**Understanding delayed access to antenatal care: a qualitative study**

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A thesis submitted in fulfilment of the requirement for the degree of Doctor of Philosophy in the Faculty of Medicine, Dentistry and Health: School of Health and Related Research, University of Sheffield.

The results, discussions and conclusions presented herein are identical to those in the printed version, with the exclusion of some appendices. The final, full, awarded and examined version is available for consultation via the University Library.

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**Publications and presentations from this work**

**Publications**

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**Presentations**

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Findings from the study were presented by the Head of Midwifery at Sheffield Teaching Hospitals NHS Foundation Trust, Dotty Watkins, and used as the basis of a workshop among practitioners considering antenatal access.

**Posters**

Royal College of Midwives annual conference 2012, Brighton.

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Abstract

**Background**

Delayed access to antenatal care (‘late booking’) is linked to poor maternal, fetal and neonatal outcomes. There have been few studies of women’s attitudes towards the initiation of antenatal care in the UK. The aim of the study was to understand why some women delay accessing antenatal care, and ultimately to improve such access and outcomes.

**Methods**

The synthesis of a large and methodologically diverse body of evidence, around perceptions and beliefs towards late booking for antenatal care, identified that antenatal care participation behaviour is complex, with a broad range of interacting barriers. A qualitative study was undertaken in Sheffield, interviewing 27 women presenting for their first hospital booking appointment after 19 weeks gestation, in community and maternity hospital settings. The interviews were transcribed verbatim and an iterative thematic analysis completed.

Results

The women were diverse in terms of age, parity, socioeconomic status and educational attainment. Three key themes relating to late booking were identified:

* ‘not knowing’: *realisation* (absence of classic symptoms, misinterpretation), *belief* (age, subfertility, contraceptive use, lay hindrance);
* ‘knowing’: *avoidance* (ambivalence, fear, self-care), *postponement* (fear, location, not valuing care, self-care);
* ‘delayed’ (professional and system failures, knowledge and empowerment issues).

**Conclusions**

The analysis suggests a new taxonomy of themes around late booking, reflecting the interaction of cognitive, emotional, social and environmental factors which must be navigated prior to a woman’s first antenatal appointment. Common themes were evident across the social spectrum, including poor reproductive health knowledge and delayed recognition of pregnancy, but also the influence of a pregnancy ‘mindset’ and previous pregnancy experience, and the perceived priority of antenatal care. Three recommendations are made, namely to

1. address unintended pregnancies through improved reproductive health literacy,
2. enhance access to early antenatal care, and
3. improve the quality and focus of care, thus influencing women’s perceptions of its value and relevance.

In combination these will facilitate the provision of timely antenatal care for **all** women.

**Thesis outline**

This thesis considers the subject of the delayed initiation of antenatal care (‘late booking’). It contains three parts. The first part considers the background to late booking, including existing guidance around antenatal access and the policies that underpin this, and also reviews the literature around women’s perceptions of delayed access to antenatal care. The second part documents the method and findings of a qualitative study undertaken in Sheffield to examine late booking women’s perceptions, and their experience of becoming pregnant and accessing antenatal care. The third part discusses the study findings and considers these in relation to previous research, and makes recommendations for future changes to policy and practice, and further research, to try to reduce late booking.

Antenatal care in the UK (United Kingdom) is a well-established and widely accepted programme of health screening, health education and, to a lesser extent, social support. National and international policies and clinical guidance encourage early and regular attendance during pregnancy. Although evidence of the impact of individual components of antenatal care is limited, as a whole it is widely acknowledged as contributing to improved pregnancy outcomes. **Chapter one** considers how late booking for antenatal care is associated with poorer outcomes for both mother and baby, though this is complicated by socio-demographic risk factors amongst many late booking women. Many authors have identified the value of examining the attitudes and beliefs of late booking women, in an attempt to improve understanding, access to care and, ultimately, health outcomes. My own perspective on late booking, as a midwife, is also considered.

Few UK based studies have been undertaken to examine the perceptions and beliefs of women in relation to barriers to the initiation of antenatal care. This is reflected in the findings of the literature review and Critical Interpretive Synthesis (CIS) presented in **chapter two**. CIS is a method which aims to bring together a large and diverse body of evidence, in terms of methodologies, settings and participants. Originally used to synthesise evidence relating to access to healthcare by vulnerable groups, it has not been used to examine antenatal access before. The findings demonstrate a broad range of interacting influences, including personal and practical barriers to care.

