Identification and management of eating disorders in pregnancy: A multi-method study of maternity and health visiting services

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I, Amanda Margaret Bye, confirm that the work presented in this thesis is my own. Where information has been derived from other sources I confirm that this has been indicated.

Signed_____

Date_____

Abstract

Pregnant women with current and past eating disorders (ED) have heightened risk of adverse maternal and infant outcomes, so it is imperative women are identified and receive enhanced care during and after pregnancy to promote optimal outcomes. However, following recent changes to the classification of ED, it is unclear how many pregnant women have had ED and research is needed to understand the barriers to their care in maternity and health visiting services.

A multi-method approach, comprising of four studies, was employed to: (1) investigate the prevalence of ED in pregnant women; and (2) explore the barriers to care from the perspectives of women, midwives and health visitors. Study one found the prevalence of ED before and during pregnancy were 8.8% and 6.7%, respectively, using a self-report questionnaire in 1,022 pregnant women. Study two estimated population prevalence for lifetime and current ED of 15.3% (95% CI, 11.80-19.71%) and 1.4% (95% CI, 0.64-3.35%), respectively, using diagnostic interviews in 543 pregnant women. Study three, which collated survey data from 103 pregnant and postnatal women, found disclosure of ED was low due to perceptions of poor awareness, stigma, lack of continuity in carer and limited capacity in maternity services. Study four, using a two-phased design with questionnaires (N = 265) and focus groups (N = 33) in midwives and health visitors, found the main barriers to identifying and caring for women with ED were insufficient training and related practice.

The findings indicate a significant proportion of pregnant women will have had ED, yet women will often be poorly identified and receive inadequate care in maternity and health visiting services. Future research should aim to develop strategies that address the barriers identified in this research to improve care for pregnant and postnatal women with ED to promote optimal outcomes for mother and child.

Impact Statement

Pregnant women with current and past eating disorders (ED) have heightened risk of adverse maternal and infant outcomes, so it is imperative women are identified and receive enhanced care during and after pregnancy to promote optimal outcomes. However, following recent changes to the classification of ED, it is unclear how many pregnant women have or have had ED and research is needed to understand the barriers to care in maternity and health visiting services.

This programme of research, comprising of four studies, examined the prevalence of ED in two UK samples of pregnant women using questionnaires and interviews. In addition, the views of women, midwives and health visitors on the barriers to care were explored. Findings indicate that up to 15% of pregnant women will have had ED at some point in their life, though particular symptoms that are less well defined and vulnerable to greater stigma can present challenges for current diagnostic instruments, i.e. binge eating. Yet women with ED will often be poorly identified and receive inadequate monitoring and support in maternity and health visiting services. This is largely due to insufficient training and related practice, as well as stigma of ED, overweight status, and perinatal mental illness.

This research has the potential to benefit several groups, including women with ED and their children, education providers, health services, clinicians involved in routine care for pregnant and postnatal women, and researchers and clinicians in the ED field. It could stimulate public initiatives to raise awareness about maternal ED and reduce stigma that can hinder disclosure and help-seeking among pregnant and postnatal women with ED. It has prompted the inclusion of ED in midwifery education programmes at universities involved in this research, to raise awareness and encourage best practice among their students. With the potential for a much wider reach, it directly contributed to a project with Dr Abigail Easter to co-produce web-based training on ED suitable for all clinicians involved in the care of pregnant and postnatal women. This was supported by The Health Foundation and King's Improvement Science, part of the Centre for Implementation Science within NIHR

Collaboration for Leadership in Applied Health Research and Care South London. It generated engagement from several national charities, education providers, professionals from a range of clinical backgrounds and women with lived experience, and interest from several media outlets. The current research has also been disseminated using traditional academic routes, including two peer-reviewed journal articles and several conference presentations. It is envisaged the findings will contribute to ongoing discussions in the ED field on the challenges with assessing ED during pregnancy, to consider the impact of stigma towards overweight status and perinatal mental illness on disclosure of ED in clinical and research settings. This research and related activities have the potential to contribute to improvements in practice that better meet the needs of pregnant and postnatal women with ED to promote optimal maternal and infant outcomes.

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I would like to thank my doctoral supervisors, Dr Nadia Micali, Professor Jill Shawe, Professor Debra Bick and Dr Paul Robinson. Thank you for sharing your knowledge and expertise to inform and further my research. I am incredibly grateful for your continued guidance and support throughout my doctoral studies.

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I would like to thank the women and healthcare professionals that participated in the research presented in this thesis.

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List of Abbreviations

American Psychiatric Association	APA
Anorexia nervosa	AN
Anorexia nervosa - restricting subtype	AN-R
Anorexia nervosa - binge-purge subtype	AN-BP
Binge eating disorder	BED
Body mass index	BMI
Bulimia nervosa	BN
Consolidated criteria for reporting qualitative research	COREQ
Diagnostic and Statistical Manual of Mental Health Disorders	DSM
Eating disorder(s)	ED
Eating Disorder Diagnostic Scale	EDDS
Eating Disorder Examination	EDE
General practitioner	GP
National Health Service	NHS
National Institute for Health and Care Excellence	NICE
Nursing and Midwifery Council	NMC
Nutrition and Stress in Pregnancy study	NEST-p study

Other specified feeding and eating disorders	OSFED
Royal College of Midwives	RCM
Structured Clinical Interview for DSM	SCID
Unspecified feeding or eating disorder	UFED
United States	US
WEll-being in pregNancy study	WENDY
World Health Organization	WHO

Overview of Thesis and Candidates Contributions to Studies

This thesis is organised into seven chapters. The first two chapters introduce the literature, aims and methodology that guided the present program of research. The following four chapters present the four studies that comprise the core of this thesis. The final chapter presents an overall discussion of this programme of research. An outline of each chapter is provided below, and overviews of the four studies are accompanied by a statement of the candidate's contribution to the study.

Chapter one

Chapter one presents a narrative review of the contextual background to this programme of research. The first section of this chapter presents an overview of the diagnostic classification of ED. The second section presents an overview of the literature on the epidemiology of ED. The third section presents an overview of the literature on maternal ED. The fourth section presents an overview of the implications for identifying and managing maternal ED in maternity and health visiting services. The chapter concludes with a summary of the gaps in the literature and an overview of the general aims of this programme of research.

Chapter two

Chapter two presents an overview of the methodological approach and methods used in this programme of research.

The four studies in this programme of research are presented in chapters three, four, five and six. They have been presented in the standard manuscript format (i.e. rationale, aims, methods, results and discussion).

Chapter three

Chapter three presents findings from a cross-sectional survey conducted as part of the Nutrition and Stress in Pregnancy (NEST-p) study, which aimed to investigate the prevalence of ED before and during pregnancy in pregnant women, using a self-

report questionnaire to determine diagnoses consistent with the fifth edition of the Diagnostic and Statistical Manual of Mental Health Disorders (DSM-5; American Psychiatric Association [APA], 2013).

This study was supervised by Dr Nadia Micali. The candidate developed the research questions and hypotheses, contributed to recruiting the participants, managed the data, and conducted all the data analysis presented in this chapter. Other members of the NEST-p research team (doctoral students from the Institute of Psychiatry, Psychology & Neuroscience, King's College London and UCL Great Ormond Street Institute of Child Health) were also responsible for recruiting the participants and entering the data. Interim survey findings have previously been published, of which the candidate conducted the data analysis and co-authored the manuscript (Easter et al., 2013).

Chapter four

Chapter four presents findings from the WEll-being in pregNancy stuDY (WENDY), which aimed to estimate the population prevalence of lifetime and current ED in pregnant women, using diagnostic interviews to determine diagnoses consistent with DSM-5 (APA, 2013).

This study was supervised by Dr Nadia Micali and Professor Louise Howard (Chief Investigator for WENDY and Professor from the Institute of Psychiatry, Psychology & Neuroscience, Kings College London). The candidate developed the research questions and hypotheses. The candidate contributed to the study set up and inclusion of measures that were relevant to the research questions. The candidate attended regular programme management meetings, team meetings and supervision meetings. The candidate conducted 146 (27%) research interviews, whilst the remaining 399 (73%) research interviews were conducted by the other members of the WENDY research team (postgraduate researchers and research midwives from the Institute of Psychiatry, Psychology & Neuroscience, King's College London). Alongside other members of the WENDY research team, the candidate contributed to data entry and data cleaning. Dr Elizabeth Ryan (former statistician from the

Institute of Psychiatry, Psychology & Neuroscience, Kings College London) prepared the sampling weights to account for the stratified sampling design, under the supervision of Professor Andrew Pickles (Professor from the Institute of Psychiatry, Psychology & Neuroscience, Kings College London). The candidate conducted all other data analysis presented in this chapter. Parts of this chapter appear in the article Bye, A., Nath, S., Ryan, E.G., Bick, D., Easter, A., Howard, L.M., Micali, N. (2020). Prevalence and clinical characterisation of pregnant women with eating disorders. *European Eating Disorders Review*, 28, 141-145.

Chapter five

Chapter five presents findings from a web-based survey study, which aimed to explore the experiences of maternity care in women with lifetime ED.

This study was supervised by Dr Nadia Micali. The candidate developed the research proposal and the self-report questionnaire, obtained the necessary approvals, negotiated the website hosting, managed the data, and conducted all the data analysis presented in this chapter. Dr Kylee Trevillion (lecturer from the Institute of Psychiatry, Psychology & Neuroscience, King's College London) contributed to the coding of the qualitative data. Dr Nadia Micali, Professor Jill Shawe, Professor Debra Bick, Dr Paul Robinson, Dr Kylee Trevillion and Dr Abigail Easter (senior research fellow from the Institute of Psychiatry, Psychology & Neuroscience, King's College London) contributed to the interpretations of the qualitative data. These contributions to the qualitative data analysis are detailed in the chapter. Parts of this chapter appear in the article Bye, A., Shawe, J., Bick, D., Easter, A., Kash-Macdonald, M., & Micali, N. (2018). Barriers to identifying eating disorders in pregnancy and in the postnatal period: a qualitative approach. *BMC Pregnancy and Childbirth*, 18, 114.

Chapter six

Chapter six presents findings from a two-phased mixed methods study, which aimed to conduct a mixed-methods exploration of the barriers to identifying and managing

pregnant and postnatal women with ED in maternity and health visiting services from the perspectives of midwives and health visitors.

This study was supervised by Dr Nadia Micali, Professor Jill Shawe and Professor Debra Bick. The candidate developed the research proposal, self-report questionnaire and focus group topic guide, obtained the necessary approvals, negotiated site access, recruited the participants, facilitated the focus groups, managed the data and conducted all the data analysis presented in this chapter. Megan Kash-Macdonald (doctoral student from UCL Great Ormond Street Institute of Child Health) contributed to the coding of the qualitative data. Dr Nadia Micali, Professor Jill Shawe, Professor Debra Bick, Dr Paul Robinson, Megan Kash-Macdonald and Dr Abigail Easter contributed to the interpretations of the qualitative data. These contributions to the qualitative data analysis are detailed in the chapter. Parts of this chapter appear in the article Bye, A., Shawe, J., Bick, D., Easter, A., Kash-Macdonald, M., & Micali, N. (2018). Barriers to identifying eating disorders in pregnancy and in the postnatal period: a qualitative approach. *BMC Pregnancy and Childbirth*, 18, 114.

Chapter seven

Chapter seven presents an overall discussion of the findings from this programme of research. It presents a summary and discussion of the main findings of this programme of research, discusses the implications for clinical practice, public initiatives and future research, and examines the overall strengths and limitations of this programme of research.

Chapter 1 Literature Review

1.1 Chapter overview

This chapter presents a narrative review of the contextual background to this programme of research. Given the breadth of the research area, a narrative rather than systematic review of the literature was considered most appropriate for this chapter. The first section of this chapter presents an overview of the diagnostic classification of ED and the limitations of the current diagnostic system. The second section presents an overview of the literature on the epidemiology of ED, including a discussion about the methodological considerations for ED research. The third section presents an overview of the literature on maternal ED, including the implications for prenatal, pregnancy and postnatal outcomes, as well as the prevalence of ED in pregnant women. The fourth section presents an overview of the implications for identifying and managing maternal ED in maternity and health visiting services, including recommendations for clinical practice and potential barriers to the effective implementation of the recommendations. The chapter concludes with a summary of the gaps in the literature and an overview of the general aims of this programme of research.

1.2 Diagnostic classification of eating disorders

ED are a complex and heterogenous group of mental illnesses characterised by severe disturbances in eating behaviours. The Diagnostic and Statistical Manual of Mental Health Disorders (DSM) is a classification system that outlines the specific criteria required for determining diagnoses of mental illness. The diagnostic criteria for ED listed in the fourth edition of the DSM (text rev.; DSM-IV-TR; American Psychiatric Association [APA], 2000) were recently revised for the latest edition (5th ed.; DSM-5; APA, 2013). The changes introduced were intended to broaden the categories of full threshold ED to reduce the predominance of individuals who present clinically that do not meet full threshold diagnostic criteria (Fairburn & Cooper, 2011). The current

diagnostic classifications for ED and the notable differences that were introduced are described below and presented in Table 1-1.

DSM-5 (APA, 2013) outlines eight categories of ED: anorexia nervosa (AN), bulimia nervosa (BN), binge eating disorder (BED), other specified feeding and eating disorders (OSFED), unspecified feeding or eating disorder (UFED), pica, rumination disorder and avoidant/restrictive food intake disorder. This thesis is specifically interested in AN, BN, BED and OSFED (with the exception of night eating syndrome) as UFED, pica, rumination disorder, and avoidant/restrictive food intake disorder were not previously classified as ED in DSM-IV-TR (APA, 2000), thus were not considered in the rationale for this research. Further, two of the four studies presented in this thesis were conducted before the revised criteria had been fully implemented into research and as such, refer to DSM-IV-TR (APA, 2000) diagnostic criteria rather than DSM-5 (APA, 2013).

1.2.1 Anorexia nervosa

AN is primarily characterised by restricting food intake by engaging in appropriate compensatory behaviours such as fasting, purging or excessive exercise, which result in significantly low body weight. According to DSM-5 (APA, 2013), AN is defined as: (A) persistent restriction of energy intake leading to significantly low body weight given the individual's age, sex, developmental trajectory, and physical health; (B) an intense fear of gaining weight or of becoming fat, or engaging in persistent behaviour that interferes with weight gain; and (C) disturbance in the way in which one's body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or denial of the seriousness of the low body weight.

AN can be further categorised in to two subtypes: restricting subtype (AN-R) and binge-purge subtype (AN-BP). AN-R refers to individuals who have not engaged in recurrent episodes of binge eating and purging behaviours (i.e. self-induced vomiting, or the misuse of laxatives, diuretics, or enemas) with weight loss being primarily achieved through dieting, fasting or excessive exercise. AN-BP refers to individuals who have engaged in recurrent episodes of binge eating and purging behaviours (i.e.

self-induced vomiting, or the misuse of laxatives, diuretics, or enemas). DSM-5 (APA, 2013) also classifies whether an individual with a history of AN can be considered in partial or full remission (dependent on whether any or none of the previously met criteria are currently met).

In comparison to DSM-IV-TR (APA, 2000), the emphasis in criteria A has shifted from the term "refusal" which implies intention or wilfulness by the individual and is difficult to assess, to a persistent engagement in behaviours to maintain low weight (APA, 2013). The threshold for determining low body weight was revised to allow for more clinical judgement and consideration of an individual's growth trajectory and weight history. Furthermore, the amenorrhea criterion for AN was removed as it precluded the classification of AN in males, premenarchal, pregnant or post-menopausal females, females taking oral contraceptives and females that continue menstruating despite severe low weight.

1.2.2 Bulimia nervosa

BN is primarily characterised by recurrent episodes of binge eating followed by an inappropriate use of behaviours to compensate for the binge eating, with the intention of maintaining or losing body weight. In DSM-5 (APA, 2013), BN is diagnosed according to the following criteria: (A) recurrent episodes of binge eating, with an episode being defined as eating within a discrete period of time (e.g. within a two hour period), an amount of food that is larger than most other people would eat during a similar period of time and under similar circumstances, accompanied by a perceived loss of control over eating (e.g. a feeling of being unable to stop eating, or control what or how much is being eaten); (B) binge eating episodes are followed by recurrent engagement in inappropriate compensatory behaviours, such as vomiting, misuse of laxatives, diuretics or other medications, fasting, or excessive exercise to counteract the effects of eating or to prevent weight gain; (C) binge eating episodes and inappropriate compensatory behaviours both occur, on average, at least once a week for a minimum of three months; (D) an undue influence of body weight or shape on self-evaluation; (E) behaviours do not occur exclusively during episodes of AN, i.e. an individual meeting criteria for both AN and BN would only be diagnosed with AN.

As with AN, an individual with a history of BN can be considered in partial or full remission.

Since DSM-IV-TR (APA, 2000), the most substantial change to the classification of BN has been a reduction in the frequency threshold for BN behaviours from at least twice a week to once a week for a minimum of three months. Also, DSM-5 (APA, 2013) no longer differentiates between purging and non-purging subtypes of BN.

1.2.3 Binge eating disorder

Similar to BN, BED is characterised by recurrent episodes of binge eating although in the absence of inappropriate behaviours to compensate for binge eating. In DSM-5 (APA, 2013), the diagnostic criteria for BED are as follows: (A) recurrent episodes of binge eating; (B) binge eating episodes are associated with three or more of the following five symptoms: (1) eating much more rapidly than normal, (2) eating until feeling uncomfortably full, (3) eating large amounts of food when not feeling physically hungry, (4) eating alone because of feeling embarrassed by how much one is eating, or (5) feeling disgusted with oneself, depressed, or very guilty afterwards; (C) significant distress about binge eating; (D) binge eating episodes occur, on average, at least once a week for a minimum of three months; (E) binge eating episodes are not followed by recurrent engagement in inappropriate compensatory behaviours and do not occur during the course of AN or BN. Further, an individual with a history of BED can be considered in partial or full remission of BED.

The most substantial change to the classification of BED since DSM-IV-TR (APA, 2000), was the recognition of BED as a distinct ED rather than a type of EDNOS. Further, similar to BN, the frequency threshold for BED behaviours was reduced from at least twice a week for six months to once a week for a minimum of three months.

1.2.4 Other specified feeding and eating disorders

OSFED is a heterogenous category for individuals with clinically significant ED who do not meet full threshold diagnostic criteria. DSM-5 (APA, 2013) proposes five examples

of types of OSFED: (1) atypical AN whereby all criteria for AN are met except despite weight loss, weight does not meet the threshold for significantly low weight; (2) sub-threshold BN, in which all criteria for BN are met except binge eating episodes and inappropriate compensatory behaviours occur less frequently or for a shorter amount of time than required for full threshold BN; (3) sub-threshold BED, in which all criteria for BED are met except binge eating episodes occur less frequently and for a shorter amount of time than required for full threshold BED; (4) purging disorder, which is classified as recurrent engagement in purging behaviours, such as vomiting, misuse of laxatives, diuretics or other medications, in the absence of episodes of binge eating; and (5) night eating syndrome, which is classified as excessive eating after the evening meal or after awakening from sleep and is not better explained by external influences such as local social norms, BED, another psychiatric or medical disorder or the effect of a medication (American Psychiatric Association, 2013).

Previously in DSM-IV-TR (APA, 2000), this heterogenous sub-threshold category was referred to as eating disorder not otherwise specified (EDNOS). Although the types listed under OSFED resemble those listed under EDNOS, there are several important differences, including: previously females meeting all criteria for AN with the exception of amenorrhea would be classified as EDNOS, whereas in DSM-5 (APA, 2013) they would be classified as AN as amenorrhea is no longer listed as a diagnostic criteria; as detailed above, the sub-threshold category of BN corresponds to the alterations to the frequency threshold for BN; as detailed above, BED was previously considered a type of EDNOS, whereas it is recognised as a distinct ED in DSM-5 (APA, 2013) and sub-threshold BED is considered a type of OSFED to correspond to the reduced frequency threshold for BED; and repeatedly chewing and spitting out but not swallowing large amounts of food is no longer listed as a type of sub-threshold ED in DSM-5 (APA, 2013).

Table 1-1 Comparison of DSM-IV-TR (APA, 2000) and DSM-5 (APA, 2013) diagnostic criteria for ED

ED diagnosis	DSM-IV-TR	DSM-5
AN		
	Refusal to maintain body weight at or above a minimally normal weight for age and height.	Persistent restriction of energy intake leading to significantly low body weight given the individual's age, sex, developmental trajectory, and physical health.
	Intense fear of gaining weight or of becoming fat.	Intense fear of gaining weight or of becoming fat, or persistent behaviour that interferes with weight gain.
	Undue influence of body weight or shape on self-evaluation, or denial of the seriousness of the low body weight.	Undue influence of body weight or shape on self-evaluation, or denial of the seriousness of the low body weight.
	In post-menarcheal females, amenorrhoea.	Criterion removed
	AN-R subtype: Weight loss achieved through dieting and/or fasting.	AN-R subtype: Weight loss achieved through dieting, fasting or excessive exercise.
	AN-BP subtype: Weight loss achieved through recurrent episodes of binge eating and/or purging behaviours.	AN-BP subtype: Weight loss achieved through recurrent episodes of binge eating and/or purging behaviours.
BN		
	Recurrent episodes of binge eating.	Recurrent episodes of binge eating.
	Episodes are followed by recurrent engagement in inappropriate compensatory behaviours.	Episodes are followed by recurrent engagement in inappropriate compensatory behaviours.

	Episodes and inappropriate compensatory behaviours both occur, on average, at least twice a week for a minimum of three months.	Episodes and inappropriate compensatory behaviours both occur, on average, at least once a week for a minimum of three months.
	Undue influence of body weight or shape on self-evaluation.	Undue influence of body weight or shape on self-evaluation.
	Behaviours do not occur during episodes of AN.	Behaviours do not occur during episodes of AN.
	Purging subtype: Compensatory behaviours (e.g. vomiting, laxatives, diuretics).	Subtype removed
	Non-purging subtype: Compensatory behaviours (e.g. fasting, excessive exercise).	Subtype removed
BED		
	Example of EDNOS	Distinct diagnostic category
	Recurrent episodes of binge eating	Recurrent episodes of binge eating
	Episodes are associated with three or more of the following five symptoms: (1) eating more rapidly than normal, (2) eating until feeling uncomfortably full, (3) eating large amounts of food when not physically hungry, (4) eating alone because of feeling embarrassed, or (5) feeling disgusted, depressed, or very guilty afterwards.	Episodes are associated with three or more of the following five symptoms: (1) eating more rapidly than normal, (2) eating until feeling uncomfortably full, (3) eating large amounts of food when not physically hungry, (4) eating alone because of feeling embarrassed, or (5) feeling disgusted, depressed, or very guilty afterwards.
	Significant distress regarding binge eating.	Significant distress regarding binge eating.

	Episodes occur, on average, at least twice a week for a minimum of six months.	Episodes occur, on average, at least once a week for a minimum of three months.
	Episodes are not followed by compensatory behaviours and do not occur during the course of AN or BN.	Episodes are not followed by compensatory behaviours and do not occur during the course of AN or BN.
EDNOS/OSFED		
	For females, all AN criteria are met except amenorrhea.	Meets criteria for AN
	All AN criteria are met except that, despite significant weight loss, weight is not significantly low.	Atypical AN: All AN criteria are met except that, despite significant weight loss, weight is not significantly low.
	Sub-threshold BN: All BN criteria are met except binge eating episodes and compensatory behaviours occur less than twice a week or for a period of less than three months.	Sub-threshold BN: All BN criteria are met except binge eating episodes and compensatory behaviours occur less than once a week or for a period of less than three months.
	Regular use of inappropriate compensatory behaviours by an individual of normal body weight after eating small amounts of food.	Purging disorder: Recurrent engagement in purging behaviours in the absence of binge eating.
	Repeatedly chewing and spitting out, but not swallowing, large amounts of food.	Type removed
	BED (see detail above)	Sub-threshold BED: All BED criteria are met except binge eating episodes occur less than once a week or for a period of less than three months.
	Type not included	Night eating syndrome: Excessive eating after the evening meal or after awakening from sleep, which is not better explained by external influences such as local social norms, BED, another psychiatric or medical disorder or the effect of a medication.

1.2.5 Limitations of diagnostic classification systems

Despite the changes in DSM-5 (APA, 2013) to generate a more clinically relevant diagnostic classification system for ED, some limitations persist. There is considerable overlap between the features of the different diagnostic categories and diagnostic instability over the lifetime is common, more frequently from restricting types to binge and binge-purge types, and subthreshold to full threshold diagnoses (Anderluh, Tchanturia, Rabe-Hesketh, Collier, & Treasure, 2009; Castellini et al., 2011; Eddy et al., 2008; Ekeroth, Clinton, Norring, & Birgegård, 2013). Thus, the different ED diagnostic categories may not be as distinct as the system purports. Some researchers have favoured a more transdiagnostic approach to defining and treating ED to give prominence to the similarities in underlying characteristics and psychopathology among all ED (Fairburn, Cooper, & Shafran, 2003). Although this approach similarly has drawbacks, as response to treatment differs between the diagnostic categories, supporting the validity of the current classification system (McElroy, Guerdjikova, Mori, & Keck, 2015; Treasure, Leslie, Chami, & Fernández-Aranda, 2018).

1.3 Epidemiology of eating disorders

1.3.1 Methodological considerations

Ascertaining the prevalence of a health condition in the general population can inform the planning of healthcare practice and services as it is a useful indicator of particular healthcare needs within the population (Smink, van Hoeken, & Hoek, 2012). Prevalence of ED is often expressed as lifetime prevalence (i.e. the proportion of people that have had an ED at any time during their life) and period prevalence (i.e. the proportion of people that have an ED at any time during a given period) (Hoek & van Hoeken, 2003). Accurately determining the prevalence of ED can be challenging though, primarily because ED are rare (Smink et al., 2012) and individuals with ED are often reluctant to disclose and seek treatment for their ED (Becker, Thomas, Franko, & Herzog, 2005; Evans et al., 2011; Hart, Granillo, Jorm, & Paxton, 2011; Hepworth & Paxton, 2007; Hudson, Hiripi, Pope, & Kessler, 2007; Swan & Andrews, 2003). Using

healthcare records to determine prevalence of ED would be a more cost and time effective method of accessing large samples compared to large general population surveys, though this approach will only reflect the more severe, hospitalised cases of ED, thus underestimating the true prevalence (Hoek, 2006; Smink et al., 2012). General population survey studies also rely on voluntary disclosure using self-report questionnaires or diagnostic interviews, and will often not capture the more severe, hospitalised cases, similarly underestimating prevalence. The preferred method of ascertaining prevalence of ED is with a cross-sectional survey in a general population sample using a two-phase sampling design. In a two-phase study, a large general population sample are screened using a self-report questionnaire to identify potential cases and non-cases and then a diagnostic interview is used to confirm cases with a proportion of the sample, so the prevalence can be weighted to the total population (Pickles, Dunn, & Vázquez-Barquero, 1995; Smink et al., 2012). However, two-phase studies often report low response rates for the second phase, are limited by the sensitivity and specificity of the self-report questionnaire and often only interview small numbers of potential non-cases (Keski-Rahkonen et al., 2006; Smink et al., 2012).

Furthermore, ED prevalence studies vary greatly in study populations (e.g. adolescents versus adults), time frames assessed (e.g. lifetime versus past 12-month prevalence), types of ED assessed (e.g. full threshold only), operational definitions of ED (e.g. DSM-IV-TR versus DSM-5 definitions), instruments used to assess ED and the mode of administration (e.g. self-report questionnaires versus face-to-face diagnostic interviews). These variations contribute to disparities in ED prevalence across studies, limiting the ability to make useful comparisons on prevalence, but also have implications for studies investigating the impact of ED. As would be expected, studies assessing prevalence of ED in adolescents report lower prevalence (Stice, Marti, Rohde, Nathan Marti, & Rohde, 2013) than studies in adults (Micali et al., 2017). Similarly, reported prevalence of lifetime prevalence is higher than period prevalence (Stice et al., 2013). Differences in types of ED included and operationalised definitions account for variations in prevalence in some studies (Fairburn & Bohn, 2005; Smink et al., 2012; Stice et al., 2013). Instruments assessing ED often do not include EDNOS

or OSFED, thus researchers need to make unvalidated adaptations to the existing instruments, which contribute to differences in operationalised definitions and reported prevalence (Smink et al., 2012). Also, self-report questionnaires frequently yield higher prevalence compared to face-to-face diagnostic interviews (Fairburn & Beglin, 1994; Keel, Crow, Davis, & Mitchell, 2002; Mond, Hay, Rodgers, & Owen, 2007). Self-report questionnaires are often thought to overestimate the prevalence of ED on the assumption that diagnostic interviews generate more reliable diagnoses as the interviewer can seek clarification where there is ambiguity particularly for less well defined symptoms such as binge eating (Beglin & Fairburn, 1992; Fairburn & Beglin, 1994) and given the difficulty assessing criterion that are frequently denied i.e. intense fear of weight gain or becoming fat in individuals with AN (Stice, Telch, & Rizvi, 2000). Further, Mond et al (2007) suggested diagnoses generated from interviews reflect the more severe ED cases, compared to diagnoses generated from self-report questionnaires. Alternatively, some studies have suggested self-report questionnaires may in part generate more disclosures of ED symptoms as they can be perceived as providing greater anonymity of participation compared to face-to-face diagnostic interviews (Keel et al., 2002).

1.3.2 Prevalence of eating disorders

Lifetime prevalence estimates for DSM-IV-TR (APA, 2000) AN, BN and BED in females reportedly range between 0.3%-2.2%, 0.9%-2.9%, and 0.17%-3.5%, respectively (Smink et al., 2012). A large representative household survey conducted in the United States (US) with a two-phase sampling design, reported lifetime prevalence estimates for DSM-IV-TR (APA, 2000) AN, BN and BED were 0.9%, 1.5%, and 3.5%, respectively, in women and 0.3%, 0.5% and 2.0%, respectively, in men (Hudson et al., 2007). The same study reported lower prevalence estimates for the past 12-month period for DSM-IV-TR (APA, 2000) BN and BED of 0.5% and 1.6% in women and 0.1% and 0.8% in men, with no cases of AN during the period, though similarly demonstrating a disproportionate sex ratio (Hudson et al., 2007). The high lifetime prevalence of BED may relate to the use of a three month rather than six month criterion duration as specified in DSM-IV-TR (APA, 2000).

A large cross-sectional survey conducted in six European countries using a two-phase design and a computerised version of a diagnostic interview, reported lifetime prevalence estimates of DSM-IV-TR (APA, 2000) AN, BN and BED were 0.93%, 0.88% and 1.92%, respectively, and 12-month prevalence estimates for AN, BN and BED of 0.01%, 0.29% and 0.55%, respectively, among women, and estimates were similarly lower among males (Preti et al., 2009). Comparatively, a large two-phase Finish twin birth cohort study reported lifetime prevalence estimates for DSM-IV-TR (APA, 2000) AN and BN were 2.2% and 1.7% in women (Keski-Rahkonen et al., 2009, 2007). However, these findings may overestimate the true prevalence as the sample were all female twins, given the role of genetics in the development of ED (Mazzeo & Bulik, 2009).

There are less studies reporting lifetime and period prevalence estimates for DSM-IV-TR (APA, 2000) EDNOS other than BED and as described previously, it is difficult to interpret figures given the limitations with diagnostic instruments and differences in operational definitions between studies (Fairburn & Bohn, 2005; Smink et al., 2012). A two-phase study conducted with adolescent girls in Portugal reported a current prevalence estimate of DSM-IV-TR (APA, 2000) EDNOS of 2.37% (Machado, Machado, Gonçalves, & Hoek, 2007). Another two-phase survey study conducted in Australia reported a higher period prevalence estimate for DSM-IV-TR (APA, 2000) EDNOS of 4.2% in adults (Hay, Mond, Buttner, & Darby, 2008). Micali et al (2013), using data from UK primary healthcare records, reported that between 2000 and 2009 the annual incidence of DSM-IV-TR (APA, 2000) AN and BN remained relatively stable whilst EDNOS increased and was the most common ED. Although this finding may not reflect an actual increase in incidence of EDNOS over the study period but rather increasing awareness of EDNOS particularly BED. Furthermore, this is only indicative of the number of new cases of ED during the study period.

Since the introduction of DSM-5 (APA, 2013), several community-based studies have attempted to investigate the implications of diagnostic changes on prevalence. A recent systematic review showed that rates of subthreshold ED diagnoses have decreased whilst rates of full threshold diagnoses have increased, as was the

intention of the revised criteria, though differences in study methods continue to contribute to wide variations between studies (Lindvall Dahlgren, Wisting, & Rø, 2017). Stice et al (2013) re-analysed diagnostic interview data with a sample of adolescent girls to enable comparisons of DSM-IV-TR (APA, 2000) and DSM-5 (APA, 2013) and demonstrated that the changes resulted in a marginal overall increase in lifetime ED prevalence, though specifically for BN and BED rather than AN. A large UK birth cohort study employed a two-phase design and estimated by mid-life 15.33% of women will have met DSM-5 (APA, 2013) criteria for an ED during their lifetime (AN 3.64%; BN 2.15%; BED 1.96%; OSFED 7.64%) (Micali et al., 2017). In the same study, 12-month prevalence of any DSM-5 (APA, 2013) ED was 3.61%, of which AN was 0.23%, BN 0.41%, BED 1.03% and OSFED 1.65% (Micali et al., 2017). Comparatively, another UK two-phase study with a more ethnically diverse older general population reported a higher 12-month prevalence estimate of ED consistent with DSM-5 (APA, 2013), most notably BED and OSFED (Solmi, Hotopf, Hatch, Treasure, & Micali, 2016).

1.3.3 Sociodemographics associated with eating disorders

Research consistently finds that ED disproportionally affect more females than males, particularly AN and BN with the sex ratio for BED being less skewed (Galmiche, Déchelotte, Lambert, & Tavolacci, 2019; Hudson et al., 2007; Micali et al., 2013). Though the small numbers of males participating in these studies and issues surrounding disclosure and identification of males with ED are likely to overestimate the reported disparity.

Exploring the relationship between ethnicity and ED is often complicated by archaic assumptions biasing recognition of ED in non-white ethnic groups, societal changes in integration between ethnic groups, and differences between countries in the ethnic composition of the population. One US survey reported AN was more prevalent among white adolescents but BN and BED were more common among ethnic minorities (Swanson, Crow, Le Grange, Swendsen, & Merikangas, 2011). Conversely, Marques et al (2011), using pooled data from three nationally representative US surveys, reported the prevalence of AN and BED did not differ between ethnic categories, whereas BN was more common among Latino and African

American adults compared to non-Latino white adults. A recent Australian survey in adolescents did not detect any significant differences in age, weight, socioeconomic and immigration status among those with and without ED (Mitchison et al., 2019). A lack of ethnic disparity in ED was similarly found in a UK study with an ethnically diverse sample of adults whereby a quarter identified as of Black or Asian ethnicity (Solmi et al., 2016).

1.3.4 Onset and course of eating disorders

Evidence indicates the age of ED onset typically varies between the different types of ED, with the onset of AN frequently cited as occurring earlier in adolescence and before adulthood, BN between late adolescence and early adulthood, and BED in early adulthood (Hudson et al., 2007; Micali et al., 2013; Preti et al., 2009). A recent study by Micali et al (2017), using retrospectively reported interview data with women in mid-life, found the median age of onset for the first DSM-5 (APA, 2013) ED diagnosis was lowest for AN-R and highest for sub-threshold BED.

Following initial onset, research indicates ED are frequently not self-limiting and there is extensive literature on the enduring nature of AN and BN for a significant proportion of individuals diagnosed with ED (Fairburn, Stice, et al., 2003; Fichter, Quadflieg, Crosby, & Koch, 2017; Steinhausen, 2002). Findings from two large general adult population surveys indicate BED may be as chronic as AN and BN, with individuals experiencing BED on average between four and eight years (Hudson et al., 2007; Kessler et al., 2013). Longitudinal data from a sample of adolescent girls reported ED episodes lasted for much shorter periods, with an average between 3-12 months, and the majority of individuals were in remission within a year of meeting diagnostic criteria (Stice et al., 2013). These potentially conflicting findings likely reflect the fluctuating nature of ED as within the adolescent sample up to a third experienced recurrence of the same ED and a similar proportion progressed from subthreshold to full threshold ED, specifically BN and BED though not AN (Stice et al., 2013).

As discussed previously, the diagnostic instability of ED over the lifetime is common, more frequently from restricting types to binge and binge-purge types, and subthreshold to full threshold diagnoses (Anderluh et al., 2009; Castellini et al., 2011; Eddy et al., 2008; Ekeroth et al., 2013). Although evidence indicates potential differential patterns of remission between the categories, individuals may meet diagnostic criteria for any ED for a longer duration than if only considering a single diagnosis, which is only captured through retrospective exploration with adults. Furthermore, it is common for ED symptoms and associated risks to persist beyond the period of remission, i.e. the association of residual ED symptoms and persistent low weight in those considered remitted from AN (Fichter et al., 2017; Hudson et al., 2007; Tomba, Tecuta, Crocetti, Squarcio, & Tomei, 2019).

1.3.5 Health outcomes associated with eating disorders

ED are known to be associated with greater levels of adverse physical and mental health outcomes, functional impairment and mortality. Mehler et al (2018), using healthcare records data from 1,026 individuals admitted for ED treatment at a single centre in the US, reported on a range of adverse medical outcomes associated with ED, with complications varying between restrictive and purging types and increasing with severity of ED, such as osteoporosis in AN-R and electrolyte imbalance among purging types. Though this sample comprised of individuals admitted directly to ED treatment so findings may not necessarily indicate risks in the general population.

In a large US general adult population survey, lifetime BN and BED was associated with numerous chronic physical health conditions, such as diabetes, hypertension and cardiovascular disease (Kessler et al., 2013). A large-scale European survey demonstrated between 40-70% of those meeting criteria for lifetime ED, met criteria for lifetime comorbid mental health disorders, predominantly diagnoses of anxiety and depression (Preti et al., 2009). Another large-scale survey conducted in the US similarly found high levels of comorbid mental health disorders among those with ED, although no specific disorders were more commonly associated (Hudson et al., 2007). The same study reported lifetime AN was associated with current low body weight,

whereas lifetime BED was associated with current severe obesity (Hudson et al., 2007).

Stice et al (2013) found adolescents with ED had marginally greater functional impairment, emotional distress, suicidality and unhealthy body weight (low and high) compared to those without ED. A recent large-scale US adult survey estimated adults with lifetime ED are between five to six times more likely to have a history of attempted suicide compared to those without ED and this risk is greater for those with comorbid conditions and psychosocial impairment (Udo, Bitley, & Grilo, 2019). Findings from a meta-analysis reported individuals with AN are five times more at risk of premature death from any cause and 18 times more likely to commit suicide than the general population (Keshaviah et al., 2014). Another meta-analysis similarly reported higher mortality rates for individuals with ED, with standardised mortality ratios of 5.86 for AN, 1.93 for BN and 1.92 for EDNOS (Arcelus, Mitchell, Wales, & Nielsen, 2011). Though few studies identified in this meta-analysis reported on predictors of mortality and particularly for BN and EDNOS, the findings indicated older age at the time of assessment was an important predictor of mortality in AN as was alcohol misuse and low body weight at the time of assessment (Arcelus et al., 2011).

Given the relatively recent recognition of BED as a distinct diagnostic category, less is known about the mortality risk in BED, though data from two nationally representative surveys indicates the relationship with comorbidity and age of onset of BED is needed to understand the relationship between BED and suicidal ideation (Forrest, Zuromski, Dodd, & Smith, 2017; Udo et al., 2019).

1.4 Maternal eating disorders

1.4.1 Menstrual disfunction and fertility

Given the typical onset of ED, the association between AN and menstrual disturbance has been well cited in the ED literature (Poyastro Pinheiro et al., 2007). Though in DSM-5 (APA, 2013) the amenorrhea criterion (absence of at least three consecutive

menstrual periods) for a diagnosis of AN was omitted in response to the increasing research criticising its role as a diagnostic criterion rather than a severity marker, with relevance across ED categories rather than as solely for AN (Attia & Roberto, 2009; Poyastro Pinheiro et al., 2007). A recent comprehensive review of the current literature found evidence of menstrual disturbance, both amenorrhea and oligomenorrhea (infrequent menstrual periods), for a majority of women with ED, including those with BED, indicating differing underlying mechanisms between the ED types contributed to these associations that were not necessarily weight-based (Kimmel, Ferguson, Zerwas, Bulik, & Meltzer-Brody, 2016).

Considering the common presence of menstrual disturbance in women with ED, it is often assumed women with ED will similarly experience impaired fertility (Cousins, Freizinger, Duffy, Gregas, & Wolfe, 2015; Stewart, Robinson, Goldbloom, & Wright, 1990). However, many general population studies have not found evidence that women with ED differ in their ability to conceive from the general population (Kimmel et al., 2016). One large UK general population birth cohort study reported that although women with ED were more likely to seek professional fertility advice, it was only women who met criteria for a history of both AN and BN who took longer to conceive and more frequently conceived their current pregnancy using assisted reproductive technology (e.g. in vitro fertilisation) (Easter, Treasure, & Micali, 2011). Several studies reported that women with ED were more likely to experience unplanned pregnancies and negative feelings towards the pregnancy, which are suggested to relate to the unexpectedness of conceiving following a history of menstrual disturbances (Bulik et al., 2010; Easter et al., 2011; Micali, dos-Santos-Silva, et al., 2014; Morgan, Lacey, & Chung, 2006; Morgan, Lacey, & Sedgwick, 1999).

1.4.2 Pregnancy and postnatal outcomes

Pregnant women with ED are known to have heightened risk of adverse pregnancy, birth and postnatal outcomes. Evidence indicates risks vary between ED categories and persist among those in remission although higher for women with active ED during pregnancy. A large UK general population birth cohort study reported an increased risk of miscarriage for women with lifetime BN (Micali, Simonoff, &

Treasure, 2007). Another study, using data extracted from medical records, reported women with lifetime BED were at risk of suffering a miscarriage, lifetime AN and lifetime subthreshold BN reflected a similar trend, whereas lifetime BN had higher risk of induced abortions (Linna et al., 2013). Findings from a smaller study comparing women with current and past BN, indicate differences in reported risk of miscarriage likely relate to whether studies assess current or past ED (Morgan et al., 2006). Although less thoroughly researched, evidence indicates current and past maternal ED are associated with several complications of pregnancy, such as increased risk of pregnancy-related vomiting and hyperemesis gravidarum in purging type diagnoses, gestational diabetes and pre-eclampsia in BN and BED, hypertension in BED, and anaemia in AN (Linna et al., 2014; Torgersen et al., 2008; Watson et al., 2017).

Research in this area has predominately focused on investigating associations of ED with adverse birth outcomes, with the most consistent findings on adverse infant growth outcomes. Current and lifetime AN has been found to increase the risk of intrauterine growth restriction and delivering an infant that is small for gestational age, small birth length and low birth weight (Eik-Nes et al., 2018; Linna et al., 2014; Micali, Simonoff, et al., 2007; Micali, Stemann Larsen, Strandberg-Larsen, & Nybo Andersen, 2016; Solmi, Sallis, Stahl, Treasure, & Micali, 2014; Watson et al., 2017). Conversely, lifetime BED, which is commonly associated with excessive body weight (de Zwaan, 2001; Hudson et al., 2007), is associated with an increased risk of delivering an infant that is large for gestational age (Bulik et al., 2009; Linna et al., 2014; Watson et al., 2017). Although there is limited research assessing the impact of OSFED on pregnancy and birth outcomes, evidence indicates that sub-threshold ED similarly reflect heightened risk (Eik-Nes et al., 2018; Linna et al., 2013; Watson et al., 2017). Other risks associated with ED include suspected foetal distress, premature birth, rapid and prolonged labour, caesarean and induced delivery, low Apgar scores (Eik-Nes et al., 2018; Linna et al., 2014; Micali et al., 2012; Morgan et al., 2006; Watson et al., 2017). Research indicates the associations are mediated by a combination of factors such as ED severity, prenatal and pregnancy nutrition, pre-pregnancy weight and gestational weight gain and heritability, suggestive of

differential mechanistic pathways between the diagnostic categories (Kimmel et al., 2016; Micali et al., 2012; Watson et al., 2017).

Research indicates maternal ED are also associated with several important early postnatal outcomes, including infant feeding practices and infant growth. Infant feeding is one of the most important parental responsibilities and evidence indicates women with ED may find the experience more challenging, though findings are somewhat discrepant possibly due to differences in study design and population. Larsson et al (2003) reported that women self-reporting lifetime ED were less likely to commence breastfeeding compared to women without ED. Alternatively, a larger general population birth cohort study reported no differences in initiation of breastfeeding between women with and without ED before pregnancy but earlier cessation of breastfeeding among women with ED and this was across all ED categories (Torgersen et al., 2010). Another large general population birth cohort study reported women with lifetime ED were more likely to initiate breastfeeding and less likely to cease breastfeeding during the first year of life, particularly women with lifetime BN (Micali, Simonoff, & Treasure, 2009). Though findings from the same study indicate women with lifetime ED were more likely to report difficulties with infant feeding, particularly among women with AN, which had implication for adverse infant weight (Micali et al., 2009). Subsequent investigations in the same sample highlight a mediating role of antenatal and postnatal depression and anxiety symptoms rather than active ED symptoms in these associations (Micali, Simonoff, Stahl, & Treasure, 2011).

