that can seem quite scary potentially, but I think it did make it clear that this is sort of support rather than a negative kind of experience."

Participant 4

5.2.5.2 MANAGING RISK OF BECOMING UNWELL

Having a comprehensive and realistic view of the individualised risk of becoming unwell for women with a diagnosis of bipolar disorder or previous experience of mental illness was considered important. Women liked that the guide covered information on ways to work towards reducing the risk of becoming unwell. The guide encouraged women to consider self-management strategies, engaging with professional services and having a strong support network.

Women explained self-management strategies were key for them during previous episodes had been, as acknowledged in the quote below. Women stated that it was important that these suggestions were included alongside the key message that some women may do all the right things to keep themselves well, but this may still not be enough.

"I think it's realistic I like the fact that … that everything that you might do might not be enough still so that's not your fault. I thought that was

> *quite nicely emphasised a couple of times in this section. Erm, no its supports in there which I wouldn't be here without erm, yeah practical things you can do erm, avoiding major life changes…"*
>
> *Participant 6*

5.2.5.3 More balanced than professional appointments

Women appreciated the balanced view the guide offered and overall, felt it provided them with hope to go ahead with planning a pregnancy.

> *"Yeah 100% it's definitely- it really feels like the first thing to support me going ahead about having a baby."*
>
> *Participant 7*

Some women commented specifically that the contents of the guide appeared more positive than discussions they had with professionals up until that point.

> *"No, I thought it was, certainly less bias than my appointment with my psychiatrist, erm I felt that was much more positive."*
>
> *Participant 2*

As discussed in theme 2, 'Using the guide with others', women revisited previous conversations about medication with their healthcare professionals after reading the guide. They felt empowered to express their own concerns and views on the option proposed by their healthcare professional. Following these discussions, women's plans regarding medication appeared to align more with their own values. This may suggest that previous discussions were biased towards a particular course of action in previous appointments before using the guide.

> *"I think my initial contact was very medication focused erm you know, what you taking, this is what you will be taking, erm and talking [about] it to the psychiatrist"*
>
> *Participant 2*

Providing women with information to consider prior to appointments encouraged them and professionals to adopt a more collaborative nature to the decision-making process. The guide appeared to motivate women to take a more active role in making decisions, fostering a more equal partnership between women and their healthcare professional.

5.2.5.4 SUPPORT: NOT JUST MEDICATION

The guide included information about different services that women may expect throughout the perinatal period. This included those involved in their mental health care, their maternity health care, in addition to other support services such as social services and peer support. Women commented that it was reassuring that services were described as not only being there to support them in relation to medication, but may also be able to offer other services such as psychological therapy or signposting to peer support.

> *"My initial preconception was all about medication and I was kind of under the impression that they were just going to be there to make sure I was medicated … I think seeing some of the other things written down erm, made me think actually you know it's not just about that, … I think like having the list of things that they do and not just medication reviews erm I think for me, certainly, was really good. … I think it just sort of made me, more positive about the perinatal team … I think seeing that the do offer sort of talking therapies or group therapies and you know like mother and baby erm, like activities, so I know now that my local one does the local walking group, peer support worker erm and I think that sort of thing is reassuring it certainly was to me"*
>
> *Participant 2*

5.2.6 Theme 4: Reflective planning and decision making
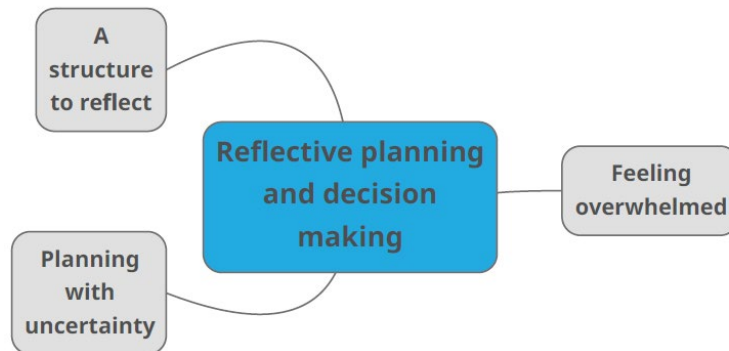
Figure 5.5 Thematic map for Theme 4: Reflective planning and decision making

As presented in Figure 5.5, data relating to theme 4 'Reflective planning and decision making' was organised into the following three subthemes: a structure to reflect; feeling overwhelmed; and planning with uncertainty. The emotional impact of planning a pregnancy was a key discussion point during the interviews. Practically, many women included in this sample felt very prepared for pregnancy. However, women described the emotional journey of planning a pregnancy as an ongoing process at all stages of planning, even during pregnancy.

> *"Ultimately, it's your decision and it isn't going to be done at a desk, it's going to be an emotive journey to go on."*
>
> *Participant 6*

For this reason, one woman discussed how the photo used for the cover of the guide (a woman sitting at a desk with a cup of tea and a notepad and pencil) may be misleading. It was felt that the guide cover should portray the reflective element of planning a pregnancy.

> *"I don't love the front cover. It makes it look quite academic … Do you know what I mean, looks a bit like, like you're going to sit down now, and this is very much a paper exercise. Whereas actually what people are doing is living their life each day and ruminating a lot of detail in my case around … you know imagining having another child in the family or, starting a family … that isn't always a desk exercise."*
>
> *Participant 6*

Following this feedback, the image on the cover of the guide was changed to be an image of a woman looking reflectively into the distance without a notepad and pencil.

5.2.6.1 A STRUCTURE TO REFLECT

As already discussed in this chapter, the guide was useful to women in a number of ways, not only as an information source, but also as a conversation prompt or a tool to validate their existing knowledge. Women also found the guide to be helpful in providing a structure to their planning. Women explained how the guide acted as a reminder on what needs to be considered or reflected upon during the process of planning a pregnancy.

> *"I like that how it gets you to really think about everything, so you know stuff that you'd think naturally about, but it's just a nice structure to actually help you plan rather than just working it out yourself and thinking of everything yourself so yeah it's literally what it's called a guide, brilliant."*
>
> *Participant 7*

Women valued the reflective exercises included in the guide as it helped them to make a conscious effort to consider their feelings and discuss with significant others or professionals involved in their care. The guide was considered a helpful reminder to reflect on feelings at different stages of the planning process.

> *"I really like the guide though, I mean it, it helps me to plan consciously rather than just you know being aware of these things and getting on with it and seeing what happens … it's really nice to have this to, to do it, I don't wanna say professionally [laughs] but to do it like with a structure, like to have it I the forefront of your mind and to be organised about it, rather than just having feelings and knowing that you've got to discuss it with your partner, discuss it with your family and you know discuss it with the doctor, it's nice to actually have a guide where you have something to follow and feel like you're really making a conscious effort about what to do."*
>
> *Participant 7*

It appeared that the guide acted as a checklist for some women when making plans for pregnancy. This was apparent when discussing the final section of the guide, 'Bringing it all together'. This section included questions such as 'Do I have enough information about my chance of becoming unwell during pregnancy and after birth?' and 'Do I understand the medication and other treatment options available during pregnancy and after the baby is born?'. Women were also provided several lines below each question as writing space. Women found it helpful to ask themselves these questions and described them as being helpful prompts for planning their next steps. It was felt however that recording lengthy responses to each question in the writing space was not necessary. Nobody utilised this writing space and instead, used them as prompts or simply answered with a 'yes' or a 'no'.

> *"I kind of just didn't really write much there's lots of space to write a lot and a lot of the questions I just answered yes or no … the following questions are all closed questions, do I understand the options available to me and I just feel that I was writing yes, no, yes no … just me personally I, I felt like I'd written enough and read enough already in the guide and I didn't really need to do much more there. Yeah maybe a chart with just ticking the boxes I don't know. I don't think it hurts to have a bit in the back where people can make more notes cos people, some people do write more than others so…"*
>
> *Participant 7*

To reflect how women used this section, the writing spaces were replaced with a 'yes' and 'no' tick box option, as shown at the end of this chapter. To accommodate women who may prefer to write more notes, three note pages were also included towards the end of the guide.

5.2.6.2 FEELING OVERWHELMED

One woman who was considering whether to start planning a pregnancy, initially felt that the guide was "overwhelming". Seeing everything written down in one place highlighted to her that deciding whether to have a child was a bigger decision than she had first thought.

> *"It's made me think am I up for giving it a serious go … I think the fact it's so comprehensive can be both good in terms of knowing what's available*

> *and the risks and things, but it can also feel a bit overwhelming … I realise it's a bigger decision really to make."*
>
> *Participant 4*

Some information that she had not encountered before, that surprised her, was the risk of experiencing depression after birth for women with bipolar disorder. This woman also commented on how reflecting on her own feelings during the interactive sections emphasised to her that there was a great deal for her to consider and think about with her partner. The guide highlighted plans that needed to be in place before having a baby, which she had not fully considered.

> *"When I first started looking at it, I thought oh blimey I've got to think of … difficult things for me in terms of my history and relapse signature … I guess, I wondered whether it has influenced me either more for you know the preparing … or whether I still feel the same in terms of possibly having a baby and it also highlighted for me although my partner has seen me unwell and we've been together for a couple of years there's quite a few things that aren't in place"*
>
> *Participant 4*

After initially feeling overwhelmed, this participant felt more positive once she had read through the whole guide. As described in the quote below, her initial reaction of feeling overwhelmed may also have been affected by current stressful life events relating to work and the COVID-19 pandemic. This person felt that other women should be advised to allow plenty of time to work through the guide and take time to digest the information.

> *"I wonder if I am sort of a bit negative in terms of it feeling a bit overwhelming because I have just had quite a lot going on recently and I don't know because I did feel quite positive by the time I sort of finished reading it I felt actually good."*
>
> *Participant 4*

Testing the guide as part of a research project may not have granted this person the opportunity to use the guide as gradually as she would have liked. All the women who took

part in the interview used the guide thoroughly within the four-week testing period. Although this person had a break from taking part due to a relapse in her bipolar disorder, she had only had the guide for two months at the time of her feedback interview.

Women involved in the project were enthusiastic about receiving the guide both to learn from it themselves, and to help develop a resource that could help other women in a similar position. It is likely that women were motivated to thoroughly cover all the guide to ensure that they were able to provide detailed feedback. Women said that the guide was something that they would in normal circumstances, pick up more than once and refer back to throughout the perinatal period. This suggested that the way in which women used the guide as part of this project may not reflect how they would use it were they not taking part in a research project.

At the beginning of the initial prototype of the guide, an 'About me' section could be found. This included space for women to write down personal information relating to their mental health history, triggers and previous treatments and self-management strategies that had worked well in the past. Women expressed that filling in the 'About me' section helped them to reflect on their own experiences. One woman considered how this could be emotionally difficult for some women, particularly if someone had little experience of reflecting on previous episodes with professionals. It was suggested that it may be helpful for women to consider the support that might be available to them while filling in information like this about themselves.

> *"It says about it will be helpful for your healthcare professional to be aware of your mental health history as you make plans, but actually what it doesn't say is actually it's useful for you to process what you've been through and the value in doing that in preparing for your next pregnancy or not erm and what support you can access to help you do that, if you need it … because I feel like that will be really triggering … Again, everybody is so different."*
>
> *Participant 6*

Following these comments, changes were made to include more prompts to encourage women to complete the 'About me' sections with others, i.e. significant others who were

likely to play a part in decision making and planning, and healthcare professionals involved in a woman's care.

5.2.6.3 PLANNING WITH UNCERTAINTY

Prototype one included reflective exercises to encourage women to think about how certain they were about their decision to have a child. This involved asking women to rate how certain they felt about this on a scale from one to five. This scale was included at the beginning and the end of the guide. Women discussed how these exercises could be unhelpful for more than one reason. It was explained that this may be particularly unhelpful for women who were already pregnant. One woman raised the concern that women may have experienced an unplanned pregnancy and could find this triggering.

> *"I remember towards the end there was like a question printed a circle how certain I am about whether or not to have baby … it almost went back to like the pre pregnancy part and I think that might be quite triggering for unplanned pregnancies maybe."*
>
> *Participant 2*

In addition to being particularly unhelpful for women who were currently pregnant, women also discussed how decisions covered in the guide were not ones with definite right or wrong answers. It may however be important to note that comments on the use of the word 'certain' were made by participants who were currently pregnant, while women who were considering or planning a pregnancy did not feel strongly about this.

> *"There was one word on the page 38 which was how certain am I about whether or not to have a baby and the word certain jarred with me a little bit … well I'm 33 weeks of pregnancy we'd hope we'd be fairly set, we are clearly confident in our decision and happy but I just felt like actually the certainty around it feels very final … I feel like there's never a right or wrong decision to it, but by attaching the words certain to it feels like that's it set in stone, decision made."*
>
> *Participant 6*

This feedback emphasised that feeling uncertain about decisions relating to the perinatal period was common and not necessarily something that needed to be resolved. The key message that there are often no right or wrong answers to the decisions that women are making appeared to be more relevant to the perinatal period. Often, women are making decisions within the context of complete information, for example, when making decisions relating to medication and pregnancy. Following this feedback, the exercises measuring how certain women were about becoming pregnant were removed in prototype two. In addition to this, the second prototype of the guide included a webpage link where women could access downloadable versions of the interactive sections and the guide as a whole. This was designed to provide women with the flexibility of printing off additional copies to re-complete interactive sections if their thoughts and opinions changed over time.

5.2.7 Impact of COVID-19 pandemic

As discussed throughout the chapter, the impact of the COVID-19 pandemic affected most women who took part in some way. This included how women used the guide, the impact on women's plans to become pregnant and the impact it had on women's wellbeing and mental health generally. Women had concerns that were very specific to the effects of COVID-19 pandemic. A key concern was the impact on social distancing rules on the partner being present during labour, visiting during inpatient stays and support networks if they were to become pregnant.

> *"The only worry is that if you're in a MBU that you can't have visitors to do with COVID … which is worrying cos obviously I have I'd want to see my friends and family mainly my son, so if I was to have to go into a MBU and then I couldn't see my child that would yeah, that would be a bit worrying."*
>
> *Participant 7*

Women also discussed concerns relating to whether it was the 'best time' to plan a pregnancy, considering the impact of COVID-19 on their mental health care generally and its potential impact on professional support if they were to become pregnant. For some women, this was coupled with a conflicting pressure of trying for a baby now, because of the concerns they had about their age in relation to fertility.

"The whole backdrop of COVID has made me sort of question a little bit more so than usual I think and I feel like it's sort of adding another pressure in terms of thinking oh my goodness you know I just recently turned 44 this summer you know it's kind of now or never in terms of trying, at the same time it's I wonder whether yeah when it's a good time because I imagine services are kind of difficult to access and it feels like there's a much bigger strain on mental health services and I wonder particularly in [name of town], because there are, I mean I think there are more services available which is a plus and that's partly in light of quite a high level of need in this area. Yeah that's my sort of impression of it and my doctor who I do sort of go to again."

Participant 4

5.3 Quantitative results

5.3.1 Overview of quantitative results

This section presents the quantitative results of pilot one collected through questionnaires before and after the guide, of participants who completed the measures at both time points. Participants completed the following measures before and after using the guide 1) Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith 1983); 2) Altman Mania Scale (AMS) (Altman et al. 1997); 3) Decisional Conflict Scale (DCS) (O'connor 1995); and 4) a bespoke acceptability measure. Further information on each questionnaire can be found in the Method section, Chapter 3.

Questionnaire data allowed me to explore two of the main project aims to determine acceptability of the guide and the feasibility of using these questionnaire measures as part of a larger scale Randomised Controlled Trial (RCT) to test the guide in the future. It was also important to determine whether using the guide had the potential to cause harm to women. Questionnaire data also allowed us to explore decisional conflict within the sample before and after using the guide. Statistical analysis of results from a small sample such as this would be inappropriate due to insufficient power. Participant questionnaire data is therefore presented using line diagrams to plot each participant's scores on the measures described above.

Table 5.2 presents the descriptive statistics for the questionnaire measures from pilot one. Results from the bespoke acceptability measure are presented separately. Of the ten participants recruited, eight participants completed the questionnaire measures before and after using the guide. One participant withdrew before testing the guide and another participant tested the guide but did not fill in the post-guide outcome measures.

Measure	Pre-guide Mean N=8 (SD)	Post-guide Mean N=8 (SD)
HADS-Anxiety	3.63 (4.72)	4.63 (5.45)
HADS-Depression	2.50 (3.34)	3.50 (6.80)
AMS	1.75 (2.96)	3.38 (4.78)
DCS – Section A	36.33 (12.74)	19.34 (14.20)
DCS – Section B	45.90 (18.16)	20.12 (13.48)

Table 5.2 Quantitative results of pilot one pre-guide and post-guide mean and standard deviation (SD) for completers

5.3.2 Hospital Anxiety and Depression Scale (HADS)

The Hospital Anxiety and Depression Scale (HADS) is a brief 14-item standardised self-rating questionnaire to detect the severity of anxiety (7 items) and depression (7 items) simultaneously (Zigmond and Snaith 1983). A higher score represents greater severity of anxiety and depression. In each subscale, scores of 11 or greater indicates a case of anxiety or depression, eight or greater indicates borderline cases, while scores lower than eight indicates no signs of anxiety or depression.
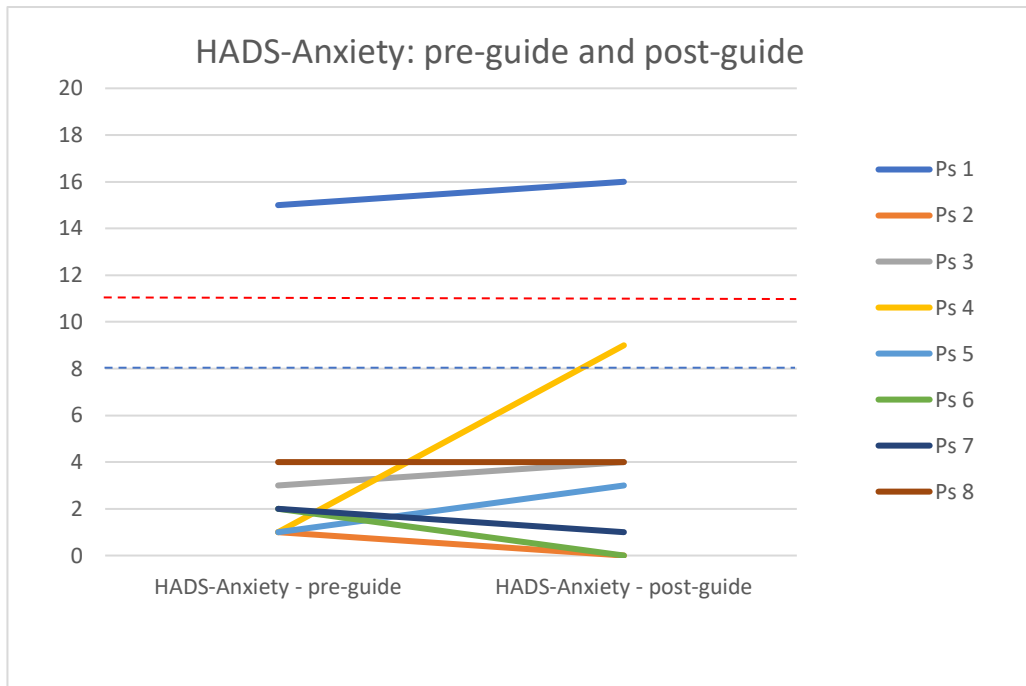
Figure 5.6 HADS-Anxiety results pre-guide and post-guide of pilot one. Red dashed line = cut off for cases (≥11). Blue dashed line = cut off for borderline cases (≥8).

The mean HADS-Anxiety score increased from pre-guide (mean = 3.63; SD = 4.72) to post-guide (mean = 4.63; SD = 5.45). Figure 5.6 presents HADS-Anxiety scores for participants before and after using the guide, with the red dashed line representing the cut off for cases (≥11) and the blue dashed line representing the cut off for borderline cases (≥8). Scores under the blue dashed line indicate no signs of anxiety. Six out of the eight participants scored below the cut off score of eight before and after using the guide. One participant increased from a score of one to nine, falling within the borderline case category. One participant scored considerably above 11 before and after using the guide, suggesting high levels of anxiety which slightly increased after using the guide (score increase from 15 to 16).

When interviewed before and after using the guide, the two participants scoring within the borderline case and case category reported experiencing current life stressors, including unemployment and work stress, which had affected their mental health in recent weeks. One of the participants revealed in her feedback interview that following ongoing discussions with her GP, she had decided to reduce her antidepressant medication during the guide testing phase. One other participant also reported having to self-isolate while living in a house in multiple occupancy due to a potential COVID-19 case within the home. She also took a break from taking part during the testing phase and experienced a relapse in bipolar disorder symptoms during this time. These factors combined may provide an explanation for the elevated scores seen post-guide.
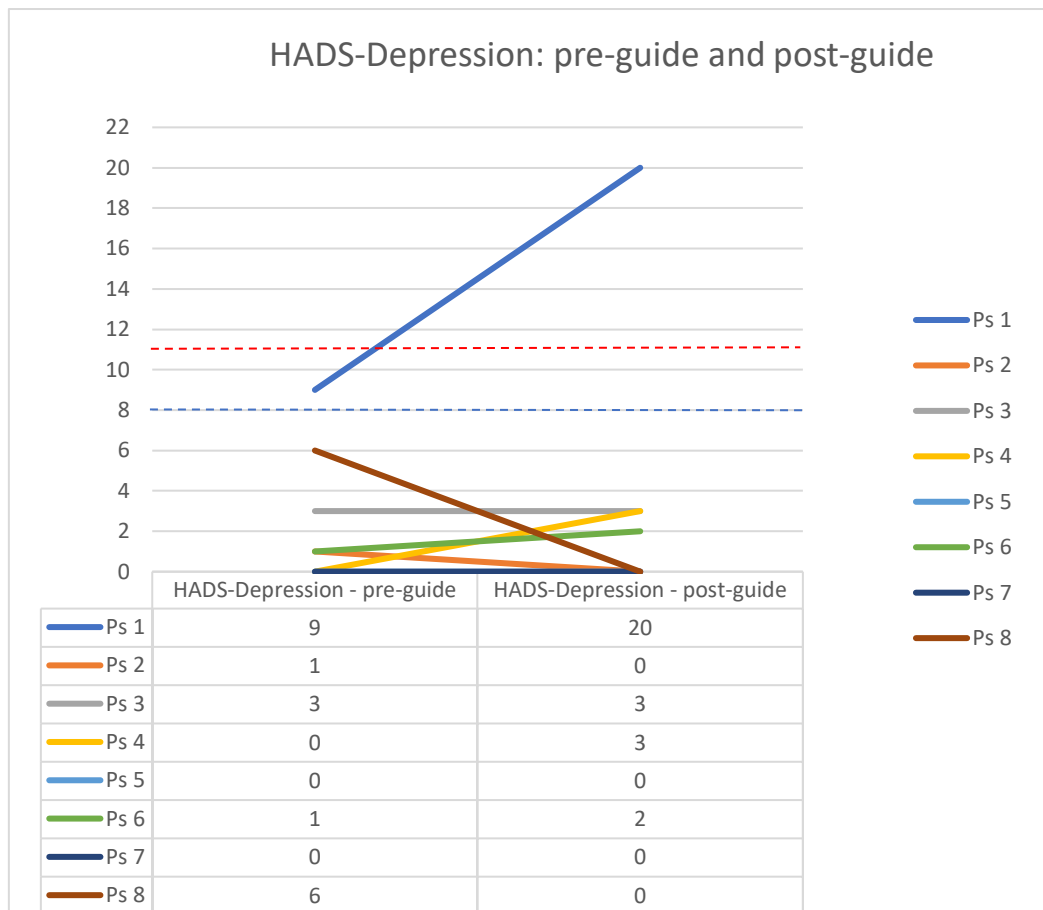
Figure 5.7 HADS-Depression results pre-guide and post-guide of pilot one. Red dashed line = cut off for cases (≥11). Blue dashed line = cut off for borderline cases (≥8).

The mean HADS-Depression score increased from pre-guide (mean = 2.50; SD = 3.34) to post-guide (mean = 3.50; SD = 6.80). Figure 5.7 presents HADS-Depression scores for participants before and after using the guide, with the red dashed line representing the cut off for cases (≥11) and the blue dashed line representing the cut off for borderline cases (≥8). Scores under the blue dashed line indicate no signs of depression.

Seven out of the eight participants presented scored below the cut off score of eight before and after using the guide. One participant fell within the borderline case for depression before using the guide (before score - 9), which increased further after using the guide to the maximum score (after score - 20). As discussed above, factors other than the use of the guide may provide explanation for this elevated score. This participant was currently reducing her dose of antidepressant medication with the advice of her GP, and attributed the change in her mental state to this.

5.3.3 Altman Mania Scale (AMS)

The Altman Mania Scale (AMS) is a self-administered questionnaire including five questions which are answered on a five-point scale to assess the presence and severity of manic or hypomanic symptoms (Altman et al. 1997). The measure has a total score of 20. The AMS assesses differences in baseline levels in five subjective and behavioural areas; elevated / euphoric mood, increased self-esteem, decreased need for sleep, pressured speech, and psychomotor agitation. A score of six or higher (≥6) is used to determine the presence of hypomania. A score of five or lower is less likely to be associated with significant symptoms of mania.

AMS scores: pre-guide and post-guide

	AMS Pre-guide	AMS Post-guide
Ps 1	0	0
Ps 2	1	0
Ps 3	6	7
Ps 4	0	11
Ps 5	7	9
Ps 6	0	0
Ps 7	0	0
Ps 8	0	0
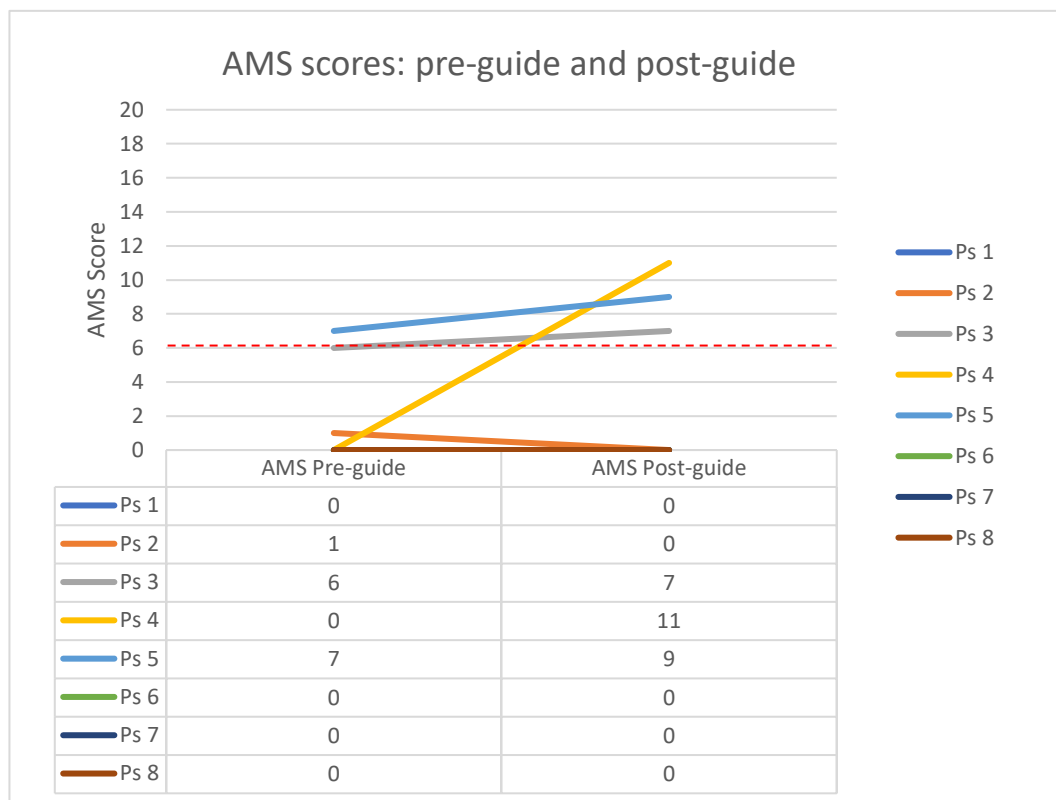
Figure 5.8 Altman Mania Scale (AMS) results pilot one. Scores on or above red dashed line = possible presence of mania or hypomania (≥6).

Figure 5.8 presents Altman Mania Scale (AMS) scores for participants before and after using the guide. The mean AMS score increased from pre-guide (mean = 1.75; SD = 2.96) to post-guide (mean = 3.38; SD = 4.78). A threshold of six or above (≥6) signifies the possible presence of mania or hypomania and is presented in the graph as a red dashed line. A data table is also included, as more than one participant scored zero pre-guide and post-guide, which is not clear from the graph.

Most participants scored the same or lower post-guide compared with pre-guide; four participants scored zero on the AMS pre-guide and post-guide and one participant scored lower on the AMS post-guide compared with pre-guide. Three participants scored above a score of six post-guide; two of whom had also been above this threshold pre-guide. One participant scored considerably higher post-guide compared with pre-guide, with an 11-point increase from 0 to 11. This was the participant who also presented a considerable increase on the HADS.

5.3.4 Decisional Conflict Scale (DCS)

The Decisional Conflict Scale (DCS) is used to measure decisional conflict and has been used widely in a wide range of studies (O'connor 1995). The traditional DCS presented in statement format was used. The traditional DCS includes 16 items and five response categories presented as a 5-point Likert response scale (strongly agree, agree, neither agree or disagree, disagree and strongly disagree). The DCS includes five subscales of decision making, which include 1) Informed (3 items); 2) Values clarity (3 items); 3) Support (3 items); 4) Uncertainty (3 items); and 5) Effective Decision (4 items). Scores above 37.5 are often categorised as high decisional conflict, scores between 25-37.5 as moderate decisional conflict, and scores lower than 25 as low decisional conflict (O'Connor 2010). Decisional conflict scores above 37.5 (>37.5) are associated with decision delay or feeling unsure about implementation, while decisional conflict scores below 25 (<25) are associated with implementing decisions (O'connor 1995).

Participants completed two separate DCS relating to the following decisions: 1) Making a decision about whether or not to have a baby; and 2) Making decisions about medication during pregnancy. Participants were asked to state their current preferred option for each decision.

5.3.4.1 SECTION A: MAKING A DECISION ABOUT WHETHER OR NOT TO HAVE A BABY

For Section A, participants were asked to state their preferred option to the statement 'Making a decision about whether or not to have a baby' from the following list: 'Having a baby', 'Having a baby, but not right now', 'Not having a baby' or 'Unsure'. An 'Other' option was also provided with space to provide more detail. Participant responses relating to their preferred option to the statement above are presented in Table 5.3.

Options Pre-guide / Post-guide		Having a baby	Having a baby, not right now	Not having a baby	Unsure	Other
Ps 1	Pre-guide		X			
	Post-guide			X		
Ps 2	Pre-guide	X				
	Post-guide	X				
Ps 3	Pre-guide					X *Not preventing but not actively trying to conceive*
	Post-guide					X *Actively trying to conceive*
Ps 4	Pre-guide	X				
	Post-guide				X	
Ps 5	Pre-guide	X				
	Post-guide	X				
Ps 6	Pre-guide	X				
	Post-guide	X				
Ps 7	Pre-guide					X *Trying to decide whether to have another baby and when*
	Post-guide		X			
Ps 8	Pre-guide		X			
	Post-guide	X				

Table 5.3 Decisional Conflict Scale (DCS) Section A preferred option responses for the statement 'Making a decision about whether or not to have a baby' pre-guide and post-guide

As shown in Table 5.3, three participants (Participant 2, Participant 5, Participant 6) remained with the same preferred option from pre-guide to post-guide. As shown in Figure 5.9, two of these participants scored within the moderate decisional conflict category (25-37.5) before using the guide, and within the low decisional conflict category (<25) after using the guide. These two participants were currently pregnant. The third participant who remained with the same option, scored within the low decisional conflict category (<25) before and after using the guide, with a reduction in score.

Of the five participants who reported a change in their preferred option, this included changing their preference from: (i) 'Having a baby, but not right now', to 'Not having a baby';

(ii) 'Not actively trying to conceive' (Other), to 'Actively trying to conceive' (Other); (iii) 'Having a baby', to 'Unsure'; (vi) 'Trying to decide whether to have another baby and when' (Other), to 'Having a baby, but not right now'; and (v) 'Having a baby, but not right now', to 'Having a baby'. Each change in option response is discussed in turn, relating to the qualitative data and decisional conflict scores presented in Figure 5.9:

(i) Participant 1 remained within the high decisional conflict category (>37.5), associated with decision delay / feeling unsure about implementation, pre-guide and post-guide. This is reflective of the participant's response during the qualitative interview, where she reflected on delaying the decision-making and focusing firstly on her own mental health. Participant 1's scores for HADS-A, HADS-D and AMS all scored above borderline or case thresholds before and after using the guide.

(ii) Participant 3 scored within the high decisional conflict category pre-guide (>37.5) and scored within the low decisional conflict category (<25) post-guide. The participants score therefore were associated with decision delay / feeling unsure about implementation pre-guide, and post-guide, was associated with implementing decisions.

(iii) Participant 4's score remained within the moderate category pre-guide and post-guide (25-37.5), but showed a slight increase in score. Participant 4 presented with an increase in score, reaching the case threshold for the HADS-A and AMS post-guide.

(iv) Participant 7 scored within the moderate decisional conflict category pre-guide and within the low decisional conflict category post-guide (associated with implementing decisions).

(v) Participant 8 scored within the high decisional conflict category pre-guide, and within the moderate decisional conflict category post-guide.
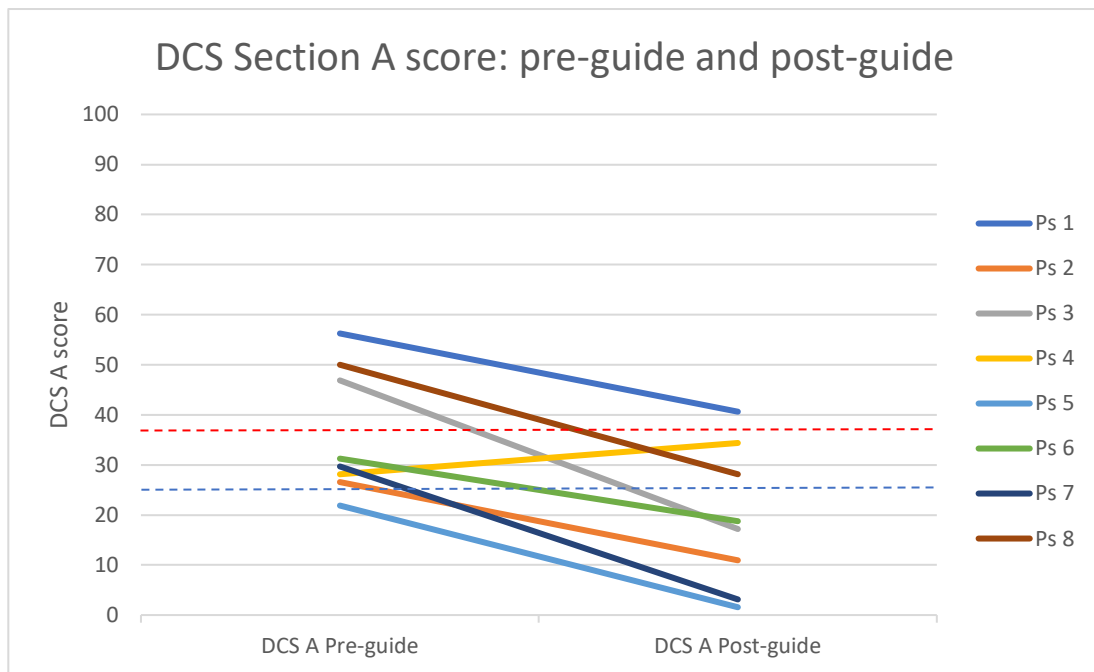
Figure 5.9 Decisional Conflict Scale (DCS) 'Making a decision about whether or not to have a baby' (Section A) results pilot one. Red dashed line = baseline for high decisional conflict scores (>37.5). Blue dashed line = threshold for low decisional conflict scores (<25).

The red dashed line presented in Figure 5.9 represents the baseline for high decisional conflict scores (>37.5), while the blue dashed line represents the threshold for low decisional conflict scores (<25).

All but one participant presented with a decrease in their DCS score relating to deciding whether to have a baby from pre-guide to post-guide. Before using the guide, three of the eight participants presented with high decisional conflict scores. All three participants presented with a lower score after using the guide, with one participant falling within the moderate decisional conflict category (25-37.5), and one within the low decisional conflict category (<25). Before using the guide, only one participant scored within the low decisional conflict category (<25). After using the guide, five participants scored within this category. One participant scored within the low decisional conflict category before and after using the guide, with her score decreasing from being at the top of the category before using the guide, to the point nearest the baseline score after using the guide (score decrease from 22.9 to 1.6). One participant (participant 4) scoring within the moderate decisional conflict category scored higher on the DCS post-guide compared to pre-guide, however her score remained within the moderate decisional conflict category.
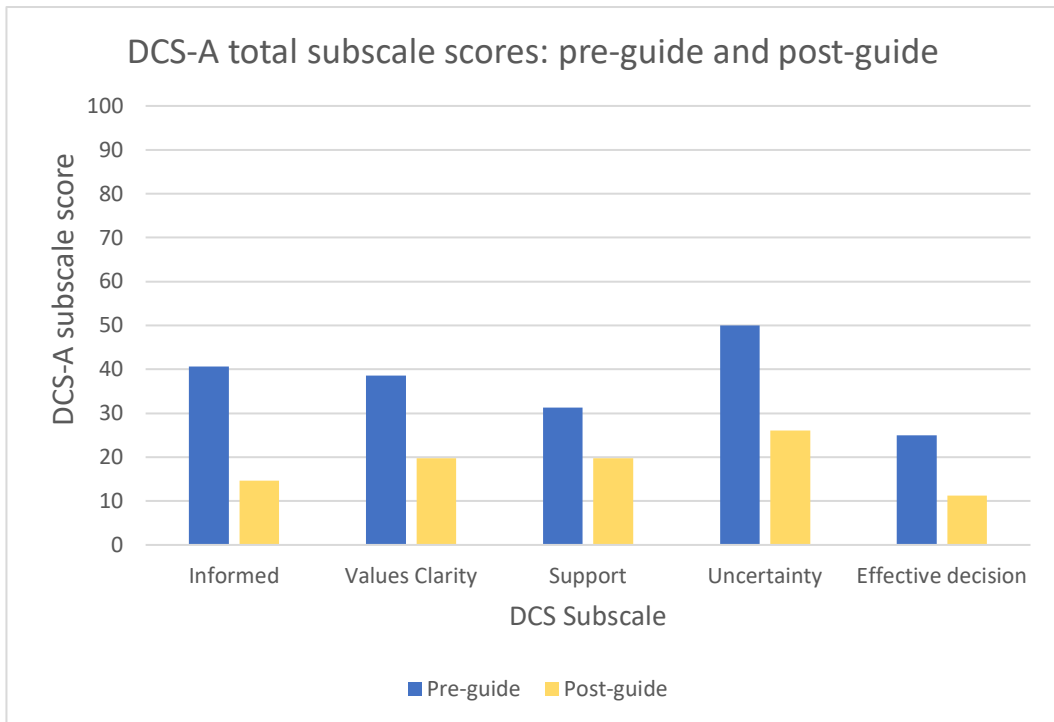
Figure 5.10 Decisional Conflict Scale (DCS) 'Making a decision about whether or not to have a baby' Section A mean subscale scores pre-guide and post-guide

As shown in Figure 5.10, all subscales show a decrease in scores from pre-guide to post guide for the DCS-A section. The 'Informed' presented the greatest reduction in score. DCS-A individual subscale scores pre-guide and post-guide for are presented in Figure 5.11.

Figure 5.11 is presented as a chart with an embedded data table:

DCS-A individual subscales scores: pre-guide and post-guide

DCS-A Subscale score (y-axis: 0–80)

	Ps 1 Pre	Ps 1 Post	Ps 2 Pre	Ps 2 Post	Ps 3 Pre	Ps 3 Post	Ps 4 Pre	Ps 4 Post	Ps 5 Pre	Ps 5 Post	Ps 6 Pre	Ps 6 Post	Ps 7 Pre	Ps 7 Post	Ps 8 Pre	Ps 8 Post
Informed	58	25	25	17	42	8	42	17	25	0	50	25	25	0	58	25
Values Clarity	75	25	33	25	50	17	17	42	8	0	42	25	25	0	58	25
Support	67	58	17	8	42	33	25	17	17	0	17	0	8	0	58	42
Uncertainty	75	50	33	8	58	8	42	75	33	8	42	33	75	0	42	25
Effective decision			25	0	44	19			25	0	13	13			38	25

Pre-guide and post-guide participant subscale scores

Legend: Informed, Values Clarity, Support, Uncertainty, Effective decision

Figure 5.11 Decisional Conflict Scale (DCS) 'Making a decision about whether or not to have a baby' Section A individual participant subscale scores pre-guide and post-guide

A table of individual scores is presented in Figure 5.11 in order to distinguish between scores of zero and subscale scores removed from the analysis (due to answering two or less of the questions in the Effective decision subscale (4-items)). Six participants showed a reduction in score for all subscales. Participant 4 showed an increase in score for the 'Values Clarity' and 'Uncertainty' subscale. As discussed above, it may have been that the change in her mental state affected her scores relating to decision making. Another participant, who was currently pregnant, showed no change in score for the 'Effective decision' subscale.

5.3.4.2 SECTION B: MAKING DECISIONS ABOUT MEDICATION DURING PREGNANCY

For this section, participants were asked to state their preferred option to the statement 'Making decisions about medication during pregnancy' from the following list: 'Continuing medication', 'Stopping medication', 'Switching to a different medication' or 'Unsure'. An 'Other' option was also provided with space to provide more detail. Participant responses on their current preferred option in relation to this statement are presented in Table 5.4.

Options *Pre-guide / Post-guide*		Continuing medication	Stopping medication	Switching to a different medication	Unsure	Other
Ps 1	*Pre-guide*		X			
	Post-guide		X			
Ps 2	*Pre-guide*					**X** *Remain medication free*
	Post-guide					**X** *Remain medication free*
Ps 3	*Pre-guide*	X				
	Post-guide	X				
Ps 4	*Pre-guide*	X				
	Post-guide	X				
Ps 5	*Pre-guide*			X		
	Post-guide			X		
Ps 6	*Pre-guide*					**X** *Start medication late pregnancy*
	Post-guide					**X** *Start medication late pregnancy*
Ps 7	*Pre-guide*	X				
	Post-guide	X				
Ps 8	*Pre-guide*		X			
	Post-guide		X			

Table 5.4 Decisional Conflict Scale (DCS) Section B preferred option responses for the statement 'Making decisions about medication during pregnancy' pre-guide and post-guide

As shown in Table 5.4, all participants reported the same preferred option pre-guide and post-guide for DCS-B. The options chosen by women included 'Continuing medication' (three participants), 'Stopping medication' (two participants), 'Switching to a different medication' (one participant) and 'Other' (two participants), which included 'Remain medication free' and 'Start medication late pregnancy'. The majority of participants presented with a reduction in score for all DCS-B subscales, presented in Figure 5.12.
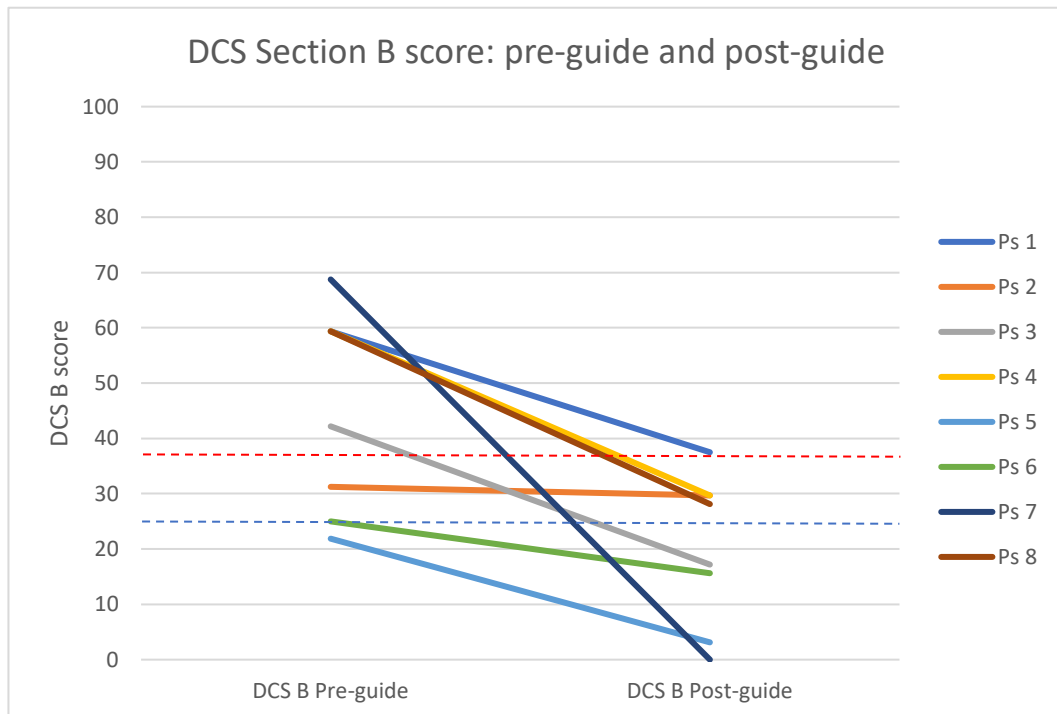
Figure 5.12 Decisional Conflict Scale (DCS) 'Making decisions about medication during pregnancy' (Section B) results pilot one. Red dashed line = baseline for high decisional conflict scores (>37.5). Blue dashed line = threshold for low decisional conflict scores (<25).

The red dashed line presented in Figure 5.12 represents the baseline for high decisional conflict scores (>37.5), while the blue dashed line represents the threshold for low decisional conflict scores (<25). As shown in Figure 5.12, all participant DCS scores relating to decisions about medication and pregnancy decreased from pre-guide to post-guide. Before using the guide, five participants presented with high decisional conflict scores (>37.5) and two with moderate decisional conflict scores (25-37.5). All but one participant moved down at least one decisional conflict category after using the guide. One participant remained within the moderate decisional conflict category before and after using the guide but showed a slight decrease in score.

After using the guide, all participants scored within the low or moderate decisional conflict categories (<25 and 25-37.5, respectively). Four participants scored within the low decisional conflict category after using the guide (<25). Of these four participants, two had presented with scores within high decisional conflict category and one within the moderate decisional conflict category before using the guide.
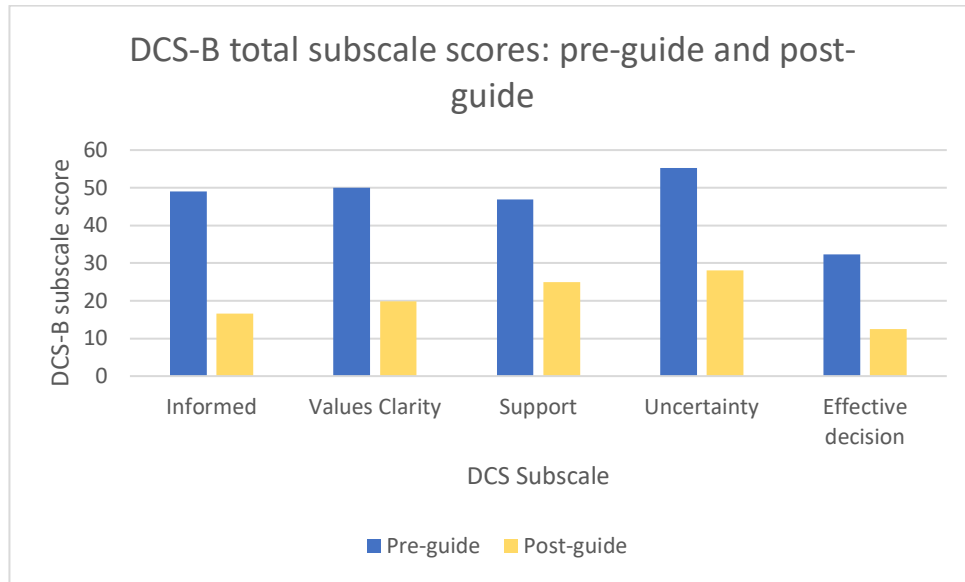
Figure 5.13 Decisional Conflict Scale (DCS) 'Making decisions about medication during pregnancy' (Section B) mean subscale scores pre-guide and post-guide

As shown in Figure 5.13, all subscales show a decrease in scores from pre-guide to post guide for the DCS-B section. The 'Informed' presented the greatest reduction in score. 'Support' subscale showed the least decrease in scores. DCS-B individual subscale scores pre-guide and post-guide for are presented in Figure 5.14.

DCS-B individual subscales scores: pre-guide and post-guide

| | Ps 1 | | Ps 2 | | Ps 3 | | Ps 4 | | Ps 5 | | Ps 6 | | Ps 7 | | Ps 8 | |
	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post
Informed	75	25	25	25	25	0	83	25	25	8	25	25	75	0	58	25
Values Clarity	58	25	25	25	50	17	67	42	25	0	25	25	75	0	75	25
Support	75	58	25	42	50	33	42	33	17	0	50	8	58	0	58	25
Uncertainty	75	50	58	42	58	17	67	58	25	8	25	8	75	0	58	42
Effective decision			25	19	31	19			19	0	6	13	63	0	50	25

Pre-guide and post-guide participant subscale scores

Legend: Informed, Values Clarity, Support, Uncertainty, Effective decision

Figure 5.14 Decisional Conflict Scale (DCS) 'Making decisions about medication during pregnancy' (Section B) results pilot one participant subscale scores

Six participants presented with a reduction in score for all DCS-B subscales, shown in Figure 5.14. Two participants showed an increase in score for one subscale. Participant 2 presented with an increase in the 'Support' subscale from the moderate decisional conflict category pre-guide to the high decisional conflict category post-guide. Participant 6 presented with an increase in the 'Effective decision' subscale, but remained within the low decisional conflict category pre-guide and post-guide. Although no participants changed their decision about medication in DCS-B, individual scores relating to feeling informed, values clarity, support, uncertainty and effective decision making was reduced for the majority of women.

5.3.5 Bespoke acceptability measure

A bespoke acceptability measure was designed for the study to allow us to learn about women's experiences of using this guide. Women were asked to respond to the following statement 'The guide was helpful for women making decisions when planning a pregnancy' with the following responses: 'strongly agree', 'agree', 'neutral', 'disagree' or 'strongly

disagree'. All eight women responded to this question, with all (100%) responding with the response 'strongly agree' or 'agree'.