The synthesis has created a fresh perspective on late booking for antenatal care, one which identifies *acceptance of personal and public pregnancies* as the core concept. Acceptance of the ‘personal’ pregnancy considers the influence of mindset in the recognition and acceptance of pregnancy. This acceptance is influenced by knowledge of pregnancy symptoms, pregnancy planning and desire, psychological factors associated with the recognition of pregnancy and the support of a woman’s immediate social network. Second, acceptance of the ‘public’ pregnancy considers women’s assessment of the social consequences of pregnancy, and the relevance and priority of antenatal care. This acceptance is influenced, amongst other things, by past experience, both positive and negative, beliefs about pregnancy and a consideration of life priorities. Late booking may result from the non-acceptance of either or both of these.

Recognition of the risks associated with late booking and a gap in the evidence base, both in terms of UK-based but also qualitative research, led to the development of a study undertaken in Sheffield. The study’s aim was to try to understand women’s reasons for late booking and to explore barriers to antenatal attendance. It was part of a larger project which also included health and social care practitioner perspectives on late booking.

The research question for the Sheffield study developed to become *“what perceptions and beliefs do late booking women express about the delayed initiation of antenatal care?”* **Chapters three and four** consider in detail the qualitative methodology and research methods chosen for the study, and the theoretical background to these. The ontological and epistemological influences behind the methodology are presented and discussed in **chapter three**, in relation to the conduct of the research, including sampling, data collection and data analysis. There is also a consideration of bias and quality in relation to the conduct of qualitative research, and the ways in which these were addressed in the study.

**Chapter four** details the conduct of the research. It considers the background to the study, the processes of sampling and recruitment, and the procedure for the 27 individual interviews that were undertaken with late booking women. Ethical issues in relation to the participants are discussed, particularly in relation to consent and confidentiality. A thematic analysis of the data was undertaken and its stages are detailed. In each section the practical decisions made at all stages of the study are presented, alongside the rationale for these choices.

The detailed themes and sub-themes emerging from the analysis of individual interviews with 27 late booking women are presented in **chapter five**. The diverse demographic characteristics of the women are presented briefly. A taxonomy of themes relating to late booking was developed and is presented in detail, illustrated with quotes from the women. Three original explanatory themes developed from the women’s interviews: women not realising or believing they were pregnant and therefore not accessing care (*not knowing*), women knowing they were pregnant and avoiding or postponing antenatal care (*knowing*) and women being prevented from accessing care by others (*delayed*). The chapter also considers additional emergent themes relating to triggers for accessing care, and the range of attitudes towards their late booking demonstrated by the women interviewed.

**Chapter six** considers the three themes identified from the qualitative analysis of the individual interviews with the late booking women, and the similarities and differences with previous research. *Not knowing* examines the influences on women’s initial recognition of their pregnancies (the personal pregnancy identified in chapter 2) and the influence of a pregnancy ‘mindset’, related to women’s expectation of becoming pregnant. The study suggests that for some women ‘not knowing’ that they are pregnant is a combination of lack of recognition, acknowledgement and acceptance of the signs, symptoms and consequences of pregnancy, in part related to the absence of pregnancy planning. *Knowing* appraises the public or social aspects to a woman’s pregnancy and the formation of her pregnancy identity. Women’s perceptions of the relevance and priority of antenatal care are considered, as is the importance of familiarity, particularly in relation to a woman’s previous pregnancy experience and her home situation. *Delayed* considers organisational barriers to accessing care, as a result of professional and system failures, but also women’s acceptance of such delays.

Whilst many of the findings from the Sheffield study concur with existing research around antenatal access, it has also generated different perspectives, reflecting in part the diverse sample of women interviewed. This contributes to a new understanding of late booking. The findings suggest that antenatal care initiation behaviour is complex, with cognitive, emotional, personal and environmental factors all interacting influences. Chaotic lifestyles and economic deprivation do influence women’s perceptions of their healthcare needs and priorities. However the themes from this study suggest a different emphasis, across the social spectrum. Whilst vulnerable groups are strongly represented in this cohort, women do not always fit a socio-cultural stereotype of a ‘late booker’. Rather, the women illustrate a different set of priorities regarding antenatal care, relating to its relevance, convenience and familiarity, using their previous pregnancy experience and embodied knowledge, and good health. Many take an active rather than passive role in their pregnancies to ensure wellbeing. There is also greater emphasis on the lack of a pregnancy mindset, relating to women’s expectation of becoming pregnant, and the creation of her pregnancy identity, as part of her ‘social’ pregnancy’. The chapter concludes with a consideration of the strengths and limitations of the qualitative methods used in the study.