Other studies have similarly identified an association of lifetime ED with infant feeding difficulties (Reba-Harrelson et al., 2010). Reports from case studies suggest women with lifetime ED find infant meal times tense and infants are prone to mirroring their mothers' disordered eating behaviours and cognitions (Little & Lowkes, 2000). Stein et al (1996) reported on longitudinal data that infants of mothers with ED were smaller compared to infants of mothers with no ED and mothers with postnatal depression. Studies in larger samples have similarly

demonstrated associations of ED with childhood growth outcomes (Easter et al., 2014).

Furthermore, research continues to investigate the effects of maternal ED on adverse infant and child outcomes, indicating potential implications for infant and child temperament, psychopathology including ED pathology, and social and cognitive development (Barona et al., 2017; Kothari, Barona, Treasure, & Micali, 2015; Micali, Stahl, Treasure, & Simonoff, 2014; Alan Stein et al., 2006; Zerwas et al., 2012).

1.4.3 Psychopathology during pregnancy

Pregnancy is a unique experience for a woman, accompanied by significant changes to a woman's sense of self and her body (Barclay, Everitt, Rogan, Schmied, & Wyllie, 1997). A recent meta-ethnographic study was conducted to systematically review and synthesise the findings from qualitative studies exploring the experiences of pregnancy and the postnatal period in women with ED (Fogarty, Elmir, Hay, & Schmied, 2018). The synthesised findings indicate that the early stages of pregnancy can be highly emotive for women with current and past ED as they encounter changes in appetite, body weight and shape, compounded by an internal conflict between their ED and the desire to protect their unborn infant from harmful ED behaviours (Fogarty et al., 2018). Most women with ED adjust as pregnancy progresses with the motivation to ensure optimum health of the unborn infant, though for some women the experience can cause them to feel a sense of loss for their pre-pregnancy ED self and women still engaging in ED behaviours during pregnancy feel shameful and guilty about not being able to stop (Fogarty et al., 2018). The early postnatal period can be another challenging time for women with ED as without the same motivation, women often experience a resurgence of ED behaviours as they try to adjust and identify with a new postnatal body that neither resembles their pre-pregnancy or pregnancy body shape (Fogarty et al., 2018).

One of the studies included in the meta-synthesis was by Taborelli et al (2015), which explored the experiences of pregnancy in a sample of postnatal women with severe ED, including several women who had been pregnant more than once. The findings

highlighted that compared to the first pregnancy, women were less motivated to change their ED behaviours during a subsequent pregnancy as they were less concerned about the potential harm to their unborn infant having felt reassured by the birth of a previous healthy infant (Taborelli et al., 2015). Without this motivation, women often continued to engage in ED behaviours during pregnancy as a means of limiting the amount of weight they gained during pregnancy that they would then feel the need to lose postnatally (Taborelli et al., 2015). These exploratory studies provide important insight on the experience during and following pregnancy for women with ED, though they have primarily focused on women with AN, with little representation of women with BED and sub-threshold ED who likely reflect an alternative perspective.

The understanding from these exploratory studies corresponds to the findings from studies employing quantitative approaches. The majority of studies report that women with ED tend to experience a reduction in ED symptoms during pregnancy (Blais et al., 2000; Crow, Agras, Crosby, Halmi, & Mitchell, 2008; Easter et al., 2015; Micali, Treasure, & Simonoff, 2007; Morgan, Lacey, et al., 1999). However, this is not the case for all women and more often behavioural symptoms (e.g. self-induced vomiting) decrease whilst cognitive symptoms persist (Blais et al., 2000; Micali, Treasure, et al., 2007; Morgan, Lacey, et al., 1999). Women with ED often report high levels of weight and shape concern and concern about gestational weight gain (Micali, Treasure, et al., 2007; Swann et al., 2009).

Watson et al (2013), using data from a large general population birth cohort study, demonstrated that the course of ED from before to during pregnancy varied across diagnostic groups. In this study, women with BED before pregnancy more often continued to meet criteria during pregnancy whereas women with BN and PD before pregnancy more often remitted during pregnancy (Watson et al., 2013). Though AN was not assessed antenatally in this study, precluding the ability to make inferences about the trajectory for this group. A prospective longitudinal study assessed symptoms of psychopathology across the perinatal period in women with current and past ED compared to a control group (Easter et al., 2015). ED symptoms reportedly

decreased during pregnancy but increased postnatally in women with current ED, whereas ED symptoms steadily increased across the perinatal period in women with past ED (Easter et al., 2015). Though irrespective of these fluctuations, ED symptoms in the two ED groups were higher than the control group and were comparable to one another by six months postpartum.

Despite the tendency for ED symptoms to decrease during pregnancy, studies often indicate that sustained remission is infrequent with symptoms often returning to pre-pregnancy levels or in some cases, worse than pre-pregnancy within the first year postpartum (Blais et al., 2000; Crow et al., 2008; Lacey & Smith, 1987; Morgan, Lacey, et al., 1999). Another investigation of general population data, explored rates of continuation and remission of ED from before pregnancy into the postnatal period and found 41-70% of women had persistent ED at three years postpartum, which varied between diagnostic groups and highest for women with BN before pregnancy (Knoph et al., 2013). Several studies have also found evidence that for a minority of women, pregnancy can trigger a worsening of ED symptoms in women with prior ED or new onset of an ED for women not previously effected, most commonly BED (Conrad, Schablewski, Schilling, & Liedtke, 2003; Easter et al., 2013; Micali, Treasure, et al., 2007; Tiller & Treasure, 1998; Watson et al., 2013). This group of women are of particular concern given the increased risk of adverse maternal and infant outcomes due to active behaviours during the perinatal period.

Several studies have reported that women with current and past ED often experience high levels of anxiety and depression symptoms during and following pregnancy (Easter et al., 2015; Maihara dos Santos et al., 2017; Mazzeo et al., 2006; Micali, Simonoff, & Treasure, 2011). Micali et al (2011) using a large general population birth cohort study, reported that women with ED were more at risk of anxiety and depression symptoms antenatally if they reported a history of depression or experienced persistent ED symptoms during pregnancy. Given the heightened levels of psychopathology during and following pregnancy in women with ED, evidence indicates that women with ED are at risk of postnatal depression, particularly women with BED and BN (Mazzeo et al., 2006; Morgan et al., 2006). Much of the literature

on the course of ED symptoms during and following pregnancy has focused on women with AN and BN, with considerably less known about the course of ED symptoms during pregnancy in women with OSFED.

1.4.4 Prevalence of eating disorders in pregnant women

There is currently insufficient and conflicting research to accurately determine how many pregnant women have a current or prior history of ED. Assessing active symptomology in pregnant women can be challenging given the typical fluctuations during pregnancy (Easter et al., 2015) and the need to distinguish disordered eating symptoms from typical pregnancy symptoms, i.e. self-induced vomiting vs. nausea and vomiting (Mitchell & Bulik, 2006). Inconsistencies in reported prevalence between studies likely relate to variations in instruments used to assess ED in the absence of a validated antenatal screening tool, and in operationalised ED definitions given the lack of appropriate algorithms for pregnant women (Paslakis & de Zwaan, 2019) and recently revised ED criteria in DSM-5 (APA, 2013). Recent reports indicate 1.9-7.6% of pregnant women may be affected by ED during pregnancy (Easter et al., 2013; Howard et al., 2018; Maihara dos Santos et al., 2017; Watson et al., 2013) and 4.5-9.2% before pregnancy (Easter et al., 2013; Watson et al., 2013).

Easter et al (2013), using an adapted version of a validated self-report questionnaire and classifications pre-emptive of DSM-5 (APA, 2013) diagnostic criteria, reported 7.5% of pregnant women in a South-East London general population sample met criteria for ED, of which the prevalence of AN, BN, BED, PD and broadly defined EDNOS were 0.5%, 0.1%, 1.8%, 0.1% and 5.0%, respectively. In this sample, prevalence before pregnancy was marginally higher with 9.2% of women retrospectively reporting ED symptoms in the year before pregnancy, of which the prevalence of AN, BN, BED, PD and broadly defined EDNOS were 0.4%, 0.1%, 1.2%, 0.1% and 6.1%, respectively (Easter et al., 2013). Although the findings reported are on interim survey findings rather than the complete dataset and classifications were prior to the release of DSM-5 (APA, 2013). Findings from a large general population birth cohort study, using an unvalidated self-report questionnaire, reported a lower prevalence of 5.0% for ED during pregnancy (BN 0.2%, BED 4.8%, PD <0.01%) and

4.5% before pregnancy (AN 0.1%, BN 1.0%, BED 3.3%, PD 0.1%), though some prevalence estimates were consistent i.e. BN during pregnancy and PD before pregnancy (Watson et al., 2013). As with the reported interim survey findings from that study (Bulik et al., 2007), ED prevalence was higher during pregnancy compared to before pregnancy due to new onset of BED cases and BED was the most common ED at both time points. This study used broadly defined categories of ED i.e. BED associated features were not included in the classification of BED, though frequencies corresponded to DSM-5 (APA, 2013) thresholds. Further, AN was not assessed during pregnancy in this Norwegian sample with the authors citing challenges assessing the weight criterion during pregnancy, which precluded the ability to explore rates of remission, continuation and incidence in this diagnostic group.

More recently, two studies (Howard et al., 2018; Maihara dos Santos et al., 2017) were the first to report using diagnostic interviews to establish prevalence of current ED during pregnancy in accordance with DSM-5 (APA, 2013). Maihara dos Santos et al (2017), using a cross-sectional survey in a Brazilian sample of second and third trimester pregnant women, reported a prevalence of 1.9% for full threshold current ED in pregnant women, of which AN, BN and BED was 0.1%, 0.7% and 1.1%, respectively. This study did not assess prevalence of OSFED during pregnancy or diagnoses before pregnancy. Howard et al (2018), using a stratified sampling design, reported an estimated prevalence of 2% for current ED during pregnancy, considerably lower than previous studies. This study did not report estimates of prevalence for the different types of ED and similarly did not report prevalence of ED prior to pregnancy.

1.5 Implications for identifying and managing maternal ED in maternity and health visiting services

1.5.1 Recommendations for clinical practice

Given the heightened risks for pregnant and postnatal women with active and remitted ED, early identification and response to a woman's healthcare needs are imperative to mitigate potentially adverse maternal and infant outcomes. Ideally

women with ED would be identified and receive appropriate treatment in the pre-conception period so that they are in a better state of health when they do try to conceive to increase the chances of having a successful and healthy pregnancy. This is not often feasible though due to the increased risk of unplanned pregnancies for women with ED (Easter et al., 2011; Micali, dos-Santos-Silva, et al., 2014). Pregnancy, particularly the early stages of a first pregnancy, presents a key opportunity when women are highly motivated to change their ED behaviours so timely and appropriate identification and support is essential (Crow, Keel, Thuras, & Mitchell, 2004; Taborelli et al., 2015).

The World Health Organization (WHO) encourages the integration of mental health approaches into existing healthcare services to enhance early identification and support of pregnant and postnatal women who have a mental illness (World Health Organization, 2018). In the UK, the National Institute for Health and Care Excellence (NICE) who produce guidance to inform health and social care practice, similarly advocate the importance of early identification and appropriate response to perinatal mental illness in routine antenatal and postnatal care, with referral to specialist services when deemed necessary (NICE, 2014).

NICE guidance highlights the need for healthcare professionals to be sensitive when enquiring with pregnant and postnatal women about mental illness, recognising that women can be reluctant to disclose a mental illness and engage with healthcare professionals due to fear of being stigmatised or avoidance associated with their mental illness (NICE, 2014). To encourage identification of pregnant and postnatal women with or at risk of developing mental illness, healthcare professionals are recommended to routinely enquire about current and history of any mental illness with all women at their first routine contact with healthcare services in pregnancy and the postnatal period (NICE, 2014). Any disclosed history of mental illness should then be explored to ascertain a woman's current mental health status and healthcare needs (NICE, 2014). The guideline for antenatal and postnatal mental health (NICE, 2014) recommends pregnant and postnatal women identified with ED should be offered treatment for their ED in accordance with the ED guideline (NICE, 2017),

should be monitored throughout pregnancy and the postnatal period including assessment of the need for foetal growth scans, and discussions should cover the importance of good nutrition and infant feeding in accordance with the maternal and child nutrition guideline (NICE, 2008b). The more recent ED guideline also recommends the nomination of a dedicated healthcare professional (for example a general practitioner [GP] or midwife) to provide the continuity of carer needed for monitoring and support throughout the perinatal period (NICE, 2017).

1.5.2 Relevance for maternity and health visiting services

In the UK, most pregnant women access National Health Service (NHS) maternity care. In the NHS, pregnant women are offered several routine contacts with a midwife (and obstetrician, depending on the woman's circumstances, health and location), for the duration of the pregnancy and following the birth up until one month post-birth, at which point they are discharged from maternity care to their GP (National Institute for Health and Care Excellence, 2008a). Health visitors (qualified nurses or midwives who have additional training as specialist community public health nurses) are also responsible for providing several routine contacts from pregnancy up until their infant is five years old as part of the national Healthy Child Programme (Department of Health, 2009). Considering the frequency of routine contacts with all pregnant and postnatal women, midwives and health visitors are ideally placed to identify and support women with ED in accordance with NICE guidance.

1.5.3 Barriers to identification and management of maternal ED

The NICE recommendations to support effective identification and management of pregnant and postnatal women with ED should be implemented into practice to reduce the risk of adverse maternal and infant outcomes, however evidence on uptake and use of the guidance is limited. The majority of research has explored barriers to identification of ED in non-pregnant populations, with limited exploration of the barriers to effective identification and support of pregnant and postnatal women with ED from the perspectives of women and healthcare professionals, and

none to the candidate's knowledge including the perspectives of midwives and health visitors. The most prominent barriers to identification and support of individuals with ED from mostly non-pregnant population studies but also some antenatal studies, are outlined below.

1.5.3.1 Lack of disclosure and help seeking in ED

Identification of ED and subsequent assessment of healthcare needs are largely dependent on an individual disclosing their ED to a healthcare professional and engaging with the support offered. Disclosure to a healthcare professional is known to increase the likelihood of an individual subsequently seeking treatment for their ED (Becker et al., 2005). However, lack of disclosure to healthcare professionals and treatment seeking has been frequently reported in the wider ED literature (Becker et al., 2005; Evans et al., 2011; Hart et al., 2011; Hepworth & Paxton, 2007; Hudson et al., 2007; Swan & Andrews, 2003). Two large general population studies in the US and Europe demonstrated that although a substantial proportion of adults with ED had previously accessed healthcare services for mental health difficulties, this was often not for their ED, particularly among those with current ED (Hudson et al., 2007; Preti et al., 2009). A UK general population study found that only 30% of individuals with ED had sought treatment for their mental health difficulties in the past year, even though comorbid mental illness and substance misuse were common (Solmi et al., 2016). Similarly, a recent UK general population birth cohort study of women followed up in mid-life reported less than a quarter of those identified with a lifetime ED had ever sought treatment or support for their ED (Micali et al., 2017).

One study investigated disclosure of ED in women attending an infertility clinic and found the majority of women identified with ED had not disclosed a history or current ED to the infertility specialist responsible for their care (Freizinger, Franko, Dacey, Okun, & Domar, 2010). A qualitative study exploring experiences of maternity care among a sample of pregnant and postnatal women with AN and BN similarly identified a reluctance among some of the women to disclose their ED to a healthcare professional involved in their maternity care (Stringer, Tierney, Fox, Butterfield, & Furber, 2010). Though barriers to disclosure were not specifically explored in this

study and the findings are limited to the experiences of maternity care among women with AN and BN. Another study in a small sample of parous and nonparous women with current and past ED, including two nonparous women with past BED, similarly found parous women were reluctant to disclose their ED to antenatal healthcare professionals with one expressing this was associated with a reluctance to receive treatment for her ED (Claydon et al., 2018).

1.5.3.2 Stigma and shame

Stigma refers to anticipated and actualised stereotyping, prejudice and discrimination to the detriment of the targeted group (Link & Phelan, 2001). Stigma has been consistently implicated as a barrier to disclosure and treatment seeking in the wider ED and mental health literature (Clement et al., 2015; Hepworth & Paxton, 2007; Swan & Andrews, 2003). A recent systematic review was conducted to explore the perceived barriers and facilitators to help seeking for ED, with stigma consistently one of the main barriers cited by individuals with ED from a range of qualitative, quantitative and mixed method studies (Ali et al., 2017). The stigma towards mental health is widely recognised and individuals with ED are often perceived by the public as being more responsible and in control of their ED behaviours, thus invoking less empathy compared to other illnesses (Ebneter & Latner, 2013; Roehrig & McLean, 2010). The stigmatising attitudes towards BED specifically are comparable to the negatives attitudes towards obesity that are present within society (Puhl et al., 2013).

A recent qualitative study explored disclosure of perinatal depression and the role of stigma in online forum discussions and reported that the main concerns among women was being stigmatised, particularly a fear of negative judgements of them as a mother and of the child being removed from their care (Moore, Ayers, & Drey, 2016). Another study explored the role of stigma in women who experienced mental illness in the postnatal period, similarly reported fears about negative perceptions of their parental ability hindered disclosure but also actualised stigma within healthcare was common (Edwards & Timmons, 2005). Two studies have explored routine enquiry about mental health in maternity services specifically and reported that reluctance among women with mental health difficulties to disclose was often due to

fear of adverse consequences, namely stigma and negative perceptions of them as a mother (Kingston et al., 2015; Yapp et al., 2019). Stringer et al (2010) reported on their qualitative findings that some women had been reluctant to disclose their ED to antenatal healthcare professionals due to feelings of shame as they felt there was an expectation on them to be positive in pregnancy which made disclosure more challenging.

1.5.3.3 Lack of enquiry

In the absence of voluntary disclosure, healthcare professionals must proactively enquire about ED to increase the likelihood of an individual making a positive disclosure about ED (Becker et al., 2005). However, given wide disparities in prevalence of ED between studies utilising healthcare records compared to general population data, it is apparent that ED are frequently poorly identified in healthcare (Boulé & McSherry, 2002; Smink et al., 2012). A survey by Morgan (1999) about clinical practice in 115 gynaecologists and obstetricians from the UK and Australia, reported that 27% of the sample rarely or never enquired about current or prior history of ED with pregnant women. Similarly, Abraham (2001) surveyed clinical practice among a sample of obstetricians in Australia and found that less than half of the sample reported enquiring with women about ED and none assessed women's pre-pregnancy weight, which could serve as a useful indicator of low maternal weight.

A survey of clinical practice in London-based GPs found that half of the sample either never enquired about ED or only enquired if there were clinical indicators of a possible ED, particularly among male GPs (Boulé & McSherry, 2002). In this sample, younger female GPs were more likely to routinely screen for ED and reported seeing higher numbers of patients with ED compared to male GPs, with the authors suggesting this may reflect a bias for female patients to request to see female healthcare professionals or enhanced awareness about ED among the female healthcare professionals given ED are more commonly experienced by women (Boulé & McSherry, 2002). A cross-sectional survey in the US with healthcare professionals including obstetricians and psychiatrists, found that only a third of the sample

reported actively enquiring about eating behaviours with patients, though more frequently in obese patients (Supina, Herman, Frye, & Shillington, 2016). A recent study by Rodino et al (2017) explored clinical practice among fertility specialists in Australia and New Zealand and found that despite high recognition among the specialists of the need to identify ED, only a minority routinely enquired about ED. Findings from a large US survey of obstetricians and gynaecologists indicated that whilst the majority were aware of the implications of ED on pregnancy and birth outcomes, enquiry about ED was still low, with many perceiving screening for ED was not part of their professional remit (Leddy, Jones, Morgan, & Schulkin, 2009). Research among women with past and current AN and BN who had previously accessed UK maternity care, similarly reported the majority of the sample had not been asked about their ED in maternity care contacts (Stringer et al., 2010).

1.5.3.4 Knowledge among healthcare professionals

Given the challenges with identifying ED in pregnant women, it is important for healthcare professionals to be adequately trained and knowledgeable about maternal ED to promote effective identification and appropriate response. However, studies have consistently demonstrated poor knowledge of ED across a range of healthcare professionals. A survey of GPs from across general practices in London reported the majority of the sample considered their training on ED to be insufficient and were more comfortable identifying rather than managing ED likely due to limited knowledge and capacity to manage the complexities of ED (Boulé & McSherry, 2002). Another UK study of GPs reported substantial deficits in ED knowledge, particularly on ED symptoms and associated health complications, though lack of knowledge was not associated with negative attitudes about ED (Currin, Waller, & Schmidt, 2009).

Williams and Leichner (2006) found that whilst a majority of Canadian psychiatry residents were interested in treating ED, the majority reported that they considered their training on ED to be inadequate, having had no clinical experience in treating ED during their training. Research in the UK with psychiatrists similarly reported deficits in knowledge and lack of confidence in identifying, with those working in

settings with opportunities to engage with individuals with ED and more qualified psychiatrists doing better (Jones, Saeidi, & Morgan, 2013).

Findings from a survey conducted by Banas et al (2013) reported that interest and comfort in identifying ED varied between specialists with those in general practice, with women and those with personal experience of an unexplained weight loss among a family member tending to be more favourable about identifying ED. Morgan (1999) reported that knowledge on ED varied considerably and in relation to level of seniority, among a sample of obstetricians and gynaecologists, with knowledge on the implications for prenatal and pregnancy outcomes being particularly poor. Rodino et al (2017) reported knowledge on ED and confidence in the ability to identify ED was considerably low, with many advocating the need for better training, among a sample of fertility specialists from clinics across Australia and New Zealand. Though unlike previous reports, this study did not detect differences in knowledge or clinical practice between fertility specialists based on their length of clinical experience.

A recent US cross-sectional survey of healthcare professionals including obstetricians and psychiatrists, reported that whilst the majority correctly recognised BED from several case vignettes, BED was frequently not recognised as a distinct ED, which has important implications for identification and response in healthcare services for this ED (Supina et al., 2016). Lack of knowledge about ED among healthcare professionals was similarly reported among women with ED whilst reflecting on their experiences in maternity care (Stringer et al., 2010).

1.6 Systems Theory

Systems theory proposes that systems such as the healthcare system are complex and comprised of multiple related factors (Anderson, 2016; Von Bertalanffy, 1968). Theorists suggest that attempting to identify a single barrier to a problem in the system without consideration for other related barriers is unlikely to provide an adequate explanation, rather it is necessary to understand all related barriers to develop a comprehensive understanding (Anderson, 2016; Grol & Grimshaw, 2003).

Furthermore, work by Ferlie and Shortell (2001) emphasised that the barriers to recommended practice often operate on multiple levels in the healthcare system, including on an individual level (i.e. a person's knowledge, attitudes and characteristics), within the care group (i.e. the healthcare professional involved in a person's care), in the organisation (i.e. the clinic or hospital), and in the wider socioeconomic and political environment.

1.7 Summary and gaps in the literature

In summary, ED are a heterogeneous group of mental illnesses characterised by severe disturbances in eating behaviour and often associated with significant distress, functional impairment and adverse health outcomes (Kessler et al., 2013; Preti et al., 2009; Stice et al., 2013). Pregnant women with ED are known to have heightened risk of adverse prenatal, pregnancy and postnatal outcomes, with risks varying between ED categories and persisting among those in remission (Eik-Nes et al., 2018; Linna et al., 2013, 2014; Micali, dos-Santos-Silva, et al., 2014; Solmi et al., 2014; Watson et al., 2017). Studies indicate pregnancy can be highly emotive for women with current or past ED, most women adjust as pregnancy progresses but there is evidence of symptoms persisting, new onset of ED during pregnancy and high risk of postnatal relapse (Blais et al., 2000; Easter et al., 2015; Fogarty et al., 2018; Knoph et al., 2013; Micali, Treasure, et al., 2007; Morgan, Lacey, et al., 1999; Watson et al., 2013).

Recent reports indicate 1.9-7.6% of pregnant women may be affected by ED during pregnancy (Easter et al., 2013; Howard et al., 2018; Maihara dos Santos et al., 2017; Watson et al., 2013) and 4.5-9.2% before pregnancy (Easter et al., 2013; Watson et al., 2013). However, there is currently insufficient and conflicting research to accurately determine how many pregnant women have current or prior history of ED, in accordance with DSM-5 (APA, 2013). Considering the changes in ED symptoms during the perinatal period and heightened risk of adverse outcomes, with differing risk profiles between categories that persist amongst those in remission, it is important to investigate the prevalence of all DSM-5 (APA, 2013) ED during and

before pregnancy, to ensure equal recognition of those with active and remitted ED during pregnancy.

Given the heightened risks associated with maternal ED, early identification and response to a woman's healthcare needs are imperative to promote optimum maternal and infant outcomes. NICE recommends healthcare professionals should routinely enquire about current and past mental illness with all women at their first routine contact with healthcare services in pregnancy and the postnatal period (NICE, 2014). NICE recommends healthcare professionals should offer women with ED enhanced monitoring and support throughout pregnancy into the postnatal period (NICE, 2017). Considering the frequency of routine contacts with all pregnant and postnatal women, midwives and health visitors are ideally placed to identify and support women with ED in accordance with NICE guidance. The recommendations to support effective identification and management of pregnant and postnatal women with ED should be implemented to reduce the risk of adverse maternal and infant outcomes, however evidence on uptake and use of the guidance is limited. There has been limited exploration of barriers to effective identification and management of pregnant and postnatal women with ED from the perspectives of women, and to the candidate's knowledge, there has not been a previous exploration from the perspectives of midwives and health visitors. It is important to explore the perspectives of women, midwives, and health visitors to develop a comprehensive understanding of the barriers that need addressing to ensure pregnant and postnatal women with ED receive the recommended standard of healthcare to promote optimal outcomes for mother and child.

1.8 General aims

Two general aims were generated from the narrative literature review and underpin this programme of research. These overarching aims were to:

1. Investigate the prevalence of current and past ED among pregnant women and implications of using different methods of data collection.

2. Explore identification and management of pregnant and postnatal women with ED in maternity and health visiting services from the perspectives of women, midwives and health visitors.

Four studies using particular methods were conducted to research the specific aims of these overarching aims. The primary aim of each study is outlined below, with secondary aims and the hypotheses presented in the relevant chapters.

Study one

The primary aim of study one was to investigate the prevalence of ED before and during pregnancy in a sample of pregnant women in South-East London, using a self-report questionnaire to determine diagnoses consistent with DSM-5 (APA, 2013).

Study two

The primary aim of study two was to estimate the prevalence of lifetime and current ED in a sample of pregnant women in South-East London, using diagnostic interviews to determine diagnoses consistent with DSM-5 (APA, 2013).

Study three

The primary aim of study three was to explore the experiences of maternity care in women with lifetime ED.

Study four

The primary aims of the study were to: 1) examine knowledge and attitudes to identifying and managing pregnant and postnatal women with ED amongst midwives and health visitors; and 2) explore the barriers to identifying and managing pregnant and postnatal women with ED in maternity and health visiting services from the perspectives of midwives and health visitors.

Chapter 2 Methodology and Methods

2.1 Chapter overview

This chapter presents an overview of the methodological approach and methods used in this programme of research. This programme of research comprised of four studies, each using a particular design and method to research the specific aims of the general aims presented in chapter one, and these are outlined in this chapter including an overview of the types of analyses conducted in these studies. Specific details on the aims, methods and analyses in each study are presented in the individual study chapters.

2.2 Philosophical orientation

There is an understanding that the philosophical beliefs about the world (i.e. what is reality and what is knowledge or truth) that are held by the researcher determine their methodological approach to a research question as they will be driven to select particular research methods and procedures to generate the type of data that would be recognised as of value according to their philosophical orientation (Creswell & Creswell, 2018). It is argued that whilst many researchers will not explicitly recognise the influence their philosophical beliefs have on the methodological approach they adopt, in doing so it encourages a more thorough and critical approach to their research (Bazeley, 2013).

The philosophical approach underpinning this programme of research is essentially one of pragmatism. Pragmatism as a philosophy originates from the work of philosophers in the 1870's, most notably Peirce, James, Dewey and Mead (Cherryholmes, 1992). More recently, Murphy (1990) and Patton (1990), among others, have sought to redefine and develop the philosophical assumptions of pragmatism. Though the assumptions under pragmatism have broadened and deviated since the work of earlier philosophers, a problem-focused and pluralistic

approach is consistently emphasised across the different versions of pragmatism (Teddlie & Tashakkori, 2009).

Pragmatism is not limited to any one philosophical belief system about the world, instead it recognises there is value in each of the different philosophical perspectives (Teddlie & Tashakkori, 2009). Researchers are encouraged to draw upon elements of different perspectives and assumptions about the world depending on what is considered most useful for addressing a particular research problem in a given context (Creswell & Creswell, 2018). This flexibility enables researchers to employ a pluralistic approach in selecting which is the most useful and practical method for addressing the research problem, rather than ascribing to and being limited to a single methodological approach and the underlying philosophical assumptions, irrespective of the type of research problem (Creswell & Creswell, 2018; Teddlie & Tashakkori, 2009). It is these presiding principles of pragmatism that provide a strong theoretical rationale for multi-method and mixed-method research (Teddlie & Tashakkori, 2009).

2.3 Multi-method research approach

This programme of research employed a multi-method research approach. Multi-method research was first defined in the 1980's at a time when the majority of research consisted of standalone studies employing a single research method. Multi-method research is defined as a planned synthesis of two or more research methods conducted independently from one another to research the specific aims of an overarching or general aim that underpins a programme of research (Brewer & Hunter, 1989; Morse, 2003).

The methods used in multi-method research are the standard methods used in research and can consist of any combination of quantitative, qualitative and mixed methods, dependent on what is considered most appropriate for the specific aim of the research. A research aim is intended to either test ideas or hypotheses, using

mainly a deductive or confirmatory approach, or to generate new knowledge, using more of an inductive or discovery approach (Morse, 2003).

A deductive theoretical approach underpins most quantitative research, involving the collation of what is known from existing theory or evidence to deduce a hypothesis that can be tested in a research study, with the findings confirming or rejecting the hypothesis and the necessary revisions being made to the existing understanding (Bryman, 2016). Quantitative methods i.e. questionnaires, are concerned with the collection and examination of numerical data to produce numerical descriptions or explanations of a population sample (Bryman, 2016). Philosophical beliefs of positivism are the premise for a deductive approach and most traditional scientific research, which essentially contend that knowledge of the world can be measured objectively and only knowledge that is measurable can be considered as true knowledge (Bryman, 2016).

Conversely, an inductive approach is the basis for most qualitative research, whereby existing theory or evidence may inform the development of a study, but the objective is to generate understanding from the research (Bryman, 2016). Qualitative methods i.e. focus groups, are concerned with the collection of narrative non-numerical data to enable understanding and interpreting individual experiences and attitudes (Creswell & Creswell, 2018). Interpretivism is considered the opposing philosophical belief system to positivism and underlies an inductive approach, which essentially recognises the subjectivity of knowledge (Bryman, 2016).

Mixed method research is relatively new compared to the other methods, stemming from the same period of time as multi-method research. It is a more controversial approach, having developed from debates on the incompatibility of quantitative and qualitative methods and their underlying theoretical principles, with advocates proposing the paradigms are not as incompatible as previously thought and both are necessary for addressing complex research problems (Creswell & Plano Clark, 2006). Mixed method research is defined as the collection and integration of both

quantitative and qualitative data in a single study, for the purposes of producing a more in-depth understanding than would be achieved from either method alone (Tashakkori & Creswell, 2007). Mixed methods research includes adaptations to the standard questionnaire method (combining open-ended questions with closed-ended questions) and the more recently defined strategies of integrating both types of data, such as a sequential explanatory design which involves the collection of quantitative data followed by the collection of qualitative data to explain and expand on the quantitative data (Creswell & Creswell, 2018).

There are several advantages to using a multi-method research design, many of which parallel the rationale for conducting mixed-method research, including triangulation, comprehension, convergence, divergence, and complementary.

It is understood that each research method generates particular types of data and has distinct strengths and weaknesses that will differ from other methods. Therefore, purposefully triangulating (or combining) different methods in a programme of research can mean the weaknesses of one research method are offset against another method that does not have the same weaknesses (Denzin, 1978).

Combining the findings obtained from two or more studies that research the specific aims of an overarching aim is considered to generate a more comprehensive and expansive understanding of the research problem than would be possible from a single study alone (Brewer & Hunter, 1989).

Convergent (or consistent) findings obtained from two or more studies will often be considered more reliable than had they have been produced from only one study, though if the convergent findings are generated from a single method then both sets of findings will be vulnerable to the same measurement error (Brewer & Hunter, 1989). Therefore, triangulating different methods that have distinct weaknesses in a research programme means any convergence in the findings generated from these different methods are likely to be reliable (Brewer & Hunter, 1989).

Divergent (or discrepant) findings generated from different methods are also useful as they can indicate that further research is necessary and interpretations on the significance of the findings are needed to consider possible explanations for the divergence (Brewer & Hunter, 1989). Furthermore, comparing divergent findings obtained from different methods can generate new perspectives or interpretations of the findings (Greene, Caracelli, & Graham, 1989; Kidder & Fine, 1987).

Finally, triangulation of different methods whereby each method is used for a different but complementarity objective can enhance the meaningfulness and interpretability of the findings that are generated (Mark & Shotland, 1987).

2.4 Programme of research

This programme of research comprised of four studies. The four studies were conducted to research the specific aims of the general aims presented in chapter one, with each study using a particular design and method of data collection that was considered most appropriate and practical. An overview of this programme of research is presented in Table 2-1. The design and method used in each of the four studies are outlined below, with specific details presented in the individual study chapters.

Table 2-1 Overview of this programme of research

General aim	Primary aim	Study	Design	Method	Type of data
1) Investigate the prevalence of current and past ED among pregnant women and implications of using different methods of data collection	1) To investigate the prevalence of ED before and during pregnancy in a sample of pregnant women in South-East London, using a self-report questionnaire to determine diagnoses consistent with DSM-5	Study 1: Prevalence of ED in pregnant women, using a self-report questionnaire	Cross-sectional survey	Self-report questionnaire	Quantitative
	2) To estimate the prevalence of lifetime and current ED in a sample of pregnant women in South-East London, using diagnostic interviews to determine diagnoses consistent with DSM-5	Study 2: Prevalence of ED in pregnant women, using diagnostic interviews	Cross-sectional survey	Diagnostic interviews	Quantitative
2) Explore identification and management of pregnant and postnatal women with ED in maternity and health visiting services from the perspectives of women, midwives and health visitors	3) To explore the experiences of maternity care in women with lifetime ED	Study 3: Experiences of maternity care in women with ED	Cross-sectional survey	Self-report questionnaire	Quantitative and qualitative
	4) To examine knowledge and attitudes to identifying and managing pregnant and postnatal women with ED amongst midwives and health visitors	Study 4: Identification and management of ED in maternity and health visiting services	Mixed method sequential explanatory design	Self-report questionnaire	Quantitative
	5) To explore the barriers to identifying and managing pregnant and postnatal women with ED in maternity and health visiting services from the perspectives of midwives and health visitors			Focus groups	Qualitative

2.5 Study designs

Each of the four studies in this programme of research used one of two study designs, cross-sectional survey or mixed-methods sequential explanatory design, the details of which are outlined below.

2.5.1 Cross-sectional survey design

A cross-sectional survey design was used for studies one, two and three, the results of which are presented in chapters three, four and five, respectively. Cross-sectional studies involve the collection of data on a sample of the population at a single time point to describe and explore associations between two or more variables (Bryman, 2016). They involve the recruitment of a relatively small sample to generate findings which have the potential to be generalised to a wider population, depending on how representative the sample is of the wider population. Cross-sectional studies can use a variety of methods of data collection, but mainly questionnaires and interviews as in the present programme of research.

Cross-sectional studies are more ethical than experimental research as they are observational so do not involve manipulating variables or treatment exposure (Bryman, 2016). However, given the data collected is limited to a single time point, this often limits the ability to determine causality from cross-sectional studies, instead longitudinal or cohort studies may be more appropriate where the objective is to assess changes over time, though these are considerably less efficient designs (Bryman, 2016). Whilst it may not be possible to determine causal relationships, a cross-sectional study can be useful for identifying areas for further research (Mann, 2003).

2.5.2 Mixed-methods sequential explanatory design

A mixed-methods sequential explanatory design was used for study four, the results of which are presented in chapter six. A sequential explanatory design is a two-phased study design, involving a quantitative phase (i.e. a questionnaire) to generate

numerical data, followed by a qualitative phase (i.e. focus groups) to generate narrative data to explain and expand on the numerical data (Creswell & Creswell, 2018).

There are several advantages to using mixed-method research that parallel those of multi-method research, as outlined above. This particular design is used for confirmatory and explanatory purposes in that the aim of the qualitative findings are to confirm and explain the quantitative findings to produce a more comprehensive and credible understanding of the research problem than could be achieved from a single method (Creswell & Creswell, 2018). Qualitative findings can often provide the context for interpreting and understanding the quantitative findings (Bryman, 2016). The quantitative research is a practical and efficient means of identifying participants for the qualitative research (Bryman, 2016). Further, the findings that are generated from mixed-methods research are often considered easier to translate into practical benefits because the range of results will be useful for a more varied audience (Bryman, 2016). The drawbacks of mixed-methods research are dependent on the different methods that are used, though limitations of a particular method are intended to be offset against the other method (Bryman, 2016).

2.6 Study methods

The four studies in this programme of research used the following methods of data collection: self-report questionnaires, diagnostic interviews and focus groups; the details of which are outlined below.

2.6.1 Self-report questionnaires

Self-report questionnaires were used in studies one, three and four, the details of which are presented below. Self-report questionnaires consist of a set of questions that are completed by the respondent, rather than being administered by a researcher (Bryman, 2016). This method is most useful for descriptive studies aimed at generating information on the characteristics, attitudes and behaviours of a

particular sample that have the potential to be generalised to the wider population (Bryman, 2016).

Self-report questionnaires are the more cost and time effective method of data collection with minimal participation burden, compared with other methods of data collection i.e. face-to-face interviews (Demetriou, Ozer, & Essau, 2015). Further, they are convenient as they allow the respondent to answer questions at their own pace rather than being directed by a researcher (Bryman, 2016). However, it is not possible to assist respondents when questions are ambiguous or there are literacy barriers, or to probe respondents to obtain further information (Bryman, 2016). Further, response rates are often low and missing data can be an issue in studies using self-report questionnaires (Bryman, 2016). Therefore, selecting the most appropriate self-report questionnaire to address the specific research objectives requires careful consideration. Preferably studies should use validated questionnaires to generate findings that can be compared with other studies. There may not always be a suitable questionnaire though that can address the specific research question so it can be necessary to develop a questionnaire specifically for the research topic. Consideration needs to be given to the design of a questionnaire to ensure the questions are valid measurements of what was intended (Coolican, 2007), though it is important to acknowledge there will be limitations.

2.6.1.1 Validated diagnostic questionnaire

An adapted version of the Eating Disorder Diagnostic Scale (EDDS) (Stice et al., 2000) was used in study one to determine diagnoses of ED before and during pregnancy in a sample of pregnant women, in accordance with DSM-5 (APA, 2013) diagnostic criteria, the results of which are presented in chapter three.

The EDDS is a validated self-report questionnaire designed to assess current symptoms and diagnoses (using a supplementary diagnostic algorithm) of AN, BN and BED, in accordance with DSM-IV (APA, 1994) diagnostic criteria. It was developed from diagnostic interviews, the Eating Disorder Examination (EDE) (Fairburn & Cooper, 1993) and the ED module of the Structured Clinical Interview for the revised

third edition of the DSM (DSM-III-R) (SCID; Spitzer, Williams, Gibbon, & First, 1990), and in reference to the diagnostic criteria in DSM-IV (APA, 1994). These diagnostic interviews are well-established as reliable and valid measures for determining mental diagnoses (Berg, Peterson, Frazier, & Crow, 2012; Lobbestael, Leurgans, & Arntz, 2011; Zanarini et al., 2000).

The EDDS consists of 22 items, using a combination of Likert-rating, dichotomous, frequency, and open-ended formats. Likert-rating scales are used to assess cognitive symptoms within the past three months. Dichotomous scoring is used to assess episodes of binge eating and associated features, which are combined with frequency scoring to assess the frequency of the episodes within the past six months (to correspond to the DSM-IV frequency threshold for BED) and three months (to correspond to the DSM-IV frequency threshold for BN). Frequency scoring is also used to assess the regularity of inappropriate compensatory behaviours (including self-induced vomiting, use of laxatives or diuretics, fasting and excessive exercise) to prevent weight gain or to counteract the effects of eating within the past three months. Respondents are also asked to provide their self-reported height and weight, regularity of menstrual periods and use of oral contraceptives.

The EDDS is appropriate for studies of prevalence as unlike other validated self-report questionnaires such as the EDE-Q (Fairburn & Beglin, 1994) and the SCOFF (Morgan, Reid, & Lacey, 1999), it generates diagnoses of ED including BED, which is particularly important given the disparities in research coverage compared to AN and BN since its recent recognition as a full threshold ED. Diagnoses determined from the EDDS have been shown to be highly concordant with diagnoses determined from the EDE, with evidence of high sensitivity, specificity and positive predictive value for discriminating between cases and non-cases of ED compared to the EDE (Stice, Fisher, & Martinez, 2004; Stice et al., 2000). Further, the EDDS has been validated in ethnically and racially diverse samples (Neyland & Bardone-Cone, 2019; Stice et al., 2004).

For study one, the time frame specified in the EDDS items and the supplementary diagnostic algorithm were adapted to determine diagnoses of ED before and during pregnancy, in accordance with DSM-5 (APA, 2013) diagnostic criteria. Although the EDDS was not designed to assess DSM-5 (APA, 2013) diagnostic criteria, DSM-5 (APA, 2013) diagnostic criteria were used to determine diagnoses of interest in study one as the DSM-5 version was not available at the time of the study. Previous studies have made similar adaptations to the EDDS (Flament et al., 2015; Forney, Brown, Holland-Carter, Kennedy, & Keel, 2017; Grillot & Keel, 2018; Linville et al., 2015; McElroy et al., 2016; Micali et al., 2017; Neyland & Bardone-Cone, 2019), and evidence demonstrated that these forms of adaptations did not compromise the validity of the EDDS (Micali et al., 2017). Micali et al (2017) compared an adapted version of the EDDS against diagnostic interviews to determine lifetime and 12 month prevalence of ED, in accordance with DSM-5 (APA, 2013), and found it to have a sensitivity of 97.3% (95% CI, 94.9–98.8%) and specificity of 74.6% (71.1–77.8%), and positive and negative predictive values of 65.1% and 98.3%, respectively. Specific details on the use of the EDDS in study one are presented in chapter four.

There are limitations with using a self-report questionnaire to establish diagnoses of ED with diagnostic interviews considered to generate more reliable diagnoses as they allow the interviewer to seek clarification where there is ambiguity (Fairburn & Beglin, 1994) and given the challenge for self-report questionnaires to assess criterion that are frequently denied i.e. intense fear of weight gain or becoming fat in individuals with AN (Stice et al., 2000). However, self-report questionnaires may be perceived with greater anonymity than face-to-interviews, thus enabling individuals to feel more comfortable with positive disclosures of ED (Keel et al., 2002).

2.6.1.2 Exploratory descriptive questionnaire

A self-report questionnaire was used in study three to explore the experiences of maternity care in women with lifetime ED, the results of which are presented in chapter five.

The questionnaire was developed specifically for this study. The contents were informed from assessment of current evidence, with input from the doctoral supervisors and other experts, including researchers and clinicians with expertise in ED, midwifery education and practice, and approaches to undertaking qualitative research, as well as representatives of the website. The questionnaire comprised of 21 items, using a combination of single and multiple choice, Likert-rating scales and open-ended formats. It was designed to generate quantitative and qualitative data on ED symptoms during pregnancy and experiences of maternity care. The adaptation of the standard questionnaire method by combining closed-ended questions with open-ended questions was preferable as it generated both descriptive and explanatory data. Primarily, the use of closed-ended questioning can illicit predetermined responses and numerical descriptions of attitudes and opinions of the population sample to enable generalisation to the wider population (Fowler, 2009). This type of quantitative data can provide an initial understanding which is then complemented with open-ended questioning to illicit emerging responses to provide meaning to the quantitative data and detail the personal experience leading to a comprehensive understanding of the research problem (Greene et al., 1989). Specific details on the use of this self-report questionnaire in study three are presented in chapter six.

2.6.1.3 Knowledge and attitudes questionnaire

A self-report questionnaire was used in the first phase of study four to examine knowledge and attitudes to identifying and managing pregnant and postnatal women with ED in midwives and health visitors, the results of which are presented in chapter six.

The questionnaire and topic guide for the focus groups were developed specifically for this study. The contents were informed from assessment of current evidence, with input from the doctoral supervisors and other experts, including researchers and clinicians with expertise in ED, midwifery and health visiting education and practice, and approaches to undertaking qualitative research. The questionnaire comprised of 14 items, using a combination of single and multiple choice formats, and Likert-rating

scales. The use of closed-ended questioning generated numerical descriptions of knowledge and attitudes of the population sample to enable generalisation to the wider population (Fowler, 2009) and provided the basis for the focus groups that followed in this study. Specific details on the use of this self-report questionnaire in study four are presented in chapter seven.