The questionnaire also asked women how helpful they found the information in the guide on a number of different topics, presented in Figure 5.15. Participants were asked to rate how helpful they found the information by circling a number between 1 and 5 (1= not at all, 2= slightly, 3= moderately, 4= very, 5= extremely). For the topics 'Mental health conditions during pregnancy and birth', 'Support during pregnancy and after birth', 'Ways that I can help myself to keep well' and 'Information for partners, family or friends', eight participants (100%) found the information 'very helpful' or 'extremely helpful'.
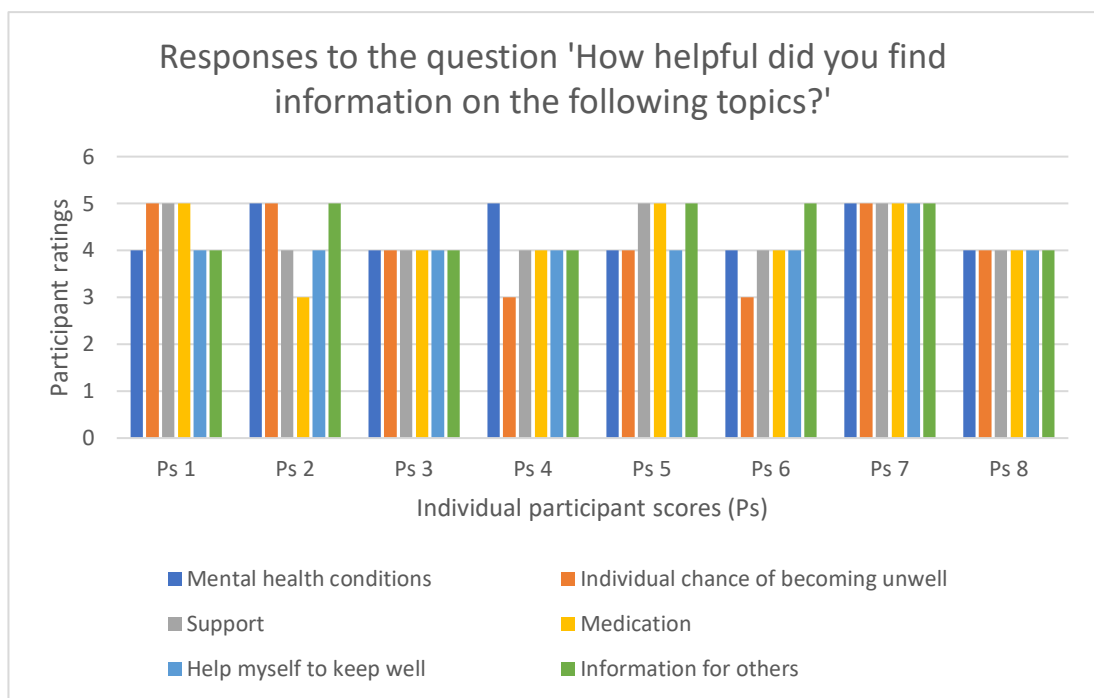
Figure 5.15 Participant responses to the question 'How helpful did you find information on the following topics?' (1 = not at all, 2 = slightly, 3 = moderately, 4 = very, 5 = extremely)

For the topic 'My individual chance of becoming unwell with my mental health during pregnancy and after birth', six participants (75%) found the information 'very helpful' or 'extremely helpful' and two participants (25%) found the information 'moderately helpful'. For the topic 'Using medication during pregnancy and after birth', seven participants (87.5%) found the information 'very helpful' or 'extremely helpful' and one participant (12.5%) found the information 'moderately helpful'.

Women were asked for their opinion on the amount of information included in the guide, by responding that it was 1) 'too much information', 2) 'too little information' or 3) just right. All women responded to this question. 100% of women felt the amount of information in

the guide was 'just right'. Women were asked 'How satisfied overall were you with the guide?' Of the seven participants that responded, 100% responded with the responses 'very satisfied' or 'satisfied'. Women were also asked whether they would recommend the guide to other women who were pregnant or planning a pregnancy. Of the seven women who responded, 100% stated that they would recommend the guide to others.

5.4 Refinements for prototype two

The analysis of the qualitative interviews presented in this chapter, alongside the review of online information, input from the advisory group and discussions with the supervisory team, informed the development of the second prototype of the guide. This section describes the second prototype of the guide, including illustrative examples from the guide.

5.4.1 Title, cover and presentation

As discussed above in Theme 4 'Reflective planning and decision making', the cover photo was updated, as seen in Figure 5.16. The previous cover photo included a woman at a desk with a notepad and pencil. It was suggested that this may give the impression that planning a pregnancy is a paper exercise that can be done at a desk. Following this feedback and discussions on the importance of reflection during this time, the updated photo was chosen for its less studious feel. In this photo, a woman is sitting casually on a chair, with a book in her lap and holding a hot drink. The subject is smiling and looking away from the camera thoughtfully. In addition to this, changes were made to the presentation to reduce the number of large blocks of text, to include more coloured text boxes.

Figure 5.16 Front cover of prototype two

5.4.2 'About me' pages

As shown in Figure 5.17, the guide included 'About me' sections for women to fill in. Information on the 'About me' sections were also provided in the introductory section of the guide (see Figure 5.18 below). Feedback during the interviews highlighted how women used the guide in different ways. Some women found it helpful to write in the 'About me' sections, while others preferred to go through these verbally, or only briefly if they had already worked through similar exercises with a healthcare professional. Some women found it helpful to work through the 'About me' sections as they read through the guide, while others planned to go back to these at a later day. Another difference in how women planned on using the 'About me' questions was that some imagined taking completed questions to healthcare appointments, whilst others felt this was something that they would prefer to keep private.

About me

The 'About me' sections are for you to fill in with information about yourself. They can be shared with a partner, family, friends and healthcare professionals - it's up to you.

They are dotted throughout this guide and can be brought together under the About me divider you will find at the end of the guide.

Writing down your information may help others to understand your decisions and know what you want to happen if you become unwell. It may also help you to prepare for healthcare appointments.

A

Figure 5.17 'About me' section (introductory page)

To accommodate the different ways of using the 'About me' sections, the following changes were made. Firstly, the 'About me' questions were dispersed throughout the guide to allow women to work through the questions alongside the corresponding information , Secondly, because some women saw the benefit of keeping 'About me' responses separately, (either due to privacy or for convenience when sharing during appointments) I provided an 'About me' divider at the back of the guide to allow women to keep these separately. To assist with separating these pages, as shown in Figure 5.17, the 'About me' section adopted a different presentation to the other pages in the guide. The 'About me' sections could be identified by the turquoise banner at the bottom of the page (rather than yellow) and a grey animated

image of a person at the top right of each first page. In addition to this, letters were used rather than page numbers so that the 'About me' section could easily be combined in the 'About me' divider. The 'About me' pages relating to previous episodes included in this section, with explanation that this information may be helpful for healthcare professionals to know.

Writing and reflecting on previous experience was described as being "overwhelming" if it was something that had not been thought of for a long time. As a result, having all of the 'About me' sections as the first section in the guide may have been daunting for some women. It was also be important to consider that one person withdrew from taking part in the project and described one of her reasons for doing was because there was too much writing involved. This highlighted the importance of the existing statements within the guide, explaining that the guide was designed to be used in any way that worked for the individual.

The inclusion of a webpage link (ncmh.info/pregnancyplanning), as shown in Figure 5.18 below, was included to enable women to download copies of the 'About me' section and the complete guide. This allowed women to print additional copies if they wanted to redo any sections, for example, after gaining additional information about their decisions.

A summary of the guide

1 **How could childbirth impact on my mental health?**
This section includes information about different mental health conditions that women with bipolar or previous experience of postpartum psychosis can experience during pregnancy and after birth. It includes information about the chance of becoming unwell during pregnancy and after birth.

The information about symptoms included here may be helpful to share with a partner, family member or friend.

2 **What do I need to think about when planning a pregnancy?**
Deciding to have a child is an important decision for any woman. For a woman with bipolar or previous postpartum psychosis, this decision may be more complex. This section includes questions to help you consider your choices and how you feel about having a baby, and when the best time would be.

3 **What support may I receive through pregnancy and after having a baby?**
In this section you'll find information about what support may be available to you before having a baby, during pregnancy and after birth.

Here you will find information about healthcare appointments and support that you can access through third sector organisations like Action on Postpartum Psychosis (APP) and Bipolar UK.

4 **What do I need to know about medication and pregnancy?**
This section includes a summary of the options available to you when making decisions about medication. This section discusses general principles to think about when considering the benefits and risks linked with taking medication during pregnancy and while breastfeeding.

About me: questions about my history and lifestyle

These are interactive sections dotted throughout the guide, filled with questions to answer about yourself. We have included a separate divider at the back of the guide if you'd like to keep these sections separate from the information in the guide.
You can also download additional copies of these interactive sections at: ncmh.info/pregnancyplanning

6

Figure 5.18 Summary of guide sections, including 'About me' questions (page 1 of 2)

5.4.3 Using this guide

Women felt that having detailed information on how to use the guide, before even reaching the information they needed, made the guide longer and more overwhelming than it needed to be. For this reason, the summary of the guide presented in this section was reduced. The initial statement included in the guide changed from "Having a baby is a major life event for any woman. For women with experience of a mental health condition there is even more to think about." to a more positive statement, "Women with bipolar or previous postpartum psychosis have shared their experiences and opinions with us on what would help them during pregnancy and childbirth" following feedback relating to the tone of the guide. It was made clearer in the introductory section of the guide that not all sections would be relevant to everyone. Included explanation that the guide can be used gradually, without the pressure of reading it cover to cover.

In pilot one, women found it helpful to skip ahead to relevant sections in the guide, particularly if they were very knowledgeable on the topic already. Women explained their difficulty in navigating through the guide, due to a lack of clear labelling of each section and clear signposting to other sections in the guide. Women commented that it was unclear when a new section began in the guide. Following this feedback, large, clear section numbers at the beginning of each section in the second prototype of the guide. In addition to this, dividers with corresponding section numbers were also added to the second prototype to make it easier to skip back and forth between sections. Additionally, for any reference to other chapters throughout the guide, clear section numbers, titles and page numbers were added. As shown in Figure 5.19 below, prototype two of the guide included seven sections, all clearly labelled with section and page numbers on the contents page to help women easily navigate the guide.

Women may have felt obligated to use the guide thoroughly to provide detailed feedback during the follow-up interview after testing the guide. It may be the case that more women would have used the guide in this less systematic, non-linear way were they not taking part in a research project. With this in mind, it felt particularly important to make the guide as easy to navigate and 'dip in and out' of as possible.

Contents

		Page
	Using this guide	4
1	How could childbirth impact on my mental health?	9
2	What do I need to think about when planning a pregnancy?	19
3	What support may I receive during pregnancy and after having a baby?	29
4	What do I need to know about medication and pregnancy?	47
5	How can I help myself stay well?	63
6	What do partners, family and friends need to know?	72
7	Bringing it all together	81

3

Figure 5.19 Contents page of guide

Women emphasised the key role that others played in making important decisions during the perinatal period, particularly their partner. Concerns were also raised about the emotional impact that filling in information about previous episodes of mental illness and triggers could be difficult for some women, especially without much experience of reflecting on this. Women suggested that it may be helpful for some women to complete some of the exercises with a healthcare professional or someone close to them. For these reasons, the role of others was further emphasised in the second prototype, as well as additional prompts being included throughout to encourage women to use the guide with others. An example of this can be seen in Figure 5.20, under the item on 'It can be used to aid discussions with significant others'. Changes were also made to the language throughout the guide to highlight the important role of others when making decisions and planning during this time.
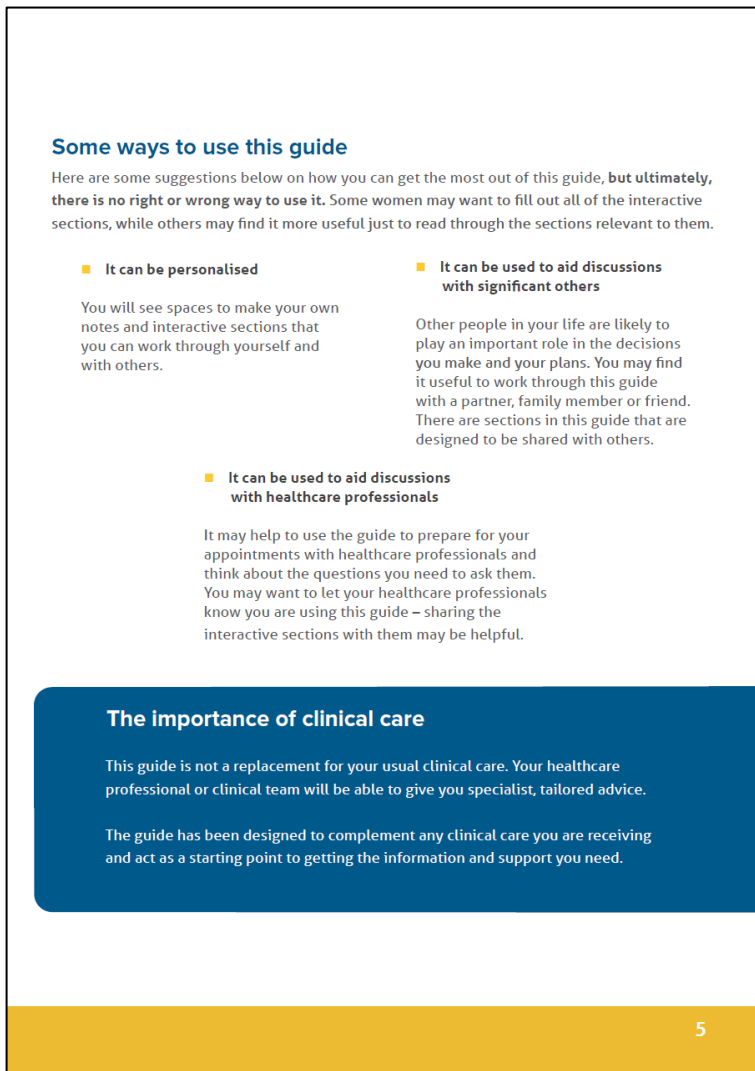
Figure 5.20 Page 5 - additional information on other people's involvement in decision making

5.4.4 Section 1: What do I need to think about when planning a pregnancy?

The question "Why am I feeling positive about having a baby?" was changed to "Am I clear about my reasons for having a baby?" following feedback that including the word "why" gave women a negative impression. The question "What are my concerns and worries about having a baby?" following feedback that there was too much emphasis on concerns, as this was already covered in the interactive scales exercise. The five-point scale to measure certainty about having a baby was removed, following feedback that women may never feel certain about the decisions that they are making, even after becoming pregnant, therefore highlighting this uncertainty was considered unhelpful.

Women suggested adding information on particular topics that played an important role in their decisions about pregnancy, such as fertility treatment. For the second prototype of the guide, a webpage on infertility was signposted following this feedback.

5.4.5 Section 2: How could childbirth impact on my mental health?

Women felt that there was little information on postpartum psychosis in comparison to other conditions, therefore additional information was added to the section on postpartum psychosis. Women found the information relating to individualised risk confusing, therefore changes were made to present this information according to diagnosis or previous perinatal episodes of illness, so that women could easily see which figures related to them.

5.4.6 Section 3: What support may I receive during pregnancy and after having a baby?

Changes to the wording were made following feedback that the information on social services could be more reassuring. This following sentence was removed: "It is rare for babies to be removed from women with bipolar or postpartum psychosis." Although this sentence intended to be reassuring, women felt that it had the opposite effect.

It was felt that the 'Important contacts' sheet should be easily accessible in case of emergency. Therefore, this page was moved to be the final page of the guide.

5.4.7 Section 4: What do I need to know about medication and pregnancy?

An addition was made to information on medication options to include the decision to start medication, for example, in late pregnancy (this was a decision that one of the participants was making).

5.4.8 Section 5: How can I help myself stay well?

A change in wording was made following a suggestion to make the guide more inclusive to women with postpartum psychosis. The sentence "You may want to think about times when you have been at your most stable in your *bipolar*" was changed to "You may want to think about times when you have been at your most stable in your *mental health*".

5.4.9 Section 6: What do partners, family and friends need to know?

As discussed in theme 2, 'Using the guide with others', women felt that the guide did not always reflect decisions as joint decisions during the perinatal period. As a result, changes were made to the language used throughout the guide when discussing decisions and plans. In addition, due to changes made to include significant others when discussing decisions, there appeared to be less of a need for a lengthy section specifically for partners, friends and family to read (Section 6, 'What do partners, family and friends need to know?'). This was further justified by feedback from women explaining that this section was not heavily used by partners during the four-week testing period. Following this feedback, this section was reduced in length and partners, family and friends were encouraged to read through the other sections in the guide. Figure 5.21 presents the first page of section 6 in the guide. A space for partners or significant others to write notes was also removed, following feedback on how significant others did not use this section.

What do partners, family and friends need to know?

6

This section is for the partners, family and friends.

This section includes information on what to consider when supporting your partner before pregnancy, during pregnancy and after birth. This section also aims to help you think about your own wellbeing during this time.

Spending time reading through the other sections in this guide will be helpful. This will increase your understanding of what early warning signs look like, what care your partner may receive and how you can help to plan and prepare for pregnancy and birth. Showing an interest and seeking to understand as much as possible can make a big difference.

Although we use the term 'partner' in this section, this information will be helpful for everyone who plays a key part in the mother's life.

Families come in all shapes and sizes and this section is for anyone who wants to know more and be supportive during this time.

While it's important to plan ahead in case your partner does become unwell, it's not inevitable that she will. Many women will remain well during pregnancy and after birth.

Thinking about having a baby

Deciding on whether to have a baby can bring up a mixture of feelings for anyone.

For women with bipolar or those who have been unwell with their mental health during previous pregnancies, thinking about having a baby can bring up a lot of worries, for them and also for their partners.

You and your partner may find that you are worried about different things. Being honest and sharing your feelings and worries will help you to make informed decisions together.

Remember that help is available. You may be able to speak to a specialist such as a perinatal psychiatrist when planning for a pregnancy.

75

Figure 5.21 Partner section (first page of section)

5.4.10 Section 7: Bringing it all together

As discussed in theme 4 'Reflective planning and decision making', the final section in the guide, 'Bringing it all together' was adapted to include 'yes' and 'no' tick boxes rather than text boxes to respond to the 'Next steps' questions (as shown in Figure 5.22). This reduced this exercise from seven and a half pages to one page. In pilot one, this was the least used section of all of the 'About me' sections. The one participant who did fill this section in, only wrote 'yes' and 'no' answers, suggesting that this change better reflects how women might use this section. Including all questions on one page provided women with a visual summary on what they might like to focus on for the next steps in their planning.

Bringing it all together 7

Now that you have come to the end of the guide, you may be better placed to make some of the difficult decisions we have discussed.

Reading through the information may have answered some questions you had and made clear the questions that you still need to ask.

You may now be looking to develop plans and discuss further with your healthcare professionals.

This section is designed to help you plan your next steps.

Next steps

Consider each of these questions and use the boxes below to write down how you feel and any plans that you have related to each one.

If you are currently pregnant, some of these questions might not apply.

Am I clear about my reasons for wanting to have a baby?   Yes ☐ No ☐

Do I know which concerns relating to having a baby are most important to me?   Yes ☐ No ☐

Do I have enough information about my chance of becoming unwell during pregnancy and after birth?   Yes ☐ No ☐

Do I understand the medication and other treatment options available during pregnancy and after the baby is born?   Yes ☐ No ☐

Do I have a clear plan in place in case I become unwell?   Yes ☐ No ☐

Am I clear about the support that may be available to me during pregnancy and after birth from both professionals and significant others?   Yes ☐ No ☐

81

Figure 5.22 Final section – 'Bringing it all together'

5.4.11 Format

The format of the guide was an A4 standard size ring binder, including dividers for each section and the 'About me' pages.

5.4.12 Other

Three additional quotes from women with lived experience of mental illness during the perinatal period were included in the second prototype of the guide. Figure 5.23 provides an example of a quote added. As discussed in theme 3, 'Realistic and positive', women responded well to the quotes in the guide and suggested including more.

Figure 5.23 Example of woman with lived experience quote added into the guide for prototype two

As discussed earlier in the chapter, some women found it helpful to only cover the information that was most relevant to them in the guide. Women found it helpful to skip through certain sections, but found this difficult and suggested clearer labelling for each section. Following this feedback, dividers and clear section numbers were included to improve navigation throughout the guide.

5.5 Conclusion

This chapter presented the qualitative and quantitative results of pilot one, which along with other sources of information outlined above, informed the second refinement of the guide. The second prototype of the guide was then tested as part of pilot two (Chapter 6).

Chapter 6 Pilot two results

6.1 Overview

The aim of pilot two was to test the second prototype of the guide and to refine it based on feedback. Prototype two was an A4 87-page loose-leaf guide printed back-to-back, presented in a plain white ring binder, with dividers for each section. It was designed specifically for women with a diagnosis of bipolar disorder or previous experience of postpartum psychosis (as was the initial prototype). As explained in the introductory section of the guide, it was also designed to be useful for women with other diagnoses, for example, schizoaffective disorder and other mood and psychosis related conditions. As with prototype one, prototype two aimed to be helpful for women at varying stages of preconception and pregnancy, i.e. those who were yet to decide whether they would like a baby, those who were currently planning a pregnancy and those who were already pregnant.

This chapter presents the qualitative and quantitative results from pilot two. Participants with lived experience of bipolar disorder and / or postpartum psychosis who were planning a pregnancy or were currently pregnant tested the guide for approximately four weeks. All participants took part in a semi-structured qualitative interview with the researcher after testing the guide. The purpose of this interview was to hear their thoughts and opinions on the guide, and any ideas or suggestions that they had for improvements. All interviews were conducted via telephone or video call during June 2021. Interviews were digitally recorded for later transcription. Participants also completed self-administered questionnaire measures before and after using the guide. The qualitative and quantitative results informed final refinements made to the prototype of the guide, and recommendations for future work, as well and providing insight into its acceptability. Changes made to the guide on the basis of this stage of the project, including examples to illustrate, are discussed at the end of this chapter.

6.1.1 Participants

A sample size target range of 8-12 women was guided by the 'Information power' concept, considering factors such as the aim of the study and different diagnoses and experiences required in the sample.

Factors that influenced the final sample size was the richness of the interview data in answering the aims of the project, the quality of the dialogue and the range of experiences

included in the samples. The final sample size was determined by factors such as the quality of the dialogue and richness of the interview data in informing the refinement of the guide. This resulted in ten participants being selected for pilot two. The sampling strategy involved recruiting women with varying diagnoses and previous experiences of mental illness episodes, within the boundaries of the inclusion criteria, and at various stages of planning a pregnancy. In line with the feedback ascertained in pilot one, the sampling strategy involved seeking representativeness from women without a partner, who were planning to have a child as a solo parent.

Of the ten women recruited, eight women used the guide and were interviewed after testing the guide (sample characteristics are presented in Table 6.1). The average interview duration was 00:58:05; the interview duration range was 00:49:14 to 01:43:11 (hours, minutes, seconds). One woman withdrew from the study on the day of her feedback interview after receiving news about her fertility treatment, which changed her situation regarding planning a pregnancy. Another participant gave birth around the time of the feedback interview and was later admitted into a Mother and Baby Unit (MBU). This interview was postponed, and the participant was invited to get in contact when she was ready, but did not do so. Of the eight participants who used the guide and took part in a feedback interview, six returned their questionnaire measures, meaning that results from eight participants were presented for the qualitative data, and results from six participants for the quantitative data.

Characteristic	Frequency (N=8) (%)
Age	
31–40 years	7 (87.5%)
>40 years	1 (12.5%)
Ethnicity	
White British	5 (62.5%)
White Irish	1 (12.5%)
Any other White background	2 (25.0%)
Employment status	
Employed, full time / part time	7 (87.5%)
Out of work and looking for work	1 (12.5%)
Level of education	
Graduate level or above	6 (75.0%)
A Levels or NVQ qualifications	2 (25.0%)
Partner / Single	
Partner	5 (62.5%)
Single	3 (37.5%)
Diagnosis	
Bipolar	4 (50.0%)
Bipolar and Postpartum Psychosis	1 (12.5%)
Postpartum Psychosis	3 (37.5%)
Pregnancy planning	
Considering or planning first pregnancy	3 (37.5%)
Considering or planning second pregnancy	4 (50.0%)
Currently pregnant (2nd pregnancy)	1 (12.5%)

Table 6.1 Demographic information of pilot two completers

6.2 Qualitative Results

6.2.1 Overview of qualitative results

This section presents the qualitative results of semi-structured interviews conducted with eight women with lived experience of bipolar disorder and / or postpartum psychosis who were considering having a baby, planning a pregnancy or were currently pregnant.

As presented in Figure 6.1, four overarching themes were identified and were used as a framework for presenting the results: 1) One size doesn't fit all; 2) Tone; 3) The guide and professional support; and 4) Feeling represented.
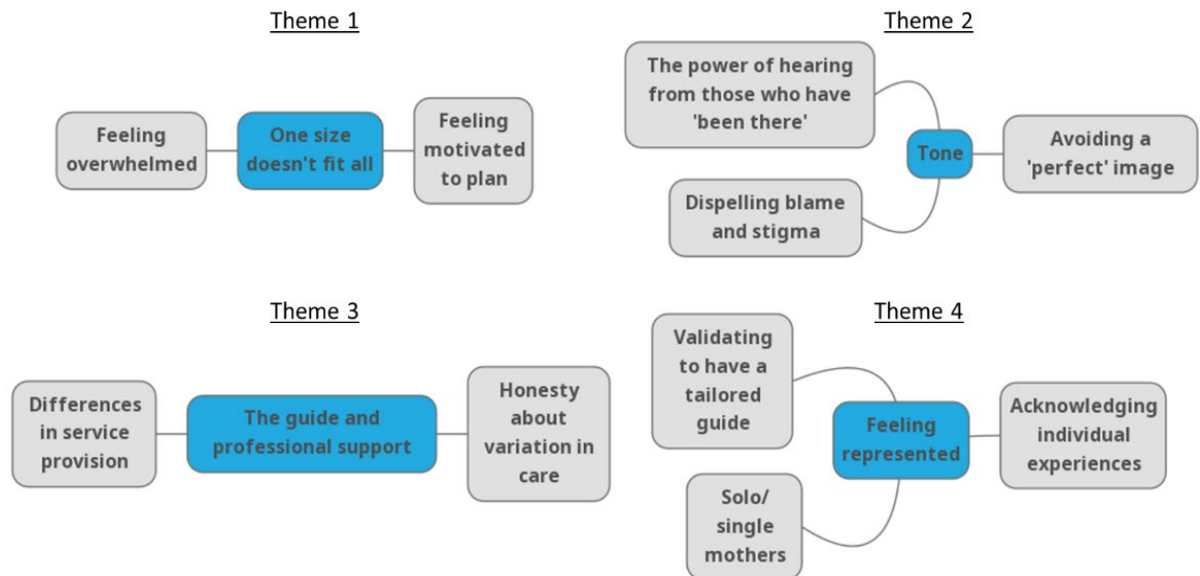
Figure 6.1 Four overarching themes identified and used as a framework for presenting pilot two qualitative interview results

6.2.2 Overall impressions of participants

As in pilot one, the feedback in pilot two demonstrated the difficulty in developing a guide to suit everyone. Factors that influenced this were diagnoses, personal circumstances, backgrounds and level of input from professionals. Some women discussed how the guide was daunting to read in some places. Feeling represented also greatly contributed to women's experience of the guide. Recommendations on making the guide more inclusive were raised, in addition to the concern that including everything may be "opening a can of worms". It appeared that it was important to recognise in the guide that women may not be coming into this from the same background and that factors such as fertility and experience of miscarriage may shape a person's journey to planning a pregnancy.

Women valued the openness of information on varying availability of perinatal mental health services across the UK. Women identified the difficulty of covering information on services, given the variability across the country. As in pilot one, feedback demonstrated how the guide can only provide a certain level of information, and that many answers relating to care can only be answered by healthcare professionals within the women's local areas.

Similar to previous stages, the tone of the guide and messages of hope and positivity were considered key. Women found statements relating to not blaming yourself for becoming unwell, and quotes from women who have 'been there' themselves, reassuring. Women also felt that the guide should avoid advocating a 'too perfect' image of pregnancy and birth, and should be mindful of contributing to women feeling pressure to undertake all of the suggestions included in the guide (for example, self-management strategies).

6.2.3 Theme 1: One size doesn't fit all
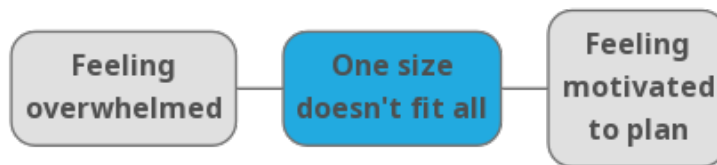
Figure 6.2 Thematic map for Theme 1: One size doesn't fit all

As presented in Figure 6.2, data relating to the theme 1 'One size doesn't fit all' was organised into the following two subthemes: 'Feeling overwhelmed', and 'Feeling motivated to plan'.

In line with discussion and feedback in previous stages, pilot two feedback included the discussion on the different needs of women using the guide. In this pilot, women discussed how the guide brought the 'idea' of pregnancy and its planning to the forefront of their mind. For some women, this was daunting to think about. However, in other instances, the guide helped motivate women to re-consider and develop their existing plans for pregnancy and the postpartum period. As in the development stage and pilot one, I found that that developing a guide that suits women with varying needs, experiences and backgrounds to be a challenging task. Different women may want or require varying levels of information based on the stage they are at in their pregnancy planning journey and their preferences for receiving information. Sample characteristics, such as education level, may also be the reason that some women favoured the guide more than others. This guide was developed for women with various diagnoses. It was designed for women planning for their first child, as well as those planning for a second or further children. Whilst this means the guide could accommodate different situations, it also made the guide longer. This may have contributed to its potential to overwhelm on first impressions. In line with the theme 'Using the guide in different ways' and its subthemes 'As a starting point', 'As a recap' and 'One size doesn't fit all' in pilot one, this pilot identified how women at different stages of the planning process

had very different experiences of using the guide. Some women found it daunting, whilst others felt reassured as it confirmed to them that they were prepared.

Similar to pilot one, women reported finding the guide comprehensive, providing the information they needed in one place. However, there appeared to be a balance to reach in being comprehensive, without overwhelming women with information. 'Feeling overwhelmed' was also a subtheme in pilot one for the theme 'Reflective planning and decision making'. In pilot one, women described the emotional journey of planning a pregnancy as an ongoing process at all stages of planning, even during pregnancy. In this pilot, women recognised the emotional difficulty of covering some of the information in the guide, and saw the benefit of going through some sections with a trained clinician or therapist. One woman recognised that she needed to be ready for the emotional journey of planning a pregnancy, prior to working through some of the 'About me' sections.

As in pilot one, women described that the amount of information presented, often through their first impression of seeing the guide, could be overwhelming. Feedback included both women finding it overwhelming for themselves, and women who were happy with the amount of information included, but anticipated that others would find it overwhelming. Overall, women felt that all of the information was relevant and helpful, however suggestions were made to reduce some of the sections. This included reducing the 'Using this guide' and 'Summary of the guide' sections in the introductory section. It was felt that reducing these would make the initial impression of the guide less daunting.

> *"Yeah it's a lot of information I think it was just so- which I know it needs to be, so I don't know how … that would change, do you know what I mean like there needs to be a lot of information cos there is a lot to think about, but I just think there was a lot, it's like a lot of writing … like before the guide really started like just about using it and also like about what's in the guide, there's a lot of information before it's even started if you know what I mean?"*
>
> *Participant 1*

As described in the quote below, this participant felt that because the guide was targeted at women with different diagnoses and planning for a first pregnancy or subsequent

167

pregnancies, this meant that she needed to read a lot of information in order to find what was relevant to her. As described in the quote below, she explained how she would prefer to only read information relevant to her, such as planning a second child, rather than read everything included in the guide. She also felt that covering information that she had already obtained from other sources, such as Action on Postpartum Psychosis (APP) and Bipolar UK, contributed to the guide feeling like too much information.

> *"Yeah but I'm just sort of like on sort of on exactly what helps having a second child or you know- because for me like with me getting this guide now it's a lot of the information I've already obtained from APP and Bipolar UK and things like that I've been like on … I just think that it's just a bit, I don't know like, it's like an information overload in a way"*
>
> *Participant 1*

Suggestions on improving navigation through the guide included using colour coding to help women find the sections most relevant to them, based on their diagnosis. Another suggestion was to include more information as bullet points, rather than full sentences to reduce the content in the guide.

> *"Yeah, yeah this is sort of like more just have bullet points and maybe like maybe colour code if it's like to do with bipolar like if you've already got a diagnosis of bipolar."*
>
> *Participant 1*

As discussed above, the format of the guide was an A4 ring binder of loose-leaf pages printed back-to-back. The nature of it being a written document may lend itself to being read in the order it is presented, compared to other formats such as a webpage or an app with sections and topics included as separate tabs. As described in the quote below, being given a 'big booklet', which may be unusual in current times, may make the information daunting compared to an electronic version of a guide. For example, with an app, it would be easier to search and navigate to required sections.

This individual also felt that she may have read the guide differently as she was taking part in a feedback interview after reading the guide. Usually, she would have gone back to the guide over a longer period of time rather than reading the guide and completing interactive

sections "all in one go". She also described how in other circumstances, she would skip to the most relevant sections, rather than reading it "cover to cover". As highlighted in pilot one, reading the guide fully in a relatively short amount of time may have contributed to making the experience of using the guide daunting.

> *"Think it seemed quite long to begin with and I kind of thought it seemed a bit daunting with all of this to look through, it wasn't that there was anything there that didn't need to be there though, but I think it's in a way, it's partly that we're kind of not, these days, we're not used to having quite such a large, like a big booklet to look through. I guess if it was like in an app or something you'd just pick the sections you wanted to know about, so I think all of the content was still really good, but it did seem quite long to sort of go through, but you know yeah, I don't know, it's difficult because I think obviously I would kind of come back to it again and again and I think rather than kind of read it cover to cover and the same would be kind of things that you fill in you wouldn't expect to do it all in one go"*
>
> *Participant 7*

This participant described the 'About me' interactive sections as being particularly daunting. The exercises that involved rating levels of concern on a scale were perceived as anxiety inducing rather than helpful.

> *"I think for me the scaling of how concerned you are can I don't know; I think that can be a bit anxiety inducing … just you know, I don't know I think it's hard to not be concerned about any of those thing's cos that is why you're reading this guide"*
>
> *Participant 7*

It was also raised that the guide overall may be daunting for others, such as a partner or family members. Having a separate section for significant others was considered a positive, as it allowed others to become more informed, without overwhelming them with a lot of new information. For sharing the guide with others, the nature of the guide being a loose-leaf paper format was considered helpful.

> *"I said to my husband that I want him to read it as well and obviously there's that family section that I can definitely like oh mum just have a read of this, so I feel probably maybe the, the initial section might scare my mum, so I think I'll just give her the family bit ((laughs))"*
>
> *Participant 2*

In line with previous stages, before taking part in this study, many women in this pilot had accumulated information for pregnancy planning over a period of time. While women had often received much of the information presented in the guide previously, receiving all the information in a short space of time may have contributed to the information feeling daunting. Much of the information that women had previously accessed was from organisations such as Bipolar UK, APP and mental health services. Women had often received support from peer supporters or mental health professionals, which would have allowed them to receive information at a level that was tailored to them. As discussed in the Development stage, an APP peer supporter explained that not overwhelming women was a key consideration for her when providing women with support and information ("Even when I'm seeing these mums now, I've got these guides from Action on Postpartum Psychosis to give them, but then I'm like "I don't want to give them too much information that it freaks them out" but they need information that they're informed, so it's finding the balance isn't it." Participant 3, Development stage, presented in Chapter 4).

One woman described seeing information on risk figures on becoming unwell written in "black and white" made the statistics shocking, despite having heard the same figures from other sources prior to reading the guide. This suggests that the format in which women receive this information, as well as the information included in the guide, is important to consider.

> *"When I first kind of started talking about this that figure of 50% was the figure that I was given which obviously to me did kind of quite shock me in a way cos I didn't realise it was so high…and I know it does go on to say that they're only ballpark figures, but that was the figure that I was given by my consultant, my perinatal, my consultant from the MBU and towards the end of my consultation period with him…I think some people would want to know, but looking at it in sort of black and white as it were its certainly quite high percentages it is sort of quite shocking statistics if that*

> *makes sense? … and like being involved with APP now and hearing about everything they're doing like I know that the support is out there, but obviously it's still growing and it could be better – so it's kind of a double edged sort of thing I feel"*
>
> *Participant 4*

It may be useful to consider the differences in receiving this information via a written resource such as this, rather than from a trained healthcare professional or a peer supporter from a third sector organisation. A healthcare professional can carefully consider what a woman's needs are and tailor the information they provide accordingly, for example, the right time to receive information and the nature in which information is delivered. This is reflective of opinions in the development stage, where healthcare professionals and peer supporters expressed caution in providing women with detailed information, particularly on sensitive topics. Responses in this pilot and the previous pilot have highlighted the importance of using the guide alongside clinical care to ensure women are also getting tailored advice and support that suit their needs.

Rather than suggesting changes to make the guide less daunting, some women discussed how it was important to be ready to approach all of the relevant information on pregnancy planning, as women would need to discuss these during appointments with professionals. Women felt it was important to be prepared and that making sure there were no "surprises" was helpful.

> *"But I do, I do think it is helpful to flag up some of these things when these people are in this situation, these aren't surprises then you know"*
>
> *Participant 3*

Women felt it was important to reflect on previous experiences and that having information relating to symptoms and treatment for women considering or planning a pregnancy was helpful to cover prior to appointments with professionals.

> *"…but equally I do think you can't pretend it- this didn't happen like I know you want to protect people and make sure we don't cause any triggers, but at the same time they've got to feel ready to talk about this stuff*

As in pilot one, women taking part in pilot two were at different stages of considering and planning a pregnancy. Those who found the guide most daunting were those who had not yet decided whether or not to have a baby, or when this would be. For women who had not made their decision, or were still coming to terms with previous experiences, the guide was a lot to take in. For women who were further ahead in their recovery journey following a postpartum episode however, the guide still brought up worries about the reality of having another baby. As presented below, one participant also explained that the use of the words "minimising symptoms" was unhelpful and raised feelings of guilt.

"And then page 76 was where I felt it got a bit real … "it's important to remember that your partner may not realise when she's unwell" I thought as much as I'm going into this with my plan … you're not gonna be able to say to your partner you're not well … maybe it was the "minimising symptoms", maybe it was all the like "trying to pretend everything is okay" … and kind of the booklet about when a parent is in hospital … it's like, "I don't wanna be in hospital!" ((laughs)) But I'm not meant to be reading this section… and maybe kind of minimising their own symptoms I guess it made me feel guilty for that"

Participant 1

This participant explained that she had already covered some of the topics in the guide's interactive sections with a counsellor. As described below, although the guide brought up some of the feelings that she had previously reflected on about her previous experience of becoming unwell, she did not view this as a negative. Instead, she explained how the guide was helpful in confirming that she was ready to have another baby. She felt it was helpful to check that she felt comfortable to read through information on topics such as MBUs, following her own experience of staying in one with her first child.

"I think it's actually a good thing to, to check that I am ok to have another baby because I definitely will feel some of those feelings and I think it is a positive tip to double check yourself that you know I started reading some

> *of these things and talking about how it was in a Mother and Baby Unit*
> *duh, duh, duh and just it obviously was very accurate to make me feel like*
> *I was reliving it type thing and I put equally you know it didn't disturb me*
> *at all and I was able to get through it in two nights like just an hour a night*
> *or something"*
>
> *Participant 1*

Some women explained that they still needed to work through the emotions relating to their previous experiences of becoming unwell after birth and felt that they were not ready to complete some of the 'About me' sections. Women felt that the guide was best used once they felt ready to consider having another baby, and had processed these previous experiences. For this reason, women who were planning a second pregnancy found some sections more difficult to work through compared to women planning their first pregnancy. As described in the quote below, one woman had chosen not to write in the guide about her previous experiences of becoming unwell, as she was still "figuring out" her past experiences. She felt that feeling ready to reflect on previous experiences was a journey and that undertaking the sections in the guide that involved reflecting on these experiences should be done at the right time for her.

> *"Other than space wise I think it's fine, it's just something I've not chosen*
> *to prepare yet because like I don't kind of know where to start, it's my*
> *journey from if that makes sense? Still figuring out sort of like past stuff*
> *has that had an effect as it were?"*
>
> *Participant 4*

Participant 4 also considered the option of filling this out with additional support from a counsellor or other healthcare professional.

> *"… perhaps maybe a counsellor or a like a trained person who can kind of*
> *guide me through it"*
>
> *Participant 4*

Again, as shown in the quote below, some women felt that it needed to be the right time to go through all sections in the guide, which for this participant, would be when she was

pregnant. Women expressed how the 'About me' interactive sections (for example, questions relating to previous history of mental illness and family history of mental illness) may be triggering for some and that working through these with someone else, such as a therapist would be helpful.

> *"I didn't really want to fill in section 3 that detailed bit about you know about lifestyle and family history I don't know that's what I feel like I've done in other therapies … it's the kind of stuff that would be a bit triggering really… reading through it … obviously if you do get pregnant and you're having to experience more therapy I'd be more likely to, but when I'm just thinking about it, I probably wouldn't want it"*
>
> *Participant 7*

There appeared to be a distinct divide between those who found the information overwhelming and those who found the amount of information beneficial. Women who were recruited through the Cardiff University Psychiatry Service (CUPS) (n=3) found the guide most helpful and utilised it the most. One woman, recruited via a Bipolar UK webinar on bipolar disorder and pregnancy, was also among those who found the guide most helpful. Similar to those who had accessed the pre-conception clinic, this individual had also accessed a high level of professional input on the instruction of her fertility clinic and was also seeing a therapist while undergoing fertility treatment. Those who had accessed the pre-conception clinic (n=3) were all trying for a baby at the time of the feedback interview, either naturally or through fertility treatment. This suggests that women who had accessed preconception counselling that covered information included in the guide tailored to their needs prior to using the guide, found it less daunting. It appeared that these women found it helpful to use the guide as a summary of what they had already worked through with a professional.

Another factor that was important when considering women's response to using the guide was the stage they were at in their recovery from a previous episode of illness. Those recruited via APP and social media (n=4), were more likely to find some sections of the guide overwhelming. They felt some sections would be more appropriate for them to look at once they had worked through previous experiences of mental illness or were pregnant. Considering this, it is likely these women had not yet looked for as much information on pregnancy planning as those who were trying for a baby.

Additionally, pilot two included a very educated sample, with the majority of women educated to degree or higher degree level. Two of the women were medical doctors, one of whom was a psychiatrist. These women may be more familiar with the volume of information included in the guide, possibly more so than the women who worked as a peer supporter, support worker or in hospitality. Whilst all women reported finding something in the guide that was new to them, there was a difference in the nature of the new information in some cases, according to women's vocational background. Those who worked within the medical field tended to pick out smaller things, such as new resources that the guide signposted to. For example, one participant, who was a medical doctor explained that she found the signposting included in the medication section useful and valued the additional detail that it provided. Another participant who worked as a psychiatrist, expressed frustration at the little detail included in the medication section.

> *"I suppose I found the medication bit slightly frustrating because it doesn't obviously refer to specific medications and that's kind of an area where I looked, I've had to sort of look at other sources in quite a lot of detail"*
>
> *Participant 6*

This contrasts to another woman's experience of the medication section. She appeared less familiar with different medications available and expressed more uncertainty in determining the risks and safety of medication, compared to participants with a medical background. In this example, the information in the guide appeared to be new to the participant and emphasised the difficulty in decision making and weighing up the risks and benefits of medication.

> *"So you can take it as a precaution, and that's where your section on all the medications is useful because I hadn't quite considered, and I know it's you only highlight the bipolar it's not acid is it but it sounds a bit like acid, you know the certain medication (Interviewer: Sodium Valproate?) yeah you mentioned that one I guess I've seen a medication that actually has, you've got evidence of it was a risk right, for me that was the first time I'd seen "Oh God medication is a real decision here" because, it depends what medication you're on, but I guess the comments to me were "was it safe in pregnancy?", but you know how much research is actually*

6.2.3.2 FEELING MOTIVATED TO PLAN

Women who had already made their decision to have a baby appreciated having all the information in one place to confirm that they were well prepared. This closely mirrored the subtheme 'To recap' as part of the theme 'Using the guide in different ways'. As in pilot one, this tended to relate to women who had accessed information from many different sources, including pre-conception counselling, prior to using the guide. In this pilot, women also explained that reading the guide helped them to reflect on their existing plans and motivated them to plan more or re-consider existing plans.

"So all the things that I'd been thinking about in different ways came
together in one handy guide … it reminded me of things that I had read
before and made me feel like I need to plan for certain things a bit more
carefully"

Participant 8

While finding some sections difficult to read, one woman felt that the guide had a positive effect on her motivation to plan.

"I felt it was almost pushing me more to prepare more, and that can only
be a positive thing so it gave me some ideas about, I can't remember
which one specifically but, things my friends and family could do, or my
husband potentially taking unpaid leave something like that. I even
thought about the bedroom because I did get quite like imagining having
a baby through reading it, and thinking about ways of relaxing the
bedroom at night … so it definitely had a really good impact in terms of
like making me take action to (A) making sure I'm making the right
decision, but (B) is there anything more I can do to make this an easier
process … and it hasn't talked me into anything different so it definitely
wasn't too like negative in terms that it's persuaded me to do something

> *different so it's probably, that concludes probably it's quite a good balance cos I'm probably quite a prepared person, so it was good then."*
>
> *Participant 2*

She explained that as a person who is usually prepared, the guide was a good balance and did not change any of her decisions relating to having a baby. For others who may be less prepared, there was a concern that too much of a focus on making plans may discourage them. This was more the case if the suggestions in the self-management section were unachievable for any given reason. The guide did however encourage women to think about initial first steps in seeking professional support, despite finding some aspects of the guide overwhelming. This is discussed further in 'Theme 3: The guide and professional support'. It also helped them work towards deciding whether to have a baby and encouraged discussions with significant others.

6.2.4 Theme 2: Tone
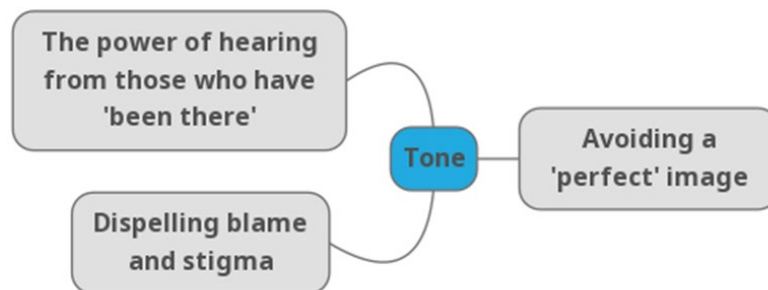
Figure 6.3 Thematic map for Theme 2: Tone

As presented in Figure 6.3, data relating to the theme 2 'Tone' was organised into the following two subthemes: 'The power of hearing from those who have 'been there'', 'Dispelling blame and stigma', and 'Avoiding a 'perfect' image'.

Discussions on the overall positive impression of the guide often referred to the tone of the guide. Feelings of guilt and ways of dispelling these feelings was discussed throughout the project, and prompted the inclusion of key messages in the guide such as "While it's important to plan for all situations, it's also important to remember that even with early planning, you may still experience issues with your mental health. This is not your fault and it's important not to blame yourself." As in pilot one, key messages such as these stood out and were appreciated by women. It appeared that participants were not familiar with

hearing statements like this. Women also commented on the colour scheme of the guide and recommended some improvements. One woman explained how some of the information boxes, with a dark grey background appeared negative and "like a warning", rather than positive.

> *"I find the black boxes with writing in them- they seem a little more like a warning, or kind of negative things almost"*
>
> *Participant 6*

6.2.4.1 THE POWER OF HEARING FROM THOSE WHO HAVE 'BEEN THERE'

Quotes from women with lived experience of planning a high risk pregnancy or becoming unwell and recovering were considered a positive component of the guide. Women valued hearing experiences of women who have 'been there' and experienced their own perinatal mental health episodes.

> *"I just thought like the quotes were like nice to read so from like real experiences and things like that, I thought that was really good"*
>
> *Participant 1*

Following feedback from pilot one, three additional quotes from women with lived experience of perinatal mental illness were added to the second prototype of the guide, which raised the total number to seven. Feedback in this current pilot included similar suggestions from women to include further quotes on specific topics. This included adding quotes from women about their experience of receiving professional support during the perinatal period.

> *"I think there you could have a quote from somebody about the additional support you know, somebody who's been there"*
>
> *Participant 7*

Other suggestions were to include quotes relating to positive elements during a woman's experience of becoming unwell for the second time and to 'soften' the information included in the guide. This point mirrors the subtheme of 'Information on sensitive topics' under the theme 'Knowledge is power' in the development stage, where women suggested using

quotes from those who have 'been there' to balance the discussion of topics that may be difficult to read and instil a sense of hope.

> *"What about trying to get are quotes from somebody who has done a second and I know some of the women like took their second child in to the mother and baby unit before the second pregnancy- I think you think the worst that it's gonna be really horrible for your second child to visit you in hospital they're gonna really miss you at home, like maybe there's a quote you could put in there just to soften it from women who have done this. … I think you just think the worst when you read it don't you and so maybe just a positive example on that page … just a little quote"*
>
> *Participant 2*

Another suggestion included providing a quote from a partner's perspective, relating to their own emotional needs during this time and seeking support for themselves.

> *"I felt that I needed to let those couple of people I've mentioned before like actually sit and look at this because I know that at least my husband had never seen me that ill before so he's coming at it obviously from another different point of view now but I think the key messages at the back of that section are helpful as well cos I think that's what partners probably need to hear a bit … A quote in there what we mentioned earlier, that would be nice and comforting as well"*
>
> *Participant 4*

Participants also valued that input from women played a key part in the development of the guide. This is stated at the beginning of the guide: "Women with bipolar or previous postpartum psychosis have shared their experiences and opinions with us on what would help them during pregnancy and childbirth. Professionals who work with women during pregnancy and childbirth took part in interviews about the information women need. Experts and Peer Supporters from the national charities Action on Postpartum Psychosis (APP) and Bipolar UK and experts from the National Centre for Mental Health (NCMH), Cardiff University have helped develop the information." It was felt that emphasising this collaboration would motivate women to engage with the guide.

> *"If they engage with something early on like that, they might find "oh actually it's been written by people in the know I'll carry on reading it""*
>
> *Participant 2*

6.2.4.2 DISPELLING BLAME AND STIGMA

Some responses suggested that women with a history of mental illness believe that their decision to have a baby may be viewed in a negative light. Women appreciated that the guide approached pregnancy planning in an encouraging way and felt the guide covered topics without any negative judgement.

> *"I thought that was really good about it, was just that it didn't make it feel at all as though having a recent health problems or having had previous pregnancy with a difficult pregnancy was in anyway a bad thing, or a negative thing and you know obviously while you can't promise that there's like an MBU in every area and things like that. It seemed, it seemed encouraging basically and not at all, yeah not at all judgemental about people choosing to have children, or anything like that when they've got mental health problems"*
>
> *Participant 6*

Some women acknowledged misunderstanding and stigma associated with mental illness. Women valued that the guide emphasised that becoming unwell is not anyone's fault and that sometimes, even the best planning cannot stop someone from becoming unwell.

> *"Don't think so, no I mean only a positive bias in that it was you know clearly saying that it's not your fault and you shouldn't feel guilty you know that's a positive thing because I think you know there's a lot of misunderstanding put there about mental and other issues, peoples' fault, and there's stuff that they can do about it, when actually it's out of their control so"*
>
> *Participant 7*

One woman however, expressed that some of the questions in the guide made her feel as if her decision to have a baby was being questioned because of her bipolar disorder. This

person felt that women planning a typical pregnancy would not be asked the question "Am I clear about my reasons for wanting to have a baby?". Suggestions were provided on changing this question to "What are your worries and fears for wanting a baby and not wanting a baby?".

> *"I just don't know how I would answer that cos it's almost like I don't know like so I just think everyone reading is similar you know this one baby like start a family, cos I just think it's, I just wouldn't know how to answer it. I would feel, I would feel a bit like what, do you think I shouldn't have a baby then, because I've had Bipolar? … "Wanting to have a baby", maybe it should be like "What are your worries and fears for wanting a baby and not wanting a baby? Overall?" I think maybe like you should just put about your worries, your worries and fears about like all your hmm if it was just like "Why do I want a baby" like, why wouldn't I want a baby? I don't know, I kind of think of when I was- I really don't know how to explain it. No, they're just like your worries and fears … I just think it's a lot- it's a big box to fill it's almost like to have a baby like I don't know, like I….I don't know"*
>
> *Participant 1*

Women discussed how the guide included encouraging messages that they had not heard before when experiencing perinatal mental illness or when reading through other resources on the topic. Women valued hearing that becoming unwell was not their fault and that they should not blame themselves.

> *"Yeah I liked the fact that it says it's not your fault, you know that if you do become unwell you know and don't blame yourself and things like that I think that's a real like key message cos that's something that I, I didn't have before … I think that I think those key things are the things that really stood out for me"*
>
> *Participant 1*

Guilt was something that women had found difficult and many of the women appreciated that the guide emphasised messages such as "While it's important to plan for all situations, it's also important to remember that even with early planning, you may still experience issues

181

with your mental health. This is not your fault and it's important not to blame yourself."
Women appreciated these messages being explicit, rather than alluded to. This participant,
as above, had not read this in any other resources as explicitly as it was in this guide.