The purpose of the Sheffield study was to try to understand late booking from the women’s perspective, and ultimately to try to inform changes in policy and practice to improve outcomes. Whilst considering the findings of the Sheffield study, and diverse research into antenatal access and attitudes to care, **chapter seven** makes three recommendations to try to reduce late booking for antenatal care. These are based around the three overlapping themes from the study, and the concept of pregnancy as having both personal and public (social) aspects. The recommendations include strategies for addressing unintended pregnancies by improving reproductive health literacy, facilitating early access to antenatal care and improving the quality of antenatal care women receive, thus influencing women’s perceptions of its relevance and value. The role midwives play in such strategies is considered, as is the potential role for financial incentives in encouraging early attendance.

It is recommended that women, their friends and families, are better informed about all aspects of reproductive health. However, if women are to value and prioritise antenatal care, it also needs to be readily accessible and perceived as relevant to their lives and pregnancies: flexible and focused on the individual, with more emphasis on choice and psychological support and less emphasis on physical aspects of care. Suggestions are made for future research, considering the impact of different models of care and antenatal or postnatal interventions, whilst also examining further the characteristics, outcomes and perceptions of women who book both early and late for antenatal care. It is suggested that multiple methodologies are required to contribute to a greater understanding of the multi-faceted nature of late booking, in order to promote the provision of timely antenatal care for all women.

**List of abbreviations and acronyms used in the thesis**

BME Black and Minority Ethnic

CCG Clinical Commissioning Group

CEMD Confidential Enquiry into Maternal Deaths

CIS Critical Interpretive Synthesis

CMACE Centre for Maternal and Child Enquiry

DCLG Department for Communities and Local Government

DHSS Department of Health and Social Security

DoH Department of Health

ESRC Economic and Social Research Council

FNP Family Nurse Partnership

GMC General Medical Council

GP General Practitioner

HES Hospital Episode Statistics

HSCIC Health and Social Care Information Centre

MRC Medical Research Council

NCCWCH National Collaborating Centre for Women’s and Children’s Health

NCT National Childbirth Trust

NPEU National Perinatal Epidemiology Unit

NHS National Health Service

NICE National Institute for Health and Care Excellence

NIHR National Institute for Health Research

NSF National Service Framework

NSPCC National Society for the Prevention of Cruelty to Children

ONS Office for National Statistics

PNCC Prenatal Care Co-ordination

PCT Primary Care Trust

PSA Public Service Agreement

RCM Royal College of Midwives

RCT Randomised controlled trial

RCOG Royal College of Obstetricians and Gynaecologists

UK United Kingdom

USA/US United States of America

WHO World Health Organisation

WMA World Medical Association

**Chapter 1: Introduction to late booking for antenatal care**

**1.1** **The background to late booking**

***1.1.1 Midwifery and ‘booking’ for antenatal care***

Antenatal care, a systematic programme of health screening, health education and social support for pregnant women, is a cornerstone of contemporary midwifery practice in the United Kingdom (UK). It has grown and developed alongside the midwifery profession itself and remains the most significant activity for many midwives, at a time when postnatal care has, in some areas, been largely delegated to other practitioners. Contemporary antenatal care originates from models developed in Europe in the early decades of the 20th century, arising from a newly emerging belief in the possibility of the avoidance of maternal, fetal and infant death ([Oakley 1982](http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD000934.pub2/full#CD000934-bbs2-0032)). Antenatal care has been widely offered to pregnant women in the UK since the late 1920s and has formed a template for maternity care worldwide (National Collaborating Centre for Women’s and Children’s Health (NCCWCH) 2008).

Regular attendance for antenatal care is an accepted part of healthcare during pregnancy for the majority of women. For some women it will be their first encounter with maternity services, and for many pregnancy will be their first personal experience of hospital-based services and health screening. From a life course perspective, women’s engagement antenatally has the potential to influence both long-term health and wellbeing and their future use of health services, for themselves and their families (National Health Service (NHS) Commissioning Board 2012, Royal College of Obstetrics and Gynaecology (RCOG) 2011).