2.6.2 Diagnostic interviews

The ED module of the SCID for DSM-IV and DSM-IV-TR Axis I disorders non-patient edition (SCID-I/NP; First, Spitzer, Gibbon, & Williams, 2002) was used in study two to determine diagnoses of lifetime and current ED in a sample of pregnant women, in accordance with DSM-5 (APA, 2013) diagnostic criteria, the results of which are presented in chapter five.

The SCID is a widely used semi-structured modular interview designed to determine current and past diagnoses of mental illnesses in accordance with DSM-IV and DSM-IV-TR (American Psychiatric Association, 1994, 2000) diagnostic criteria. The SCID is well-established as a reliable and valid measure for determining diagnoses of mental illnesses, including ED (Lobbestael et al., 2011; Zanarini et al., 2000).

The ED module is comprised of several open-ended questions designed to assess the presence of behavioural (e.g. weight loss, amenorrhea, binge eating and inappropriate compensatory behaviours) and cognitive symptoms (e.g. fear of fatness, body and shape concerns) of ED to enable the interviewer to determine whether each of the diagnostic criteria required for a diagnosis of ED are met. Each question is followed by a specific prompt to obtain further information to ensure the reliability of the diagnoses determined by the interviewer. Given all diagnostic criteria must be met to determine a diagnosis, interviewers are advised to use skip rules when individuals do not meet the individual criteria.

The SCID was not designed to assess DSM-5 (APA, 2013) diagnostic criteria however, DSM-5 (APA, 2013) diagnostic criteria was used to determine diagnoses of interest in study two as the DSM-5 version of the SCID was not available at the time of the study.

Although the SCID refers to DSM-IV (APA, 1994), and DSM-IV-TR (APA, 2000), the ED module includes sections on AN, BN and EDNOS BED so it is possible to determine lifetime and current diagnoses of all ED categories in accordance with DSM-5 (APA, 2013) diagnostic criteria. As in previous ED research (Micali et al., 2017; Smink, van Hoeken, Oldehinkel, & Hoek, 2014; Solmi, Hatch, Hotopf, Treasure, & Micali, 2015), the SCID-I ED module 'skip rules' were not applied and information on type, frequency and duration of ED symptoms were collected to enable classification of diagnoses consistent with DSM-5 (APA, 2013) (i.e. considering the reduced frequency threshold for binge eating and compensatory behaviours from at least twice a week to once a week for a minimum of 3 months). This information was obtained in response to the original SCID-I ED module questions without the need for alterations.

The SCID was designed to be administered by clinicians, or alternatively non-clinician researchers who have sufficient experience with the study population and are trained to use the SCID. For study two, researchers (postgraduate researchers and research midwives) responsible for administering the SCID were trained to administer the SCID using the official training materials (i.e. DVD format of sample interviews with expert commentaries and guidance) and module-specific training sessions delivered by trainers with previous extensive experience in the use of the SCID, followed by regular supervision meetings with expert clinicians for the study duration. Specific details on the use of the SCID, including researcher training and quality assurance, in study two are presented in chapter five.

Diagnostic interviews are often considered to produce more reliable diagnoses than self-report questionnaires (Fairburn & Beglin, 1994; Mond et al., 2007). However, face-to-face interviews are a costly and timely method of data collection, so their use is often limited to larger prevalence studies, and they present a higher participation burden compared to self-report questionnaires.

2.6.3 Focus groups

Focus groups were used in the second phase of study four to conduct an in-depth exploration of the barriers to identifying and managing pregnant and postnatal

women with ED in maternity and health visiting services from the perspectives of midwives and health visitors, the results of which are presented in chapter six.

A focus group is defined as an organised group discussion which is guided by a facilitator, to elicit multiple experiences and perspectives on a particular topic (Powell & Single, 1996). Participants are selected to participate in a focus group on the basis of a common characteristic relating to the study objectives i.e. their professional status (Powell & Single, 1996). Focus groups are frequently used in healthcare research of a complex but not personally sensitive nature, where previous research is insufficient (Powell & Single, 1996).

The facilitator has an important role to provide structure to the discussion, stimulate reflection and ensure a good level of participation, whilst not being obtrusive (Bryman, 2016). This approach enables participants to interact, discuss and challenge one another, rather than discussions being directed by the researcher in the standard question and answer format in interviews, which are considered to produce a more genuine and comprehensive understanding of the subject (Bryman, 2016). Furthermore, focus groups are a relatively cost and time effective method of data collection that enables exploration of a research question from multiple perspectives at the same time.

The main limitation of focus groups is the subjective nature of the results and lack of generalisability given they often involve non-probability sampling to recruit a small sample size (Stewart et al., 2007). However, these are a necessary limitation for all qualitative methods that seek to explore personal experiences and perspectives that cannot be captured using quantitative methods. The intention of qualitative research is not to produce data that can be generalised to a wider population, instead sufficient descriptive detail about the study can enable other researchers to consider whether the findings apply to other settings (Mays & Pope, 2000).

It is recognised the facilitator has less control over the data produced compared to other methods, though there is flexibility for the facilitator to guide discussions more

if needed to ensure specific questions are addressed (Morgan, 1997). Given the role of the researcher, involvement will inevitably introduce bias to the research process, but a reflective approach can seek to minimise this bias. Individuals may be more prone to express socially acceptable views rather than their personal views in this form of group setting (Bryman, 2016). This challenge can be addressed by a trained facilitator to create an environment whereby participants develop familiarity with one another and feel supported with expressing potentially divergent views amongst the group (Powell & Single, 1996). Furthermore, there is potential for group discussions to be dominated by a minority of more vocal participants though similarly a trained facilitator can often negotiate this challenge and familiarity among the group participants will often encourage whole group participation (Powell & Single, 1996). Specific details on the focus groups used in study four are presented in chapter six.

2.7 Data analysis

The different methods used in this programme of research generated both quantitative and qualitative data. All four studies generated quantitative data and studies three and four also generated qualitative data. Specific details on the analyses in each study are presented in the individual study chapters, therefore this section provides a general summary of the analyses conducted in this programme of research.

2.7.1 Quantitative data analysis

The quantitative data generated from the four studies were managed and analysed using SPSS versions 22.0 and 25.0 (IBM Corp, 2013, 2017) and STATA version 15 (StataCorp, 2017). Results from statistical tests were two-tailed and P-values of 0.05 and 95% Confidence Intervals were used to determine group differences.

2.7.2 Qualitative data analysis

The qualitative data generated from studies three and four were analysed using the thematic analysis framework described by Braun and Clark (2006). Brain and Clark (2006) proposed the following six phases of thematic analysis: familiarisation with data; generation of initial codes; searching for themes among codes; reviewing themes; defining and naming themes; producing the final report (see Table 2-2). In these studies, all qualitative data were attended to in the analysis process to ensure thoroughness. The process was inductive and iterative throughout, meaning emerging themes were driven by the data rather than theory or a priori assumptions, similar to a grounded theory approach (Charmaz, 2014; Glaser, 1992; Patton, 1990). There was continual reference to the original data to explore those that appeared to deviate from responses of the majority (Creswell & Creswell, 2018), and to validate and refine the emerging themes. Emerging themes were clustered into subordinate themes, and superordinate themes.

Table 2-2 Six phases of thematic analysis (Braun & Clarke, 2006)

Phase		Description of the process
1	Familiarising yourself with your data	Transcribing data (if necessary), reading and rereading the data, noting down initial ideas.
2	Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3	Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme.
4	Reviewing themes	Checking in the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic "map" of the analysis.
5	Defining and naming themes	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells; generating clear definitions and names for each theme.
6	Producing the report	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

2.7.2.1 Quality of findings

Reliability and validity are important concepts for evaluating quality in quantitative research, however they do not directly translate to qualitative research given the non-standardised role of the researcher in the analysis process (Bryman, 2016). Alternatively, the concept of trustworthiness has been proposed for evaluating quality in qualitative research. Table 2-3 provides an overview of the techniques used to ensure the trustworthiness of the qualitative analyses conducted in studies three and four, with specific details presented in the relevant chapters, aside from the critical reflections of the candidate which are outlined below.

Table 2-3 Techniques for ensuring trustworthiness of the qualitative analysis

Criteria	Reference	Detail
Iterative analysis	(Creswell & Creswell, 2018; Glaser, 1992)	Inductive and systematic analysis process to repeatedly review the data to revise the emerging explanations so the emerging themes were driven by the data rather than theory or a priori assumptions
Deviant case analysis	(Creswell & Creswell, 2018)	Searching for and discussing data that contradicts or differs from the majority of the data, to refine the analysis process
Cross checks	(Barbour, 2001; Bazeley, 2013; Giacomini & Cook, 2000)	Independent coding of the data by another researcher and contributions from supervisors to provide a cross check and comparative perspective on the coding process to reduce bias of a single researcher
Transparency	(Bazeley, 2013; Mays & Pope, 2000; Yin, 2003)	Transparent account of data collection and data analysis, and audit trail of interpretative ideas
Reflexivity	(Bazeley, 2013; Creswell & Creswell, 2018)	Critical reflection of any personal biases that the background and experiences of the researcher may have on the research process
Prolonged time in the research area	(Creswell & Creswell, 2018)	Experience in the research area enables the researcher to develop a comprehensive understanding of the research problem, which enhances the accuracy of the interpretations
Member checking	(Bazeley, 2013; Lincoln & Guba, 1985)	Checks for agreement on the interpretations and conclusions made by the researcher with the participants or other stakeholders

2.8 Reflexivity

More often highlighted within qualitative research due to its subjective nature though also relevant to quantitative research, the researcher is a non-standardised component in the research process with personal bias that influences data collection and interpretation of the findings (Creswell & Creswell, 2018). Therefore it is important for researchers to critically reflect on any personal biases that their background and experiences may have on the research process to encourage a more impartial approach to their research (Bazeley, 2013; Creswell & Creswell, 2018).

I am a white British female and mother to two children. I have worked as a researcher for several years across a range of studies in women and children's health, and health services research, since starting in the mental health field as a psychology graduate. From personal experience, I am aware of the many challenges that women encounter during the transition to motherhood, particularly changes to a woman's sense of self, often complicated by societal expectations and pressures on new mothers. Through doing research with pregnant and postnatal women with current and past ED, several of who had never received treatment for their ED, I developed my understanding of women that experience these challenges to a greater extent. A number of women discussed negative experiences with midwives and health visitors, largely attributed to a lack of awareness and understanding about ED. These experiences contributed to women feeling reluctant to discuss their healthcare needs with the healthcare professionals involved in their care, thus limiting their ability to access the necessary support. These experiences developed my interest in adding to the existing literature by investigating how many pregnant women in the general population have been affected by ED, who may or may not have disclosed their ED to a healthcare professional in the past, and exploring the barriers to recognising and responding to the healthcare needs of pregnant and postnatal women with ED from the perspectives of women but also the relevant healthcare professionals.

I recognise my understanding of maternal ED is limited in the absence of lived experience and minimal previous research experience in women with BED specifically. Women with BED are known to be consistently underrepresented in ED research and services, likely related to misconceptions about ED and weight stigma (Puhl & Suh, 2015). This group is particularly relevant to research examining the role of healthcare professionals in identifying and managing ED given these women have increased risk of obesity (Hudson et al., 2007), which is a current priority in healthcare (National Institute for Health and Care Excellence, 2006, 2010). I have made significant attempts to increase my engagement and understanding of pregnant and postnatal women with BED, such as utilising anonymous recruitment methods in two of the studies in this programme of research and through other research I have been

involved in (Easter, Bye, Sandall, & Mackintosh, 2018), to ensure their experiences are represented.

When starting the exploratory research, I anticipated the findings may confirm the negative experiences women with ED had previously highlighted and I was keen to identify barriers that have the potential to be addressed to improve the quality of healthcare for other women with ED. These motivations may have inadvertently introduced bias to the research. Through working with midwives and health visitors in this and other research, I went on to develop a comprehensive understanding of the culture and contextual factors that influence the quality of healthcare. These experiences enhanced my appreciation for the high expectations on these healthcare professionals to support women and their families with increasingly complex health and social needs, and their keen interest to fulfil these expectations. Furthermore, my continued involvement in related research provided opportunities to informally check the accuracy of my conclusions and resonance with the experiences among members of the same communities to those that participated in this programme of research, including midwives, health visitors and women with ED (Bazeley, 2013; Easter et al., 2018; Lincoln & Guba, 1985). I consider the understanding I gained before and during this programme of research was of benefit in developing it and interpreting the findings with consideration for the particular concerns of pregnant and postnatal women with ED whilst acknowledging the limitations in maternity and health visiting services. I sought to minimise the influence of bias I may have introduced to the analysis process and interpretations by involving others in the research process as outlined above and detailed in the relevant study chapters.

2.9 Ethics approval and consent procedures

Ethics approval was sought for each of the four studies in this programme of research before they were undertaken. Participants in each of the four studies provided informed consent prior to taking part. Specific details on the ethics approval and consent procedures for each study are presented in the individual study chapters.

2.10 Conclusion

In summary, this chapter has provided an overview of:

- The overarching methodological approach underpinning this programme of research.
- The particular design and method used in each of the four studies that comprise this programme of research.
- The types of analyses conducted in this programme of research, including the techniques used for ensuring trustworthiness of the qualitative analysis.

The following four chapters present the specific details on each of the four studies in this programme of research individually.

Chapter 3 Prevalence of ED in pregnant women, using a self-report questionnaire

3.1 Rationale for undertaking the research

Pregnancy can be a highly emotive period for women with a current or remitted ED as they encounter changes to their body and appetite (Fogarty et al., 2018; Koubaa, Hällström, & Hirschberg, 2008). Most women adjust as pregnancy progresses with the motivation to ensure optimum health of the unborn infant (Fogarty et al., 2018), often experiencing a decrease in their symptoms during this time (Blais et al., 2000; Crow et al., 2008; Fogarty et al., 2018; Micali, Treasure, et al., 2007; Morgan, Lacey, et al., 1999). However, this is not the case for all women and more often behavioural symptoms such as self-induced vomiting, decrease whilst cognitive symptoms persist (Blais et al., 2000; Fogarty et al., 2018; Micali, Treasure, et al., 2007; Morgan, Lacey, et al., 1999). Often symptom changes are temporary for the majority of women with ED, with a high risk of relapse postnatally (Crow et al., 2008; Knoph et al., 2013; Morgan, Lacey, et al., 1999). Further, for a small number of women without ED before pregnancy, pregnancy can be a risk period for the onset of ED (Watson et al., 2013). Much of the literature on remission, continuation and incidence of ED during pregnancy has focused on women with AN and BN, with considerably less known about women with BED and OSFED.

Pregnant women with ED are known to have heightened risk of adverse pregnancy and birth outcomes. Evidence indicates risks vary between ED categories and persist among those in remission, though higher for women with active ED during pregnancy, including impaired fertility, unplanned pregnancy and delivering low birth weight babies in women with lifetime AN (Linna et al., 2013, 2014; Micali, dos-Santos-Silva, et al., 2014; Solmi et al., 2014), and miscarriage and delivering large for gestational age babies in women with lifetime BED (Linna et al., 2013, 2014; Watson et al., 2017). Although there is limited research assessing the impact of OSFED on pregnancy and birth outcomes, evidence indicates that sub-threshold ED similarly lead to heightened risk (Eik-Nes et al., 2018; Linna et al., 2013; Watson et al., 2017).

Given the risks associated with active and remitted ED, early identification and response to the healthcare needs of affected women is imperative to promote optimal maternal and infant outcomes. In accordance with NICE guidance, ideally women identified with ED (including those in remission of AN) should be offered preconception care so that they are in a better state of health when they do try to conceive to minimise the adverse maternal and infant outcomes (NICE, 2017). Although this is not often feasible due to the heightened risk of unplanned pregnancy in women with ED (Easter et al., 2011; Micali, dos-Santos-Silva, et al., 2014). To enhance identification of mental illnesses, NICE recommends clinicians should routinely enquire about past and current severe mental illness with all women at their first contact with NHS maternity services in England and Wales (NICE, 2014). NICE recommends clinicians should offer women identified with ED enhanced monitoring and support throughout pregnancy into the postnatal period (NICE, 2017).

Identifying ED during pregnancy is challenging given typical fluctuations in ED symptoms during this time (Blais et al., 2000; Easter et al., 2015; Micali, Treasure, et al., 2007; Watson et al., 2013) and the need to distinguish ED symptoms from pregnancy symptoms, including nausea and vomiting. Currently, there is insufficient and conflicting research to accurately determine how many women in pregnancy have a current or prior history of ED. It is suggested that between 1.9-7.6% of pregnant women may be affected by ED during pregnancy (Easter et al., 2013; Howard et al., 2018; Maihara dos Santos et al., 2017; Watson et al., 2013) and 4.5-9.2% pre-pregnancy (Easter et al., 2013; Watson et al., 2013). The inconsistencies likely relate to variations in instruments used to assess ED in the absence of a validated antenatal screening tool, and in operationalised ED definitions given the lack of appropriate algorithms for pregnant women (Paslakis & de Zwaan, 2019) and recently revised ED criteria in DSM-5 (APA, 2013). The recent revisions have had important implications for prevalence studies in non-pregnant populations (Lindvall Dahlgren et al., 2017).

Easter et al (2013), using an adapted version of a standardised self-report questionnaire found 7.5% of pregnant women met criteria for current ED and 9.2% met criteria in the period before pregnancy. Though this publication only reported interim survey findings rather than on the complete dataset and used classifications pre-emptive but not directly in accordance with DSM-5 (APA, 2013). A mother and child cohort study, using a non-standardised self-report questionnaire reported a lower prevalence of 5.0% during pregnancy and 4.5% before pregnancy (Watson et al., 2013). However, the study used broadly defined categories of ED and AN was not assessed during pregnancy in this Norwegian sample with the authors citing challenges assessing the weight criterion during pregnancy, which precluded the ability to explore rates of remission, continuation and incidence within this diagnostic group. More recently, two studies (Howard et al., 2018; Maihara dos Santos et al., 2017) were the first to use diagnostic interviews to establish prevalence of current ED during pregnancy in accordance with DSM-5 (APA, 2013). Maihara dos Santos et al (2017) reported a prevalence of 1.9% for active ED amongst pregnant women, though this study did not report prevalence of OSFED during pregnancy or ED before pregnancy. Howard et al (2018), using a stratified sampling design based on an antenatal depression screen, reported an estimated prevalence of 2% for current ED during early pregnancy although it similarly did not report prevalence of ED prior to pregnancy and did not include estimates of prevalence for the different types of ED.

Diagnostic interviews are often considered to produce more reliable diagnoses than self-report questionnaires as they enable the interviewer to seek clarification where there is ambiguity (Beglin & Fairburn, 1992; Fairburn & Beglin, 1994) and given the challenge for self-report instruments to assess criterion that are frequently denied i.e. intense fear of weight gain or becoming fat in individuals with anorexia nervosa (Stice et al., 2000). However, interviews are not without disadvantages as they are costly and timely to administer and contribute to increased participation burden, which often restricts the potential sample size. Furthermore, self-report questionnaires may be perceived as providing greater anonymity of participation compared to face-to-face interviews thus enabling respondents to feel more comfortable with positive disclosures of ED symptoms (Keel et al., 2002).

This study presents further secondary analysis of data presented by Easter et al (2013) to expand on the reported interim survey findings. Considering the fluctuations in ED symptoms from preconception to pregnancy, risk of onset of new ED and the heightened risk of adverse outcomes, with varying risks between categories that persist amongst those in remission, it is important to determine the prevalence of the different types of ED before and during pregnancy, using a validated diagnostic tool, to ensure equal recognition of those active and remitted during pregnancy.

3.2 Research aims

Primary aim of this study was to:

1 To investigate the prevalence of ED before and during pregnancy in a sample of pregnant women in South-East London, using a self-report questionnaire to determine diagnoses consistent with DSM-5 (APA, 2013).

Secondary aim of this study was to:

1 Examine rates of remission, continuation, diagnostic cross-over and new onset of ED during pregnancy in a sample of pregnant women.

Hypotheses under investigation were:

1. ED will be more prevalent before pregnancy than during pregnancy.
2. Sub-threshold ED will be more prevalent than full threshold ED, both before and during pregnancy.
3. The majority of women with ED before pregnancy will be in remission during pregnancy and whilst new onset of ED during pregnancy will be rare, it will more commonly BED.

3.3 Methods

3.3.1 Design

Data were obtained from a cross-sectional survey conducted as part of the NEST-p study. The NEST-p study is an observational prospective study of pregnant women and their infants. The primary aim of the NEST-p study was to investigate the effects of maternal eating, nutrition and stress in pregnancy on maternal and infant outcomes in women with current and past ED compared to a healthy control group. Women were identified for the NEST-p study using three recruitment strategies: a cross-sectional survey at an NHS maternity service; following referral to a psychiatric service for ED treatment; and self-referral via online study information or study posters displayed at study sites. Further detail on the NEST-p study is provided in a publication (Easter et al., 2015). The details applicable to data from the cross-sectional survey that are presented in this thesis are described in the following sections.

3.3.2 Ethical approval

Ethical approval for the NEST-p study was granted by The Joint South London and the Institute of Psychiatry NHS Research Ethics Committee' (Ref. 09/H0807/12).

3.3.3 Study setting

Women were recruited at their routine ultrasound scan appointment at an antenatal clinic in an inner-city NHS maternity service in South-East London. Current NICE recommendations are that all women attending NHS maternity services in England and Wales are offered two ultrasound scans, including the dating scan (usually offered around 10 to 14 weeks gestation) and the anomaly scan (usually offered around 18 to 21 weeks gestation) (NICE, 2008a).

3.3.4 Participants

Women were eligible to participate in the study if they were 16 years old or above, capable of completing the questionnaire in English and attending a routine ultrasound scan appointment. Women were ineligible to participate in the study if they were less than 16 years old, unable to complete the questionnaire in English and attending a non-routine appointment. Women were included in this study if they were less than 22 weeks gestation to enable the assessment of symptoms before pregnancy (retrospective assessment of symptoms within the past 6-12 months) and during pregnancy (assessment of symptoms within the past 3 months) in accordance with the time frames specified in the adapted version of the self-report questionnaire.

3.3.5 Recruitment

Between March 2010 and May 2012, the research team (postgraduate researchers and clinicians) routinely visited the clinic to recruit women to take part in the study. During a visit to the clinic, the researcher approached women whilst they were waiting to attend their appointment. The researcher explained the purpose of the study and what participation would involve, before assessing eligibility and inviting women to participate. Women were advised that participation in the study would not affect their medical care or legal rights, and consent to participate was implied by completion of the questionnaire. Women who agreed to participate were asked to complete and return the questionnaire to the researcher on that same day before attending their appointment.

3.3.6 Measures

The EDDS (Stice et al., 2000) is a validated self-report questionnaire designed to assess current symptoms and diagnoses (using a supplementary diagnostic algorithm) of AN, BN and BED, in accordance with DSM-IV (APA, 1994) diagnostic criteria. It was developed from diagnostic interviews, the EDE (Fairburn & Cooper, 1993) and the ED module of the SCID for DSM-III-R (Spitzer et al., 1990), and in

reference to the diagnostic criteria in DSM-IV (APA, 1994). These diagnostic interviews are well-established as reliable and valid measures for determining mental diagnoses (Berg et al., 2012; Lobbestael et al., 2011; Zanarini et al., 2000). Diagnoses determined from the EDDS have been shown to be highly concordant with diagnoses determined from the EDE, with evidence of high sensitivity, specificity and positive predictive value for discriminating between cases and non-cases of ED compared to the EDE (Stice et al., 2004, 2000). Further, the EDDS has been validated in ethnically and racially diverse samples (Neyland & Bardone-Cone, 2019; Stice et al., 2004).

In this study, the time frames specified in the EDDS items used to determine diagnoses were adapted to enable the assessment of symptoms in the past 6-12 months (retrospective assessment of symptoms before pregnancy) and past three months (assessment of symptoms during pregnancy) and supplementary items were adapted to obtain appropriate participant information (see Appendix I). The revised time frames correspond to the gestation (in weeks) of the women included in this study to enable assessment of symptoms before and during pregnancy. Due to slight variations across questionnaires in the specified time frames for items assessing inappropriate compensatory behaviours, responses to "the past six months" and "past 12 months" were combined to reflect behaviours within the past year prior to pregnancy. Also, the addition of several time frames for these particular items meant the respondent was required to provide a response for the most recent time period (no other items were formatted in this manner), thus it was necessary to assume an inappropriate compensatory behaviour during pregnancy was a continuation of that same behaviour from before pregnancy to reduce the likelihood of underestimating the prevalence of behavioural symptoms before pregnancy and overestimating incidence of behavioural symptoms during pregnancy. Items assessing regularity of menstrual periods and use of oral contraceptives were altered for use with an antenatal sample and supplemented with items for respondents to provide their age (in years) and gestation (in weeks). The adaptations described did not interfere with the phrasing or scoring format of the diagnostic items so are not anticipated to have altered the psychometric properties of the EDDS.

Age (in years) was categorised as 16-19 years, 20-29 years, 30-39 years and 40 years or above. Gestation (in weeks) was categorised in to first and second trimester of pregnancy. Self-reported height and weight were used to calculate body mass index (BMI, kg/m^2) and categorised in accordance with the WHO classification system; underweight (BMI <18.5 kg/m^2), normal weight (BMI 18.5-24.9 kg/m^2), overweight (BMI 25.0-29.9), and obese (BMI≥30.0 kg/m^2) (World Health Organization, 2006). The WHO classification of underweight was used as it is more lenient given the survey was conducted on a community-based sample and is in accordance with other similar studies (Easter et al., 2013; Watson et al., 2017). Data on pre-pregnancy weight was not collected in the questionnaire, precluding the calculation of pre-pregnancy BMI, thus the low weight criterion for diagnoses of AN before and during pregnancy had to be inferred using weight provided at the time of the questionnaire completion (i.e. during pregnancy).

3.3.6.1 Classification of ED diagnoses

The accompanying diagnostic algorithm was similarly adapted to correspond to the modifications made to the EDDS, to determine diagnoses of ED before and during pregnancy, in accordance with the DSM-5 (APA, 2013) (see Appendix II). Although the EDDS was not designed to assess DSM-5 (APA, 2013) diagnostic criteria, DSM-5 (APA, 2013) diagnostic criteria was used to determine diagnoses of interest as the DSM-5 version of the EDDS was not available at the time of the study. Previous studies have made similar adaptations to the time frames specified in the EDDS (Linville et al., 2015; Micali et al., 2017; Neyland & Bardone-Cone, 2019) and to establish diagnoses consistent with DSM-5 (APA, 2013) diagnostic criteria (Flament et al., 2015; Forney et al., 2017; Grillot & Keel, 2018; McElroy et al., 2016; Micali et al., 2017; Neyland & Bardone-Cone, 2019); and evidence has demonstrated that these forms of adaptations did not compromise the validity of the EDDS (Micali et al., 2017).

The adapted diagnostic algorithm was used to determine diagnoses of AN, BN, BED, purging disorder and a broadly defined OSFED (purging disorder was not included in this category as it was defined separately) before and during pregnancy, according to the following criteria:

- AN was determined according to two definitions. Firstly, AN was diagnosed if (1) classified as underweight, as defined above; (2) intense fear of weight gain or becoming fat; and (3) undue influence of body weight or shape on self-evaluation. Secondly, AN was diagnosed if (1) classified as underweight; (2) regular use of inappropriate compensatory behaviours; and (3) undue influence of body weight or shape on self-evaluation.
- BN was defined as: (1) regular episodes of binge eating; (2) regular use of inappropriate compensatory behaviours; and (3) undue influence of body weight or shape on self-evaluation.
- BED was defined as: (1) regular episodes of binge eating; (2) endorsement of at least three associated features; (3) marked distress about binge eating; and (4) absent of inappropriate compensatory behaviours. Of note, this algorithm was supplemented to prevent misclassification of underweight women who met all the criteria for BED but not AN.
- Purging disorder was defined as: (1) undue influence of body weight or shape on self-evaluation; (2) absent of episodes of binge eating; and (3) regular use of purging behaviours (i.e. self-induced vomiting and misuse of laxatives or diuretics).
- Broadly defined OSFED was determined according to two definitions: Firstly, (1) undue influence of body weight or shape on self-evaluation; and (2) episodes of binge eating, irrespective of regularity. Secondly, (1) undue influence of body weight or shape on self-evaluation; and (2) use of inappropriate compensatory behaviours, irrespective of regularity.

In accordance with the revised frequency threshold in DSM-5 (APA, 2013) for establishing diagnoses of BN and BED, regular referred to the occurrence of behavioural symptoms at least once a week. Consistent with Stice et al (2000), diagnoses of AN trumped BN and BN trumped BED. Further, women who did not meet sufficient diagnostic criteria to be diagnosed with any ED for a particular time period were described as not having an ED at that time point.

3.3.6.2 Definition of remission, continuation, diagnostic cross-over and new onset

Using a similar approach to previous research (Bulik et al., 2007; Watson et al., 2013), women with ED before and/or during pregnancy were categorised according to the following: remission (met criteria for a diagnostic category before pregnancy but not during pregnancy), continuation (met criteria for the same diagnostic category before and during pregnancy) and new onset (met criteria for a diagnostic category during pregnancy but not before pregnancy). Rather than classifying women whose symptoms changed during pregnancy as partially remitted (Bulik et al., 2007; Watson et al., 2013), diagnostic cross-over was used to refer to women who met criteria for a diagnostic category before pregnancy but met criteria for a different diagnostic category during pregnancy.

3.3.7 Analysis

All study data were managed and analysed using SPSS 25.0 (IBM Corp, 2017). Cross tabulations and chi-square tests (or Fisher's exact where appropriate) were used to describe differences in sample characteristics between cases and non-cases of ED before and during ED.

3.3.8 Missing data

There were missing data for each diagnostic criterion due to missing data for individual EDDS items. Of the total sample (N = 1,022), 56 (6%) women were missing some diagnostic data for the period before pregnancy, of which 42 (4.1%) were missing data for diagnoses of AN (all were missing data on BMI), 14 (1.4%) BN, 25 (2.4%) BED, 21 (2.1%) purging disorder and 34 (3.3%) broadly defined OSFED. Of the total sample, 55 (5%) women were missing some diagnostic data for the period during pregnancy, of which 36 (3.5%) were missing data for diagnoses of AN (all were missing data on BMI), 12 (1.2%) BN, 25 (2.4%) BED, 20 (2.0%) purging disorder and 32 (3.1%) broadly defined OSFED.

Women were treated as missing observations if they were: (1) completely missing diagnostic data across diagnostic categories; (2) missing diagnostic data for one or

more diagnostic categories and not meeting diagnostic criteria for any other diagnostic category; and (3) missing data for a diagnostic criteria and meeting the other diagnostic criteria for a diagnostic category. List-wise deletion (performed in SPSS) was used to calculate frequencies of ED in the women with available data for before and during pregnancy. Given the proportion of women in the study sample missing diagnostic data, sensitivity analyses were conducted for the prevalence of any ED before and during pregnancy in which these missing observations were treated as cases of ED and then as non-cases of ED.

3.4 Results

3.4.1 Sample characteristics

Of the initial 1,296 women who participated in the cross-sectional survey, 1,022 (78.9%) women met the criteria outlined above for inclusion in this study sample (refer to 3.3.4 Participants). This included women (N = 84) who were in early pregnancy but unable to provide their gestation in weeks at the time of completion as they were waiting for this detail to be established at their upcoming dating scan appointment. Overall, a response rate of ∼94% was achieved from women who were invited to participate in the cross-sectional survey. The study sample comprised of women who completed the adapted version of the EDDS at a median of 12 weeks gestation (interquartile range 12-13 weeks and range 4-21 weeks). Of the study sample, 966 (94%) women provided responses for the EDDS items referring to the period before pregnancy and 967 (95%) for the period during pregnancy. Women with available data for before and during pregnancy were similar to the study sample on gestation, trimester, age and BMI (see Table 3-1).

Table 3-1 Characteristics of the study population

N (%)		Total sample †	Sample with data available before pregnancy	Sample with data available during pregnancy
		N = 1022	N = 966	N = 967
Gestation (in weeks)		Mean: 13.11 Range: 4-21	Mean: 13.09 Range: 4-21	Mean:13.11 Range: 4-21
Pregnancy trimester				
	First	813 (87%)	784 (87%)	781 (87%)
	Second	125 (13%)	118 (13%)	119 (13%)
Age (in years)		Mean: 30.62 Range: 16-45	Mean: 30.69 Range: 16-45	Mean: 30.62 Range: 16-45
	<20	33 (4%)	30 (3%)	32 (3%)
	20-29	345 (36%)	331 (36%)	330 (36%)
	30-39	507 (54%)	488 (54%)	487 (54%)
	40+	62 (6%)	61 (7%)	60 (7%)
BMI (kg/m^2)		Mean: 24.23 Range:14-52	Mean:24.18 Range:14-52	Mean: 24.20 Range:14-52
	Underweight	41 (5%)	41 (5%)	40 (5%)
	Normal weight	524 (61%)	515 (61%)	515 (61%)
	Overweight	208 (24%)	201 (24%)	198 (23%)
	Obese	93 (11%)	89 (10%)	89 (11%)

† Missing data not included in the table.

Table 3-2 presents a comparison of sample characteristics between cases and non-cases of ED before and during pregnancy. Significant differences were found between cases of ED before pregnancy (N = 85) and non-cases (N = 881), with women with ED before pregnancy more commonly being younger (i.e. aged 20-29 years: 52% vs. 35%) and overweight (33% vs. 23%) or obese (20% vs. 10%).

Table 3-2 Comparison of characteristics between cases and non-cases of ED before and during pregnancy

N (%)		Non-cases of ED before pregnancy	Cases of ED before pregnancy	P value	Total	Non-cases of ED during pregnancy	Cases of ED during pregnancy	P value	Total
		N = 881	N = 85		N = 966	N = 902	N = 65		N = 967
Gestation (in weeks)		Mean: 13.10 Range: 4-21	Mean: 13.06 Range: 6-21		Mean: 13.09 Range: 4-21	Mean: 13.12 Range: 4-21	Mean: 13.04 Range: 6-21		Mean: 13.11 Range: 4-21
Pregnancy trimester †									
	First	717 (87%)	67 (86%)	P = 0.727	784 (87%)	729 (87%)	52 (87%)	P = 0.979	781 (87%)
	Second	107 (13%)	11 (14%)		118 (13%)	111 (13%)	8 (13%)		119 (13%)
Age (in years) ‡		Mean: 30.79 Range: 16-45	Mean: 29.56 Range: 18-41		Mean: 30.69 Range: 16-45	Mean: 30.64 Range: 16-45	Mean: 30.33 Range: 20-44		Mean: 30.62 Range: 16-45
	<20	29 (3%)	1 (1%)	P = 0.028	30 (3%)	32 (4%)	-	P = 0.434	32 (3%)
	20-29	291 (35%)	40 (52%)		331 (36%)	305 (36%)	25 (43%)		330 (36%)
	30-39	457 (55%)	31 (40%)		488 (54%)	457 (54%)	30 (52%)		487 (54%)
	40+	56 (7%)	5 (7%)		61 (7%)	57 (6%)	3 (5%)		60 (7%)

BMI (kg/m^2) §		Mean: 24.05 Range: 14-52	Mean: 25.54 Range: 14-40		Mean: 24.18 Range: 14-52	Mean: 24.15 Range: 14-52	Mean: 24.84 Range: 14-35		Mean: 24.20 Range: 14-52
	Underweight	35 (5%)	6 (8%)	P = 0.001	41 (5%)	35 (4%)	5 (9%)	P = 0.053	40 (5%)
	Normal weight	486 (63%)	29 (39%)		515 (61%)	491 (62%)	24 (45%)		515 (61%)
	Overweight	177 (23%)	24 (33%)		201 (24%)	183 (23%)	15 (28%)		198 (23%)
	Obese	75 (10%)	14 (20%)		89 (10%)	80 (10%)	9 (17%)		89 (11%)

† 64 women before pregnancy (57 non-cases of ED before pregnancy; 7 cases of ED before pregnancy) and 67 women during pregnancy (62 non-cases of ED during pregnancy; 5 cases of ED during pregnancy) had missing data on trimester.

‡ 56 women before pregnancy (48 non-cases of ED before pregnancy; 8 cases of ED before pregnancy) and 58 women during pregnancy (51 non-cases of ED during pregnancy; 7 cases of ED during pregnancy) had missing data on age.

§ 120 women before pregnancy (108 non-cases of ED before pregnancy; 12 cases of ED before pregnancy) and 125 women during pregnancy (113 non-cases of ED during pregnancy; 12 cases of ED during pregnancy) had missing data on BMI.

3.4.2 Prevalence of ED before and during pregnancy

Table 3-3 presents the prevalence of ED before and during pregnancy. The prevalence of ED before pregnancy was 8.80% (N = 85) and during pregnancy was 6.72% (N = 65). Of full threshold ED, the prevalence of ED before pregnancy was 3.62% (N = 35) and during pregnancy was 3.31% (N = 32). Broadly defined OSFED was the most prevalent ED before (N = 40; 4.14%) and during pregnancy (N = 30; 3.10%). BED was also common before pregnancy (N = 20; 2.07%) and marginally more so during pregnancy (N = 25; 2.59%). AN was the least prevalent ED before pregnancy (N = 5; 0.52%). BN (N = 2; 0.21%) and purging disorder (N = 3; 03%) were the least prevalent ED during pregnancy. Given the proportion of missing diagnostic data in the study sample, sensitivity analyses were conducted to examine the implications on reported prevalence of any ED before and during pregnancy. Sensitivity analyses demonstrated that when all women with missing diagnostic data are assumed to have ED, the prevalence for any ED was 13.80% before pregnancy and 11.74% during pregnancy, and when assumed not to have ED, the prevalence for any ED was 8.32% before pregnancy and 6.36% during pregnancy.

Table 3-3 Prevalence of ED before and during pregnancy

Diagnostic category	Before pregnancy	During pregnancy
	N = 966	N = 967
Any ED	85 (8.80%)	65 (6.72%)
Any full threshold ED	35 (3.62%)	32 (3.31%)
AN	5 (0.52%)	5 (0.52%)
BN	10 (1.04%)	2 (0.21%)
BED	20 (2.07%)	25 (2.59%)
Purging disorder	10 (1.04%)	3 (0.31%)
Broadly defined OSFED	40 (4.14%)	30 (3.10%)

3.4.3 Remission, continuation, diagnostic cross-over and new onset of ED

Table 3-4 presents the rates of remission, continuation, diagnostic cross-over and new onset of ED during pregnancy. Amongst the women with ED before pregnancy, the rates of remission during pregnancy were highest for purging disorder (N = 7; 70%) and lowest for AN (N = 1; 20%) and BN (N = 2; 20%). Of the women with ED before pregnancy, rates of continuation were lowest for BN (N = 1; 10%) and highest for AN (N=4; 80%), followed by BED (N = 13; 65%). Rates of diagnostic cross-over from before to during pregnancy were limited to pre-pregnancy BN (N = 7; 70%) and broadly defined OSFED (N = 2; 5%), and predominantly to diagnoses of BED during pregnancy. A quarter of women with ED during pregnancy were cases of new onset (N = 18; 28%), predominantly broadly defined OSFED (N = 13; 72%) and BED (N = 4; 22%).

Table 3-4 Rates of remission, continuation, diagnostic cross over and new onset of ED during pregnancy

Pattern	AN	BN	BED	Purging disorder	Broadly defined OSFED
Remission	1	2	7	7	21
Continuation	4	1	13	3	17
Diagnostic cross over	-	7 †	-	-	2 ‡
New onset	-	1	4	-	13

† Seven women met criteria for BN before pregnancy and BED during pregnancy.

‡ Two women met criteria for broadly defined OSFED before pregnancy and a different diagnostic category during pregnancy (one AN and one BED).

3.5 Discussion

3.5.1 Prevalence of eating disorders before and during pregnancy

In this UK inner-city antenatal sample, the prevalence for DSM-5 (APA, 2013) ED before pregnancy was 8.80% (N = 85) and during pregnancy was 6.72% (N = 65). A substantial proportion of women in the sample had ED in the 12 months before pregnancy, and marginally less had active ED during pregnancy, with the exception of BED which was more frequent during than before pregnancy. These findings indicate a substantial number of pregnant women may be vulnerable to adverse pregnancy and birth outcomes and subsequently have increased healthcare needs during and after pregnancy (Fogarty et al., 2018; Koubaa et al., 2008; Linna et al., 2013, 2014; Micali, dos-Santos-Silva, et al., 2014; Solmi et al., 2014; Watson et al., 2017).

The prevalence of ED before and during pregnancy reported in this study are in line with the 9.2% and 7.6%, respectively, reported on the interim survey findings (Easter et al., 2013), as would be anticipated particularly given the previous classifications used were pre-emptive of DSM-5 (APA, 2013). Though the prevalence was higher

than 4.5% before pregnancy and 5.0% during pregnancy reported by Watson et al (2013), that study used unvalidated self-report items and did not establish prevalence for all diagnostic categories, i.e. AN during pregnancy and other types of OSFED with the exception of purging disorder. The prevalence of current ED during pregnancy is considerably greater than 1.9-2% reported by the two studies that used diagnostic interviews to determine diagnoses in accordance with DSM-5 (APA, 2013) criteria (Howard et al., 2018; Maihara dos Santos et al., 2017). Although, Maihara et al (2017) similarly did not report the prevalence of current OSFED during pregnancy, only full threshold diagnoses, and Howard et al (2018) used a stratified sampling design based on an antenatal depression screen, which could have resulted in underestimating the actual prevalence of current ED.

The discrepancies between studies using self-report questionnaires and those using diagnostic interviews are in accordance with previous research in non-pregnant populations (Fairburn & Beglin, 1994; Keel et al., 2002; Mond et al., 2007). Research suggests self-report questionnaires may inflate ED prevalence, with diagnostic interviews often considered to yield more reliable information given the ability for the interviewer to seek clarification where there is ambiguity (Fairburn & Beglin, 1994). This is particularly important given the self-report questionnaire in this study was reliant on women being able to independently distinguish their disordered eating symptoms from typical pregnancy symptoms, i.e. nausea and vomiting, and increased appetite. Further, Stice et al (2000) noted the challenge for self-report questionnaires to assess criterion that are frequently denied i.e. intense fear of weight gain or becoming fat in individuals with AN. Though this study likely mitigated this particular challenge to a degree as diagnoses of AN also included individuals who rather reporting an intense fear of weight gain or becoming fat, reported persistent behaviour that interfered with weight gain, in accordance with DSM-5 (APA, 2013).

The disparities in current prevalence of ED also related to the inclusion of a broadly defined OSFED in the present study, particularly considering OSFED has not been consistently assessed in other studies. Given the heterogeneity of OSFED and limitations of the self-report questionnaire, the broadly defined category of OSFED

was used to reflect pregnant women who were reporting some clinically significant cognitive and behavioural symptoms that may be indicative of a potential ED, warranting further investigation. Due to the over inclusive nature of this category, interpretations understandably need to be mindful. Considering women with perinatal ED are often reluctant to disclose their ED to healthcare professionals (Bye, Shawe, et al., 2018; Stringer et al., 2010), the higher prevalence in this study may also relate in part to the higher perceived anonymity from participating in the singularly distributed questionnaire, that enabled women to feel more comfortable with disclosing ED symptoms.

The prevalence of AN and BN during pregnancy are fairly consistent in the most recent studies including this study, irrespective of the type of diagnostic tool used, ranging between 0.1-0.5% and 0.1-0.7%, respectively (Easter et al., 2013; Maihara dos Santos et al., 2017; Watson et al., 2013). Prevalence of AN before pregnancy in this study is also fairly consistent with previous reports with figures ranging between 0.1-0.52% (Easter et al., 2013; Watson et al., 2013). Alternatively, reported prevalence of BN before pregnancy is more variable, with the prevalence in this study consistent with Watson et al (2013), though higher than the interim survey findings (Easter et al., 2013). Prevalence of BED before and during pregnancy is similarly higher whereas broadly defined OSFED before and during pregnancy is lower than the interim survey findings (Easter et al., 2013). These discrepancies with the interim findings are reflective of the changes in DSM-5 (APA, 2013), specifically the reduced frequency threshold for binge eating and inappropriate compensatory behaviours.

There is considerable variability across studies on the prevalence of BED during pregnancy, ranging between 1.1-4.8% including this study, with higher prevalence generated from the studies using self-report questionnaires (Easter et al., 2013; Maihara dos Santos et al., 2017; Watson et al., 2013). This discrepancy may highlight the difficulty for self-report questionnaires to assess binge eating behaviours given this is less well defined compared to other ED symptoms such as self-induced vomiting (Beglin & Fairburn, 1992; Fairburn & Beglin, 1994). Nonetheless, this study is consistent with previous reports that BED is the most common full threshold ED

during pregnancy (and more so than before pregnancy where included) (Easter et al., 2013; Maihara dos Santos et al., 2017; Watson et al., 2013), suggesting women most commonly experience difficulties with excessive uncontrollable eating during pregnancy. It is important to note, given the small numbers of women with ED across the studies, any slight variations in prevalence may not reflect a true difference as is likely to be the case with the reported prevalence for purging disorder during pregnancy, which ranges between <0.01-0.31%, including the current findings (Easter et al., 2013; Watson et al., 2013).