> *"…and then page 17 … in the black section. Love that section … plan for all situations "It's also important to remember that even with early planning you may still experience issues with your mental health this is not your fault". I think that's something I really struggled with, but it's definitely not your fault and it's probably the first leaflet that I've seen it just plain as day like that sometimes they might allude to it but it's not like this is not your fault and it's important not to blame yourself, I thought that was really good"*
>
> *Participant 2*

One woman valued a quote from a woman with lived experience of postpartum psychosis.
The quote described how realising that she may get unwell again, regardless of whether she
decided to have a baby, helped with her decision. This appeared to be a comfort to her to
know that her decision could not control whether she became unwell again.

> *"Oh I tell you what is there somewhere in here where it says … about you know the fact that you could get unwell even without having another baby, so that has been a clincher for someone, was that a quote? … that was interesting to me because … I think it has felt for me like, not having another baby was a way of staying well, but actually there is a risk of you know becoming unwell again even if you don't have another baby through trauma or through menopause or other life events. So that's not such a straightforward you know. … oh yes this is it, page 19 "realising that there is a possibility of experiencing another episode whether I had another pregnancy or not" … that was quite a long quotation from someone I found that interesting"*
>
> *Participant 7*

As in pilot one, women liked the self-management strategies and the guide motivated them to adopt some of the suggestions. In pilot two however, there was more discussion on how women might feel if the strategies suggested were unachievable for them. Women discussed how the guide may be setting expectations that women felt they needed to achieve. An example included asking significant others for support. Women considered how women without a partner would feel if they were unable to put support in place prior to the birth.

> *"Well I guess it's that the arrange in a period of leave or unpaid leave for your partner, if you don't have a partner it might, you'd be like "Oh God like they're saying I should need as much help as-" not just me … but a partner and they're saying I should get that help as well"*
>
> *Participant 2*

A woman without a partner also discussed not having family that would be able to support her (discussed further in theme 4). Another woman with a partner, explained that she did not have family living close enough to support on a day-to-day basis, for example with night feeds. In the guide it states "Support with night feeds may be needed because of the medication that you are on. If you are taking antipsychotics after the birth, it's important to consider that some antipsychotics can cause drowsiness. This may make it difficult for you to wake in the night for feeds." Women felt that the guide should avoid suggesting that support is "needed", considering how it could make women feel if they did not have this support available to them. In the quote below, the participant emphasised that making suggestions in the guide may make women worry if they are unachievable for them.

> *"People may not have family and friends … I guess like put in "you may need a lot of support by the way", that could terrify people you know my mum and dad don't live locally, neither does [husband parents] so by saying like "you might need help with night feeds", I'm a bit like well I don't have anybody that that's local that isn't working the next day and I can't ask them, you know they can't be feeding my baby and going to work actually they'd be exhausted … They were good ideas, but we just need to consider that they might it might then worry others if they can't do it"*

Women expressed that it was important for the guide, while remaining positive, not to come across as advocating a too perfect an impression of pregnancy and birth. One woman felt that this impression of pregnancy and birth was promoted through some of the images in the guide of women smiling. Similarly in pilot one, an image of a woman smiling received negative feedback as it was felt that the woman was "smirking".

> *"I don't know just flicking through a lot of the photos things are looking quite positive and lovely and it's obviously not, not always like that when the reality of pregnancy with psychosis, you obviously wouldn't want pictures that are gonna be disturbing or triggering but I just wonder you know like the page, the ones on sort of pages 52 or where's the other one, that one's a bit more I probably like that one better than the kind of, of smiley faces of "oh look at me and I'm all sorted" … the cover one yeah I don't know there's nothing wrong with it it's nice it's a positive picture I think it just looks very perfect doesn't it?"*
>
> *Participant 7*

In contrast, one woman described the positive impact that an image of people smiling in the guide had on her. This image included a male and female couple smiling down at their newborn child wrapped in a blanket. In this instance, the participant felt that the image gave her a sense of hope that another couple had managed what she was planning for.

> *"I found the picture I like page 80 the couple bathing the baby … that gives women hope I think that you know there's two parents that are- that have managed this"*
>
> *Participant 2*

This demonstrated how women value reassurance that having a baby is attainable and can be a positive experience, despite having a history of mental illness. This again, presented a challenge in choosing images to suit everyone. This mirrors the theme 'Positivity and Reassurance' in the development stage, where women felt that despite there being a great deal to plan and think about, that the guide should also consider pregnancy as a happy time for women.

6.2.5 Theme 3: The guide and professional support
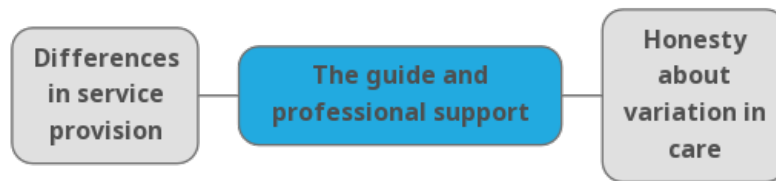
Figure 6.4 Thematic map for Theme 3: The guide and professional support

As presented in Figure 6.4, data relating to the theme 3 'The guide and professional support' was organised into the following two subthemes: 'Differences in service provision', and 'Honesty about variation in care'.

In line with pilot one, key discussion points in this pilot were the information relating to support and how the guide could be used alongside clinical care. Information relating to support appeared to be one of the key sections where women learnt new information. Women found it helpful to have information on what care they might expect to receive, particularly women who were planning a pregnancy for the first time.

> *"Yes so I thought this was all quite helpful because again I kind of found out over time what was available in my local area, but it's useful to know in terms what to look for and I think also it's really good to have it kind of written down what you could expect, you know what you could ask for, because I know I've been told verbally before what hopefully would be sort of available sort of in my areas, but I never quite trust it because working in mental health you know myself I know not always we don't always provide what we want for everybody so I think having it written down kind of what you should hope to get is really helpful because you can ask various people ask for it, so yeah I thought that was helpful obviously if you haven't had children before and you're having just the schedule of appointments was and it says somewhere, oh yeah the pre-birth planning meeting and things like that, that's the kind of thing that I kind of wonder actually does it happen, or does it kind of get forgotten sometimes"*
>
> *Participant 6*

Similar to pilot one, women described how the guide had helped them to identify the initial steps in seeking professional support.

> *"I have really like enjoyed kind of like looking through it to kind of get my thoughts kind of more concrete … I have identified like what step I wanted to take next."*
>
> *Participant 4*

Women valued the honesty attached to covering information on services and felt this was different to other resources they had encountered. At each stage of this project, participants discussed using the guide with healthcare professionals. Women also discussed using the guide to prepare for appointments. In this pilot, there was more of a distinction on which professionals women would most likely use the guide with. Women felt that using the guide in this way could help with prompting professionals to consider referrals to a perinatal mental health team. One woman discussed how the guide could complement General Practitioner (GP) appointments. Information on services in the guide could help reassure women that their GP was referring them to specialist care when appropriate, or if not, the information in the guide could help guide this process. Women felt reassured knowing what care they may expect to receive after reading the guide, which in turn allowed them to know whether they were getting the care they needed or whether additional steps were required.

> *"You can then kind of see "oh my GP is doing all the right things", and you don't know that, so it's nice to know what the process should be and then when you go into the system that you've then got a bit of a path to follow … had I not had APP I wouldn't have known there is a perinatal team cos I literally told the GP who to refer me to, where is if I had that guide it would say there might be a perinatal team in your area, you should find out there is a website to say is there one in your area, so yeah that would definitely help a lot of people."*
>
> *Participant 2*

Women discussed using the guide with newly qualified healthcare professionals. Similarly, the guide was seen as something that may help guide appointments and could be used in a collaborative way.

> *"I can see myself- if I get to the stage where you know I'm comfortable you know to become pregnant and start that journey again. I can see myself physically taking it with me like to ... initial appointments and sort of cos I don't know who my next midwife would be, cos I'm in a new area I've met local health visitor, but I haven't met local midwives and they might not, if they're newly trained I don't know what their knowledge of all this would be, so I can take this with me and sort of say you know guide them through it with me kind of thing"*
>
> *Participant 4*

6.2.5.1 DIFFERENCES IN SERVICE PROVISION

While women found the information on services helpful, they also recognised the limits in how a guide in the current format could provide them with all the information they needed on this topic.

> *"I felt like it's a, it's a challenge to write because you can't say you will be offered a space in a Mother and Baby Unit, or you know you will have a perinatal mental health service to help you."*
>
> *Participant 8*

After reading the guide, women had many questions relating to their local provision and the likelihood of receiving different types of care if they became unwell following birth (i.e. MBU, home treatment and general inpatient treatment). Whilst reading the guide helped women to feel more informed on the services that may be available to them, it also left them with unanswered questions. Women who were planning a pregnancy as a solo parent discussed how they had additional worries about who would look after the baby if they needed to be admitted to a general inpatient ward.

> *"I guess, I don't know maybe it would be reasonable to know how often that does happen you know ... how frequently they're actually able to access a Mother and Baby Unit, how often that is not available and you then have to go for home treatment, or in the worst case scenario be admitted to a standard mental health unit ... and that's an awful scenario and like me solo you know, and there isn't somebody else, there isn't a*

> *partner so I think, I think it would probably be helpful also to kind of have a realistic, you know, to let people know that it may not always be possible to, to be admitted into a Mother and Baby Unit if that's needed, … if you are admitted to a non-mother and baby unit, what happens to the baby you know? What if you're single you know because yes that's huge and what if you're breastfeeding you know, how would you be supported you know that's kind of yeah I don't have the answers to that"*
>
> *Participant 3*

6.2.5.2 HONESTY ABOUT VARIATION IN CARE

Women appreciated the honesty on the variation in care and how it cannot be guaranteed that services such as MBUs would be available to them when needed. One woman reflected on her experience of becoming unwell and her family's expectation that if she became unwell, that she would be admitted to an MBU.

> *"Also just the fact that it's just honest about the Mother and Baby Units as well not all being available, there just being so honest about that because from my experience when I, I was under the perinatal team, but they told me that if it all went wrong I would go to the Mother and Baby Unit, but they weren't available, they might not be available, there might be a wait. You just sort of having that phone call that conversation so I was- it meant my family was expecting me to just, 'Okay she's unwell, let's go into the Mother and Baby Unit' and it just didn't happen, not straight away I had to wait for weeks"*
>
> *Participant 1*

One woman described the guide as a more "robust" source of information compared to other sources that she had previously accessed. This was partly because of how information on services, and their availability, was discussed in an open and honest way.

> *"I'd just only heard soundbites of things, there hadn't been anything that told me how the process should run … I just think [the guide] felt a lot more robust than you know at a café group a mum giving me a bit of advice about something, it was kind of like here's the NHS recommended*

things, and the fact that there's perinatal teams and then being very open about those perinatal teams in some regions but not others"

Participant 2

6.2.6 Theme 4: Feeling represented
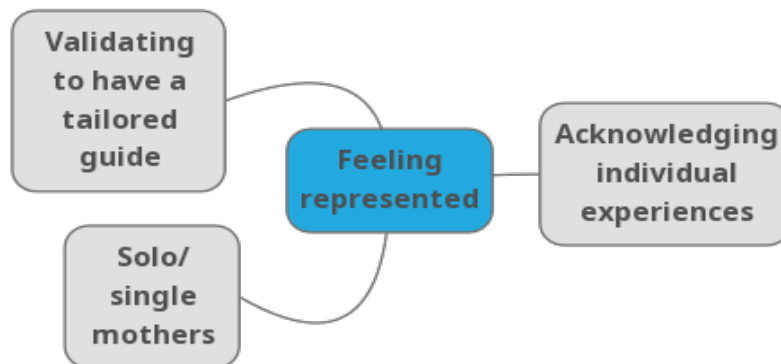
Figure 6.5 Thematic map for Theme 4: Feeling represented

As presented in Figure 6.5, data relating to the theme 4 'Feeling represented' was organised into the following three subthemes: 'Validating to have a tailored guide', 'Acknowledging individual experiences', and 'Solo / single mothers'.

Following pilot one feedback, changes were made to improve inclusivity in prototype two of the guide. This included wording changes to the section 'What do partners, family and friends need to know?' to better recognise that some women receive support from someone other than a partner. When considering changes for prototype two, improving inclusivity also needed to be balanced with feedback on how the guide could make partners feel left out, particularly relating to the decision on whether to have a baby. The issue of partners feeling left out was discussed in pilot one ("I think he found it a little bit, sort of woman focused … all quite focused on the woman rather than the couple … so I think he felt a bit excluded." Participant 8, Chapter 5). This demonstrates the difficulty in developing a resource that all women can relate to. Efforts to not assume that a woman has a partner, could be problematic for those who are making a joint decision with their partner on whether or not to have a baby.

Women valued that their needs had been recognised in that a guide had been developed specifically for women with bipolar disorder and / or previous experience of postpartum psychosis.

> *"It was quite validating to have something that was specific to my situation and it felt good that people were thinking about the things that could happen to me and that kind of quality of guide, I think it's nice to be able to have it in the quality version"*
>
> *Participant 8*

In previous stages of this study, women discussed how the guide appeared more tailored towards women with a diagnosis of bipolar disorder, rather than those without a diagnosis, but had previously experienced postpartum psychosis. As discussed in Chapter 5, changes were made to ensure the guide applied to both women with bipolar disorder and those with previous experience of postpartum psychosis. In this pilot, there were fewer comments relating to the guide being more focused towards bipolar disorder. Some comments were made relating to the 'About me' sections, such as the life chart and 'My personal triggers' being more relevant to women with bipolar disorder.

> *"This lady that's filled in the one on the left kind of said that major life events tend to trigger her, but you know in reading it travelling, pregnancy, mum's death, maybe I don't know, is that something that's more Bipolar related cos I guess I can't reflect just childbirth was my trigger really, cos I was unwell from that moment on but should I be thinking more about sleep or I don't know?"*
>
> *Participant 2*

When asked further about opinions on the guide for women with postpartum psychosis, this participant explained that it could be seen as a positive that some sections may apply less to her as she has only experienced one episode of mental illness. She felt that this highlighted that compared to women with bipolar disorder, her situation was less complex as she had fully recovered from her episode of postpartum psychosis.

> *"Well one of the takes is that it all makes as a positive for me kind of like highlights that I'm probably pretty lucky to not have that complexity as well so that I have fully recovered, so it can only be a positive thing for other women I think that they're not on medication now they don't need to worry about having it in pregnancy, and then things like that life chart becomes very simple in terms of it was just a pregnancy and then maybe 12 months after and then that was it"*
>
> *Participant 2*

As discussed above and in previous chapters, this may reflect the difficulty in developing a guide that suits everyone. As discussed above in the theme 'One size doesn't fit all', developing the guide to suit women with different histories also meant that the guide was longer and that some sections did not apply to everyone.

6.2.6.2 ACKNOWLEDGING INDIVIDUAL EXPERIENCES

In pilot one, women mentioned various experiences that had shaped their experience of planning a pregnancy or pregnancy and birth, but were not discussed in the guide. This included having fertility treatment and having a caesarean birth. The decision was made to include signposting information for fertility and the causes of infertility for prototype two. In this pilot, three women were currently undergoing fertility treatment. Women commented that while the guide mentioned fertility briefly, it would be helpful to have more acknowledgement on the impact that fertility treatment can have on wellbeing.

> *"Maybe in the section then in the planning you know maybe if just kind of it's something to think about isn't it that there may be additional factors to think about like you know chances are there will be other people going through IVF fertility treatment which you know is, I think additionally stressful and more of a drain you know on people's, people's mental resources"*
>
> *Participant 3*

In line with the quote above, the quote below discusses how it was important to recognise experiences such as fertility treatment and miscarriages and the impact this may have on people's mental health. It was important not to assume that everyone reading this guide and

planning a pregnancy would be coming to it from the same background. This participant also recognised how including information on all topics may be "opening a can of worms". This participant suggested that even a brief sentence to acknowledge difficult experiences that people may have had would be sufficient, rather than detailed information.

> *"I mean I suppose it might be opening a can of worms for people who are using fertility treatment and things, may well find the whole thing more stressful … I don't think that IVF is mentioned at all I don't know quite what to think about it's I imagine you know the kind of more common, so I imagine that they've these categories people are having it, and it could just be that could be one of a number of different kind of different situations that people are in I suppose it's people who've had miscarriages and things might also kind of precipitate more stress and likely to have a breakdown of mental health and things like that I suppose if possible you know just a sentence of kind of "help might be possible" actually people can be in, they can be in a difficult situation … it doesn't mean that people are coming at it from a really stable background sort of thing"*
>
> *Participant 6*

6.2.6.3 SOLO / SINGLE MOTHERS

It was recognised that there was no representation from women without a partner in the sample for pilot one. For this pilot, the sampling strategy involved seeking participants who did not have a partner. As shown in Table 6.1, three women in this pilot were planning a pregnancy without a partner. In this pilot, women felt that overall, the guide was written in an inclusive way. Women planning a pregnancy without a partner valued that the guide was catering for their situation.

> *"I mean I thought it was quite well worded with the section six 'What do partners, family, and friends need to know?', so it says "although we use the term partner in this section the information will be helpful for everyone who plays a key role in the mother's life". I thought that made it very inclusive and families come in all shapes and sizes so that, I liked that when I got to that bit I was like "oh they are thinking about me" ((laughs))"*
>
> *Participant 8*

Women did however recommend improvements that could be made. One recommendation was to include more recognition that women planning a pregnancy without a partner may have additional things to think about and plans to put in place compared to those with a partner.

> *"...and then you know you might need some additional planning if the solo mum, or single mum in terms of say respite night support you know if people can, or if you can plan for people to be around for the first few days and weeks for example, but yeah I just, I know that, that's my situation, but I don't imagine that I'm the only one so I just thought that might be nice it might make it a little more inclusive, cos not everyone is gonna be the standard married with partner and trying naturally."*
>
> *Participant 3*

Improvements were also suggested to make the information relating to conceiving more inclusive. It was suggested that this could be more of a recognition of the different ways in which a woman may conceive, rather than adding detailed information on fertility treatment.

> *"I mean you've got here "There are factors that can affect a couple's chance of conceiving" which is a general, so and most couples will get pregnant within a year things like that, but obviously there are these, you know like I said miscarriages and people trying with IVF either as a couple or singularly, but it might be you know that something applied to you, they might sort of feel they hadn't been quite recognised in that … I probably wouldn't make it, make a big thing of it because it's too big to kind of go into in a way, it's more just recognising it so people who might come in that categorically feel that they're being included"*
>
> *Participant 6*

In this pilot, it was also recognised that women may not have close family that can be there to support during the perinatal period. Similar to issues raised in theme 2, while women found the self-management strategies and information on ways in which others can support helpful, they also recognised that women without this support may feel left out or feel that their plans are not good enough.

> *"I think for the partner's family and friends I think it was really this section that I, I felt slightly left out, I know that it wasn't intended because I know you said you know read partner as friend, family or whatever, but there may be other ways but I thought maybe, maybe if I think maybe just an acknowledgement that you may not have a partner you may not have family you know you- maybe it's just you"*
>
> *Participant 3*

The guide included an image of a couple holding hands and holding a baby, with their faces outside the image frame. A woman planning a pregnancy without a partner commented on how this may not cater for women like her. Contrastingly, in pilot one, a participant discussed that she related to this same image and felt that it positively contributed to the guide ("I do I love images of people … and so like for example the one on page 25, that image of the- it's like a family, erm I related to that … it shows support, it shows the baby involved somehow" Participant 6, Chapter 5). It appeared that images that some women find helpful and could relate to, proved problematic for others.

> *"I suppose as a- I know it's a very picky point, as a mum who's going to be going through this on my own on page 16 you've got the kind of happy couple holding hands … but you know I can't expect to have everything catered towards me ((laughs)) … and then on page 18 you've got a mum and a child so that's fine."*
>
> *Participant 8*

As discussed above, one woman described the positive impact that an image of a family had on her. The participant felt that it gave her a sense of hope. Feedback on images in this pilot and the previous pilot clearly demonstrated the positive impact that images that people can relate to can have. The feedback also shows how feeling different from what is portrayed in an image, for example, a single person looking at an image of a couple and a baby, may make an individual feel like they are not being accommodated.

6.2.7 Impact of COVID-19 pandemic

The impact of the COVID-19 pandemic on participants in this pilot appeared to be less pronounced than those who participated in pilot one. Compared to pilot one, COVID-19 and

its effects did not come up as much during interviews. Women were asked whether COVID-19 had affected their experience of planning for a pregnancy in any way at the end of the interview. Women reported that the COVID-19 pandemic resulted in them delaying the decision of whether to plan for a pregnancy or delaying fertility treatment. Women also discussed their concerns about being in a MBU during a lockdown.

> *"Just I wouldn't want to get ill at this moment in time, so we didn't exactly rush the pregnancy decision, cos I didn't want to be in a MBU that was locked down and I heard it said they go home for the weekend and then they've got to self-isolate until their test comes back which can be 2-3 days so you're basically without nurse support which is pretty bad isn't it?"*
>
> *Participant 2*

As in pilot one, one woman explained that the COVID-19 pandemic had impacted on her clinical appointments in that they were now being held remotely. This had also affected women's fertility treatment. In the quote below, one woman recognised that this had put further pressure on her as she was 47 years old and approaching the maximum age that she was able to receive fertility treatment. This woman also discussed how the COVID-19 pandemic had also impacted on her mental health which had further delayed her plans to become pregnant.

> *"So, it's delayed things for me by at least a year and I don't have many years to play with because I'm 47 and there's not much leeway in the fact that the human fertility in embryological association (HFEA) will only allow embryo transfers up to the age of 50 so I've got a bit of a deadline and wasn't a year with covid related issues has been quite frustrating, but also in terms of covid and my mental health I had a massive manic episode just after covid broke out and it was definitely stress related because of the pandemic which sort of also put my pregnancy plans on hold a bit"*
>
> *Participant 1*

6.3 Quantitative results

6.3.1 Overview of quantitative results

This section presents the quantitative results of pilot two collected through questionnaires before and after the guide, of participants who completed the measures at both time points. Participants completed the following measures before and after using the guide 1) Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith 1983); 2) Altman Mania Scale (AMS)(Altman et al. 1997); 3) Decisional Conflict Scale (DCS) (O'connor 1995); and 4) a bespoke acceptability measure. Further information on each questionnaire and the development of the acceptability measure can be found in Chapter 3.

As in pilot one, statistical analysis of results from a small sample of participants such as this would be inappropriate on the basis of insufficient power. Participant questionnaire data is therefore presented using line diagrams to plot each participant's scores on the measures described above. Questionnaire data allowed the exploration of two of the main objectives in this project. These were to determine acceptability of the guide, and the feasibility of using these questionnaire measures as part of a larger scale Randomised Controlled Trial (RCT) to test the guide in the future. It was also important to determine whether using the guide could cause harm to women. Questionnaire data also enabled us to explore decisional conflict within the sample before and after using the guide and along with the qualitative results, inform refinements made to the guide prototype.

Table 6.2 presents the descriptive statistics (mean, standard deviation) for the questionnaire measures from pilot two. Results from the bespoke acceptability measure are presented separately. As discussed above, six participants completed the questionnaire measures before and after using the guide (for more information, see section '6.1.1 Participants'). Of these six participants, one did not complete DCS Section A.

Measure	Pre-guide Mean N=6 (SD)	Post-guide Mean N=6 (SD)
HADS-Anxiety	6.83 (4.36)	7.83 (6.34)
HADS-Depression	3.50 (2.66)	3.00 (2.53)
AMS	2.00 (2.10)	3.17 (2.64)
DCS – Section B	35.68 (16.64)	25.78 (15.93)
	N=5 (SD)	N=5 (SD)
DCS – Section A	27.81 (9.07)	16.56 (10.75)

Table 6.2 Quantitative results of pilot two pre-guide and post-guide mean and standard deviation (SD) for completers

6.3.2 Hospital Anxiety and Depression Scale (HADS)

The Hospital Anxiety and Depression Scale (HADS) was used to measure symptoms of anxiety and depression (Zigmond and Snaith 1983). Further information on the measure and its scoring is included in Chapter 5.
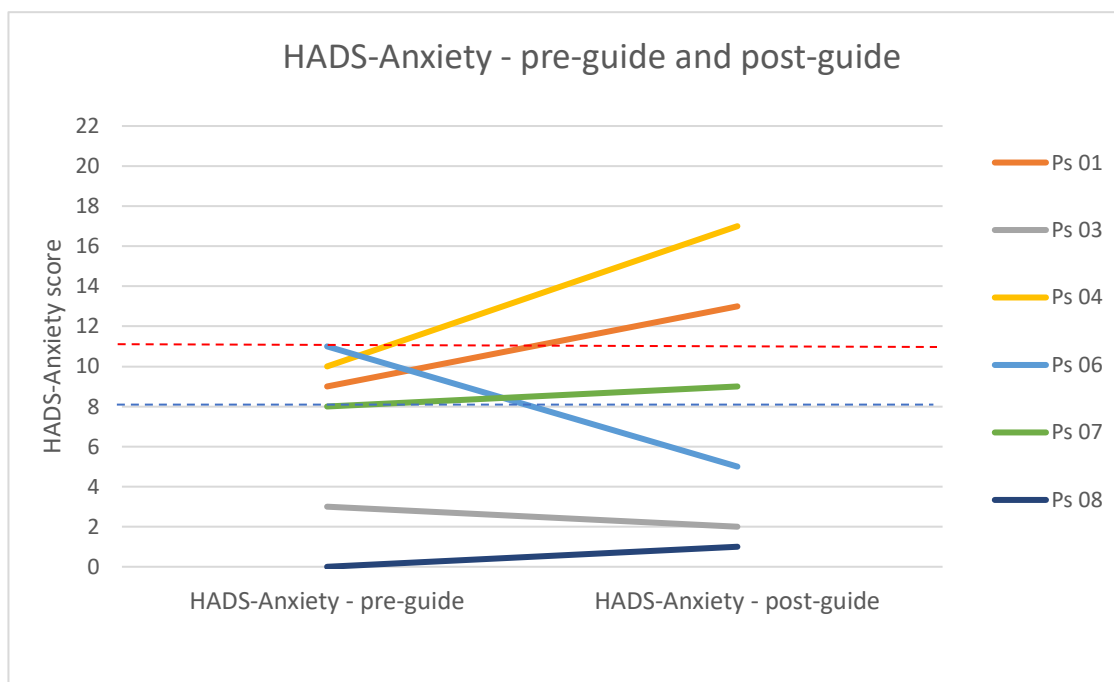
Figure 6.6 HADS-Anxiety results pre-guide and post-guide of pilot two. Red dashed line = cut off for cases (≥11). Blue dashed line = cut off for borderline cases (≥8).

The mean HADS-Anxiety score increased from pre-guide (mean = 6.83; SD = 4.36) to post-guide (mean = 7.83; SD = 6.34). Figure 6.6 presents HADS-Anxiety scores for participants before and after using the guide, with the red dashed line representing the cut off for cases (≥11) and the blue dashed line representing the cut off for borderline cases (≥8). Scores under the blue dashed line indicate no signs of anxiety.

Four participants showed an increase in score post-guide, with two participants increasing from the borderline range pre-guide to above the cut off for cases (≥11) post-guide. One participant showed a decrease in score from the case category (≥11) pre-guide to a score of 5 post-guide, below the cut off. Two out of the six participants scored below the cut off score for borderline cases (≥8), before and after using the guide (each showing a change of one point pre-guide compared with post-guide).
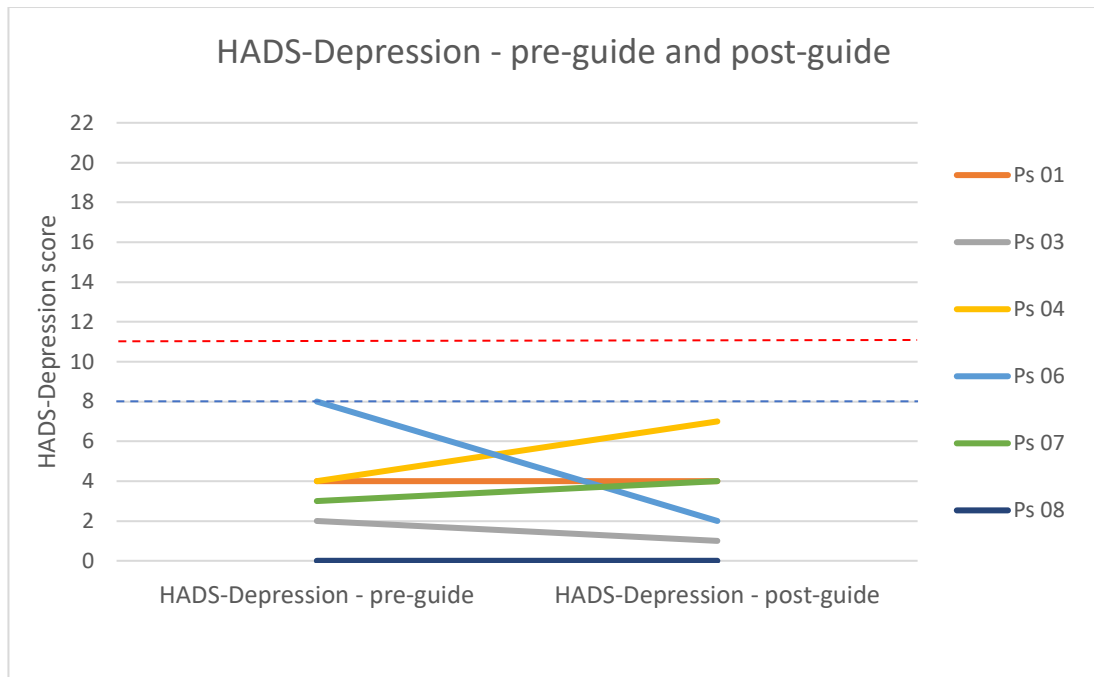
Figure 6.7 HADS-Depression results pre-guide and post-guide of pilot two. Red dashed line = cut off for cases (≥11). Blue dashed line = cut off for borderline cases (≥8).

The mean HADS-Depression score decreased from pre-guide (mean = 3.50; SD = 2.66) to post-guide (mean = 3.00; SD = 2.53). Figure 6.7 presents HADS-Depression scores for participants before and after using the guide, with the red dashed line representing the cut off for cases (≥11) and the blue dashed line representing the cut off for borderline cases (≥8). Scores under the blue dashed line indicate no signs of depression.

Two participants showed an increase in score, two showed a decrease in score, and two presented with the same score pre-guide and post-guide. Five out of the six participants scored below the cut off score for borderline cases (≥8) pre-guide and post-guide. One participant scored within the borderline category pre-guide, and within the no case category post-guide indicating no depressive symptoms present.

6.3.3 Altman Mania Scale (AMS)

The Altman Mania Scale (AMS) was used to measure symptoms of mania or hypomania (Altman et al. 1997). Further information on the measure and its scoring is included in Chapter 5.
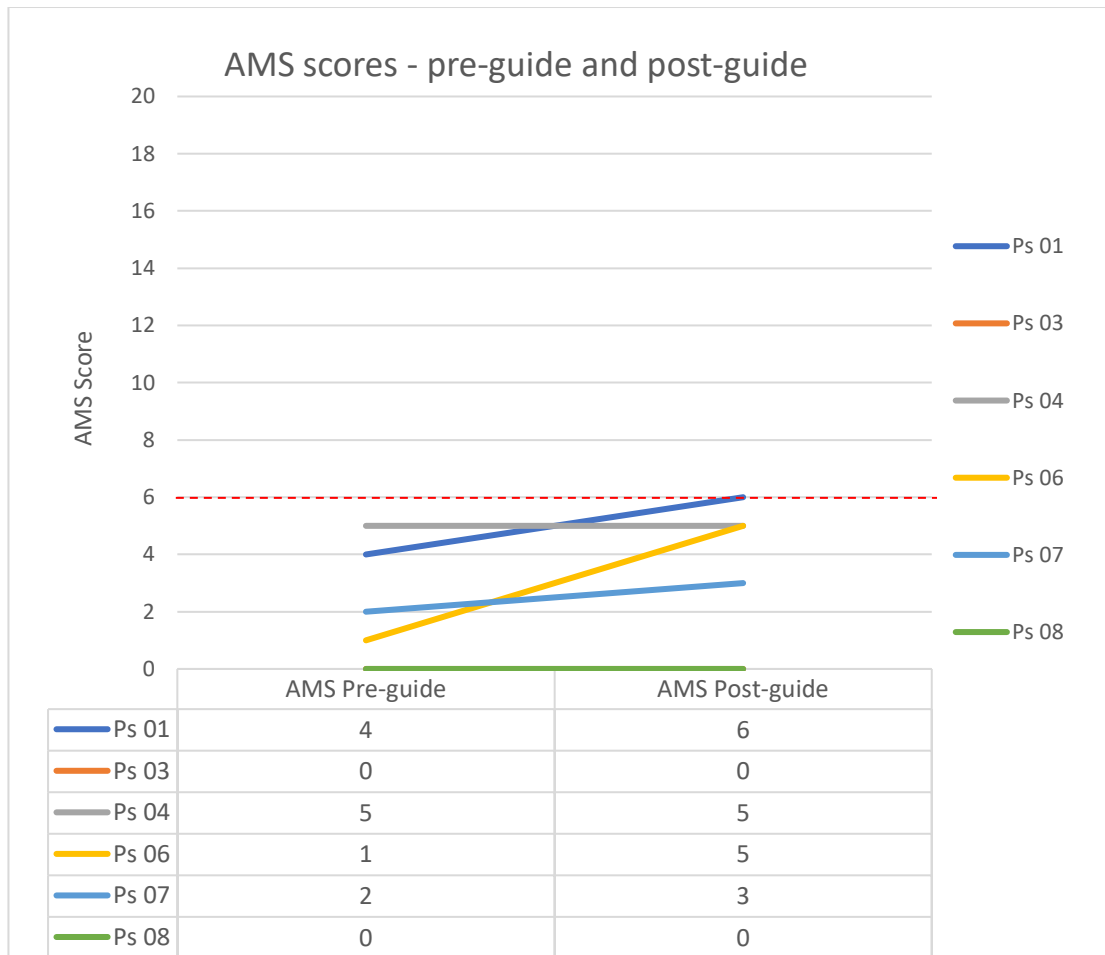
Figure 6.8 Altman Mania Scale (AMS) results pilot two. Scores on or above red dashed line = possible presence of mania or hypomania (≥6).

The mean AMS score increased from pre-guide (mean = 2.00; SD = 2.10) to post-guide (mean = 3.17; SD = 2.64). Figure 6.8 presents AMS scores for participants before and after using the guide. A threshold of six or above (≥6) signifies the possible presence of mania or hypomania and is presented in the graph as a red dashed line. A data table is also included, as more than one participant scored zero pre-guide and post-guide, which is not clear from the graph.

Five out of six participants scored below the threshold pre-guide and post-guide. One participant showed an increase in score from four to six, representing a score above the threshold (≥6) post-guide, indicating the possible presence of mania or hypomania. Of the five participants scoring below the threshold pre-guide and post-guide; two participants showed an increase in score; and three remained the same (two of whom scoring zero pre-guide and post-guide).

6.3.4 Decisional Conflict Scale (DCS)

The Decisional Conflict Scale (DCS) was used to measure decisional conflict (O'connor 1995). Further information on the measure and its scoring is included in Chapter 5.

Participants completed two separate DCS relating to the following decisions: 1) Making a decision about whether or not to have a baby; and 2) Making decisions about medication during pregnancy. Participants were asked to state their current preferred option for each decision.

6.3.4.1 SECTION A: MAKING A DECISION ABOUT WHETHER OR NOT TO HAVE A BABY

For Section A, participants were asked to state their preferred option to the statement 'Making a decision about whether or not to have a baby' from the following list: 'Having a baby', 'Having a baby, but not right now', 'Not having a baby' or 'Unsure'. An 'Other' option was also provided with space to provide more detail. Participant responses relating to their preferred option to the statement above are presented in Table 6.3.

Options *Pre-guide / Post-guide*		Having a baby	Having a baby, not right now	Not having a baby	Unsure	Other
Participant 1	*Pre-guide*		X			
	Post-guide		X			
Participant 3	*Pre-guide*	X				
	Post-guide					**X -** Having a baby once travel abroad for fertility treatment possible due to pandemic
Participant 4	*Pre-guide*		X			
	Post-guide				X	
Participant 6	*Pre-guide*	X				
	Post-guide	X				
Participant 7	*Pre-guide*		X			

		X				
	Post-guide	X				
Participant 8	Pre-guide	X				
	Post-guide	X				

Table 6.3 Decisional Conflict Scale (DCS) Section A preferred option responses for the statement 'Making a decision about whether or not to have a baby' pre-guide and post-guide

As shown in Table 6.3, three participants (Participant 1, Participant 6, and Participant 8) remained with the same preferred option from pre-guide to post-guide. These choices included 'Having a baby' and 'Having a baby, but not right now'. As shown in Figure 6.9, Participant 1 showed a decrease in score from the moderate DCS category to the low DCS category. Participant 6 and participant 8 scored within the low DCS category pre-guide and post-guide.

Three participants reported a change in their preferred option after reading the guide. The changes included the following: (i) 'Having a baby' to 'Other (Having a baby once travel abroad for fertility treatment possible due to pandemic)' (Participant 3); (ii) 'Having a baby, not right now' to 'Unsure' (Participant 4); and 'Having a baby, not right now' to 'Having a baby' (Participant 6). As shown in the free text, Participant 3's option changed due to external factors (the impact of the COVID-19 pandemic on travel restrictions to access fertility treatment abroad). Of the two other participants who changed their mind, one participant became more unsure of her decision to have a baby after having a baby (Participant 4), while another participant decided to have a baby more imminently after reading the guide (Participant 7). Participant 7 showed a decrease in DCS score, reducing from a score within the high decisional conflict category to the moderate decisional conflict category. Participant 4 did not complete the post-guide DCS (Section A).
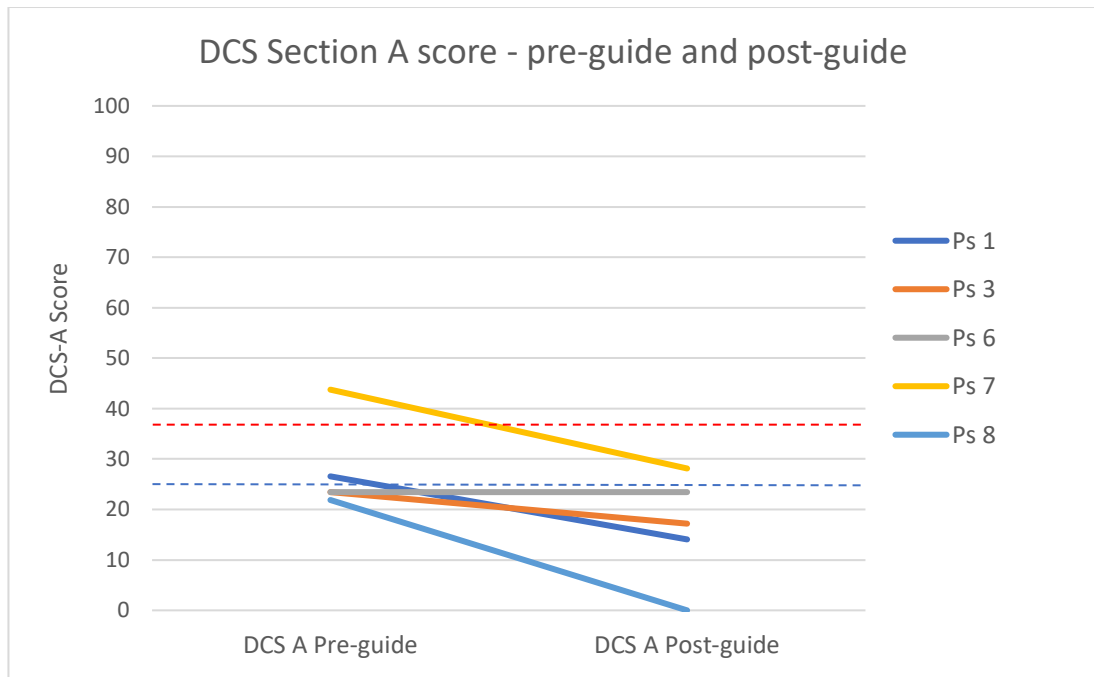
Figure 6.9 Decisional Conflict Scale (DCS) 'Making a decision about whether or not to have a baby' (Section A) results pilot two. Red dashed line = baseline for high decisional conflict scores (>37.5). Blue dashed line = threshold for low decisional conflict scores (<25).

The red dashed line presented in Figure 6.9 represents the baseline for high decisional conflict scores (>37.5), while the blue dashed line represents the threshold for low decisional conflict scores (<25).

Of the five participants that completed the DCS (Section A) questionnaire, four participants showed a decrease in decisional conflict score and one participant's score remained the same score pre-guide and post-guide. Before using the guide, one participant scored within the high decisional conflict category, one within the moderate decisional conflict category, and three within the low decisional conflict category. After using the guide, one participant scored within the moderate decisional conflict category and four within the low decisional conflict category. One participant scored within the low decisional conflict category before and after using the guide, scoring near the top of the category pre-guide (score - 22), to scoring zero post-guide, representing no decisional conflict.
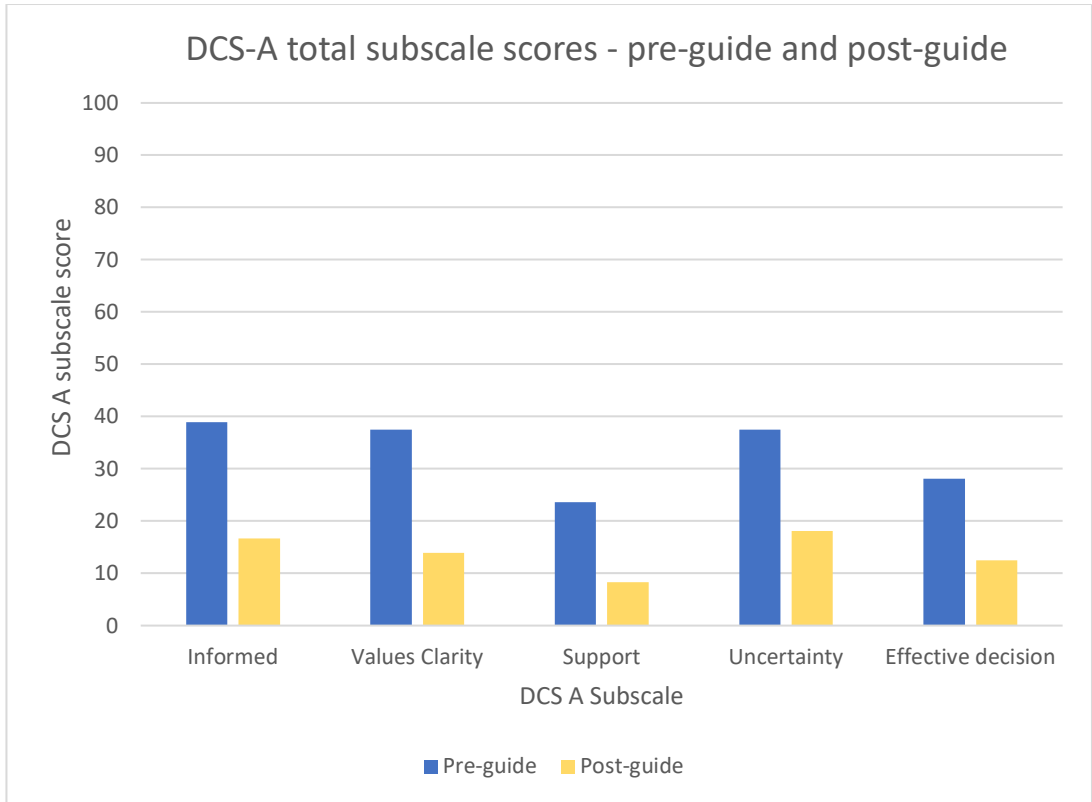
Figure 6.10 Decisional Conflict Scale (DCS) 'Making a decision about whether or not to have a baby' (Section A) mean subscale scores pre-guide and post-guide

As shown in Figure 6.10, all subscales show a decrease in scores from pre-guide to post guide for the DCS-A section. Three subscales (Informed, Values Clarity and Uncertainty) showed a mean score within the high decisional conflict category (>37.5) pre-guide and within the low decisional conflict category post-guide (<25); one showed a decrease from the moderate to low decisional conflict category (Effective decision); and one remained within the low decisional conflict category (<25) pre-guide and post-guide (Support). After using the guide all subscales mean scores were within the low (<25) decisional conflict category. DCS (Section A) individual subscale scores pre-guide and post-guide for are presented in Figure 6.11.

DCS-A individual subscales scores - pre-guide and post-guide

	Ps 1		Ps 3		Ps 4		Ps 6		Ps 7		Ps 8	
	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post
Informed	25	25	33	25	75		33	25	50	25	17	0
Values Clarity	25	8	33	25	58		33	25	50	25	25	0
Support	25	0	17	17	33		17	17	33	17	17	0
Uncertainty	33	8	17	25	58		17	25	67	50	33	0
Effective decision	25	25	19	0	63		19	25	25	25	19	0

Pre-guide and post-guide participant subscale scores

Informed   Values Clarity   Support   Uncertainty   Effective decision

Figure 6.11 Decisional Conflict Scale (DCS) 'Making a decision about whether or not to have a baby' (Section A) individual participant subscale scores pre-guide and post-guide

A table of individual scores is presented below the graph in Figure 6.11 in order to distinguish between scores of zero and instances when the scale was not completed (Participant 4). Individual subscale scores mostly showed a decrease in score, or the same score from pre-guide and post-guide. Of the scores that reduced from pre-guide to post-guide, the majority reduced by one DCS category. All participants showed a reduction in score for the 'Values Clarity' subscale. There were three instances out of the 25 individual subscale scores where an increase in score was shown: Participant 3 for the 'Uncertainty' subscale, and Participant 6 for the 'Uncertainty' and 'Effective decision' subscale. Participant 3 showed a decrease in her overall decisional conflict score (Section A), and showed a change in her preferred choice. Participant 3's preferred choice changed from 'Continuing medication' pre-guide to 'Unsure (free text: reducing dosage of current medication)' post-guide. Participant 6's overall

decisional conflict score (Section A) and preferred choice ('Having a baby') remained the same pre-guide to post-guide.

6.3.4.2 SECTION B: MAKING DECISIONS ABOUT MEDICATION DURING PREGNANCY

For this section, participants were asked to state their preferred option to the statement 'Making decisions about medication during pregnancy' from the following list: 'Continuing medication', 'Stopping medication', 'Switching to a different medication' or 'Unsure'. An 'Other' option was also provided with space to provide more detail. Participant responses on their current preferred option in relation to this statement are presented in Table 6.4.

Options Pre-guide / Post-guide		Continuing medication	Stopping medication	Switching to a different medication	Unsure	Other
Participant 1	Pre-guide	X				
	Post-guide	X				
Participant 3	Pre-guide	X				
	Post-guide					X - reducing dosage of current medication
Participant 4	Pre-guide			X		
	Post-guide					X - starting medication again
Participant 6	Pre-guide	X				
	Post-guide	X				
Participant 7	Pre-guide					X - Not sure whether to take medication as a precaution later in pregnancy
	Post-guide					X
Participant 8	Pre-guide	X				
	Post-guide	X				

Table 6.4 Decisional Conflict Scale (DCS) Section B preferred option responses for the statement 'Making decisions about medication during pregnancy' pre-guide and post-guide

As shown in Table 6.4, four participants (Participant 1, Participant 6, Participant 7 and Participant 8) remained with the same preferred option from pre-guide to post-guide. These choices included 'Continuing medication', and 'Other (free text: Not sure whether to take medication as a precaution later in pregnancy)'. As shown in Figure 6.12, two of these participants showed a decrease in DCS score, two from the high decisional conflict category

to moderate decisional conflict category, and one remained within the low decisional conflict category pre-guide and post-guide. One participant showed a small increase in DCS score from 22 to 25, therefore scoring within the moderate decisional conflict category post-guide, compared to within the low decisional conflict category pre-guide.

Two participants reported a change in their preferred option after reading the guide (Participant 3 and Participant 4). The changes included the following: (i) 'Continuing medication' to 'Other (reducing dosage of current medication)' (Participant 3); and (ii) 'Switching medication' to 'Other (starting medication again)' (Participant 4). As shown in Figure 6.12, two of the changes in preferred options did not represent a change from taking medication or not, but rather showed changes in reducing dosage and which medication they were taking. Participant 3 showed a reduction in score, from the high decisional conflict category pre-guide to moderate decisional conflict category post-guide. Participant 4 showed a slight reduction in score, but remained within the high decisional conflict category pre-guide and post-guide.
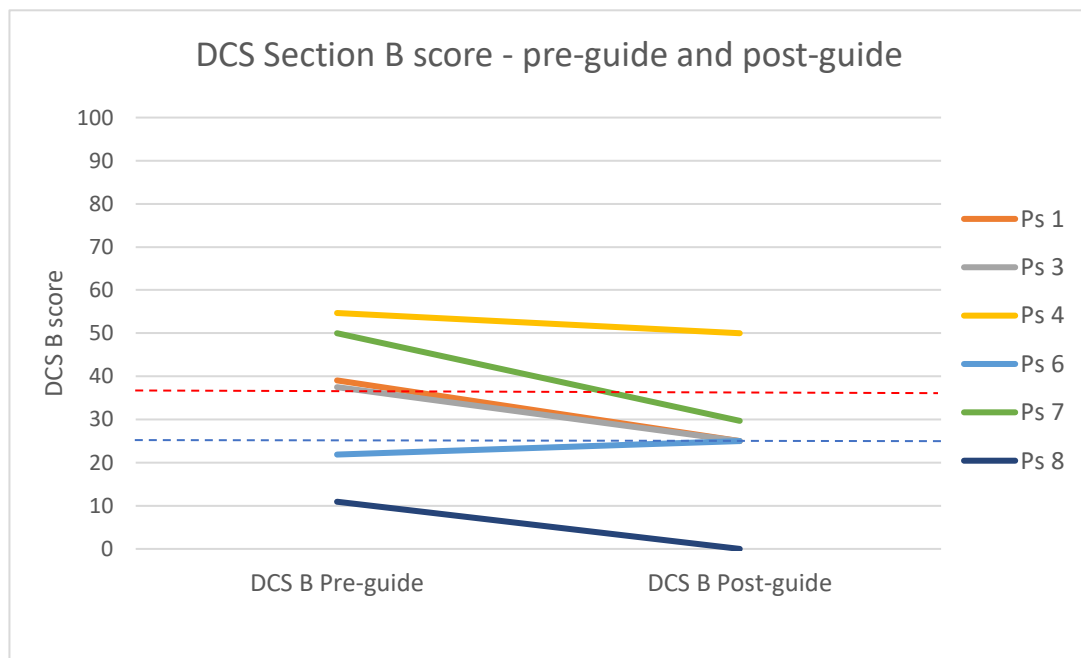
Figure 6.12 Decisional Conflict Scale (DCS) 'Making decisions about medication during pregnancy' (Section B) results pilot two. Red dashed line = baseline for high decisional conflict scores (>37.5). Blue dashed line = threshold for low decisional conflict scores (<25).

The red dashed line presented in Figure 6.12 represents the baseline for high decisional conflict scores (>37.5), while the blue dashed line represents the threshold for low decisional conflict scores (<25).

As shown in Figure 6.12, all but one participant's decisional conflict score decreased from pre-guide to post-guide for Section B. Four participants remained within the same category (one within the high decisional conflict category, two within the moderate decisional conflict category, one within the low decisional conflict category) and two participant scores reduced from the high decisional conflict category to moderate decisional conflict category. One participant showed an increase in score (21 to 25), signifying an increase from the low decisional conflict category to moderate decisional conflict category (Participant 6).