The initial antenatal or ‘booking’ appointment is one of the most important parts of a woman’s pregnancy care: *“the importance of the antenatal booking interview cannot be over-emphasised”* (Centre for Maternal and Child Enquiry (CMACE) 2011: 152). The meeting, usually between a midwife and the woman, provides an opportunity to discuss, plan and implement care for the duration of the pregnancy, the birth and postnatal period. Midwives play a key role: it is an essential opportunity for midwives to develop a positive relationship, a partnership with women, and to evaluate the potential physical, psychological and social effects of pregnancy on the woman and her family. They can offer referral for specialist and multidisciplinary input when there are risk factors that could impact on the pregnancy (or vice versa), and offer support at a time when a woman may feel overwhelmed by the changes occurring in her body and the prospect of pregnancy, birth and motherhood. Counselling and screening for infectious diseases and hereditary conditions, chromosomal abnormalities and fetal anomalies, form a significant part of antenatal booking. It is also an important contact point for health and lifestyle advice during the critical early stages of fetal development, for example advice about smoking cessation and diet (Viccars 2009, Bharj and Henshaw 2011, CMACE 2011). In Sheffield this booking appointment is in two parts, one at the woman’s family doctor (GP), local children’s centre or in her home with her community midwife, the other at the maternity hospital (The Jessop Wing).

***1.1.2 The pattern of antenatal care and recommendations for early booking***

Despite antenatal care’s longevity, it follows a pattern that some have argued has evolved with little scientific basis (Thorley, Rouse and Campbell 1997, NCCWCH 2008). Dowswell *et al* (2010), in their Cochrane systematic review, acknowledge that since the inception of modern antenatal care, few of its common components have been formally evaluated, and there is little reliable evidence of the relative merits, hazards and costs of alternative packages of care. Stephens’ feminist viewpoint (2004) similarly argues that while maternity care has been established, challenged and individualised, there is still no real evidence to show what is an ideal pattern of care. Steer’s frequently cited obstetric perspective (1993) suggests that antenatal care (“*a pattern of largely ineffective ritual*” p697) is valued as much for the reassurance and social contact it offers pregnant women, as its clinical effectiveness.

There is similarly a lack of consensus about the exact significance of delayed access to antenatal care and limited evidence about exactly when booking should take place (Villar *et al* 2001, Cresswell *et al* 2013). However despite this, the World Health Organisation (WHO) and national clinical practice guidelines for antenatal care from, for example, the UK, United States of America (USA) and Australia, highlight the value of early initiation of antenatal care (Kupek *et al* 2002, WHO 2006, Philippi 2009, Australian Department of Health and Ageing 2012). These are summarised in table 1.1.2. UK reports and guidance recommend that women seek professional healthcare in early pregnancy, to obtain evidence-based information to help them plan their pregnancies and to benefit from antenatal screening and health promotion activities (Bharj and Henshaw 2011). Additionally, repeated Confidential Enquiry into Maternal Deaths (CEMD) reports (Lewis 2007, CMACE 2011, Knight *et al* 2014) have stressed the importance of early booking.

The current National Institute for Health and Care Excellence (NICE) guidance *Antenatal care: routine care for the healthy pregnant woman* (Clinical Guideline 62, NCCWCH 2008) aims to offer evidence-based information on best practice for uncomplicated pregnancies. The authors suggest that the ethos of the guideline is that pregnancy is a normal physiological process and that, as such, any interventions offered should have known benefits (as well as be acceptable to pregnant women) (p1). Though it considers in detail the evidence relating to frequency of appointments, there is no such consideration of the optimum time for antenatal booking. Rather this NICE publication and others: *Pregnancy and Complex Social Factors* (CG110, 2010) and *Quality Standard for Antenatal Care* (QS22, 2012), and NHS Screening Programme guidelines simply recommend that pregnant women should attend for their booking appointment as early as possible, ideally before ten weeks gestation (NCCWCH 2008, NCCWCH 2010, NHS Sickle Cell and Thalassaemia Screening Programme 2011, NICE 2012).

NICE (CG62, 2008) recommends that as part of this booking for pregnancy, all screening blood tests, excluding screening for gestational diabetes, are offered before ten weeks gestation, and that women should also be offered the most accurate early screening for Downs Syndrome between 11 weeks and 13 weeks and 6 days gestation. An early ultrasound scan should be offered between 10 weeks and 13 weeks and 6 days to determine accurately gestational age and reduce the incidence of unnecessary induction of labour for prolonged pregnancy. A fetal anomaly scan should also be offered between 18 weeks and 20 weeks and 6 days (p12, 15, 20).