3.5.2 Remission, continuation, diagnostic cross-over and new onset

Among the women meeting criteria for ED in this study, women with AN before pregnancy most often continued to meet diagnostic criteria during pregnancy. Women meeting criteria before pregnancy for ED classified according to the presence of inappropriate compensatory behaviours, more often met criteria for BED or were in remission during pregnancy, which is consistent with previous reports highlighting that behavioural rather than cognitive symptoms typically decrease during pregnancy (Blais et al., 2000; Crow et al., 2004; Fogarty et al., 2018; Micali, Treasure, et al., 2007; Morgan, Lacey, et al., 1999), likely because women recognise the potential harm to their unborn infant of persistently engaging in inappropriate compensatory behaviours during pregnancy i.e. self-induced vomiting (Fogarty et al., 2018). New onset of ED was highest for broadly defined OSFED and BED, and suggests heightened gestational weight concern and excessive uncontrollable eating among some pregnant women (Coker & Abraham, 2015; Easter et al., 2013; Swann et al., 2009; Watson et al., 2013). For these women who did not have ED during the pre-conception period, findings suggest pregnancy may represent a risk period for the onset of these ED symptoms (Bulik et al., 2007). Alternatively, it could be that these women were actually in remission of a past ED during the pre-pregnancy period considering women with past ED are known to experience difficulties adjusting to pregnancy (Fogarty et al., 2018; Koubaa et al., 2008).

3.5.3 Strengths

The main strength of the study were the use of a validated self-report diagnostic tool to conduct a comprehensive assessment of the prevalence of DSM-5 (APA, 2013) ED before and during pregnancy in a sizeable sample of pregnant women. The study setting provided a cost and time effective means of accessing a large population of non-treatment seeking pregnant women attending routine antenatal care. Furthermore, there was a high response rate amongst the women invited to participate, which was likely aided by the low participation burden.

3.5.4 Limitations

The interpretation of the study findings needs to consider the limitations. The EDDS was not designed to assess DSM-5 (APA, 2013) diagnostic criteria and the adapted version used in this study has not been validated against diagnostic interviews or for use in antenatal samples. The study used a non-probability based sampling method which may have resulted in the recruitment of a biased sample. Although it is likely the sample reflected the local diverse population, it is difficult to determine their representativeness of the wider population given minimal sociodemographic information was collected. Information was not collected on lifetime ED, which prevented the opportunity to explore the relationship between perinatal and historical ED. Objective measurements of weight and height are often preferable as self-reports can be prone to measurement error as individuals tend to slightly overestimate height and underestimate weight (Brunner Huber, 2007; Stommel & Schoenborn, 2009) and it could have reduced the level of missing data on BMI. Furthermore, respondents were only asked to provide their weight at the time of the questionnaire completion, which may not have been an accurate reflection of their pre-pregnancy weight given typical weight gain during early pregnancy.

3.5.5 Conclusions and implications

A significant number of pregnant women in the sample met DSM-5 (APA, 2013) diagnostic criteria for ED in the 12 months before pregnancy and marginally less

during pregnancy, with the exception of BED which was more common during pregnancy. Women with AN before pregnancy were most likely to continue to meet criteria for AN during pregnancy compared to the other diagnostic groups. Within the sample, few women met criteria for AN and BN during pregnancy, broadly defined OSFED and BED were the most prevalent types of ED. Future research is needed to validate a self-report questionnaire for determining DSM-5 (APA, 2013) ED in pregnant women. Furthermore, to replicate the current findings in larger cohorts of pregnant women. It is important to accurately ascertain the proportions of pregnant women with ED around the time of pregnancy to inform the effective planning and provision of maternity care services and training to better support women with ED in the perinatal period.

Chapter 4 Prevalence of ED in pregnant women, using diagnostic interviews

Parts of this chapter appear in the article Bye, A., Nath, S., Ryan, E.G., Bick, D., Easter, A., Howard, L.M., Micali, N. (2020). Prevalence and clinical characterisation of pregnant women with eating disorders. *European Eating Disorders Review*, 28, 141-145.

4.1 Rationale for undertaking the research

Pregnancy can be a highly emotive period for women with a current or prior history of ED as they encounter changes to their body and appetite (Fogarty et al., 2018; Koubaa et al., 2008). Most women will adjust as pregnancy progresses with the motivation to ensure optimum health of the unborn infant, often experiencing temporary relief from their ED symptoms during this time (Fogarty et al., 2018; Micali, Treasure, et al., 2007). However, there is evidence of symptoms persisting for some women, new onset of ED, most commonly BED, and high risk of postnatal relapse (Blais et al., 2000; Micali, Treasure, et al., 2007; Watson et al., 2013).

Symptoms of depression and anxiety during pregnancy are common amongst women with current and remitted ED (Easter et al., 2015). Pregnant women with ED are also known to have heightened risk of adverse pregnancy and birth outcomes, with risks varying between ED categories and persisting among those in remission, including impaired fertility, unplanned pregnancy and delivering low birth weight babies in women with lifetime AN (Linna et al., 2013, 2014; Micali, dos-Santos-Silva, et al., 2014; Solmi et al., 2014), and miscarriage and delivering large for gestational age babies in women with lifetime BED (Linna et al., 2013, 2014; Watson et al., 2017). Although there is limited research assessing the impact of OSFED on pregnancy and birth outcomes, evidence indicates that sub-threshold ED similarly reflect heightened risk (Eik-Nes et al., 2018; Linna et al., 2013; Watson et al., 2017).

Given the risks associated with maternal ED, early identification and response to the healthcare needs of affected women is imperative to promote optimum maternal and infant outcomes. In accordance with NICE guidance, ideally women identified with ED (including those in remission of AN) should be offered preconception care so that they are in a better state of health when they do try to conceive to minimise the adverse maternal and infant outcomes (NICE, 2017). Although this is not often feasible due to the heightened risk of unplanned pregnancy in women with ED (Easter et al., 2011; Micali, dos-Santos-Silva, et al., 2014). To enhance identification of mental illnesses, NICE recommends clinicians should routinely enquire about past and current severe mental illness with all women at their first contact with NHS maternity services in England and Wales (NICE, 2014). NICE recommends clinicians should offer women identified with ED enhanced monitoring and support throughout pregnancy into the postnatal period (NICE, 2017).

Identifying ED during pregnancy is challenging given typical fluctuations in ED symptoms during this time (Blais et al., 2000; Easter et al., 2015; Micali, Treasure, et al., 2007; Watson et al., 2013) and the need to distinguish ED symptoms from pregnancy symptoms, including nausea and vomiting. Currently, there is insufficient and conflicting research to accurately determine how many women in pregnancy have a current or prior history of ED. It is suggested that between 1.9-7.6% of pregnant women may be affected by ED during pregnancy (Easter et al., 2013; Howard et al., 2018; Maihara dos Santos et al., 2017; Watson et al., 2013) and 4.5-9.2% pre-pregnancy (Easter et al., 2013; Watson et al., 2013). To the candidate's knowledge, no studies have reported the prevalence of lifetime ED in pregnant women using diagnostic interviews. The inconsistencies in reported prevalence between studies are largely due to variations in screening tools in the absence of a validated antenatal screening tool, and in operationalised ED definitions given the lack of appropriate algorithms for pregnant women (Paslakis & de Zwaan, 2019) and recently revised ED criteria in DSM-5 (APA, 2013). The recent revisions have had important implications for prevalence studies in non-pregnant populations (Lindvall Dahlgren et al., 2017).

Easter et al (2013), using an adapted version of a standardised self-report questionnaire and classifications pre-emptive but not directly in accordance with DSM-5 (APA, 2013), found 7.5% of pregnant women met criteria for current ED and 9.2% met criteria in the period before pregnancy. A mother and child cohort study, using a non-standardised self-report questionnaire and broadly defined ED categories, reported a lower prevalence of 5.0% during pregnancy and 4.5% before pregnancy (Watson et al., 2013). More recently, two studies (Howard et al., 2018; Maihara dos Santos et al., 2017) were the first to use diagnostic interviews to establish prevalence of current ED during pregnancy in accordance with DSM-5 (APA, 2013). Diagnostic interviews are considered to produce more reliable diagnoses than self-report questionnaires as they enable the interviewer to seek clarification where there is ambiguity (Beglin & Fairburn, 1992; Fairburn & Beglin, 1994) and given the challenge for self-report instruments to assess criterion that are frequently denied i.e. intense fear of weight gain or becoming fat in individuals with anorexia nervosa (Stice et al., 2000). Maihara dos Santos et al (2017) reported a prevalence of 1.9% for active ED amongst pregnant women, though this study did not assess OSFED. Howard et al (2018) reported an estimated population prevalence of 2% for current ED during early pregnancy although it did not include estimates of prevalence for the different types of ED.

This study presents further secondary analysis of data presented by Howard et al (2018) to expand on the reported findings with respect to ED. As ED are a highly heterogeneous group of disorders with differing risk profiles between categories and enhanced healthcare needs in women with past as well as current ED, it is important to estimate the prevalence of the different types of ED, according to lifetime and current diagnoses to ensure these diagnoses receive equal attention.

4.2 Research aims

The primary aim of this study was to:

1. Estimate the prevalence of lifetime and current ED in a sample of pregnant women in South-East London, using diagnostic interviews to determine diagnoses consistent with DSM-5 (APA, 2013).

The secondary aims of this study were to:

1. Examine rates of remission, continuation and diagnostic cross-over amongst pregnant women with lifetime ED.
2. To examine the clinical characteristics of pregnant women with lifetime and current ED.
3. To examine the identification of ED by midwives in antenatal care for a sample of pregnant women in South-East London.

The hypotheses under investigation were:

1. Lifetime ED will be prevalent amongst pregnant women and more so than current ED.
2. Lifetime and current diagnoses of sub-threshold ED will be as prevalent as full threshold ED.
3. The majority of women with ED before pregnancy will be in remission during pregnancy and there will be considerable diagnostic cross-over during the life course.
4. Women with lifetime and current ED will be likely to have comorbid mental disorders.
5. ED will be poorly identified by midwives in antenatal care.

4.3 Methods

4.3.1 Design

Data were obtained from the WEll-being in pregNancy stuDY (WENDY). WENDY is a cross-sectional survey using a sampling design stratified according to women being positive or negative on the Whooley questions. The Whooley is a two-item

questionnaire to identify symptoms of depression: (1) “During the past month, have you often been bothered by feeling down, depressed or hopeless?”; (2) “During the past month, have you often been bothered by little interest or pleasure in doing things?” (Whooley, Avins, Miranda, & Browner, 1997). “Whooley positive” is determined by an answer of “yes” to either of the questions and “Whooley negative” is determined if responses to both questions are “no”. Current NICE recommendations are that all women attending NHS maternity services in England and Wales are screened using these questions at their antenatal booking appointment, which occurs around 10 weeks gestation (NICE, 2014). The primary aim of WENDY was to establish the effectiveness of the Whooley questions to identify antenatal depression. Further detail on the rationale, sampling, and representativeness in WENDY is provided in a publication (Howard et al., 2018). The details applicable to data from the cross-sectional survey that are presented in this thesis are described in the following sections.

4.3.2 Ethical approval

Ethical approval for WENDY was granted by the National Research Ethics Service, London Committee - Camberwell St Giles (ref no 14/LO/0075).

4.3.3 Study setting

Women were recruited at their antenatal booking appointment at an inner-city NHS maternity service in South-East London.

4.3.4 Participants

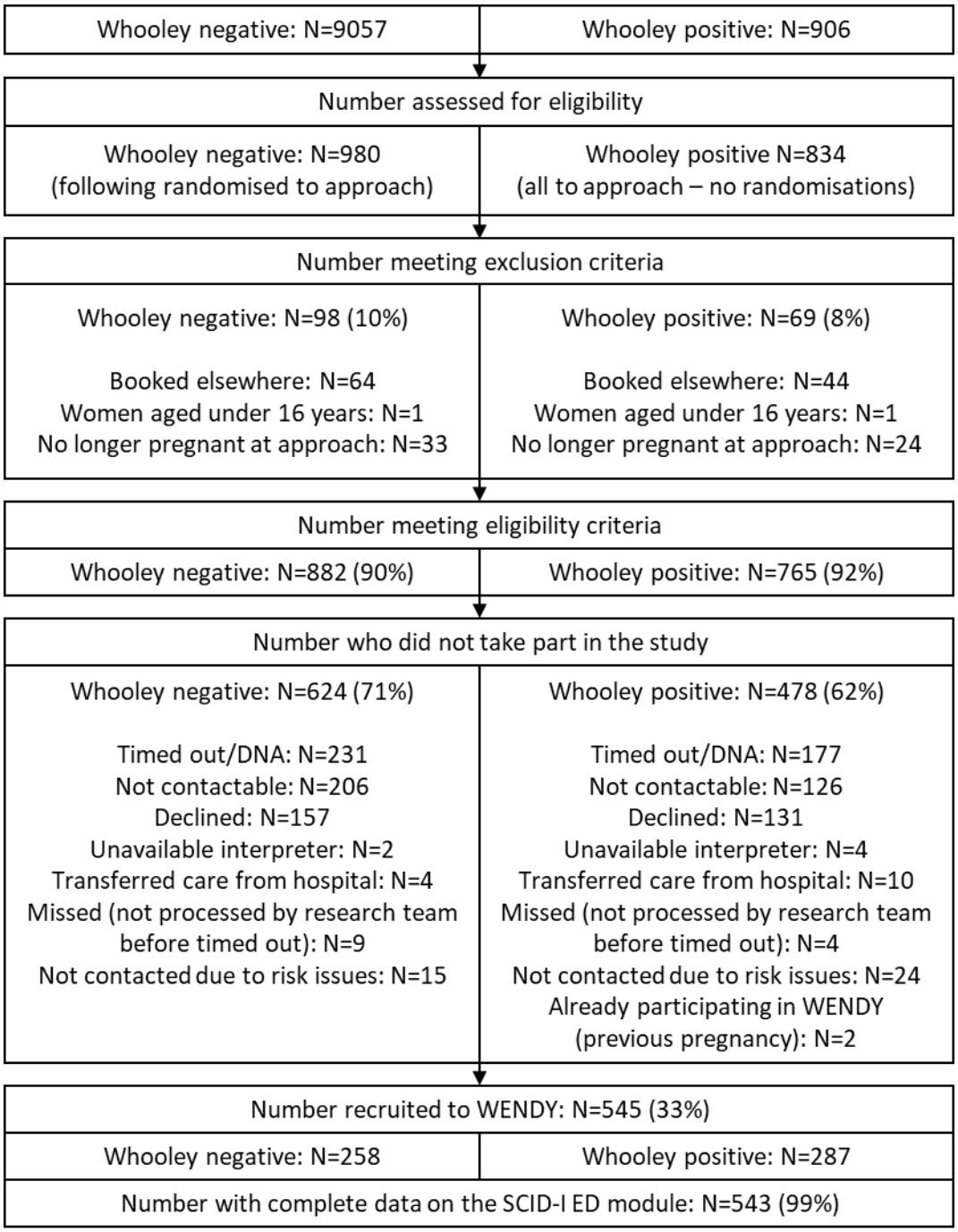
Women were eligible to participate if they were 16 years old or above and had a response to the Whooley questions recorded on their electronic maternity record. Women were ineligible to participate if they were less than 16 years old, no data was available on their response to the Whooley questions, they had already attended an antenatal booking appointment elsewhere in the UK or had a miscarriage or termination of pregnancy prior to the study interview.

4.3.5 Recruitment

Between October 2014 and June 2016, a study advertisement was included with the pre-booking information routinely posted to women in advance of attending their antenatal booking appointment. At the antenatal booking appointment, midwives routinely asked women the Whooley questions (Whooley et al., 1997) and Whooley status (positive or negative) was recorded via an electronic maternity records system. The research team (postgraduate researchers and research midwives) were provided with daily lists of women attending antenatal booking appointments, which included Whooley status, of which to identify those to approach for participation. All Whooley positive women and a random sample of Whooley negative women were selected to be approached for participation in WENDY. The random sampling of Whooley negatives was carried out by the research team using a web-based audit-trailed randomisation system. Initially, the randomisation of Whooley negatives was set at a ratio of 1:4 and this was later adjusted to 1:6 to prevent the oversampling of Whooley negatives in accordance with the WENDY sample size calculation (Howard et al., 2018).

The researchers contacted women who were selected to be approached, in person on the same day but after their appointment, or by telephone, email or letter if this was not possible. The researcher explained the purpose of the research, what participation would involve and invited women to participate. Women who agreed to participate were recruited within a maximum of three weeks from their antenatal booking appointment. Research interviews were conducted at the study setting or women's homes. Women provided written informed consent before the start of the research interview, which also asked for permission to extract information from their electronic maternity record (see Appendix III). Figure 4-I illustrates the flow of women through WENDY and the sample included in the current analysis.

Figure 4-I Flow chart of women through WENDY and the present study



4.3.6 Measures

Data collected from the research interview and women's electronic maternity records are outlined below.

4.3.6.1 Structured Clinical Interview for DSM-IV and DSM-IV-TR Axis I and Axis II disorders

Researchers administered the SCID for Axis I disorders (SCID-I; First et al., 2002) and Axis II disorders (SCID-II; First, Gibbon, Spitzer, Williams, & Benjamin, 1997). The SCID is a widely used semi-structured modular interview to determine diagnoses consistent with DSM-IV and DSM-IV-TR (APA, 1994, 2000). The SCID is a reliable and valid measure for determining diagnoses of mental illnesses (Lobbestael et al., 2011; Zanarini et al., 2000). The SCID was not designed to assess DSM-5 (APA, 2013) diagnostic criteria however, DSM-5 (APA, 2013) diagnostic criteria was used to determine diagnoses of interest as the DSM-5 version of the SCID was not available at the time of the study. Furthermore, although the SCID refers to DSM-IV (APA, 1994), and DSM-IV-TR (APA, 2000), the ED module includes sections on AN, BN and EDNOS BED so it is possible to determine lifetime and current diagnoses of all ED categories in accordance with DSM-5 (APA, 2013) diagnostic criteria.

The SCID-I ED module was used to determine lifetime and current diagnoses of AN, BN BED and OSFED, including atypical anorexia, purging disorder and a combined category of subthreshold BN or BED. As in previous ED research (Micali et al., 2017; Smink et al., 2014; Solmi et al., 2015), the SCID-I ED module 'skip rules' were not applied and information on type, frequency and duration of ED symptoms were collected to enable classification of diagnoses consistent with DSM-5 (APA, 2013) (i.e. considering the reduced frequency threshold for binge eating and compensatory behaviours from at least twice a week to once a week for a minimum of three months). This information was obtained in response to the original SCID-I ED module questions without the need for alterations. A current ED diagnosis was determined if all criteria were met in the past month. A lifetime diagnosis was determined if all criteria were met at any time point, including in the past month.

Evidence indicates diagnostic cross-over between ED over the lifetime is common, more often crossing from restrictive to binge/binge-purge types (Anderluh et al., 2009; Eddy et al., 2008). In accordance with previous research (Micali, Holliday, et al., 2007; Micali et al., 2017), a hierarchical approach was used to categorise women who met criteria for more than one lifetime ED diagnosis to ensure diagnostic groups were mutually exclusive: full threshold ED (AN; BN; BED) trumped OSFED subtypes; BED trumped BN; BN trumped AN. Partial remission of an ED was determined if all the criteria were previously met but not all were met in the past month. Full remission was determined if all the criteria were previously met but none were met in the past month. Age at onset of ED was defined as the age at which a woman first met criteria for an ED as determined in the diagnostic interview.

The SCID-I mood episodes, mood disorders and anxiety disorders module was used to diagnose common mental health illnesses, specifically current (in the past month) depression and anxiety disorders. Diagnoses of current depression included mild, moderate and severe major depressive episodes and mixed anxiety and depression. Diagnoses of any current anxiety disorder included generalised anxiety disorder, panic disorder, agoraphobia without panic disorder, social phobia and specific phobia, consistent with DSM-5 (APA, 2013) (with the exception of post-traumatic stress disorder and obsessive compulsive disorder, consistent with DSM-5). The SCID-II personality disorders sub-section module was used to establish diagnoses of borderline personality disorder. History of deliberate self-harm or attempted suicide was determined from responses to the SCID interview questions, including “Have you tried to hurt or kill yourself or ever threatened to do so?” with a follow up prompt “Have you ever cut, burned, or scratched yourself on purpose?” (personality disorders sub-section). Any disclosed act of deliberate self-harm (with or without attempted suicide) was classified as a history of deliberate self-harm or attempted suicide.

Training and quality assurance

Researchers (postgraduate researchers and research midwives) responsible for administering the SCID were trained to administer the SCID using the official training materials (i.e. DVD format of sample interviews with expert commentaries and guidance) and module-specific training sessions delivered by trainers with previous extensive experience in the use of the SCID, followed by regular supervision meetings with expert clinicians for the study duration. Dr Nadia Micali (ED expert on WENDY) ran an introductory training session on the administration of the SCID-I ED module, which was followed by mock interviews using vignettes prepared by Dr Radha Kothari (postdoctoral researcher with extensive experience in administering the SCID) and regular supervision meetings. All potential ED cases were discussed in the supervision meetings to achieve consensus on ED diagnoses with Dr Nadia Micali. Ms Susan Conroy (postgraduate researcher with extensive experience in administering and training researchers on the SCID) ran several training sessions on the administration of the SCID-I mood episodes, mood disorders and anxiety disorders module, which included mock interviews and quality control checks at regular study intervals. Professor Paul Moran (personality disorder expert on WENDY) ran an introductory training session on the SCID-II personality disorders sub-section module for borderline personality disorder, which was followed by supervision meetings where needed to discuss potential diagnoses. With the exception of potential ED cases, all other potential diagnoses were discussed in consensus meetings with Professor Louise Howard (Chief Investigator for WENDY).

4.3.6.2 Data extracted from electronic maternity records

Of the women who consented for information to be extracted from their electronic maternity record (N = 515; 95%), information was extracted on identification of ED at the antenatal booking appointment in response to routinely asked questions about past and current severe mental illness (NICE, 2014). Information was extracted from brief free text recorded via the electronic maternity records system by the clinician and categorised dichotomously by combining identification of past and/or current ED.

4.3.6.3 Sample characteristics

Self-reported socio-demographic, obstetric and health information were collected at the research interview (see Appendix IV). Outcomes of interest included age in years, ethnicity, highest education level, employment status, gross annual household income, relationship status, late booking, parity, whether the current pregnancy had been planned, whether the current pregnancy was conceived using assisted reproductive technology (e.g. in vitro fertilisation), height and pre-pregnancy weight (to calculate pre-pregnancy BMI), current smoking status, and current or chronic medical conditions. Late bookers were defined as women who had their antenatal booking appointment at ≥13 weeks of pregnancy. Self-reported pre-pregnancy BMI was calculated as weight (kg) divided by height in metres squared (m^2) and categorised in accordance with the WHO classification system; underweight (BMI <18.5 kg/m^2), normal weight (BMI 18.5 - 24.9 kg/m^2), overweight (BMI 25.0-29.9), and obese (BMI≥30.0 kg/m^2) (World Health Organization, 2006). The WHO classification of underweight was used as it is more lenient given the survey was conducted on a community-based sample and is in accordance with other similar studies (Easter et al., 2013; Watson et al., 2017).

4.3.7 Patient and public involvement and engagement

An advisory group, comprising of women with lived experience of perinatal mental health problems, was established for WENDY and the other related studies undertaken as part of the same programme of work (https://www.kcl.ac.uk/ioppn/depts/hspr/research/CEPH/wmh/projects/A-Z/esmi). The group met regularly throughout the study period to input into various elements of WENDY, including the protocol, study measures, recruitment, participant information sheets and consent forms. No members of the advisory group participated in the study or assisted in recruitment.

4.3.8 Analysis

All WENDY data were managed and analysed using STATA 15 (StataCorp, 2017). This study employed a similar analysis approach to previously published work (Howard et

al., 2018; Nath et al., 2018). Cross tabulations and chi-square tests (or Fisher's exact where appropriate) were used to describe differences in sample characteristics, comorbid mental disorders and healthcare outcomes between cases and non-cases of lifetime and current ED. Since these were exploratory analyses, we did not perform corrections to the p-values to account for multiple testing. Estimates of population prevalence of ED were obtained using sampling weights to account for the stratified sampling design (A Pickles, Dunn, & Vázquez-Barquero, 1995). More specifically, sampling weights were based on the number of Whooley positives and Whooley negatives in the WENDY sample, out of the total number of Whooley positives and Whooley negatives that attended their first antenatal booking appointment at the study setting during the study period; this consisted of 906/287 for Whooley positives and 9057/258 for Whooley negatives (Howard et al., 2018). Population prevalence of lifetime and current ED were estimated based on responses from diagnostic interviews (weighted) using the survey (svy) command in STATA, which permits stratified sampling and provides robust estimation of 95% confidence intervals (CIs).

4.3.9 Missing data

Among the total sample, 24 (4%) women had some SCID data missing, of which two (0.4%) women had missing data for the SCID-I ED module. Missing data for the SCID-I ED module were treated as missing observations using list-wise deletion performed in STATA. Only women with complete SCID-I ED module data were used to calculate population prevalence estimates.

4.4 Results

4.4.1 Sample characteristics

Between 10th November 2014 and 30th June 2016, 10,004 women attended their first antenatal booking appointment at the maternity service, 41 of whom had no data available on their responses to the Whooley questions. The base population was therefore comprised of 9,963 women. Of the women identified as eligible to

participate (N = 1,647), a total of 545 (33%) women were recruited to WENDY and the sample was similar to the base population in age, ethnicity and parity (Howard et al., 2018). Of the WENDY sample, 543 women provided responses to the SCID-I ED module (see Figure 4-I). Women with available data for the SCID-I ED module were also similar to the WENDY sample and the base population on age, ethnicity and parity (see Table 4-1).

Table 4-1 Characteristics of wider base population and study population

N (%)		Base population †	WENDY sample	Sample with SCID-I ED data
		N = 9963	N = 545	N = 543
Age (in years)		Mean: 31.67 Range: 14-52	Mean: 32.85 Range: 16-47.5	Mean: 32.88 Range: 16-47.5
	<20	232 (2%)	8 (1%)	7 (1%)
	20-29	3048 (30%)	150 (28%)	149 (27%)
	30-39	6240 (61%)	341 (63%)	341 (63%)
	40≥	705 (7%)	46 (8%)	46 (9%)
Ethnicity				
	White	4914 (51%)	284 (52%)	284 (52%)
	Black	3162 (33%)	177 (32%)	177 (33%)
	Asian	594 (6%)	25 (5%)	24 (4%)
	Mixed	308 (3%)	23 (4%)	22 (4%)
	Other	646 (7%)	36 (7%)	36 (7%)
Parity				
	0	5077 (50%)	271 (50%)	269 (50%)
	1	3209 (31%)	175 (32%)	175 (32%)
	≥2	1939 (19%)	99 (18%)	99 (18%)

† Missing data not included in the table.

Table 4-2 presents a comparison of sample characteristics between cases and non-cases of lifetime and current ED. Significant differences were found between women with lifetime ED (n = 108) and women without lifetime ED (n = 435), with women with lifetime ED more commonly being white (66% vs. 49%), educated to degree level or above (62% vs. 49%), and in a relationship although not cohabiting (21% vs. 14%). Women with current ED (n = 16) and women without current ED (n = 527) differed significantly on the distribution of pre-pregnancy BMI categories (25% vs. 6% underweight; 33% vs. 64% normal weight; 42% vs. 20% overweight; 0% vs. 10% obese, respectively).

Table 4-2 Comparison of sample characteristics between cases and non-cases of lifetime and current ED

N (%)		Non-cases of lifetime ED	Cases of lifetime ED	P value	Non-cases of current ED	Cases of current ED	P value	Total
		N = 435	N = 108		N = 527	N = 16		N = 543
Age (in years)								
	16-19	7 (2%)	-	P = 0.387	7 (1%)	-	P = 0.072	7 (1%)
	20–29	116 (27%)	33 (30%)		140 (27%)	9 (56%)		149 (27%)
	30–39	272 (62%)	69 (64%)		334 (63%)	7 (44%)		341 (63%)
	40≥	40 (9%)	6 (6%)		46 (9%)	-		46 (9%)
Ethnicity								
	White	213 (49%)	71 (66%)	P = 0.002	277 (53%)	7 (44%)	P = 0.189	284 (52%)
	Black	155 (36%)	22 (20%)		173 (33%)	4 (25%)		177 (33%)
	Asian	21 (5%)	3 (3%)		23 (4%)	1 (6%)		24 (4%)

	Mixed	14 (3%)	8 (7%)		21 (4%)	1 (6%)		22 (4%)
	Other	32 (7%)	4 (4%)		33 (6%)	3 (19%)		36 (7%)
Highest education level								
	None or school qualifications	105 (24%)	14 (13%)	P = 0.020	117 (22%)	2 (13%)	P = 0.670	119 (22%)
	College, diploma, higher national certificate or training	116 (27%)	27 (25%)		139 (26%)	4 (25%)		143 (26%)
	Degree level or above	214 (49%)	67 (62%)		271 (51%)	10 (63%)		281 (52%)
Employment status †								
	Employed	275 (63%)	79 (73%)	P = 0.086	342 (65%)	12 (75%)	P = 0.577	354 (65%)
	Student	12 (3%)	3 (3%)		15 (3%)	-		15 (3%)
	Unemployed	59 (14%)	5 (5%)		64 (12%)	-		64 (12%)

	Homemaker	60 (14%)	14 (13%)		71 (14%)	3 (19%)		74 (14%)
	Not working due to illness or other reason	27 (6%)	7 (6%)		33 (6%)	1 (6%)		34 (6%)
Income ‡								
	< £15,000	60 (19%)	17 (19%)		74 (18%)	3 (23%)		77 (19%)
	£15,000 - £30,999	55 (17%)	16 (18%)		68 (17%)	3 (23%)		71 (17%)
	£31,000 - £45,999	51 (16%)	9 (10%)	P = 0.635	57 (14%)	3 (23%)	P = 0.165	60 (14%)
	£46,000 - £60,999	50 (15%)	13 (14%)		60 (15%)	3 (23%)		63 (15%)
	≥ £61,000	108 (33%)	36 (40%)		143 (36%)	1 (8%)		144 (35%)
Relationship status								
	Single	63 (15%)	7 (7%)		67 (13%)	3 (19%)		70 (13%)
	Partner, not cohabiting	59 (14%)	23 (21%)	P = 0.021	77 (15%)	5 (31%)	P = 0.063	82 (15%)

	Married or cohabiting	313 (72%)	78 (72%)		383 (73%)	8 (50%)		391 (72%)
Parity								
	0	207 (48%)	62 (57%)	P = 0.142	260 (49%)	9 (56%)	P = 0.440	269 (50%)
	1	148 (34%)	27 (25%)		172 (33%)	3 (19%)		175 (32%)
	≥2	80 (18%)	19 (18%)		95 (18%)	4 (25%)		99 (18%)
Late booker								
	Yes	78 (18%)	17 (16%)	P = 0.592	91 (17%)	4 (25%)	P = 0.499	95 (18%)
	No	357 (82%)	91 (84%)		436 (83%)	12 (75%)		448 (82%)
Planned pregnancy								
	Yes	279 (64%)	76 (70%)	P = 0.223	346 (66%)	9 (56%)	P = 0.435	355 (65%)
	No	156 (36%)	32 (30%)		181 (34%)	7 (44%)		188 (35%)
Assisted pregnancy								

	Yes	415 (95%)	103 (95%)	P = 0.989	503 (95%)	15 (94%)	P = 0.535	25 (5%)
	No	20 (5%)	5 (5%)		24 (5%)	1 (6%)		518 (95%)
Pre-pregnancy BMI §		Mean: 23.73 Range: 16.9-53.9	Mean: 24.59 Range: 17.3-47.2		Mean: 23.91 Range: 16.9-53.9	Mean: 23.48 Range: 17.3-29.7		Mean: 23.90 Range: 16.9-53.9
	Underweight	23 (7%)	6 (7%)	P = 0.217	26 (6%)	3 (25%)	P = 0.011	29 (7%)
	Normal	220 (66%)	46 (54%)		262 (64%)	4 (33%)		266 (63%)
	Overweight	62 (19%)	23 (27%)		80 (20%)	5 (42%)		85 (20%)
	Obese	30 (9%)	10 (12%)		40 (10%)	-		40 (10%)
Current smoker								
	Yes	16 (4%)	6 (6%)	P = 0.376	20 (4%)	2 13%)	P = 0.133	22 (4%)
	No	419 (96%)	102 (94%)		507 (96%)	14 (87%)		521 (96%)

Current/ chronic medical conditions ¶								
	Yes	185 (43%)	55 (51%)	P = 0.120	231 (44%)	9 (56%)	P = 0.445	240 (44%)
	No	249 (57%)	53 (49%)		295 (56%)	7 (44%)		302 (56%)

† Two women had missing data on employment status (2 non-cases of lifetime/current ED).

‡ 128 women had missing data on gross annual household income (111 non-cases of lifetime ED, 17 cases of lifetime ED; 125 non-cases of current ED, 3 cases of current ED).

§ 123 women had missing data on pre-pregnancy BMI (100 non-cases of lifetime ED, 23 cases of lifetime ED; 119 non-cases of current ED; 4 cases of current ED).

¶ One woman had missing data on current or chronic medical conditions (1 non-case of lifetime/current ED).

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4.4.2 Comorbid mental disorders

Table 4-3 presents a comparison of comorbid mental disorders between cases and non-cases of lifetime and current ED. Women with lifetime ED were significantly more likely to have current depression and anxiety compared to women without lifetime ED (34% vs. 25% and 29% vs. 19%, respectively). Women with current ED were more likely to have current anxiety and borderline personality disorder compared to women without current ED (50% vs. 20% and 19% vs. 2%, respectively). Women with lifetime ED were more likely to have a history of deliberate self-harm or attempted suicide compared to women without lifetime ED (21% vs. 12%), and this trend was reflected in women with current ED compared to women without current ED (31% vs. 13%).

Table 4-3 Comparison of comorbid mental disorders between cases and non-cases of lifetime and current ED

N (%)		Non-cases of lifetime ED	Cases of lifetime ED	P value	Non-cases of current ED	Cases of current ED	P value	Total
		N = 435	N = 108		N = 527	N = 16		N = 543
Current depression								
	Yes	109 (25%)	37 (34%)	P = 0.054	142 (27%)	4 (25%)	P = 1.00	146 (27%)
	No	326 (75%)	71 (66%)		385 (73%)	12 (75%)		397 (73%)
Current anxiety								
	Yes	84 (19%)	31 (29%)	P 0.032	107 (20%)	8 (50%)	P = 0.009	115 (21%)
	No	351 (81%)	77 (71%)		420 (80%)	8 (50%)		428 (79%)
Borderline personality disorder †								
	Yes	8 (2%)	5 (5%)	P = 0.149	10 (2%)	3 (19%)	P = 0.005	13 (2%)
	No	426 (98%)	103 (95%)		516 (98%)	13 (81%)		529 (98%)

History of deliberate self-harm or attempted suicide ‡								
	Yes	52 (12%)	23 (21%)	P = 0.012	70 (13%)	5 (31%)	P = 0.056	75 (14%)
	No	382 (88%)	85 (79%)		456 (87%)	11 (69%)		467 (86%)

† One woman had missing data for the SCID-II personality disorders sub-section module (1 non-case of lifetime/current ED).

‡ One woman had missing data for history of deliberate self-harm or attempted suicide (1 non-case of lifetime/current ED).

4.4.3 Identification of mental disorders in antenatal care

Table 4-4 presents data on mental disorders identified in antenatal care between cases and non-cases of lifetime and current ED. Women with lifetime and current ED were more often Whooley positive than the women in the comparison groups (66% and 81% vs. 49% and 52%, respectively). Identification of ED at the antenatal booking appointment was low compared to the numbers identified using the diagnostic interview (2% vs. 20%).

Table 4-4 Mental disorders identified in antenatal care for cases and non-cases of lifetime and current ED

N (%)		Non-cases of lifetime ED	Cases of lifetime ED	P value	Non-cases of current ED	Cases of current ED	P value	Total
		N = 435	N = 108		N = 527	N = 16		N = 543
Whooley status								
	Positive	215 (49%)	71 (66%)	P = 0.002	273 (52%)	13 (81%)	P = 0.022	286 (53%)
	Negative	220 (51%)	37 (34%)		254 (48%)	3 (19%)		257 (47%)
Identification of ED †								
	Yes	3 (1%)	9 (9%)	P < 0.001	10 (2%)	2 (13%)	P = 0.047	12 (2%)
	No	393 (99%)	92 (91%)		472 (98%)	13 (87%)		485 (98%)

† 46 women had missing data on the identification of ED at the antenatal booking appointment (39 non-cases of lifetime ED, 7 cases of lifetime ED; 45 non-cases of current ED, 1 case of current ED).

4.4.4 Prevalence estimates of lifetime and current ED

Table 4-5 presents the weighted population prevalence estimates of lifetime and current ED. The weighted lifetime prevalence of ED was 15.35% (95% CI, 11.80-19.71%) and the current prevalence was 1.47% (95% CI, 0.64-3.35%). Of full threshold ED, the weighted lifetime prevalence was 9.37% (95% CI, 6.66-13.03%) and weighted current prevalence 0.61% (95% CI, 0.19-1.96%). AN was the most prevalent lifetime ED (7.13%; 95% CI, 4.75-10.58%), particularly AN-R (5.14%; 95% CI, 3.17-8.23%). OSFED were also common with a lifetime prevalence of 5.97% (95% CI, 3.83-9.21%), particularly atypical anorexia (2.63%; 95% CI, 1.31-5.21%). Conversely, lifetime prevalence was lowest for BN (0.58%; 95% CI, 0.17-1.97%) and there were no current cases of BN. OSFED were the most common ED during pregnancy (0.87%; 95% CI, 0.28-2.69%), particularly purging disorder (0.71%; 95% CI, 0.18-2.79%).

Table 4-5 Weighted population prevalence estimates of lifetime and current ED

Diagnostic category	Subtype	N	Weighted lifetime prevalence, % (95% CI)	N	Weighted current prevalence, % (95% CI)
Any ED		108	15.35 (11.80-19.71)	16	1.47 (0.64-3.35)
Any full threshold ED		72	9.37 (6.66-13.03)	9	0.61 (0.19-1.96)
AN		42	7.13 (4.75-10.58)	3	0.09 (0.03 – 0.30)
	AN-R	30	5.14 (3.17-8.23)	2	0.06 (0.02 – 0.26)
	AN-BP	12	1.99 (0.91-4.30)	1	0.03 (0.00 – 0.23)
BN		8	0.58 (0.17-1.97)	-	-
BED		22	1.67 (0.79-3.46)	6	0.51 (0.13-2.02)
OSFED		36	5.97 (3.83-9.21)	7	0.87 (0.28-2.69)
	Atypical anorexia	12	2.63 (1.31-5.21)	1	0.03 (0.00 – 0.23)
	Purging disorder	7	1.51 (0.60-3.74)	2	0.71 (0.18-2.79)
	Sub-threshold BN or BED	17	1.83 (0.85-3.90)	4	0.13 (0.05 – 0.34)

4.4.5 Remission, continuation and diagnostic cross-over

Amongst the pregnant women in the sample with lifetime ED (N=108), there was considerable diagnostic cross-over during the life course. Of the women with lifetime AN (N=42; 39%), three (7%) were current cases, four (10%) met criteria previously but were current OSFED (one atypical anorexia; one purging disorder; two subthreshold BN or BED) and 35 (83%) were past cases who did not meet criteria for any current ED (34 in full remission; 1 in partial remission). Of the women with lifetime BN (N=8; 7%), none met criteria for any current ED (six in full remission; two in partial remission). Of the women with lifetime BED (N=22; 20%), six (27%) were

current cases, one (5%) met criteria previously but was current OSFED (subthreshold BN or BED), and 15 (68%) were past cases who did not meet criteria for any current ED (14 in full remission; 1 in partial remission). Of the women with lifetime atypical anorexia (n=12; 11%), none met criteria currently (11 in full remission; one in partial remission). Of the women with lifetime purging disorder (N=7; 6%), one (14%) met current criteria and six (86%) were in remission (five in full remission; one in partial remission). Of the women with lifetime sub-threshold BN or BED (N=17; 16%), one (6%) was a current case and sixteen (94%) were in remission (14 in full remission; 2 in partial remission). Of note, all women in this study who met criteria for lifetime OSFED only met criteria for one OSFED subtype, so it was not necessary to expand the hierarchical approach outlined in the methods section. Amongst the women with lifetime ED, the median age of onset for the first ED diagnosis was lowest for the sub-threshold BN or BED category (16.5, range 14-37) and highest for BED (23; range 7-36) and purging disorder (23; range 14-40).

4.5 Discussion

4.5.1 Prevalence of lifetime and current ED in pregnant women

In this UK inner-city antenatal sample of women, the estimated population prevalence for lifetime ED was 15.35% (95% CI, 11.80-19.71%) and for active ED during pregnancy was 1.47% (95% CI, 0.64-3.35%). The findings highlight that by early pregnancy, a significant proportion of women will have had ED, although less typically active ED during pregnancy. These findings, together with those of previous studies (Fogarty et al., 2018; Koubaa et al., 2008; Linna et al., 2013, 2014; Micali, dos-Santos-Silva, et al., 2014; Solmi et al., 2014; Watson et al., 2017), suggest a considerable number of pregnant women are vulnerable to adverse pregnancy and birth outcomes and likely to have increased healthcare needs during pregnancy and postnatally.

To the candidate's knowledge, this is the first study to use diagnostic interviews to estimate population prevalence of lifetime ED in pregnant women. The estimated lifetime prevalence reported in this study supports a prevalence of 15.33% (95% CI, 13.48–17.42%) reported in a recent study of women who participated in a

longitudinal birth cohort study, the majority of whom reported that onset of ED was prior to pregnancy (Micali et al., 2017). There are marginal discrepancies in prevalence estimates for individual ED categories between the studies. Estimated prevalence for lifetime AN of 7.13% (95% CI, 4.75-10.58%) was higher in the current study than the prevalence of 3.64% (95% CI, 2.81-4.72%) reported by Micali et al (2017). This may reflect recall bias given the longer follow-up in the previous findings (Micali et al., 2017), as the women were assessed later in life with an average age of 47.78 years compared to 32.88 years in this study, considering typical onset of AN is during adolescence (Hudson et al., 2007). Estimated prevalence for lifetime BN of 0.58% (95% CI, 0.17-1.97%) was somewhat lower than 2.15% (95% CI, 1.70-2.74%) reported by Micali et al (2017). The lifetime prevalence estimate for OSFED of 5.97% (95% CI, 3.83-9.21%) was comparable to a prevalence of 7.64% (95% CI, 6.32-9.24%) reported by Micali et al (2017). As evidenced in the study findings, a large proportion of pregnant women would be classified with sub-threshold ED despite the recent changes to DSM to broaden the full threshold ED categories to reduce the predominance of individuals presenting clinically who do not meet full threshold diagnostic criteria (Fairburn & Cooper, 2011).

The findings indicate that ED may not be as common during pregnancy as some previous reports of 5-7.6% (Easter et al., 2013; Watson et al., 2013), though it does parallel 1.9% reported by Maihara dos Santos et al (2017). None of the women in the current study met diagnostic criteria for BN during pregnancy compared to 0.1-0.7% reported previously (Easter et al., 2013; Maihara dos Santos et al., 2017; Watson et al., 2013). This finding likely relates to previous research indicating that most women stop or decrease disordered eating behaviours during pregnancy, i.e. self-induced vomiting (Micali, Treasure, et al., 2007). Only estimated prevalence for AN during pregnancy (0.09%, 95% CI 0.03-0.30%) was similar to a prevalence of 0.1% reported in the more recent study (Maihara dos Santos et al., 2017). The high rates of remission during pregnancy found in this study indicates that the pre-conception period could be an opportune time for healthcare professionals to identify women with a history of ED to assess their current healthcare needs and provide information about pregnancy planning to promote optimal physical and mental health prior to

pregnancy commencement. Though given the increased risk of unplanned pregnancies associated with AN (Micali, dos-Santos-Silva, et al., 2014), this may not always be plausible.

The discrepancies in reported prevalence of current ED compared to previous antenatal prevalence studies may reflect the present study using a more stringent and comprehensive assessment of ED diagnoses consistent with DSM-5 (APA, 2013). This study used the SCID which is considered one of the "gold standard" instruments for establishing ED diagnoses (Lobbestael et al., 2011; Zanarini et al., 2000), though it is not without its limitations given it was not designed to assess DSM-5 (APA, 2013) diagnostic criteria and the lack of validation studies for assessing OSFED or ED in antenatal samples. The findings highlight the importance of consistency in the diagnostic criteria operationalised in studies and support the validation of suitable instruments for use with antenatal populations (Bannatyne, Hughes, Stapleton, Watt, & MacKenzie-Shalders, 2018).