Before using the guide, three participants presented with high decisional conflict scores (>37.5), two with moderate decisional conflict scores (25-37.5) and one with low decisional conflict scores (<25). After using the guide, one participant presented with high decisional conflict scores (>37.5), four with moderate decisional conflict scores (25-37.5) and one with low decisional conflict scores (<25).
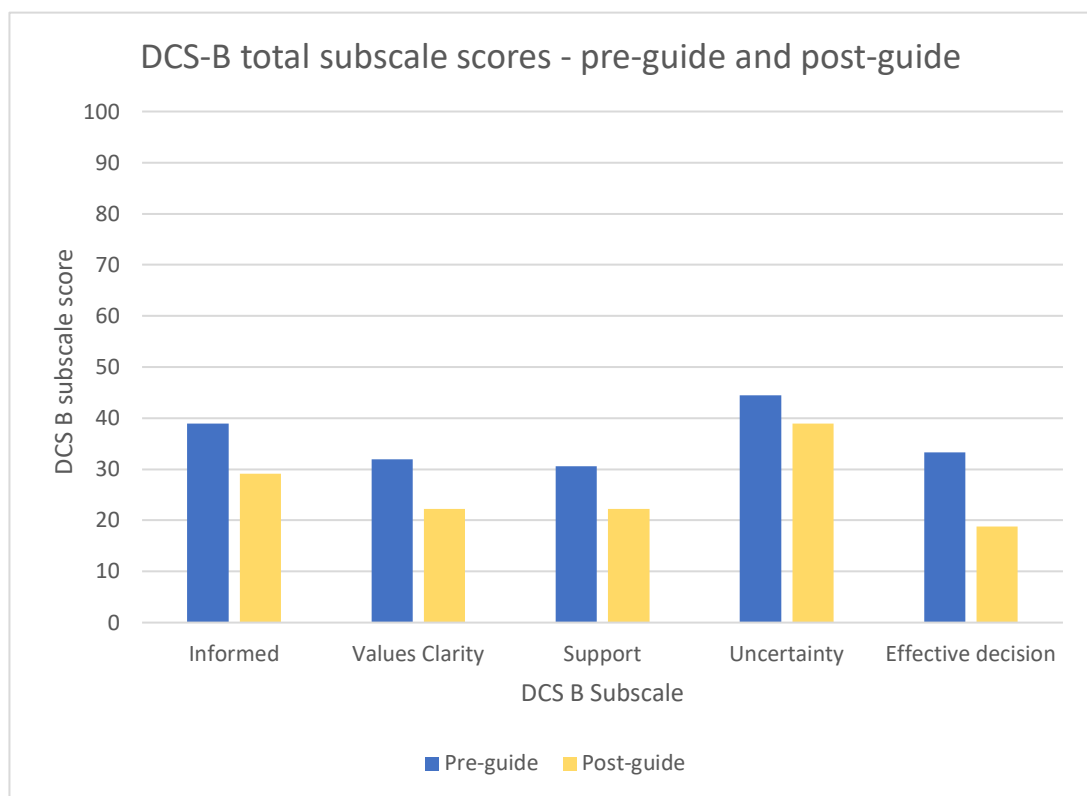

Figure 6.13 Decisional Conflict Scale (DCS) 'Making decisions about medication during pregnancy' (Section B) mean subscale scores pre-guide and post-guide

As displayed in Figure 6.13, all subscales show a decrease in scores from pre-guide to post guide for DCS (Section B). Before using the guide, the mean scores for two subscales (Informed and Uncertainty) were within the high decisional conflict category, and three subscales (Values Clarity, Support and Effective Decision) within the moderate decisional

conflict category. Of the two mean subscale scores within the high decisional conflict category pre-guide, one reduced to be within the moderate decisional conflict category post-guide (Informed), and one remained within the high decisional conflict category post-guide (Uncertainty). All three mean subscale scores within the moderate decisional conflict category pre-guide, reduced to be within the low decisional conflict category post-guide. DCS (Section B) individual subscale scores pre-guide and post-guide for are presented in Figure 6.14.

DCS-B individual subscales scores - pre-guide and post-guide

	Ps 1		Ps 3		Ps 4		Ps 6		Ps 7		Ps 8	
	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post
Informed	33	25	25	25	75	75	25	25	50	25	25	0
Values Clarity	25	25	25	17	50	25	17	25	50	42	25	0
Support	42	25	33	33	42	42	25	25	33	8	8	0
Uncertainty	50	25	50	25	67	75	25	25	75	83	0	0
Effective decision	44	25	50	25	44	38	19	25	44		0	0

Pre-guide and post-guide participant subscale scores

Informed   Values Clarity   Support   Uncertainty   Effective decision

Figure 6.14 Decisional Conflict Scale (DCS) 'Making decisions about medication during pregnancy' (Section B) individual participant subscale scores

As shown in Figure 6.14, the majority of individual subscale scores showed a decrease in score (15 items), or remained the same from pre-guide to post guide (10 items). Participant 1, Participant 3 and Participant 8's reduced from pre-guide to post-guide for three subscales, and remained the same for two subscales.

Of the 29 individual subscale scores presented in Figure 6.14, four scores increased, indicating an increased level of decisional conflict. The subscales with increases in individual scores were 'Uncertainty', 'Values Clarity' and 'Effective Decision'. Participant 4 and Participant 7 showed an increase in their 'Uncertainty' subscale score, with both scoring within the high decisional conflict category pre-guide and post-guide. Participant 4 changed her preferred option from 'Switching to a different medication' to 'Other (free text: starting medication again)' and Participant 7 preferred option remained the same, but signified uncertainty, i.e. 'Other (free text: Not sure whether to take medication as a precaution later in pregnancy)' (see Table 6.4). Participant 6 showed an increase in score for the subscales 'Values Clarity' and 'Effective Decision', both showing an increase from a low to moderate decisional conflict score from pre-guide to post-guide. Participant 6 remained with the preferred option of 'Continuing medication' pre-guide and post-guide (see Table 6.4).

6.3.5 Bespoke acceptability measure

As in pilot one, results from a bespoke acceptability measure designed for this study is presented below. Additional information on the measure and its development is included in Chapter 3.

Women were asked to respond to the following statement 'The guide was helpful for women making decisions when planning a pregnancy' with the following responses: 'strongly agree', 'agree', 'neutral', 'disagree' or 'strongly disagree'. Of the six women who responded to the post-guide measures, one participant responded with 'strongly agree', four with 'agree', and one with 'neutral'.

The questionnaire also asked women how helpful they found the information in the guide on several different topics. Participants were asked to rate how helpful they found the information by circling a number between 1 and 5 (1 = not at all, 2 = slightly, 3 = moderately, 4 = very, 5 = extremely).
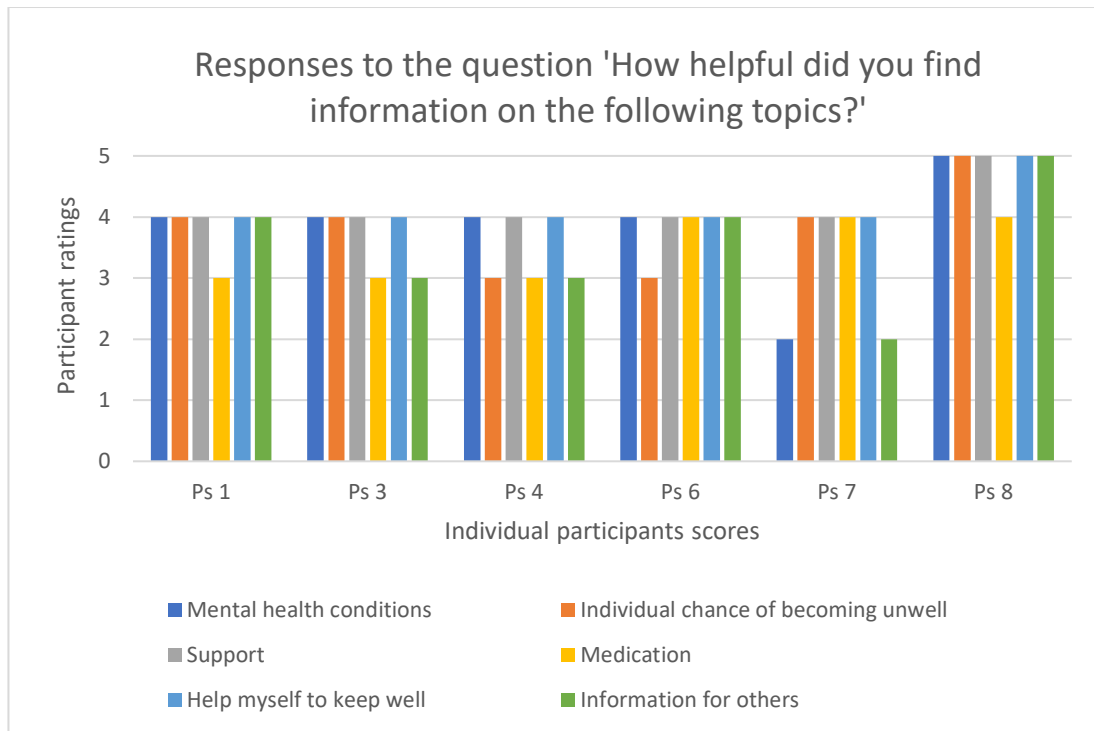
Figure 6.15 Participant responses to the question 'How helpful did you find information on the following topics?' (1 = not at all, 2 = slightly, 3 = moderately, 4 = very, 5 = extremely)

As shown in Figure 6.15, the topics 'Support during pregnancy and after birth' and 'Ways that I can help myself keep well' scoring the highest, with all six participants rating these sections as 'very helpful' or 'extremely helpful'. Ratings for other topics were mixed. For 'Mental health conditions during pregnancy and birth', participants rated 'extremely helpful' (n=1), 'Very helpful' (n=4) and 'Slightly helpful' (n=1). For 'My individual chance of becoming unwell with my mental health during pregnancy and after birth', participants rated 'extremely helpful' (n=1), 'Very helpful' (n=3) and 'Moderately helpful' (n=2). For 'Using medication during pregnancy and after birth', participants rated 'Very helpful' (n=3) and 'Moderately helpful' (n=3). For 'Information for partners, family or friends', participants rated 'Extremely helpful' (n=1), 'Very helpful' (n=2), 'Moderately helpful' (n=2) and 'Slightly helpful' (n=1).

Participants were also asked for their opinions on the interactive 'About me' sections in the guide. They were asked to respond to the following statement 'The interactive sections (e.g. Writing information about yourself, notes or responding to scales) were helpful' with 'Strongly agree', 'Agree', 'Neutral', 'Disagree', and 'Strongly Disagree'. One participant responded to the statement with, 'Strongly agree', two with 'Agree' and three with 'Neutral'.

Women were asked their opinion on the amount of information included in the guide, by responding that it was either 1) 'too much information'; 2) 'too little information'; or 3) 'just

right'. Four participants felt the amount of information in the guide was 'just right', and two participants felt that the guide was 'too much information'. Of those who responded with 'Too much information', the following comments were made: "It was rather overwhelming" (Participant 1) and "Erring on too much – it's a comprehensive guide but I can imagine some would find it overwhelming" (Participant 7).

Participants were asked 'How satisfied overall were you with the guide?'. All six participants responded with the responses 'very satisfied' (n=2) or 'mostly satisfied' (n=4). One of the participants who responded with 'mostly satisfied', also added the comment "It's impossible to make the decision 100% clear to someone, always going to be a hard one to make".

Women were also asked whether they would recommend the guide to other women who were pregnant or planning a pregnancy. Five participants said that they would recommend the guide to others. One participant did not respond, and included the following comment: "I would have to properly decide for myself who I feel would benefit most from looking at the guide with a view to using one for themselves".

6.4 Final prototype

The qualitative and quantitative results presented in this chapter, alongside the review of online information, input from the advisory group and discussions with the supervisory team, informed the refinement of the final prototype of the guide. Guide changes are presented in Table 6.5. As the complete final prototype of the guide is presented in Appendix O, this section does not include examples to illustrate guide changes, as presented in previous chapters.

Section / component	Guide refinements
Title, cover and presentation	The colour scheme was lightened to include a lighter grey and blue colour, for a more positive appearance following feedback on the importance of representing positivity.
'About me' pages	No change.
Using this guide	Women felt that having detailed information on how to use the guide, before even reaching the information they needed, made the guide longer and more overwhelming than it needed to be. For this reason, the summary of the guide presented in this section was reduced. The initial statement included in the guide changed from "Having a baby is a major life event for any woman. For women with experience of a mental health condition there is even more to think about." to a more positive statement, "Women with bipolar or previous postpartum psychosis have shared their experiences and opinions with us on what would help them during pregnancy and childbirth" following feedback relating to the tone of the guide. Explanation that a guide designed for women at different stages of planning and pregnancy with different previous experiences may mean that not all sections will be relevant to everyone. Included explanation that the guide can be used gradually, without the pressure of reading it cover to cover. The role that women with lived experience of bipolar disorder and / or previous postpartum psychosis in developing the guide was highlighted again in the main body of the guide. Following feedback about the length of the guide and how women felt that it included too much information, the following information was added to emphasise that women did not have to read all sections in the guide if they did not feel ready: "Developing a guide for women with different experiences of mental illness at different stages of planning and pregnancy means that not all sections in the guide will be relevant for everyone. The guide does not need to be read cover to cover. It is up to you at what stage in your journey of planning a pregnancy you'll find the information in each section most useful and feel ready to work through."
Section 1: What do I need to think about when planning a pregnancy?	More recognition about additional factors that may influence someone's experience of considering a pregnancy was included (e.g. miscarriage, fertility treatment) following feedback from both pilot results and the advisory group. The question "Am I clear about my reasons for wanting to have a baby?" was changed to "What are my current thoughts on having, or not having, a baby?" following feedback that the previous

	statement made a woman feel as if her decision was being questioned. A sentence was added to recognise that women who are planning a pregnancy as a solo person may have additional things to think about: "Thinking about whether to have a baby may be a decision that you are considering with a partner, or as a solo person. If you are planning a pregnancy without a partner, there may be additional things to think about and plans to put in place."
Section 2: How could childbirth impact on my mental health?	Following feedback on the individualised risk figures being daunting to read, efforts were made to convey a more reassuring tone as much as possible. The word "risk" was changed to "chance" and as well as including the likelihood of relapse, the likelihood of remaining well was added. Following this information, the section ended with information on ways in which women may aim to reduce their chances of relapse, to work towards remaining well through accessing support and self-management. In prototype one and two, this section was the first information section following the initial pages. In prototype three, this became section two, so that women did not read information that they may find most daunting first.
Section 3: What support may I receive during pregnancy and after having a baby?	Women felt that additional information should be included on what support third sector organisations can offer, which was added. An 'About me' page was added for women to write in information about any support or services available to them locally following feedback.
Section 4: What do I need to know about medication and pregnancy?	No changes.
Section 5: How can I help myself stay well?	In this pilot study, women explained the potential negative effect on women if they were unable implement some of the self-management strategies in the guide. Therefore, two additional sentences were included to make it clearer that the these were suggestions only. "It is important to note that these are suggestions, rather than essential strategies that you need to adopt. Some of these strategies may not be possible or appeal to everyone. These are ideas that you can consider, but you shouldn't feel pressure to take them all on board."
Section 6: What do partners, family and friends need to know?	Wording relating to how women may "minimise" their symptoms while unwell, was removed following feedback that this could promote feelings of guilt in women The original sentence was as follows, "It's important to remember that your partner may not realise when she is unwell and may minimise her

	symptoms, making them more difficult for you to spot."
Section 7: Bringing it all together	No changes.
Format	There was no change to the format, however, recommendations for considering an electronic version are discussed in the next chapter.
Other	

Table 6.5 Guide changes made following pilot two

6.5 Conclusion

This chapter presented the qualitative and quantitative results from pilot two, involving participants testing the second prototype of the guide. These results, alongside other sources of information, informed refinements made to develop the final prototype for this study, which was discussed in the latter part of this chapter, and is presented in Appendix O, or can be accessed through the following webpage www.ncmh.info/pregnancyplanning. Chapter 7 includes further discussion on the feedback presented in this chapter, as well as detailed recommendations for further development of the guide.

Chapter 7 Discussion

7.1 Overview

In this chapter, I will summarise the main findings of the project and discuss how each specific aim in this thesis was addressed. I will then discuss the strengths and limitations of the project and the research implications, describing possible solutions that could be piloted in future work, in relation to particular issues that arose during the course of the project. Finally, I will discuss the development of an app or web-based guide.

The overarching aim of this project was to develop and test a pregnancy planning guide for women at risk of severe mental illness during the perinatal period. In Chapter 1, the following aims were outlined:

1. To determine the critical components of a pregnancy planning guide for women with lived experience of bipolar disorder or postpartum psychosis who are at high risk of severe perinatal mental illness.
2. To establish whether the guide is acceptable to women with lived experience of bipolar disorder and / or postpartum psychosis at high risk of severe perinatal mental illness.
3. To determine whether a further phase 2 randomised controlled trial (RCT) of the guide would be feasible.

The research aims above were investigated as part of a review of online information available to women (Aim 1) in Chapter 2, and the subsequent development and piloting stages of the project (Aim 1, 2 and 3) in Chapters 4, 5 and 6.

7.2 Aim 1

> *To determine the critical components of a pregnancy planning guide for women with lived experience of bipolar disorder or postpartum psychosis who are at high risk of severe perinatal mental illness.*

The first aim of the project was to determine the critical components of the pregnancy planning guide. This involved following a systematic process of feedback and refinement throughout each stage of the project, in line with the Medical Research Council (MRC) Guidance for developing and evaluating complex interventions (Craig et al. 2008). This project implemented the initial two steps outlined in the MRC framework: 'Developing an

intervention' and 'Piloting and Feasibility' (Craig et al. 2008). This involved a development stage to inform the initial prototype of the guide, and two pilot studies to refine the guide based on feedback. Alongside this, an advisory group of women with lived experience of bipolar disorder and / or postpartum psychosis, as well as the supervisory team, were consulted at each stage of the project.

7.2.1 Development stage findings

The initial step within the development phase of the MRC framework was to identify the relevant existing evidence base (Craig et al. 2008). A rapid review of relevant literature was undertaken to identify and examine studies looking into the development or evaluation of a pregnancy planning guide or decision tool for women with bipolar disorder or previous postpartum psychosis. The search identified no relevant studies. As previous research has found that women at high risk of severe perinatal mental illness consult the internet for information relating to pregnancy and recovery (Heron et al. 2012; Dolman et al. 2016), the decision was made to conduct a review of online information available to these women. The specific objectives for this evaluation were: (i) to develop an understanding of the online information currently available to women; (ii) to establish a basis for information to consider when developing the initial prototype of the guide; and (iii) to establish relevant, high-quality sources of information that the guide could signpost women to.

Thirty-six unique websites were included in the review, which found that the number of topics covered, and the quality and readability level of each website, varied greatly. Symptoms and medication were the most prevalent topics mentioned within websites, while topics such as genetic risk of bipolar disorder and information for significant others were mentioned less frequently. Websites for the Royal College of Psychiatrists, Tommy's, Action on Postpartum Psychosis (APP), and Bipolar UK, mentioned the highest number of topics (between 80% and 83%) included in the coding checklist developed for the review, however no website mentioned all topics. The majority of websites encouraged women to seek professional advice, whilst very few websites included stories from women with lived experience of bipolar disorder and / or postpartum psychosis.

The reading difficulty level of websites in the review was assessed using the readability measuring tools Flesch Reading Ease (FRE) Scale and Flesch-Kincaid (FK) grade level formula (Flesch 1948; Kincaid et al. 1975) (see Chapter 2 for more information on these measures). The average reading difficulty for all websites was above what is recommended for health

information (Hutchinson et al. 2016), reflecting a "difficult" level according to the FRE, and "fairly difficult" level according to the FK grade level (Flesch 1948; Kincaid et al. 1975). The Journal of the American Medical Association (JAMA) benchmarks tool was used to measure quality, according to how clearly information on authorship, referencing content, disclosure of ownership and advertising, and dates of information upload or updates, were presented on the website (Silberg et al. 1997). Based on this tool, quality varied considerably, with most websites clearly disclosing ownership and advertising information, however the majority did not include references for the information included. The review enabled me to establish information to consider while developing the guide and to identify content-rich information of high quality to signpost to within the guide.

Alongside the review of online information, qualitative interviews with 8 women with lived experience of bipolar disorder and / or previous postpartum psychosis, and 14 healthcare professionals working within the field, were conducted as part of the development stage. A process of reflexive thematic analysis was used to analyse the qualitative interviews (Braun and Clarke 2006; Braun and Clarke 2019). Table 7.1 presents a summary of the themes and subthemes used as a framework for presenting the results in the development stage.

Development stage results	
Themes	**Subthemes**
Knowledge is power	*Accessing support* *Balance* *Information on sensitive topics*
Planning and preparing	*Personalising the guide* *Protective factors*
Positivity and reassurance	*Key messages* *Pregnancy as a happy time* *A focus on wellness*
Using the guide with others	*To educate* *To use in conjunction with appointments* *To encourage conversations* *A specific section for significant others*

Table 7.1 Summary of the development stage qualitative results

The qualitative analysis of the development stage interviews provided guidance on what information should be included in the guide, to what extent, and how to approach sensitive topics. Topics that women were concerned about, and considered important to cover in the guide, included individualised risk of becoming unwell, the hereditary of bipolar disorder, and medication options during the perinatal period. This corresponds with previous research

on the concerns that women had when considering having a baby (Dolman et al. 2013; Dolman et al. 2016; Stevens et al. 2018; Anke et al. 2019).

Women and professional stakeholders felt that providing information on what services may be available would empower the women to seek additional, tailored information that they needed when planning a pregnancy. Some felt that the guide should be comprehensive with "lots and lots of detail", while others suggested taking caution in including too much information and therefore overwhelming women. Themes emerging from this project related to striving for a balance between recognising the difficult decisions that women face during this time, without losing sight of this as a happy and exciting time for them and their families. This is consistent with qualitative work within the literature, which demonstrates women balancing two identities: being a woman with bipolar disorder and becoming a mother (Anke et al. 2019). In Dolman et al's (2016) qualitative work on factors influencing pregnancy decision making for women with bipolar disorder, the centrality of becoming a mother to women was apparent. It was felt that the guide should recognise topics that women may be concerned about, for example, individualised risk of becoming unwell, but that the guide should have an overall positive and reassuring tone. Consistent with these findings, women in previous qualitative research also felt that tone was important, and stated their preference to have a guide that was not "doomy and gloomy" (Dolman et al. 2016).

Participants suggested the benefits of having the option of personalising the guide, but without being too prescriptive, and to allow for flexibility in how the guide was used. This was one suggestion that clearly distinguished the guide from the online information that was currently available to women. Including an option to personalise the guide was seen as a way of advocating a sense of ownership in women over their pregnancy planning, and to aid with sharing personal information, for example, this included sharing information on previous episodes of mental illness with healthcare professionals. Many different ways of using the guide were discussed, for example, prior to or during appointments and to encourage conversations with others. A specific section for significant others was also suggested, to assist with identifying signs and symptoms, and to prompt significant others to recognise their own feelings and emotions during this time. Many discussed the key role that a partner plays when planning a pregnancy, which corresponds with the findings of Dolman et al (2016), who found that women considered their partner's involvement in the decision to have a child as essential. The analysis of the qualitative interviews described, alongside on-

going discussions with the advisory group and supervisory team, informed the development of the initial prototype of the guide.

7.2.2 Findings of the pilot studies

The prototype of the guide was tested during two pilot studies and refined based on feedback from qualitative interviews and quantitative questionnaire data. As in the development stage, a process of reflexive thematic analysis was used to analyse the qualitative interviews and identify themes (Braun and Clarke 2006; Braun and Clarke 2019). Table 7.2 presents a summary of the themes and subthemes used as a framework for presenting the results in pilot one and pilot two.

Pilot	Themes	Subthemes
Pilot one	Using the guide in different ways	*As a starting point* *As a gateway to support* *To recap* *One size doesn't fit all*
	Using the guide with others	*Joint decision making* *Sharing thoughts and feelings* *Validation* *Health professionals*
	Realistic and positive	*Sensitive topics* *Managing risk of becoming unwell* *More balanced than professional appointments* *Support: not just medication.*
	Reflective planning and decision making	*A structure to reflect* *Feeling overwhelmed* *Planning with uncertainty*
Pilot two	One size doesn't fit all	*Feeling overwhelmed* *Feeling motivated to plan*
	Tone	*The power of hearing from those who have 'been there'* *Dispelling blame and stigma* *Avoiding a perfect image*
	The guide and professional support	*Differences in service provision* *Honesty about variation in care*
	Feeling represented	*Validating to have a tailored guide* *Acknowledging individual experiences* *Solo/single mothers.*

Table 7.2 Summary of pilot one and pilot two qualitative results

A key theme throughout each pilot was 'one size doesn't fit all'. For some women, the guide confirmed that they were well prepared, whilst for others, the guide felt "daunting" or "overwhelming". Some women felt that this was a time of many concerns for them, and that

bringing these concerns to the forefront of their mind was not always helpful. As in Anke et al (2019), a qualitative study on perinatal concerns of women with bipolar disorder (discussed in Chapter 1), women in this project used emotional words such as "fear" and "frightening" when discussing their individual risk of becoming unwell and postpartum inpatient treatment. Women acknowledged that some topics in the guide were emotionally difficult to cover, but also felt they were important to include in the guide.

It became apparent over the course of the project that women who were at different stages of planning and working through their feelings from previous episodes of becoming unwell, with varying levels of professional involvement, experienced the guide in different ways. For some, information on individualised risk of relapse encouraged them to plan more, while for others, reading this information felt daunting. Many of the women taking part were already very knowledgeable, having accumulated a great deal of information about becoming pregnant over a number of years. It appeared that women who had done the most extensive planning, received the most professional input, and had worked through their feelings of previous perinatal episodes, found the guide most helpful. This highlighted the difficulty in developing a guide to suit women in different circumstances.

This study also identified other characteristics that influenced women's opinions and experience of the guide. This included planning a pregnancy without a partner, which to my knowledge, has not been represented in detail in previous qualitative work on this topic (Dolman et al. 2016; Stevens et al. 2018; Anke et al. 2019). Diagnosis also appeared to have a considerable impact on women's experience of the guide. Women with a diagnosis of postpartum psychosis found it difficult to relate to some aspects of the guide and felt it was more tailored to those with a diagnosis of bipolar disorder. Contrastingly, a member of the advisory group with a diagnosis of bipolar disorder, felt that the signposting and quotes in the guide focused more on postpartum psychosis. Difficulty in accommodating the views of everyone, particularly women with partners and those without, also extended to the use of photographs in the guide.

Signposting to helpful and reliable online websites was an important aspect of the guide. It allowed the guide to be concise, whilst also providing the option of seeking more detailed information for those who wanted to. The format and presentation of the guide meant that women could easily navigate their way through and skip sections that were less relevant or they did not wish to cover, and revisit sections when required. As discussed later in this chapter, the ability to effectively navigate through the guide in this way may not lend itself

as well to a paper-based guide like this, compared to a digital version. I found that women used the guide in different ways: as a gateway to support, as confirmation that they were well prepared, and as a conversational tool with significant others and professionals.

As in the development stage, a considerable amount of the pilot study feedback focused on the overall tone and message that the guide conveyed. All women commented on the inclusion of quotes from women with lived experience as a positive addition that instilled hope. Women appreciated a colour scheme that they considered positive, and interpreted stock photographs of women smiling or couples with their babies as being hopeful that they, like these people in the photographs, could get through this difficult journey of planning a pregnancy. However, it appeared that for some, portraying a perfect image was not helpful. It was important that the guide aimed to dispel guilt in relation to becoming unwell or taking medication, and avoid the promotion of a "perfect" image of pregnancy.

Women valued that the guide supported their decision to have a baby, with one participant explaining that reading the guide was the first time they had felt fully supported in their decision. Contrastingly, another participant commented on feeling her decision to have a baby as a woman with bipolar disorder was being "questioned" in the guide. This feedback suggests that women may have been aware of potential stigma associated with their decision to have a baby, which is in keeping with discussion in previous qualitative work in the field (Dolman et al. 2016).

Although the sample sizes did not allow for meaningful statistical analysis, the results from individual women provided further participant feedback on the guide and provided the opportunity to test their potential use prior to a larger scale study. Quantitative measures of decisional conflict supported the qualitative data suggesting that the pregnancy planning guide helped women with decision making on whether to have a baby, as well as decision making relating to medication during this time. Regarding decisions about whether or not to have a baby, 85% (11/13) of completers in pilot one and pilot two scored lower on the Decisional Conflict Scale (DCS) post-guide in comparison to pre-guide, whilst decisions about medication, 93% (13/14) of completers in pilot one and pilot two scored lower on the DCS post-guide in comparison to pre-guide. These results are in line with previous research, which found that the use of a decision making tool reduced scores of decisional conflict (Khalifeh et al. 2019; Vigod et al. 2019).

Outcome measures of anxiety, depression and mania were also used: (i) Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith 1983); and (ii) Altman Mania Scale (AMS) (Altman et al. 1997). In line with previous evaluations of decision aids used in other healthcare contexts (Prunty et al. 2008; Meade et al. 2015; McGrath et al. 2017; Khalifeh et al. 2019; Vigod et al. 2019), there was no clear pattern in the direction of change in scores on these measures in pilot one or pilot two. While some participant scores in these measures did increase after using the guide compared to before, participants did not attribute this to using the guide. In pilot two however, some participants did discuss that thinking about becoming pregnant for the second time after experiencing postpartum psychosis was difficult to think about. Therefore, it may be that using the guide brought a great deal of concerns and worries that they may not have thought about for a long time to the forefront of their mind. Additionally, considering that many of the women testing the guide had a diagnosis of bipolar disorder, it would be expected for mood to fluctuate across the two time points.

A greater number of participants showed elevated scores after using the guide compared to before in pilot two compared to pilot one. In pilot two, the average participant scores before using the guide were greater than average participant scores before using the guide in pilot one. It is however difficult to attribute scores to the guide itself, considering that bipolar disorder is characterised by episodes of high mood and low mood that are expected to vary over time. Other external factors may also have impacted on outcome measures. At the time of testing the guide, some women were in the process of making medication changes in preparation for pregnancy. For example, one participant was currently stopping her antidepressants under guidance from her General Practitioner (GP), which would not have been accounted for in the outcome measures.

Additionally, since pilot one was conducted during Autumn 2020 and pilot two during Spring/Summer 2021, it is possible that the COVID-19 pandemic impacted on results. Women in this study were considering pregnancy at a very unique time, with additional decisions to face compared with pre-pandemic times. Studies have found increased symptoms of anxiety and depression reported in the UK and many other countries during the COVID-19 pandemic compared to previously (Pierce et al. 2020; Xiong et al. 2020). There have been concerns about the impact of the COVID-19 pandemic on particular groups, including women, and users of mental health services (Moreno et al. 2020; Pierce et al. 2020). In this study, women reported the impact the COVID-19 pandemic had on their mental health, their work and

healthcare appointments. Women also described the impact the pandemic had on their pregnancy plans. Concerns included fertility treatment being delayed, reduced access to services, and the impact of social distancing measures on access to their support network, particularly if they needed to be treated in hospital as an inpatient. Therefore, it is likely that some women were considering factors relating to COVID-19 in their decision of whether to have a baby, as part of the DCS measure.

7.2.3 Guide refinement

Refinement of each prototype of the guide was conducted based on the findings of each stage in the project (development, pilot one and pilot two), the advisory group and supervisory team discussions. Further detail on each prototype and the changes made can be found at the end of Chapters 4, 5 and 6. As shown in results Chapters 4, 5 and 6, some guide components were determined at the development stage or pilot one, and little refinement was made following this. However, for other components, the process of refinement was less linear. Examples included the use of photographs in the guide, and content relating to the involvement of a partner. Early in the process, care was taken to be inclusive of women in all situations from all family structures, for example, those with a partner, and those without. This involved ensuring that the content in the guide did not assume that women had a partner at any stage of considering or planning a pregnancy. This resulted in feedback from a woman in pilot one explaining that her partner had read the information in the guide about the decision to have a baby and felt left out. Similar feedback was also received from the advisory group. Contrastingly, women who were planning a pregnancy as a single person noticed content in the same section, where they did not feel accommodated for. Similar issues were raised in relation to photographs, where women with partners and women who were single found different photographs helpful.

The option of personalising the guide was considered an important part of the initial prototype. Changes were made to the interactive 'About me' pages after each pilot study depending on whether women utilised the sections. Revisions included reducing the amount of writing space. Providing too much writing space set an expectation that these should all be completed, contributing to the guide appearing like homework. Changes were also made to accommodate the different ways that women used the guide, for example, providing the ability to store their 'About me' sections at the back of the guide, separate from the information, for privacy or ease of access for appointments.

Many of the guide revisions made throughout the project were minor wording changes. Although these were minor, these had important implications for the overall tone of the guide. Women identified information in the guide that had made them feel guilty or questioned their decision to have a baby. Overall, the tone of the guide was considered to be positive and reassuring, which was valued by women. Changes were made to further promote this, through additional quotes from women with lived experience of bipolar disorder and / or postpartum psychosis. Whilst determining some of the critical components of the guide, it became apparent that additional pilot work may be needed to gain further feedback to deliver an optimal guide in the most efficient way. Options to consider in future development of the guide are discussed in section '7.6 Research implications'.

7.3 Aim 2

To establish whether the guide is acceptable to women with lived experience of bipolar disorder and / or postpartum psychosis at high risk of severe perinatal mental illness.

The second aim of the project was to establish whether the guide was acceptable to women with lived experience of bipolar disorder and / or postpartum psychosis. Overall, women found the guide very helpful when making decisions on whether to have a baby and whether to stop, switch or continue with the medication they were on. Women were very pleased that a guide like this had been developed for their situation and were grateful to have had the opportunity to use it as part of the study. Women valued having the information they needed "all in one place". This echoes the findings of previous research, where women have identified the need for, and voiced disappointment at the absence of, "a central credible trustworthy information" (Heron et al. 2012). The guide was described as comprehensive, with the majority of women describing the amount of information as "just right".

Quantitative data from the bespoke acceptability measure supported the qualitative results, finding that overall, women found the guide acceptable and would recommend it to others. In response to the statement 'The guide was helpful for women making decisions when planning a pregnancy', 100% (8/8) of those who completed the questionnaire responded with 'Strongly agree' or 'Agree' in pilot one, and 100% (5/5) in pilot two. In pilot two however, a sixth participant did not respond to this question, but included the following comment: "I would have to properly decide for myself who I feel would benefit most from looking at the guide with a view to using one for themselves". When asked whether they were satisfied

with the guide, 100% responded with 'very satisfied' or 'mostly satisfied' in pilot one (8/8) and in pilot two (6/6). These high acceptability rates are in line with results found in studies evaluating the use of decision aids for antidepressant use (Khalifeh et al. 2019; Vigod et al. 2019).

When asked to judge the amount of information provided, 100% (8/8) responded with 'just right' in pilot one. However, it may be that those who dropped out or did not return their post-guide questionnaires in pilot one (drop out: n=1; missing data: n=1) and pilot two (drop out: n=2; missing data: n=2) found the guide less acceptable than those who responded to the measure. In pilot two, 67% (4/6) responded with 'just right' and in line with the qualitative data, 33% (2/6) responded that the amount of information was 'too much'. Of the two women who responded with the option 'too much', one was educated to A-level, currently under the care of a CMHT, and had received preconception counselling from a specialist perinatal psychiatrist. The second woman was educated to degree level, had previously received preconception counselling from a perinatal mental health team, but was not currently under the care of a mental health team. Future research, including larger samples, could investigate the characteristics of the women who find the guide less, and more, acceptable. As discussed in more detail below, many women in this study had accrued a great deal of knowledge prior to using the guide, which would be useful to explore further.

One participant, who was in her third trimester of pregnancy, dropped out from pilot one, explaining that her bipolar disorder was "getting the best" out of her. She also explained that there was far too much to fill out, referring to the interactive 'About me' sections. Although the guide explained that these were optional, this shows that for some women, the inclusion of the 'About me' sections put pressure on them to complete them. There were no other complaints or severe adverse events following the use of the guide. Another two participants dropped out of pilot two, however this was due to circumstances not related to the guide (described in the next section), and both participants expressed that they had found the guide helpful.

7.4 Aim 3

> *To determine whether a further phase 2 randomised controlled trial (RCT) of the guide would be feasible.*

This project aimed to test the feasibility of conducting further evaluation of the guide. This included, but was not limited to, considering information on recruitment, attrition and patient flow during each pilot to inform a larger scale project (Chapters 5 and 6, with further discussion in Chapter 7), the acceptability of the guide, and the process of taking part in the study. Recruitment targets were reached for each stage of the project. For pilot one, the dropout rate was 10% (1/10) and for pilot two it was 20% (2/10), demonstrating feasibility of retaining participants. Reasons for drop out in pilot one (n=1) are described above (in section '7.3 Aim 2'), and reasons for drop out in pilot two (n=2) related to unsuccessful IVF treatment and a hospital admission to Mother and Baby Unit (MBU) following birth. Both pilot studies also had missing data as a result of post-guide questionnaires not being returned: missing data from 10% of participants in pilot one and 20% in pilot two. This is in line with a Randomised Controlled Trial (RCT) of a decision aid for women with rheumatoid arthritis considering motherhood, where of the 96 participant who commenced with the pre-intervention measures, 67 completed the post-intervention measures, resulting in a 30% reduction in sample size (Meade et al. 2015). Follow up rates of the current study were however lower than those of Khalife et al (2019) and Vigod et al (2019), which were both around 90%.

Ways of improving the completion rate of outcome measures could be considered prior to a feasibility RCT. Women were sent three reminder emails to complete outcome measures, however it may be helpful to consider phone call reminders in future. Future research should also account for perinatal specific reasons that may affect participation, discussed in more detail below. Considerations may include adjusting sample size targets to accommodate for this and considering women's estimated date of delivery during the testing phase, considering the time-limited nature of pregnancy.

The optimal outcomes of a feasibility RCT would be that those receiving the guide would show a greater decrease in levels of decisional conflict (measured by the DCS), and higher levels of acceptability (measured by a bespoke measure of acceptability) compared to a control group. An outcome measure of depression and anxiety (measured by the Hospital Anxiety and Depression Scale (HADS)) should also be included, with the optimal outcome being that the measure shows no negative impact from using the guide, signified by no significant increases in scores for those using the guide compared to the control group. It would also be helpful to collect qualitative information relating to life events and wellbeing during this time, to provide context on any other factors that may contribute to anxiety and

depression levels at the time of using the guide. In this sample, it would also be important to consider symptoms of mania (measured by the Altman Mania Scale (AMS)), again to assess whether using the guide has a negative impact on women, and to provide context on women's current mental health at the time of using the guide.

There are issues to consider with the use of the DCS in future research. Section A involved the statement 'Making a decision about whether or not to have a child', which one woman explained may be insensitive to women who may already be pregnant. For section B of the DCS, women were asked to choose an option relating to their decision on medication. The options were 'Continuing medication', 'Stopping medication', 'Switching to a different medication', 'Other' and 'Unsure'. A number of women used the 'Other' box, suggesting that many medication options had not been included in the options, for example, starting medication or changing dosage. Future use of the measure should include additional medication options, based on women's responses in this study and discussions with the advisory group.

Qualitative information obtained during each pilot illustrated how knowledgeable women were when considering preconception and pregnancy decisions prior to receiving the guide. In this study, women who had received the most specialist input and carried out the most independent research, appeared to be those who found the guide most acceptable. These women also appeared to be the most decided on whether or not to have a baby, and on treatment options. Therefore, more knowledgeable women may not have benefited as much from the guide, compared with those who were less knowledgeable. In a future feasibility RCT, having an objective measure of knowledge may help to understand the effect of guide use on knowledge levels, and whether baseline knowledge is related to scores of other outcome measures, such as decisional conflict. In turn, this may aid understanding of the potential underlying mechanisms of change and who may benefit the most from using the guide. A bespoke measure of knowledge could be developed for a feasibility RCT, such as that developed in McGrath et al (2017), which included 15 multiple choice questions about pregnancy in epilepsy that women completed before and after using the decision aid.

While the recruitment targets were met in each stage of this project, there was a lack of diversity and representativeness among the participants. While this was largely affected by the impact of the COVID-19 pandemic on the recruitment strategy, making adaptations to the sampling strategy may also be helpful in a feasibility RCT. Discussion on the lack of diversity within the sample and how this could be improved is included below.

7.5 Strengths and limitations

A key strength of this project is that a novel pregnancy planning guide was developed following the MRC guidelines for the development of a complex intervention (Craig et al. 2008). To our knowledge, this is the first study to systematically develop and test a comprehensive pregnancy planning guide for women with bipolar disorder and / or previous postpartum psychosis. The guide was designed and piloted with the concepts of coproduction in mind. Whilst there is no single definition of coproduction, key features include developing equal relationships with those who use services and recognising the benefits that their expertise brings to the project (Social Care Institute for Excellence (SCIE) 2013). An international systematic review found that effective patient and public involvement (PPI) in research promotes the development of high-quality research that is beneficial to services users (Jackson et al. 2020). Two prototypes of the guide were tested with samples of women with lived experience of bipolar disorder and / or postpartum psychosis who were planning a pregnancy or currently pregnant. Alongside this, the study benefited from an advisory group of women to consult at each stage when refining each prototype. Previous participants were also invited to continue commenting on each prototype of the guide. This resulted in substantial input from women with lived experience of bipolar disorder and / or previous postpartum psychosis and professional stakeholders involved in working with women throughout the project. A limitation however, was that the advisory group of women largely consisted of volunteers and peer supporters from Action on Postpartum Psychosis (APP), with little representation from women with a diagnosis of bipolar disorder.

Another strength of this project was the potential clinical implications of the guide. The National Institute for Health and Care Excellence (NICE) guidance recognises the importance of discussions on pregnancy planning for all women with a diagnosis of bipolar disorder or previous postpartum psychosis of childbearing age (National Institute for Health and Care Excellence 2014a). Studies however suggest that women feel let down by the lack of specialist pre-conception care available to them (Dolman et al. 2016). NICE recommend the use of patient decision aids within healthcare settings to support shared decision making (National Institute for Health and Care Excellence 2021). This guide provides evidence-based knowledge relevant to the decisions that women are making, and information on accessing specialist care for tailored advice from healthcare professionals. This is especially important considering disparities in access to specialist perinatal mental health care across the UK

(Fernandez Turienzo et al. 2021). The guide may help women to prepare for appointments and encourage them to take an active role in discussions with their healthcare professionals and feel confident to voice their questions and concerns.

Reliable and widely used techniques were used to collect and analyse data during the development stage and pilot one and two. Recruitment targets for the professional stakeholders sample were guided by the 'information power' concept, a pragmatic method proposed as an alternative to data saturation. Researchers have criticised the concept of data saturation as a fixed point of data completeness, arguing that there are always new insights that can be generated if data collection is continued (Malterud et al. 2016; Low 2019; Braun and Clarke 2021b). As such, this project did not aim for data saturation or completeness, but used the 'information power' method to reach a point in which the data provided robust information to answer the research question, while also taking into consideration the resources available for this study. While the lack of saturation could be considered a limitation in this study, the 'information power' method allowed the development of recruitment target ranges, which was necessary for effective planning of the study. The sample target ranges were reviewed throughout data collection to ensure data sufficiency, based on key considerations (e.g. aim of the study, sample specificity and quality of the dialogue). The sample included professionals from primary care, secondary care mental health services and specialist perinatal mental health services (Malterud et al. 2016). The original target of 8-12 professionals in the development stage was exceeded (n=14) in order to target specific areas of interest, for example, social services, and to ensure there was sufficient richness in the data collected.

As in the development stage, a process of 'Information power' (Malterud et al. 2016) was adopted for pilot one and pilot two. The sampling strategy involved including women with different diagnoses, varying experiences of planning a pregnancy, for example, first / second child and varying demographics, age, ethnicity and level of education. In line with the 'information power' concept, the sampling strategy for pilot two was adapted following feedback to include women without a partner (Malterud et al. 2016). The strength of using this approach was that it allowed me to set specific recruitment target ranges, while also providing a flexible approach of evaluating the sample size throughout the project.

While good representation was sampled in terms of diagnoses and lived experience of pregnancy and mental illness, the sampling strategy was however limited in its success to sample women of varying demographics relating to age, ethnicity and level of education.

While attempts were made to represent women with varying personal characteristics and levels of education, the majority of completers for each pilot were of white ethnic background (pilot one: 78% (7/9); pilot two: 100% (8/8)) and educated at degree level or higher (pilot one: 78% (7/9); pilot two: 75% (6/8). This is a similar problem found within the wider literature on decision making interventions, where white, educated women are overrepresented (Stacey et al. 2017b). This limits the conclusions that can be made on the usefulness of the guide for people from different educational backgrounds across the social gradient. Given the issues with this current sample, future research could broaden the recruitment strategy to include primary care, community mental health teams and specialist perinatal mental health teams. Whilst this was difficult to achieve in the current project due to the COVID-19 pandemic, recruiting from these avenues may help diversify future samples, by recruiting women with varying levels of prior knowledge and readiness to plan a pregnancy.

While this was largely related to issues with recruiting from the National Health Service (NHS) during the COVID-19 pandemic, future research should consider broadening the recruitment strategy to include other avenues included in this study. For example, this may include recruiting from third sector organisations which support individuals from diverse backgrounds. This is likely to be a helpful strategy going forward, considering that Khalife et al (2019) also had difficulty in solely relying on healthcare teams for their recruitment prior to the COVID-19 pandemic. As discussed, there was a considerable difference in the feedback received on the guide depending on the level of specialist care that women were receiving. In order to better explore the potential affect that this may have on outcomes, future research could compare the amount of care received and measure women's knowledge on relevant topics prior to piloting the guide.

There was also a lack of representation from younger mothers, with only one participant in the pilot studies being under 30 years old. Research has suggested that younger mothers experience motherhood differently to older mothers and may experience additional challenges in adapting to motherhood (Wakschlag et al. 2000). It is therefore unclear how acceptable or helpful younger mothers would find the guide. The sample included representatives from women seeking fertility treatment, which may have been overrepresented, considering that this was not a particular area of interest for this study. In pilot two 3/8 (37.5%) of the interviews were women seeking fertility treatment, more so than the UK average, which is around 10% of women (Office for National Statistics. 2020).

The lack of diversity in the pilot samples is likely to have been influenced by one of the main recruitment avenues being the CUPS clinic, a specialist pre-conception counselling service with a Consultant Perinatal Psychiatrist. There appeared to be a considerable difference between those receiving specialist care compared to those who did not, in how they perceived the guide. Other important differences that would likely affect the feedback received on the guide are socioeconomic status. Women taking part in the qualitative interviews throughout the project shared suggestions to include in the guide that would not be accessible for all women, such as hiring a doula for postpartum support and booking pregnancy yoga classes. The lack of diversity in relation to these factors are a limitation of this project, which may reduce the suitability of the guide to women of all socioeconomic status.

Recruitment for pilot one and two was conducted during the COVID-19 pandemic. Many of the original recruitment avenues for this project were affected by the pandemic, including NHS community mental health teams and a specialist perinatal mental health team. This affected recruitment plans involving meetings with the Cardiff & Vale Perinatal Community Mental Health Team (CMHT) and CMHTs within the health board and recruit in patient waiting forms via flyers or in-person. Although I attended a virtual team meeting at the Cardiff & Vale Perinatal CMHT in November 2020 to present the project and discuss recruitment, this did not result in any participants. Due to the NCMH not recruiting new participants during the pandemic, potential participants were not passed on as planned. I was also unable to recruit from the NCMH public engagement events. As discussed above, this is likely to have resulted in a biased sample and represents a key limitation of the project.

The study set out to conduct focus groups with professionals, while also offering individual interviews to offer flexibility. Due to difficulty in aligning schedules, all participants took part in individual qualitative interviews. This may be a limitation, considering that interaction between group members in a focus group can facilitate the sharing and refinement of thoughts and opinions. The lack of focus groups therefore meant that the project may not have benefited from members building on each other's suggestions and ideas for the guide (Braun and Clarke 2013).

As discussed above, many participants were several years into their journey of considering and planning a pregnancy, and consequently, had accumulated a great deal of knowledge and professional input. The majority of women were recruited from a specialist pre-conception clinic or leading third sector organisations in the area. Women were also

identified through webinars run by National Centre for Mental Health and Bipolar UK, and the Cardiff University Psychiatry Service (CUPS) offering pre-conception support. Our primary recruitment avenues for the initial sample of pilot one (n=10) and pilot two (n=10) were APP (pilot 1: 40%, pilot two: 40%), Bipolar UK (pilot 1: 20%, pilot two: 30%) and the CUPS clinic (pilot 1: 20%, pilot two: 30%). Women were identified via advertisements on websites, in newsletters and social media of third sector organisations, NCMH and Bipolar Education Programme Cymru (BEP-C) (a psychoeducation course run by Cardiff University).

Readability scores were slightly lower than the average of all websites, but scored above the recommended level for health information (Hutchinson et al. 2016). Women commended how the guide was written and felt it was accessible, however as discussed earlier in this chapter, the majority of women in the pilot studies were highly educated. The pregnancy planning guide scored within the category "fairly difficult" for both the FRE (score: 59.1) and the FK grade level formula (score: 9.6). While efforts were made to write the guide in a patient-friendly, accessible way, these scores reflect a limitation of the guide and demonstrate the difficulty in writing comprehensive information, at the recommended level of difficulty.

In Chapter 2, relevant resources were identified that were of high-quality and content-rich, while also scoring within the recommended range for online information (Hutchinson et al. 2016). Efforts should be made to improve the readability of the guide, while maintaining quality and the richness of content, prior to a feasibility RCT. The NHS Digital service manual team have developed a 'Content style guide' for developing information resources for the NHS (www.service-manual.nhs.uk/content) that could be used. This includes specific recommendations to improve readability, such as aiming for information written at a reading age level of 11 to 14 years old. Recommendations are made on writing concisely: using short words, short sentences (up to 20 words), and short paragraphs (up to 3 sentences), in addition to using the active voice, e.g. "find a pharmacy" rather than "a pharmacy can be found".

I was responsible for data collection from participants during each pilot. Considering this, participants may have felt obliged to comment favourably on the guide and less comfortable in criticising it during the feedback interview. Additionally, participants recruited from the CUPS clinic (run by supervisor Professor Ian Jones) were likely to know Professor Ian Jones's link with the project. Similarly, women recruited from APP were likely to be aware of Dr Jess Heron's (supervisor and APP director) link to the project. Again, it is possible that this may

have influenced women's desirability to provide positive feedback. Honest opinions were however encouraged throughout the interviews, and the aim of the project, i.e. to refine and improve the guide based on their feedback, was emphasised.

The majority of interviews with professionals and women with lived experience were conducted via video or telephone call. It may be reasonable to question whether conducting interviews virtually could have been a limitation, by negatively affecting rapport. Internet connection difficulties have been suggested to have a potential impact on rapport (Seitz 2016), however in the context of this project, the few interruptions due to poor internet connection did not appear to negatively impact on rapport. In line with suggestions included in Seitz (2015), I spoke to each participant a number of times via telephone and / or video call and email prior to the qualitative interview, which helped to strengthen rapport. Research has shown that conducting interviews remotely via videoconferencing technologies are considered favourably by researchers and participants, sometimes more so than face-to-face and telephone (Archibald et al. 2019). I therefore feel that overall, using videoconferencing technology in this study was considered beneficial. As well as being cost-effective compared to face-to-face meetings due to travelling, it also offered greater flexibility for women with other commitments, such as working and looking after young children.

A process of reflexive thematic analysis was used to analyse qualitative interviews during the development and piloting stages of the project (Braun and Clarke 2006; Braun and Clarke 2019). Using this inductive approach allowed the project to be guided throughout by stakeholder input throughout, rather than being guided by the researcher's preconceived ideas on what the guide should look like. Semi-structured qualitative interviews were used, which allowed the interview to be guided by what participants felt was important, whilst also allowing the interviewer to probe for more details on topics of interest (Braun and Clarke 2013). Throughout the three stages of the project, at least 10% of interviews were coded by an additional researcher. As researcher subjectivity is not seen as a source of bias in reflexive thematic analysis, but rather as a resource, this exercise was performed to develop a richer understanding of the data and to encourage new ideas (Braun and Clarke 2006; Braun and Clarke 2019). It could be argued that a more deductive approach, such as 'codebook' thematic analysis (Braun et al. 2018) could have been adopted for the pilots, where areas of interest could have been pre-determined. While this approach may have been helpful in

some ways, for example to compare feedback for each prototype in a systematic way, the 'data-led' inductive approach lent itself well to exploring novel opinions and ideas.