It is important to acknowledge though the estimated prevalence of ED may underestimate the true proportion as some women may have been reluctant to disclose ED symptoms in the research interview, particularly those currently experiencing difficulties, due to fear of being stigmatised and negative judgements of them as a mother (Bye, Shawe, et al., 2018). Fear of negative consequences as a result of a disclosure may have been a particular concern for women in this study given recruitment was directly via their antenatal care, women may have incorrectly assumed that a disclosure could impact on their care, despite reassurances from the researchers. Additionally, given the sampling weights employed in this study were based on a routine depression screen rather than a screening tool for ED, although often comorbid (Easter et al., 2015), this may have resulted in the study not capturing all pregnant women who might have ED.

4.5.2 Clinical characteristics of pregnant women with lifetime and current ED

The findings support previous research that pregnant women with current and past ED often experience depression and anxiety during pregnancy (Easter et al., 2015).

History of deliberate self-harm or attempted suicide have not been studied previously in pregnancy but both are associated with ED in the general population (Keski-Rahkonen & Mustelin, 2016; Udo et al., 2019). In this study, pregnant women with lifetime ED were more commonly white, well-educated, and in a relationship, which are the types of socio-demographics that are often associated with a low risk profile so healthcare professionals may not consider these women to have a psychiatric history. Furthermore, pregnant women with active ED during pregnancy more commonly presented with pre-pregnancy BMI's outside the healthy weight range, which is in accordance with previous research in young adults with ED (Stice et al., 2013).

4.5.3 Identification of ED in antenatal care

Amongst the women in this study, ED were poorly identified in antenatal care. To the candidate's knowledge, this is the first study to investigate rates of identification of ED by midwives using data from maternity records. The disparity in the rate of women identified with ED using a diagnostic interview with those identified at the antenatal booking appointment indicates some women may have intentionally not disclosed symptoms in the clinic appointment, but also indicates a lack of enquiry or in a few cases, inaccurate diagnoses by clinicians (Bye, Shawe, et al., 2018; Stringer et al., 2010).

4.5.4 Strengths

The main strength was the novel use of diagnostic interviews to obtain estimates of population prevalence of lifetime and current ED diagnoses consistent with DSM-5 (APA, 2013) amongst women in early pregnancy. The sample were diverse and representative of the local inner city population, aided by the use of language interpreters for non-English speaking women, which supports the generalisability of the findings to similar populations. A wealth of data were collected, meaning that it was possible to compare rates of women identified using a diagnostic interview with those identified at the antenatal booking appointment. Furthermore, there was minimal missing data on study outcomes.

4.5.5 Limitations

There are several limitations that warrant consideration. The SCID was not designed to assess DSM-5 (APA, 2013) diagnostic criteria and has not been validated to assess OSFED or for use in antenatal samples. Despite the use of sampling weights to account for the stratified sampling, this may have led to the overestimation or underestimation of prevalence estimates of ED. The diagnostic interview relied upon recall of ED symptoms during the woman's life course which may have been susceptible to recall bias. Amongst the women with ED in the present sample, the extent of diagnostic instability over the lifetime was not as common as suggested from prior evidence (Anderluh et al., 2009; Eddy et al., 2008; Micali et al., 2017). This may be because the ED module was one part of a research interview that collected a wealth of other data whereby ED was not the predominant focus of the research. The small sample size for current ED diagnoses limited the statistical power to explore group differences and limits the conclusions that can be drawn from this sample. Furthermore, the study sample was recruited from a single inner-city maternity site, with a poor response rate among those identified as eligible to participate, though this is not common in two-phased studies and does not necessarily indicate a biased sample (Hartge, 2006).

4.5.6 Conclusions and implications

This study estimated the prevalence of lifetime and current ED in a sample of pregnant women in South-East London, using diagnostic interviews to establish diagnoses consistent with DSM-5 (APA, 2013). The findings indicate that by early pregnancy, a significant proportion of pregnant women will have had ED, although less typically active ED during pregnancy, and psychiatric comorbidity is common. ED were poorly identified in antenatal care, which increases the likelihood of inadequate healthcare provision and adverse outcomes for pregnant women with ED. Future research should aim to replicate these findings with larger cohorts of pregnant women. The findings make an important contribution to the previous research, highlighting the clinical importance of increasing awareness about ED to improve identification and response to the healthcare needs of pregnant women with lifetime

and current ED. Planning of professional training programmes and maternity and psychiatric services need to ensure healthcare professionals are able to provide the best standard of healthcare for pregnant women with lifetime and current ED to promote optimum maternal and infant outcomes.

Chapter 5 Experiences of maternity care in women with eating disorders

Parts of this chapter appear in the article Bye, A., Shawe, J., Bick, D., Easter, A., Kash-Macdonald, M., & Micali, N. (2018). Barriers to identifying eating disorders in pregnancy and in the postnatal period: a qualitative approach. *BMC Pregnancy and Childbirth*, 18, 114. The reporting of this study followed the consolidated criteria for reporting qualitative research (COREQ) guidance (Tong, Sainsbury, & Craig, 2007).

5.1 Rationale for undertaking the research

Pregnant women with lifetime ED are known to have heightened risk of adverse pregnancy and birth outcomes. Evidence indicates risks vary between ED categories and are higher for women with active ED during pregnancy, including impaired fertility, unplanned pregnancy and delivering low birth weight babies in women with lifetime AN (Linna et al., 2013; Micali, dos-Santos-Silva, et al., 2014; Solmi et al., 2014) and miscarriage and delivering large for gestational age babies in women with lifetime BED (Linna et al., 2013; Watson et al., 2017). Although there is limited research assessing the impact of sub-threshold diagnoses on pregnancy and birth outcomes, recent evidence indicates that sub-threshold ED similarly reflect heightened risk (Eik-Nes et al., 2018; Linna et al., 2013; Watson et al., 2017).

Pregnancy can be challenging for women with lifetime ED (Fogarty et al., 2018). Research suggests most women adjust as pregnancy progresses, often experiencing a decrease in their ED symptoms (Blais et al., 2000; Crow et al., 2008; Easter et al., 2015; Micali, Treasure, et al., 2007; Morgan, Lacey, et al., 1999). However, this is not the case for all women and evidence indicates more often behavioural symptoms such as self-induced vomiting decrease whilst cognitive symptoms persist (Blais et al., 2000; Crow et al., 2004; Fogarty et al., 2018; Micali, Treasure, et al., 2007; Morgan, Lacey, et al., 1999). Furthermore, for a small minority, pregnancy can be a risk period for the onset of ED (Watson et al., 2013). Much of the literature on the prevalence of

ED symptoms during pregnancy has been on women with AN and BN, considerably less is known about women with BED and sub-threshold ED.

Given the risks associated with lifetime ED, early identification and prompt response to the healthcare needs of pregnant and postnatal women with ED is imperative to promote optimal outcomes. Healthcare professionals are recommended to routinely enquire about current and history of any mental illness with all women at their first routine antenatal contact with healthcare services (NICE, 2014). Further, women identified with ED should be offered enhanced monitoring and support during and following pregnancy (NICE, 2014, 2017). These recommendations are relevant to all healthcare professionals responsible for providing maternity care, though particularly midwives as they are responsible for routine contacts with women from pregnancy until the early postnatal period.

Exploratory research on women's experiences in maternity care is needed to ascertain whether healthcare professionals working in these settings are effectively identifying and sufficiently meeting the needs of this population, or whether improvements to care are needed (NICE, 2012). Most research on barriers to identification of ED has been in non-pregnant populations, with limited exploration of the barriers to identification and support from the perspectives of pregnant and postnatal women.

One qualitative study has explored experiences of maternity care in a small sample of pregnant and postnatal women with AN and BN, and found some had been reluctant to disclose their ED due to feelings of shame and women felt healthcare professionals often did not enquire and lacked sufficient knowledge about ED (Stringer et al., 2010). Another study in a small sample of parous and nonparous women with current and past ED, including two nonparous women with past BED, also found women were reluctant to disclose their ED to healthcare professionals, including one woman who associated it with a reluctance to receive treatment for her ED (Claydon et al., 2018). However, barriers to disclosure were not specifically

explored in either of these studies and the findings are largely limited to the experiences of women with AN and BN.

Considering typical symptom changes during pregnancy and heightened risk, that is more so for women with active symptoms, it is important to expand on the previous research to include women with BED and sub-threshold ED, and examine whether active symptomology related to disclosure of ED. Given the need to identify and support pregnant and postnatal women with lifetime ED, it is important to understand the experiences of maternity care including barriers to engagement, from the perspectives of women with ED including women with BED and sub-threshold ED. The findings can inform recommendations for healthcare improvements to promote effective identification and support and contribute to improving patient experience for this population group.

5.2 Research aims

The primary aim of this study was to:

1. Explore the experiences of maternity care in women with lifetime ED, including:
    a. Satisfaction with maternity care.
    b. Disclosure of ED to a healthcare professional in maternity care.
    c. Recommendations for improvements to maternity care for women with ED.

The secondary aims of this study were to:

1. Examine the prevalence of ED symptoms during pregnancy in women with lifetime ED.
2. Examine the association of ED symptoms during pregnancy with disclosure of ED to healthcare professionals in maternity care in women with lifetime ED.

5.3 Methods

5.3.1 Design

A web-based exploratory descriptive survey.

5.3.2 Ethical approval

Ethical approval for the study was granted by the University College London's Research Ethics Committee (Ref. 3735/002).

5.3.3 Study setting

Women were recruited from a national parenting website.

5.3.4 Participants

Women were eligible to participate if they reported they were between 18 to 50 years old, had a current or past ED, and were pregnant or already had a child. Women were ineligible to participate if they were less than 18 years old or above 50 years old, and unable to complete the survey in English.

5.3.5 Recruitment

The study was advertised on the website between June 2014 and December 2014. Women who clicked on the study advertisement were directed to another webpage, which provided the participant information. The participant information outlined the purpose of the study, what participation would involve including the consent process and eligibility criteria, and invited women to participate by clicking on a link to a self-complete questionnaire. Women were advised that consent to participate was implied by completion of the questionnaire.

5.3.6 Measures

The self-report questionnaire was developed specifically for this study (see Appendix V). The contents were informed from assessment of current evidence, with input

from the doctoral supervisors and other experts, including researchers and clinicians with expertise in ED, midwifery education and practice, and approaches to undertaking qualitative research, as well as representatives of the website.

The questionnaire was designed to generate numerical and narrative data on the prevalence of ED symptoms during pregnancy and experiences in maternity care, including satisfaction, disclosure of ED and recommendations for improvements. It used a combination of single and multiple choice, Likert-rating scales and open-ended formats. Single choice items were used to assess the following: type of self-reported current or past ED (according to DSM-IV diagnostic criteria); whether healthcare professionals were aware of the ED; whether women disclosed their ED to a healthcare professional; whether women were offered additional monitoring, support or specialist referral following their disclosure of an ED; and agreement with routine enquiry about ED in maternity care. Multiple choice items were used to assess ED symptoms during pregnancy (purging, binge eating, calorie or food restriction, excessive exercise and low weight). Five-point Likert-rating scales were used to assess satisfaction with maternity care and if relevant, how women felt about disclosing their ED to a healthcare professional. Satisfaction with maternity care was categorised as "satisfied" (including "yes a lot" and "yes somewhat"), "neither satisfied nor dissatisfied" and "dissatisfied" (including "very dissatisfied" and "a little dissatisfied"). How women felt about disclosing their ED to healthcare professionals was categorised as "happy" (including "happy" and "somewhat happy"), "unhappy" (including "very unhappy" and "a little unhappy") and "unsure". Open-ended items were used to detail reasons for dissatisfaction with maternity care, non-disclosure of their ED to a healthcare professional, and recommendations for improvements to maternity care for women with ED. Respondents were also asked to provide information on whether they were currently pregnant, age category, highest educational qualification and UK region of residence.

5.3.7 Analysis

The quantitative data were managed in SPSS 22.0 (IBM Corp, 2013) and summarised using descriptive statistics. Cross tabulation and chi-square test were used to test the

association of ED symptoms during pregnancy with disclosure of ED to healthcare professionals in maternity care.

The qualitative data were managed in Microsoft Word. The qualitative data were analysed using the thematic analysis approach described by Braun and Clark (2006): familiarisation with data; generation of initial codes; searching for themes among codes; reviewing themes; defining and naming themes; and producing the final report.

Responses to the open-ended items were read repeatedly to ensure familiarity and clarity. Reading was an active process of searching for meaning and recording brief memos to track the thought process (Braun & Clarke, 2006). Following this familiarisation phase, the data were coded manually line-by-line into codes that were semantic and interpretative in nature (Gibbs, 2007). Codes were sorted into categories to allow for the identification of patterns within the data (Bazeley, 2013), initially grouped by semantic content which progressed to interpretation of the possible meanings and implications (Patton, 1990). The process of identification was inductive and iterative, meaning the emerging themes were driven by the data rather than theory, similarly to a grounded theory approach (Charmaz, 2014; Glaser, 1992; Patton, 1990). There was continual reference to the original data to explore those that appeared to deviate from responses of the majority (Creswell & Creswell, 2018), and to validate and refine the emerging themes. The emerging themes were clustered into subordinate themes, and superordinate themes. The analysis process was systematic, and amendments were recorded, which facilitated the reiterative and reflective approach and provided an auditable trail of the generation of interpretative ideas (Bazeley, 2013; Yin, 2003). Quotes that were illustrative of the themes and subthemes are presented in the results.

5.3.7.1 Cross checks

All qualitative data were coded by the candidate and a third of the data were independently coded by a second researcher, Dr Kylee Trevillion. This proportion of second coding is above the accepted standard particularly for independent projects

(Barbour, 2001; Bazeley, 2013). The purpose of the second coder was to provide a cross check and comparative perspective on the coding process (Bazeley, 2013; Creswell & Creswell, 2018). Once coding was complete, the candidate and the second coder discussed the independently derived codes together, with 89% inter-rater agreement about how the data had been grouped and categorised. The level of agreement is above the minimum recommended (Miles & Huberman, 1994). The percentage calculation of inter-rater agreement was considered preferable to an artificial test of reliability, which arguably does not ensure the robustness of the analysis (Bazeley, 2013). During the analysis process as outlined above, the candidate regularly met with the second coder and doctoral supervisors to discuss and review the emerging themes to ensure the rigorousness of the process. A negotiated agreement approach was employed in these discussions whereby codes with similar information were grouped, discrepancies were examined and agreement sought before amendments were made and emerging themes were refined (Campbell, Quincy, Osserman, & Pedersen, 2013). The doctoral supervisors, Dr Kylee Trevillion and Dr Abigail Easter for the published findings (Bye, Shawe, et al., 2018) contributed to the refining and naming of the final agreed themes.

5.4 Results

5.4.1 Sample characteristics

A total of 103 women with self-reported lifetime ED participated in the study, 10 (10%) of whom were currently pregnant at the time of completing the survey. The women in the sample were predominantly between the ages of 20-29 years old (N = 49; 48%), educated to degree level or above (N = 45; 44%) and resident in the North of England (N=27; 27%) (see Table 5-1).

Table 5-1 Characteristics of the study sample

Characteristics			N (%)
			N = 103
Currently pregnant †			
	Yes		10 (10%)
	No		92 (90%)
Age (in years) ‡			
	<20		2 (2%)
	20-29		49 (48%)
	30-39		44 (43%)
	40≥		7 (7%)
Education §			
	GCSE or equivalent		27 (27%)
	A level or equivalent		28 (28%)
	Degree level or above		45 (44%)
UK region ¶			
	England		
		London	16 (16%)
		Midlands and East of England	18 (18%)
		North of England	27 (27%)
		South of England	24 (24%)
	Scotland		5 (5%)

	Wales		6 (6%)
	Northern Ireland		3 (3%)

† One woman had missing data on whether currently pregnant.

‡ One woman had missing data on age (in years).

§ Three women had missing data on education.

¶ Four women had missing data on UK region.

5.4.2 Eating disorder symptoms during pregnancy

Table 5-2 presents the prevalence of reported ED symptoms during pregnancy amongst the women in the sample. The majority of women self-reported lifetime AN (N = 35; 35%) and fewest self-reported lifetime BN (N = 16; 16%). Two thirds of women reported experiencing ED symptoms during their current or past pregnancy (N = 64; 62%), and most frequently calorie or food restriction (N = 31; 47%) and binge eating (N = 29; 44%).

Table 5-2 Prevalence of eating disorder symptoms during pregnancy among the women in the sample

ED symptoms		N (%)
		N = 103
Lifetime ED type †		
	AN	35 (35%)
	BN	16 (16%)
	BED	24 (24%)
	EDNOS	25 (25%)
ED symptoms during pregnancy		
	Yes	64 (62%)
	No	39 (38%)
Type of ED symptoms during pregnancy (N = 66)		
	Purging	12 (18%)
	Binge eating	29 (44%)
	Calorie or food restriction	31 (47%)
	Excessive exercise	14 (21%)
	Low weight	17 (26%)

† Three woman had missing data on lifetime ED type.

5.4.3 Satisfaction with maternity care

The majority of women reported feeling satisfied with their maternity care (N = 61; 60%), though nearly a third were unsatisfied (N = 28; 28%) and the rest were neither

satisfied nor unsatisfied (N = 12; 12%). Women who were unsatisfied (or neither satisfied nor unsatisfied) with their maternity care provided reasons for their dissatisfaction (N=30). The findings generated five themes for dissatisfaction with maternity care, including: poor awareness; insufficient support; stigma; lack of familiarity; and insufficient time.

Poor awareness

An important issue raised by several women was poor awareness of ED amongst the healthcare professionals they had contact with during pregnancy. Women felt healthcare professionals were lacking in knowledge on the range of ED, which contributed to poor recognition.

> "My diet was not discussed as I'm not particularly overweight"
>
> (Participant 4)

> "I was seen on extra appointment because my weight was slightly low but because it wasn't dramatically low, I was simply advised to eat more and sent on my way"
>
> (Participant 27)

A couple of women reported healthcare professionals were dismissive of the significance of identifying ED.

> "When filling in my booking in forms the midwife ticked off the sections on mental health/eating disorders as no problems without asking"
>
> (Participant 83)

> "They didn't take my eating disorder seriously"
>
> (Participant 91)

Responses from some women indicated that poor knowledge of ED contributed to some healthcare professionals using insensitive and inappropriate language when interacting with them.

> "Lack of knowledge, well-meaning midwife who made unhelpful comments. Consultant seemed clueless"
>
> (Participant 40)

> "I was fat and that's all I heard at every appointment by midwifes [sic], consultants, nurses so I starved myself and lost three stone"
>
> (Participant 53)

> "Constant reference to BMI makes me feel inadequate"
>
> (Participant 85)

One woman described being praised by a healthcare professional as her ED meant she had not gained excessive weight during pregnancy.

> "I was told it was a good thing I hadn't gained a lot of weight during pregnancy and that was the way it should be with all mothers"
>
> (Participant 100)

Insufficient support

Multiple women reported feeling dissatisfied with the lack of support they received for their ED, including one woman who received caseload midwifery care which is intended to provide better continuity of carer.

> "I had a caseload midwife because of my problems but they weren't very attentive"
>
> (Participant 50)

> "Very little was discussed about weight or help to maintain a balance during pregnancy"
>
> (Participant 58)

> "The health centre where I went for my antenatal appointments did the bare minimum required"
>
> (Participant 81)

> "Nobody offered or gave support or advice related to my eating disorder"
>
> (Participant 83)

Stigma

Several women reported experiencing unkind and judgemental attitudes from healthcare professionals, particularly the midwives involved in their maternity care.

> "When explaining to midwives my concerns they were quite rude and unsupportive"
>
> (Participant 3)

> "I felt ignored and also patronised several times"
>
> (Participant 68)

> "My midwife was very judgmental and harsh on many things inc [sic] breast feeding support, mental health in general"
>
> (Participant 82)

Lack of familiarity

An important theme for dissatisfaction with maternity care was the lack of familiarity with a healthcare professional, namely a midwife. Women felt poor continuity of carer impacted on their ability to engage and develop a patient-clinician relationship.

> "Never seen same person twice so couldn't build a trust with anyone and most appointments felt quite rushed and had to keep explaining when they didn't seem as if anything was in notes"
>
> (Participant 3)

> "I had approximately six midwives throughout my pregnancy so couldn't speak to any about my bad food habits"
>
> (Participant 21)

One woman indicated first time mothers-to-be would find it particularly hard to navigate maternity care without a single point of contact for who they could go to with their concerns.

> "Luckily this is my second pregnancy, so I knew the ropes but it's so confusing and very difficult to know what to do, when to plan your appointments, who to talk to, contact your midwife and to receive sound advice. I was given so much different advice in pregnancy it would make your head spin"
>
> (Participant 37)

It was also indicated by one woman that poor continuity of carer likely contributed to a lack of follow up about her particular health concerns.

> "I was told I was dangerously iron deficient and told to go on bed rest. Neither was followed up on"
>
> (Participant 65)

Insufficient time

A couple of women commented on a lack of time in maternity care, specifically insufficient time in maternity care contacts for midwives to provide the necessary support for women with ED, as well as extensive delays in women receiving specialist mental health support during pregnancy.

> "Poor, impersonal, inconsistent and time stretched staff"
>
> (Participant 70)

> "Far too long to wait for mental health support"
>
> (Participant 46)

5.4.4 Disclosure of eating disorders in maternity care

The majority of women reported healthcare professionals involved in their maternity care were not aware of their ED (N = 62; 62%) and only 27% (N = 26) of women reporting they had disclosed their ED to a healthcare professional (see Table 5-3). Women who reported experiencing ED symptoms during pregnancy were no more likely to disclose their ED to a healthcare professional in maternity care than women who reported being absent of ED symptoms during pregnancy, $\chi 2$ (1; N = 98) = 2.840; P = 0.092. Among the women who had disclosed their ED to a healthcare professional, the majority reporting feeling unhappy or indifferent about having disclosed (N=18; 72%). Furthermore, it only resulted in 58% (N = 15) of these women being offered additional monitoring, support or specialist referral during pregnancy.

Table 5-3 Disclosure of eating disorders in maternity care for the women in the sample

Identification of ED		N (%)
		N = 103
Awareness of their ED among healthcare professionals †		
	Yes	22 (22%)
	No	62 (62%)
	Not sure	16 (16%)
Disclosure of their ED to a healthcare professional ‡		
	Yes	26 (27%)
	No	72 (73%)
How women felt about disclosing their ED to a healthcare professional (N = 26) §		
	Happy	7 (28%)
	Unhappy	9 (36%)
	Unsure	9 (36%)
Offer of additional monitoring, support or specialist referral following the disclosure (N = 26)		
	Additional support or specialist referral offered and accepted	6 (23%)
	Additional support or specialist referral offered but not accepted	4 (16%)
	Enhanced monitoring only	5 (19%)
	No	11 (42%)

† Three women had missing data on awareness of their ED among healthcare professionals.

‡ Five women had missing data on disclosure of their ED to a healthcare professional.

§ One woman had missing data on how she felt about disclosing the ED to healthcare professionals.

Women who reported not disclosing their ED to a healthcare professional involved in their maternity care provided their reasons for not disclosing (N=71). The findings generated five themes, including: stigma, lack of opportunity, preference for self-management, current ED symptomatology and illness awareness.

Stigma

Stigma was an important barrier for women in disclosing their ED to a healthcare professional, which included feelings of shame and embarrassment, and fear of consequences following a disclosure of ED.

Shame and embarrassment

Several women in the sample reported feelings of shame about their ED prevented them from disclosing to a healthcare professional.

"Embarrassed and ashamed"

(Participant 13)

"Shame, I didn't want to be told off or for them to think I was a bad mum"

(Participant 64)

"Shame. I wasn't skinny enough to back it up. I looked normal and fat"

(Participant 65)

Some women described feeling judged by healthcare professionals based on their weight status.

> “I was overweight according to my BMI. I didn't think they would believe me to tell them I had an actual problem. I was patronised by more than one healthcare professional who tried to educate me on nutrition. I got the impression they thought I was just lazy and ate junk food all of the time when this wasn't the case. I felt they were too judgemental to approach”
>
> (Participant 42)

Fear of consequences

Some women feared that disclosing their ED to a healthcare professional would result in unwanted referrals to other services such as social services.

> “Fear of intervention”
>
> (Participant 17)

> “I would have been too worried to discuss with my midwife etc. for fear of being reprimanded for it (i.e. referred to social services”
>
> (Participant 49)

Lack of opportunity

A lack of opportunity in maternity care contacts to openly discuss and disclose their ED to a healthcare professional was described by some women.

Limited and insufficient enquiry

Women felt there was limited and insufficient enquiry by healthcare professionals about ED.

> “I expected them to know and bring it up, but they never did”
>
> (Participant 28)

> “They didn't ask, and it wasn't raised as a concern"
>
> (Participant 67)

Inability to establish a rapport

One woman expressed difficulties in establishing a rapport with a healthcare professional that may have otherwise facilitated a positive disclosure.

> "I didn't have the same midwife for long enough to speak to them, it was rather stressful and upsetting"
>
> (Participant 21)

Preference for self-management

Some women reported not disclosing their ED to a healthcare professional as they did not feel they needed or wanted specialist ED care, instead indicating a preference to self-manage their condition.

> "I don't like to talk about it and think I can manage on my own"
>
> (Participant 26)

> "I just wanted to deal with it myself"
>
> (Participant 36)

For a couple of these women, preference for self-management was related to the duration of having an ED.

> "I don't really like to talk about it I have had some sort of disordered eating for a very long time it is very much part of me and no one else's business"
>
> (Participant 27)

> "I've never had a diagnosis so why start now"
>
> (Participant 37)

Current ED symptomatology

For some women, disclosure of an ED was dependent on their current mental health status and the perception that a history of ED was not relevant to current maternity care and so it was not necessary to discuss it with a healthcare professional.

> "I didn't think it was relevant as I have been OK for a few years now"
>
> (Participant 23)

> "I wasn't unwell at the time so didn't seem like something which needed bringing up as they didn't ask"
>
> (Participant 44)

Similarly, a couple of women reported recent improvements in ED symptoms during pregnancy meant they did not feel it necessary to disclose their ED to a healthcare professional.

> "I felt like I was a lot better when I fell pregnant"
>
> (Participant 30)

> "It wasn't affecting me during my pregnancy, it helped"
>
> (Participant 50)

Illness awareness

In some cases, disclosure of an ED was dependent on the woman's awareness about ED and recognition that her symptoms were that of an ED. This was particularly notable in women with BED as women dismissed their binge eating behaviours as overeating.

> "Binge eating doesn't seem like that big of an issue and I've never seen it as an eating disorder before"
>
> (Participant 4)

> "I have only really just recognised that I have an issue and at the time I was pregnant did not realise. I just thought I was a greedy person"
>
> (Participant 34)

5.4.5 Recommendations for improvements to maternity care

Most women in the sample approved of routine enquiry about ED in maternity care (N = 51; 51%), although a considerable proportion were undecided (N = 38; 38%) or opposed to the practice (N = 11; 11%). Women provided their recommendations for improvements to maternity care for women with ED (N = 59; 59%), which were categorised into six themes: training; tailor routine practice; compassionate care; active and sensitive enquiry; increase capacity; and multidisciplinary care approach.

Training

An important theme highlighted by several women was the importance of training all healthcare professionals who are responsible for providing maternity care to enhance knowledge and awareness in ED.

> "The best place to start would be to train GPs in taking the issue seriously and cultivating a relationship where a patient (expectant mother or otherwise) could raise the issue and get appropriate support. Midwives should also get training"
>
> (Participant 34)

One woman recommended that training should cover information on the range of ED.

> "Inform them that anorexia and bulimia are not the only eating disorders and bingeing can also be a disorder"
>
> (Participant 19)

Another woman suggested that training needs to be specific to the pregnancy period to cover the challenges with body image that women with ED are likely to experience during pregnancy.

> "Giving professionals training on how pregnancy can affect women with a poor body image due to an eating disorder"
>
> (Participant 8)

Tailor routine practice

Another important recommendation for improving maternity care for women with ED was the tailoring of routine practice to meet the specific needs of this group. Women suggested that routine dietary advice could be more in-depth and directive to educate women with ED about the importance of nutrition for fetal development.

> "Perhaps seeing how it might affect the baby like smokers are explained the effects they have might help understanding, also perhaps nutritional information so if you don't want to eat then knowing which foods are a must when you do eat therefore maximising the nutritional value of the foods that are actually eaten"
>
> (Participant 27)

> "Better information about nutrition rather than stuffing your face"
>
> (Participant 32)

> "Give a recommended meal plan for pregnancy"
>
> (Participant 100)

Several women recommended healthcare professionals offer women with ED support with gestational weight gain.

> "More frequent weighing's, as I was only weighed near the beginning and end of pregnancy and then felt ashamed about my weight"
>
> (Participant 29)

"Support on coping with weight gain"

(Participant 33)

"Be more sensitive around being weighed. I hated the fact I was putting on weight yet was still informed of my weight changes anyway"

(Participant 81)

"More consideration of how they approach topics relayed to weight and BMI"

(Participant 85)

One woman suggested healthcare professionals could be educating women about the impact of ED on pregnancy outcomes.

"Explaining the complications it can have in conceiving or for your unborn child"

(Participant 101)

Compassionate care

Several women highlighted the need for healthcare professionals to show more compassion and support to women with ED.

"They shouldn't make you feel like your starving yourself and baby, they should support not judge"

(Participant 35)

"More personal, caring staff"

(Participant 70)

"Approach it gently with respect"

(Participant 87)

One woman highlighted the need for healthcare professionals to establish a rapport with women.

> "They need to build more of a rapport with women suffering from eating disorders that are pregnant"
>
> (Participant 81)

Active and sensitive enquiry

Some women discussed the need for healthcare professionals to actively enquire about ED. There were some discrepancies with how the subject could be approached with women, with most woman advocating routine enquiry with all women whereas one woman felt it more appropriate for healthcare professionals to enquire in response to women displaying symptoms or signs of ED.

> "More questions and more help"
>
> (Participant 36)

> "It should be talked about!"
>
> (Participant 45)

> "Routinely asking all women in a sensitive manner about a history of eating disorders"
>
> (Participant 83)

> "Shouldn't straight out ask if they have eating disorder. Should identify high risk or low risk for eating disorder"
>
> (Participant 71)

One woman highlighted the need for healthcare professionals to create a safe and private space to ask questions of a sensitive nature.

"To be asked / to ensure privacy when it comes to the father of the baby"

(Participant 10)

Increase capacity

Several women reported that maternity care could be improved by providing more time within maternity contacts and the potential for additional maternity contacts to be offered when needed.

"There isn't enough personal treatment given to pregnant women. It's very routine and rushed"

(Participant 4)

"Monitor things a bit more and be a bit more receptive"

(Participant 50)

"More thorough, more frequent, more personal, caring staff"

(Participant 70)

One woman highlighted the need for healthcare professionals to be able to familiarise themselves with a woman's medical history in advance of their maternity contact.

"Reading the medical notes to start with!"

(Participant 28)

Multidisciplinary care approach

Several women indicated a multidisciplinary approach is needed for pregnant women with ED. Women suggested community and peer support groups could provide opportunities for women with ED to engage with women who do not have ED so they can learn to normalise their behaviours and cognitions. Further, it would enable women with ED to support one another.

> "Maybe they should meet more women or attend groups of women which are not aimed at those with eating disorders alone so that they can realise that it is okay to eat whilst pregnant and to be comfortable with their growing bodies"
>
> (Participant 21)

> "Local support groups, helplines"
>
> (Participant 26)

Women suggested affected women would benefit from being referred to specialist services to receive appropriate support for their mental health and nutrition needs.

> "More mental health support if struggling (without judgement)"
>
> (Participant 40)

> "Dieticians, advice, support groups"
>
> (Participant 41)

Further, it was indicated by one woman that all healthcare services involved in the care of a woman need to work together to provide coordinated care.

> "All working together; I was told contradicting things from different people, so I gave up asking for help""
>
> (Participant 94)

5.5 Discussion

5.5.1 Eating disorder symptoms during pregnancy

The study sample comprised of women from across the range of ED categories. ED symptoms during pregnancy were reportedly common, affecting 64% of women in the sample during a current or previous pregnancy. This finding is higher than some previous reports (Blais et al., 2000; Crow et al., 2008; Morgan, Lacey, et al., 1999), though largely consistent with the majority of research indicating that although

women tend to experience an overall decrease in ED symptoms during pregnancy, high levels of symptoms during pregnancy are still common (Crow et al., 2004; Easter et al., 2015; Micali, Treasure, et al., 2007). Women in the current sample reportedly struggled most often with restricting and excessive food intake, and less often with purging behaviours. Previous findings similarly reported higher levels of binge eating behaviours and lower levels of purging (Crow et al., 2004; Micali, Treasure, et al., 2007), though women in the present study reported higher levels of restrictive food behaviours than previously reported (Micali, Treasure, et al., 2007). Unlike these previous studies, the present sample included women with self-reported EDNOS, who may experience different symptoms persist during pregnancy. Similarly, less is known about levels of ED symptoms during pregnancy in women with lifetime BED as this diagnostic group has only been included in small heterogeneous samples (Crow et al., 2008).

5.5.2 Experiences of maternity care

The majority of women in the sample reported feeling satisfied with the maternity care they had received, though there remained a considerable number of women who felt unsatisfied or indifferent about their care. Most women considered healthcare professionals involved in their maternity care were not aware of their ED with only a quarter reporting they disclosed their ED to a healthcare professional. Among the women who disclosed their ED, there were some discrepant cases whereby women were unsure if a healthcare professional was aware of their ED suggesting the disclosure may not have been discussed. Disclosure of mental illness in healthcare settings is often advocated with the expectation it results in enhanced support being offered, however for the women in this study disclosure did not consistently result in additional monitoring, support or specialist referral in accordance with the clinical guidelines (NICE, 2017), and there was a tendency among women to feel unhappy or indifferent about having disclosed their ED.

There was considerable overlap between the reasons for dissatisfaction and non-disclosure and recommendations for improving practice in maternity care, most notably training needs of healthcare professionals, stigma, and lack of familiarity,

capacity and enquiry in maternity care, as well as an association of disclosure and current symptoms during pregnancy.

5.5.2.1 Training needs of healthcare professionals

Women in the study reported healthcare professionals involved in their maternity care lacked knowledge and understanding about ED, particularly on the heterogeneity of ED and implications for pregnancy. Lack of knowledge was suggested to impact on recognition and support of pregnant women with ED. Findings are consistent with previous research in women that similarly highlighted poor awareness about ED among healthcare professionals in maternity care, with implications for voluntary disclosure (Stringer et al., 2010). Similar findings have also been reported in studies with gynaecologists and obstetricians (Leddy et al., 2009; Morgan, 1999).

Women in this study considered poor awareness contributed to the use of insensitive language, with an overriding concern among healthcare professionals on excessive maternal weight. This attention to excessive maternal weight reported by women likely relates to the key priorities in NHS maternity services to address maternal obesity (National Institute for Health and Care Excellence, 2010). Although there is an understandable public health need to address obesity, the findings indicate a lack of consideration for possible ED in women who are obese (de Zwaan, 2001) and of the common concerns with gestational weight gain in women with ED (Swann et al., 2009). Women recommended enhanced training should be made available to all healthcare professionals with responsibilities for providing maternity care, to enable them to provide tailored advice and support to women with ED.

5.5.2.2 Stigma of maternal ED

There were several reports of women feeling dissatisfied with their maternity care due to experiences of overtly unkind and judgemental comments from healthcare professionals. Women felt healthcare professionals need to show women with ED more compassion. Similarly, women reported not disclosing their ED to a healthcare professional as they felt shameful about their ED and feared adverse consequences

following a disclosing of ED. These types of experiences of actualised and feared stigma have been consistently implicated as barriers to disclosure and treatment-seeking in the ED literature (Ali et al., 2017; Hepworth & Paxton, 2007; Swan & Andrews, 2003), within the broader context of mental health (Clement et al., 2015) and more recently in perinatal mental health research (Kingston et al., 2015; Nagle & Farrelly, 2018; Viveiros & Darling, 2018; Yapp et al., 2019).

Research suggests people can be less empathic towards individuals with ED compared to other mental illnesses due to misconceptions of them being responsible and in control of their ED behaviours (Crisp, 2005; Ebneter & Latner, 2013; Roehrig & McLean, 2010). The negative weight-based attitudes reportedly experienced by some of the women in this study relate to research suggesting that obese individuals with BED can be susceptible to increasingly negative attitudes as they are considered more personally responsible for their condition than other ED types (Ebneter & Latner, 2013; Puhl & Suh, 2015; Reas, 2017). Furthermore, findings are consistent with previous research indicating that pregnant women with perinatal mental illness often report a fear of being discredited as a mother (Kingston et al., 2015; Nagle & Farrelly, 2018; Viveiros & Darling, 2018; Yapp et al., 2019). Pregnant women with ED can be increasingly vulnerable to stigmatising attitudes given their belonging to multiple stigmatised groups, which in turn can impact on engagement with healthcare professionals involved in their maternity care.

5.5.2.3 Familiarity, time and enquiry in maternity care

Lack of familiarity with a healthcare professional in maternity care reportedly impacted on satisfaction and disclosure of ED. Women felt there was no continuity of carer that would have enabled them to foster a trusting relationship with a healthcare professional who could provide them with ongoing monitoring and support. The caseloading model of midwifery care recognises these relational aspects of healthcare and is considered to promote better continuity of carer in pregnancy as advocated in UK policy and guidance (Department of Health, 2007; NHS England, 2016, 2017). A previous report indicated that the caseloading model of midwifery care was associated with better patient satisfaction compared to traditional models

of maternity care (Forster et al., 2016), however provision in the UK remains variable and limited (Care Quality Commission, 2020).

Women described a lack of time within maternity care contacts to discuss concerns in a comfortable way that would have otherwise encouraged disclosure. Increasing capacity was recommended as an important change needed in maternity care for women with ED. Some women described a lack of routine enquiry about ED in maternity contacts that may have facilitated a positive disclosure, with women tending to agree this should be done but in a sensitive manner. Lack of enquiry about ED by healthcare professionals in maternity care has been previously reported in studies with women (Stringer et al., 2010) and healthcare professionals (Abraham, 2001; Leddy et al., 2009; Supina et al., 2016). Findings from a recent US study similarly reported on the lack of enquiry about ED by healthcare professionals, suggesting that detailed history taking contributed to effective identification of ED (Supina et al., 2016).

5.5.2.4 Disclosure and current symptoms during pregnancy

The quantitative findings in this study indicate women who experienced ED symptoms during pregnancy were no more likely to disclose their ED to a healthcare professional than women who did not experience ED symptoms during pregnancy. Exploration of the reasoning for non-disclosure indicates the relationship with current symptoms was complex. Some women preferred to self-manage their ED, some women at the time had not recognised their symptoms were that of an ED, and other women who were absent of current symptoms during pregnancy, had not considered a remitted ED relevant to their current maternity care. Collectively these three groups highlight a lack of awareness about ED among women, particularly with regard to their increased pregnancy and postnatal risks (Knoph et al., 2013; Linna et al., 2013; Micali, dos-Santos-Silva, et al., 2014; Solmi et al., 2014; Watson et al., 2017). The sense of ambivalence and poor recognition of the need for treatment identified in this study corresponds to previous exploratory research on the barriers to disclosure and engagement with treatment in antenatal and adult populations (Ali et

al., 2017; Claydon et al., 2018; Leavey, Vallianatou, Johnson-Sabine, Rae, & Gunputh, 2011).

5.5.3 Strengths

The main strength of this study was the novel exploration of experiences in maternity care including disclosure of ED, among a heterogeneous sample of women with lifetime ED. The adaptation of the traditional questionnaire format generated numerical descriptions of patient experiences, complemented by narrative descriptions that provided meaning and depth to the findings. The website hosting of the questionnaire provided cost and time effective access to a large nationwide population of pregnant women and mothers. A substantial number of pregnant women and mothers with lifetime ED from across the UK were recruited to the study, including women with BED who are frequently underrepresented in maternal ED research. The anonymity of participating in the study may have enabled women to feel comfortable with participating and being open in their responses, which is particularly relevant in gaining negative feedback on maternity care. The size and heterogeneity of the study sample support the generalisability and robustness of the findings given the commonality in the emerging themes across the dataset (Robinson, 2014). Furthermore, the rigorous approach to analysis was supported by the use of a second coder, of whom there was a high level of concordance, and interpretive contributions from doctoral supervisors and co-authors on the published findings (Bye, Shawe, et al., 2018).

5.5.4 Limitations

The interpretation of the study findings needs to consider the limitations. The self-report questionnaire has not undergone rigorous testing or validation. Self-reported ED to determine group identity may not have been a reliable measure of lifetime ED, although there is not a validated antenatal screening tool for ED and self-reported ED has been previously validated in an antenatal sample (Micali et al., 2012). The women that provided narrative descriptions of their experiences in maternity care represented a proportion of the total sample, thus the interpretations based on these

select experiences may not be representative of the experiences among the whole sample. The representativeness of the sample and the ability to generalise the findings to other pregnant women and mothers with lifetime ED in the UK is limited for several reasons. This includes the use of a non-probability sampling method, lack of sociodemographic information collected using the self-report questionnaire, and language and literacy barriers to participation. Recall bias may have influenced the findings as there was no restriction placed on the length of time since women accessed maternity care. The use of a web-based questionnaire as opposed to qualitative interviews limited the depth of information collected and precluded the ability to clarify responses and ask complex questions, though this was a trade-off for convenience and sample size. Qualitative research is often criticised for its subjective nature and lack in transparency and generalisability, though the analytic rigour and complementary use of quantitative methodology employed in this study serve to minimise these disadvantages (Bryman, 2016). Cognitive symptoms during pregnancy were not captured in the questionnaire so it was not possible to examine the prevalence of the full breadth of ED symptoms during pregnancy among the women in the sample to enable further study comparisons. Furthermore, ED symptoms before pregnancy were not captured in the questionnaire which precluded the ability to examine changes in symptoms before and during pregnancy.

5.5.5 Conclusion and implications

This study explored experiences of maternity care among a heterogenous sample of pregnant and postnatal women. The findings indicate that although most women had satisfactory experiences in maternity care, disclosure of ED was infrequent and did not consistently lead to enhanced monitoring or support. The overarching factors that impacted on satisfactory experiences and disclosure were lack of knowledgeable healthcare professionals, stigma of maternal ED, lack of continuity in carer and capacity in maternity care, and poor personal awareness of ED and implications for pregnancy. Several of these factors correspond to the recommendations for improving maternity care for women with ED, including enhanced training opportunities to provide healthcare professionals with the specialist knowledge and

skills required to tailor routine maternity healthcare. Future research should aim to replicate and expand on the study findings using in-depth qualitative interviews with pregnant and postnatal women with lifetime ED. It is imperative that maternity care improvements are informed by women with lived experience of ED to encourage identification and support of women with ED by knowledgeable and compassionate healthcare professionals to mitigate potential adverse maternal and infant outcomes associated with ED.

Chapter 6 Identification and management of eating disorders in maternity and health visiting services

Parts of this chapter appear in the article Bye, A., Shawe, J., Bick, D., Easter, A., Kash-Macdonald, M., & Micali, N. (2018). Barriers to identifying eating disorders in pregnancy and in the postnatal period: a qualitative approach. *BMC Pregnancy and Childbirth*, 18, 114. The reporting of this study followed the COREQ guidance (Tong et al., 2007).

6.1 Rationale for undertaking the research

Pregnant women with ED are known to have heightened risk of adverse pregnancy and birth outcomes that persist among those in remission (Eik-Nes et al., 2018; Linna et al., 2013, 2014; Micali, dos-Santos-Silva, et al., 2014; Solmi et al., 2014; Watson et al., 2017). Given the risks associated with lifetime ED, early identification and prompt response to the healthcare needs of pregnant and postnatal women with ED is imperative to promote optimal maternal and infant outcomes. In recent years, there have been several changes to NICE guidelines with recommendations to improve the identification and support offered to women with ED before, during and following pregnancy (NICE, 2014, 2017). Healthcare professionals are recommended to routinely enquire about current and history of any mental illness with all women at their first routine antenatal and postnatal contact with healthcare services (NICE, 2014). Further, women identified with ED should be offered enhanced monitoring and support during and after pregnancy (NICE, 2014, 2017). Midwives and health visitors are ideally placed to identify and support women with ED in line with these recommendations as they are responsible for routine contacts with women from pregnancy until the child is aged five.

The recommendations aim to reduce the risk of adverse maternal and infant outcomes for pregnant and postnatal women with ED, however evidence on uptake and use of the guidance is limited. There has been limited exploration of the barriers to effective identification and support of pregnant and postnatal women with ED

from the perspectives of women and healthcare professionals, and to the candidate's knowledge, no previous studies have explored the barriers from the perspectives of midwives and health visitors.

One qualitative study explored experiences of maternity care in women with ED and reported some were reluctant to disclose their ED to a healthcare professional due to fear of stigma and healthcare professionals lacked sufficient knowledge and did not enquire about ED with women (Stringer et al., 2010). Research with healthcare professionals including obstetricians, have similarly reported deficiencies in clinician knowledge of ED and a lack of routine enquiry (Abraham, 2001; Banas et al., 2013; Boulé & McSherry, 2002; Morgan, 1999; Supina et al., 2016). Morgan (1999) reported that knowledge on ED varied considerably and related to level of seniority in a sample of obstetricians and gynaecologists from Australia and the UK, with knowledge on the implications for prenatal and pregnancy outcomes being particularly poor.

A survey with London-based GPs reported training on ED was considered insufficient and enquiry about ED in the absence of clinical indicators was poor (Boulé & McSherry, 2002). A recent cross-sectional survey in the US with doctors including obstetricians and gynaecologists, found that only a third of the sample reported actively enquiring about eating behaviours with their patients, though more frequently with obese patients (Supina et al., 2016). Findings from a large US survey of obstetricians and gynaecologists indicated that whilst the majority were aware of the implications of ED for pregnancy and birth outcomes, enquiry about ED remained low, with many considering screening for ED was not part of their professional remit (Leddy et al., 2009).

Given the need to identify and support women with lifetime ED, it is important to understand barriers to this from the perspectives of midwives and health visitors who have the most frequent and routine contact with all pregnant and postnatal women (unlike obstetricians who will only care for women who have a high risk pregnancy). This would enable actions to be taken to address these barriers to better identify and

support pregnant and postnatal women with ED to promote optimal maternal and infant outcomes.

6.2 Research aims

The aims of this study were to:

1. Examine knowledge and attitudes to identifying and managing pregnant and postnatal women with ED amongst midwives and health visitors.
2. Explore the barriers to identifying and managing pregnant and postnatal women with ED in maternity and health visiting services from the perspectives of midwives and health visitors.

6.3 Methods

6.3.1 Design

A mixed methods sequential explanatory design using a two-phased approach. Phase one used a self-report questionnaire, followed by focus groups in phase two to explain and expand on the findings generated from phase one.

6.3.2 Ethical approval

Ethical approval was granted by the University College London's Research Ethics Committee (Ref. 3735/001) and the Joint Research and Development Office for Great Ormond Street Hospital for Children NHS Foundation Trust & The UCL Institute of Child Health (Ref. 11BS33).

6.3.3 Study setting

Participants were recruited from several universities and NHS hospital and community services in the South of England.

6.3.4 Participants

Eligibility criteria to participate included students registered on midwifery and health visiting training programmes at the universities, and qualified midwives and health visitors employed by the NHS maternity and community services.

6.3.5 Recruitment

The study was conducted between April 2012 and February 2013. Midwifery and health visiting students who met criteria to participate were identified by university course leads. Qualified midwives and health visitors were identified by clinical practice leads. Those identified as eligible were invited to participate in phase one of the study by the candidate at a university lecture or staff meeting. Healthcare professionals provided written informed consent before taking part in phase one (see Appendix VI). They were also invited to provide their contact details if interested in taking part in phase two of the study. Those who indicated an interest in participating in phase two, were contacted directly with an invitation to participate in a focus group, with informed consent taken for this phase at the focus group. Focus groups were conducted at the trust sites and facilitated by the candidate. Each focus group began with an introduction to outline the session objectives and format.

6.3.6 Measures

The self-report questionnaire and topic guide for the focus groups were developed specifically for this study. The contents were informed from assessment of current evidence, with input from the doctoral supervisors and other experts, including researchers and clinicians with expertise in ED, midwifery and health visiting education and practice, and approaches to undertaking qualitative research.

6.3.6.1 Knowledge and attitudes questionnaire

The self-report questionnaire was designed to examine midwives and health visitors' knowledge and attitudes to identifying and managing pregnant and postnatal women with ED for phase one (see Appendix VII). The questionnaire used a combination of single and multiple choice, and Likert-rating scales formats. Single choice items were

to assess knowledge on the prevalence of ED and multiple choice items were to assess knowledge on the diagnostic features of ED (according to DSM-IV-TR diagnostic criteria), associated risks of maternal ED and recommendations for clinical practice in maternity and health visiting services, using a series of correct and incorrect statements. Further, a multiple choice item was used to assess source of knowledge on ED. Four-point Likert-rating scales assessed attitudes to identifying and managing pregnant and postnatal women with ED, with responses categorised as "agree" (including "strongly agree" and "agree") and "disagree" (including "strongly disagree" and "disagree").

6.3.6.2 Topic guide

The topic guide for the phase two focus groups was designed to explain and expand on the findings generated from the phase one questionnaire to provide a detailed understanding of barriers to identifying and managing pregnant and postnatal women with ED (see Appendix VIII). The topic guide comprised of open-ended questions to facilitate an informal discussion. The questions were designed to provide structure to the discussion and exploration of specific research objectives, whilst enabling the flexibility to pursue details that were salient to the participants (Bryman, 2016). The role of the candidate was to facilitate the structure of the discussion, to stimulate reflection and ensure a good level of participation, whilst not being obtrusive (Bryman, 2016).

6.3.6.3 Sample characteristics

Self-reported sample characteristics were collected on all study participants at the time of their participation, including professional status, date of birth, sex and ethnicity. Participants were asked whether mental health and ED were included in any clinical training programmes they were currently or had previously attended. Qualified healthcare professionals were also asked to report the number of years they had been qualified and if they completed their training at an institution in the UK.

6.3.7 Analysis

The quantitative data were managed in SPSS version 22.0 (IBM Corp, 2013) and summarised using descriptive statistics.

The qualitative data were analysed using the thematic analysis approach described by Braun and Clark (2006): familiarisation with data; generation of initial codes; searching for themes among codes; reviewing themes; defining and naming themes; and producing the final report. Each focus group was recorded, and brief field notes were written following each group to record information considered pertinent to the research objectives. The audio recordings were transcribed verbatim and transcripts anonymised and checked for inaccuracies. The initial familiarisation phase began during this transcription process with each audio recording listened to in its entirety and repeatedly to transcribe verbatim. The process provided an opportunity to review and enhance knowledge of all the data collected (Bazeley, 2013). The completed transcripts were then read through to further enhance familiarity and clarity. Reading of the transcripts was an active process of searching for meaning and recording of brief memos to track the thought process and any emerging themes or salient information (Braun & Clarke, 2006). Once familiar with the data and in preparation for coding, the transcripts were imported to qualitative software, QSR International's NVivo 11 Software (QSR International Pty Ltd, 2015).

The coding process started with open coding of the data whereby every identifiable unit of text such as a paragraph, was labelled with any relevant codes based on the candidate's understanding of what the text was about (Bazeley, 2013). These initial codes emerged from the data rather than the topic guide and were predominantly descriptive but also somewhat semantic and interpretative in nature (Bazeley, 2013; Gibbs, 2007). All data were attended to systematically in this process to ensure thoroughness. Once coding was completed, codes were reviewed, refined and sorted into categories to enable identification of patterns within the data (Bazeley, 2013). First, the codes were grouped by semantic content which then progressed towards interpretation of the possible meanings and implications of the data (Patton, 1990).

The entire process of identification was inductive and iterative, meaning the emerging themes were driven by the data rather than theory or a priori assumptions, similar to a grounded theory approach (Charmaz, 2014; Glaser, 1992; Patton, 1990). There was continual reference to the original data to explore those that appeared to deviate from responses of the majority (Creswell & Creswell, 2018), and to validate and refine the emerging themes. The emerging themes were clustered into subordinate themes, and superordinate themes. The analysis process was systematic, and amendments were recorded, which facilitated the reiterative and reflective approach and provided an auditable trail of the generation of interpretative ideas (Bazeley, 2013; Yin, 2003). Quotes that were illustrative of the themes and subthemes are presented in the results.

6.3.7.1 Cross checks

All qualitative data were independently coded by the candidate and a second researcher (Megan Kash-Macdonald). This proportion of second coding is above the accepted standard particularly for independent projects (Barbour, 2001; Bazeley, 2013). The purpose of the independent second coder was to provide a cross check and comparative perspective on the coding process (Bazeley, 2013; Creswell & Creswell, 2018). Once coding was complete, the candidate and the second coder discussed the independently derived codes together, with 79% inter-rater agreement about how the data were grouped and categorised. The percentage calculation of inter-rater agreement was considered preferable to an artificial test of reliability, which arguably does not ensure the robustness of the analysis (Bazeley, 2013).

During the analysis process as outlined above, the candidate regularly met with the second coder and the supervisory team to discuss and review the emerging themes and ensure the rigorousness of the process. A negotiated agreement approach was employed in these discussions whereby codes with similar information were grouped, discrepancies were examined and agreement sought before amendments were made and emerging themes were refined (Campbell et al., 2013). The doctoral supervisors and co-authors (Megan Kash-Macdonald and Dr Abigail Easter) on the

published findings (Bye, Shawe, et al., 2018) contributed to the refining and naming of the final agreed themes.

6.4 Results

6.4.1 Phase one

6.4.1.1 Sample characteristics

In total, 265 healthcare professionals were recruited to phase one, of which 127 (48%) were student midwives, 56 (21%) student health visitors, 58 (22%) qualified midwives and 24 (9%) qualified health visitors. Participants had a mean age of 32.46 years (range 18-73 years), were predominantly female (N = 261; 99%) and white (N = 169; 67%) (see Table 6-1). Qualified healthcare professionals had been qualified for a mean of 12.37 years (range 0-40) and the majority had completed their midwifery or health visitor training in UK institutions (N = 75; 95%). Most reported mental health had been included in the midwifery or health visiting training programmes they were currently or had previously attended (N = 191; 75%), considerably less reported ED had been included (N = 77; 30%).

Table 6-1 Sample characteristics

Characteristics			N (%)
			N = 265
Age (in years) †			Mean: 32.46 Range: 18-73
		<20	1 (<1%)
		20-29	111 (42%)
		30-39	40 (15%)
		40≥	59 (22%)
Gender ‡			
		Female	261 (99%)
		Male	1 (<1%)
Ethnicity §			
		White	169 (67%)
		Black, Asian or other	83 (33%)
Professional status			
		Student midwife	127 (48%)
		Student health visitor	56 (21%)
		Qualified midwife	58 (22%)
		Qualified health visitor	24 (9%)
Mental health included in training ¶			
		Yes	191 (75%)

		No	65 (25%)
ED included in training ±			
		Yes	77 (30%)
		No	182 (70%)
Of the qualified healthcare professionals (N = 82):			
	Number of years qualified ≠		Mean: 12.37 Range: 0-40
	Training in the UK ¥		
		Yes	75 (95%)
		No	4 (5%)

† 54 participants had missing data on age (in years).

‡ Three participants had missing data on gender.

§ 13 participants had missing data on ethnicity.

¶ Nine participants had missing data on mental health training.

± Six participants had missing data on ED training.

≠ Six participants had missing data on number of years qualified.

¥ Three participants had missing data on training in the UK.

6.4.1.2 Knowledge on eating disorders and recommendations for clinical practice in maternity and health visiting services

Table 6-2 presents the level of knowledge on eating disorders and recommendations for clinical practice in maternity and health visiting services. Overall, there were varying levels of knowledge on ED regarding the prevalence, diagnostic features, associated risks and recommendations for clinical practice (with between 13-97% selecting the correct answer). Most reported their knowledge on ED was informed by the media (N = 138; 54%) and less so from training (N = 65; 26%) and patient experience (N = 67, 26%).

Table 6-2 Level of knowledge on eating disorders and recommendations for clinical practice in maternity and health visiting services

Knowledge items		N (%) indicated answer was correct
Prevalence of ED		
	Prevalence of ED in women of childbearing age (approximately 5%) †	77 (29%)
	Prevalence of ED in pregnant women (approximately 5-10%) ‡	95 (37%)
Diagnostic features of AN		
	Body Mass Index below 17.5	208 (79%)
	Missing periods	187 (71%)
	Fear of gaining weight	239 (90%)
	Loss of interest in activities	82 (31%)
	Decreased appetite	109 (41%)
Diagnostic features of BN		
	Unable to stop overeating	115 (43%)
	Making one's self sick or using laxatives after eating	257 (97%)
	Exercising excessively to prevent weight gain	118 (45%)
	Normal body image	30 (11%)
	Body Mass Index >20	32 (12%)
Statements on maternal ED		
	ED can develop during pregnancy	241 (91%)
	Women with ED are at an increased risk of preeclampsia	73 (28%)
	Women with ED are more likely to suffer from miscarriage and stillbirth	180 (68%)

	Women with ED are more likely to suffer from postnatal depression	243 (92%)
	Women with BN are likely to continue to breastfeed their baby for the first year	34 (13%)
	Women with current ED are unable to get pregnant	28 (11%)
	Women with ED are likely to have a planned pregnancy	29 (11%)
	Women with past ED are not likely to relapse after giving birth	17 (6%)
	Neither past nor current ED impact on the baby's birth weight	29 (9%)
	Most women with ED seek treatment themselves prior to pregnancy	16 (6%)
	Women with a past ED are likely to disclose their history to a healthcare professional due to the impact on the infant	92 (35%)
Statements on recommendations for clinical practice		
	NICE guidelines recommend increased support for women with ED during pregnancy and the postpartum period	167 (63%)
	NICE guidelines do not recommend a screening tool for ED that could be used in antenatal and postnatal care	67 (25%)
Source of knowledge on ED §		
	Patient experience	67 (26%)
	Training	65 (26%)
	Personal experience	81 (32%)
	Media	138 (54%)

Italics indicate that the statement is incorrect.

† One participant had missing data on prevalence of ED in women of childbearing age.

‡ Five participant had missing data on prevalence of ED in pregnant women.

§ 11 participant had missing data on the source of knowledge on ED.

6.4.1.3 Attitudes to identifying and managing pregnant and postnatal women with eating disorders in maternity and health visiting services

Table 6-3 presents the attitudes to identifying and managing pregnant and postnatal women with ED in the sample. A minority agreed ED was not relevant to midwifery and health visiting practice (N = 29; 11%). Most agreed ED can be identified by midwives and health visitors (N = 216; 82%). Only a third (N = 80; 31%) of participants agreed they felt confident in recognising a pregnant or postnatal woman with an ED, and even fewer agreed they felt confident about giving specialised support to a woman (N = 37; 14%). Most participants agreed midwives and health visitors lacked sufficient knowledge on ED (N = 192; 73%) and would benefit from specialist training (N = 261; 98%). Around half of the sample felt there was limited time in practice to manage women effectively (N = 120; 45%).

Table 6-3 Attitudes to identifying and managing pregnant and postnatal women with eating disorders in maternity and health visiting services

Attitude items	N (%) in agreement	N (%) in disagreement
I don't think ED are really relevant to a midwife or health visitor - it should be dealt with by other professionals †	29 (11%)	235 (89%)
I think ED can be identified by midwives and health visitors ‡	216 (82%)	46 (18%)
I feel confident that I could recognise a pregnant woman or mother with an ED §	80 (31%)	182 (69%)
I feel confident about giving specialised support to a pregnant woman or mother with an ED	37 (14%)	228 (86%)
I believe midwives and health visitors are often unaware of the effects of ED on pregnancy and pregnancy outcomes ¶	192 (73%)	72 (27%)
I think midwives and health visitors need better training to help confidently and successfully identify ED in pregnant women and mothers to promote healthy outcomes for mother and child	261 (98%)	4 (2%)
I don't think there is the time in antenatal care or health visiting practice to manage pregnant women and mothers with ED ±	120 (45%)	144 (55%)

† One participant had missing data.

‡ Three participants had missing data.

§ Three participants are missing data.

¶ One participants had missing data.

± One participant had missing data.

6.4.2 Phase two

6.4.2.1 Sample characteristics

Thirty-three healthcare professionals participated in five focus groups (one group per professional category, except for qualified midwives who required two separate groups due to time and resource constraints). The sample comprised of 5 (15%) student midwives, 5 (15%) student health visitors, 14 (42%) qualified midwives and 9 (27%) qualified health visitors (see

Table 6-4). Study ID numbers 1-5 were allocated to student midwives, 6-10 to student health visitors, 11-24 to qualified midwives and 25-30 to qualified health visitors. Participants had a mean age of 36.18 years (range 21-60 years), were predominantly female (N = 32; 97%) and white (N = 24; 77%). Qualified healthcare professionals had been qualified for a mean of 7.71 years (range 1-31) and the majority had completed midwifery or health visitor training in UK institutions (N = 18; 86%). The majority reported that mental health had been included in the midwifery or health visiting training programmes they were currently or had previously attended (N = 24; 86%), considerably more than the numbers reporting that ED had been included (N = 10; 33%).

Table 6-4 Sample characteristics

Characteristics			N (%)
			N = 33
Age (in years) †			Mean: 36.18 Range: 21-60
		20-29	11 (41%)
		30-39	5 (18%)
		40≥	11 (41%)
Gender			
		Female	32 (97%)
		Male	1 (3%)
Ethnicity ‡			
		White	24 (77%)
		Black, Asian or other	7 (13%)
Professional status			
		Student midwife	5 (15%)

		Student health visitor	5 (15%)
		Qualified midwife	14 (42%)
		Qualified health visitor	9 (27%)
Mental health included in training §			
		Yes	24 (86%)
		No	4 (14%)
ED included in training ¶			
		Yes	10 (33%)
		No	20 (67%)
Of the qualified healthcare professionals (N = 23):			
	Number of years qualified ±		Mean: 7.71 Range: 1-31
	Training in the UK ≠		
		Yes	18 (86%)
		No	3 (14%)

† Seven participants had missing data on age (in years).

‡ Two participants had missing data on ethnicity.

§ Five participants had missing data on mental health training.

¶ Three participants had missing data on ED training.

± Two participants had missing data on number of years qualified.

≠ Two participants had missing data on training in the UK.

6.4.2.2 Barriers to identifying and managing pregnant and postnatal women with eating disorders in maternity and health visiting services

Four main themes emerged on the barriers to identifying and managing pregnant and postnatal women with ED in maternity and health visiting services: system constraints; recognition of role; stigma and taboo; individual attitudes and characteristics.

System constraints

System constraints was the dominant theme hindering the identification and management of maternal ED in maternity and health visiting services. This comprised of five subthemes: lack of evidence-based training; practice relating to identification and management; limited time; inadequate communication; and multidisciplinary support.

Lack of evidence-based training

All healthcare professionals reported receiving minimal, if any, training on ED as part of their pre or post-registration clinical education.

> "I know what an eating disorder is, but I've not come across it through my health visitor training"
>
> (Participant 7 – Student health visitor)

Among those who reported they had received training on ED, they expressed it was not taught in detail and had not included recommendations for clinical practice.

> "Mentioned in passing as a mental health issue, it includes this, this and this but not exactly what it entails"
>
> (Participant 5 -Student midwife)

> "There wasn't really any practical advice of what we need to do"
>
> (Participant 17 – Qualified midwife)

A few qualified healthcare professionals could not recall whether ED had been included in training, though recognised that once qualified, they were expected to continue to update their knowledge.

> "It was a long time ago since I was a student and I don't remember… I guess midwives to a certain extent are expected to keep up to date themselves by reading journals and things to be fair… one has to take responsibility for updating one's self as well"
>
> (Participant 15 – Qualified midwife)

Similarly, student midwives expressed the expectation that they would continue to expand their learning whilst in practice.

> "University often relies on us learning this kind of thing in practice, obviously we've got so much learning in the three years"
>
> (Participant 4 – Student midwife)

Several participants made direct comparisons with the level of coverage in training on depression and obesity.

> "Depression is such a big thing in pregnancy… we get an awful lot of training on [like] what we, [like] how to care for women with depression, I think [kind of] eating disorders, [kind of] gets, [kind of like] left to the side"
>
> (Participant 4 – Student midwife)

> "We've covered obesity of course because that's [like] the big hot topic… and we talk about the same things, like nutrition"
>
> (Participant 3 – Student midwife)

Healthcare professionals felt knowledge on ED had to be inferred from other related taught subjects.

> "It wouldn't be a module… it would be linked into mental ill health or BMI"

(Participant 22 – Qualified midwife)

Further, there were differences in the level of pre and post clinical training among healthcare professionals, meaning those that had also studied nursing or psychology were at an advantage.

> "I qualified last year, and I didn't have any in my health visitor training… we did absolutely nothing on eating disorders during it, it's only from my paediatric training that we did eating disorders"

(Participant 27 – Qualified health visitor)

> "Probably media and doing a Psychology A level, we did a lot about that and the research with that"

(Participant 16 – Qualified midwife)

Regardless of prior training, the majority of participants considered the media to be a key source of information on ED, although this was not necessarily reliable or evidence-based information.

> "I don't know if the information that I've got from the media, I don't use it as the gospel [do you know], as evidence-based knowledge to base my practice on as a student midwife because… you don't know where they are getting their sources from necessarily or how reputable the information is"

(Participant 3 – Student midwife)

Healthcare professionals felt their lack of appropriate training contributed to their understanding of ED being limited to symptoms of food-restriction and low weight associated with AN and self-induced vomiting with BN.

> "My knowledge is limited to anorexia nervosa"

(Participant 18 – Qualified midwife)

As such, there was poor recognition of other ED symptoms and of the implications for maternal and infant health.

> "Just the most common ones, bulimia, anorexia, [uhm] but probably not, I've never had any, I'm not aware I've actually had any formal training on them and certainly actually never probably linked to parenting or the impact that a history of that would have on families and parents and children"
>
> (Participant 32 – Qualified health visitor)

A few healthcare professionals were not certain that ED were classified as a distinct group of mental health disorders.

> "I have a very limited knowledge about the, those terms as in bulimia and anorexia, I've heard the words being thrown round quite a lot… but what I know as well is that it's kind of linked… to mental health issues"
>
> (Participant 30 – Qualified health visitor)

Several participants indicated their limited understanding about ED effected their confidence to be able to identify and support affected women appropriately.

> "It's really hard when you've, when people give you information, but you don't know anything about it"
>
> (Participant 17 – Qualified midwife)

Furthermore, this was expected to affect how women would feel about disclosing to healthcare professionals.

> "It's that [kind of] feeling that, [like] a bit awkward and stuff, [like] you don't really know what to say and then it's not going to help the women open up and discuss anymore with you"
>
> (Participant 4 – Student midwife)

Practice relating to identification and management

Healthcare professionals related their lack of relevant training on ED to a poor awareness of relevant policies, guidance, care management plans and referral pathways.

> "If it's in the trust policy and guidelines I haven't found it yet because I haven't sort of come across it or it hasn't been emphasised in the training"
>
> (Participant 3 – Student midwife)

Participants recognised the need for active enquiry by healthcare professionals about sensitive matters to encourage disclosure by women.

> "It's always harder volunteering information than if someone asks you a direct question"
>
> (Participant 12 – Qualified midwife)

However, several participants expressed they do not routinely enquire about ED when asking women about a history of mental health disorders.

> "Routinely we don't ask… I don't think even in the box where you select if they say 'yes' they have, it even has eating disorders"
>
> (Participant 1 – Student midwife)

> "I never mention those words, I don't think I ever ask a question that, [you know]"
>
> (Participant 11 – Qualified midwife)

Others said they do ask women, but often only at the initial contact with a woman.

> "Ours is routine, it's in our booking questionnaire"
>
> (Participant 5 – Student midwife)

Some participants were reluctant to enquire about ED as they were unsure how to respond to a disclosure and felt there was no care pathway or protocol they could follow.

> "There's no point in asking the question if you don't know what to say next"
>
> (Participant 13 – Qualified midwife)

> "If there's no service there to refer into, what do we do with that information once we've got it, and to be able to know what to do with it, where to take it once we've identified it, so the service has to be out there for us to refer in to"
>
> (Participant 10 – Student health visitor)

> "I've had a couple of women who we've booked, and the midwife doesn't really know what to do that much, even if they are open about it"
>
> (Participant 4 – Student midwife)

Comparisons were made with clearly defined care management plans for women with high and low BMI's, though mental health was not a feature in either of these care pathways.

> "If the BMI is lower than normal then we refer to the dietician but it's more related to the physical than the mental"
>
> (Participant 2 – Student midwife)

> "there's more of a protocol isn't there, [yeah] if their BMI is over a certain amount then there is a check list you have to do, you have to refer them to the right people, have to take different bloods"
>
> (Participant 14 – Qualified midwife)

Participants felt a care pathway and practical guidance on how to provide ongoing support from pregnancy to the postnatal period was needed.

> "The midwifery remit ends, and the mother will go on in many cases to get pregnant again and who is going to provide her with support around this area of her life if she's suffering from eating disorders and raising small children"
>
> (Participant 20 – Qualified midwife)

Limited time

All healthcare professionals felt there was insufficient time to effectively and sensitively identify women with ED, due to the time constraints they had to contend with during antenatal and postnatal contacts with women.

> "These really big questions [you know], which can't just be rushed over"
>
> (Participant 15 – Qualified midwife)

Within maternity services, opportunity to ask women about any physical and mental health problems was often restricted to the initial antenatal booking appointment rather than subsequent antenatal contacts.

> "It gives us much more time to [kind of] get to know the woman, [like] we're asking them a lot of in-depth information"
>
> (Participant 4 – Student midwife)

Student and qualified midwives advocated use of a caseloading model of midwifery care, as this enabled midwives to offer women more time in appointments if needed.

> "In caseload midwifery [you know] we can build on the relationship at that appointment and if a woman's crying, we don't have to think 'oh my goodness you've got to get out of the room in five minutes, [you know] I've got another person coming in'… for women with mental health issues this is vital"
>
> (Participant 11 – Qualified midwife)

Health visitors reported often asking women about any mental health difficulties at the first postnatal visit as this was allocated more time than other routine clinic

appointments. However, it was emphasised that this should not be the only opportunity to enquire as it is likely to be more appropriate in future contacts with a health visitor who the woman has developed a familiarity with.

> "When you see them for the first visit… you know the chances are you won't see that person again… I've got someone who comes to clinic… the health visitor probably never saw her again anyway, whereas now it would be much more appropriate for me to say to her"
>
> (Participant 31 – Qualified health visitor)

One student health visitor, although in favour of supporting women with ED, recognised that opportunities to provide continual support to women postnatally would be determined by capacity and other competing demands.

> "It just depends how many health visitor hours that you have in a certain practice area to be able to do 'cos [sic] obviously you have to prioritise what's happening… those supportive visits may not be as frequent as you'd like them to be because there's physically not enough time in the day to cover everything"
>
> (Participant 9 – Student health visitor)

Communication within and between services

Midwives and health visitors all described that the sharing of information about a woman's physical and mental health among relevant clinicians was problematic and often reliant on the woman to disclose any problems.

> "I've had quite a few in only the last few months of being qualified where there's things that we should have known about and didn't"
>
> (Participant 27 – Qualified health visitor)

> "I didn't know her history 'cos [sic] she just moved into the area"
>
> (Participant 33 – Qualified health visitor)

Several midwives felt there were limited means to pass on sensitive information or raise concerns about a woman's mental health with colleagues also involved in her care. Reliance on handheld maternity notes to document a woman's pregnancy and medical history raised concerns about confidentiality. Several midwives used domestic violence as an example to illustrate the limitations with this practice.

> "Obviously because they are handheld notes, we're very careful of what we write in them"
>
> (Participant 3 – Student midwife)

Communication between services particularly within primary care, such as with the family doctor (GP), midwives and health visitors, were described by some qualified health visitors as limited due to increasingly fragmented acute and primary health services.

> "There was one midwife in every Sure Start and we were all attached so we would always be able to liaise with that midwife and they would liaise with us… now it's [like] five midwives, [like] different midwives' every time and they, they don't build up that kind of rapport"
>
> (Participant 26 – Qualified health visitor)

Lack of multidisciplinary and specialist support

Attendees felt there were few opportunities to be involved in shared care as part of a multidisciplinary team, resulting in limited access to mental health expertise within teams or between services, particularly so in health visiting.

> "If you had some supervision around those sorts of issues, any sorts of issue where you're just feeling like you're holding something, but you haven't necessarily got the skills"
>
> (Participant 26 – Qualified health visitor)

A few qualified health visitors felt that poor awareness about ED was not isolated to health visiting but was an issue across health and social services more broadly, which

impacted on the ability to refer women to other services and to apply a multidisciplinary approach to care.

> "I mean having tried to refer to safeguarding for an eating problem before, it came straight back to me and they weren't interested at all… I do really think that if we had it, everybody else in the community teams would need it too because there would be no point in just training us if it then stopped with us"
>
> (Participant 27 – Qualified health visitor)

Recognition of role

An important theme identified was the need to clarify the clinician's role in identifying and supporting pregnant and postnatal women with ED, which would require a broadening of their current remit.

Role in mental health

The majority of participants were in favour of enquiring about a woman's history of ED and offering appropriate support following a positive disclosure.

> "I think it's something that we should ask the same as we ask, if, well everything we ask, some questions that are very difficult to ask… we should ask if she's ever had an eating disorder in the past"
>
> (Participant 2 – Student midwife)

> "It would obviously add to our workload if we were going to take that role as well, but we do, we do support families and women with other issues so I guess it would go along the same lines really"
>
> (Participant 9 – Student health visitor)

Some considered their role was to offer women advice and support, rather than be the lead clinician responsible for decision-making and coordinating a woman's care.

> "I don't know whether it would be our role to manage them as such, I think we would be more of a supportive role, I don't think we would be taking a lead"
>
> (Participant 8 – Student health visitor)

Student midwives indicated the practice among midwives was to offer women general nutritional advice rather than have a discussion with women about their eating behaviours, which could potentially reveal symptoms of disordered eating.

> "We tell people what not to eat but not how do you eat"
>
> (Participant 3 – Student midwife)

Focus on infant health

Some midwives felt that the priority in maternity care was the wellbeing of the unborn infant, so a woman's mental health would not be the focus unless it was or had the potential to impact on the infant.

> "We would be just making sure that the baby was growing adequately… and then leaving the woman well alone, in a way just focusing on the wellbeing of the baby"
>
> (Participant 11 – Qualified midwife)

This presiding focus on the infant was similarly expressed by some health visitors.

> "I think from my point of view it's more about her mental ability to be looking after the baby, her bond with the baby, sort of looking from that point of view"
>
> (Participant 6 – Student health visitor)

A few student midwives felt that women's perceptions of the different clinical roles could either act as a benefit or a hindrance in discussions about ED.

> "A midwife… usually it's for normal pregnancies, normality, and also is a figure that only she's for the women and babies, and the doctors maybe

> they seem, or the mental health services don't sound probably very nice… maybe it's easier because they know that this, the midwife is gonna [sic] follow them through the pregnancy"
>
> (Participant 2 – Student midwife)

> "The health visitors, [kind of] some were viewed for the baby and [kind of] for the child's sake, not someone to support the mum"
>
> (Participant 4 – Student midwife)

Stigma and taboo

All groups discussed the stigma of ED and mental health more broadly, with some referring to ED as a 'taboo' subject that hindered enquiry as well as disclosure. Less experienced healthcare professionals expressed greater levels of anxiety with asking women about ED.

> "It does feel [kind of] sometimes like it's one of those taboo questions, a bit like domestic violence and probably depression a little bit but less so 'cos [sic] women are more aware of it, but you [kind of like] skirt over, [like] 'you haven't ever had any eating disorders, have you? No right moving on' "
>
> (Participant 4 – Student midwife)

> "Not just for her, both sides of the coin very, a little bit uncomfortable to ask"
>
> (Participant 5 – Student midwife)

Weight stigma was also highlighted as a potential obstacle, as illustrated by one health visitor during a discussion in which she expressed feeling more comfortable discussing ED with women who were underweight rather than women who were obese.

> "[You know] I'd actually find it quite hard probably saying to someone who was really [you know] obese, asking them have you had any eating disorders because it's quite plain to see"
>
> (Participant 26 – Qualified health visitor)

Perceived stigma of mental health was understood to lead most women to feel reluctant to disclose a mental illness to a healthcare professional.

> "It's quite a big [kind of] word isn't it for women, no one wants to have a mental health problem do they, a bit of a stigma"
>
> (Participant 12 – Qualified midwife)

One qualified midwife expressed how perceived stigma of mental health can make women fearful of potential adverse consequences following a disclosure.

> "One needs to be sensitive about these things, mental health issues equal social services take away baby"
>
> (Participant 15 – Qualified midwife)

Personal attitudes and characteristics

Several participants discussed the influence the personal attitudes and characteristics of the healthcare professional can have on the interaction with a woman. The majority of midwives, for example, described that they need to have a consistently positive attitude during interactions with women and that by showing women compassion this can encourage disclosure and engagement.

> "There is no room for negativity in midwifery"
>
> (Participant 12 – Qualified midwife)

Alternatively, some of the participants considered that more of a pragmatic attitude may be preferable to women.

> "Each midwife has their unique way of interacting with the woman and some… 'cos [sic] some women, like you can be really friendly, really bubbly and that's not what they want"
>
> (Participant 3 – Student midwives)

One qualified midwife felt it was important for training providers to acknowledge and address the individual differences among healthcare professionals that effect how they engage with women.

> "Those that give dietary advice who have a high BMI challenge themselves feel guilty, those that smoke use mints and spray… and then go into a booking and then give advice about smoking… we make assumptions that we all will deliver that health promotion message when actually attitudes and beliefs are integral to who we are, influence how we ask the question"
>
> (Participant 22 – Qualified midwife)

6.5 Discussion

6.5.1 Phase one

The findings from phase one of the study indicate that training on ED was infrequent, knowledge of ED varied greatly and confidence to identify and manage pregnant and postnatal women with ED was low amongst participants. The need for specialist training was advocated, and the majority of healthcare professionals recognised their role in identifying pregnant and postnatal women with ED. However, nearly half of the sample considered capacity was not sufficient to enable effective identification and support of pregnant and postnatal women with ED.

6.5.2 Phase two

The findings from phase two confirmed and expanded on the findings from phase one. The main barriers to identifying and managing pregnant and postnatal women with ED from the perspectives of midwives and health visitors were grouped in terms of the constraints within the healthcare system. Recognition of their professional role, stigma, and personal attitudes and characteristics of the individual clinician were also important barriers highlighted.

6.5.2.1 System constraints

6.5.2.1.1 Insufficient training and related practice

Findings from phase two further highlighted a consistent lack of training opportunities for midwives and health visitors to advance their understanding of ED. In the cases for whom training on ED had been available, it was considered insufficient and did not include recommendations for clinical practice. Lack of training contributed to limited awareness of ED beyond the more common presentations of AN and BN, and did not cover on how best to identify and manage pregnant and postnatal women with ED. There were inconsistencies described in the routine enquiry of ED due to poor awareness of the need to identify ED and subsequent concern about management of positive disclosure. Comparisons were made with other mental and physical health conditions i.e. depression and obesity, that were felt to receive more attention in training and practice, with clearly defined and implemented care pathways. The lack of consistent training and care planning likely gives way to more influence of the personal biases of the individual clinician. The findings are consistent with previous reports of poor knowledge and routine enquiry about ED among other healthcare professionals including those also responsible for providing maternity care i.e. obstetricians (Abraham, 2001; Banas et al., 2013; Boulé & McSherry, 2002; Morgan, 1999; Stringer et al., 2010; Supina et al., 2016). Unlike Morgan (1999) although similar to Rodino et al (2017), the findings did not indicate differences in knowledge on ED related to level of seniority among clinicians. Indeed, it was the opposite in some cases, though mostly related to pre-registration training i.e. prior nursing or psychology undergraduate training.

Universities are responsible for developing their own curriculum and clinical services for developing care pathways and policies for their particular trust, which should be in line with recommendations from the various regulatory authorities i.e. NICE, Nursing and Midwifery Council (NMC) and Royal College of Midwives (RCM). The lack of coverage in pre and post-registration training, as highlighted in the present study, is likely because ED are not stipulated in the core clinical competencies required as part of pre-registration training or post-registration standards for midwives and

health visitors in the UK (NMC, 2004, 2009). The more recent inclusion of ED in some training programmes as suggested from the study findings may relate to growing awareness among those developing new curriculum content rather than those setting the standards. This indicates a poor integration of available guidance in to pre and post-registration training and clinical practice (NICE, 2014, 2017).

6.5.2.1.2 Insufficient time and communication in healthcare

Healthcare professionals described a consistent lack of time and opportunity during contacts with women to discuss ED in a sensitive manner to encourage disclosure and provide women with consistent support, with midwives advocating the benefits of a caseloading model of midwifery care. This model of midwifery care is deemed to promote better continuity of care in pregnancy and is advocated in UK policy and guidance (Department of Health, 2007; National Institute of Health and Care Excellence, 2012) and other countries with similar healthcare systems to the UK i.e. Australia (Commonwealth of Australia, 2009). The caseloading model of midwifery care has been associated with better short-term maternal and infant outcomes, patient satisfaction, and cost effectiveness in comparison to other continuity models of maternity care (Forster et al., 2016; Sandall, Soltani, Gates, Shennan, & Devane, 2016; Tracy et al., 2013). Of note, is that only five small trials included in the Cochrane review were based in the UK, where women in control arms would have received continuity of care as part of standard care. As the most recent of the UK trials was published in 2003 (Sandall et al., 2016), care has to be taken when assuming any benefit from such models of care for women today, especially with such limited evidence of any longer-term benefits for women's health.

Clinicians in the present study highlighted the lack of communication between healthcare professionals working within the same care group and between services. Methods of relaying concerns about women were complicated by need to balance communication of crucial information with respecting the sensitive and confidential nature of disclosure. Communication between clinicians about women's care needs is clearly being affected by the increasingly fragmented and poorly integrated primary care services, including maternity and health visiting services (Watton, 2013).

6.5.2.2 Recognition of role

The midwives and health visitors in this study recognised the potential to be involved in identifying and supporting women with ED but expectations were felt to be poorly defined. Further, infant health was considered to be an overriding priority across the healthcare system, which has implications for when they would intervene and expectations from women on their clinical role. The findings relate to a previous report by Leddy et al (2009) of a large US survey of obstetricians and gynaecologists which indicated that whilst the majority of the sample were aware of the implications of ED on pregnancy and birth outcomes, enquiry about ED was low, with many perceiving screening for ED as not part of their professional remit.

6.5.2.3 Stigma of maternal ED

Study findings indicated that the stigma of maternal ED caused healthcare professionals, particularly students and those with less clinical experience and with ED specifically, to be anxious about raising this with women. As with previous research (Currin et al., 2009), deficits in ED knowledge did not relate to negative attitudes about ED. The anxiety largely related to concerns that women with ED would fear being stigmatised and this would hinder disclosure and engagement.

Stigma of mental health is widely recognised and individuals with ED are often perceived by the public as being more responsible and in control of their ED behaviours, potentially invoking less empathy compared to other illnesses (Ebneter & Latner, 2013; Roehrig & McLean, 2010). The stigmatising attitudes towards BED specifically is comparable to the negatives attitudes towards obesity that are present within society (Puhl et al., 2013). As reflected by one participant in this study, previous research has suggested that negative attitudes towards obese individuals can be common among health professionals and affect the quality of care they deliver (Phelan et al., 2015).

The concerns expressed by clinicians in this study are consistent with concerns raised by women in previous studies on the acceptability of routine enquiry about mental health in maternity services. These studies have reported that women with mental

health difficulties were often reluctant to disclose due to fear of adverse consequences, namely stigma and negative perceptions of them as a mother (Kingston et al., 2015; Yapp et al., 2019). Similarly, Stringer et al (2010) conducted qualitative research with pregnant and postnatal women with ED and reported that some women were reluctant to disclose their ED to healthcare professionals involved in their maternity care due to feelings of shame.

6.5.3 Strengths

The main strength of this study was the novel exploration of the barriers to the identification and management of ED in maternity and health visiting services from the perspectives of those providing routine care. The mixed methods design generated both numerical and narrative data to produce a more comprehensive understanding of the research problem than would have been possible using a single approach in isolation (Creswell & Creswell, 2018). The sequential nature of the design provided a practical and efficient means of identifying participants from the quantitative phase for the qualitative phase of the study. The study sites provided cost and time effective access to a large population of both student and qualified healthcare professionals who provide care for ethnically and socially diverse populations of pregnant and postnatal women. The size and heterogeneity of the study samples support the generalisability and robustness of the findings given the commonality in the emerging themes (Robinson, 2014). Furthermore, the analysis process was rigorous with the complete dataset being independently coded by a second researcher and interpretive contributions from the doctoral supervisors and co-authors on the published findings (Bye, Shawe, et al., 2018).

6.5.4 Limitations

The interpretation of the study findings needs to consider the limitations. The self-report questionnaire used in phase one of this study had not been previously validated or undergone rigorous testing, although this was necessary as there was not a suitable alternative, this does limit the conclusions that can be drawn from the findings that were generated. The study used non-probability sampling and was

limited to study sites in the South of England, which may limit the representativeness of the sample and generalisability of the findings to other healthcare professionals across the UK. The qualitative findings may help to understand deficits in knowledge and particular attitudes among the wider sample indicated from the questionnaire, however, the sample for the focus groups were not representative of this same population. Qualitative research is often criticised for its subjective nature and lack of generalisability, though the analytic rigour and complementary use of quantitative methodology employed in this study serve to minimise these disadvantages (Bryman, 2016). The use of focus groups can be criticised as individuals may be more prone to express socially acceptable views rather than their personal views (Bryman, 2016) and transcribing group discussions is more time consuming than individual interviews. However, this may have contributed to a more comprehensive understanding of the barriers to healthcare as it enabled participants to discuss and challenge one another, rather than discussions being directed by the interviewer in the standard question and answer format employed in interviews (Bryman, 2016).

6.5.5 Conclusion and implications

The study findings indicate the barriers to effective identification and management of pregnant and postnatal women with ED operated on multiple levels. The main barriers were insufficient training and related practice, which contributed to healthcare professionals lacking the necessary evidence-based knowledge to effectively identify and support pregnant and postnatal women with ED, in accordance with the clinical guidance. The configuration and provision of maternity and health visiting services were considered not to be conducive to the effective identification and care management of these types of complex and stigmatised conditions. Future research could aim to expand on the findings by exploring perspectives in a wider range of stakeholders, including GPs and specialists in perinatal mental health and ED, to inform strategies for implementing change in clinical training and practice. It is imperative that action is taken to address the barriers to ensure healthcare professionals are effectively identifying and supporting

pregnant and postnatal women with ED to promote optimal maternal and infant outcomes, in accordance with clinical guidance.

Chapter 7 General Discussion

7.1 Chapter overview

This chapter presents an overall discussion of the findings from this programme of research. It presents a summary of the main findings from each of the four studies, with reference to the aims. This is followed by a discussion of the main findings overall from this programme of research, in relation to prior literature. The potential implications of this research for clinical practice, public initiatives and future research are then considered. Finally, the overall strengths and limitations of this programme of research are examined.

7.2 Summary of main findings

The general aims of this thesis were to investigate the prevalence of current and past ED among pregnant women and implications of using different methods of data collection. In addition, to explore identification and management of pregnant and postnatal women with ED in maternity and health visiting services from the perspectives of women, midwives and health visitors. Four studies were conducted in this programme of research to research the specific aims of these two overarching aims.

7.2.1 Study 1: Prevalence of ED in a sample of pregnant women, using a self-report questionnaire

The aim of study one was to investigate the prevalence of ED before and during pregnancy in a sample of pregnant women in South-East London, in accordance with DSM-5 (APA, 2013), using a self-report questionnaire. Further, to examine rates of remission, continuation, diagnostic cross-over and new onset of ED during pregnancy.

The findings indicate the prevalence of ED in the 12 months before pregnancy was 8.80% (N = 85), of which AN was 0.52% (N = 5), BN 1.04% (N = 10), BED 2.07% (N = 20), purging disorder 1.04% (N = 10), and broadly defined OSFED 4.14% (N = 40). The prevalence of ED during pregnancy was marginally lower at 6.72% (N = 65), of which AN was 0.52% (N = 5), BN 0.21% (N = 2), BED 2.59% (N = 25), purging disorder 0.31% (N = 3), and broadly defined OSFED 3.10% (N = 30). Of the women with ED before pregnancy, women with AN (N=4; 80%) and BED (N = 13; 65%) most commonly continued to meet diagnostic criteria during pregnancy, whereas women with purging disorder more often remitted during pregnancy (N = 7; 70%). Women with BN before pregnancy more frequently met diagnostic criteria for BED instead during pregnancy (N = 7; 70%). A quarter of women with ED during pregnancy were cases of new onset (N = 18; 28%), predominantly broadly defined OSFED (N = 13; 72%) and BED (N = 4; 22%).

7.2.2 Study 2: Prevalence of ED in a sample of pregnant women, using structured clinical interviews

The aim of study two was to estimate the prevalence of lifetime and current ED in a sample of pregnant women in South-East London, in accordance with DSM-5 (APA, 2013), using diagnostic interviews. Further, to examine rates of remission, continuation and diagnostic cross-over amongst pregnant women with lifetime ED, the clinical characteristics of pregnant women with lifetime and current ED, and identification of ED by midwives in maternity care.

The findings indicate the estimated population prevalence for lifetime ED was 15.35% (95% CI, 11.80-19.71%), of which AN was 7.13% (4.75-10.58), BN 0.58% (0.17-1.97), BED 1.67% (0.79-3.46) and OSFED 5.97% (3.83-9.21), including purging disorder 1.51% (95% CI, 0.60-3.74). The estimated population prevalence for active ED during pregnancy was much lower at 1.47% (95% CI, 0.64-3.35%), of which AN was 0.09% (95% CI, 0.03 – 0.30), BED 0.51% (95% CI, 0.13-2.02) and OSFED 0.87% (95% CI, 0.28-

2.69), including purging disorder 0.71% (95% CI, 0.18-2.79). None of the women in the study met diagnostic criteria for BN during pregnancy. The majority of women with lifetime ED were in full remission during pregnancy. Women with lifetime ED were more likely to have current depression and anxiety and a history of deliberate self-harm or attempted suicide, whereas women with current ED were more likely to have current anxiety and borderline personality disorder compared to non-cases of ED. Finally, identification of ED in maternity care was low compared to the numbers identified by the diagnostic interview.