7.6 Research implications

Whilst this project allowed us to identify and refine many of the guide's critical components, it also highlighted areas of uncertainty, suggesting that the guide may benefit from further development. Adequate development and piloting work is an important part of the MRC framework, and therefore conducting a large-scale study, without first exploring the recommendations below on a smaller scale would likely prove to be uneconomical (Craig et al. 2008). Therefore, prior to considering a Phase II RCT following this project, I suggest further piloting, based on the options presented below:

1. The need for tailoring
2. Length and size of the guide
3. Lived experience content

7.6.1 The need for tailoring

7.6.1.1 ISSUES

During this project, the difficulty in developing a guide for women with different diagnoses, personal characteristics, and at different stages of their pregnancy planning journey, became apparent. The qualitative results of each pilot highlighted the importance of women being able to relate to the content in the guide.

Women with bipolar disorder, and those with previous experience of postpartum psychosis share a similarity, in that they are both at high risk of experiencing a severe episode of illness after birth. As a result, much of the guide's content would be applicable to both groups. However, pilot stage feedback highlighted the challenges in designing one guide targeted at both groups. Participants with no diagnosis of bipolar disorder identified several aspects of the guide that they felt were more relevant to women with a diagnosis of bipolar disorder. Examples included interactive sections to record information on previous episodes of mental illness, a life chart and personal triggers. Women felt that these sections were tailored more to women with experience of recurring bipolar disorder episodes, rather than a single episode of postpartum psychosis. Whilst not a prominent theme during the development stage, one woman expressed that she felt it was "weird", that as a woman with previous experience of postpartum psychosis and no other diagnoses, to be associated with bipolar

disorder, explaining that it was something she got annoyed about. This contrasted to feedback from the advisory group, where a woman with a diagnosis of bipolar disorder highlighted that there were no quotes from women with bipolar disorder in the guide, only from women with previous postpartum psychosis.

It became apparent during the pilot studies that the majority of the women who found the guide most helpful were those who had received a considerable amount of specialist input while considering and planning for a pregnancy. These women felt it was beneficial that they had already covered topics with a healthcare professional and valued using the guide as confirmation that they were well prepared. For women who were less prepared, earlier in their journey of considering a pregnancy or working through feelings from a previous perinatal episode, some of the interactive sections could be emotionally difficult. During the piloting stage, women discussed how they were not emotionally ready for some of the sections in the guide. In these instances, women suggested that it may be helpful to complete these sections at a later date, or possibly with a healthcare professional. Efforts to accommodate the different needs of women meant that the guide was of a considerable length, which to some women, was overwhelming. Women felt that guide refinements should be made to make the guide easier to navigate through. Women suggested that it would be helpful to navigate to sections most relevant to them, for example, according to diagnosis, having a first or second child. They felt that this would be beneficial in reducing the amount of information women needed to work through.

7.6.1.2 SOLUTIONS TO PILOT

In this section, I provide options on how the guide could be tailored to accommodate a narrower group of women. This could involve the development of a guide with a narrower focus, or the development of a series of guides. For example, guide(s) could be tailored according to:

(i)   Diagnosis: women with bipolar disorder, and / or women with previous experience of postpartum psychosis

         a.   This would allow information on topics which may differ between each group of women, such as previous episodes, and individualised risk of becoming unwell to be tailored according to diagnosis and previous experience of mental illness.

(ii)   Perinatal stage: pre-conception, pregnancy, postpartum period

      a. This would allow women to go through what was most relevant to them. Women who were considering having a child, but had not yet decided to, found it unhelpful to read information about care and treatment. Having a series of guides would better allow women to consider each stage in turn, according to where they were at with their decision.

(iii)   Parity (number of times given birth): first pregnancy, second or further pregnancies

      a. Similarly to above, this would allow women to focus on the issues most relevant to their situation.

An alternative to having different versions of the guide could be, as suggested by a participant in pilot two, a colour coded scheme, with various streams (for example, diagnosis) that were easily identifiable according to colour. This would allow women to navigate themselves to the sections that were relevant to them. In view of this, future research could pilot using the guide within a clinical context. As discussed in this chapter and the previous results chapters, women described how they did not always feel emotionally ready for some of the sections in the guide. Involving a professional in the use of the guide would allow the professional to carefully consider what information would be most helpful for the woman to cover and when. Healthcare professionals can use their clinical judgement to determine what is most helpful for the woman at that time. For example, this could involve having a series of guides according to perinatal stage, and introducing each section of the guide in turn, based on their clinical opinion of the woman's needs. App or web-based formats of the guide may lend itself to providing women with information in a more gradual way. For example, this could include modules that could be completed at different time points, dependent on the woman's information needs at the time. Using the guide in this collaborative way would also mean that professionals would be available to answer any additional questions the woman may have, and provide information on local services available to her. The result of narrowing the focus of a guide may also result in making the guide briefer and more concise, an issue described in more detail below.

7.6.2 Length and size of the guide

7.6.2.1 ISSUES

A prominent issue, which was apparent in the qualitative and quantitative results, was the length of the guide and how its initial impression made women feel. Women explained how

the length of the guide was initially daunting, describing it as a "big booklet" and "bulky". Once they had read through the information however, women felt that the guide appeared less daunting to them, and they did not feel that any of the information should be removed from the guide. In pilot two, one participant explained how in current times, it is unusual to receive a physical copy of a guide as information is often distributed electronically. Therefore, women may not be as used to seeing information in a physical format like this.

7.6.2.2 SOLUTIONS TO PILOT

App or web-based formats of the guide may lend itself well to women who only want to access specific sections. For example, a webpage or an app could organise information according to tabs that women could access in a non-linear way, according to their needs. Another option would be for the guide to remain in its physical format, but presented as an A5 booklet, rather than A4. Considering that the guide includes relatively large text and generous spacing, text could be made smaller and denser to reduce the overall length of the guide. This should be considered alongside the recommendations relating to readability discussed above.

7.6.3 Increasing lived experience content

7.6.3.1 ISSUES

During each pilot, all women valued the inclusion of quotes from women with lived experience of planning a high risk pregnancy, and many suggested including more content like this for prototype two and the final version of the guide. Women valued hearing from others with lived experience, and many felt it contributed to the overall hopeful tone of the guide. The challenge of including more quotes, whilst not making the guide longer, was raised during the pilot interviews. Concerns relating to the length of the guide may have contributed to a conservative approach in including more lived experience content.

7.6.3.2 SOLUTIONS TO PILOT

An app or web-based format may lend itself well to increasing the lived experience content included in the guide. In future versions of the guide, whether digital or paper based, an accompanying website could be launched alongside the guide, with women sharing their stories more extensively than what is currently included. As well as having written accounts, this could be expanded to incorporate other multimedia elements, such as videos or

animations of women telling their stories. In a RCT of a decision aid for women with rheumatoid arthritis, quotes from women were included throughout the decision aid, and a section at the end of the decision aid was devoted to personal accounts of women's experiences (Meade et al. 2011; Meade et al. 2013; Meade et al. 2015). The process of bringing together personal accounts from women is described in Meade et al (2012), which could be adopted to develop content for this guide in future.

7.6.4 Developing an app or web-based guide

Many of the issues and solutions discussed above, lend themselves well to having an app or web-based version of the guide. This section includes issues that should be considered in future studies to adapt the current format of the guide into an app or web-based interactive guide. A limitation of the guide's paper format was that it was difficult to work through the guide in a non-linear way and skip to the most relevant sections. To improve navigation throughout the guide, an app or web-based version may include (i) a homepage including a menu of sections and clear labelling of the information included (ii) hyperlinks guiding women to more in-depth information; and (iii) tabs that include additional information when clicked on without sending the user to another page, to reduce the amount of content on the main page. Refinements to the presentation and colour scheme of the guide based on pilot feedback could also be carried forward when developing an app or web-based version of the guide.

A number of studies have developed electronic decision aids (Meade et al. 2015; Vigod et al. 2016a; McGrath et al. 2017; Khalifeh et al. 2019; Vigod et al. 2019). Some of these have been electronic documents, without interactive features that allow the user to engage in exercises or add personal information (Meade et al. 2015; McGrath et al. 2017). Vigod et al (2019) developed a website including interactive exercises where women had unlimited logins to a website, using their own personal login and secure password. This current study highlighted the importance of having the option to use the guide interactively, to help with reflection on previous experiences and pregnancy plans. Many women commented on the benefit of having a paper guide when sharing with others. It may be beneficial for an app or web-based guide to have a function where personal information and responses to reflective exercises can be printed and shared with others to enhance the experience of shared decision making and planning.

Future development of an app or web-based guide should be guided by input from an advisory group of women with lived experience of bipolar disorder and / or previous postpartum psychosis. Important considerations include whether women would be most likely to use a guide on their computer (laptop or desktop), a smartphone, or a tablet. In their evaluation of a web-based decision aid, Vigod et al (2019) found that most women used the decision aid on a computer (88.6%), and a small majority using a tablet (5.7%). A proportion of women (22.9%) also used the decision aid on their smartphone at some point during the study. Considering the functionality of the guide on different devices will likely have important implications for good user experience and guide acceptability.

In addition to the development of the guide itself, having an app or web-based guide could also have benefits in administering a future study. For example, an app-based guide could be set up with notifications to remind women to complete post-guide outcome measures, which could be completed online and accessed via a hyperlink in the app.

7.7 Final conclusions

A study has been carried out to determine the critical components of a pregnancy planning guide for women at risk of severe perinatal mental illness, following the MRC guidelines for the development of a complex intervention (Craig et al. 2008). This project allowed us to improve the knowledge base on what information women need when planning a pregnancy and how best to provide women with this information. The final prototype of the guide developed in this project was an 88-page loose leaf guide presented in a white ring binder, designed for women with bipolar disorder and / or previous postpartum psychosis to use when planning or considering a pregnancy, or while pregnant.

A review of freely available online information for women with bipolar disorder and / or previous postpartum psychosis considering a pregnancy or currently pregnant was presented in Chapter 3. This provided a framework to evaluate and compare the final prototype of the pregnancy planning guide with other sources of available information. To do this, I applied the same criteria used to evaluate the online information to this guide. A content analysis of the pregnancy planning guide found that 97% of coding checklist topics were mentioned in the guide. The only topic not included was 'Parenting with bipolar disorder'. The reason I did not include this topic was because participants in the development stage discussed how including this information may have appeared as if the guide was discriminating against women with bipolar disorder, compared to women planning a typical pregnancy. Readability

scores were slightly lower than the average of all websites, but scored above the recommended level for health information (Hutchinson et al. 2016), demonstrating an important consideration for future development of the guide.

The pregnancy planning guide developed in this project is a valuable addition to the current resources available to women. The guide offers women a key source of information including all the information they need in one place. While the evaluation of online information in Chapter 3 found that high-quality, informative websites exist for these women, this guide goes further in providing women with an opportunity to personalise the guide. The guide is beneficial in its potential to empower women and promote patient centred care and shared decision making. In this project, the guide gave women confidence to initiate conversations with healthcare professionals on their concerns and uncertainties. It also aided women in validating their own concerns and feelings with family and friends when making plans for the perinatal period. It offered a structure for women to reflect on their knowledge and plans and prepare in a practical way for appointments and pregnancy.

The rich lived experience input throughout this project was key. While it could be considered an advantage to have a researcher with lived experience of bipolar disorder and / or previous postpartum psychosis conducting the qualitative interviews with women, I felt that not having lived experience was an advantage in that it emphasised the role of the participants as the experts on the topic. All participants were invited to feedback on further prototypes of the guide after taking part in qualitative interviews, meaning that alongside the advisory group, the project benefited from many different perspectives throughout.

I learnt that many of the guide's critical components did not necessarily relate to the information topics covered, but the tone. The inclusion of quotes from women with lived experience of planning a high risk pregnancy was highly valued, as well as the knowledge that this guide had been developed with input from other women. The value of feeling recognised in the guide was also evident throughout the project. As described above, the inclusion of women with lived experience in the development and refining of the guide allowed us to identify small nuances in language that contributed to feelings of blame or guilt. Without the guidance from women who understood how it felt to become unwell or to plan a high risk pregnancy from a personal perspective, it would have been difficult to improve on issues such as these.

A key challenge of this project was accommodating the wide range of women that the guide targeted. I felt that striving to include all suggestions on additional content for the guide,

took my attention away from the overall experience of using the guide. It was apparent that too much content could contribute to a less positive experience of using the guide overall. Once content was included in the guide, I found it challenging to determine what should be removed, as women explained that there was nothing in the guide that was not needed. Considering this, it may have been beneficial to take a more conservative approach to the initial prototype of the guide, allowing for the guide to develop more gradually with each pilot.

Overall, the pregnancy planning guide was acceptable to women; they found it helpful when planning and making decisions during the pre-conception and perinatal period. Decisional conflict scores were reduced after using the guide compared to before, representing less uncertainty after using the guide. Participant data on depression and anxiety symptoms showed no clear direction in whether scores increased or decreased after reading the guide. The guide appeared to be best suited to a certain population of women: those who had received specialist professional input. For those without this input, the guide was sometimes overwhelming. The guide made women reflect on their plans and readiness to have a baby. This was a positive experience if women already had detailed plans in place, but for those who did not, it emphasised to them that they were not yet ready to consider making plans. This suggests an important population of women, i.e. women at the beginning of their journey of planning a pregnancy, who have not been as well accommodated in the guide.

To conclude, I recommend the use of the current iteration of the guide to complement care within specialist perinatal mental health contexts. Prior to wider dissemination of the guide and a RCT of its use, I recommend further development work. However this project provides a systematic process, including key stakeholder input throughout, to follow in future studies.

References

Alonso, J. et al. 2011. Days out of role due to common physical and mental conditions: Results from the WHO World Mental Health surveys. Molecular Psychiatry 16(12), pp. 1234–1246. doi: 10.1038/mp.2010.101.

Altman, E.G. et al. 1997. The Altman Self-Rating Mania Scale. Biological Psychiatry 42(10), pp. 948–955. doi: 10.1016/S0006-3223(96)00548-3.

Andreassen, H.K. et al. 2007. European citizens' use of E-health services: A study of seven countries. BMC Public Health 7(1), pp. 1–7. doi: 10.1186/1471-2458-7-53.

Anke, T.M.S. et al. 2019. "What if I get ill?" perinatal concerns and preparations in primi- and multiparous women with bipolar disorder. International Journal of Bipolar Disorders 7(7). Available at: https://doi.org/10.1186/s40345-019-0143-2.

Archibald, M.M. et al. 2019. Using Zoom Videoconferencing for Qualitative Data Collection: Perceptions and Experiences of Researchers and Participants. International Journal of Qualitative Methods 18. Available at: https://us.sagepub.com/en-us/nam/open-access-at-sage [Accessed: 1 September 2021].

American Psychiatric Association 2013. Diagnostic and statistical manual of mental disorders (DSM-5®). American Psychiatric Pub.

Attride-stirling, J. 2001. Qualitative Research. Qualitative Research 1(3), pp. 385–405.

Baldessarini, R.J. et al. 2010. Morbidity in 303 first-episode bipolar I disorder patients. Bipolar Disorders 12(3), pp. 264–270. doi: 10.1111/j.1399-5618.2010.00812.x.

Baldwin, D.S. and Amaro, H.J.F. 2020. Prescription of Valproate-Containing Medicines in Women of Childbearing Potential who have Psychiatric Disorders: Is It Worth the Risk? CNS Drugs 34(2), pp. 163–169. doi: 10.1007/s40263-019-00694-4.

Barry, M.J. and Edgman-Levitan, S. 2012. Shared Decision Making — The Pinnacle of Patient-Centered Care. New England Journal of Medicine 366(9), pp. 780–781. Available at: https://www.nejm.org /doi/10.1056/NEJMp1109283 [Accessed: 7 February 2022].

Bauer, A. et al. 2014. The costs of perinatal mental health problems: Report Summary. Centre for Mental Health (October). doi: 10.13140/2.1.4731.6169.

Belmaker, R.H. 2004. Bipolar Disorder. The New England journal of Medicine 351(5), pp. 476–486.

Bergink, V. et al. 2012. Prevention of postpartum psychosis and mania in women at high risk. American Journal of Psychiatry 169(6), pp. 609–615. doi: 10.1176/appi.ajp.2012.11071047.

Bergink, V. et al. 2016. Postpartum psychosis: Madness, mania, and melancholia in motherhood. American Journal of Psychiatry 173(12), pp. 1179–1188. doi: 10.1176/appi.ajp.2016.16040454.

Bidmon, S. and Terlutter, R. 2015. Gender differences in searching for health information on the internet and the virtual patient-physician relationship in Germany: Exploratory results on how men and women differ and why. Journal of Medical Internet Research 17(6), p. e156. Available at: www.jmir.org/2015/6/e156 [Accessed: 6 September 2021].

Birth characteristics in England and Wales - Office for National Statistics. Available at: www-ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/bulletins/birthcharacteristicsinenglandandwales/2019 [Accessed: 26 August 2021].

Bodén, R. et al. 2012. Risks of adverse pregnancy and birth outcomes in women treated or not treated with mood stabilisers for bipolar disorder: Population based cohort study. BMJ (Online) 345(7883), pp. 1–10. doi: 10.1136/bmj.e7085.

Braun, V. et al. 2018. "Thematic Analysis." In Handbook of Research Methods in Health and Social Sciences. Liamputtong, P. ed. Singapore: Springer.

Braun, V. and Clarke, V. 2006. Using thematic analysis in psychology. Qualitative research in psychology 3(2), pp. 77–101. doi: 10.1017/CBO9781107415324.004.

Braun, V. and Clarke, V. 2013. Successful qualitative research: A practical guide for beginners.

Braun, V. and Clarke, V. 2019. Reflecting on reflexive thematic analysis. Qualitative Research in Sport, Exercise and Health 11(4), pp. 589–597. doi: 10.1080/2159676X.2019.1628806.

Braun, V. and Clarke, V. 2021a. One size fits all? What counts as quality practice in (reflexive) thematic analysis? Qualitative Research in Psychology 18(3), pp. 328–352. doi: 10.1080/14780887.2020.1769238.

Braun, V. and Clarke, V. 2021b. To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. Qualitative Research in Sport, Exercise and Health 13(2), pp. 201–216. doi: 10.1080/2159676X.2019.1704846.

Brockington, I. et al. 2017. An international position paper on mother-infant (perinatal) mental health, with guidelines for clinical practice. Archives of Women's Mental Health 20(1), pp. 113–120. doi: 10.1007/s00737-016-0684-7.

Broughton, L.C. et al. 2021. Effectiveness of patient decision aids in women considering psychotropic medication use during pregnancy : a literature review. Archives of Women's Mental Health 24, pp. 569–578. Available at: https://doi.org/10.1007/s00737-021-01118-3.

Cantwell, R. et al. 2011. Centre for Maternal and Child Enquiries (CMACE). Saving mothers' lives: reviewing maternal deaths to make motherhood safer: 2006-2008: the Eighth Report of the Confidential Enquiries into Maternal Deaths in the United Kingdom. BJOG 118(suppl 1), pp. 1–203.

Casanova Dias, M. and Jones, I. 2016. Perinatal Psychiatry. MEDICINE 44(12), pp. 720–723. doi: 10.1016/B978-0-08-097086-8.27082-7.

Cassell, C. et al. 2017. The SAGE Handbook of Qualitative Business and Management Research Methods: Methods and Challenges. SAGE Publications. doi: 10.4135/9781526430236.

Catalao, R. et al. 2020. Preconception care in mental health services : planning for a better future. The British Journal of Psychiatry 216, pp. 180–181. doi: 10.1192/bjp.2019.209.

Cerminara, C. et al. 2014. Use of the DISCERN tool for evaluating web searches in childhood epilepsy. *Epilepsy and Behavior* 41, pp. 119–121. doi: 10.1016/j.yebeh.2014.09.053.

Charles, C. et al. 1997. Shared decision-making in the medical encounter: What does it mean? (Or it takes, at least two to tango). Social Science and Medicine 44(5), pp. 681–692. doi: 10.1016/S0277-9536(96)00221-3.

Charles, C. et al. 2013. Decision making in the physician-patient encounter: Revisiting the shared treatment decision-making model. In: The Sociology of Health and Illness: A Reader., pp. 229–241. doi: 10.4324/9781315013015-30.

Cipriani, A. et al. 2013. Valproic acid; valproate and divalproex in the maintenance treatment of bipolar disorder. Cochrane Database of Systematic Reviews 10(1–73), p. CD003196. Available at: www.ncbi.nlm.nih.gov/pubmed/11687047.

Craig, P. et al. 2008. Medical Research Council's Developing and evaluating complex interventions: new guidance., pp. 1–39. Available at: www.mrc.ac.uk/complexinterventionsguidance.

Dennis, C. and Hodnett, E. 2007. Psychosocial and psychological interventions for treating postpartum depression (Review). The Cochrane Library (4).

Diflorio, A. and Jones, I. 2010. Is sex important Gender differences in bipolar disorder. International Review of Psychiatry 22(5), pp. 437–452. doi: 10.3109/09540261.2010.514601.

Dolman, C. et al. 2013. Pre-conception to parenting: A systematic review and meta-synthesis of the qualitative literature on motherhood for women with severe mental illness. Archives of Women's Mental Health 16(3), pp. 173–196. doi: 10.1007/s00737-013-0336-0.

Dolman, C. et al. 2016. Women with bipolar disorder and pregnancy: factors influencing their decision-making. BJPsych Open 2(05), pp. 294–300. doi: 10.1192/bjpo.bp.116.003079.

Doucet, S. et al. 2009. Differentiation and clinical implications of postpartum depression and postpartum psychosis. JOGNN - Journal of Obstetric, Gynecologic, and Neonatal Nursing 38(3), pp. 269–279. doi: 10.1111/j.1552-6909.2009.01019.x.

Durand, M.A. et al. 2014. Do interventions designed to support shared decision- making reduce health inequalities? A systematic review and meta-analysis. PLoS ONE 9(4), p. e94670. Available at: www.plosone.org.

Elwyn, G. et al. 2006. Developing a quality criteria framework for patient decision aids: online international Delphi consensus process. BMJ 333(7565), p. p.417. Available at: www.bmj.com/ [Accessed: 15 August 2021].

Elwyn, G. et al. 2010. Implementing shared decision making in the NHS. BMJ 341(7780), pp. 971–972. Available at: https://www.bmj.com/content/341/bmj.c5146 [Accessed: 2 February 2022].

England, N. 2019. The NHS Long Term Plan. Available at: www.longtermplan.nhs.uk [Accessed: 23 August 2021].

Fernandez Turienzo, C. et al. 2021. Addressing inequities in maternal health among women living in communities of social disadvantage and ethnic diversity. BMC Public Health 21(1). Available at: https://doi.org/10.1186/s12889-021-10182-4 [Accessed: 9 September 2021].

Finlay, L. 2002. 'Outing' the researcher: The provenance, process, and practice of reflexivity. Qualitative Health Research 12(4), pp. 531–545. doi: 10.1177/104973202129120052.

Fitelson, E. et al. 2011. Treatment of postpartum depression : clinical , psychological and pharmacological options. International Journal of Women's Health 3, pp. 1–14. doi: 10.2147/IJWH.S6938.

Flesch, R. 1948. A new readability yardstick. Journal of Applied Psychology 32(3), pp. 221–233.

Di Florio, A. et al. 2013a. Perinatal episodes across the mood disorder spectrum. JAMA Psychiatry 70(2), pp. 168–175. doi: 10.1001/jamapsychiatry.2013.279.

Di Florio, A. et al. 2013b. Postpartum psychosis. The Nebraska state medical journal 15, pp. 145–50. doi: 10.1111/tog.12041.

Di Florio, A. et al. 2017. Lithium Use in Pregnancy and the Risk of Cardiac Malformations. The New England Journal of Medicine 377(9), p. 893. doi: 10.1097/01.ogx.0000526705.23869.b5.

Di Florio, A. et al. 2018. Stratification of the risk of bipolar disorder recurrences in pregnancy and postpartum. The British journal of psychiatry : the journal of mental science 213(3), pp. 542–547. doi: 10.1192/bjp.2018.92.

Freeman, M.P. and Gelenberg, A.J. 2005. Bipolar disorder in women: Reproductive events and treatment considerations. Acta Psychiatrica Scandinavica 112(2), pp. 88–96. doi: 10.1111/j.1600-0447.2005.00526.x.

Friedman, D.B. et al. 2006. Health literacy and the World Wide Web: Comparing the readability of leading incident cancers on the Internet. Informatics for Health and Social Care 31(1), pp. 67–87. doi: 10.1080/14639230600628427.

Friedman, D.B. et al. 2008. Evaluation of online disaster and emergency preparedness resources. Prehospital and Disaster Medicine 23(5), pp. 438–446. doi: 10.1017/S1049023X00006178.

Garritty, C. et al. 2020. Cochrane rapid reviews. Interim guidance from the Cochrane Rapid Reviews Methods Group.

Gaynes, B. and Gavin, N.I. 2005. Perinatal Depression: Prevalence, Screening Accuracy, and Screening Outcomes Perinatal Depression: Prevalence, Screening Accuracy, and Screening Outcomes Prepared for: In AHRQ evidence report summaries. Agency for Healthcare Research and Quality (US). AHRQ evidence report summaries.

Goodwin, F.K. and Jamison, K.Re. 2007. Manic-depressive illness: bipolar disorders and recurrent depression. Oxford University Press.

GOV.UK 2016. Prime Minister pledges a revolution in mental health treatment. Available at: https://www.gov.uk.

Grande, I. et al. 2016. Bipolar Disorder. The Lancet 387(10027), pp. 1561–1572. Available at: http://dx.doi.org/10.1016/S0140-6736(15)00241-X.

Guest, G. et al. 2012. Applied Thematic Analysis. doi: 10.4135/9781483384436.n1.

Guille, C. et al. 2019. Shared Decision-Making Tool for Treatment of Perinatal Opioid Use Disorder. Psychiatric Research and Clinical Practice 1(1), pp. 27–31. doi: 10.1176/appi.prcp.20180004.

Hall, P. 2006. Mothers' experiences of postnatal depression: an interpretative phenomenological analysis. Community Practitioner : the journal of the Community Practitioners' & Health Visitors' Association. 79(8), pp. 256–260.

Heringhausen, J. and Montgomery, K.S. 2002. Web Sites that Address Postpartum Depression. The Journal of Perinatal Education 11(3), pp. 48–50. doi: 10.1891/1058-1243.11.3.48.

Heron, J. et al. 2008. Early postpartum symptoms in puerperal psychosis. BJOG: An International Journal of Obstetrics and Gynaecology 115(3), pp. 348–353. doi: 10.1111/j.1471-0528.2007.01563.x.

Heron, J. et al. 2012. Information and support needs during recovery from postpartum psychosis. Archives of Women's Mental Health 15(3), pp. 155–165. doi: 10.1007/s00737-012-0267-1.

Herrmann, C. 1997. International experiences with the hospital anxiety and depression scale - A review of validation data and clinical results. Journal of Psychosomatic Research 42(1), pp. 17–41. doi: 10.1016/S0022-3999(96)00216-4.

Higgins, O. et al. 2011. A literature review on health information-seeking behaviour on the web: a health consumer and health professional perspective. Insights into health communication. Stockholm, Sweden.

Howard, L.M. et al. 2014. Non-psychotic mental disorders in the perinatal period. The Lancet 384(9956), pp. 1775–1788. Available at: http://dx.doi.org/10.1016/S0140-6736(14)61276-9.

Howard, L.M. and Khalifeh, H. 2020. Perinatal mental health: a review of progress and challenges. World Psychiatry 19(3), pp. 313–327. doi: 10.1002/wps.20769.

Hutchinson, N. et al. 2016. Examining the Reading Level of Internet Medical Information for Common Internal Medicine Diagnoses. American Journal of Medicine 129(6), pp. 637–639. doi: 10.1016/j.amjmed.2016.01.008.

Huybrechts, K.F. et al. 2016. Antipsychotic use in pregnancy and the risk for congenital malformations. JAMA Psychiatry 73(9), pp. 938–946. Available at: 10.1001/jamapsychiatry.2016.1520 [Accessed: 12 September 2021].

IPDAS 2005. IPDAS Collaboration Background Document: International Patient Decision Aid Standards. Available at: http://ipdas.ohri.ca/IPDAS_Background.pdf.

Jackson, T. et al. 2020. Patient and public involvement in research: From tokenistic box ticking to valued team members. BMC Medicine 18(1). Available at: https://doi.org/10.1186/s12916-020-01544-7 [Accessed: 1 September 2021].

Jamison, K.R. 1997. An Unquiet Mind: A Memoir of Moods and Madness. Vintage.

Johnson, S.L. et al. 2015. Understanding Creativity in Bipolar I Disorder. Psychology of Aesthetics, Creativity, and the Arts 9(3), pp. 319–327. doi: 10.1037/a0038852.

Jones, I. et al. 2014. Bipolar disorder, affective psychosis, and schizophrenia in pregnancy and the post-partum period. The Lancet 384, pp. 1789–1799. Available at: http://dx.doi.org/10.1016/S0140-6736(14)61278-2.

Jones, I. 2020. Postpartum psychosis: an important clue to the etiology of mental illness. World Psychiatry 19(3), pp. 334–336. doi: 10.1002/wps.20780.

Jones, I. and Cantwell, R. 2010. The classification of perinatal mood disorders — suggestions for DSMV and ICD11. Archives of Women's Mental Health 13(1), pp. 33–36. doi: 10.1007/s00737-009-0122-1.

Jones, I. and Craddock, N. 2001. Familiality of the Puerperal Trigger in Bipolar Disorder: Results of a Family Study. American Journal of Psychiatry 158(6), pp. 913–917. doi: 10.1176/appi.ajp.158.987.913.

Jones, I. and Craddock, N. 2005. Bipolar disorder and childbirth: The importance of recognising risk. British Journal of Psychiatry 186, pp. 453–454. doi: 10.1192/bjp.186.6.453.

Jones, I. and Shakespeare, J. 2014. Postnatal depression. BMJ (Online) 349(August), pp. 1–3. Available at: http://dx.doi.org/doi:10.1136/bmj.g4500.

Jones, I. and Smith, S. 2009. Puerperal psychosis: Identifying and caring for women at risk. Advances in Psychiatric Treatment 15(6), pp. 411–418. doi: 10.1192/apt.bp.107.004333.

Joseph-Williams, N. et al. 2014. Toward minimum standards for certifying patient decision aids: A modified delphi consensus process. Medical Decision Making 34(6), pp. 699–710. Available at: www.sagepub.com/journalsPermissions.nav [Accessed: 13 February 2022].

Judd, L.L. et al. 2002. The long-term natural history of the weekly symptomatic status of bipolar I disorder. Archives of general psychiatry 59(6), pp. 530–7. Available at: www.ncbi.nlm.nih.gov/pubmed/12044195.

Kenny, M. et al. 2013. Mother-infant interaction in mother and baby unit patients : Before and after treatment. Journal of Psychiatric Research 47(9), pp. 1192–1198. Available at: http://dx.doi.org/10.1016/j.jpsychires.2013.05.012.

Khalifeh, H. et al. 2019. Patient decision aids for antidepressant use in pregnancy: a pilot randomised controlled trial in the UK. BJGP Open 3(4). Available at: https://bjgpopen.org/content/3/4/bjgpopen19X101666 [Accessed: 6 February 2022].

Kincaid, J.P. et al. 1975. Derivation of new readability formulas for navy enlisted personnel. Naval Technical Training Command Millington TN Research Branch.

Kirby, P.L. et al. 2018. Evaluating the quality of perinatal anxiety information available online. Archives of Women's Mental Health 21(6), pp. 813–820. Available at: https://doi.org/10.1007/s00737-018-0875-5.

Kreps, G.L. and Maibach, E.W. 2008. Transdisciplinary Science: The Nexus Between Communication and Public Health. Journal of Communication 58(4), pp. 732–748. doi: 10.1111/J.1460-2466.2008.00411.X.

Lee, D.T.S. and Chung, T.K.H. 2007. Postnatal depression : an update. 21(2), pp. 183–191. doi: 10.1016/j.bpobgyn.2006.10.003.

Lewis-Beck, M. et al. 2012. The SAGE Encyclopedia of Social Science Research Methods. Sage Publications, Inc. doi: 10.4135/9781412950589.

Lindley, L.L. et al. 2012. Becoming Visible: Assessing the Availability of Online Sexual Health Information for Lesbians. Health Promotion Practice 13(4), pp. 472–480. doi: 10.1177/1524839910390314.

Low, J. 2019. A Pragmatic Definition of the Concept of Theoretical Saturation. Sociological Focus 52(2), pp. 131–139. Available at: https://www.tandfonline.com/doi/abs/10.1080/00380237.2018.1544514 [Accessed: 20 February 2022].

Malterud, K. et al. 2016. Sample Size in Qualitative Interview Studies: Guided by Information Power. Qualitative Health Research 26(13), pp. 1753–1760. doi: 10.1177/1049732315617444.

Marengo, E. et al. 2015. Unplanned pregnancies and reproductive health among women with bipolar disorder. Journal of Affective Disorders 178, pp. 201–205. doi: 10.1016/J.JAD.2015.02.033.

Mcallister-Williams, R.H. et al. 2017. British Association for Psychopharmacology consensus guidance on the use of psychotropic medication preconception, in pregnancy and postpartum 2017. Journal of Psychopharmacology 31(5), pp. 519–552. Available at: https://doi.org/10.1177/0269881117699361 [Accessed: 12 September 2021].

McGrath, A. et al. 2017. Evaluation of a Decision Aid for Women with Epilepsy Who Are Considering Pregnancy: A Randomized Controlled Trial. Medical Decision Making 37(5), pp. 589–599. doi: 10.1177/0272989X17697304.

Meade, T. et al. 2011. Motherhood Choices: A Decision Aid for Women with RA. Intervention Manual. doi: 10.1186/s12891-015-0713-0.

Meade, T. et al. 2013. Navigating Motherhood Choices in the context of Rheumatoid Arthritis: Women's Stories. Musculoskeletal Care 11(2), pp. 73–82. doi: 10.1002/msc.1031.

Meade, T. et al. 2015. The motherhood choices decision aid for women with rheumatoid arthritis increases knowledge and reduces decisional conflict: a randomized controlled trial. BMC Musculoskeletal Disorders 16(1), pp. 1–8. Available at: https://bmcmusculoskeletdisord.biomedcentral.com/articles/10.1186/s12891-015-0713-0 [Accessed: 15 August 2021].

Meltzer-brody, S. et al. 2018. Postpartum psychiatric disorders. Nature Publishing Group 4(1), pp. 1–18. Available at: http://dx.doi.org/10.1038/nrdp.2018.22.

Merikangas, K.R. et al. 2011. Prevalence and Correlates of Bipolar Spectrum Disorder in the World Mental Health Survey Initiative. 68(3), pp. 241–251.

Metcalfe, K.A. et al. 2007. Development and testing of a decision aid for breast cancer prevention for women with a BRCA1 or BRCA2 mutation. Clinical Genetics 72(3), pp. 208–217. doi: 10.1111/j.1399-0004.2007.00859.x.

Mitchell, P.B. et al. 2006. The management of bipolar disorder in general practice. Medical Journal of Australia 184(11), pp. 566–570.

Moore, D. and Ayers, S. 2011. A review of postnatal mental health websites: Help for healthcare professionals and patients. Archives of Women's Mental Health 14(6), pp. 443–452. doi: 10.1007/s00737-011-0245-z.

Moreno, S.C. et al. 2020. Position Paper How mental health care should change as a consequence of the COVID-19 pandemic. 7. Available at: www.thelancet.com/psychiatry [Accessed: 29 August 2021].

Munk-Olsen, T. et al. 2006. New Parents and Mental Disorders, A Population-based Register Study. JAMA 296(21), pp. 2582–2589.

Murray, K.E. et al. 2019. Readability and Quality of Online Information on Osteoarthritis: An Objective Analysis With Historic Comparison. Interactive Journal of Medical Research 8(3), p. e12855. Available at: https://www.i-jmr.org/2019/3/e12855.

National Institute for Health and Care Excellence 2014a. Antenatal and postnatal mental health: clinical management and service guidance. Available at: www.nice.org.uk/guidance/cg192.

National Institute for Health and Care Excellence 2014b. Bipolar Disorder: Assessment and Management. Available at: www.nice.org.uk/guidance/cg185.

National Institute for Health and Care Excellence 2021. Shared decision making. Available at: www.nice.org.uk/guidance/ng197.

Nghiem, A.Z. et al. 2016. Evaluating the quality of internet information for breast cancer. Breast 25, pp. 34–37. doi: 10.1016/j.breast.2015.10.001.

NHS MH Long Term Plan Steering Group 2019. NHS Mental health implementation plan 2019/20 – 2023/24. Available at: www.longtermplan.nhs.uk/publication/nhs-mental-health-implementation-plan-2019-20-2023-24 [Accessed: 23 August 2021].

Nora, J.J. et al. 1974. Lithium, Ebstein's anomaly, and other congenital heart defects. The Lancet 304(7880), pp. 594–595. doi: 10.1016/S0140-6736(74)91918-7.

O'Connor, A. and Cranney, A. 1996. User manual–acceptability [modified 2002]. Ottawa, Ontario. Available at: https://decisionaid.ohri.ca/docs/develop/user_manuals/um_acceptability.pdf.

O'connor, A.M. 1995. Validation of a Decisional Conflict Scale. Medical Decision Making 15(1), pp. 25–30. doi: 10.1177/0272989X9501500105.

O'Connor, A.M. 2010. User Manual—Decisional Conflict Scale (16 Item Statement Format) [Document on the Internet]. Ottawa. Available at: http://decisionaid.ohri.ca/docs/develop/User_Manuals/UM_Decisional_Conflict.pdf.

O'Hara, M.W. et al. 1991. Prospective Study of Postpartum Blues: Biologic and Psychosocial Factors. Archives of General Psychiatry 48(9), pp. 801–806. doi: 10.1001/archpsyc.1991.01810330025004.

O'Hara, M.W. and Wisner, K.L. 2014. Perinatal mental illness: Definition, description and aetiology. Best Practice and Research: Clinical Obstetrics and Gynaecology 28(1), pp. 3–12. Available at: http://dx.doi.org/10.1016/j.bpobgyn.2013.09.002.

Office for National Statistics 2018. Internet access – households and individuals, Great Britain - Office for National Statistics. Office for National Statistics . Available at: www.ons.gov.uk/peoplepopulationandcommunity/householdcharacteristics/homeinternet andsocialmediausage/bulletins/internetaccesshouseholdsandindividuals/2018 [Accessed: 6 September 2021].

Patel, S. et al. 2013. An exploration of illness beliefs in mothers with postnatal depression. Midwifery 29(6), pp. 682–689. doi: 10.1016/J.MIDW.2012.06.012.

Perich, T. et al. 2017. Menopause and illness course in bipolar disorder: A systematic review. Bipolar Disorders 19(6), pp. 434–443. doi: 10.1111/bdi.12530.

Perry, A. et al. 2021. Phenomenology, Epidemiology and Aetiology of Postpartum Psychosis: A Review. Brain Sciences 11(1), pp. 1–14. Available at: www.ncbi.nlm.nih.gov/pmc/articles/PMC7824357 [Accessed: 23 August 2021].

Pierce, M. et al. 2020. Mental health before and during the COVID-19 pandemic: a longitudinal probability sample survey of the UK population. The Lancet Psychiatry 7(10), pp. 883–892. Available at: www.thelancet.com/psychiatry [Accessed: 1 September 2021].

Poels, E.M.P. et al. 2018. Lithium during pregnancy and after delivery: a review. International Journal of Bipolar Disorders 6(1). Available at: https://doi.org/10.1186/s40345-018-0135-7.

Pompili, M. et al. 2013. Epidemiology of suicide in bipolar disorders : a systematic review of the literature. (5), pp. 457–490. doi: 10.1111/bdi.12087.

Post, R. et al. 2003. Morbidity in 258 bipolar outpatients followed for 1 year with daily prospective ratings on the NIMH life chart method. The Journal of clinical psychiatry 64(6), pp. 680–90. Available at: www.ncbi.nlm.nih.gov/pubmed/12823083.

Post, R.M. 2005. The impact of bipolar depression. Journal of Clinical Psychiatry 66(SUPPL. 5), pp. 5–10.

Prunty, M.C. et al. 2008. The motherhood choice: A decision aid for women with multiple sclerosis. Patient Education and Counseling 71(1), pp. 108–115. doi: 10.1016/J.PEC.2007.10.021.

QSR International Pty Ltd. 2018. NVivo. Available at: https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home.

Rai, S. et al. 2015. Postpartum psychiatric disorders: Early diagnosis and management. Indian Journal of Psychiatry 57

Reynolds, K.A. et al. 2015. How well do websites concerning childrens anxiety answer parents questions about treatment choices? Clinical Child Psychology and Psychiatry 20(4), pp. 555–569.

Reynolds, M. et al. 2018. Assessing the quality, reliability and readability of online health information regarding systemic lupus erythematosus. Lupus 27(12), pp. 1911–1917. doi: 10.1177/0961203318793213.

Riel, N. Van et al. 2017. The effect of Dr Google on doctor–patient encounters in primary care: a quantitative, observational, cross-sectional study. BJGP Open 1(2). doi: 10.3399/BJGPOPEN17X100833.

Ritchie, J. et al. 2013. Qualitative research practice: A guide for social science students and researchers. SAGE Publications.

Rosso, G. et al. 2020. Age at Menarche in Women With Bipolar Disorder: Correlation With Clinical Features and Peripartum Episodes. Frontiers in Psychiatry 11(September), pp. 1–7. doi: 10.3389/fpsyt.2020.00851.

Rourke, L. and Anderson, T. 2004. Validity in quantitative content analysis. Educational Technology Research and Development 52(1), pp. 5–18. doi: 10.1007/BF02504769.

Royal College of Psychiatrists 2018. Withdrawal of, and alternatives to, valproate-containing medicines in girls and women of childbearing potential who have a psychiatric illness.

Saunders, E.F.H. et al. 2014. Gender differences, clinical correlates, and longitudinal outcome of bipolar disorder with comorbid migraine. Journal of Clinical Psychiatry 75(5), pp. 512–519. doi: 10.4088/JCP.13m08623.

Seitz, S. 2016. Pixilated partnerships, overcoming obstacles in qualitative interviews via Skype: a research note. Qualitative Research 16(2), pp. 229–235. doi: 10.1177/1468794115577011.

Silberg, W.M. et al. 1997. Assessing, Controlling, and Assuring the Quality of Medical Information on the Internet: Caveant Lector et Viewor - Let the Reader and Viewer Beware. Generations 21(3), pp. 53–55. doi: 10.1001/jama.1997.03540390074039.

Smith, M.S. et al. 2019. Barriers to accessing mental health services for women with perinatal mental illness: Systematic review and meta-synthesis of qualitative studies in the UK. BMJ Open 9(1). doi: 10.1136/bmjopen-2018-024803.

Social Care Institute for Excellence (SCIE) 2013. Co-Production: What it is and How to Do it., p. SCIE Guide 51.

Stacey, D. et al. 2017a. Decision aids for people facing health treatment or screening decisions. Cochrane Database of Systematic Reviews (4). Available at: https://www.cochranelibrary.com /cdsr/doi/10.1002/14651858.CD001431.pub5/full [Accessed: 7 February 2022].

Stacey, D. et al. 2017b. Patient decision aids to engage adults in treatment or screening decisions. JAMA - Journal of the American Medical Association 318(7), pp. 657–658. doi: 10.1001/jama.2017.10289.

Statcounter Global Stats 2021. Desktop, Tablet & Console Search Engine Market Share United Kingdom - Statcounter Global Stats. Available at: https://gs.statcounter.com/search-engine-market-share/desktop-tablet-console/united-kingdom [Accessed: 6 September 2021].

Stevens, A.W.M.M. et al. 2018. Thoughts and Considerations of Women With Bipolar Disorder About Family Planning and Pregnancy: A Qualitative Study. Journal of the American Psychiatric Nurses Association 24(2), pp. 118–126. doi: 10.1177/1078390317711251.

Stevens, A.W.M.M. et al. 2019. Risk of recurrence of mood disorders during pregnancy and the impact of medication: A systematic review. Journal of Affective Disorders 249(January), pp. 96–103. Available at: https://doi.org/10.1016/j.jad.2019.02.018.

Stevenson, F.A. et al. 2007. Information from the Internet and the doctor-patient relationship: The patient perspective - A qualitative study. BMC Family Practice 8, pp. 1–8. doi: 10.1186/1471-2296-8-47.

Summers, A.L. and Logsdon, M.C. 2005. Web sites for postpartum depression. MCN The American Journal of Maternal/Child Nursing 30(2), pp. 88–94. doi: 10.1097/00005721-200503000-00004.

Synnot, A.J. et al. 2016. Online health information seeking: How people with multiple sclerosis find, assess and integrate treatment information to manage their health. Health Expectations 19(3), pp. 727–737. doi: 10.1111/hex.12253.

Tan, S.S.L. and Goonawardene, N. 2017. Internet health information seeking and the patient-physician relationship: A systematic review. Journal of Medical Internet Research 19(1), p. e9. doi: 10.2196/jmir.5729.

Teatero, M.L. et al. 2014. Effects of the menstrual cycle on bipolar disorder. Bipolar Disorders 16, pp. 22–36. doi: 10.1111/bdi.12138.

Trevillion, K. et al. 2019. Protocol for a quasi-experimental study of the effectiveness and cost-effectiveness of mother and baby units compared with general psychiatric inpatient wards and crisis resolution team services (The ESMI study) in the provision of care for women in the p. BMJ Open 9(3), p. e025906. doi: 10.1136/bmjopen-2018-025906.

Vigod, S. et al. 2016a. A patient decision aid for antidepressant use in pregnancy : study protocol for a randomized controlled trial. Trials , pp. 1–9. Available at: http://dx.doi.org/10.1186/s13063-016-1233-4.

Vigod, S. et al. 2016b. A patient decision aid for antidepressant use in pregnancy: Study protocol for a randomized controlled trial. Trials 17(1), pp. 1–9. Available at: http://dx.doi.org/10.1186/s13063-016-1233-4.

Vigod, S.N. et al. 2019. A patient decision aid for antidepressant use in pregnancy: Pilot randomized controlled trial. Journal of Affective Disorders 251, pp. 91–99. doi: 10.1016/j.jad.2019.01.051.

Viguera, A.C. et al. 2007. Risk of recurrence in women with bipolar disorder during pregnancy: Prospective study of mood stabilizer discontinuation. American Journal of Psychiatry 164(12), pp. 1817–1824. doi: 10.1176/appi.ajp.2007.06101639.

Wakschlag, L.S. et al. 2000. Early parenthood in context: Implications for development and intervention. Handbook of infant mental health., 2nd ed. , pp. 129–144. Available at: https://psycnet.apa.org/record/2000-07057-007 [Accessed: 3 September 2021].

Wang, L.W. et al. 2013. Assessing readability formula differences with written health information materials: Application, results, and recommendations. Research in Social and Administrative Pharmacy 9(5), pp. 503–516. doi: 10.1016/j.sapharm.2012.05.009.

Welsh Government 2016. Minister announces extra staff to support new mothers. Available at: http://gov.wales.

Wesseloo, R. et al. 2016. Risk of postpartum relapse in bipolar disorder and postpartum psychosis: A systematic review and meta-analysis. American Journal of Psychiatry 173(2), pp. 117–127. doi: 10.1176/appi.ajp.2015.15010124.

White, M.D. and Marsh, E.E. 2006. Content analysis: A flexible methodology. Library Trends 55(1), pp. 22–45. doi: 10.1353/lib.2006.0053.

Witcombe-Hayes, S. et al. 2018. From bumps to babies: perinatal mental health care in Wales - full report (English). (June). Available at: https://www.nspcc.org.uk/globalassets/documents/research-reports/from-bumps-to-babies-perinatal-mental-health-care-in-wales-full-report-english.pdf.

World Health Organisation 2008. The global burden of disease 2004 Update. WHO Press. Available at: www.who.int/evidence/bod.

World Health Organisation 2018. International classification of diseases for mortality and morbidity statistics (11th Revision). Available at: www.icd.who.int/en [Accessed: 12 September 2021].

Xiong, J. et al. 2020. Impact of COVID-19 pandemic on mental health in the general population: A systematic review. Journal of Affective Disorders 277, pp. 55–64. Available at: https://doi.org/10.1016/j.jad.2020.08.001 [Accessed: 1 September 2021].

Ybarra, M. and Suman, M. 2008. Reasons, assessments and actions taken: Sex and age differences in uses of Internet health information. Health Education Research 23(3), pp. 512–521. doi: 10.1093/her/cyl062.

Zigmond, A.S. and Snaith, R.P. 1983. The Hospital Anxiety and Depression Scale. Acta Psychiatrica Scandinavica 67(6), pp. 361–370. doi: 10.1111/j.1600-0447.1983.tb09716.x.

Appendices

<u>Appendix A</u> - Database search method for EMBASE and Ovid MEDLINE for Rapid Review

Database:
Embase <1974 to 2021 August 19>
Ovid MEDLINE(R) ALL <1946 to August 19, 2021>

#	Query	Results from 19 Aug 2021 (EMBASE and Ovid MEDLINE
1	exp bipolar disorder/ or bipolar.mp.	202,745
2	"mixed mania and depression"/ or bipolar mania/ or mania/	20,276
3	hypomania/	5,279
4	mania*.mp.	39,898
5	puerperal psychosis/	1,262
6	((perinatal or postpartum or puerperal) adj2 psychosis).mp.	2,025
7	1 or 2 or 3 or 4 or 5 or 6	218,637
8	exp pregnancy/	1,627,558
9	pregnan*.mp.	2,042,770
10	pre$conception.mp. or maternal care/ or prepregnancy care/	31,741
11	motherhood.mp. or mother/	146,770
12	perinatal.mp. or perinatal care/ or perinatal period/	229,420
13	8 or 9 or 10 or 11 or 12	2,257,902
14	decision making.mp.	711,922
15	(decision adj3 (patient or support or aid* or tool* or making or resource or guide*)).mp.	787,525
16	exp Family Planning Services/ or planning.mp. or Health Planning/	924,252
17	14 or 15 or 16	1,649,277
18	7 and 13 and 17	427
19	remove duplicates from 18	366

Coding checklist	
Category	**Topic**
Signs and symptoms	Postpartum psychosis
	Postnatal depression / baby blues / high moods
Individualised risk	Risk factors for postpartum psychosis
	Risk factors for other perinatal mental health episodes
	Individualised risk of becoming unwell
Medication	Stopping / switching medication when trying for a baby or when becoming pregnant
	Taking medication during pregnancy
	Medication and breastfeeding
	Medication in the postpartum period
	Uncertainty surrounding evidence on medication and pregnancy
	Teratogenic effects
	Risk of stopping medication
Treatment	Mother and Baby Unit (MBU)
	Psychological treatment
	Electroconvulsive therapy (ECT)
	General inpatient Admission
Support	Seeking professional help (e.g. encouraging women to do this, emphasising the importance of this)
	How to seek professional specialist perinatal support
	Support network
	Social services
Other	Self-management and lifestyle
	Sleep
	Genetic risk of bipolar
	Recovery from postpartum psychosis / perinatal mental health
	Parenting with bipolar disorder
	Making plans for perinatal period e.g. care plans, forward directives
Additional information	Stories from women with lived experience of bipolar disorder / postpartum psychosis
	Information for partners, family, friends, carers
	Signposting to other relevant information

Appendix C – Website information (sorted according to number of codes present)

Initial webpage	Website	Total codes present **(/29)**	Affiliation	Country
Postpartum psychosis	Royal college of psychiatrists	24	Non-profit	UK
Bipolar disorder in pregnancy	Tommy's	23	Non-profit	UK
What is postpartum psychosis?	Action on postpartum psychosis (APP)	24	Non-profit	UK
Bipolar disorder, pregnancy and childbirth	Bipolar UK	23	Non-profit	UK
Bipolar disorder and having a baby	Birmingham and Solihull mental health NHS	19	Public	UK
Taking mood stabilisers while pregnant	Mind	18	Non-profit	UK
Bipolar Pregnancy: Risks, What to Expect, and More	Healthline	17	Public	America
Postpartum Psychosis | Symptoms, Tests and Treatment | Patient	Patient.info	19	Private	UK
Prenatal - Wellbeing - Emma's diary	Emma's diary	15	Private	UK
Bipolar disorder & pregnancy | The Royal Women's Hospital	The Royal Women's Hospital	17	Public	Australia
Bipolar mood disorders	Postpartum.net	16	Non-profit	Spain
Bipolar disorder treatments during pregnancy and the postnatal period	Black dog institute	16	Non-profit	Australia
Postpartum psychosis: what is it	NCT	16	Non-profit	UK
Pregnancy outcomes bipolar disorder	Women's mental health	15	Public	USA
Postpartum psychosis	NHS	14	Public	UK
Postpartum Psychosis	Birmingham and Solihull mental health	13	Public	UK
Mental health problems and pregnancy	NHS	12	Public	UK
Postpartum Psychiatric Disorders	Womensmentalhealth.org	14	Non-profit	USA
Bipolar disorder in pregnancy	WebMD	12	Public	America

Bipolar disorder in pregnancy	COPE	10	Non-profit	Australia
Postpartum psychosis	Tommy's	11	Non-profit	UK
Do pregnancy and bipolar disorder mix?	health.com	11	Private	USA
Postpartum Psychosis: Symptoms, Treatment and More	Healthline	9	Private	USA
The Truth About Postpartum Psychosis	Seleni.org	10	Non-profit	USA
Bipolar and pregnancy	Psycom	9	Private	USA
Pregnancy and Bipolar disorder	The Mental Elf	8	Private	UK
Postpartum psychosis	Pregnancybirthbaby.org	7	Public	Australia
Bipolar disorder treatment	NHS	8	Public	UK
Postpartum psychosis	MIND	7	Non-profit	UK
Postpartum psychosis	Wikipedia	8	Non-profit	USA
Postpartum psychosis (psychosis after childbirth)	NI Direct	7	Public	UK
Postpartum psychosis | Ready Steady Baby!	NHS inform	6	Public	UK
Postpartum Psychosis -	Everyday health.com	7	Private	USA
Postnatal Psychosis	PaNDa	7	Public	Australia
Postpartum psychosis	HSE.ie	5	Public	Republic of Ireland
Postpartum depression - Symptoms and causes	Mayo clinic	5	Non-profit	USA

Appendix D - **Total JAMA benchmarks score for websites (n=30)**

Website	Weblink	Total
		0 = No, 1 = Yes
Tommy's	tommys.org	4
Healthline	healthline.com	4
Psycom	psycom.net	4
The Mental Elf	nationalelfservice.net	4
Royal College of Psychiatrists	rcpsych.ac.uk	4
WebMD	webmd.com	3
Women's mental health	womensmentalhealth.org	3
health.com	health.com	3
Wikipedia	wikipedia.org	3
NCT	nct.org.uk	3
Patient.info	patient.info	3
PaNDa	panda.org.au	3
preegnancybirthbaby.org	pregnancybirthbaby.org.au	3
Bipolar UK	bipolaruk.org	2
The royal women's hospital	thewomens.org.au	2
NHS	nhs.uk	2
postpartum.net	postpartum.net	2
Black Dog Institute	blackdoginstitute.org.au	2
Mind	mind.org.uk	2
APP network	app-network.org	2
NI Direct	nidirect.gov.uk	2
Everyday health.com	everydayhealth.com	2
HSE.ie	www2.hse.ie	2
Seleni.org	seleni.org	2
NHS inform	nhsinform.scot	2
Emma's diary	emmasdiary.co.uk	1
Birmingham and Solihull Mental health NHS	bsmhft.nhs.uk	1
COPE	cope.org.au	1
Mayo clinic	mayoclinic.org	1
NHS	nhs.uk	0

Bipolar and Postpartum Psychosis: Pregnancy Planning (PREP) Study

Help make a difference by taking part in our maternal mental health research.

Researchers from the National Centre for Mental Health (NCMH) will work with Action on Postpartum Psychosis (APP), Bipolar UK, and women with lived experience of bipolar disorder and postpartum psychosis to develop a new guide to aid decision making related to pregnancy and the postpartum period.

To do this, we are looking for women with lived experience of bipolar disorder and / or postpartum psychosis to help us develop and test the guide. This will include women of a range of ages, including women who have previously been pregnant and those who are considering starting a family.

You can learn more about getting involved by visiting:

www.ncmh.info/prep or contacting Elen Thomas on 02920 688 403 / thomase45@cardiff.ac.uk.

Appendix F – Recruitment flyer

Appendix G – **Participant information sheet – Development stage**

(see overleaf)

Participant Information Sheet: Qualitative Interview (Stage 1)

Bipolar and Postpartum Psychosis: PREP Study

PREgnancy Planning Study

You are being invited to take part in a research project. Before you decide whether or not to take part, you should understand why the research is being done and what it will involve. Please take time to read the following information. Contact us if anything is not clear or if you would like more information.

What is the purpose of the research?

Researchers from the National Centre for Mental Health (NCMH) will work with Action on Postpartum Psychosis (APP) (www.app-network.org), the leading 3rd sector organisation in this area, women with lived experience of bipolar disorder and / or postpartum psychosis and their partners or significant others to develop and test a 'collaborative guide'.

The 'collaborative guide' will be a decision aid that will aim to help women make decisions about pregnancy and the postpartum period, and improve their access to care if they experience an episode of illness. The guide will include information that women have reported to find hard to access when making decisions about pregnancy and childbirth. For example, information about the balance of risks and benefits for mother and child when stopping, switching or continuing medications during this period.

The aim of the guide is to help women to be actively involved in making decisions about pregnancy and the postpartum period with their clinicians, by providing them with the information they need to make informed decisions.

By working with women with lived experience of bipolar disorder and / or postpartum psychosis, we are hoping to learn about the experience of decision making surrounding pregnancy and the postpartum period and what information is needed during this time. Our aim is to use the experiences and knowledge of those who are experts by experience to help shape the contents of the 'collaborative guide'.

Who is being asked to take part?

You have been invited for one of the following reasons:
1. You have lived experience of bipolar disorder and / or postpartum psychosis.
2. You will also be given the option of inviting your partner or significant other to take part with you.

What does taking part involve?

- The researcher will discuss the details of the study with you and you will be able to ask any questions you may have. You will be asked to sign a consent form stating that you agree to take part in the study. You will be given a copy to keep along with this information sheet.

- The researcher will complete an interview with you (lasting in the region of 60-120 minutes). You will be asked to share your thoughts, knowledge and experience related to pregnancy and childbirth in women with bipolar disorder or previous postpartum psychosis. The areas for discussion will include: decisions about starting a family; decisions about medication in pregnancy and after delivery; plans for labour and delivery; individualised early warning signs of recurrence; plans for breast/bottle feeding including consideration of pros and cons; and issues around sleep as a trigger. You will also be provided with background information and will be asked to consider the content and presentation of the 'collaborative guide', as well as being able to introduce your own topics for discussion.

- An interview with the researcher can take place in your own/family member's home, at a local health clinic, at a University site, a voluntary organisation site or via phone / video call.

- Interviews will be recorded. We will ask you to provide consent for these recordings which will be held anonymously.

- With your permission, the Cardiff University research team will also look at relevant sections of your medical records.

- You will be given the opportunity to provide feedback on the 'collaborative guide' following the first stage and following each pilot study in order to help with its development.

- Reasonable travel expenses will be paid by Cardiff University.

What will the data be used for?

We hope that this project will create a useful guide that will provide relevant information, as well as including sections that women can work through and personalise with their clinical teams and partners or family members.

The data will be used to determine the contents of the guide and to establish whether it is acceptable to women with lived experience of bipolar disorder and / or postpartum psychosis.

What are the possible benefits of taking part?

We hope that the input you give will help us create a guide that will help women make decisions about becoming pregnant, reduce their risk of becoming unwell in the perinatal period, and improve their access to care if they experience an episode of illness. However, these remain long-term aims and you will not benefit directly from taking part in this study.

What are the possible disadvantages and risks of taking part?

We acknowledge that some people find it difficult or upsetting to answer questions related to mental health. You may skip any questions that you do not wish to answer, take a break or terminate the interview at any point.

Declining and withdrawing from the study

You do not have to take part in this study. If you do decide to take part you are still free to withdraw at any time without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not alter the care you receive. If you decide to withdraw, any data which has already been collected may be retained and used for research purposes unless you inform the study team that you do not wish the information to be used. In the unlikely event that you lose capacity, the research team will retain your identifiable data and continue to use it in the research.

We will not access your medical records if you decide to withdraw your consent to this in the future. However data that has already been extracted from your medical records will have been anonymised and it will not be possible to destroy it as it will no longer be identifiable as yours.

Data confidentiality

All information collected during the course of the research will be kept strictly confidential. There are strict laws that safeguard your privacy at every stage. In accordance with the Data Protection Act, your personal information will be kept confidential by assigning a unique study code to your data. Your name or any identifying information will not be passed onto anyone outside Cardiff University. The audio recording of the interview will be kept until transcription is complete. Audio recordings will be destroyed immediately after transcription.

We will not pass on any of the information we collect about you unless we have serious concerns about your mental or physical health or the care that you are receiving.

Your anonymous research data will be retained for 15 years after the study has finished, in line with Cardiff University's record retention policy. Research data will be stored on Cardiff University IT systems.

How will my personal data be managed?
Cardiff University is the Sponsor for this study based in the United Kingdom. We will be using information from you and/or your medical records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Cardiff University will keep identifiable information about you for 15 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information at: https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection or by contacting the University's Data Protection Officer: inforequest@cardiff.ac.uk

Cardiff University will use your name and contact details to contact you about the research study, make sure that relevant information about the study is recorded for your care and to oversee the quality of the study. Individuals from Cardiff University and regulatory organisations may look at your medical and research records to check the accuracy of the

research study. The NHS will pass these details to Cardiff University along with the information collected from you and your medical records. The only people in Cardiff University who will have access to information that identifies you will be people who need to contact you to conduct the study, process any travel expenses claims or audit the data collection process.

Cardiff University will keep identifiable information about you from this study for 15 years after the study has finished.

Indemnity

Insurance for the design, conduct and management of the study is provided through the Sponsor, Cardiff University. NHS indemnity will also be in place for any NHS staff providing clinical care in the study. If you are harmed or injured as a result of taking part in the study then you may have grounds for compensation but you may have to pay for your legal costs.

What will happen to the results of the study?

We hope the results of this study will inform the future care of women with bipolar disorder and postpartum psychosis to prevent or reduce the adverse consequences of mental illness during pregnancy and the postpartum period.

We will report the findings on the study publicly through news items on the NCMH and APP websites, and articles in the NCMH newsletter. The study findings will also be used for the purposes of a PhD being carried out by Elen Thomas at Cardiff University.

It is our intention to publish the results of this study in academic journals and present findings at conferences. You will not be identified in any report, publication or presentation. We will also write a summary report of the study that will be sent out to each participant.
You will not have any claim to any future commercial use of results from the study in which your data has been used.

Who is organising the research and why?

This study is a PhD studentship that is being funded by Health and Care Research Wales, Welsh Government, based at the NCMH, School of Medicine, Cardiff University. This project will be carried out by Elen Thomas (PhD student at NCMH) and is supervised by Professor Ian Jones (NCMH Director), Dr Catrin Lewis (NCMH Research Associate and Field Team Manager) and Dr Jessica Herron (APP Director).

Future research opportunities

We would like to keep in contact with you about this study and other related research following this study. You will be free to decline if you do not want to take part in these other research opportunities – just as you are free to withdraw from this study at any time.

Who has reviewed this study?

All research in the NHS is reviewed by an independent group of people, called a Research Ethics Committee. They are there to protect your safety, rights, wellbeing and dignity. This

project has been reviewed and given a favourable opinion by Wales REC 2 and NHS (Research and Development) permission has also been obtained.

Additional Information

Joining the National Centre for Mental Health (NCMH) Cohort

In addition to the main study, we would like to tell you about NCMH to see if you would like to join their cohort. The NCMH is made up of researchers from Cardiff, Swansea and Bangor Universities. It is being funded by Health and Care Research Wales, Welsh Government. The Director of the NCMH is Professor Ian Jones. They are working to find out more about what causes mental health problems such as bipolar disorder, schizophrenia, ADHD and PTSD.

What is the NCMH Cohort?

Researchers at the NCMH are trying to understand why some people experience problems with their mental health in order to improve understanding of conditions such as bipolar disorder and postpartum psychosis and help find better treatments in the future. The researchers aim to invite several thousand people to join the NCMH cohort and we would be grateful if you would like to help.

What would it involve for me?

Joining the NCMH cohort will not require you to do anything in addition to the main study. We will simply share the information collected through the main study with researchers at the NCMH. They will keep this information strictly confidential. They may contact you in the future with updates about the research and may invite you to complete some further questionnaires or give you information about other studies that you may want to take part in, but there will be **no obligation** for you to get involved with these future opportunities.

What data will NCMH use?
They may look at or if necessary, copy and anonymise your medical records in strict confidence to gain further details about the kind of symptoms and treatments you have had. The information you provide in the main study may be linked anonymously to routinely collected data. This is called data linkage. These existing datasets, and data that may be collected in the future, contain anonymous health and social record information (for example, general practice records, hospital records). An example of such a databank that we will link to in Wales is the Secure Anonymised Information Linkage (SAIL) dataset at Swansea University. All data linkage is undertaken in line with the Data Protection Act (1998) and University governance.

All data linkage is undertaken in line with the Data Protection Act (1998) and University Governance. The information collected through this study may also be shared anonymously with other researchers, but the NCMH will never pass on personal / identifying information (for example, your name, address, date of birth).

Do I have to join the cohort?

No, you do not have to join the cohort to take part in the main study. However, if you do join, we are able to get more from the data you share with us in the main study.

Can I withdraw from the cohort?

If you choose to join the NCMH cohort and change your mind in the future, you can withdraw by contacting the main project research team. If you withdraw from the cohort, consent for medical records or assessment data that has already been linked to routinely collected, anonymised datasets such as SAIL cannot be withdrawn as the information will no longer be identifiable as yours.

If you have further questions about the study please contact:

Elen Thomas (PhD Student)		
National Centre for Mental Health	**Phone**	**029 20688403**
Cardiff University		
Hadyn Ellis Building,		
Maindy Road, Cathays,	**Email**	
Cardiff		**thomase45@cardiff.ac.uk**
CF24 4HQ		

Professor Ian Jones (Chief Investigator)	**Phone**	**029 20688401**
National Centre for Mental Health		
Cardiff University		
Hadyn Ellis Building,	**Email**	**jonesir1@cardiff.ac.uk**
Maindy Road, Cathays,		
Cardiff		
CF24 4HQ		

What if I am unhappy with an aspect of the study or wish to complain? If for whatever reason you are unhappy with any aspect of the study and wish to speak with someone independent to the study please contact:

Vanessa Davies
Institute Manager
Neuroscience and Mental Health
Research Institute
3rd Floor, Hadyn Ellis Building
Maindy Road
CARDIFF
CF244HQ

Phone	**029 20688340**
Email	
	daviesvj@cardiff.ac.uk

Appendix H – Participant consent form – Development stage

(see overleaf)

Participant Consent Form (Stage 1)
Bipolar and Postpartum Psychosis: PREP Study
PREgnancy Planning Study

	Please initial each box as appropriate
(1) I have read the attached information sheet (V1.1 dated 21 May 2019) and have had the opportunity to ask questions about the project. I know how to contact the research team if I need to and have a copy of the information sheet.	
(2) I agree to take part in an interview with a researcher which will be used to inform the content and presentation of the 'collaborative guide' (lasting in the region of 60-120 minutes).	
(3) I agree to be contacted about the opportunity to view further versions of the guide and to provide feedback on future versions of the guide. I understand that I am free to decline if I do not wish to help with the further development of the guide.	
(4) I give permission for my medical records, including any future psychiatric treatment I may receive, to be looked at or if necessary, copied and anonymised and analysed in strict confidence by members of the Cardiff University research team. I understand that the research team will no longer be able to access my medical records once I decide to withdraw my consent to this in the future. However data that has already been extracted from my medical records will have been anonymised and it will not be possible to destroy it as it will no longer be identifiable as mine.	
(5) I agree to the interview being recorded and held anonymously at Cardiff University.	
(6) I agree for the researchers to use quotes from the interviews. I understand that these will be anonymous and I will not be identifiable from the quotes.	
(7) I understand that the information I have provided for this study will be held confidentially by the research team.	
(8) I understand that participation in this project is voluntary and that I am free to withdraw from the study without giving a reason and without my medical care being affected.	
(9) I understand that if I withdraw from the study, any data that I have already provided will be retained and used for research purposes, unless I inform the research team that I do not wish for the information to be used.	
(10) I agree to be contacted about this study and related studies and understand that I am free to decline if I do not wish to participate in these future research opportunities.	
(11) I understand that my research data will be held anonymously and retained for 15 years after the study has finished, in line with Cardiff University's retention policy.	
(12) I understand that my personal bank details will be held by the Cardiff University Finance Department for the purposes of processing any travel expenses I may claim.	

NAME: _____ SIGNED: _____ DATE: _____

WITNESSED: _____ SIGNED: _____ DATE: _____

THANK YOU FOR PARTICIPATING IN OUR RESEARCH YOU WILL BE GIVEN A COPY OF THIS CONSENT FORM TO KEEP

275

Participant Consent Form: National Centre for Mental Health (NCMH)

<u>Additional optional consent</u> to join the NCMH Cohort

	Please initial each box as appropriate
(1) I agree to join the NCMH cohort and for information that I provide as part of the main study to be shared with researchers at NCMH, where my information will be kept strictly confidential.	
(2) I give permission for my medical records, including any future psychiatric treatment I may receive, to be looked at or if necessary, copied and anonymised and analysed in strict confidence by members of the NCMH research team. I understand that the research team will no longer be able to access my medical records once I decide to withdraw my consent to this in the future. However data that has already been extracted from my medical records will have been anonymised and it will not be possible to destroy it as it will no longer be identifiable as mine.	
(3) I agree that my assessment data can be linked to routinely collected, anonymised datasets (such as those held in the Secure Anonymised Information Linkage (SAIL) databank), in order to answer future research questions related to mental health. I understand that the data within any such dataset will be fully anonymised and I would not be identifiable in any way. I understand that if I withdraw from the study, assessment data that has already been linked to routinely collected, anonymised datasets such as SAIL cannot be withdrawn as it will no longer be identifiable as mine.	
(4) I understand that participation in the NCMH Cohort is voluntary and that I am free to withdraw without giving a reason and without my medical care being affected.	
(5) I agree to be contacted about this and related studies and understand that I am free to decline if I do not wish to participate in these future research opportunities.	

NAME: _____ SIGNED: _____ DATE: _____

WITNESSED: _____ SIGNED: _____ DATE: _____

THANK YOU FOR PARTICIPATING IN OUR RESEARCH YOU WILL BE GIVEN A COPY OF THIS CONSENT FORM TO KEEP

Appendix I – Participant information sheet – Pilot study

(see overleaf)

Participant Information Sheet (Stage 2)

Bipolar and Postpartum Psychosis: PREP Study

PREgnancy Planning Study

You are being invited to take part in a research project. Before you decide whether or not to take part, you should understand why the research is being done and what it will involve. Please take time to read the following information. Contact us if anything is not clear or if you would like more information.

What is the purpose of the research?

Researchers from the National Centre for Mental Health (NCMH) will work with Action on Postpartum Psychosis (APP) (www.app-network.org), the leading 3rd sector organisation in this area, and women with lived experience of bipolar disorder and / or postpartum psychosis to develop and test a 'collaborative guide'.

The 'collaborative guide' will be a decision aid that will aim to help women make decisions about pregnancy and the postpartum period, and improve their access to care if they experience an episode of illness. The guide will include information that women have reported to find hard to access when making decisions about pregnancy and childbirth. For example, information about the balance of risks and benefits for mother and child when stopping, switching or continuing medications during this period.

The aim of the guide is to help women to be actively involved in making decisions about pregnancy and the postpartum period with their clinicians, by providing them with the information they need to make informed decisions.

By working with women with lived experience of bipolar disorder and / or postpartum psychosis, we are hoping to learn about the experience of decision making surrounding pregnancy and the postpartum period and what information is needed during this time. Our aim is to use the experiences and knowledge of those who are experts by experience to help shape the contents of the 'collaborative guide'.

Who is being asked to take part?

You have been invited because you have lived experience of bipolar disorder and / or postpartum psychosis.

What does taking part involve?

- The researcher will discuss the details of the study with you and you will be able to ask any questions you may have. You will be asked to sign a consent form stating that you agree to take part in the study. You will be given a copy to keep along with this information sheet.

- You will also be given the option of consenting to the study remotely during a telephone/video call. This will involve a member of the research team contacting you via phone/video call to explain the study further and to answer any questions that you have. If you are happy to take part, the researcher will then read each of the consent statements out loud and you will be asked to respond 'yes' or 'no' aloud. The conversation will be audio recorded on an encrypted device and transcribed by a member of the research team. Audio recordings will be destroyed

immediately after transcription. You will be sent a copy of the completed electronic consent form via post or email.

- You will be provided with a copy of the guide and asked to use this at home and with your clinician to help you make decisions during the perinatal period. This will involve reading through the guide at home and taking it along to appointments with your clinician. You will be asked to use the guide for approximately 1 month, however the amount of time will be tailored to each participant. The guide will be used to help with joint-decision making related to pregnancy and the postpartum period.

- Before you start using the guide, the researcher will complete a brief assessment with you and ask you to complete a pack of questionnaires (this will take approximately 30-60 minutes). After using the guide, the researcher will complete an interview with you and ask you to complete a pack of questionnaires (lasting in the region of 60-120 minutes). This will be to learn about your experience of using the guide and your mood before and after using the guide.

- An interview with the researcher can take place in your own/family member's home or if you prefer, at a local health clinic, at a University site, at a voluntary organisation site or via phone / video call.

- Interviews will be recorded. We will ask you to provide consent for these recordings which will be held anonymously.

- After we have piloted and refined the 'collaborative guide' you will be given the opportunity to provide feedback on the guide in order to help with its development.

- Reasonable travel expenses will be paid by Cardiff University.

What will the data be used for?

We hope that this project will create a useful guide that can provide relevant information, as well as including sections that women can work through and personalise with their clinical teams and partners or family members.

The data will be used to determine the contents of the guide and to establish whether it is acceptable to women with lived experience of bipolar disorder and / or postpartum psychosis.

What are the possible benefits of taking part?

We hope that this guide will help women make decisions about becoming pregnant, reduce their risk of becoming unwell in the perinatal period, and improve their access to care if they experience an episode of illness.

What are the possible disadvantages and risks of taking part?

We acknowledge that some people find it difficult or upsetting to answer questions related to mental health. You may skip any questions that you do not wish to answer, take a break or terminate the interview at any point.

Declining and withdrawing from the study

You do not have to take part in this study. If you do decide to take part you are still free to withdraw at any time without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not alter the care you receive. If you decide to withdraw, any data which has already been collected may be retained and used for research purposes unless you inform the study team that you do not wish the information to be used. In the unlikely event that you lose capacity, the research team will retain your identifiable data and continue to use it in the research.

We will not access your medical records if you decide to withdraw your consent to this in the future. However data that has already been extracted from your medical records will have been anonymised and it will not be possible to destroy it as it will no longer be identifiable as yours.

Data confidentiality

All information collected during the course of the research will be kept strictly confidential. There are strict laws that safeguard your privacy at every stage. In accordance with the Data Protection Act, your personal information will be kept confidential by assigning a unique study code to your data. Your name or any identifying information will not be passed onto anyone outside Cardiff University. The audio recording of the interview will be kept until transcription is complete. We may use a Cardiff University approved professional transcription service to transcribe interviews. The transcription service will sign a confidentiality agreement before undertaking any transcribing. Audio recordings will be destroyed immediately after transcription.

We will routinely inform your GP that you are taking part. We will not pass on any of the information we collect about you unless we have serious concerns about your mental or physical health or the care that you are receiving.

Your anonymous research data will be retained for 15 years after the study has finished, in line with Cardiff University's record retention policy. Research data will be stored on Cardiff University IT systems.

How will my personal data be managed?
Cardiff University is the Sponsor for this study based in the United Kingdom. We will be using information from you and/or your medical records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Cardiff University will keep identifiable information about you for 15 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information at: https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection or by contacting the University's Data Protection Officer: inforequest@cardiff.ac.uk

Cardiff University will use your name and contact details to contact you about the research study, make sure that relevant information about the study is recorded for your care and to oversee the quality of the study. Individuals from Cardiff University and regulatory organisations may look at your medical and research records to check the accuracy of the research study. The NHS will pass these details to Cardiff University along with the information collected from you and your medical records.

The only people in Cardiff University who will have access to information that identifies you will be people who need to contact you to conduct the study, transcribe interviews, process any travel expenses claims or audit the data collection process.

Cardiff University will keep identifiable information about you from this study for 15 years after the study has finished.

Indemnity

Insurance for the design, conduct and management of the study is provided through the Sponsor, Cardiff University. NHS indemnity will also be in place for any NHS staff providing clinical care in the study. If you are harmed or injured as a result of taking part in the study then you may have grounds for compensation but you may have to pay for your legal costs.

What will happen to the results of the study?

We hope the results of this study will inform the future care of women with bipolar disorder and postpartum psychosis to prevent or reduce the adverse consequences of mental illness during pregnancy and the postpartum period.

We will report the findings on the study publicly through news items on the NCMH and APP websites, and articles in the NCMH newsletter. The study findings will also be used for the purposes of a PhD being carried out by Elen Thomas at Cardiff University.

It is our intention to publish the results of this study in academic journals and present findings at conferences. You will not be identified in any report, publication or presentation. We will also write a summary report of the study that will be sent out to each participant.

You will not receive specific results or feedback about your clinical information. You will not have any claim to any future commercial use of results from the study in which your data has been used.

Who is organising the research and why?

This study is a PhD studentship that is being funded by Health and Care Research Wales, Welsh Government, based at the NCMH , School of Medicine, Cardiff University. This project will be carried out by Elen Thomas (PhD student at the NCMH) and is supervised by Professor Ian Jones (NCMH Director), Dr Catrin Lewis (NCMH Research Associate and Field Team Manager) and Dr Jessica Herron (APP Director).

Future research opportunities

We would like to keep in contact with you about this study and other related research following this study. You will be free to decline if you do not want to take part in these other research opportunities – just as you are free to withdraw from this study at any time.

Who has reviewed this study?

All research in the NHS is reviewed by an independent group of people, called a Research Ethics Committee. They are there to protect your safety, rights, wellbeing and dignity. This project has been reviewed and given a favourable opinion by Wales REC 2 and NHS (Research and Development) permission has also been obtained.

Additional Information

Joining the National Centre for Mental Health (NCMH) Cohort

In addition to the main study, we would like to tell you about NCMH to see if you would like to join their cohort. The NCMH is made up of researchers from Cardiff, Swansea and Bangor Universities. It is being funded by Health and Care Research Wales, Welsh Government. The Director of the NCMH is Professor Ian Jones. They are working to find out more about what causes mental health problems such as bipolar disorder, schizophrenia, ADHD and PTSD.

What is the NCMH Cohort?

Researchers at the NCMH are trying to understand why some people experience problems with their mental health in order to improve understanding of conditions such as bipolar disorder and postpartum psychosis and help find better treatments in the future. The researchers aim to invite several thousand people to join the NCMH cohort and we would be grateful if you would like to help.

What would it involve for me?

Joining the NCMH cohort will not require you to do anything in addition to the main study. We will simply share the information collected through the main study with researchers at the NCMH. They will keep this information strictly confidential. They may contact you in the future with updates about the research and may invite you to complete some further questionnaires or give you information about other studies that you may want to take part in, but there will be **no obligation** for you to get involved with these future opportunities.

What data will NCMH use?

They may look at or if necessary, copy and anonymise your medical records in strict confidence to gain further details about the kind of symptoms and treatments you have had. The information you provide in the main study may be linked anonymously to routinely collected data. This is called data linkage. These existing datasets, and data that may be collected in the future, contain anonymous health and social record information (for example, general practice records, hospital records). An example of such a databank that we will link to in Wales is the Secure Anonymised Information Linkage (SAIL) dataset at Swansea University. All data linkage is undertaken in line with the Data Protection Act (1998) and University governance.

All data linkage is undertaken in line with the Data Protection Act (1998) and University Governance. The information collected through this study may also be shared anonymously with other researchers, but the NCMH will never pass on personal / identifying information (for example, your name, address, date of birth).

Do I have to join the cohort?

No, you do not have to join the cohort to take part in the main study. However, if you do join, we are able to get more from the data you share with us in the main study.

Can I withdraw from the cohort?

If you choose to join the NCMH cohort and change your mind in the future, you can withdraw by contacting the main project research team. If you withdraw from the cohort, consent for medical records or assessment data that has already been linked to routinely collected, anonymised datasets such as SAIL cannot be withdrawn as the information will no longer be identifiable as yours.

If you have further questions about the study please contact:
Elen Thomas (PhD Student)
National Centre for Mental Health   Phone   029 20688403
Cardiff University
Hadyn Ellis Building,
Maindy Road, Cathays,   Email   thomase45@cardiff.ac.uk
Cardiff
CF24 4HQ

Professor Ian Jones (Chief Investigator)Phone   029 20688401
National Centre for Mental Health
Cardiff University
Hadyn Ellis Building,   Email   jonesir1@cardiff.ac.uk
Maindy Road, Cathays,

Cardiff
CF24 4HQ

What if I am unhappy with an aspect of the study or wish to complain? If for whatever reason you are unhappy with any aspect of the study and wish to speak with someone independent to the study please contact:
Vanessa Davies
Institute Manager
Neuroscience and Mental Health Research
Institute
3rd Floor, Hadyn Ellis Building
Maindy Road
    CARDIFF
    CF244HQ

Phone	**029 20688340**
Email	**daviesvj@cardiff.ac.uk**

Appendix J – Participant consent form – Pilot study

(see overleaf)

Participant Consent Form (Stage 2)
Bipolar and Postpartum Psychosis: PREP Study
PREgnancy Planning Study

	Please initial each box as appropriate	For completion electronically	
(1) I have read the attached information sheet (V1.4 dated 06 August 2020) and have had the opportunity to ask questions about the project. I know how to contact the research team if I need to and have a copy of the information sheet.		Yes ☐	No ☐
(2) I agree to complete a brief assessment and self-report questionnaires before using the guide (approximately 30-60minutes) and an interview and self-report questionnaires after using the guide (lasting in the region of 60-120 minutes) asking about my experience of using the guide.		Yes ☐	No ☐
(3) I agree to be contacted about the opportunity to view further versions of the guide and to provide feedback on future versions of the guide. I understand that I am free to decline if I do not wish to help with the further development of the guide.		Yes ☐	No ☐
(4) I give permission for my medical records, including any future psychiatric treatment I may receive, to be looked at or if necessary, copied and anonymised and analysed in strict confidence by members of the Cardiff University research team. I understand that the research team will no longer be able to access my medical records once I decide to withdraw my consent to this in the future. However data that has already been extracted from my medical records will have been anonymised and it will not be possible to destroy it as it will no longer be identifiable as mine.		Yes ☐	No ☐
(5) I agree to the interview being recorded and held anonymously at Cardiff University.		Yes ☐	No ☐
(6) I agree for the researchers to use quotes from the interviews. I understand that these will be anonymous and I will not be identifiable from the quotes.		Yes ☐	No ☐
(7) I understand that this guide is not a replacement for my current mental health care and is designed to be used alongside your usual care.		Yes ☐	No ☐
(8) I understand that the information I have provided for this study will be held confidentially by members of the Cardiff University research group and the Cardiff University approved transcription service.		Yes ☐	No ☐
(9) I understand that interviews may be transcribed by a Cardiff University approved professional transcription service. The transcription service will sign a confidentiality agreement before undertaking any transcribing.		Yes ☐	No ☐

(10) I understand that participation in this project is voluntary and that I am free to withdraw from the study without giving a reason and without my medical care being affected.		Yes ☐	No ☐
(11) I understand that if I withdraw from the study, any data that I have already provided will be retained and used for research purposes, unless I inform the research team that I do not wish for the information to be used.		Yes ☐	No ☐
(12) I agree for the researchers to inform my GP that I am taking part.		Yes ☐	No ☐
(13) I agree to be contacted about this and related studies and understand that I am free to decline if I do not wish to participate in these future research opportunities.		Yes ☐	No ☐
(14) I understand that my research data will be held anonymously and retained for 15 years after the study has finished, in line with Cardiff University's retention policy.		Yes ☐	No ☐
(15) I understand that my personal bank details will be held by the Cardiff University Finance Department for the purposes of processing any travel expenses I may claim.		Yes ☐	No ☐

NAME: _____ SIGNED: _____ DATE: _____

WITNESSED: _____ SIGNED: _____ DATE: _____

THANK YOU FOR PARTICIPATING IN OUR RESEARCH YOU WILL BE GIVEN A COPY OF THIS CONSENT FORM TO KEEP

Participant Consent Form: National Centre for Mental Health (NCMH)

	Please initial each box as appropriate	For completion electronically
(1) I agree to join the NCMH cohort and for information that I provide as part of the main study to be shared with researchers at NCMH, where my information will be kept strictly confidential.		Yes ☐ No ☐
(2) I give permission for my medical records, including any future psychiatric treatment I may receive, to be looked at or if necessary, copied and anonymised and analysed in strict confidence by members of the NCMH research team. I understand that the research team will no longer be able to access my medical records once I decide to withdraw my consent to this in the future. However data that has already been extracted from my medical records will have been anonymised and it will not be possible to destroy it as it will no longer be identifiable as mine.		Yes ☐ No ☐
(3) I agree that my assessment data can be linked to routinely collected, anonymised datasets (such as those held in the Secure Anonymised Information Linkage (SAIL) databank), in order to answer future research questions related to mental health. I understand that the data within any such dataset will be fully anonymised and I would not be identifiable in any way. I understand that if I withdraw from the study, assessment data that has already been linked to routinely collected, anonymised datasets such as SAIL cannot be withdrawn as it will no longer be identifiable as mine.		Yes ☐ No ☐
(4) I understand that participation in the NCMH Cohort is voluntary and that I am free to withdraw without giving a reason and without my medical care being affected.		Yes ☐ No ☐
(5) I agree to be contacted about this and related studies and understand that I am free to decline if I do not wish to participate in these future research opportunities.		Yes ☐ No ☐

<u>Additional optional consent</u> to join the NCMH Cohort

NAME: _____ SIGNED: _____ DATE: _____

WITNESSED: _____ SIGNED: _____ DATE: _____

THANK YOU FOR PARTICIPATING IN OUR RESEARCH YOU WILL BE GIVEN A COPY OF THIS CONSENT FORM TO KEEP

<u>Appendix K</u> – Professional stakeholder information sheet – Development stage

(see overleaf)

Key Stakeholder Information Sheet: Focus Group (Stage 1)

Bipolar and Postpartum Psychosis: PREP Study

PREgnancy Planning Study

You are being invited to take part in a research project. Before you decide whether or not to take part, you should understand why the research is being done and what it will involve. Please take time to read the following information. Contact us if anything is not clear or if you would like more information.

What is the purpose of the research?

Researchers from the National Centre for Mental Health (NCMH) will work with Action on Postpartum Psychosis (APP) (www.app-network.org), the leading 3rd sector organisation in this area, and women with lived experience of bipolar disorder and / or postpartum psychosis to develop and test a 'collaborative guide'.

The 'collaborative guide' will be a decision aid that will aim to help women make decisions about pregnancy and the postpartum period, and improve their access to care if they experience an episode of illness. The guide will include information that women have reported to find hard to access when making decisions about pregnancy and childbirth. For example, information about the balance of risks and benefits for mother and child when stopping, switching or continuing medications during this period.

The aim of the guide is to help women to be actively involved in making decisions about pregnancy and the postpartum period with their clinicians, by providing them with the information they need to make informed decisions.

By working with women with lived experience of bipolar disorder and / or postpartum psychosis and key stakeholders, we are hoping to learn about the experience of decision making surrounding pregnancy and what information is needed during this time, to help shape the contents of the 'collaborative guide'.

Who is being asked to take part?

You have been invited because you have experience of working with women with lived experience of bipolar disorder and / or postpartum psychosis.

What does taking part involve?

- The researcher will discuss the details of the study with you and you will be able to ask any questions you may have. You will be asked to sign a consent form stating that you agree to take part in the study. You will be given a copy to keep along with this information sheet.

- The researcher will ask you to take part in a focus group with other key stakeholders (lasting in the region of 30-60 minutes). If you are unable to take part in a focus group, the researcher will invite you to take part in an individual interview. You will be asked about your knowledge and experience relating to women with bipolar disorder and the perinatal period. Discussions will also include considering background information provided, covering topics such as risk factors for postpartum psychosis, self-management strategies and medication for women with bipolar

disorder during the perinatal period. You will be asked to share your thoughts and opinions on the content and presentation of the guide and to introduce your own topics for discussion.

- The focus group or interview can take place at your place of work, at a University site, a voluntary organisation site or via phone / video call.

- Interviews will be recorded. We will ask you to provide consent for these recordings which will be held anonymously.

- You will be given the opportunity to provide feedback on the 'collaborative guide' following the first stage and following each pilot study in order to help with its development.

- Reasonable travel expenses will be paid by Cardiff University.

What will the data be used for?

We hope that this project will create a useful guide that can provide relevant information, as well as including sections that women can work through and personalise with their clinical teams and partners.

The data will be used to determine the contents of the guide and to establish whether it is acceptable to women with lived experience of bipolar disorder and / or postpartum psychosis.

Declining and withdrawing from the study

You do not have to take part in this study. If you do decide to take part you are still free to withdraw at any time without giving a reason. If you decide to withdraw, any data which has already been collected may be retained and used for research purposes unless you inform the study team that you do not wish the information to be used. In the unlikely event that you lose capacity, the research team will retain your identifiable data and continue to use it in the research.

Data confidentiality

All information collected during the course of the research will be kept strictly confidential. There are strict laws that safeguard your privacy at every stage. In accordance with the Data Protection Act, your personal information will be kept confidential by assigning a unique study code to your data. Your name or any identifying information will not be passed onto anyone outside Cardiff University. The audio recording of the focus group or interview will be kept until transcription is complete. Audio recordings will be destroyed immediately after transcription.

Due to the nature of focus groups, there is a risk of accidental disclosure through the involvement of other members of the group, however all participants will be informed of their responsibility to maintain the confidentiality of what is said in the group.

Your anonymous research data will be retained for 15 years after the study has finished, in line with Cardiff University's record retention policy. Research data will be stored on Cardiff University IT systems.

How will my personal data be managed?

Cardiff University is the Sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Cardiff University will keep identifiable information about you for 15 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information at: https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection or by contacting the University's Data Protection Officer: inforequest@cardiff.ac.uk

Cardiff University will use your name and contact details to contact you about the research study, make sure that relevant information about the study is recorded and to oversee the quality of the study. Individuals from Cardiff University and regulatory organisations may look at the research records to check the accuracy of the research study. The only people in Cardiff University who will have access to information that identifies you will be the people who need to contact you to conduct the study or audit the data collection process.

Cardiff University will keep identifiable information about you from this study for 15 years after the study has finished.

Indemnity

Insurance for the design, conduct and management of the study is provided through the Sponsor, Cardiff University. NHS indemnity will also be in place for any NHS staff providing clinical care in the study. If you are harmed or injured as a result of taking part in the study then you may have grounds for compensation but you may have to pay for your legal costs.

What will happen to the results of the study?

We hope the results of this study will inform the future care of women with bipolar disorder and postpartum psychosis to prevent or reduce the adverse consequences of mental illness during pregnancy and the postpartum period.

We will report the findings on the study publicly through news items on the NCMH and APP websites, and articles in the NCMH newsletter. The study findings will also be used for the purposes of a PhD being carried out by Elen Thomas at Cardiff University.

It is our intention to publish the results of this study in academic journals and present findings at conferences. You will not be identified in any report, publication or presentation. We will also write a summary report of the study that will be sent out to each participant.

You will not have any claim to any future commercial use of results from the study in which your data has been used.

Who is organising the research and why?

This study is a PhD studentship that is being funded by Health and Care Research Wales, Welsh Government, based at the National Centre for Mental Health, School of Medicine, Cardiff University. This project will be carried out by Elen Thomas (PhD student at NCMH) and is supervised by Professor Ian Jones (NCMH Director), Dr Catrin Lewis (NCMH Research Associate and Field Team Manager) and Dr Jessica Herron (APP Director).

Future research opportunities

We would like to keep in contact with you about this study and other related research following this study. You will be free to decline if you do not want to take part in these other research opportunities – just as you are free to withdraw from this study at any time.

Who has reviewed this study?

All research in the NHS is reviewed by an independent group of people, called a Research Ethics Committee. They are there to protect your safety, rights, wellbeing and dignity. This project has been reviewed and given a favourable opinion by Wales REC 2 and NHS (Research and Development) permission has also been obtained.

If you have further questions about the study please contact:

Elen Thomas (PhD Student)		
National Centre for Mental Health	**Phone**	**029 20688403**
Cardiff University		
Hadyn Ellis Building,		
Maindy Road, Cathays,	**Email**	**thomase45@cardiff.ac.uk**
Cardiff		
CF24 4HQ		
Professor Ian Jones (Chief Investigator)	**Phone**	**029 20688401**
National Centre for Mental Health		
Cardiff University		
Hadyn Ellis Building,	**Email**	**jonesir1@cardiff.ac.uk**
Maindy Road, Cathays,		
Cardiff		
CF24 4HQ		

What if I am unhappy with an aspect of the study or wish to complain? If for whatever reason you are unhappy with any aspect of the study and wish to speak with someone independent to the study please contact:

Vanessa Davies
Institute Manager
Neuroscience and Mental Health Research Institute
3rd Floor, Hadyn Ellis Building
Maindy Road
   CARDIFF
   CF244HQ

Phone	**029 20688340**
Email	**daviesvj@cardiff.ac.uk**

<u>Appendix L</u> – Professional stakeholder consent form – Development stage

(see overleaf)

Key Stakeholder Consent Form (Stage 1)

Bipolar and Postpartum Psychosis: PREP Study

PREgnancy Planning Study

	Please initial each box as appropriate
(1) I have read the attached information sheet (V1.2 dated 23 August 2019) and have had the opportunity to ask questions about the project. I know how to contact the research team if I need to and have a copy of the information sheet.	
(2) I agree to take part in a focus group / interview with a researcher asking about my opinions about the content and presentation of a 'collaborative guide' to inform women who are at high risk of experiencing severe postpartum episodes of illness (lasting in the region of 30-60 minutes).	
(3) I agree to be contacted about the opportunity to view further versions of the guide and to provide feedback on future versions of the guide. I understand that I am free to decline if I do not wish to help with the further development of the guide.	
(4) I agree to the focus group / interview being recorded and held anonymously at Cardiff University.	
(5) I agree for the researchers to use quotes from the focus group / interview. I understand that these will be anonymous and I will not be identifiable from the quotes.	
(6) I understand that the information I have provided for this study will be held confidentially by the research team.	
(7) I understand that participation in this project is voluntary and that I am free to withdraw from the study without giving a reason.	
(8) I understand that if I withdraw from the study, any data that I have already provided will be retained and used for research purposes, unless I inform the research team that I do not wish for the information to be used.	
(9) I agree to be contacted about this and related studies and understand that I am free to decline if I do not wish to participate in these future research opportunities.	
(10) I understand that my research data will be held anonymously and retained for 15 years after the study has finished, in line with Cardiff University's retention policy.	

NAME: _____ SIGNED: _____ DATE: _____

WITNESSED: _____ SIGNED: _____ DATE: _____

THANK YOU FOR PARTICIPATING IN OUR RESEARCH YOU WILL BE GIVEN A COPY OF THIS CONSENT FORM TO KEEP

Appendix M – General Practitioner (GP letter)

PRIVATE & CONFIDENTIAL

ADDRESS

Dear NAME,

Re: PATIENT NAME AND DOB

The patient named above has agreed to take part in the **Bipolar and Postpartum Psychosis: Pregnancy Planning (PREP) Study** sponsored by Cardiff University. The study aims to develop and pilot a guide for women with lived experience of bipolar disorder and postpartum psychosis to use when planning a pregnancy and making decisions during pregnancy and the postpartum period. The aim of the guide is to help women consider with their clinicians the issues raised by pregnancy and childbirth, by providing them with information to help make informed decisions.

Participants will be provided with a copy of the guide and asked to use this at home which may help inform discussions during clinical appointments. Before and after using the guide, the participant will complete self-report questionnaires and an interview with a trained researcher. This will be to learn about their experience of using the guide.

This project has been given a favourable ethical opinion by Wales Research Ethics Committee (REC) 2 and local National Health Service (NHS) Research and Development (R&D) departments.

Information about the study can be found at www.ncmh.info/prep. If you have any questions about the study, please do not hesitate to contact Elen Thomas (PhD Student) on 02920 686 403 or thomase45@cardiff.ac.uk.

I'd be grateful if you don't share this any further.

Yours sincerely,

Professor Ian Jones

Chief Investigator

Appendix N – Participant questionnaire pack

(see overleaf)

Bipolar and Postpartum Psychosis: PREP Study

PREgnancy Planning Study

Stage 2 participant questionnaires

Please complete the questionnaires in this pack before / after using the guide. The questionnaires will take approximately 15 minutes to complete.
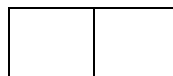
Questionnaire 1

Tick the box beside the reply that is closest to how you have been feeling in the past week. Don't take too long over you replies: your immediate is best.

I feel tense or 'wound up':	
Most of the time	
A lot of the time	
From time to time, occasionally	
Not at all	
I still enjoy the things I used to enjoy:	
Definitely as much	
Not quite so much	
Only a little	
Hardly at all	
I get a sort of frightened feeling as if something awful is about to happen:	
Very definitely and quite badly	
Yes, but not too badly	
A little, but it doesn't worry me	
Not at all	
I can laugh and see the funny side of things:	
As much as I always could	
Not quite so much now	
Definitely not so much now	
Not at all	
Worrying thoughts go through my mind:	
A great deal of the time	
A lot of the time	
From time to time, but not too often	
Only occasionally	
I feel cheerful:	
Not at all	
Not often	
Sometimes	
Most of the time	
I can sit at ease and feel relaxed:	
Definitely	
Usually	
Not Often	
Not at all	
I feel as if I am slowed down:	
Nearly all the time	

Very often	
Sometimes	
Not at all	
I get a sort of frightened feeling like 'butterflies' in the stomach:	
Not at all	
Occasionally	
Quite Often	
Very Often	
I have lost interest in my appearance:	
Definitely	
I don't take as much care as I should	
I may not take quite as much care	
I take just as much care as ever	
I feel restless as I have to be on the move:	
Very much indeed	
Quite a lot	
Not very much	
Not at all	
I look forward with enjoyment to things:	
As much as I ever did	
Rather less than I used to	
Definitely less than I used to	
Hardly at all	
I get sudden feelings of panic:	
Very often indeed	
Quite often	
Not very often	
Not at all	
I can enjoy a good book or radio or TV program:	
Often	
Sometimes	
Not often	
Very seldom	

Questionnaire 2

This questionnaire asks about how you feel **today**.

On this questionnaire are groups of five statements. Please read each group of statements carefully and choose **one** statement in each group that **best** describes how you feel **today**. *(Please note, the word "occasionally" when used here means once or twice. "Often" means several times or more. "Frequently" means most of the time).*

1. ☐ I do not feel happier or more cheerful than usual.
   ☐ I occasionally feel happier or more cheerful than usual.
   ☐ I often feel happier or more cheerful than usual.
   ☐ I feel happier or more cheerful than usual most of the time.
   ☐ I feel happier of more cheerful than usual all of the time.

2. ☐ I do not feel more self-confident than usual.
   ☐ I occasionally feel more self-confident than usual.
   ☐ I often feel more self-confident than usual.
   ☐ I feel more self-confident than usual most of the time.
   ☐ I feel more self-confident than usual all of the time.

3. ☐ I do not need less sleep than usual.
   ☐ I occasionally need less sleep than usual.
   ☐ I often need less sleep than usual.
   ☐ I frequently need less sleep than usual.
   ☐ I can go all day and night without any sleep and still do not feel tired.

4. ☐ I do not talk more than usual.
   ☐ I occasionally talk more than usual.
   ☐ I often talk more than usual.
   ☐ I frequently talk more than usual.
   ☐ I talk constantly and cannot be interrupted.

5. ☐ I have not been more active (either socially, sexually, at work, home or school) than usual.
   ☐ I have occasionally been more active than usual.
   ☐ I have often been more active than usual.
   ☐ I have frequently been more active than usual.
   ☐ I am constantly active or on the go all the time.

Questionnaire 3

Please answer the questions in the sections below that are relevant to you. If either of these sections are not relevant to you, please leave the questions blank.

<u>Section A</u>

Making a decision about whether or not to have a baby

   Which option do you currently prefer? Please check one.

    ☐ Having a baby
    ☐ Having a baby, but not right now
    ☐ Not having a baby
    ☐ Other: _____
    ☐ Unsure

Please answer the following questions:

Please note that question 13 to 16 will only apply to you if you have already made a decision.

	Strongly Agree [0]	Agree [1]	Neither Agree Or Disagree [2]	Disagree [3]	Strongly Disagree [4]
1. I know which options are available to me.	☐	☐	☐	☐	☐
2. I know the benefits of each option.	☐	☐	☐	☐	☐
3. I know the risks and side effects of each option.	☐	☐	☐	☐	☐
4. I am clear about which benefits matter most to me.	☐	☐	☐	☐	☐
5. I am clear about which risks and side effects matter most.	☐	☐	☐	☐	☐
6. I am clear about which is more important to me (the benefits or the risks and side effects).	☐	☐	☐	☐	☐
7. I have enough support from others to make a choice.	☐	☐	☐	☐	☐
8. I am choosing without pressure from others.	☐	☐	☐	☐	☐
9. I have enough advice to make a choice.	☐	☐	☐	☐	☐
10. I am clear about the best choice for me.	☐	☐	☐	☐	☐
11. I feel sure about what to choose.	☐	☐	☐	☐	☐
12. This decision is easy for me to make.	☐	☐	☐	☐	☐
13. I feel I have made an informed choice.	☐	☐	☐	☐	☐
14. My decision shows what is important to me.	☐	☐	☐	☐	☐
15. I expect to stick with my decision.	☐	☐	☐	☐	☐
16. I am satisfied with my decision.	☐	☐	☐	☐	☐

Making decisions about medication during pregnancy

Which medication option do you currently prefer? Please check one.

- □ Continuing medication
- □ Stopping medication
- □ Switching to a different medication
- □ Other: _____
- □ Unsure

Please answer the following questions:

Please note that question 13 to 16 will only apply to you if you have already made a decision.

	Strongly Agree [0]	Agree [1]	Neither Agree Or Disagree [2]	Disagree [3]	Strongly Disagree [4]
1. I know which options are available to me.	□	□	□	□	□
2. I know the benefits of each option.	□	□	□	□	□
3. I know the risks and side effects of each option.	□	□	□	□	□
4. I am clear about which benefits matter most to me.	□	□	□	□	□
5. I am clear about which risks and side effects matter most.	□	□	□	□	□
6. I am clear about which is more important to me (the benefits or the risks and side effects).	□	□	□	□	□
7. I have enough support from others to make a choice.	□	□	□	□	□
8. I am choosing without pressure from others.	□	□	□	□	□
9. I have enough advice to make a choice.	□	□	□	□	□
10. I am clear about the best choice for me.	□	□	□	□	□
11. I feel sure about what to choose.	□	□	□	□	□
12. This decision is easy for me to make.	□	□	□	□	□
13. I feel I have made an informed choice.	□	□	□	□	□
14. My decision shows what is important to me.	□	□	□	□	□
15. I expect to stick with my decision.	□	□	□	□	□
16. I am satisfied with my decision.	□	□	□	□	□

Questionnaire 4 After only

We would like to know what you think about the guide you have used.