7.2.3 Study 3: Experiences of maternity care in women with ED

The aim of study three was to explore experiences of maternity care amongst women with lifetime ED, including women's satisfaction with maternity care, disclosure of ED to a healthcare professional, and recommendations for improvements to maternity care for women with ED. Further, to examine the prevalence of ED symptoms during pregnancy in women with lifetime ED and the association with disclosure of ED to a healthcare professional in maternity care.

The sample comprised predominantly of women with self-reported lifetime AN. Two thirds of women had active ED symptoms during a current or past pregnancy, most commonly restricting and excessive food intake, less often purging. Most women were satisfied with their maternity care, yet only a quarter had disclosed their ED to a healthcare professional, and this was irrespective of whether women had active ED symptoms during pregnancy. Amongst those that had disclosed their ED, disclosure had not consistently resulted in additional monitoring, support or specialist referral in accordance with the clinical guidelines (NICE 2014, 2017), and women were more often unhappy or indifferent about having disclosed their ED.

There was considerable overlap between women's reasons for dissatisfaction and non-disclosure in maternity care and their recommendations for improvements to

maternity care. Women in this study felt healthcare professionals involved in their maternity care lacked the necessary expertise to appropriately identify and support pregnant women with ED, with many advocating specialist training should be provided to healthcare professionals to enhance their knowledge and awareness about maternal ED. Experiences of actualised stigma and fear of stigma in maternity care impacted negatively on women's perceptions of maternity care and hindered disclosure of ED, with women highlighting the importance of healthcare professionals showing women with ED more compassion. Lack of familiarity, time and active enquiry about ED in maternity care was felt by women to contribute to missed opportunities for women to disclose their ED and access the necessary support. Finally, disclosure of ED for some women was hindered by a sense of personal ambivalence and poor recognition of the need to access support from healthcare professionals involved in their maternity care.

7.2.4 Study 4: Identification and management of ED in maternity and health visiting services

The aims of study four were firstly, to examine knowledge and attitudes to identifying and managing pregnant and postnatal women with ED amongst midwives and health visitors, and secondly, to explore the barriers to identifying and managing pregnant and postnatal women with ED in maternity and health visiting services from the perspectives of midwives and health visitors.

The findings from the first phase of the study demonstrated that training on ED was infrequent, knowledge on ED varied greatly, and confidence to identify and manage pregnant and postnatal women with ED was low amongst the participants. The majority of participants advocated the need for specialist training on maternal ED and recognised their role in identifying and supporting pregnant and postnatal women with ED. However, nearly half of the sample considered capacity in healthcare was not sufficient to enable them to do this effectively.

These findings were explored in greater depth in the second phase of the study, outlining several important barriers to identifying and managing pregnant and postnatal women with ED. The main barriers related to system constraints, including lack of consistent training, limited routine enquiry, lack of care management planning, and ineffective infrastructure to support the role of healthcare professionals with caring for women with complex healthcare needs. Recognition of their role to identify and support pregnant and postnatal women with ED requires a shift from the current prioritisation in healthcare of infant health, which in some respects is above the health of the mother, particularly her mental health. The stigma of maternal ED can cause healthcare professionals, as well as women, to feel reluctant to discuss ED. Finally, personal attitudes and characteristics of the individual healthcare professional effect how discussions about ED are approached and advice provided.

7.3 Discussion of main findings

7.3.1 Prevalence of ED in pregnant women

7.3.1.1 Prevalence of lifetime ED

To the candidate's knowledge, study two is the first to use diagnostic interviews to estimate population prevalence of lifetime ED in an antenatal sample. The estimated lifetime prevalence reported in study two is in line with the prevalence of 15.33% (95% CI, 13.48–17.42%) reported in a recent study of women participating in a longitudinal birth cohort study, the majority of whom reported that onset of ED was prior to pregnancy (Micali et al., 2017). There are marginal discrepancies in prevalence estimates for individual ED categories between the studies. Estimated prevalence of lifetime AN of 7.13% (95% CI, 4.75-10.58%) was higher in study two than the prevalence of 3.64% (95% CI, 2.81-4.72%) reported by Micali et al (2017). Estimated prevalence for lifetime BN of 0.58% (95% CI, 0.17-1.97%) was somewhat lower than 2.15% (95% CI, 1.70-2.74%) reported by Micali et al (2017). Comparing

these findings with previous reviews (Lindvall Dahlgren et al., 2017; Smink et al., 2012), and given there were no cases of current BN during pregnancy, suggest the current investigation may overestimate the prevalence of lifetime AN and underestimate lifetime BN. There are some important distinctions though between the current investigation and these reviews as study two was in an antenatal sample whereas the samples included in these reviews were either much younger or represented a much wider age range (Lindvall Dahlgren et al., 2017; Smink et al., 2012). The lifetime prevalence estimate for OSFED of 5.97% (95% CI, 3.83-9.21%) was comparable to a prevalence of 7.64% (95% CI, 6.32-9.24%) reported by Micali et al (2017) and in line with findings from the recent systematic review by Lindvall Dahlgren et al (2017). The findings demonstrate a large proportion of women continue to be classified with sub-threshold ED despite recent changes to DSM to broaden the full threshold ED categories (Fairburn & Cooper, 2011).

7.3.1.2 Prevalence of ED in the pre-conception period

There are few studies that have investigated the prevalence of ED in the pre-conception period in the general population, with more focus on the prevalence of ED in fertility clinic attendees (Freizinger et al., 2010). Therefore, comparisons with the present findings are limited and likely more useful to asses changes in diagnoses during the perinatal period. Nonetheless, the prevalence of 8.8% for ED before pregnancy in study one is in line with the 9.2% reported on the interim survey findings (Easter et al., 2013), as would be anticipated given the previous definitions were pre-emptive of DSM-5 (APA, 2013). Though the prevalence was higher than 4.5% before pregnancy reported by Watson et al (2013), the authors did not establish prevalence for other types of OSFED except for purging disorder.

Prevalence of AN before pregnancy in study one is consistent with previous reports, ranging between 0.1-0.5%, including the present findings (Easter et al., 2013; Watson et al., 2013). Reported prevalence of BN, BED and purging disorder before pregnancy

are more variable, ranging between 0.1-1.0%, 1.2-3.3% and 0.1-1.4%, respectively (including the present findings) (Easter et al., 2013; Watson et al., 2013). Findings demonstrate study one is consistent with Watson et al (2013) but higher than the interim survey findings (Easter et al., 2013), with the exception of purging disorder. Conversely, prevalence of the broadly defined sub-threshold category before pregnancy is lower than the interim survey findings (Easter et al., 2013). Inconsistencies with the interim findings (Easter et al., 2013) are also evident in diagnoses of ED during pregnancy, reflecting the implications on prevalence of the revised thresholds outlined in DSM-5 (APA, 2013) as has been similarly demonstrated in non-pregnant populations (Lindvall Dahlgren et al., 2017). As intended, the changes introduced in DSM-5 (APA, 2013) have reduced the number of individuals with ED grouped under a heterogeneous diagnostic category and attempts to group those displaying more similar symptomology, making the diagnostic classifications more useful for research as well as clinical practice.

7.3.1.3 Prevalence of current ED during pregnancy

The prevalence of current DSM-5 (APA, 2013) defined ED during pregnancy reported in study one was considerably higher at 6.72% compared to the estimated prevalence in study two at 1.47% (95% CI, 0.64-3.35%). Likewise, prevalence figures according to each of the ED diagnostic categories were higher in study one (AN 0.52%; BN 0.21%; BED 2.59%; broadly defined OSFED 3.10%) compared to study two (AN 0.09% [95%CI, 0.03 – 0.30]; BED 0.51% [95% CI, 0.13-2.02]; OSFED 0.87% [95% CI, 0.28-2.69]). The exception to this pattern was purging disorder, of which the prevalence in study one was 0.31% compared to 0.71% (95% CI, 0.18-2.79) in study two. Though the reported prevalence of purging disorder in study one fits within the 95% CI reported in study two and considering the small numbers of women with ED, slight variations in prevalence are unlikely to reflect a true difference.

Given the studies surveyed pregnant women accessing the same inner-city NHS maternity service, the disparities are suggested to relate mainly to differences in diagnostic tools, as well as differences in how these tools were administered and women were identified. In study one, pregnant women were approached in a hospital waiting area, having not been identified beforehand, to complete a self-report questionnaire independently and anonymously. This compares to study two, whereby pregnant women were recruited directly via their maternity care to participate in a face-to-face diagnostic interview administered by a researcher.

These explanations for the inconsistencies between studies one and two are in line with findings from previous antenatal studies. Evidence indicates reported prevalence for current ED during pregnancy is widely disparate, ranging between 1.47%-7.5%, with higher prevalence in studies using self-report questionnaires, ranging between 5-7.5% (including study one), and lower in studies using diagnostic interviews, ranging between 1.47%-1.9% (including study two) (Easter et al., 2013; Howard et al., 2018; Maihara dos Santos et al., 2017; Watson et al., 2013). Contrastingly, reported prevalence of current AN, BN and purging disorder during pregnancy is comparable across studies using different diagnostic tools, ranging between 0.09%-0.52%, 0.1%-0.7% and <0.01%-0.71%., respectively, including the present findings (Easter et al., 2013; Maihara dos Santos et al., 2017; Watson et al., 2013). Whereas, reported prevalence of current BED during pregnancy ranges substantially between 0.51%-4.8% (including the present findings), with lower prevalence and more consistency in studies using diagnostic interviews (Easter et al., 2013; Maihara dos Santos et al., 2017; Watson et al., 2013). Prevalence of current OSFED during pregnancy, with the exception of purging disorder, has not consistently been assessed so it is difficult to interpret, though figures are similarly disparate, with self-report questionnaires generating higher prevalence, including the present findings (Easter et al., 2013; Watson et al., 2013).

In the wider ED literature, self-report questionnaires are frequently found to generate higher prevalence of ED compared to diagnostic interviews (Fairburn & Beglin, 1994; French et al., 1998; Keel et al., 2002; Mond et al., 2007). Diagnostic interviews are often considered to generate more reliable diagnoses as the interviewer can seek clarification where there is ambiguity. Fairburn and Beglin (1994) suggest this is most relevant for less well defined symptoms such as binge eating compared to symptoms where there is more consensus, such as low body weight and self-induced vomiting, as indicated in the review of the antenatal findings. Likewise, given the challenge for a self-report questionnaire to reliably assess OSFED considering the heterogeneity and threshold of symptoms that are grouped under this diagnostic category. Hence, study one used an over-inclusive definition of OSFED, intended to signify a potential ED that warrants further investigation, rather than a diagnosis as in study two, which employed a stricter definition in accordance with DSM-5 (APA, 2013).

Alternatively, some research indicates self-report questionnaires may to some degree, generate more disclosures of ED symptoms as they can be perceived as providing participants with greater anonymity compared to face-to-face diagnostic interviews (Keel et al., 2002). Anonymity is an important consideration for prevalence studies given stigma is consistently cited as a barrier to engagement with healthcare services in the ED literature (Ali et al., 2017; Hepworth & Paxton, 2007; Swan & Andrews, 2003). This is likely particularly relevant for assessing BED given the association with obesity (de Zwaan, 2001; Hudson et al., 2007), as individuals who are obese and have BED may experience greater stigma than other ED groups, due to the addition of weight stigma (Ebneter & Latner, 2013; Puhl & Suh, 2015; Reas, 2017). Antenatal research indicates that fear of being stigmatised and discredited as a mother is a significant barrier to disclosure of perinatal mental illness (Kingston et al., 2015; Nagle & Farrelly, 2018; Viveiros & Darling, 2018; Yapp et al., 2019). Pregnant women with ED could be increasingly vulnerable to stigma given their belonging to

multiple stigmatised groups, which will likely impact on positive disclosures of ED. Therefore, the perceived anonymity from participating in antenatal studies using self-report questionnaires, particularly when administered in an unobtrusive way as in study one, may to some extent enable pregnant women to feel more comfortable with disclosing active ED symptoms.

7.3.1.4 Changes in ED symptoms during the perinatal period

Findings in studies one and three indicate that active ED symptoms during pregnancy were common among the women in these respective samples. This is consistent with the majority of research suggesting that although women with ED tend to experience an overall decrease in symptoms during pregnancy, high levels persist (Crow et al., 2004; Easter et al., 2015; Micali, Treasure, et al., 2007).

Findings from both studies are in line with previous research, evidencing that women with ED tend to cease purging behaviours during pregnancy, whereas binge eating behaviours persist (Crow et al., 2004; Micali, Treasure, et al., 2007). However, study three also identified higher levels of restrictive eating behaviours than previously reported (Micali, Treasure, et al., 2007). The present studies expand on the existing evidence base though to reflect the experiences of women with a wider range of ED including women with BED and sub-threshold ED, who have often not been included in previous investigations. Findings suggest that whilst women may be aware of the risk of harm to their unborn infant from engaging in certain behaviours, they are not necessarily aware of others, highlighting a limited understanding of their nutritional needs during pregnancy. The persistence of symptoms during pregnancy likely relates to challenges with adjusting to changes in appetite, body weight and shape, that competes with their desire to protect their unborn infant from harmful behaviours (Fogarty et al., 2018).

Findings from study one are consistent with previous research, indicating that some women may develop heightened gestational weight concern and excessive uncontrollable eating during pregnancy, having not previously had an ED (Coker & Abraham, 2015; Easter et al., 2013; Swann et al., 2009; Watson et al., 2013). It could be that pregnancy represents a risk period for the onset of ED symptoms as a result of some women struggling to adapt to common pregnancy changes (Bulik et al., 2007). The alternative suggestion is that these women have a history of ED that was not captured or disclosed during the study period, given women who have recovered from a past ED are known to experience difficulties adjusting to pregnancy (Fogarty et al., 2018; Koubaa et al., 2008).

7.3.1.5 Comorbidity in pregnant women with ED

Findings in study two support previous research that pregnant women with current and past ED often experience depression and anxiety during pregnancy (Easter et al., 2015). High levels of comorbid depression and anxiety in ED have been similarly demonstrated in non-pregnant populations (Preti et al., 2009). Further, although history of deliberate self-harm or attempted suicide have not been studied previously in pregnancy, both are known to be associated with ED in the general population, reflecting important risk factors (Keski-Rahkonen & Mustelin, 2016; Udo et al., 2019).

7.3.2 Identification and management of pregnant and postnatal women with ED in maternity and health visiting services

7.3.2.1 Identification of ED

Given the risks associated with maternal ED, it is essential that women with ED are identified and offered monitoring and support in accordance with the clinical guidance (NICE, 2014, 2017). However, study two found that rates of identification of ED in maternity care were extremely poor compared to the numbers identified in the study. Similarly, the majority of women in study three did not consider the midwives and other healthcare professionals involved in their maternity care were

aware of their ED. This is in line with the ED literature, that has consistently demonstrated wide disparities in the prevalence of ED between healthcare records and general population data, with the former frequently reflective only of the more severe cases of ED (Hoek, 2006; Smink et al., 2012).

7.3.2.2 Disclosure of ED

Disclosure to a healthcare professional is known to increase the likelihood of an individual subsequently seeking treatment for their ED (Becker et al., 2005). However, findings in study three indicate that disclosure to healthcare professionals in maternity care was low, with three quarters of women not disclosing and even those most at risk due to active ED symptoms during pregnancy, not being more motivated to disclose. Lack of disclosure and treatment seeking for ED has been frequently reported in the ED literature (Becker et al., 2005; Evans et al., 2011; Hart et al., 2011; Hepworth & Paxton, 2007; Hudson et al., 2007; Swan & Andrews, 2003). Though there are fewer comparable studies, lack of disclosure of ED has been reported by women attending infertility clinics (Freizinger et al., 2010) and among smaller samples of pregnant women and postnatal women (Claydon et al., 2018; Stringer et al., 2010). The present findings relate to findings from general population studies that have demonstrated access to treatment for ED was poor, particularly in those with active ED (Hudson et al., 2007; Preti et al., 2009).

7.3.2.3 Routine enquiry about ED

In the absence of spontaneous disclosure, healthcare professionals need to actively enquire about ED to increase the likelihood of an individual making a positive disclosure about ED (Becker et al., 2005). However, as previously evidenced in research with women and other healthcare professionals (Abraham, 2001; Leddy et al., 2009; Morgan, 1999; Stringer et al., 2010; Supina et al., 2016), findings from studies three and four indicate routine enquiry about ED in maternity and health visiting services is poor. As indicated in study four, Leddy et al (2009) found that

routine enquiry about ED was low among obstetricians and gynaecologists, with many considering screening for ED was not part of their professional remit. Although unlike obstetricians and gynaecologists who only care for women classed with high risk pregnancies, midwives and health visitors are often the primary point of contact antenatally and postnatally, responsible for assessing and monitoring the healthcare needs of women in routine practice.

7.3.2.4 Knowledge and training

Women in study three felt there was a lack of awareness about ED among healthcare professionals in maternity care, particularly on the range of ED and their specific healthcare needs, which impacted on the recognition of ED and appropriate support being offered to women. This corresponds to the findings in study four, which demonstrated inconsistencies in knowledge on ED and related practice due to limited pre or post-registration training opportunities for midwives and health visitors.

Lack of awareness was reported to have impacted on women's engagement with maternity care in a previous study using interviews in pregnant and postnatal women with ED, though among a less diverse sample than the present study (Stringer et al., 2010). The findings are also in line with previous survey studies in other healthcare professionals including GPs and obstetricians, which have cited substantial deficits in knowledge and insufficient training opportunities as barriers to identification (Abraham, 2001; Banas et al., 2013; Boulé & McSherry, 2002; Currin et al., 2009; Jones et al., 2013; Leddy et al., 2009; Morgan, 1999; Rodino et al., 2017; Stringer et al., 2010; Supina et al., 2016; Williams & Leichner, 2006). Women's experiences particularly related to a recent survey of healthcare professionals that indicated poor recognition of BED as a distinct ED had important implications for identification and response in healthcare services of this ED (Supina et al., 2016). In comparison to a previous study by Morgan (1999), study four did not identify any differences in knowledge of ED in relation to level of seniority among clinicians, in some cases it was

the opposite, though mostly related to pre-registration training i.e. prior nursing or psychology undergraduate training.

Universities are responsible for developing their own curriculum as clinical services are for developing trust-specific care pathways and policies, which are intended to be in line with the recommendations from the various regulatory authorities i.e. NICE, NMC and RCM. The lack of coverage in training highlighted in study four likely relates to ED not being stipulated in the core clinical competencies required as part of pre-registration training or post-registration standards for midwives or health visitors in the UK (NMC, 2004, 2009). The study findings suggest the more recent inclusion of ED in some training programmes may relate to growing awareness among those developing new curriculum content rather than those setting the standards. This indicates a poor integration of available guidance in to pre and post-registration training and clinical practice (NICE, 2014, 2017).

7.3.2.5 Stigma

Findings from studies three and four indicated that stigma of ED and mental health more broadly, presented a significant barrier to disclosure of ED in maternity care for women, as well as enquiry of ED by midwives and health visitors. The types of negative and judgemental attitudes experienced by some of the women in study three, were not expressed by any of the healthcare professionals participating in study four. Instead, there was recognition that women would likely be concerned about being judged and of negative consequences following a disclosure, stressing the need to be sensitive to these concerns when asking women about ED or other sensitive topics, which made some feel anxious with not wanting to cause any upset.

The findings are in line with the wealth of previous evidence, citing stigma as a barrier to disclosure and treatment-seeking in the wider ED and mental health literature (Ali et al., 2017; Clement et al., 2015; Hepworth & Paxton, 2007; Swan & Andrews, 2003).

Similarly with research exploring the experiences of women with mental illness in the perinatal period, with fear of being stigmatised and discredited as a mother, as well as experiences of actualised stigma for a minority, being a significant barrier to disclosure (Edwards & Timmons, 2005; Kingston et al., 2015; Moore et al., 2016; Nagle & Farrelly, 2018; Viveiros & Darling, 2018; Yapp et al., 2019). The findings relate to research by Stringer et al (2010), indicating that a perceived expectation on women to be positive during pregnancy made some feel shameful and reluctant to engage with healthcare professionals involved in their maternity care. These previous studies though have been from the perspective of the individual, rather than from the healthcare professional, which is useful to identify commonalities and implications on enquiry and the process of identification of ED more broadly.

The concerns expressed by individuals are understandable given the negative and stigmatising attitudes that are common within society towards individuals with mental illnesses. Evidence suggests individuals with ED are perceived as being more responsible and in control of their ED behaviours compared to other conditions (Crisp, 2005; Ebneter & Latner, 2013; Roehrig & McLean, 2010), and so are potentially considered less in need of support from healthcare services. Individuals who are obese and have BED can be particularly susceptible to increasingly negative attitudes as they are considered more personally responsible for their condition than other ED (Ebneter & Latner, 2013; Puhl & Suh, 2015; Reas, 2017). This is due to addition of weight stigma, which is well recognised and in some respects, reinforced by the more pervasive anti-obesity campaigns (Puhl et al., 2013). This is in line with the findings in study three that indicated there was particularly poor recognition and understanding of ED in pregnant women who were overweight or obese. The attention to excessive maternal weight reported by women likely relates to the key priorities in NHS maternity services to address maternal obesity (National Institute for Health and Care Excellence, 2010). Although there is an understandable public health need to address obesity, the findings indicate a lack of consideration for possible ED. There has been

a lack of previous research exploring the role of stigma in disclosure among pregnant women who are overweight or obese and have ED, although it is likely the stigma that pregnant women with ED experience and fear will be compounded by their weight status, which in turn can impact on their engagement with services.

7.3.2.6 Lack of time and familiarity

Findings from studies three and four were consistent, with women and healthcare professionals describing a lack of familiarity and time in routine care contacts to discuss ED in a sensitive way that would encourage disclosure and provide opportunity for ongoing monitoring and support. Midwives advocated the potential benefit of a 'case loading' model of midwifery care. This model of midwifery care recognises the relational aspects of healthcare and is considered to promote better continuity of carer in pregnancy as advocated in UK policy and guidance (Department of Health, 2007; NHS England, 2016, 2017). The model has been associated with better short-term maternal and infant outcomes, patient satisfaction, and cost effectiveness in comparison to other continuity models of maternity care (Forster et al., 2016; Sandall et al., 2016; Tracy et al., 2013). Although, only five small trials included in the Cochrane review were based in the UK, where women in control arms would have received continuity of care as part of standard care. As the most recent of the UK trials was published in 2003 (Sandall et al., 2016), care has to be taken when assuming any benefit from such models of care for women today, especially with such limited evidence of any longer-term benefits for women's health.

7.3.2.7 Communication in healthcare services

Findings from study four indicated poor communication between healthcare professionals was another barrier to identification and support of pregnant and postnatal women with ED. It was felt that methods of relaying concern about women were complicated by the need to balance communication of crucial information with respecting the sensitive and confidential nature of disclosure. Communication

between clinicians about women's care needs is clearly being affected by the increasingly fragmented and poorly integrated primary care services, including maternity and health visiting services (Watton, 2013). This is particularly challenging for health visitors given changes in funding and guidance relating to their role (Lowenhoff, Appleton, Davison-Fischer, & Pike, 2017).

7.3.2.8 Ambivalence about accessing support

The relationship between disclosure and active ED symptoms during pregnancy was complex as indicated in study three, with some women being ambivalent about accessing support driven by a preference to self-manage their ED. This sense of ambivalence has similarly been reported in a study of parous and nonparous women with ED, having been cited as a barrier to treatment by one woman in the sample (Claydon et al., 2018). Exploratory research on barriers to treatment of ED in non-attendees also reported on the implications of ambivalence on engagement with healthcare services (Leavey et al., 2011). Leavey et al (2011) suggested individuals, particularly those with a long history of ED, may feel ambivalent about accessing support for their ED as it would require them to challenge and change their current coping mechanism for managing their anxiety, that would likely be so engrained in their everyday functioning that the prospective of doing so would be immensely challenging.

7.3.2.9 Poor recognition of the need to access support

Finally, the findings in study three indicated poor personal awareness of ED and relevance to maternity care contributed to some women not recognising the need to disclosure their ED to a healthcare professional. Ali et al (2017) recently reported on findings from a systematic review that similarly identified poor personal awareness as a barrier to treatment-seeking. Several campaigns have been launched in the UK to raise public awareness and reduce stigma about mental health, such as the 'Time to Change' campaign (Time to Change Ltd., 2007). Similarly, several initiatives have

been launched to address perinatal mental health awareness specifically, such as the 'Better Births' initiative (Royal College of Midwives, 2016). However, ED have been largely neglected in these mental health awareness campaigns, which likely contributes to poor public awareness of the symptoms and signs of ED.

7.4 Implications for clinical practice

The findings in this programme of research have indicated several potential implications for clinical practice. These have been highlighted in the individual study chapters and are outlined below.

Studies one and three indicate that women with ED often continue to struggle with binge eating during pregnancy. It is essential that healthcare professionals offer women with ED appropriate advice and support with managing their eating during pregnancy, including educating women on their nutritional needs during and following pregnancy. As indicated in this research, it is important to recognise though that weight stigma is likely to impact on disclosure and discussions about ED. This highlights the need for much greater awareness on the potential of ED among pregnant and postnatal women who are overweight or obese. These implications are of relevance from an ED perspective but also for current policy and practice aimed at addressing rising maternal obesity (National Institute for Health and Care Excellence, 2006, 2010; Public Health England, 2019).

Findings in study one indicates that for some women, pregnancy may trigger symptoms of ED, although this needs further investigation, this remains important to inform what and how routine prenatal care could be implemented to help women prepare for common pregnancy changes to body weight and shape, and appetite. Among women with a history of ED, high rates of remission during pregnancy found in study two indicates that the pre-conception period could be an opportune time for clinicians to identify women in remission to assess current healthcare needs and

provide information about pregnancy planning to promote optimal physical and mental health prior to pregnancy commencement.

ED are often comorbid with other psychiatric conditions as indicated in study two. This has important implications for history taking at the first routine contact with healthcare services in pregnancy and the postnatal period that are intended to ascertain a woman's current healthcare needs including her mental health status. Healthcare professionals should be mindful of the potential for these associated outcomes when routinely enquiring about current and past mental illness at these contacts. Furthermore, findings in study two suggested that low and high pre-pregnancy BMI were more common among women with active ED during pregnancy. Although sample size limited the ability to make reliable recommendations, this could also have important implications for current routine practice. Pre-pregnancy BMI is not routinely collected in maternity care, instead weight status is determined by BMI at the first contact with services when women are already pregnant (Barber, Rankin, & Heslehurst, 2017). This is particularly relevant for recognising women with AN who may gain weight during the early stages of pregnancy so would not be identified as underweight at their first contact with maternity services.

Findings in study two indicates ED are not often recognised by midwives and as found in the qualitative investigations, there are several explanations for this, one of which is lack of enquiry about ED in maternity and health visiting services. It is essential that healthcare professionals routinely enquire about current and past ED in pregnant and postnatal women to ensure that appropriate advice and support can be provided.

Findings in studies three and four indicate a lack of consistent training on ED for midwives and health visitors. This has significant implications for practice as it is essential these healthcare professionals have sufficient and applicable knowledge to effectively identify and support pregnant and postnatal women with ED. Recent

training initiatives have sought to raise awareness about maternal ED (Bye, Walker, et al., 2018; Easter et al., 2018). However, opportunities remain largely limited as training developments are challenging to implement considering midwives and health visitors are under increasing pressure to support pregnant women with a multitude of complex health needs, and as such there are many competing demands on the course content of which ED may be considered less of a priority.

Findings in studies three and four highlight the lack of capacity in maternity and health visiting services. This is a consistent concern across healthcare services in the current financial climate, which has had important implications particularly for health visiting (Institute of Health Visiting, 2019; Lowenhoff et al., 2017) and warrants addressing.

Finally, in a universal healthcare system such as the NHS where regular routine contacts in pregnancy and the postnatal period are provided, clinical recommendations to promote effective identification and management of pregnant and postnatal women with ED need to be implemented to reduce the risk of adverse outcomes. However, findings in this programme of research indicate use of these recommendations in practice is likely limited and warrants exploration and improvement to the current strategies to guidance implementation.

7.5 Implications for public initiatives

Findings in this programme of research indicates new public initiatives are needed to raise public awareness about ED and address the different types of stigma that can hinder disclosure and help-seeking among pregnant and postnatal women with ED. In the UK, several campaigns have been launched to raise public awareness and reduce the stigma in society towards mental illness (Time to Change Ltd., 2007). Similarly, several initiatives have sought to raise awareness about perinatal mental illness specifically (Royal College of Midwives, 2016). However, ED continue to be

largely neglected in these types of activities. Likewise, BED along with the broader issue of weight stigma, is often overlooked within national anti-obesity and healthy eating campaigns (Public Health England, 2019). Only by raising the profile of ED and reducing stigma will disclosure and engagement with healthcare professionals be encouraged among pregnant and postnatal women with ED.

7.6 Implications for future research

The findings in this programme of research have indicated several potential areas for future research. These have been highlighted in the individual study chapters and are outlined below.

The discrepancies between studies one and two in reported prevalence of ED among pregnant women warrants further research with larger cohorts of pregnant women using more robust sampling techniques and diagnostic tools. The findings highlighted particular challenges with determining diagnoses of ED in pregnant women, including difficulties distinguishing typical changes in appetite during pregnancy from objective binge eating episodes, as well as the implications of stigma on disclosure of ED. It is important for researchers to co-design and validate an appropriate instrument for determining full and subthreshold ED in accordance with DSM-5 (APA, 2013) diagnostic criteria, for use in pregnant women. Furthermore, as discussed previously, future prevalence studies need to recognise and address the potential impact of stigma on disclosure in research, i.e. by ensuring recruitment approaches are acceptable to pregnant women with ED.

Findings in studies one and three indicate that women with ED often continue to struggle with binge eating during pregnancy, with suggestions this may relate to a lack of awareness about the implications on pregnancy outcomes and on their nutritional needs during the perinatal period. Given previous research has been predominantly in women with AN and BN, more research is needed to better

understand the changes in symptoms during pregnancy among women with a wider range of ED, specifically BED and OSFED.

Findings in study one indicate that for some women, pregnancy may trigger symptoms of ED. Although this could be misleading as it was not possible to ascertain whether these women were susceptible to relapsing during pregnancy following a prior history of ED that was not captured in the study period. A prospective observational study would be most appropriate to explore this further and ascertain whether some women previously unaffected by ED, have heightened risk of developing ED symptoms as a result of common pregnancy changes.

Findings in study two indicate an association between ED and history of deliberate self-harm or attempted suicide in pregnant women. Only information on lifetime history was available though, so it was not possible to make a distinction between past and current behaviours. Future research is needed to replicate and expand on the findings in larger cohorts of pregnant women, reporting current and past behaviours separately. Findings also suggest that low and high pre-pregnancy BMI were more common among women with active ED during pregnancy. Although the small sample size of women with current ED limited the ability to compare outcomes between the ED types and make reliable conclusions. Future research should aim to replicate this finding in larger cohorts of pregnant women with active ED.

As with previous evidence in other healthcare professionals, studies three and four both indicate a lack of training available for midwives and health visitors. Future research is needed to assess course content in training programmes across the UK to determine more conclusively what the current provision on ED is in the UK. This would inform future knowledge-translation research to develop training on ED for midwives and health visitors that would meet their professional needs.

Findings in this programme of research indicate weight stigma is likely to impact on disclosure of ED to a healthcare professional among pregnant women. However, this was not directly addressed in the present research and there is a lack of previous research with this focus. Future research is needed to further explore the implications of weight stigma on disclosure of ED among pregnant women who are overweight or obese. This would be useful to inform how strategies to address maternal obesity need to be adapted to recognise and address potential ED.

Several significant barriers to identifying and supporting women with ED in maternity and health visiting services were highlighted in studies three and four, many of which were overlapping whilst others reflected the particular group perspective. Future research could aim to expand on these findings by applying systems theory and related framework (Anderson, 2016; Ferlie & Shortell, 2001; Von Bertalanffy, 1968) to engagements with a wider range of stakeholders involved in a woman's care pathway, including GPs and specialists in perinatal mental health and ED, as well as policy and funding advisors, to generate comprehensive strategies for implementing change in clinical training and practice across the NHS.

7.7 Strengths and limitations

Specific details on the strengths and limitations of each of the four studies were discussed in the individual study chapters. Therefore, this section provides a general discussion of the overall strengths and limitations of this research programme.

7.7.1 Multi-method research approach

The main strength of this programme of research was the use of a multi-method research approach, which enabled the use of both quantitative and mixed methods, according to what was most appropriate to address the specific aims in each of the four studies. Quantitative methods were most appropriate for studies one and two

to generate numerical descriptions of ED prevalence among relatively large population samples of pregnant women. This enabled comparison of the findings with the previous evidence, as well as between the two studies where they converge (i.e. active ED during pregnancy), to consider potential explanations for any consistencies and discrepancies. Alternatively, mixed method approaches were most appropriate for studies three and four that sought to describe and explore the experiences and challenges of identifying and supporting women with ED in maternity and health visiting services. These studies generated a considerable amount of numerical data from larger samples of women and healthcare professionals than would have been feasible using qualitative methods in isolation. This was complemented by narrative data to provide potential explanations and expand on the numerical data, offering greater insight on the perspectives of women and healthcare professionals. The use of different mixed methods with distinct weaknesses that offset one another in studies three and four, enhances the reliability of the themes that were found to be common among women and healthcare professionals. Overall, the combination of these different approaches in this programme of research was beneficial for providing practical recommendations for clinical practice, public initiatives and future research that can be considered representative of wider populations.

There were some limitations with using a multi-method research approach that relate to the potential incompatibilities with synthesising the findings generated from different methods. The methods used in studies one and two were not directly comparable to one another as they utilised data from different sources. This limited the ability to compare the findings beyond the prevalence of active ED during pregnancy. A proportion of the total sample in study three provided narrative descriptions of their experiences in maternity care, therefore interpretations based on their experiences may not be representative of experiences among the whole sample. Similarly, whilst findings from the focus groups in study four may help to

understand knowledge deficits and attitudes among the wider sample of healthcare professionals, the samples are not necessarily representative of the same population. Furthermore, although the qualitative findings from studies three and four indicate a likely explanation for the disparities in study two of women identified with ED in research compared to clinically, these samples are not representative of the same populations.

7.7.2 Samples

An important strength of this programme of research was the recruitment of relatively large samples of women and healthcare professionals across the four studies. Studies one, two and three recruited relatively large population samples of pregnant and postnatal women, which enhances the ability to generalise the findings to other similar populations. Considering poor rates of disclosure and treatment seeking among individuals with ED, it is essential to understand the prevalence of ED among pregnant women in the community and how best to identify these women and support their needs specifically. Though it is important to acknowledge that clinical samples are likely to have different experiences with accessing support that also warrant addressing.

Considering studies one and two were conducted in the same inner-city NHS maternity service in South-East London, although there was minimal sociodemographic information available from study one, it is highly likely that both samples were representative of the local population and findings can be generalised to similar populations in the UK. The sample in study three was highly heterogeneous, comprising of pregnant and postnatal women from regions across the UK and self-reporting the full spectrum of ED. The common themes among the women in the sample increases the likelihood that their perspectives are representative of other pregnant and postnatal women with ED in the UK.

Study four recruited a large sample of student and qualified midwives and health visitors from several universities and NHS trusts in the South of England. Their perspectives are likely representative of the barriers in maternity and health visiting services more widely but certainly within their catchment areas. The ability to generalise the findings and propose recommendations that will apply consistently across the UK may be limited though due to the variations in healthcare across the UK.

The use of stratified random sampling in study two to recruit a sample of pregnant women that were representative of the wider population of women accessing antenatal care, enhances the generalisability of the findings to similar populations. Non-random sampling methods in the other three studies though may have resulted in the recruitment of biased samples for these particular studies. Researcher bias is likely not a concern in study one and the first phase of study four as all women and healthcare professionals at the particular settings at the time of the researcher attending, were approached to participate. However, given participants self-selected to take part in study three and the second phase of study four, this may have limited the representativeness of the resulting samples. It is possible that women who had particular experiences in maternity care that they related to their ED, may have been more inclined to participate in study three. Similarly, healthcare professionals with more experience of or interest in ED than their colleagues may have been more likely to participate in the second phase of study four.

Despite the potential limitations of using non-probability sampling methods, they were more cost and time efficient than probability sampling would have been, and they provided women participating in studies one and three with greater anonymity which is important considering the issues around stigma and disclosure of ED. Furthermore, they were appropriate for studies three and four whereby the primary

focus was to understand the complexities of identifying and supporting women with ED rather than to generate generalisable data.

7.7.3 Eating disorder classification

Integrating the findings from studies one, two and three is somewhat limited given they each used different methods to classify ED. However, there is not yet a gold standard diagnostic tool for determining ED diagnoses according to DSM-5 (APA, 2013) diagnostic criteria. The majority of the validated instruments for assessing ED were not designed to assess DSM-5 (APA, 2013) diagnostic criteria and do not include sub-threshold diagnoses of ED. Of relevance for antenatal research specifically, there is not yet an instrument for assessing ED that been validated for use in antenatal samples. Therefore, researchers are either required to adapt existing instruments as was done with the EDDS (Stice et al., 2000) and the SCID (First et al., 2002) in studies one and two, respectively, or use self-report items as was done in study three.

The EDDS was designed to determine diagnoses of AN, BN and BED, in accordance with DSM-IV (APA, 1994) diagnostic criteria, and has been validated in non-pregnant populations. Whereas, it was adapted for study one to determine diagnoses of ED before and during pregnancy in a sample of pregnant women, in accordance with DSM-5 (APA, 2013) diagnostic criteria. The DSM-5 version of the EDDS was not available at the time of the study though and remains under development, having not yet been validated. Furthermore, previous studies have made similar adaptations to the time frames specified in the EDDS (Linville et al., 2015; Micali et al., 2017; Neyland & Bardone-Cone, 2019) and to establish diagnoses consistent with DSM-5 (APA, 2013) diagnostic criteria (Flament et al., 2015; Forney et al., 2017; Grillot & Keel, 2018; McElroy et al., 2016; Micali et al., 2017; Neyland & Bardone-Cone, 2019); and evidence has demonstrated that these forms of adaptations did not compromise the validity of the EDDS (Micali et al., 2017).

Similarly, the SCID was designed to determine current and past diagnoses of mental illnesses in accordance with DSM-IV and DSM-IV-TR (American Psychiatric Association, 1994, 2000) diagnostic criteria and is considered one of the "gold standard" instruments for establishing ED diagnoses (Lobbestael et al., 2011; Zanarini et al., 2000). Whereas it was used in study two to determine diagnoses of lifetime and current ED in a sample of pregnant women, in accordance with DSM-5 (APA, 2013) diagnostic criteria. The DSM-5 version of the SCID was not available at the time of the study and in any case, it is yet to be as extensively validated as the previous version. Furthermore, although the SCID refers to DSM-IV (APA, 1994), and DSM-IV-TR (APA, 2000), the ED module includes sections on AN, BN and EDNOS BED so it is possible to determine lifetime and current diagnoses of all ED categories in accordance with DSM-5 (APA, 2013) diagnostic criteria without the need for alterations.

Alternatively, simple self-report items were used in study three to determine group identity of lifetime ED among respondents to the online survey. This method was appropriate given the focus of the survey and to minimise participant burden, as well as the lack of a validated antenatal screening tool. Although self-report may not be considered the most reliable method for identifying individuals with lifetime ED, evidence suggests it is comparable to other commonly used instruments (Keski-Rahkonen et al., 2006; Micali et al., 2012).

7.8 Concluding comments

In conclusion, the findings in this programme of research indicate a significant proportion of pregnant women have had ED. Yet women will often be poorly identified and receive inadequate support in maternity and health visiting services due to lack of training and related practice, as well as stigma, limited capacity and poor continuity of carer. Implications for research and practice are discussed, with

the intention of improving identification and support of pregnant and postnatal women with ED to promote optimal maternal and infant outcomes.

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Appendix

Appendix I Study 1: Adapted version of the EDDS

KING'S College LONDON
University of London

Nutrition, Eating and Stress in Pregnancy (NEST-p)
EATING SCREEN

We are studying the effect of stress and eating during your pregnancy and we would be grateful if you could fill in this questionnaire. Please be aware that this is voluntary and will not affect your medical care or legal rights.

	Not at all		Slightly		Moderately		Extremely
1. Have you **ever** felt fat?	0	1	2	3	4	5	6
2. Have you **ever** had a definite fear that you might gain weight or become fat?	0	1	2	3	4	5	6
What about within the **last 3 months**?	0	1	2	3	4	5	6
What about within the **last 6 months**?	0	1	2	3	4	5	6
3. Has your weight **ever** influenced how you think about (judge) yourself as a person?	0	1	2	3	4	5	6
What about within the **last 3 months**?	0	1	2	3	4	5	6
What about within the **last 6 months**?	0	1	2	3	4	5	6
4. Has your shape ever influenced how you think about (judge) yourself as a person?	0	1	2	3	4	5	6
What about within the **last 3 months**?	0	1	2	3	4	5	6
What about within the **last 6 months**?	0	1	2	3	4	5	6

5. **Have there ever** been times when you felt you have eaten what other people would regard as an unusually large amount of food (e.g., a tub of ice cream) given the circumstances? **YES NO**

   What about within the **last 3 months**? **YES NO**

   What about within the **last 6 months**? **YES NO**

6. **During the times when you ate an unusually large amount of food**, did you experience a loss of control (or feel you couldn't stop eating or control what how much you were eating)? **YES NO**

   What about within the **last 3 months**? **YES NO**

   What about within the **last 6 months**? **YES NO**

you have answered yes <u>to both question 5 AND 6</u> please answer questions 7-14 (If no go to Q15) →

During these episodes of overeating and loss of control…

7. How many **<u>DAYS per week</u>** on average did you eat an unusually large amount of food and experience a loss of control? **0 1 2 3 4 5 6 7**

8. How many **<u>TIMES per week</u>** on average did you eat an unusually large amount of food and experience a loss of control? **0 1 2 3 4 5 6 7 8 9 10 11 12 13 14**

9. Did you eat much more rapidly than normal? **YES NO**
10. Did you eat until you felt uncomfortably full? **YES NO**
11. Did you eat large amounts of food when you didn't feel physically hungry? **YES NO**
12. Did you eat alone because you were embarrassed by how much you were eating? **YES NO**
13. Feel disgusted with yourself, depressed, or very guilty after overeating? **YES NO**
14. Feel very upset about your uncontrollable overeating or resulting weight gain? **YES NO**

15a. Have you ever made yourself vomit to prevent weight gain or counteract the effects of eating? **YES NO**

15b. **If yes…When? LAST 3 MONTHS** ☐ **LAST 6 MONTHS** ☐ **MORE THAN A YEAR AGO** ☐

15c. How many **times per week** on average did you make yourself vomit to prevent weight gain or counteract the effects effects of eating?

0 1 2 3 4 5 6 7 8 9 10 11 12 13 14

16a. Have you ever used laxatives or diuretics to prevent weight gain or counteract the effects of eating? **YES NO**

16b. **If yes…When? LAST 3 MONTHS** ☐ **LAST 6 MONTHS** ☐ **MORE THAN A YEAR AGO** ☐

16c. How many **times per week** on average have you used laxatives or diuretics to prevent weight gain or counteract the effects of eating?

0 1 2 3 4 5 6 7 8 9 10 11 12 13 14

17a. Have you ever fasted (skipped at least 2 meals in a row) to prevent weight gain or counteract the effect of eating? **YES NO**

17b. **If yes…When? LAST 3 MONTHS** ☐ **LAST 6 MONTHS** ☐ **MORE THAN A YEAR AGO** ☐

17c. How many **times per week** on average did you fast (skip at least 2 meals in a row) to prevent weight gain or counteract the effects of eating?

0 1 2 3 4 5 6 7 8 9 10 11 12 13 14

18a. Have you ever engaged in excessive exercise specifically to counteract the effects of overeating episodes? **YES NO**

18b. **If yes…When? LAST 3 MONTHS** ☐ **LAST 6 MONTHS** ☐ **MORE THAN A YEAR AGO** ☐

18c. How many **times per week** on average have you engaged in excessive exercise specifically to counteract the effects of overeating episodes?

0 1 2 3 4 5 6 7 8 9 10 11 12 13 14

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19. How much do you weigh? If uncertain, please give your best estimate. _____**stones ____lbs / _____ kg**

20. How tall are you? **_____ft _____in / ____cm**

21. What is your age? .....

22. How many weeks pregnant are you?.....

23. When was the last day of your last menstrual period prior to becoming pregnant?

24. Were you taking the contraceptive pill/breastfeeding in the 6 months to becoming pregnant? **YES NO**

If no, did you miss any periods in the last 6 months before becoming pregnant? **YES NO**

If yes, how many? .....