1. Please rate each section, by circling **'strongly agree', 'agree', 'neutral', 'disagree'** or **'strongly disagree'** to show what you think about the following statements:

Guide layout and presentation					
1) The guide was easy to use	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
2) The interactive sections (*e.g. writing information about yourself, notes or responding to scales*) were easy to follow	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
3) The guide was visually appealing	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
4) The colours, fonts and font sizes made the guide easy to read	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
5) Information was laid out in a logical, organised manner	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
Guide content and usefulness					
6) The information was easy to understand	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
7) There was information that I had <u>not</u> covered during clinical appointments	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
8) There was information that I had <u>not</u> come across before from other sources (e.g. Online resources)	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
9) The information was overwhelming	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
10) There was enough information about mental health conditions during pregnancy and birth	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
11) There was enough information about my individual chance of becoming unwell with my mental health during pregnancy and after birth	Strongly disagree	Disagree	Neutral	Agree	Strongly agree

12) There was enough information about support during pregnancy and after birth	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
13) There was enough information about using medication during pregnancy and after birth	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
14) There was enough information on ways that I can help myself to keep well	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
15) There was enough information for partners, family or friends	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
16) The website links and signposting information were helpful	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
17) The guide was free from judgement and / or bias	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
18) The guide was helpful for women making decisions when planning a pregnancy or during pregnancy	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
19) The guide was helpful to discuss information, decisions and plans with others	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
20) The interactive sections (*e.g. Writing information about yourself, notes or responding to scales*) were helpful	Strongly disagree	Disagree	Neutral	Agree	Strongly agree

Comments:

2. How helpful did you find information on the following topics?

Please rate how helpful you found the information by circling a number between 1 and 5

(1= not at all, 2= slightly, 3= moderately, 4= very, 5= extremely)

Mental health conditions during pregnancy and birth	1	2	3	4	5
My individual chance of becoming unwell with my mental health during pregnancy and after birth	1	2	3	4	5
Support during pregnancy and after birth	1	2	3	4	5
Using medication during pregnancy and after birth	1	2	3	4	5
Ways that I can help myself to keep well	1	2	3	4	5
Information for partners, family or friends	1	2	3	4	5

Comments:

3. The amount of information included was *(check one)*

☐ Too much information

☐ Too little information

☐ Just right

Comments:

4. We are interested to know how you used the guide. Please answer the following questions:

   A. I used the guide with:

	Yes	No
Partner, family or friends *Please specify:_____*	Yes	No
Healthcare professionals	Yes	No

If applicable, please rate each statement by circling **'strongly agree'**, **'agree'**, **'neutral'**, **'disagree'** or **'strongly disagree'**:

The guide was helpful to discuss decisions and plans with my partner / family / friends	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
The guide was helpful to discuss decisions and plans with my healthcare professionals	Strongly agree	Agree	Neutral	Disagree	Strongly disagree

Comments:

B. Did you use any of the interactive sections (e.g. involving writing down information about yourself, making notes, filling in scales)?

☐ Yes

☐ No

☐ Partly

Which of the following sections did you use?

Reflecting on the decision to start a family or have another baby	Yes	No	Partly
Previous episodes of mental illness	Yes	No	Partly
Family history of mental illness	Yes	No	Partly
Your medication and treatment information	Yes	No	Partly
What do I need to think about when making decisions about pregnancy?	Yes	No	Partly
Early warning signs that I'm becoming unwell	Yes	No	Partly
My personal triggers	Yes	No	Partly
You may want to think about times when you have been at your most stable in your mental health	Yes	No	Partly
'Bringing it all together' section	Yes	No	Partly
Important contacts	Yes	No	Partly

Comments:

```
┌──────────────────────────────────────────────────────────────────┐
│                                                                    │
│                                                                    │
│                                                                    │
│                                                                    │
│                                                                    │
│                                                                    │
│                                                                    │
└──────────────────────────────────────────────────────────────────┘
```

5. Did you find this guide helpful when making plans and decisions related to pregnancy and birth?

    ☐ Yes

    ☐ No

6. How satisfied overall were you with the guide?

    ☐ Unsatisfied

    ☐ Somewhat satisfied / Neutral

    ☐ Mostly satisfied

    ☐ Very satisfied

7. Would you recommend the guide to other women who are pregnant or planning a pregnancy?

    ☐ Yes

    ☐ No

```
┌──────────────────────────────────────────────────────────────────┐
│ Comments:                                                          │
│                                                                    │
│                                                                    │
│                                                                    │
│                                                                    │
│                                                                    │
└──────────────────────────────────────────────────────────────────┘
```

Appendix O – Final guide prototype

(see overleaf)

Planning your pregnancy

Information for women with bipolar or previous postpartum psychosis, to read and personalise

Women with bipolar or previous postpartum psychosis have shared their experiences and opinions with us on what would help them during pregnancy and childbirth. Professionals who work with women during pregnancy and childbirth took part in interviews about the information women need.

Experts and Peer Supporters from the national charities Action on Postpartum Psychosis (APP) and Bipolar UK and experts from the National Centre for Mental Health (NCMH), Cardiff University have helped develop the information.

Contents

Using this guide

Planning your pregnancy

Women with bipolar or previous postpartum psychosis have shared their experiences and opinions with us on what would help them during pregnancy and childbirth.

This guide is for women with bipolar or previous postpartum psychosis who are planning a pregnancy.

Women with lived experience of other severe mental illnesses such as, schizoaffective disorder or psychotic depression are also likely to find this guide useful.

This guide may also be useful for women who are currently pregnant.

Developing a guide for women with different experiences of mental illness at different stages of planning and pregnancy means that not all sections in the guide will be relevant for everyone.

The guide does not need to be read cover to cover. It is up to you at what stage in your journey of planning a pregnancy you'll find the information in each section most useful and feel ready to work through.

This guide was created because women with bipolar or previous postpartum psychosis face many decisions when planning a pregnancy and may find it difficult to get the information they need.

The guide includes information, links to reliable and trustworthy resources and interactive sections that you can work through.

> 66 *When I was expecting another baby after an episode of postpartum psychosis, there wasn't much information available to help me.*
>
> *This guide will be really valuable for helping women think about their choices around pregnancy, birth and the period after their baby is born and what they might like to do to try and manage any other episodes.*
>
> *Also for partners and clinicians, who are just as important in this journey and have such an important part to play.* 99
>
> A woman who experienced postpartum psychosis with her first child

Some ways to use this guide

Here are some suggestions below on how you can get the most out of this guide, **but ultimately, there is no right or wrong way to use it.** Some women may want to fill out all of the interactive sections, while others may find it more useful just to read through the sections relevant to them.

■ **It can be personalised**

You will see spaces to make your own notes and interactive sections that you can work through yourself and with others.

■ **It can be used to aid discussions with significant others**

Other people in your life are likely to play an important role in the decisions you make and your plans. You may find it useful to work through this guide with a partner, family member or friend. There are sections in this guide that are designed to be shared with others.

■ **It can be used to aid discussions with healthcare professionals**

It may help to use the guide to prepare for your appointments with healthcare professionals and think about the questions you need to ask them. You may want to let your healthcare professionals know you are using this guide – sharing the interactive sections with them may be helpful.

The importance of clinical care

This guide is not a replacement for your usual clinical care. Your healthcare professional or clinical team will be able to give you specialist, tailored advice.

The guide has been designed to complement any clinical care you are receiving and act as a starting point to getting the information and support you need.

A summary of the guide

1

What do I need to think about when planning a pregnancy?
This section includes questions to help you consider your choices and how you feel about having a baby, and when the best time would be.

2

How might childbirth impact on my mental health?
This section includes information about different mental health conditions that women with bipolar or previous experience of postpartum psychosis can experience during pregnancy and after birth.

3

What support may I receive through pregnancy and after having a baby?
In this section you'll find information about what support may be available to you before having a baby, during pregnancy and after birth.

4

What do I need to know about medication and pregnancy?
This section discusses general principles to think about when considering taking medication during pregnancy and while breastfeeding.

5

How can I help myself stay well?
This section includes self-management strategies on your lifestyle and working with your healthcare professionals to get your medication right.

6   What do partners, family and friends need to know?

This section is for partners, family and friends who want to understand better how to be supportive during this time.

7   Bringing it all together

This section is designed to help you think about what you've worked through in the guide and to plan your next steps.

About me: questions about my history and lifestyle

These are optional interactive sections dotted throughout the guide, filled with questions to answer about yourself. We have included a separate divider at the back of the guide in case you'd like to keep these sections separate from the information in the guide.

You can also download additional copies of these interactive sections at: ncmh.info/pregnancyplanning

What do I need to think about when planning a pregnancy?

Deciding to have a child is an important decision for any woman. For a woman with bipolar or previous postpartum psychosis, this decision may be more complex.

This section has been designed to help you consider your choices when thinking about having a baby.

You may be deciding whether to have a baby for the first time, or you may be considering or planning a second baby after becoming unwell in a previous pregnancy.

Thinking about whether to have a baby may be a decision that you are considering with a partner, or as a solo person. If you are planning a pregnancy without a partner, there may be additional things to think about and plans to put in place.

If you are already pregnant, you may decide to skip ahead to the next section.

> " *There were so many more things for us to consider when deciding to have our second child: Would I get ill again? How would it affect our firstborn? Would I want to take medication during pregnancy?*
>
> *While I was still in recovery from postpartum psychosis, I could never imagine wanting to take the risk of PP again. Yet I knew that I desperately wanted to give my son the joy of a sibling. So we found out everything we could about the risks of PP reoccurring and how it might be possible, with careful planning, to prevent another episode. In the end realising that there was a possibility of experiencing another episode of psychosis whether I had another pregnancy or not, cemented our decision.*
>
> *We decided to have another child, and weather whatever storm may come – except this time we would be fully prepared for the worst. Thankfully, we prevented a second episode of PP with medication and a supportive perinatal team. We are now a family of four.* "

A woman who experienced postpartum psychosis with her first child

Next steps: deciding when to have a child

Once you have decided that you would like to have a baby, the next step will involve making decisions about when you want to have a baby. There may never be a 'perfect' time to have a baby for any woman.

How long does it usually take to get pregnant?

Most couples will get pregnant within a year if they have regular sex and don't use contraception (about 84 out of every 100).

There are factors that can affect a couple's chance of conceiving which include general health and lifestyle.

Another factor is age. From the mid 30s a woman's ability to get pregnant starts to decline gradually.

Some medications used by women with a mental illness may impact on fertility. If this is a concern, you should discuss this with the doctor who prescribes your medication.

You can find out more about fertility (the ability to get pregnant) and the causes of infertility in the PregnancyHub on the Tommy's website, **Fertility and causes of infertility: tommys.org**

Getting as well as possible

Being in good health before deciding to try for a baby can help with your chances of conceiving and help you stay as healthy as possible throughout your pregnancy. Now is a good time to consider your physical health and lifestyle.

This is also a good time to consider how well you are in terms of your mental health and reviewing your medication. It may be helpful to discuss this with your GP or mental health professional.

For tailored advice on how to improve pregnancy health, try out Tommy's Planning for Pregnancy digital tool.

This tool will take you through a questionnaire and use your answers to provide information on what you can do to have a healthy pregnancy and baby.

It also provides supportive email follow-up with tips and advice. Search **Planning for pregnancy tool: tommys.org**

Deciding on the best time for you and your family

As well as thinking about how you're feeling about having a child and when in terms of your physical and mental health, you may also have thought about when the best time is for your family as a whole.

If I have bipolar will my children get it too?

As with many physical and mental illnesses, bipolar seems to run in families. There is evidence to suggest that both genetics and things that happen to us play a role in making someone more likely to develop bipolar.

A large number of genes are likely to be involved in increasing someone's chance of developing bipolar, some increasing risk by a small amount and others decreasing risk. What is clear is that there isn't a single 'bipolar gene'.

For children of a parent who has bipolar, around 1 in 10 may develop bipolar although mood disorders such as depression may also be more common. Although of course another way of looking at this is that 9 in 10 children won't develop bipolar.

Most people when they understand these numbers feel reassured that the risk wasn't as high as they had thought.

Although the chance of developing bipolar is higher than the general population (which is around 1-3%) these children are still more likely to not develop bipolar than to develop the condition.

Two other points should also be made:

Firstly, knowing about an increased risk of developing bipolar is likely to help it to be picked up more quickly and treated early – for many people with bipolar it takes far too long to get the right diagnosis.

Secondly, we are likely to understand much more about bipolar and how best to treat it in the next 10 - 20 years, so hopefully there will be new and better treatments available should a child become unwell later in life.

Key messages

- Having a baby is a big decision for anyone, but for women with a diagnosis of bipolar or previous postpartum psychosis, there is more to think about.

- It will be helpful to think about what your thoughts and preferences are about whether or not to have a baby.

- This section and the 'About me' pages that follow might be something that you revisit and consider over time. Your decision may change as you work through the information in this guide and with your healthcare professionals.

Remember it's ok to reconsider your decision over time.

About me

The 'About me' sections are for you to fill in with information about yourself. They can be shared with a partner, family, friends and healthcare professionals - it's up to you.

They are dotted throughout this guide and can be brought together under the About me divider you will find at the end of the guide.

Writing down your information may help others to understand your decisions and know what you want to happen if you become unwell. It may also help you to prepare for healthcare appointments.
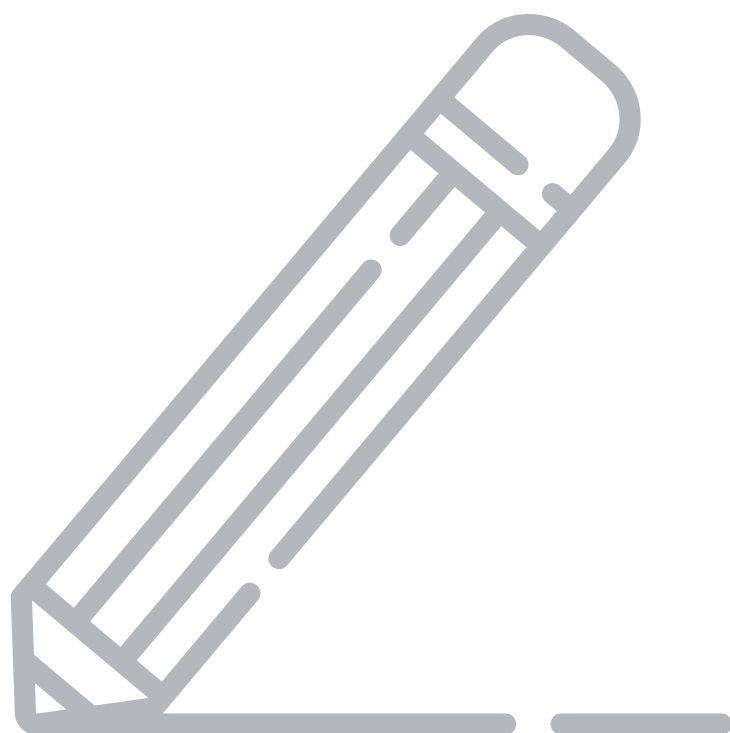
About me
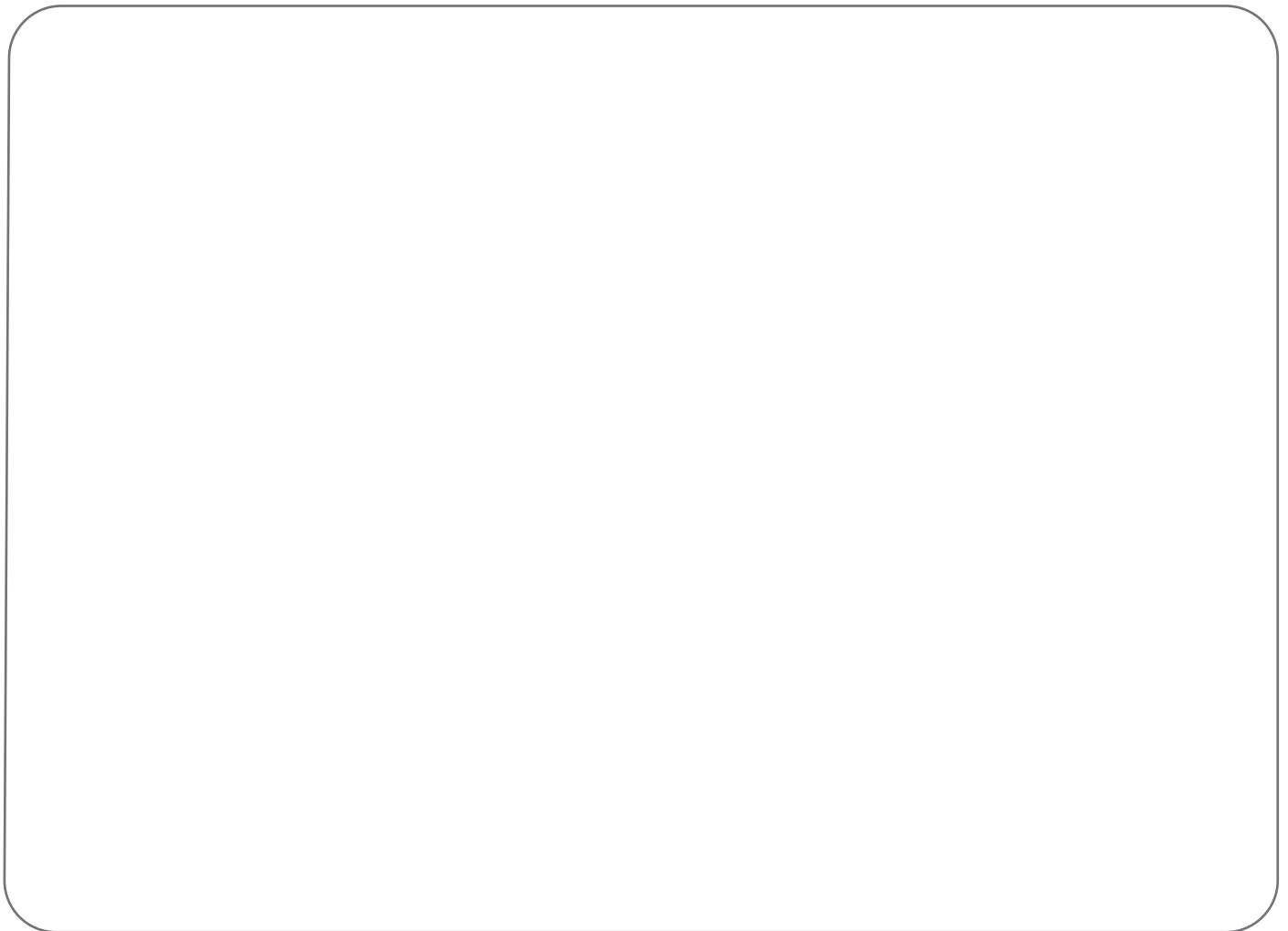
Reflecting on the decision to start a family or have another baby

The following questions are designed to provide you with a starting point to help you explore how you are feeling about having a baby.

You may find this section useful to revisit once you've had time to read through the information in this guide.

Spend some time noting down your thoughts below. You may find it helpful to work through these questions with a partner, family member or a friend.

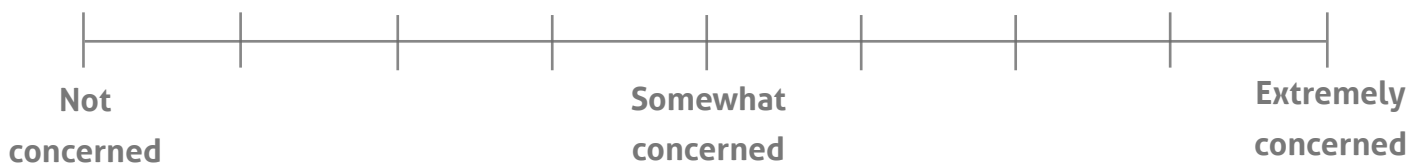What are my worries and fears for having a baby, or not having a baby?

Consider the statements below - how do you relate to each one?

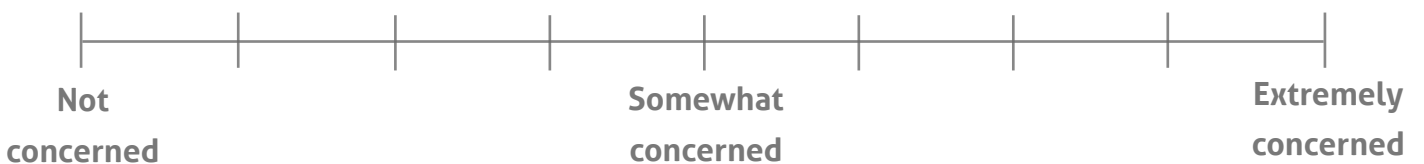*Put a cross on the scale at the point that best fits how concerned you are*
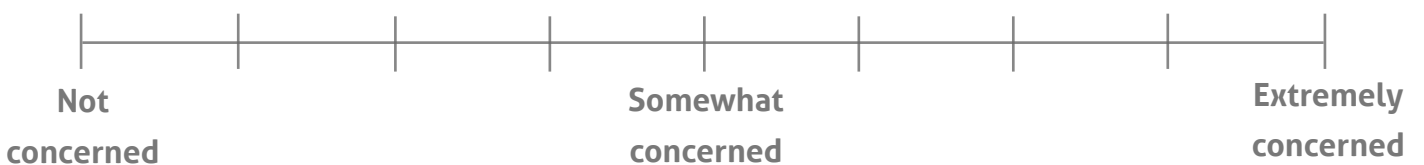
The chance of becoming unwell if I become pregnant

Not concerned   Somewhat concerned   Extremely concerned
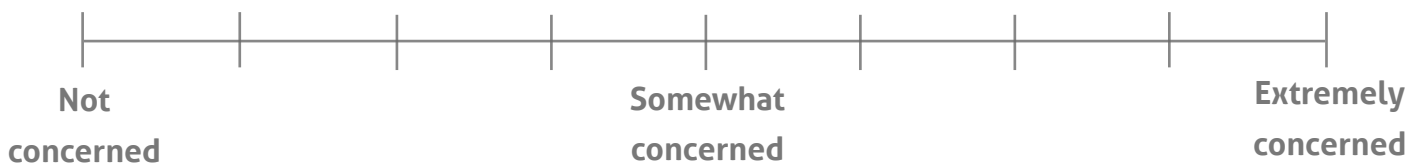
How being a mum would impact on my illness

Not concerned   Somewhat concerned   Extremely concerned

Not being able to stay on my current medication

Not concerned   Somewhat concerned   Extremely concerned

Coping with everything that comes with having a baby

Not concerned   Somewhat concerned   Extremely concerned

C

About me

Being the parent I want to be

Not
concerned   Somewhat
concerned   Extremely
concerned

Bonding with my baby if I become unwell

Not
concerned   Somewhat
concerned   Extremely
concerned

Are there any important considerations for you personally that are not listed here?

Use the blank sections or the note box below to write down your own personal considerations that are important to you:
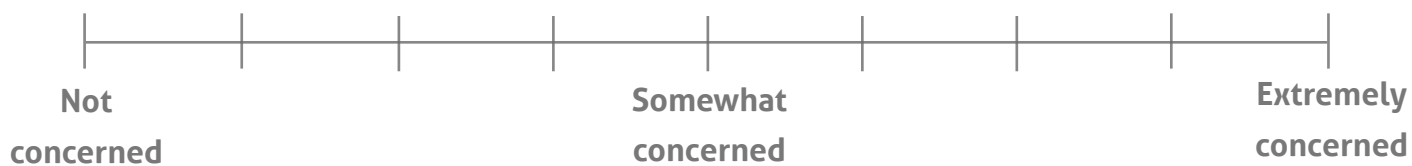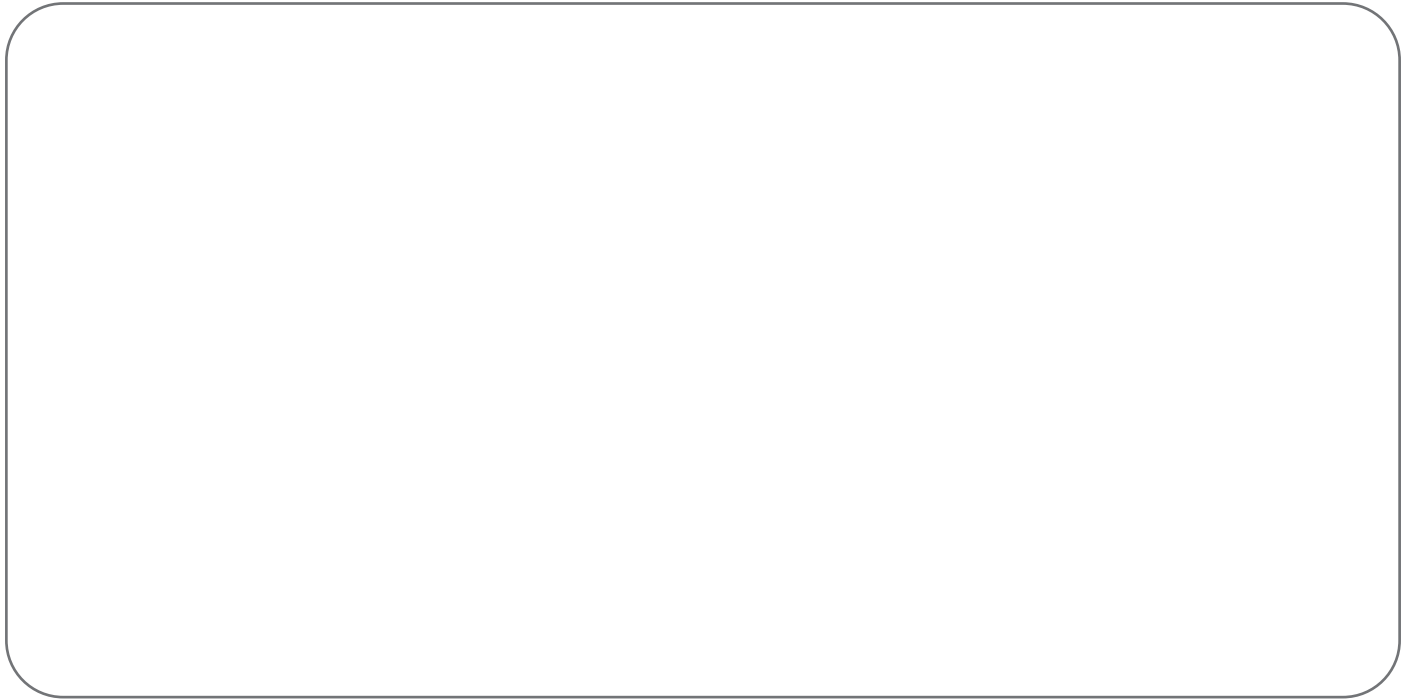
My other important consideration: _____

Not
concerned   Somewhat
concerned   Extremely
concerned

_____

Not
concerned   Somewhat
concerned   Extremely
concerned

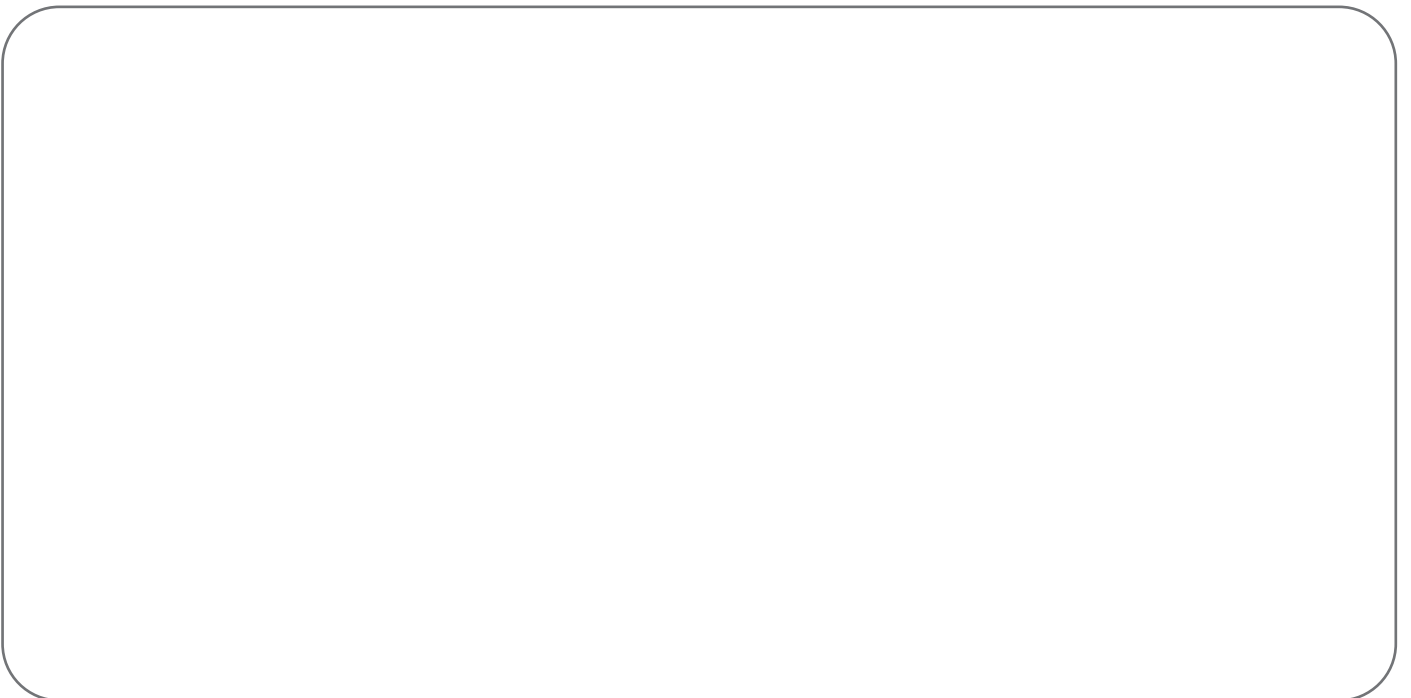_____

Not
concerned   Somewhat
concerned   Extremely
concerned

In what ways can a partner, friend or family member support me with this

Additional notes

About me

When is the right time for me to have a baby?

Factors that may affect this decision will be different for everyone. Here are some things that may be important to consider:

- Your age
- The right time for you in terms of your career or your relationship
- The support system you have around you
- Your mental and physical health
- Financial factors
- Housing factors

Who can I talk to that can help me make a decision?

There may be pre-conception consultations available to you from a perinatal mental health service. A good place to start is discussing what services are available in your area with your GP.

It will be helpful to discuss your thoughts and feelings with those close to you. Many women also find it helpful to access peer support services through third sector organisations.

How might childbirth impact on my mental health?

Mental health conditions are common during pregnancy and within the first year of giving birth (the perinatal period), affecting more than 1 in 10 women (10%).

An episode during pregnancy or after having a baby may be the first instance of mental illness for some women, while others may have experienced a previous mental health condition.

In this section we will first look at the mental health conditions that women may experience in pregnancy or in the postpartum. We can't discuss all episodes in detail, but we will cover the baby blues, postnatal depression and postpartum psychosis.

Following this, we will then consider the particular issues for women with bipolar or who have experienced a previous postpartum psychosis.

If this is the first time you have thought about these issues, it may all feel a bit daunting. It's good to have all the relevant information when making the difficult decisions covered in this guide.

Discussing your situation with the clinicians involved in your care will help you better understand your individual chances of becoming unwell and the best ways to help you stay well.

Although the numbers we discuss below may feel scary, remember most women with bipolar or previous postpartum psychosis faced with these decisions will go on to try for a baby, and even if they become unwell, they will recover and go on to be great mothers.

While it's important to plan for all situations, it's also important to remember that even with early planning, you may still experience issues with your mental health.

This is not your fault and it's important not to blame yourself.

It's important that early symptoms of more serious mental illnesses such as postnatal depression or postpartum psychosis are not dismissed as 'baby blues'.

If you or those close to you are unsure about your symptoms, it's best to ask a professional to assess you. More serious mood episodes can begin suddenly and can get worse quickly.

Postnatal blues or 'baby blues'

The 'baby blues' are a normal reaction to having a baby, affecting more than 50% of women, and don't require treatment.

Symptoms can include feeling a little down, tearful or irritable and having difficulty sleeping.

Symptoms usually start within two to three days after giving birth and come to an end within 10 to 12 days after birth without requiring treatment.

For women with symptoms that last longer than this, it's important to have further assessments as around 20% of women with the baby blues go on to develop postpartum depression within the first year following childbirth.

> **"** *I think it is all in the planning - knowing what the options are, knowing what treatments work for you and having plans in place. It's like planning for the worst and hoping for the best.* **"**

A woman planning for a second pregnancy
after experiencing postpartum psychosis

Postnatal depression

Postpartum psychosis is one of the most severe episodes of illness that can occur following childbirth. It is much less common than postnatal depression and affects 1 in every 500 to 1,000 births. As we will discuss later, it is much more common in women with bipolar or who have previously experienced postpartum psychosis.

Postpartum psychosis can begin suddenly, often within a few days or weeks of giving birth.

An episode of postpartum psychosis usually lasts between 2-12 weeks. It may take longer, up to 6-12 months, for you to recover fully and feel your normal self again. Women may also experience a period of depression, anxiety and low confidence following the initial period of psychosis.

It's important to remember though, that most women do make a full recovery.

These are some of the symptoms of postnatal depression:

- Feeling low, unhappy and tearful for much or all of the time
- Feeling anxious or irritable
- Having trouble sleeping, even when your baby sleeps
- Having a poor appetite or comfort eating
- Feeling unable to enjoy anything
- Feeling that life isn't worth living
- Difficulty bonding with your baby
- Difficulty concentrating or making decisions

Treatment

The choice of treatment for postnatal depression depends on how severe the symptoms are and individual choice.

Improving sleep habits, reducing stress, and eating healthily and exercising can all help to improve mood. Spending more time with friends, and connecting with people can help with symptoms of depression. For many women, however, more specific help is needed.

A range of treatments are recommended for postnatal depression -from measure such as "pram walking" to psychological therapies such as cognitive behavioural therapy (CBT) and medication such as antidepressants.

More rarely, if symptoms are very severe or if other treatment hasn't worked, electro-convulsive therapy (ECT) may be considered.

Antidepressant medications may be particularly helpful if symptoms are severe or if a woman has not responded to psychological treatments alone.

For women with a diagnosis of bipolar, an episode of depression may need to be treated differently as antidepressants alone may not be as effective and may lead to a high episode or cycling between high and low mood.

It's important to discuss your individual situation with a healthcare professional.

You can find more information by searching treatment for postnatal depression on the NHS website: **nhs.uk**

In women with a history of bipolar or postpartum psychosis however, it's important that any mood symptoms in the postpartum period are taken very seriously and help is sought quickly.

For women with a diagnosis of bipolar, an episode of depression may need to be treated differently.

Postnatal anxiety

Postnatal anxiety affects around 1 in 10 women. Around half of women who experience postnatal depression will also experience postnatal anxiety.

Symptoms of postnatal anxiety include worrying beyond the normal concerns of a new mum.

This can include persistent, generalised worry and more focused worrying relating to the health, wellbeing or the safety of their baby.

Other mental health conditions during pregnancy and after birth

There are many other mental health conditions that can occur during pregnancy and after giving birth.

 These include anxiety, obsessive compulsive disorder (OCD), post- traumatic stress disorder (PTSD), as well as depression or psychosis occurring in pregnancy itself.

You can find more information by searching mental health conditions on the Tommy's website: **tommys.org**

Postpartum Psychosis

Postpartum psychosis is one of the most severe episodes of illness that can occur following childbirth. It is much less common than postnatal depression and affects 1 in every 500 to 1,000 births.

As we will discuss later, it is much more common in women with bipolar or who have previously experienced postpartum psychosis.

Postpartum psychosis can begin suddenly, often within a few days or weeks of giving birth.

An episode of postpartum psychosis usually lasts between 2-12 weeks. It may take longer, up to 6-12 months, for you to recover fully and feel your normal self again.

Women may also experience a period of depression, anxiety and low confidence following the initial period of psychosis.

It's important to remember though, that most women do make a full recovery.

" *Within days of being at home, after two sleepless nights at hospital, I started accelerating into mania, but very different to episodes I had experienced before. I was very anxious and irritable one minute, singing and laughing the next, unable to sleep or relax; becoming paranoid and hallucinating... it was several more weeks before I felt "well" again.* "

A mum with bipolar

These are some of the symptoms of postpartum psychosis:

- Feeling high, manic or 'on top of the world'
- Low or depressed mood and tearfulness
- Rapid changes in mood involving a mixture of feeling extremely happy or high and as well as feeling low and depressed

- Severe confusion
- Feelings of fear, anxiety and irritability
- Experiencing racing thoughts
- Being more talkative or sociable than usual
- Having trouble sleeping or not wanting to sleep

- Psychosis - for example losing touch with reality and having trouble telling what is real and what is not. Symptoms of psychosis include delusion and hallucinations:

  - Delusions involve a person being convinced that something is true, even when it's not. Examples include thinking that people are out to get you and your baby

  - Hallucinations involve hearing, seeing, feeling or smelling things that are not really there. For example, hearing voices that other people can't hear or seeing people that aren't really there.

If you have postpartum psychosis, you may not realise that you're ill and it may be a partner, family or friend that is worried about you and seeks help.

Treatment

Postpartum psychosis is a serious condition and needs immediate assessment and treatment, in most cases in hospital.

National guidelines recommend that women who require in-patient care for a mental health condition during late pregnancy up to 12 months postpartum should be admitted to a specialised Mother and Baby Unit (MBU). You will find more information about MBUs on page 36-37.

Episodes of postpartum psychosis, at least in the initial stages, are usually treated with medication. Psychological support is important as well, particularly in the recovery phase.

You can talk to other women who have recovered from postpartum psychosis through Action on Postpartum Psychosis' (APP) peer support service (app-network. org). APP and Bipolar UK (bipolaruk.org) also have online peer support forums where you can read other people's posts or write your own for support from other members and volunteers.

Women are likely to take medication for the first 6-12 months following recovery from an episode, or longer in order to keep well. Medications used to treat postpartum psychosis include antipsychotics, mood stabilisers, antidepressants and sleeping tablets.

More rarely, if symptoms are very severe or if other treatment hasn't worked, electro-convulsive therapy (ECT) may be considered. You can find more information about ECT on the Royal College of Psychiatrists website.
Search for: Electroconvulsive therapy
rcpsych.ac.uk/mental-health

Early, well-planned care is likely to help women to recover more quickly. You can find more information about treatment for postpartum psychosis and recovery in the Action on Postpartum Psychosis (APP) 'Insider Guides' which can be found on their website:
app-network.org

Bipolar, postpartum psychosis and childbirth

Women with experience of bipolar or previous psychosis are more likely to become unwell during pregnancy or in the year after giving birth compared to those who have not experienced these conditions.

In the final part of this section, we look at the chances of becoming unwell in pregnancy and following childbirth if you have experienced bipolar or postpartum psychosis.

For most women, it's the days and weeks after the baby is born that are a particular time of risk. However, other women may become unwell during pregnancy, particularly if medication has been stopped to try for a baby.

Although we can talk in general terms here about the chances of becoming ill, all women are different and it's important to discuss with the clinicians involved with your care your individual risks. This will help you plan ahead to reduce the chance of becoming unwell, and to think about the care you may receive if you do become unwell.

It's very important to bear in mind that while some women with bipolar or previous postpartum psychosis become unwell during pregnancy or after childbirth, many will remain well during this time.

It's important to think positively while doing what you can to keep well.

What if I have a diagnosis of bipolar or have experienced previous postpartum psychosis?

If you have a diagnosis of bipolar, there is an increased chance of becoming unwell in pregnancy and particularly after the baby is born.

The chance of experiencing an episode of postpartum psychosis is higher for women with bipolar (200 in 1000 or 20%) compared to the general population (1 in 1000 or 0.1%).
In addition, there is a further chance of experiencing depression during pregnancy or the postpartum period (around 250 in 1000 or 25%).

If you have a diagnosis of bipolar, therefore, your overall chance of becoming unwell with postpartum psychosis or postnatal depression is around 450 in 1000 or 45%.

Alternatively, you can think of this as around 550 in 1000 or 55% chance of staying well.

The type of bipolar episodes you have expe rienced is important, however. These figures are for women with Bipolar I, that is women who have experienced a severe episode of high mood (mania).

The risk of postpartum psychosis is lower in women with Bipolar II, that is women who have experienced less severe high episodes (hypomania). In women with Bipolar II, the risk of postpartum depression may be higher, so the risk of experiencing some form of perinatal mood episode is also high.

If you have previously experienced postpartum psychosis, your chance of experiencing a further episode of postpartum psychosis following another pregnancy is higher (around 400 in 1000 or 40%).

Again, there is the risk of an episode of depression in pregnancy or following delivery, so the overall chance of becoming unwell may be around 500 in 1000 or 50%, or higher.

It's important to remember that you can also think about this as a 500 in 1000 or 50% chance of remaining well.

What else may influence my chances of becoming unwell?

These are only approximate figures, however. It will be important to discuss your individual chances of becoming unwell with your healthcare professionals.

There are many other factors that may be impact on your chances of becoming unwell. For example, if a sister or your mother had an episode of illness following childbirth, this may increase your risk.

Other factors that may be important are how well you are going into the pregnancy, and the number and severity of your past episodes.

We also know that the type of bipolar you have is important, as discussed above.

Whilst reading through these figures may feel daunting, it may help you to make choices that are right for you when planning a pregnancy.

In sections 3, 4 and 5, we discuss support (professional and support network), medication and self-management strategies that you may like to think about.

Considering these and thinking about what has helped you to stay well in the past, may reduce your chances of becoming unwell.

There's a good chance now that I know and understand the condition so much better that I might stay well, and yes there is a strong chance that I could get ill, but at least if I do we'll be prepared.

A woman planning for a second pregnancy after experiencing postpartum psychosis

Key messages

- It's important to be able to tell the difference between postnatal depression and postpartum psychosis, and the mood changes that women experience as part of the 'baby blues' that are normal after having a baby.

- Postpartum psychosis is a serious mental illness and should be treated as a medical emergency. Postpartum depression may also be very severe - all episodes of illness need to be taken seriously in women with a history of severe mental illness.

- It's important to plan and make decisions in advance in case you become unwell.

- Early planning is helpful but sometimes isn't enough to stop you from becoming unwell.

- It's not your fault if you become unwell with your mental health during the pregnancy or in the postnatal period. Women can become unwell even with the most careful planning.

What support may I receive during pregnancy and after having a baby?

3

During your pregnancy you will have several different healthcare professionals involved in the care of your physical and mental health.

It will be important for all healthcare professionals to know about your mental health history, including those who are firstly concerned with your physical health, such as your midwife.

You will find 'About me' questions at the end of this section to fill in with information about yourself. You may want to share this with those involved in your care.

You may develop a care plan during pregnancy with your healthcare professionals, detailing the care that you will receive.

The care plan may be given to you and shared with all health professionals involved in your care.

What appointments should I expect during pregnancy?

If you have a current or previous history of a severe mental health condition, you may expect more appointments compared to other women. This will be to ensure that your mental health is considered when planning your care.

Maternity health appointments

You will have regular antenatal appointments to check the health of you and your baby.

Antenatal appointments are important for keeping an eye on how your baby is growing and checking the health of your baby through blood tests and ultrasound scans. They are also important to monitor your health and pick up conditions such as pre-eclampsia.

You can book an appointment with your GP or directly with your midwife as soon as you find out you're pregnant.

Many women will have midwife led care, but some women may be under the care of an obstetrician (doctor specialising in pregnancy).

'Booking in' appointment - 8-12 weeks

Once you know you are pregnant, you should contact a GP or midwife to arrange this as soon as possible.

Antenatal appointments - throughout pregnancy

If you're pregnant with your first baby, you'll have more appointments than women who already have children. Some women may receive extra appointments in certain circumstances. Antenatal appointments may take place at a GP surgery, hospital, other community settings or in your own home – ask your local team what is available for you.

Ultrasound scans - 8-14 and 18-21 weeks

You will receive a 'dating scan' at around 8-14 weeks to see how far along in your pregnancy you are and to check your baby's development.

All pregnant women are offered a 'mid-pregnancy' scan at around 18 to 21 weeks of pregnancy to check for some physical conditions that your baby may have.

Some women are offered more than two scans which depends on their health and their pregnancy.

If you are taking medication during pregnancy, you may be offered additional scans to make sure that your baby is developing normally.

Mental health appointments during pregnancy and after birth

It's important that you are given the opportunity to discuss your mental health and the treatment and care options available to you.

Even if you are well at present, it's a good idea to be seen by a mental health team. If you have been well and are pregnant, now may be a good time to ask about a referral back to a community mental health team or a specialist perinatal team if available.

You may be referred to the perinatal mental health team if there is one in your local area.

This is a mental health team specifically for women planning a pregnancy, pregnant women and new mothers. You should ask your GP about what's available in your area.

If there isn't a perinatal mental health team in your area, you may be referred to a community mental health team (CMHT) if you are not already under their care.

Healthcare professionals involved in your usual antenatal care, such as your GP and midwife, will also be involved in your mental health care.

Other appointments

You will be offered additional appointments throughout your pregnancy.

You can find more information about when to expect your appointments are and what each one will involve on the NHS website. Search for **Your antenatal appointments** on**:**
 www.nhs.uk

What is a perinatal mental health service?

A perinatal mental health service is for women with mental health conditions who are either planning a pregnancy, pregnant or have given birth in the last year.

The aim of a perinatal mental health service is to help you stay as well as possible during pregnancy and the postpartum period and to help and support those close to you, such as a partner or family member.

Ideally, all women with a severe mental health condition should have access to specialist perinatal mental health care during pregnancy and after giving birth.

While access to specialist perinatal mental health services has improved in recent years, there are still some local areas where access to these services are limited.

To find out what is available in your local area, speak to your GP or midwife who will be able to tell you what services are available to you.

You can also see the progress in perinatal mental health service availability here: everyonesbusiness.org.uk

How can a perinatal mental health service help me?

Perinatal mental health services can provide you with specialist advice about a wide range of mental health conditions during the preconception period, pregnancy and after birth.

If you have a current or previous severe mental health condition, you may be offered a one-off appointment with a perinatal mental health specialist when planning a pregnancy.

Perinatal mental health services offer the following:

- Advice about your chance of becoming unwell during pregnancy or after giving birth. They will also be able to help you with trying to reduce your chance of becoming unwell.

- Discussing what services will be available to you during pregnancy and after birth.

- Medication reviews and advice relating to medication use during pregnancy and breastfeeding.

- Psychological treatments, such as talking therapies, group therapies and 'parent-infant' therapies during the postpartum period.

- Working with you to plan for your care throughout the perinatal period.

- Providing a partner or family members with information about your mental health condition, your chance of becoming unwell and how they can support you during this time.

- Referring you to other services which may help you, such as third sector organisations.

- Arranging an admission to a Mother and Baby Unit (MBU) if you become unwell after giving birth.

- They may work with other healthcare professionals involved in your care.

Pre-birth planning meeting

This appointment at around 32 weeks of pregnancy will involve developing a plan help keep you as well as possible during pregnancy and after birth and make sure that everyone involved in your care is aware of what's been decided.

Not everyone will be offered a pre-birth planning meeting. This will depend on the service offered in your area and your individual circumstances.

For more information about Perinatal Mental Health Services, the Royal College of Psychiatrists have developed a leaflet on Perinatal Mental Health Services.

Search for: **Perinatal Mental Health Service rcpsych.ac.uk/mental-health**

What is a Mother and Baby Unit?

If you become unwell during the perinatal period, you may be treated in a Mother and Baby Unit (MBU). An MBU is an inpatient service for new mothers with severe mental health conditions which is designed to keep mothers and their baby together. Although units may differ, women can usually be admitted during late pregnancy up until one year after giving birth.

MBUs offer treatments including medication and psychological therapies such as cognitive behavioural therapy (CBT) and group therapies.

MBUs may also offer additional activities such as cooking, arts and crafts, baby massage and relaxation activities. Staff are available on the ward 24 hours a day, every day, meaning that you and your baby are always looked after and that you are supported to care for your baby.

All staff will have specialised knowledge and experience in caring for women with severe mental health conditions during the perinatal period and their babies. The team of professionals who work on an MBU usually include a psychiatrist, perinatal mental health nurses and nursery nurses, psychologists, occupational therapists and a pharmacist.

An MBU will also work closely with the perinatal or community mental health service, maternity service and health visitors involved in your care.

> *The MBU was my home from home, I felt safe and cared for and most importantly I was reunited with my baby, who I was apart from when in a general ward in the early days of my illness. I didn't realise it at the time because I wanted to be at home but I couldn't, I was too unwell. Looking back I'll be forever grateful to the staff who cared for me, my baby and my husband and helped our family in that time.*

Experience of a woman admitted to a MBU with postpartum psychosis

Things to think about with a Mother and Baby Unit

It will be worth discussing with the healthcare professionals involved in your care about what would happen if you needed to be admitted during the perinatal period, and whether an MBU would be an option for you.

MBUs can usually offer a visit to you and a partner or family member before you go in, although this may not be possible if you need to go in as an emergency.

While MBU admission is the gold standard care for new mothers with severe mental health conditions, unfortunately, there may not always be a bed available for when you need it.

Although there has been an increase in the number of beds at MBUs in the UK over the last few years, numbers are still limited meaning that other options may need to be considered, such as being under the care of a home treatment team or receiving inpatient treatment in a general psychiatric ward.

This website can be used to check the availability of beds at all MBUs in the UK and the likelihood of a bed becoming free in the near future: **nhswebbeds.co.uk**

Some women are treated in a general psychiatric ward while waiting for an MBU bed to become free. Some women and their partner or family decide to receive inpatient treatment in a general psychiatric ward because of how far the MBU is from their home.

It's a very personal decision and it's important to discuss your preferences and the options available to you in advance with a partner or family and professionals involved in your care.

For more information about MBUs, the Royal College of Psychiatrists have developed a leaflet on MBU's.

Search for: **Mother and Baby Units rcpsych.ac.uk/mental-health**

Will I be referred to social services?

It's important to say that the majority of women with bipolar or previous experience of severe postpartum episodes go on to be great mothers with an excellent relationship with their babies.

Professionals have a responsibility to make sure you and your baby are safe, however, and some women may need a referral to Children and Families Social Services.

It's normal to be anxious about this and some women worry that a referral means that people think they can't care for their baby. This isn't usually the case.

Social Services assessments are to establish whether women have the support they need from family, friends and professionals.

If you have less support than is needed, Social Services may be able to identify where you can get more help.

Some women will be referred in pregnancy because of their high risk of a severe postpartum episode.

Social Services will want to check what support you have from family, friends and professionals and make sure there is a safe plan in place for your baby if you become too unwell to care for them.

Some women worry about sharing that they are unwell with professionals, but this shows that they are taking positive steps to look after themselves and their baby as best they can.

Things to remember:

- The main aim of Social Services is to check that you have the help and support that you need and that you are ok.
- Social Services prefer to keep families together and will never take a baby into care just because the mother has a mental illness.
- Although it might take a while, most women recover fully from a postpartum episode of mental illness. It's rare for babies to be removed from women with bipolar or postpartum psychosis.

If you want to read more about this:

Visit Tommy's – a website providing information for parents to be.

**Why do social services want to check on me after I've had baby
tommys.org/pregnancy-information**

How can third sector organisations help me?

You may find it helpful to look into other support that may be available to you, such as those offered by third sector organisations.

Action on Postpartum Psychosis (APP) is a national charity that supports women and their families who are affected by postpartum psychosis.

They offer a range of services including a peer support service so that you can talk to other women and partners that have 'been there', through their online support services.

You can find out more information here **app-network.org/peer-support**

They also have an online community forum which you can access following this link: **app-network.org/pptalk**

APP have produced a series of guides with the help of women that have experienced PP and their partners which you can access here: **app-network.org/what-is-pp/app-guides/**

Bipolar UK is a national charity that supports individuals with a diagnosis of bipolar, their families and carers.

They have a peer support line **bipolaruk.org/support-line** and an online forum for those affected by bipolar **bipolaruk.org/ecommunity**

You can join their Pregnancy and Parenting e-forum where there's a pregnancy thread for women thinking about having children or already pregnant to talk to each other: **ecommunity.bipolaruk.org/**

They also offer a range of services including support groups across England, Wales and Northern Ireland.

Support from partner, family and friends

A partner, family members or friends may also play important roles in supporting you during your pregnancy and after birth.

Having someone who knows about your mental health history and what your symptoms can look like will be helpful. The 'About me' dotted throughout the guide are designed to be shared with others.

This section includes practical suggestions on how a partner, family member or friend can help support you during this time in Section 5 ('How can I help myself stay well' page 65) and Section 6 ('What do partners, family and friends need to know?' page 77).

Key messages

- All your healthcare professionals should be aware of your mental health history, even those who are mainly looking after your physical health.

- The availability of perinatal mental health services differ across the UK. You should ask your GP what specialist perinatal mental health services are available in your area.

- In addition to NHS healthcare services, third sector organisations such as Action on Postpartum Psychosis (APP) and Bipolar UK offer services to help you and your partner, family or friend during the perinatal period.

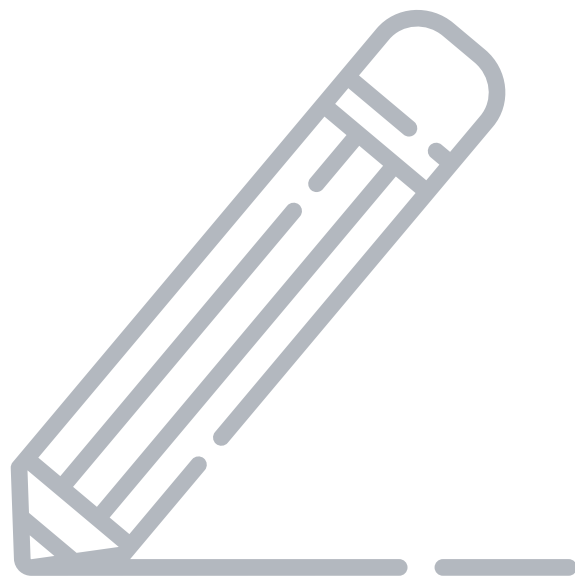# About me

Previous episodes of mental illness

Information about previous episodes of mental illness can help predict and plan for future episodes.

It will be helpful for your healthcare professional to be aware of your mental health history as you make plans and decisions relating to your pregnancy and after you have your baby.

This section is for you to write about previous episodes of mental illness that you have experienced.

You will see that you have the option of either writing about these by filling out a life chart or by writing in the note boxes.

Do what works best for you.

About me

Drawing a life chart

A life chart can be useful to visualise your history, and see if there are any associations or triggers to your mood episodes.

Before you start you may find it helpful to make some bullet points or notes about important things that you'll be including in your life chart.

Drawing a life chart might not be right for everyone – if you prefer to make a few notes instead, that's fine – do whatever works for you.

Below is an example of a filled-out life chart. Your life chart may be more or less detailed than this.
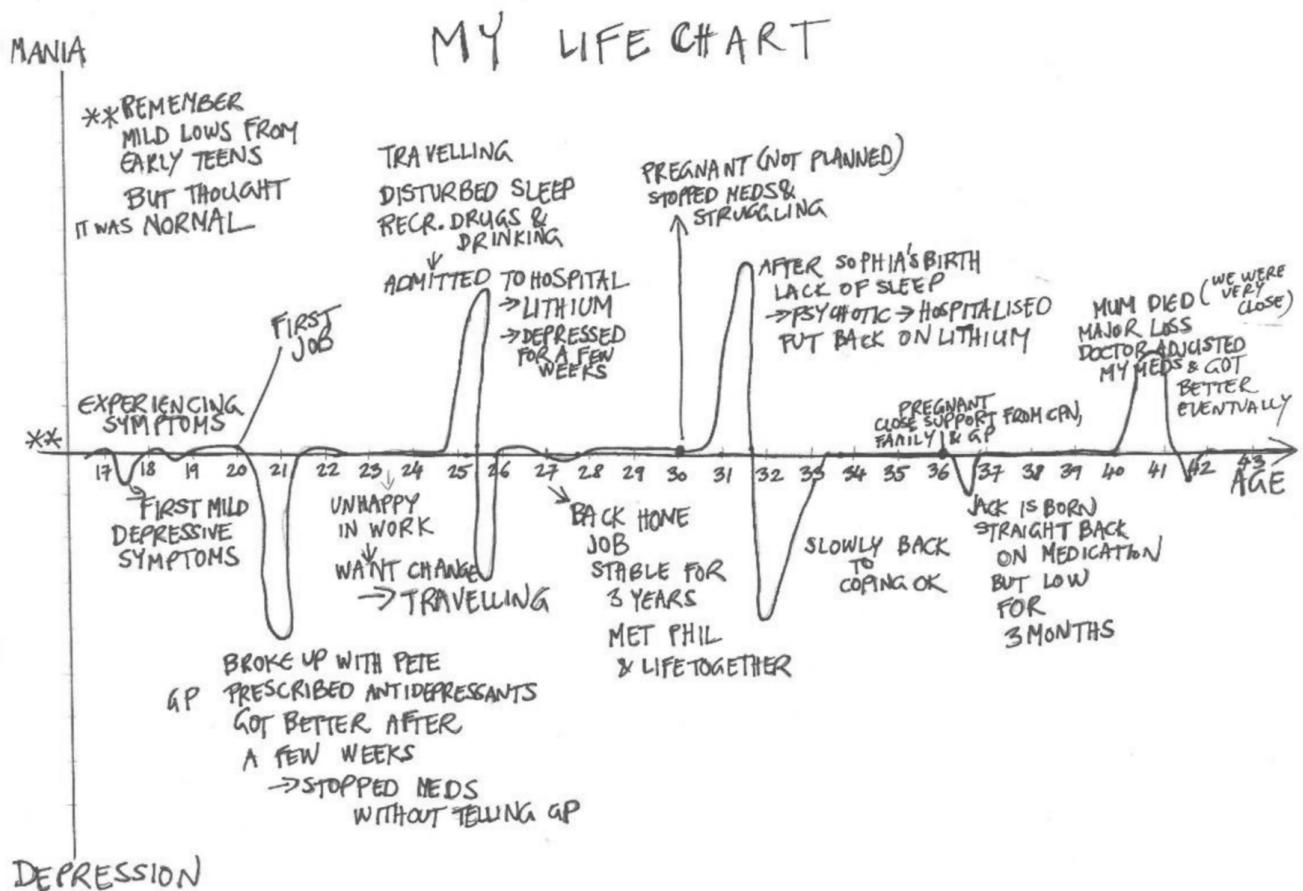
Here are some suggestions on what you can include in your life chart:

- How old are you now?

- How old were you when you first experienced problems with your mood/mental health?

- At that time, do you think you had depression (low mood) or mania (high mood) or something else?

- On a scale of 0-10 how severe was this episode (for example, needing to go into hospital would score a 10, needing to start on medication would score a 5, a definite change from normal, but without many problems would score a 1)?

- Roughly, how long did this episode of illness last?

- Were there any possible triggering factors?

- Did you require treatment? Were you treated as an outpatient or an inpatient?

- Were you treated with medication or psychological therapies?

- How old were you when you next experienced serious problems with your mood, including any previous episodes during pregnancy or after birth?

- Repeat this process for any other episodes, and write down any other major life events you would like to include.

- Have you noticed any effect on your mood from use of contraception or hormonal treatments?

Notes for life chart

Mania

Age

Depression

J

Previous episodes of mental illness

What mental health conditions have you experienced (not related to pregnancy and childbirth)?
e.g. number of episodes, diagnoses, medication and/or treatment received

What mental health conditions have you experienced (not related to pregnancy and childbirth)? continued...

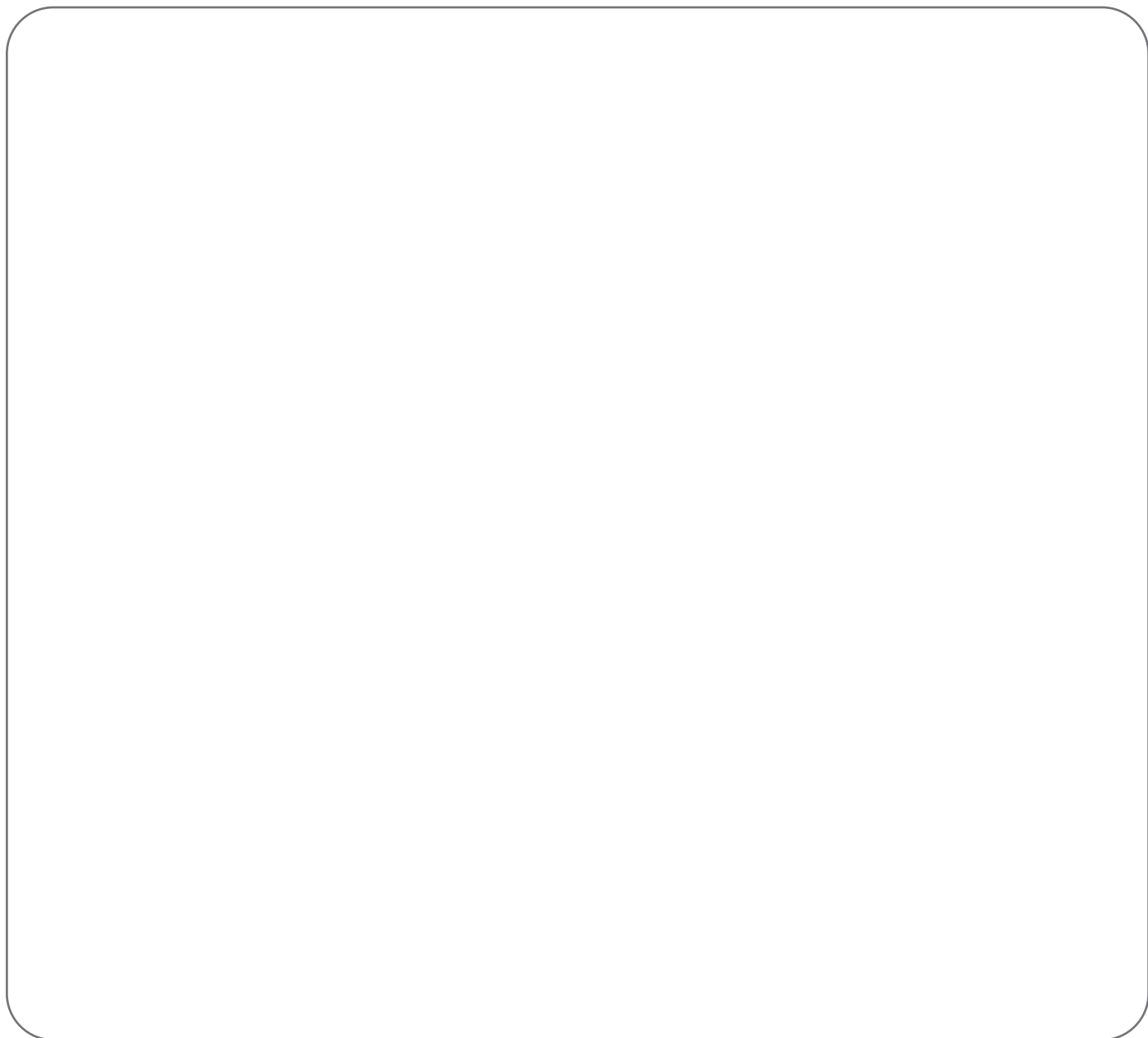# Previous episodes of mental illness during pregnancy or after birth

Information about previous episodes of illness in pregnancy or after having a baby, if this is not your first pregnancy:

- Have you previously experienced any mental health episodes during pregnancy or after birth?
- How severe was the episode? Did you require treatment?
  - Were you treated as an in-patient or an outpatient?
  - Were you treated with medication?
  - Were you treated with medication immediately after birth?
- Did you experience psychosis during the episode?
- How long did the episode last?
- Did the episode affect your ability to function? In what way?

Family history of mental illness

Has your mother or a sister experienced bipolar or postpartum psychosis?

Write any information that you know about their symptoms, episode severity or the treatment that they received below:

Knowing your chances of becoming unwell during the postpartum period can help you to prepare as best you can in advance.

What do I need to know about medication and pregnancy?

Women with bipolar or previous postpartum psychosis have many important decisions to make when planning a pregnancy.

These include deciding whether to stop, switch or continue medication, with all these options having possible risks and benefits.

There are many different factors that you will need to consider when weighing up the benefits and risks of taking medication during pregnancy.

Women not currently taking medication will also have decisions to make on whether or not to take medication during pregnancy and after birth.

Whether a particular medication is safe to use during pregnancy is often not an easy question to answer.

No medication can be guaranteed completely safe to use during pregnancy and when breastfeeding.

There is still a lot that is unknown about the safety of medication and new information is coming out all the time.

This can make it very difficult to make decisions. It will be important to consider your own preferences in relation to using medication and managing your condition.

Because what we know about the safety of medication is changing constantly, a detailed review of each medication isn't possible in this guide, however this section will cover information for you to consider when making these decisions.

A key point to make here is that there are no right or wrong answers when it comes to deciding whether to take medication – it's a very personal choice.

What if I find out I'm pregnant unexpectedly while I'm on medication

It's very important that you don't stop taking your medication suddenly as this can increase your chances of becoming unwell.

Contact your healthcare professional as soon as you find out that you're pregnant so that they can talk through your options and help you decide what to do.

Weighing up the risks and benefits of taking medication

It's important that you come to the decision that feels right for you. Following discussion with your health care professionals, it will be a matter of weighing up the risks and the benefits of all the options available to you.

- **What are the possible risks of taking medication?**
  Some medication used to treat bipolar may carry risks when you are pregnant and breastfeeding. This includes a greater chance of the baby experiencing problems – during pregnancy and birth or later in childhood.

  These can include problems evident at birth such as heart defects, or disorders that can affect learning, emotion or memory that become noticeable later in childhood. The increased risk for these effects are often small and should be discussed in detail with your healthcare professional.

- **What are the possible benefits of taking medication?**
  We tend to focus, understandably perhaps, on the risks of medication but stopping medication also has risks. There may be risks to your baby from becoming unwell in pregnancy and taking medication may reduce the risk of becoming unwell.

Sodium valproate

Although every medication can't be discussed in this guide, there is one medication which can cause particular issues in pregnancy.

Sodium valproate, also called valproic acid is a medication used for bipolar and also as an anticonvulsant in people with epilepsy.

There's a lot of evidence suggesting that sodium valproate can cause harm to the baby if taken during pregnancy.

This includes the baby having a birth defect such as spina bifida (where the bones of the spine don't join up properly), cleft lip and cleft palate (where the upper lip or bones in the face are split) and abnormalities of the limbs, heart, kidney, urinary tract and sexual organs.

It can also cause problems with development, learning and memory that become noticeable later in childhood.

There are therefore particular concerns about taking this medication in pregnancy or when pregnancy is possible, when compared to other medicines that are used to treat bipolar.

Because of this, sodium valproate is not recommended for use in women who could get pregnant and they shouldn't be prescribed it unless alternative treatments are unsuitable and there is a pregnancy prevention programme in place.

If you are currently taking sodium valproate, speak with your healthcare professional about what other options are available to you.

For more information, visit the Best Use of Medicines in Pregnancy (Bumps) website which provides reliable and up-to-date information about sodium valproate: **medicinesinpregnancy.org**

Feeling guilty about taking medication during pregnancy

After considering all the alternatives, taking medication during pregnancy may be the best option for some women.

Unfortunately there is still stigma attached to this and many women feel guilty about making this decision.

Women have to take medication for many different physical and mental health problems in pregnancy and it's just as important to have the treatment you need for a severe mental illness as it is for a physical one. You may be doing the best thing for your baby to take medication if the alternative is potentially having a very serious episode of illness.

Every woman's situation is different and after careful weighing up of the pros and cons with their healthcare professional, there should be no shame attached to deciding that taking medication during pregnancy if it's the best decision for you and your baby.

Likewise, if, after careful consideration and talking it through with your doctor, your decision is to not take medication, that's ok too.

What's important is that you make the right decision for you and one you feel comfortable with.

> *I was determined in the planning stage that I would not take medication during pregnancy, and just use it immediately after birth. But in my 3rd trimester, after speaking to the perinatal psychiatrist who rated my risk of recurrence as very high and strongly recommended medication before the birth, I found myself reconsidering (albeit with tears!).*
>
> *It's definitely ok for women to change their minds and adapt plans. Things can feel very different towards the late stage of pregnancy when the possibility of illness is looming closer.*

A woman with lived experience of postpartum psychosis discussing her experience of making decisions about medication during pregnancy

Who can I discuss my options with?

It's important to discuss medication plans with the doctors prescribing for you - your psychiatrist, or GP for example, ideally before you become pregnant.

A pharmacist may also be able to give you information.

If you have a perinatal mental health team in your area, they may be able to offer you an appointment even before you are pregnant to discuss your options.

The options to consider are summarised in the box below.

Your options with medication and pregnancy:

If you are currently taking medication, there are three broad options that you will need to consider with the professionals involved in your care: no change, switch or stop

- **No change -** continue your current medication through pregnancy and after birth
- **Switch -** stop one or more of your current medication and start another medication(s)
- **Stop -** come off your current medication

  There are two options if stopping:
  - To stop taking medication throughout the pregnancy and after the baby is born – restarting only if you become unwell

  - To stop taking medication and then restart medication later in the pregnancy or after birth to help keep you as well as possible

There are also options for you to consider if you are currently not taking medication, including starting medication during pregnancy or after the birth to help keep you well or starting medication should you develop symptoms.

What about breastfeeding?

Most women with postpartum psychosis or an episode of bipolar during pregnancy or after birth need treatment with medication.

Small amounts of medication can be passed on to a baby in breast milk. It is however possible to breastfeed whilst taking a number of medications.

A perinatal psychiatrist or a specialist team will be able to talk through your options and discuss the risks and benefits of medications in breastfeeding with you.

It's possible that you won't be able to breastfeed if you need a medication which is not considered safe for breastfeeding. Some women feel guilty if they are unable to breastfeed, but you shouldn't feel this way.

If you become unwell with your mental health during pregnancy or after birth, it's not your fault. It's important for your baby that you have the treatment you need so that you get better.

The Choice and Medication website has advice on specific medications, their side-effects and whether they are safe for breastfeeding:
choiceandmedication.org/ncmh

Where can I find more information about using medication during pregnancy and while breastfeeding?

- **Bump (Best Use of Medicines in Pregnancy) leaflets**
  This website (provided by the UK teratology information services – UKTIS, a national organisation hosted by the Newcastle upon Tyne hospital NHS Foundation trust) provides reliable and accurate information about use of medication in pregnancy, in the form of freely available patient information leaflets.
  medicinesinpregnancy.org/Medicine--pregnancy/

- **Drugs and Lactation Database (LactMed)**
  The LactMed® database contains information relating to medication and breastfeeding.

  This includes information on the levels of the medication in breast milk and infant blood, and the possible risks to babies who are breastfed on certain medications. The information is based on information from scientific research articles.
  ncbi.nlm.nih.gov/books/NBK501922/

- **Royal College of Psychiatrists information on 'Antipsychotics in pregnancy and breastfeeding'**
  The Royal College of Psychiatrists provide user-friendly and evidence-based information on mental health and treatment, written by psychiatrists with help from patients and carers.
  Search for '**Antipsychotics in pregnancy**' and '**Lithium in pregnancy and breastfeeding**'
  rcpsych.ac.uk/mental-health

Questions about medication:

- What is known about the safety of each medication option?

- What is your mental health history?

- Have you been unwell before during pregnancy or after having a baby?

- How severe were your previous episodes?

- How long has it been since you experienced your last episode of mental illness and how well are you now?

- Your experience of medications – which medications have been effective, which less effective, which have led to side effects, what options have not been tried?

- Are you planning on breastfeeding?

Key messages

- Women with bipolar or previous postpartum psychosis have a number of options when thinking about medication and pregnancy. These options include stopping, switching, or continuing with the medication that they're on, with all these options having potential risks and benefits.

- Data on the safety of using medication during the perinatal period is sometimes limited and changes all the time, making it difficult for women to get the information they need and make decisions about medication.

- There is no right or wrong when it comes to deciding whether to take medication or not. It's important to discuss your options with a healthcare professional involved in your care.

About me

Your medication and treatment information

This section is designed to help you record information about treatments that worked for you, or did not work well. This will help you work with your healthcare professionals and partner or others supporting you when making decisions about pregnancy and birth.

Use the next pages to record your current medication and previous medications you have taken:

- Name of current medication - Dose - Date started	Any side effects?	Do they help?

- Name of previous medication - Dose - Date started and stopped	Any side effects?	Did they help?

About me

Psychological therapies

Have you received any psychological therapies e.g. cognitive behavioural therapy (CBT)?

- What have you tried? What helped? What didn't?

About me

What do I need to think about when making decisions about medication?

Making an informed decision about medication will involve considering your own thoughts and preferences alongside the evidence-based information and advice from your healthcare professional.

These decisions are not easy. These statements may help you to think about what you'd find helpful to talk through with your healthcare professional.
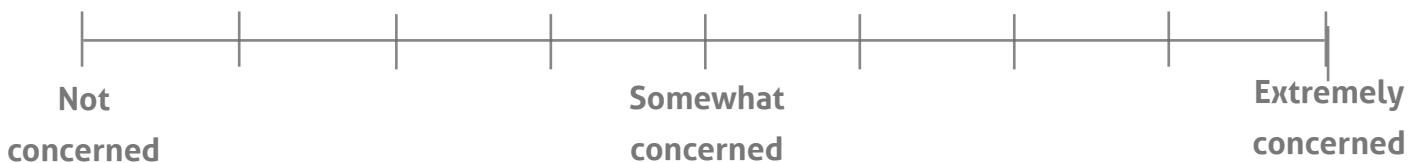
Consider the statements below - how do you relate to each one?

Put a cross on the scale at the point that best fits how concerned you are

Staying well during pregnancy may be less likely if I stop medication

Not concerned   Somewhat concerned   Extremely concerned
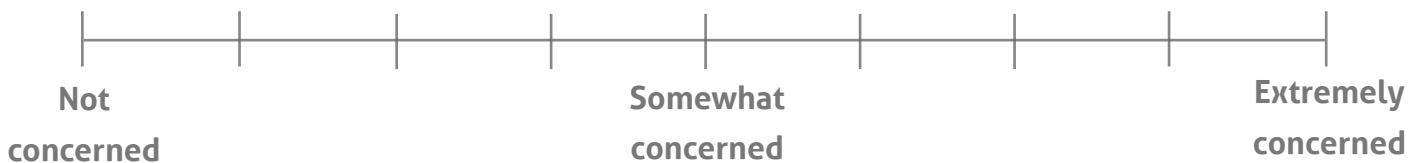
Not taking medication and becoming unwell in pregnancy may affect my baby

Not concerned   Somewhat concerned   Extremely concerned

Taking medication during pregnancy may be associated with some risks for my baby

Not concerned   Somewhat concerned   Extremely concerned

Needing to take higher doses or other medication if I become ill in pregnancy

Not concerned   Somewhat concerned   Extremely concerned

R

Are there any important considerations for you personally that are not listed here?

Use the blank scales or the note box below to write down your own personal considerations.

My other important consideration: _____

Not concerned	**Somewhat concerned**	**Extremely concerned**

_____

Not concerned	**Somewhat concerned**	**Extremely concerned**

_____

Not concerned	**Somewhat concerned**	**Extremely concerned**

_____

Not concerned	**Somewhat concerned**	**Extremely concerned**

_____

Not concerned	**Somewhat concerned**	**Extremely concerned**

About me

Notes

You can use this space to list questions and concerns when preparing for appointments. You can also make notes from the conversations with healthcare professionals during your appointments and outline your next steps.

How can I help myself stay well?

Working with your healthcare professionals will play a vital role in helping you to keep well.

This will include decisions about medication that are right for you. But there are other things you can do alongside this to help you keep well on a day-to-day basis.

This section includes suggestions on how to help yourself keep well during pregnancy and after giving birth.

Most of these suggestions are useful for women with bipolar to consider at any time.

Some of these suggestions are likely to be most useful for women with bipolar, however there are many suggestions that may be helpful to women with other mental health conditions.

It is important to note that these are suggestions, rather than essential strategies that you need to adopt. Some of these strategies may not be possible or appeal to everyone.

These are ideas that you can consider, but you shouldn't feel pressure to take them all on board.

66 *I decided to have a second baby when my eldest daughter was five. I was very well supported in this pregnancy – but as my due date loomed I was definitely more nervous. Being thoughtful about my own wellness helped me to recognise 'early warning' signs and put my plan into action.* **99**

A woman with previous experience of Postpartum Psychosis

Your support network

It will be helpful to start thinking about who you have around you for support and help during pregnancy and once your baby is here.

A partner, family or friends can help you to keep track of your mood and spot any early warning signs if you are becoming unwell.

Those close to you can help by providing practical support too. Here are some suggestions:

- Batch cooking and freezing meals in advance, so that you have meals that are easy to prepare during the first few weeks after giving birth.
- Helping around the house, for example cleaning and tidying.
- Looking after the baby while you sleep or have a break. For example, to have a walk outside on your own.
- Helping to look after older siblings.
- Providing transport if it's helpful for you to get out of the house, especially if you are unable to drive after giving birth.

Visitors

Those close to you can help to manage visitors during the first few days or weeks after giving birth. You may want to think about times of the day that best suits you for people to visit.

It may be helpful to make sure that you have enough time to rest in between visits.

Those close to you can explain to family and friends how important it is that you are getting enough sleep and rest.

Some visitors may be helpful however. For example, it may be helpful to arrange for a family member to look after the baby for a short time so that you can have a rest or some sleep.

Practical ways to prepare for when your baby is born

You may find it helpful to prepare for the early weeks after giving birth in advance, to help reduce the stress. Practical things that you can consider include:

- Arranging weekly supermarket deliveries.

- Batch cooking and freezing meals for yourself in advance.

- A convenient, but less cost effective option are meal delivery boxes. These are services that deliver fresh, pre-portioned ingredients and step-by-step recipes to your home. Popular services include 'Hello Fresh' and 'Gousto'. This is more costly than buying the ingredients yourself from the supermarket, so it may not be the best option for everyone.

- Planning self care for when your baby is here. You may want to share a plan of things that you can do to look after your wellbeing with those close to you. For example, this might be taking some time out for yourself each day to have a hot drink, a short walk or a bath while someone looks after your baby.

Avoiding major life changes

Pregnancy may be the time to avoid major life changes. For example, if you are thinking of moving house, it may be worth thinking whether you can postpone for a year or so, until you have had your baby.

Thinking about your physical health

It will be important to keep yourself well by not smoking or drinking, eating well and doing gentle exercise.

Dealing with stress

Sometimes you can't avoid stress. Unexpected things can happen during pregnancy and after the birth.

If you do experience stress during this time, it doesn't mean that you'll definitely become unwell. Or if you do become unwell, it doesn't mean that this was because of the stress that you experienced. It's important not to blame yourself if you become ill. However it may be worth thinking about how you can avoid stressful situations.

Find ways to relax that work for you - this will look different for everyone. You may find going for a walk, listening to music or having a bath helps. Or you may find it helpful to practice relaxation exercises, such as mindfulness, breathing exercises or yoga.

You can find an example of a simple breathing exercise on the NHS website. Search for 'ways to relieve stress': **nhs.uk**

The 'NHS Apps Library' includes a list of apps and online tools designed to help with managing your mental health. You can find this here: **nhs.uk/apps-library/**

Getting enough sleep

Sleep loss can trigger an episode of high mood during pregnancy and after birth. Women with bipolar or previous postpartum psychosis are likely to be more sensitive to the effect of sleep loss on their mood.

You will likely experience dramatic changes in your sleep pattern and sleep quality during late pregnancy and once your baby is here, so getting enough sleep may be something that feels difficult to achieve.

It's important to be realistic about how much sleep you will be able to get.

Here are some suggestions on how you can plan to get some extra sleep during late pregnancy and once your baby is here:

- Plan to get extra rest and sleep during pregnancy, especially during late pregnancy.
- Include sleeping arrangements in your care plan. It will be helpful for you to know the options available to you at your hospital and what your preferences are. For example, this could include requesting a single room after having your baby.

Feeding your baby

There are many ways in which women feed their babies, this includes breastfeeding, formula feeding or combination feeding.

A perinatal mental health specialist should be able to talk to you about your options, but it's your decision to make.

The benefits of breastfeeding are well known, but breastfeeding will also mean getting up in the night to feed your baby, which could make you more vulnerable to becoming unwell.

As discussed in the previous section on medication, breastfeeding isn't always possible.

You shouldn't feel guilty if you are unable to breastfeed or have chosen not to. It's important that you have the treatment that you need and are able to rest.

If you're planning on breastfeeding, establishing breastfeeding in the first few days can be very tiring and stressful. Make time for rests.

Some women decide to combine breastfeeding and bottle feeding. This is called combination feeding and involves feeding your baby bottles of expressed breast milk or formula alongside breastfeeding.

Women may decide to combination feed for a number of reasons, for example, as a way to share feeds with a partner.
If you are bottle-feeding and have a partner or family member that can help you, don't be afraid to ask for their help with feeding.

You can find more information on breastfeeding, bottle feeding and combination feeding by searching Feeding your baby on the Tommy's website: **tommys.org/pregnancy-information**

Night feeds

Support with night feeds may be needed because of the medication that you are on.

If you are taking antipsychotics after the birth, it's important to consider that some antipsychotics can cause drowsiness. This may make it difficult for you to wake in the night for feeds.

If you have someone that can support you with night feeds, you can ask for help with the feeds or nappy changing so that you can get some sleep. You may find it helpful to create a rota ahead of time so that it takes the stress away.

In addition to medication, sleep is also likely to be a factor that you think about when making decisions about whether or not to breastfeed your baby. Your decision will involve carefully weighing up the pros and cons.

Monitoring your mood and identifying triggers

If you have a diagnosis of bipolar, monitoring your mood is a useful way of recognising when you're becoming unwell.

This helps you to recognise the relationship between what's going on in your life and how this might affect your mood.

Monitoring mood symptoms is useful at any time for women with bipolar, and is also likely to be useful during pregnancy and after birth.

While monitoring your mood can be helpful, childbirth is a very powerful trigger and it may not be possible to avoid becoming unwell, even with the most careful monitoring.

Monitoring your mood can be something that you include in your weekly routine. For example, some people use a mood diary to keep track of their moods and write a short description or a score of how they're feeling each week.

Using a mood scale and diary

You may find it helpful to use a mood scale to help with your mood-monitoring. A mood scale helps you to describe your moods. Bipolar UK have an example on their website:
bipolaruk.org

Some people find it helpful to personalise their own mood scale based on previous symptoms they have experienced.
Mood diary templates are also available on the Bipolar UK website:
bipolaruk.org

You may also find it helpful to use an online mood management programme such as True Colours, which can be found on the Bipolar Disorder Research Network (BDRN) website:
bdrn.org

Lifestyle and triggers

Your lifestyle may act as a trigger for a mood episode, for example, disrupted sleep, stressful events, alcohol, work and relationship issues.

Some triggers are important for lots of people, such as too little sleep, whilst other triggers will be individual to you.

Some triggers may also be more important during pregnancy and following birth, such as sleep disruption, while others, such as work issues, may be less relevant.

Writing a list of early warning triggers and sharing this with your healthcare professional, partner or close family members may be helpful. You will find space to do this in the 'About me' pages following this section.

It may be helpful to ask your partner or someone that knows you well whether they are aware of anything that appears to be a trigger for you when you are becoming unwell.

Key messages

- There are some things that you can do to help yourself stay well alongside working with your healthcare professional. For example, monitoring your mood and planning support and time for yourself after the birth of your baby.

- Some of these suggestions are likely to be particularly useful for women with bipolar.

- Childbirth is a very powerful trigger and because of this, it may not be possible to avoid becoming unwell. By doing all you can to prepare, you're giving yourself the best chance of staying well.

- If you do become unwell, it's important to try not to feel guilty and to focus on getting better

About me

Early warning signs that I'm becoming unwell

Looking back at times where you've been unwell with your mental health, you may have noticed certain thoughts, feelings or behaviours that emerge early on in an episode.

Recognising these early warning signs and sharing them with those you are close to may help you get help quickly when you're becoming unwell. Write these in the box below.

If you are unsure if you experience any warning signs, you could talk to others around you and ask if they noticed any warning signs, or what they think the first symptoms you experience are.

You could also take a look at information about symptoms in Section 1 of this guide ('How might childbirth impact on my mental health?' page 9)

Early warning signs

My personal triggers

Have you noticed anything that you feel triggered previous episodes? If you have experienced postpartum psychosis, was there anything else that you feel increased your risk of becoming ill? Write these here:

e.g. getting less sleep, changes in medication

You may want to think about times when you have been at your most stable in your mental health

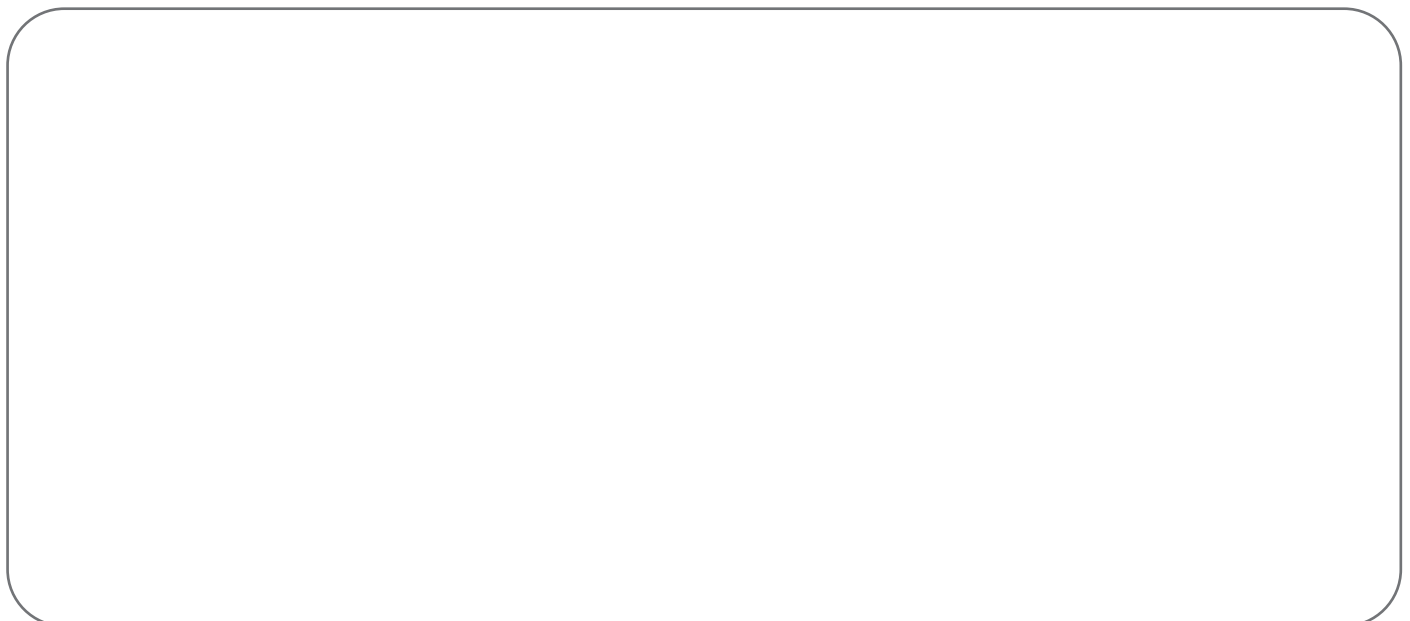*What were the things that may have helped keep you well?*
Was this a particular medication? Or were there other things like practising self-management, mood monitoring or making changes to your lifestyle that could have been important?

Use this box to write down anything you feel may have helped you to keep well:

Notes

Is there anything that you are planning to put in place or prepare?

W

What do partners, family and friends need to know?

This section is for the partners, family and friends.

This section includes information on what to consider when supporting your partner before pregnancy, during pregnancy and after birth. This section also aims to help you think about your own wellbeing during this time.

Spending time reading through the other sections in this guide will be helpful. This will increase your understanding of what early warning signs look like, what care your partner may receive and how you can help to plan and prepare for pregnancy and birth. Showing an interest and seeking to understand as much as possible can make a big difference.

Although we use the term 'partner' in this section, this information will be helpful for everyone who plays a key part in the mother's life.

Families come in all shapes and sizes and this section is for anyone who wants to know more and be supportive during this time.

While it's important to plan ahead in case your partner does become unwell, it's not inevitable that she will. Many women will remain well during pregnancy and after birth.

Thinking about having a baby

Deciding on whether to have a baby can bring up a mixture of feelings for anyone.

For women with bipolar or those who have been unwell with their mental health during previous pregnancies, thinking about having a baby can bring up a lot of worries, for them and also for their partners.

You and your partner may find that you are worried about different things. Being honest and sharing your feelings and worries will help you to make informed decisions together.

Remember that help is available. You may be able to speak to a specialist such as a perinatal psychiatrist when planning for a pregnancy.

Things to consider when planning for pregnancy and birth

If your partner has been unwell with her mental health before, she may know what can act as a trigger.

You may not have seen your partner unwell before. It will be useful to discuss with your partner what early symptoms she has shown in the past and what might have triggered previous episodes.

It's important to remember that your partner may not realise when she is unwell.

Episodes of mental illness after birth may look different to episodes at other times in her life. You may be the first person to recognise that your partner is showing early symptoms.

It will be important for you to know where to find important contact numbers so you can act quickly to get the help she needs.

You can find a list for your partner to fill in on the final page of this guide.

Don't hesitate to reach out for help (for example, from the mental health crisis team, your GP or your local A&E department) if you are concerned for the safety of your partner, your baby or yourself.

Sleep

Research suggests that sleep disturbance might be involved in women becoming unwell with postpartum psychosis.

In the early days after giving birth, you and your partner may want to think of ways to ensure she has enough time to sleep and rest.

This can include managing visitors, helping with night feeds and looking after the baby so that your partner can have a nap during the day.

It may be helpful to discuss this with your partner before the birth.

Your work

You may be feeling worried about work and how you will be able to manage everything once your parental leave ends. It may be helpful to keep your employer informed of what is going on.

There may be options available to you, such as arranging a period of paid sick leave, compassionate leave or unpaid parental leave.

You may plan to take annual leave so that you can have a longer period of paid parental leave.

Getting support from family, friends and volunteers

Your partner becoming unwell after giving birth may mean that you take on more responsibilities than you imagined, including looking after your partner and your baby.

Severe mental illness during pregnancy and childbirth can be distressing for partners, family and friends. You may need emotional and practical support of your own.

Older siblings may also need support if your partner becomes unwell. South London and Maudsley NHS foundation have created booklets designed for different age groups that provide clear and simple explanations about mental illness and when a parent is in hospital.

They are available free from the Our Time website, search for When a parent is in hospital: **ourtime.org.uk**
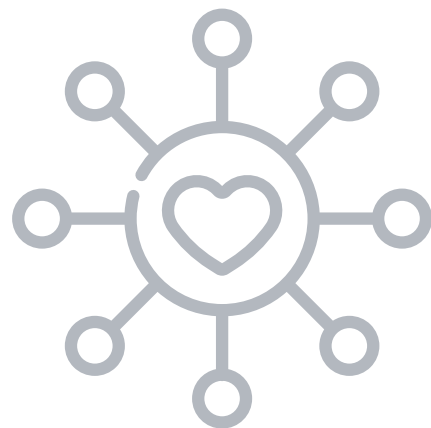
Looking after your own health

If your partner becomes unwell, looking after your partner and baby will likely feel like a lot to cope with. You may notice that you are feeling stressed, anxious, low or unwell - this is understandable.

You may also feel other emotions, such as guilt, disloyalty or relief if you have to seek support for your partner – it's common to feel like this. Try not to feel guilty about this, what matters is that your partner gets the treatment and support she needs during this time.

If you can, try to take time for yourself, away from hospital visiting or baby care. This could be something as simple as taking a walk or catching up with a friend.

It's important that you seek support for yourself during this time.

Reach out to a friend or family member to let them know how you are feeling.

If you are struggling to cope or having trouble sleeping, talk to your GP.

You may find it helpful to speak with other partners who have been through a similar experience.

Action on Postpartum Psychosis (APP), a third sector organisation for women and families affected by postpartum psychosis, have an online peer support service where you can talk to other partners who have 'been there'.

You can find details on the next page under 'Support and helpful resources'.

Support and helpful resources

Action on Postpartum Psychosis (APP) is the national charity for women and families affected by postpartum psychosis

- Information about early symptoms - **app-network.org/early-symptoms**
- Visit their online support forum to ask questions to other partners and discuss issues that are worrying you - **healthunlocked.com/app-network**
- APP have developed an 'insider guide' for partners - **Postpartum Psychosis a Guide for Partners**
- APP have a number of resources available for partners - **app-network.org**
- APP also have personal descriptions of PP from women and their partners who have been through it
- Puerperal Psychosis: A Carer's Survival Guide by Craig Allatt: **app-network.org**

Mind, a mental health charity, have developed information about support and services for people who are helping others seek help **-** search for 'Helping someone else seek help' on their guides to support and services section

Key messages

- You may not have seen your partner unwell before. It will be useful to discuss the early warning signs your partner has shown in the past.

- It will be important for you to know where to find the contact numbers needed to act quickly to get the help she needs.

- Severe mental illness during pregnancy and childbirth can be distressing for partners, family and friends. You may need emotional and practical support of your own from family, friends or volunteers.

- It's important that you seek support for yourself during this time. Make sure to reach out to a friend or family member to let them know how you are feeling.

- While it's important to plan ahead in case your partner does become unwell, it's not inevitable that she will. Many women will remain well during pregnancy and after birth.

Bringing it all together

Now that you have come to the end of the guide, you may be better placed to make some of the difficult decisions we have discussed.

Reading through the information may have answered some questions you had and made clear the questions that you still need to ask.

You may now be looking to develop plans and discuss further with your healthcare professionals.

This section is designed to help you plan your next steps.

Next steps

Consider each of these questions and use the boxes below to write down how you feel and any plans that you have related to each one.

If you are currently pregnant, some of these questions might not apply.

Am I clear about my reasons for wanting to have a baby? **Yes** ☐
No ☐

Do I know which concerns relating to having a baby are most important to me? **Yes** ☐
No ☐

Do I have enough information about my chance of becoming unwell during pregnancy and after birth? **Yes** ☐
No ☐

Do I understand the medication and other treatment options available during pregnancy and after the baby is born? **Yes** ☐
No ☐

Do I have a clear plan in place in case I become unwell? **Yes** ☐
No ☐

Am I clear about the support that may be available to me during pregnancy and after birth from both professionals and significant others? **Yes** ☐
No ☐

If you feel you don't have enough professional support, you may want to think about what steps you need to take to find out what's available to you in your area.

If you are not currently under the care of a community mental health team or a perinatal mental health team, the first step in accessing more support will be to contact your GP.

For more information about professional support during the perinatal period, refer to Section 3 'What support may I receive during pregnancy and after having a baby?" on page 31.

What do you need more information about?
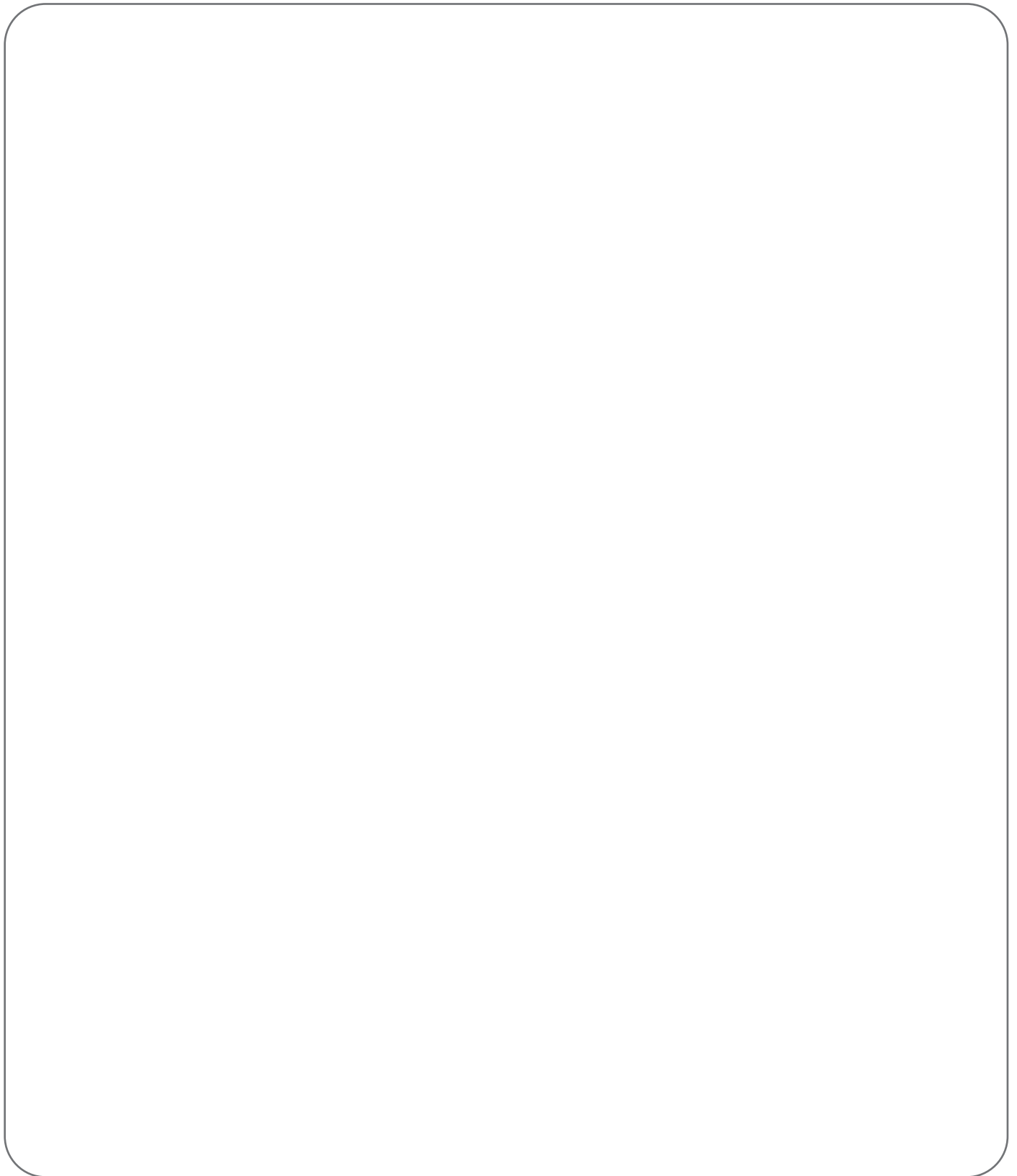
You may have questions that you haven't got answers for yet and plan to ask your healthcare professional about or look into further yourself. Use this space to identify these questions:

Questions What questions do I have for my healthcare professional?	My notes Information to help answer my questions:

Making a plan

You may like to use the space below to summarise any steps that you now plan to take:

eg Make an appointment with my GP to discuss pre-conception services available in my area
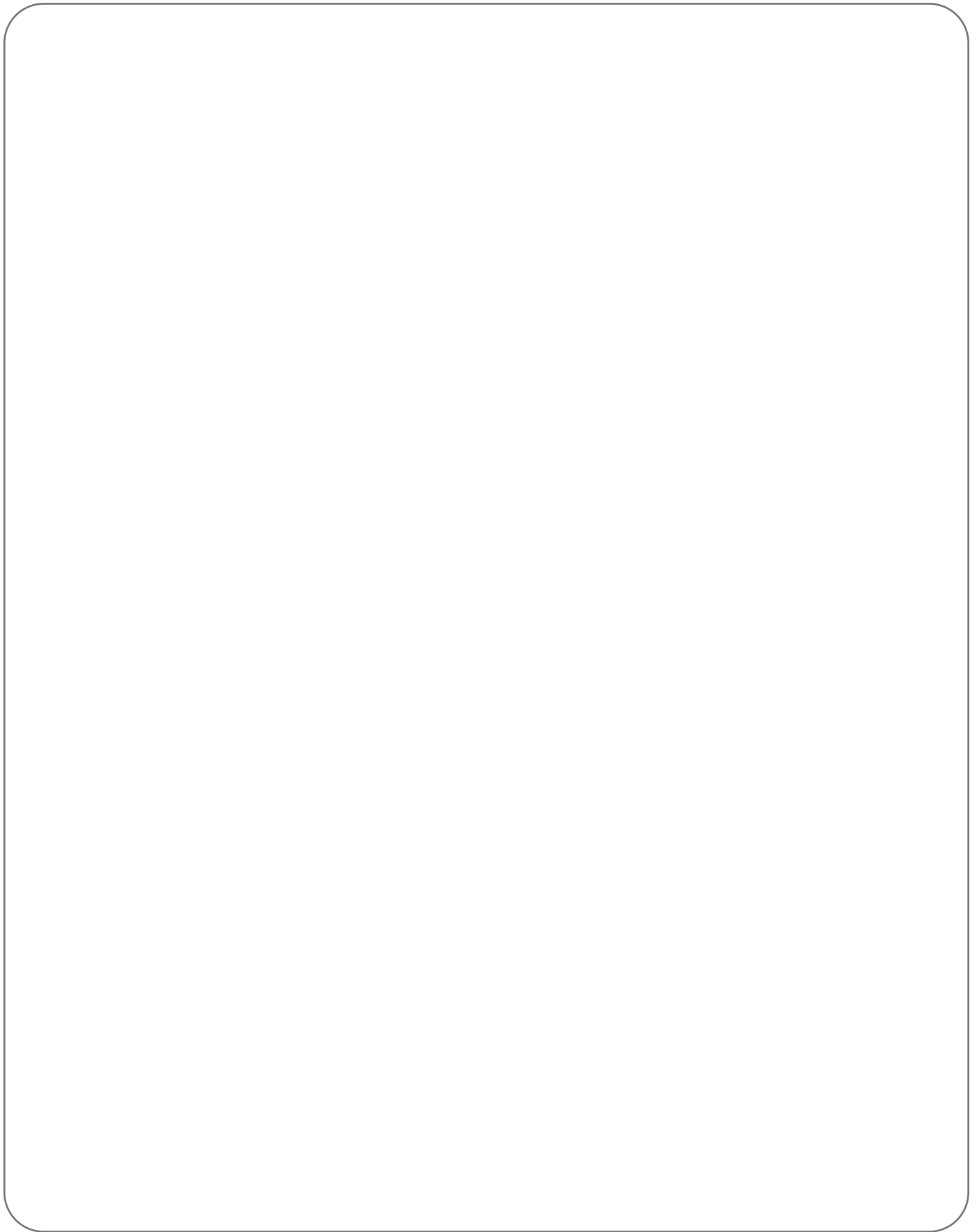
Notes

Notes

About me

Important contacts

Use the list below to record contact details for those who are involved in your care and friends, family and significant others who will be able to provide support. This list could be very helpful during times of crisis or relapse.

Making it easily accessible for partners, family or friends will help them to access help for you easily should you need it.

Name: _____ Role: _____

Contact details: _____

Name: _____ Role: _____

Contact details: _____

Name: _____ Role: _____

Contact details: _____

Name: _____ Role: _____

Contact details: _____

Name: _____ Role: _____

Contact details: _____

Name: _____ Role: _____

Contact details: _____

Name: _____ Role: _____

Contact details: _____

Name: _____ Role: _____

Contact details: _____

NCMH

National Centre for Mental Health

APP

Action on Postpartum Psychosis

bipolar UK

SUPPORTING PEOPLE AFFECTED BY BIPOLAR