25. Was your pregnancy planned? **YES NO**

Appendix II Study 1: Adapted diagnostic algorithm for the EDDS

AN was determined according to two definitions. Firstly, AN was diagnosed if (1) classified as underweight, (BMI <18.5 kg/m^2),; (2) intense fear of weight gain or becoming fat as determined by a response of four or more on item two; and (3) undue influence of body weight or shape on self-evaluation as determined by a response of four or more on either item three or four. Secondly, AN was diagnosed if (1) classified as underweight (BMI <18.5 kg/m2), as described above; (2) regular use of inappropriate compensatory behaviours as determined by a response of one or more on items 15c, 16c, 17c or 18c; and (3) undue influence of body weight or shape on self-evaluation as determined by a response of four or more on either item three or four.

BN was defined as: (1) regular binge eating accompanied by a perceived loss of control as determined by a response of "yes" to items five and six, and a response of one or more on item eight; (2) regular use of inappropriate compensatory behaviours as determined by a response of one or more on items 15c, 16c, 17c or 18c; and (3) undue influence of body weight or shape on self-evaluation as determined by a response of four or more on either item three or four.

BED was defined as: (1) regular binge eating accompanied by a perceived loss of control as determined by a response of "yes" to items five and six, and a response of one or more on item eight; (2) endorsement of at least three associated features as determined by response of "yes" to at least three of items 9, 10, 11, 12, and 13; (3) marked distress about binge eating as determined by a response of "yes" to item 14; and (4) absent of inappropriate compensatory behaviours as determined by no response for the time frame on items 15b, 16b, 17b or 18b. Of note, this algorithm was supplemented to prevent misclassification of underweight women who met all the criteria for BED but not AN.

Purging disorder was defined as: (1) undue influence of body weight or shape on self-evaluation as determined by a response of four or more on either item three or four; (2) absent of binge eating accompanied by a perceived loss of control, irrespective of regularity, as determined by a response of “no” to items five and six; and (3) regular use of purging behaviours (i.e. self-induced vomiting and misuse of laxatives or diuretics) determined by a response of one or more on items 15c and 16c.

Broadly defined OSFED was determined according to two definitions: Firstly, (1) undue influence of body weight or shape on self-evaluation as determined by a response of four or more on either item three or four; and (2) binge eating accompanied by a perceived loss of control, irrespective of regularity, as determined by a response of “yes” to items five and six. Secondly, (1) undue influence of body weight or shape on self-evaluation as determined by a response of four or more on either item three or four; and (2) use of inappropriate compensatory behaviours, irrespective of regularity, as determined by a response for the time frame on items 15b, 16b, 17b or 18b.

Appendix III Study 2: Participant information sheet and consent form

KING'S College LONDON Founded 1829 University of London

King's College Hospital NHS
NHS Foundation Trust

Participant Information Sheet

Title of Project: Well-being in pregnancy in an inner city maternity service

We would like to invite you to take part in a study about well-being during pregnancy and how health services can improve well-being in pregnant women. We will provide an interpreter if you need help speaking English. Please take time to consider the following information and discuss it with other people if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you would like to take part.

What is the purpose of the study? It is not currently clear how midwives can best assess emotional well-being in pregnancy. This study is part of a larger research programme looking at well-being of women during and after pregnancy.

Do I have to take part? No. It is up to you to decide whether or not to take part. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to leave the study at any time and without giving a reason. This will not affect the care you receive either now or at any time in the future.

What will happen to me if I take part? When you come in for your antenatal booking we will ask you to take part in an interview about your emotional well-being. The interview will take about 40-55 minutes. There are no right or wrong answers to any of the questions. If you are not able to complete the interview at your antenatal booking, we will aim to complete the interview within the next two weeks, at a convenient time and location for you. When you are around 28 weeks pregnant and at three months post-delivery, we will carry out an interview and/or post you a questionnaire. Alongside the three month post-delivery research interview, we would like to make a short video with you and your baby playing as you normally would. This video would last for no longer than 5-10 minutes and is used to observe mother-infant interactions. You can choose not to agree to this specific aspect of the study while still participating in the interview.

Expenses and payments You will receive a £15 Love2Shop voucher, to thank you for taking part in the research. We will also reimburse any travel expenses.

Will my information be confidential? The information you provide will be confidential, in accordance with the Data Protection Act 1998, and any identifiable details will be stored separately from the answers you give during the interview. Only members of the research team will have access to your confidential information, which will only be used for the

purposes of this study. The only exception to this is if you tell us information which suggests a risk of serious danger to yourself or others. If this happens, we will inform the staff involved in your care. Video-tapes will be securely stored after the interview and will remain confidential.

What are the possible advantages of taking part? We cannot promise that the study will help you but your information will help to increase the understanding of how health services can improve well-being in pregnant women. We will offer everybody information about sources of help and support.

What are the possible disadvantages of taking part? We will ask you questions about your well-being which you may find personal. You can take time in answering and do not have to answer questions that you do not want to. You can discuss any concerns at the end of the interview and we will ask if you would like your midwife to be told, so that they can provide further support.

What if there is a problem? If you have any concerns about the study, you should ask to speak to the researchers, who will do their best to answer your questions (Telephone: [redacted]). If you are unhappy about the research and would like to make a formal complaint, you can do this through the NHS Complaint Procedure. Details are available from the South London and Maudsley NHS Foundation Trust.

What will happen to the results of the study? The results of this study are likely to be published as a report and as an academic publication. We will not use your name or details that could identify you in any publication. Copies of all publications will be available from the researchers.

Who is funding and organising the study? The study is funded and commissioned by the National Institute for Health Research. King's College London is organising the study.

Who has reviewed the study? All research in the NHS is looked at by an independent group of people called a Research Ethics Committee, to protect your safety, rights, well-being and dignity. This study has received favourable opinion by London Camberwell St. Giles NHS Research Ethics Committee (reference number: 14/LO/0075).

Contact for further information: Dr Kylee Trevillion (Programme Manager), PO31 Institute of Psychiatry, De Crespigny Park, London, SE5 8AF. Email: [redacted] Telephone: [redacted]

Thank you very much for reading this information sheet.

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University of London

King's College Hospital NHS
NHS Foundation Trust

Study number:
Participant identification number:

CONSENT FORM
Title of Project: Well-being in pregnancy in an inner city maternity service
Chief Investigator: Louise M. Howard

	Please initial box
1. I confirm that I have read and understood the Participant Information Sheet v4 17 07 15 for the above study. I have had the opportunity to think about the information, ask questions about the study, and have had my questions answered.	☐
2. I understand that taking part in the study is voluntary and that I can leave at any time, without giving any reason, without my medical care or legal rights being affected.	☐
3. I agree to take part in this study.	☐
4. I give permission for researchers to have access to my medical records.	☐
5. I agree to be contacted by the researchers about ethically approved related studies.	☐
6. I agree to parts of the interview being recorded for quality control and for analysis of discussions about experiences at antenatal booking. Recordings will be anonymised and stored securely. Original copies of the recordings will be destroyed securely at the end of the study	☐
7. I agree to my midwife being informed of my participation in this study.	☐
8. I would like to be sent a summary of the research findings upon completion of the study.	☐
9. I agree to the video-taped play interactions with me and my infant	☐

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

When completed: one copy for participants, one copy for researcher site file.

Appendix IV Study 2: Research interview pack

COVER SHEET FOR WENDY RESEARCH INTERVIEW ED ☐

Date of Research Interview:			
Whooley Status P/N:		**Team type**	
Researcher @ Interview Initials:			
Participant ID (to be assigned at data upload):			
MACRO PIN **[to be assigned at data upload]:**			
		DOB:	Initials:

iPad offered?		
Yes	**No**	**Reason:** Ipad not available ____ No WiFi access ____ Unable to read English ____ Other_____
Accepted?		
Yes	**No**	**Reason:** Declined IPad ____ Unable to read English ____ Other_____
Enter last 3 digits of hospital no:		

Consent sought for digital tape recording of interview?		
Yes	**No**	**Reason:**
Consent Given?		
Yes	**No**	**Reason:**

Gestation at Booking	Due date by LMP	Due date by Ultrasound Scan	Date of Delivery

*LMP = Last Menstrual Period

Whooley Status at Booking		
Down or depressed mood?	Loss of interest?	Help wanted?

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PART 1: BACKGROUND AND DEMOGRAPHIC INFORMATION						
Participant Study ID:						
1	**Do you need an interpreter?**	☐ Yes ☐ No				
2	**What is your first language?**	☐ English ☐ Other				
3	**How old are you?**	☐ 16-19 years ☐ 20-24 years ☐ 25-29 years ☐ 30-34 years ☐ 35-39 years ☐ 40-44 years ☐ 45-49 years ☐ 50+				
4a	**How do you describe the ethnic group to which you belong?**	*White*	*Black African/Caribbean or Black British*	*Asian / Asian British*	*Mixed / Multiple ethnic groups*	*Other Ethnic Groups*
		☐ English / Welsh / Scottish / Northern Irish / British ☐ Irish ☐ Gypsy or Traveller ☐ Any white other (describe) _____ _____	☐ Black British ☐ Black Caribbean ☐ Black African ☐ Any Black other (describe) _____ _____ _____ _____	☐ Asian / Asian British Indian ☐ Asian / Asian British Pakistani ☐ Asian / Asian British Bangladeshi ☐ Asian / Asian British Chinese ☐ Any other Asian (describe) _____ _____ _____ _____	☐ White and Black Caribbean ☐ White and Black African ☐ White and Asian ☐ Any other mixed / multiple ethnic (describe) _____ _____	☐ Arab ☐ Any other ethnic group (specify in question 5b)
4b	**Any other ethnic group (specify):** _____					

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5	**What is your country of birth?**	☐ UK ☐ Northern Europe *(i.e. Åland Islands, Channel Islands, Denmark, Estonia, Faeroe Islands, Finland, Guernsey, Iceland, Ireland, Isle of Man, Jersey, Latvia, Lithuania, Norway, Sark, Svalbard and Jan Mayen Islands, Sweden)* ☐ Eastern Europe *(i.e. Belarus, Bulgaria, Czech Republic, Hungary, Poland, Republic of Moldova, Romania, Russian Federation, Slovakia, Ukraine)* ☐ Southern Europe *(i.e. Albania, Andorra, Bosnia and Herzegovina, Croatia, Gibraltar, Greece, Holy See, Italy, Malta, Montenegro, Portugal, San Marino, Serbia, Slovenia, Spain, The former Yugoslav Republic of Macedonia, Yugoslavia)* ☐ Western Europe *(i.e. Austria, Belgium, France, Germany, Liechtenstein, Luxembourg, Monaco, Netherlands, Switzerland)* ☐ Eastern Africa *(i.e. Burundi, Comoros, Djibouti, Eritrea, Ethiopia, Kenya, Madagascar, Malawi, Mauritius, Mayotte, Mozambique, Réunion, Rwanda, Seychelles, Somalia, South Sudan, Uganda, United Republic of Tanzania, Zambia, Zimbabwe)* ☐ Middle Africa *(i.e. Angola, Cameroon, Central African Republic, Chad, Congo, Democratic Republic of Congo, Equatorial Guinea, Gabon, Sao Tome and Principe)* ☐ Northern Africa *(i.e. Algeria, Egypt, Libya, Morocco, Sudan, Tunisia, Western Sahara)* ☐ Southern Africa *(i.e. Botswana, Lesotho, Namibia, South Africa, Swaziland)* ☐ Western Africa *(i.e. Benin, Burkina Faso, Cabo Verde, Cote d'Ivoire, Gambia, Ghana, Guinea, Guinea-Bissau, Liberia, Mali, Mauritania, Niger, Nigeria, Saint Helena, Senegal, Sierra Leone, Togo)* ☐ Central Asia *(i.e. Kazakhstan, Kyrgyzstan, Tajikistan, Turkmenistan, Uzbekistan)* ☐ Eastern Asia *(i.e. China, Japan, Mongolia, North Korea, South Korea)* ☐ Southern Asia *(i.e. Afghanistan, Bangladesh, Bhutan, India, Iran, Maldives, Nepal, Pakistan, Sri Lanka)* ☐ South-Eastern Asia *(i.e. Brunei, Cambodia, Indonesia, Lao, Malaysia, Myanmar, Philippines, Singapore, Thailand, Timor-Leste, Vietnam)* ☐ Western Asia *(i.e. Armenia, Azerbaijan, Bahrain, Cyprus, Georgia, Iraq, Israel, Jordan, Kuwait, Lebanon, Oman, Qatar, Saudi Arabia, Palestine, Turkey, UAE, Yemen)* ☐ Northern America ☐ Central America ☐ South America ☐ The Caribbean ☐ Australasia/Oceania
6	**What year did you come to the UK (if applicable)?**	☐ 1961-1970 ☐ 1971-1980 ☐ 1981-1990 ☐ 1991-2000 ☐ 2001-2003 ☐ 2004-2006 ☐ 2007-2009 ☐ 2010-2011 ☐ 2012-2013 ☐ 2014-2015 ☐ 2016
7a	**What is your immigration status?**	☐ UK National ☐ EEA citizen ☐ Indefinite leave to remain ☐ Exceptional leave to remain ☐ Temporary admission ☐ Awaiting initial decision ☐ Appealing initial refusal ☐ Refused asylum ☐ Other (specify in question 8b)
7b	**Other immigration status (specify):** _____	

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8	**What is your highest qualification?**	☐ No formal qualifications ☐ GCSE or equivalent ☐ A-level or equivalent ☐ NVQ level: _____ ☐ BTEC level: ____ ☐ Higher national certificate/Diploma ☐ Bachelors degree ☐ Masters degree ☐ Doctoral degree ☐ Relevant professional training (specify): _____
9a	**What is your employment status?**	☐ Full-time paid work, working ☐ Full-time paid work, on leave ☐ Part-time paid work, working ☐ Part-time paid work, on leave ☐ Voluntary Job ☐ Student (not also employed) ☐ Student (also in employment) ☐ Unemployed ☐ Not working due to looking after the home ☐ Not working due to illness/disability ☐ Other (specify in question 10b)
9b	**Other employment status (specify):** _____	
10	**What is your gross yearly household income?**	☐ £0- £5475 ☐ £5476- £14,999 ☐ £15, 000 – £30, 999 ☐ £31,000 - £45,999 ☐ £46,000 - £60,999 ☐ £61,000-more ☐ would rather not say
11	**What is your relationship status?**	☐ Single ☐ Partner but not cohabiting ☐ Married /Cohabiting ☐ Separated/Divorced/widowed
12a	**Who are you currently living with?**	☐ Alone ☐ Spouse/Partner ☐ Parent(s) ☐ Friends ☐ Other family members ☐ Foster carer(s) ☐ Acquaintance ☐ Other (specify in question 13b)
12b	**Other living status (specify):** _____	
13	**Is this a late booking (over 12wks pregnant)**	Reason for late booking:
14a	**Do you have any living children?**	☐ Yes >> go to question 14b ☐ No >> go to end of questionnaire
14b	**How many children do you have?**	☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6+
14c	**Who are your children currently living with [child one]?**	☐ Alone ☐ With Participant ☐ With a current Spouse/Partner ☐ With an ex-Spouse/Partner ☐ With maternal grandparent(s) ☐ With paternal grandparent(s) ☐ With Other Family Members ☐ With Friends ☐ With Foster Carer(s) ☐ With Adopted Parents ☐ Other (specify in question 14d)

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14d	**Other (specify)**	Specify: _____
14e	**(If applicable), who are your children currently living with [child two]?**	☐ Alone ☐ With Participant ☐ With a current Spouse/Partner ☐ With an ex-Spouse/Partner ☐ With maternal grandparent(s) ☐ With paternal grandparent(s) ☐ With Other Family Members ☐ With Friends ☐ With Foster Carer(s) ☐ With Adopted Parents ☐ Other (specify in question 14f)
14f	**Other (specify)**	Specify: _____
14g	**(If applicable), who are your children currently living with [child three]?**	☐ Alone ☐ With Participant ☐ With a current Spouse/Partner ☐ With an ex-Spouse/Partner ☐ With maternal grandparent(s) ☐ With paternal grandparent(s) ☐ With Other Family Members ☐ With Friends ☐ With Foster Carer(s) ☐ With Adopted Parents ☐ Other (specify in question 14h)
14h	**Other (specify)**	Specify: _____
14i	**(If applicable), who are your children currently living with [child four]?**	☐ Alone ☐ With Participant ☐ With a current Spouse/Partner ☐ With an ex-Spouse/Partner ☐ With maternal grandparent(s) ☐ With paternal grandparent(s) ☐ With Other Family Members ☐ With Friends ☐ With Foster Carer(s) ☐ With Adopted Parents ☐ Other (specify in question 14j):
14j	**Other (specify)**	Specify: _____
14k	**(If applicable), who are your children currently living with [child five]?**	☐ Alone ☐ With Participant ☐ With a current Spouse/Partner ☐ With an ex-Spouse/Partner ☐ With maternal grandparent(s) ☐ With paternal grandparent(s) ☐ With Other Family Members ☐ With Friends ☐ With Foster Carer(s) ☐ With Adopted Parents ☐ Other (specify in question 14l):_____
14l	**Other (specify)**	Specify: _____
14m	**(If applicable), who are your children currently living with [child six]?**	☐ Alone ☐ With Participant ☐ With a current Spouse/Partner ☐ With an ex-Spouse/Partner ☐ With maternal grandparent(s) ☐ With paternal grandparent(s) ☐ With Other Family Members ☐ With Friends ☐ With Foster Carer(s) ☐ With Adopted Parents ☐ Other (specify in question 14n):_____

14n	**Other (specify)**	Specify: _____
14o	**(If applicable), who are your children currently living with [child seven]?**	☐ Alone ☐ With Participant ☐ With a current Spouse/Partner ☐ With an ex-Spouse/Partner ☐ With maternal grandparent(s) ☐ With paternal grandparent(s) ☐ With Other Family Members ☐ With Friends ☐ With Foster Carer(s) ☐ With Adopted Parents ☐ Other (specify in question 14p):_____
14p	**Other (specify)**	Specify: _____

PART 2: SAFEGUARDING CATEGORY			
1	**Do any of your children have a social worker?**	☐ Yes ☐ No	
2	**Has a referral to Social Services been made for this pregnancy?**	☐ Yes ☐ No	
Which of the following apply?			
3a	Child registered as Child in Need ☐ Yes ☐ No	**3b**	How many children: _____
4a	Child on Child Protection Plan ☐ Yes ☐ No	**4b**	How many children: _____
5a	Child currently formally fostered within extended family (agreement with Social Services) ☐ Yes ☐ No	**5b**	How many children: _____
6a	Child currently formally fostered outside of family (agreement with Social Services) ☐ Yes ☐ No	**6b**	How many children: _____
7a	Child in care of local authority e.g. residential home ☐ Yes ☐ No	**7b**	How many children: _____
8a	Child adopted ☐ Yes ☐ No	**8b**	How many children: _____
9a	Child has social worker (UNSURE OF CATEGORY) ☐ Yes ☐ No	**9b**	How many children: _____
10a	Other ☐ Yes >> go to question 11b ☐ No >> go to end of questionnaire	**10b**	Specify (describe): _____ _____ _____
10c	How many children: _____		

PART 3: OBSTETRIC HISTORY FORM *(note: only ask this section if informants did not consent to review of medical records)*		
1	**Was this pregnancy.....**	☐ Planned ☐ Unplanned
2	**Was this pregnancy a result of IVF, or ovarian stimulation?**	☐ Yes ☐ No
3a	**(If already has children), was your child(ren) born at less than 37 weeks gestation?**	☐ Yes >> go to question 4b ☐ No >> go to question 5a
3b	**How many of your child(ren) were born at less than 37 weeks gestation?**	☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6+ >> go to questions 4c-4h
Identify gestational age for all children born <37 weeks:		
4a	**Baby one - gestational age(s):**	☐ Very pre-term (≤33 weeks) ☐ Pre-term (34-36 weeks)
4b	**(If applicable) Baby two - gestational age(s):**	☐ Very pre-term (≤33 weeks) ☐ Pre-term (34-36 weeks)
4c	**(If applicable) Baby three - gestational age(s):**	☐ Very pre-term (≤33 weeks) ☐ Pre-term (34-36 weeks)
4d	**(If applicable) Baby four - gestational age(s):**	☐ Very pre-term (≤33 weeks) ☐ Pre-term (34-36 weeks)
4e	**(If applicable) Baby five - gestational age(s):**	☐ Very pre-term (≤33 weeks) ☐ Pre-term (34-36 weeks)
4f	**(If applicable) Baby six - gestational age(s):**	☐ Very pre-term (≤33 weeks) ☐ Pre-term (34-36 weeks)
4g	**(If applicable) Baby seven - gestational age(s):**	☐ Very pre-term (≤33 weeks) ☐ Pre-term (34-36 weeks)
For all children born at term, specify gestational age for all children:		
5a	**Baby one - gestational age at term:**	☐ Full-term (37-40 weeks) ☐ Overdue (>40 weeks)
5b	**(If applicable) Baby two - gestational age at term:**	☐ Full-term (37-40 weeks) ☐ Overdue (>40 weeks)
5c	**(If applicable) Baby three - gestational age at term:**	☐ Full-term (37-40 weeks) ☐ Overdue (>40 weeks)
5d	**(If applicable) Baby four - gestational age at term:**	☐ Full-term (37-40 weeks) ☐ Overdue (>40 weeks)
5e	**(If applicable) Baby five - gestational age at term:**	☐ Full-term (37-40 weeks) ☐ Overdue (>40 weeks)
5f	**(If applicable) Baby six - gestational age at term:**	☐ Full-term (37-40 weeks) ☐ Overdue (>40 weeks)
5g	**(If applicable) Baby seven - gestational age at term:**	☐ Full-term (37-40 weeks) ☐ Overdue (>40 weeks)
Have you ever had any pregnancies that did not result in a live birth, for example, a pregnancy that.....		

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6a	ended in miscarriage or stillbirth	☐ Yes >> go to question 6b ☐ No >> go to question 7a
6b	How many pregnancies ended this way?	☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6+ >> go to questions 6c – 6i
6c	Baby one - gestational age:	☐ 1st trimester (0-12 weeks) ☐ 2nd trimester (13-27 weeks) ☐ 3rd trimester (28-40+ weeks)
6d	(If applicable) Baby two - gestational age:	☐ 1st trimester (0-12 weeks) ☐ 2nd trimester (13-27 weeks) ☐ 3rd trimester (28-40+ weeks)
6e	(If applicable) Baby three - gestational age:	☐ 1st trimester (0-12 weeks) ☐ 2nd trimester (13-27 weeks) ☐ 3rd trimester (28-40+ weeks)
6f	(If applicable) Baby four - gestational age:	☐ 1st trimester (0-12 weeks) ☐ 2nd trimester (13-27 weeks) ☐ 3rd trimester (28-40+ weeks)
6g	(If applicable) Baby five - gestational age:	☐ 1st trimester (0-12 weeks) ☐ 2nd trimester (13-27 weeks) ☐ 3rd trimester (28-40+ weeks)
6h	(If applicable) Baby six - gestational age:	☐ 1st trimester (0-12 weeks) ☐ 2nd trimester (13-27 weeks) ☐ 3rd trimester (28-40+ weeks)
6i	(If applicable) Baby seven - gestational age:	☐ 1st trimester (0-12 weeks) ☐ 2nd trimester (13-27 weeks) ☐ 3rd trimester (28-40+ weeks)
Have you ever had any pregnancies that did not result in a live birth, for example, a pregnancy that.....		
7a	Any termination of pregnancies?	☐ Yes >> go to question 7b ☐ No >> go to end of questionnaire
7b	How many pregnancies ended this way?	☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6+ >> go to questions 7c – 7i
7c	Baby one - gestational age:	☐ 1st trimester (0-12 weeks) ☐ 2nd trimester (13-27 weeks) ☐ 3rd trimester (28-40+ weeks)

7d	(If applicable) Baby two - gestational age:	☐ 1st trimester (0-12 weeks) ☐ 2nd trimester (13-27 weeks) ☐ 3rd trimester (28-40+ weeks)
7e	(If applicable) Baby three - gestational age:	☐ 1st trimester (0-12 weeks) ☐ 2nd trimester (13-27 weeks) ☐ 3rd trimester (28-40+ weeks)
7f	(If applicable) Baby four - gestational age:	☐ 1st trimester (0-12 weeks) ☐ 2nd trimester (13-27 weeks) ☐ 3rd trimester (28-40+ weeks)
7g	(If applicable) Baby five - gestational age:	☐ 1st trimester (0-12 weeks) ☐ 2nd trimester (13-27 weeks) ☐ 3rd trimester (28-40+ weeks)
7h	(If applicable) Baby six - gestational age:	☐ 1st trimester (0-12 weeks) ☐ 2nd trimester (13-27 weeks) ☐ 3rd trimester (28-40+ weeks)
7i	(If applicable) Baby seven - gestational age:	☐ 1st trimester (0-12 weeks) ☐ 2nd trimester (13-27 weeks) ☐ 3rd trimester (28-40+ weeks)

PART 4: MEDICAL HISTORY FORM *(note: only ask this section if informants did not consent to review of medical records)*		
1	**Do you have any current and/or chronic MEDICAL conditions?**	☐ Yes >> code under relevant category in question 3 and go to question 2a ☐ No >> go to question 2a
2a	**Do you have any current and/or chronic MENTAL HEALTH issues?**	☐ Yes >> code under relevant category in question 3 and go to question 2b ☐ No >> go to question 3
2b	**Have you taken any medication for this?**	☐ Yes >> go to question 2c ☐ No >> go to question 3
2c	**Was this medication taken in the past year?**	☐ Yes ☐ No
3	**Is there any relevant significant medical conditions in the following systems?**	
	Cardiovascular Disease (e.g. coronary/ischaemic heart disease)	☐ Yes ☐ No Please specify:_____Onset date:_____
	Cerebrovascular Disease (e.g. hypertension, stroke)	☐ Yes ☐ No Please specify:_____ Onset date:_____
	Respiratory or lung disease (e.g. asthma, Chronic obstructive airways disease)	☐ Yes ☐ No Please specify:_____Onset date:_____
	Hepatic problems (e.g. hepatitis)	☐ Yes ☐ No Please specify:_____ Onset date:_____
	Gastro-intestinal problems (e.g. IBS, coeliac, Crone's disease)	☐ Yes ☐ No Please specify:_____ Onset date:_____
	Genito-urinary (e.g. urinary-tract infection)	☐ Yes ☐ No Please specify:_____ Onset date:_____
	Gynaecological problem (e.g. polycystic ovarian syndrome, endometriosis)	☐ Yes ☐ No Please specify:_____ Onset date:_____
	Endocrine disorder (e.g. thyroid disease, diabetes, Cushing's disease)	☐ Yes ☐ No Please specify:_____ Onset date:_____
	Haematological problems (e.g. sickle cell)	☐ Yes ☐ No Please specify:_____ Onset date:_____
	Disease of Bones and Joints and/or muscle disease (e.g. osteoporosis, arthritis, chronic fatigue, myopathy)	☐ Yes ☐ No Please specify:_____ Onset date:_____
	Disease of the Nervous System (e.g. epilepsy, Parkinson's, Alzheimer's)	☐ Yes ☐ No Please specify:_____ Onset date:_____

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	Psychiatric problems (e.g. depression, anxiety disorders)	☐ Yes ☐ No Please specify:_____ Onset date:_____
	Disease of immune system (e.g. rheumatoid arthritis, rhinitis, diabetes, AIDS)	☐ Yes ☐ No Please specify:_____ Onset date:_____
	Other	☐ Yes ☐ No Please specify:_____ Onset date:_____
3a	**Have you ever been a patient in a psychiatric hospital?**	☐ Yes ☐ No
3b	**If "yes" what was that for?**	_____
3c	**How many times?**	_____
3d	**Do you have a history of self-harm or suicide?**	☐ Yes ☐ No
4	**Have you ever smoked cigarettes or other tobacco products?**	☐ Yes >> go to question 5 ☐ No >> go to question 8
5	**How much did you smoke before you found out you were pregnant?**	Number of cigarettes per day:_____
6	**How much do you smoke nowadays?**	Number of cigarettes per day:_____
7	**Do you currently use nicotine replacements such as gum or patches/e-cigarettes?**	☐ Yes ☐ No Specify (e.g. gum/patches, strength, frequency): _____
8a	**What was your weight before you became pregnant?**	_____
8b	**What is your weight now?**	_____
8c	**What is your height?**	_____

PART 5: MEDICATION FORM		
1	**Are you currently taking any *regular* medications , including oral medication (e.g. dietary supplement), creams and inhalers)?**	☐ Yes >> go to question 2 ☐ No >> go to end of questionnaire
2	**Medication details .....**	

Drug One:

Is this medication for mental health? ☐ Yes ☐ No

Body system code:
1. Cardiovascular
2. Cerebrovascular
3. Respiratory
4. Hepatic
5. Gastro-intestinal
6. Genito-urinary
7. Gynaecological
8. Endocrine
9. Haematological
10. Musculo-skeletal
11. Nervous system
12. Psychiatric
13. Immunological
14. Other

Drug/Treatment Name_____

Body system:_____

Start date *(month / year)* _____ / _____

Dose (mg/day) _____

Route of administration: _____

Frequency:_____

Route of administration code:
1. Oral
2. Topical
3. Transdermal
4. Suppository
5. Pessary
6. Inhaler
7. Injection

Frequency codes:
1. 1. Once daily
2. 2. Twice daily
3. 3. Three times daily
4. 4. Four times daily
5. 5. As required
6. 6. Continuous
7. Other (please specify)

Drug Two (If applicable):

Is this medication for mental health? ☐ Yes ☐ No

Drug/Treatment Name_____

Body system:_____

Start date *(month / year)* _____ / _____

Dose (mg/day) _____

Route of administration: _____

Frequency:_____

Body system code:
1. Cardiovascular
2. Cerebrovascular
3. Respiratory
4. Hepatic
5. Gastro-intestinal
6. Genito-urinary
7. Gynaecological
8. Endocrine
9. Haematological
10. Musculo-skeletal
11. Nervous system
12. Psychiatric
13. Immunological
14. Other

Route of administration code:
1. Oral
2. Topical
3. Transdermal
4. Suppository
5. Pessary
6. Inhaler
7. Injection

Frequency codes:
1. Once daily
2. Twice daily
3. Three times daily
4. Four times daily
5. As required
6. Continuous
7. Other (please specify)

	Drug Three (If applicable): Body system code: 1. Cardiovascular 2. Cerebrovascular 3. Respiratory 4. Hepatic 5. Gastro-intestinal 6. Genito-urinary 7. Gynaecological 8. Endocrine 9. Haematological 10. Musculo-skeletal 11. Nervous system 12. Psychiatric 13. Immunological 14. Other Route of administration code: 1. Oral 2. Topical 3. Transdermal 4. Suppository 5. Pessary 6. Inhaler 7. Injection Frequency codes: 13. 1. Once daily 14. 2. Twice daily 15. 3. Three times daily 16. 4. Four times daily 17. 5. As required 18. 6. Continuous 7. Other (please specify)	Is this medication for mental health? ☐ Yes ☐ No Drug/Treatment Name_____ Body system:_____ Start date *(month / year)* _____ / _____ Dose (mg/day) _____ Route of administration: _____ Frequency:_____

Appendix V Study 3: Exploratory descriptive questionnaire

Netmums Survey Questions

Have you struggled with an eating disorder, perhaps been over-weight or underweight and perhaps had trouble with binge eating or controlling what you ate?

The University College London is looking at whether eating disorders are discussed by doctors and midwives in pregnancy, and it would be really helpful to hear about your experiences.

Thanks to all those who are able to help, we hope it will give real insight so midwives and doctors have a better understanding of the issues in future.

1. How old are you?
   - 19 years old or under
   - 20-24 years old
   - 25-29 years old
   - 30-35 years old
   - 36-40 years old
   - 41 years old or above

2. How many children do you have?
   - I'm pregnant at the moment
   - 1
   - 2
   - 3
   - 4 or more

3. Do you have or have you had an eating disorder?
   - Yes
   - No

4. If yes to item 3, which eating disorder did you have during or around the time of your pregnancy?
   - Anorexia nervosa
   - Bulimia nervosa
   - Binge eating disorder
   - Eating disorder not otherwise specified (EDNOS)

5. Did you suffer with eating disorder symptoms while you were pregnant? (Tick those symptoms that applied)
   - No. I wasn't unwell at the time
   - Purging
   - Binging
   - Calorie/food restriction
   - Excessive exercising
   - Low weight
   - Other (please explain) [open-ended response]

6. Did any of these symptoms improve during pregnancy? (Tick all those that apply)
    - Purging
    - Binging
    - Calorie/food restriction
    - Excessive exercising
    - Low weight
    - Other (please explain) [open-ended response]

7. Were you concerned that your difficulties might affect your baby while you were pregnant?
    - Yes, I was concerned
    - Possibly, I wasn't sure
    - No, I didn't think it would have an impact

8. After your baby was born, did your eating disorder affect breastfeeding?
    - Yes, but I breastfed anyway
    - Yes, I wanted to, but struggled to breastfeed
    - No, my eating disorder did not affect breastfeeding
    - No, the disorder didn't matter as I didn't want to breastfeed anyhow

9. Did your eating disorder affect you when you weaned your child to solids?
    - Yes
    - No
    - Not sure

10. Overall, while you were pregnant, were you satisfied with the antenatal care you received?
    - Yes, a lot
    - Yes somewhat
    - Neither satisfied nor unsatisfied
    - A little unsatisfied
    - Very unsatisfied

11. If a little or very unsatisfied, can you explain why?
    [open-ended response]

12. Were midwives and doctors you saw during your pregnancy aware of your eating disorder?
    - Yes
    - No
    - Not sure

13. Did you let them know or talk to them about having an eating disorder?
    - Yes (go to Q 14)
    - No (skip to Q 16)

14. If you talked to them, how did you feel about discussing your eating disorder?
    - Happy
    - Somewhat happy
    - Unsure
    - A little unhappy
    - Very unhappy

15. Did they offer you any additional support?
    - No
    - No, they just monitored me more closely
    - Yes, they offered me help/referred me on for psychological/nutritional help (but I chose not to make use of it)
    - Yes, they offered me help/referral and I made use of this

16. If you didn't talk to the antenatal care professionals, what stopped you?
    - [open-ended response]

17. Do you think it would be good to routinely ask women whether they have difficulties related to eating disorders?
    - Yes, they should be asked
    - Yes, maybe
    - Unsure
    - No, some women would rather not talk and that should be respected

18. In what ways do you think antenatal service could be improved for women with eating disorders?
    - [open-ended response]

19. Are there any further comments you would like to make on this subject?
    - [open-ended response]

20. A couple of demographic questions. Where do you live?
    - North East England
    - North West England
    - Yorkshire and Humber
    - East Midlands
    - West Midlands
    - East of England
    - London
    - South East England
    - South West England
    - Wales
    - Scotland
    - Northern Ireland

21. What is your highest educational qualification?
    - GCSEs
    - A Levels
    - University degree/higher degree (MSc/PhD)

Appendix VI Study 4: Participant information sheet and consent forms

Information Sheet: Student midwives

You will be given a copy of this information sheet.

Title of Project: Eating Disorders in pregnancy: can we improve assessment and identification?

This study has been approved by the UCL Research Ethics Committee (Project ID Number): 3735/001

Research names	Dr Nadia Micali (Principal Investigator)	Ms Amanda Bye (PhD Student)
Contact Details	n.micali@ucl.ac.uk	a.bye@ucl.ac.uk
	[redacted]	[redacted]
Address	Behavioural and Brain Sciences Unit, 4th Floor, UCL Institute of Child Health	

We would like to invite you to participate in this research project.

Details of Study:

Aim:
We are aiming to investigate the knowledge, attitudes and healthcare practice in relation to Eating Disorders in pregnancy, among midwives and health visitors, the health professional's women have the most frequent contact with in antenatal and postnatal care settings. Exploration of midwives and health visitors educational needs may highlight gaps that could be targeted by informed training.

We are inviting to take part:
Student midwives at King's College London, City University London and the University of Surrey.

Taking part will involve:

- If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form about completing a questionnaire.
- If you agree to take part you will be asked whether you are happy to be contacted about taking part in a focus group, and if so to provide your contact details. Your participation in this study will not be affected should you choose not be re-contacted.
- We will give you a short questionnaire on knowledge, attitudes and healthcare practice in relation to ED in pregnancy, that will take no longer than 5 minutes to complete.
- Please return the completed questionnaire to us directly during the lesson period.
- If you are happy to take part in the focus group we will contact you to let you know when and where it will be held. You can let us know if you are able to attend.
- If you decide to take part you will be asked to sign a consent form about the focus group. Please be aware the focus group will be taped and transcribed (written up) and then the tape will be wiped clear.

- The focus group will involve an informal discussion for 30mins-1hr, with between 5-10 students, on knowledge, attitudes and healthcare practice in relation to Eating Disorders in pregnancy.

Potential risks of taking part:
The topic of focus is a sensitive issue and so you may be distressed by taking part. Please be aware that if you choose to take part in the focus group you will be shown the questions we will be focusing at the start. If you no longer wish to take part you can withdraw immediately from either completing the questionnaire or the focus group, and this will not affect the standard of education you receive or your legal rights.

Benefits of taking part:
Taking part could lead to personal development, and curriculum and training developments.

Confidentiality:
- Please be aware that processing of your personal information is solely for the purposes of this research study, and no data will be collected for the purposes of assessing individual practitioner performance.
- All information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.
- Recorded focus groups will be transcribed (written up) and the tape will then be wiped clear.
- Confidentiality and anonymity will be maintained and it will not be possible to identify me from any publications.

Please discuss the information above with others if you wish or ask us if there is anything that is not clear or if you would like more information.

It is up to you to decide whether to take part or not; choosing not to take part will not disadvantage you in any way. If you do decide to take part you are still free to withdraw at any time and without giving a reason.

Informed Consent Form: Questionnaire
Student midwives

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Project: Eating Disorders in pregnancy: can we improve assessment and identification?

This study has been approved by the UCL Research Ethics Committee (Project ID Number): 3735/001

Thank you for your interest in taking part in this research. Before you agree to take part, the person organising the research must explain the project to you.

If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you to decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

Participant's Statement

I (Please fill in your full name)

- have read the notes written above and the Information Sheet, and understand what the study involves.
- understand that if I decide at any time that I no longer wish to take part in this project, I can notify the researchers involved and withdraw immediately.
- consent to the processing of my personal information for the purposes of this research study.
- understand that no data will be collected for the purposes of assessing individual practitioner performance.
- understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.
- agree that the research project named above has been explained to me to my satisfaction and I agree to take part in this study.
- understand that the information I have submitted will be published. Confidentiality and anonymity will be maintained and it will not be possible to identify me from any publications.

Signed: Date:

Further, please tick the box if you agree to be contacted by UCL researchers who would like to invite you to participate in the focus group, as outlined in the Information Sheet ☐

If so, please provide contact details:
Address:
Tel:

Email:

Informed Consent Form: Focus Group

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Project: Eating Disorders in pregnancy: can we improve assessment and identification?

This study has been approved by the UCL Research Ethics Committee (Project ID Number): 3735/001

Thank you for your interest in taking part in this research. Before you agree to take part, the person organising the research must explain the project to you.

If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you to decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

Participant's Statement

I (Please fill in your full name)

- have read the notes written above and the Information Sheet, and understand what the study involves.
- understand that if I decide at any time that I no longer wish to take part in this project, I can notify the researchers involved and withdraw immediately.
- consent to the processing of my personal information for the purposes of this research study.
- understand that no data will be collected for the purposes of assessing individual practitioner performance.
- understand that my participation will be taped and I consent to use of this material as part of the project
- understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.
- agree that the research project named above has been explained to me to my satisfaction and I agree to take part in this study.
- understand that the information I have submitted will be published. Confidentiality and anonymity will be maintained and it will not be possible to identify me from any publications.

Signed: Date:

Appendix VII Study 4: Knowledge and attitudes questionnaire

Knowledge and Attitudes Questionnaire: Student Midwives

The following questions are on your knowledge on eating disorders in pregnancy and in relation to healthcare practice.

1. **Approximately, how many women of child-bearing age have eating disorders?**

1 in 100	1 in 50	1 in 20	1 in 5	Don't know
☐	☐	☐	☐	☐

2. **How many pregnant women have eating disorders in the general population?**

2%	5%	10%	20%	Don't know
☐	☐	☐	☐	☐

3. **Which of the following are diagnostic features of anorexia nervosa?** ***(tick as many as apply)***

Body Mass Index below 17.5	Loss of interest in activities	Missing periods	Fear of gaining weight	Decreased appetite
☐	☐	☐	☐	☐

4. **Which of the following are diagnostic features of bulimia nervosa?** ***(tick as many as apply)***

Normal body image	Unable to stop overeating	Making one's self sick or using laxatives after eating	Exercising excessively to prevent weight gain	Body Mass Index above 20
☐	☐	☐	☐	☐

5. **Which of the following pregnancy-related statements are true?** ***(tick as many as apply)***

- ☐ Eating disorders can develop during pregnancy.
- ☐ Women with eating disorders are at an increased risk of preeclampsia.
- ☐ Women with current eating disorders cannot get pregnant.
- ☐ Women with past eating disorders are not likely to be unhappy about pregnancy weight gain.
- ☐ Women with eating disorders are likely to have a planned pregnancy.

6. **Which of the following pregnancy outcome-related statements are true?** ***(tick as many as apply)***

- ☐ Women with past eating disorders are not likely to relapse after giving birth.
- ☐ Women with bulimia are likely to continue to breastfeed their baby past one year old.
- ☐ Neither past nor current eating disorders impact on the baby's birth weight.
- ☐ Women with eating disorders are more likely to suffer from miscarriage and stillbirth.
- ☐ Women with eating disorders are more likely to suffer from postnatal depression.

7. **Which of the following healthcare practice statements are true?** ***(tick as many as apply)***

- ☐ Healthcare professionals do not routinely screen for current or past eating disorders during antenatal and postnatal care
- ☐ NICE guidelines recommend increased support for women with an eating disorder during pregnancy and the postpartum period.
- ☐ NICE guidelines do not recommend a screening tool for eating disorders that could be used in antenatal and postnatal care.
- ☐ Most women with eating disorders seek treatment themselves prior to pregnancy.
- ☐ Women with a past eating disorder are likely to disclose their history to a health professional due to the impact on the infant.

1

The following statements are about healthcare practice related to eating disorders in pregnancy. Please tick your attitude to the following statements. There is no right or wrong answer; we are interested in your opinions as a student midwife.

8. **I think eating disorders can be identified in antenatal care by midwives**

Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree ☐

9. **I believe midwives are often unaware of the effects of eating disorders on pregnancy and pregnancy outcomes**

Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree ☐

10. **I feel confident that I could recognise a pregnant woman with an eating disorder**

Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree ☐

11. **I feel confident about giving specialised support to a pregnant woman with an eating disorder**

Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree ☐

12. **I don't think eating disorders are really relevant to a midwife- it should be dealt with by other professionals**

Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree ☐

13. **I don't think there is the time in antenatal care to manage eating disorders in pregnant women**

Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree ☐

14. **I think midwives need better training to help confidently and successfully identify eating disorders in pregnancy to promote healthy outcomes for mother and child**

Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree ☐

Please fill out your details:

Date of birth: _____

Gender:
Male ☐ Female ☐

How would you describe your ethnic origin?:

White		**Black or Black British**		**Asian or Asian British**	
British	☐	Caribbean	☐	Indian	☐
Irish	☐	African	☐	Pakistani	☐
Any other White background	☐	Any other Black background	☐	Bangladeshi	☐
				Any other Asian background	☐

Dual heritage		**Chinese or other ethnic group**		**Not Stated**	
White and Black Caribbean	☐	Chinese	☐		
White and Black African	☐	Other ethnic group	☐		
White and Asian	☐				
Any other Dual background	☐				

Which University do you attend?
King's College London ☐ City University ☐ Surrey University ☐
Which University course do you attend?:
Midwifery BSc (direct entry) ☐ 18 month midwifery programme ☐
Midwifery Post Graduate Diploma ☐

Have you studied mental health as part of your midwifery training?:
No ☐ Yes ☐ Please briefly describe_____
_____
_____
_____

Have you studied eating disorders as part of your midwifery training?:
No ☐ Yes ☐ Please briefly describe_____
_____
_____
_____

Have you studied mental health prior to your midwifery training?:
No ☐ Yes ☐ Please briefly describe_____
_____
_____
_____

What do you think has most informed your knowledge about eating disorders?:
Training ☐ Personal experience ☐ Patient experience ☐ Media ☐
e.g. university e.g. affected family/friend e.g. television

Would you like to receive training on eating disorders in pregnancy?
No ☐ Yes ☐

Any comments?:
_____
_____
_____

Appendix VIII Study 4: Topic guide

Focus group topic guide

1. From your training, what do you know about eating disorders?
2. From your training, what do you know about the impact of eating disorders on pregnancy and birth outcomes, including the postnatal period?
3. From your training, what specialised support do you think pregnant women and mothers with eating disorders may need?
4. Based on your experience, what do you think about the current training on eating disorders?
5. Based on your experience, what do you think about routine screening for eating disorders in pregnant and postnatal women?
6. Based on your experience, do you think midwives and health visitors should be involved in the care management plans for pregnant and postnatal women with eating disorders?