***Table 1.1.2: Antenatal booking recommendations from different countries***

|  |  |  |
| --- | --- | --- |
| **Location** | **Publication and year** | **Recommendations regarding initiation of antenatal care** |
| **UK** | National Collaborating Centre for Women’s and Children’s Health (NCCWCH). *NICE Clinical Guideline CG62: Antenatal Care: routine care for the healthy pregnant woman.* 2008. RCOG Press, London. | *“The booking appointment needs to be earlier in pregnancy (ideally by 10 weeks) than may have traditionally occurred, because of the large volume of information needs in early pregnancy”* (p78). This also allows arrangements to be made for tests that are most effective early in the pregnancy (eg gestational age assessment by ultrasound scan and nuchal screening for Down’s syndrome by 13 weeks). Screening for sickle cell diseases and thalassaemias should be offered to all women as early as possible in pregnancy (ideally by 10 weeks). |
| **UK** | NCCWCH. NICE *Clinical Guideline CG110: Pregnancy and complex social factors: A model for service provision for pregnant women with complex social factors.* 2010. RCOG Press, London. | *“At first contact with any healthcare professional discuss the need for antenatal care, offer the woman a booking appointment in the first trimester, ideally before 10 weeks if she wishes to continue the pregnancy”* (p5). Current policy supports booking by 12 weeks for all women.  *“The main rationale… is to allow women to participate in antenatal screening programmes for haemoglobinopathies and Down‘s syndrome in a timely fashion, to have their pregnancies accurately dated using ultrasound scan, and to develop a plan of care for the pregnancy which sets out the number of visits required and additional appointments that may need to be made”* (p11). |
| **Australia** | Australian Department of Health. *Clinical Practice Guidelines – Antenatal care - Module I.* 2012. Australian Government, Department of Health and Ageing, Canberra. | *“Consensus-based recommendation: at the first contact with a woman during pregnancy, make arrangements for the first antenatal visit, which requires a long appointment and should occur within the first 10 weeks”* (p 32). |
| **Australia**  **and New**  **Zealand** | The Royal Australian and New Zealand College of Obstetricians and Gynaecologists. *Standards of maternity care in Australia and New Zealand.* 2014. RANZCOG, East Melbourne, Australia. | *“Booking should take place in early pregnancy and ideally all pregnant women should have had their first full booking visit and a hand held maternity record completed by 12 weeks of pregnancy”* (p20). |
| **USA** | McGlynn EA *et al*. Prenatal care interventions, in *The Quality of Health Care Delivered to Adults in the United States,* RAND Health working paper. 2006. RAND Corp., Santa Monica, CA. | *“The first prenatal visit should occur in the first trimester”* (p40). |
| **USA** | US Dept for Health and Human Services, Agency for Healthcare Research and Quality. Akkerman D *et al.* Routine Prenatal Care. 2012. Institute for Clinical Systems Improvement, Bloomington, MN | *“Expeditious access to prenatal care: Early confirmation of pregnancy is important because it allows for early intervention to mitigate risk factors. This includes early screening* (p10).” Recommended first visit by 6-8 weeks gestation. |
| **Europe** | EURO-PERISTAT project. *European Perinatal Health Report: the health and care of women and babies in Europe in 2010.* 2013. | *“In Europe, despite enormous variability in what constitutes basic prenatal care during pregnancy, there is a general consensus that it should begin early... An early first antenatal visit has become the accepted standard for antenatal care”* (p87-88) - by the end of the first trimester. |
| **Global**  **(WHO)** | World Health Organisation (WHO). *Standards for maternal and neonatal care: Provision of effective antenatal care.* 2006. WHO, Geneva. | *“Evidence suggests that, given the need for early identification of underlying problems to ensure efficacious treatment, the first ANC visit should be as early as possible in pregnancy, preferably in the first trimester”* (p4). |

The NICE guideline *Pregnancy and Complex Social Factors* identifies three milestones in terms of access to early pregnancy care: 10, 12+6 and 20 weeks gestation (NCCWCH 2010: 41). Ten weeks was chosen as this is the target set out in the NICE Antenatal Care clinical guideline (CG62) for early booking. However, the authors acknowledge this is a difficult target to attain, especially for women in vulnerable groups. They have therefore added a second target for early booking, identifying this as one which is well recognised within maternity services and research relating to access to antenatal care: booking by the end of the first trimester of pregnancy (12+6 weeks). The definition of late booking being at 20 weeks reflects *“a widely accepted definition and which is associated with the upper limit for carrying out serum screening for Down‘s syndrome and anomaly screening using ultrasound”* (p41), though this is identified as 20 weeks rather than 20+6. Maternity care commissioners in the UK must now ensure that the number of women booking at these points in pregnancy are recorded.

***1.1.3 Why is late booking important?***

In the UK and internationally, early booking and access to regular antenatal care are widely accepted as normal and appropriate pregnancy behaviour, beneficial for both mother and baby. The ‘cause and effect’ of poor engagement and poor outcomes is sometimes presented simplistically, for example with statements like *“early, quality prenatal care is critical to improving pregnancy outcomes”* (Gazmararian *et al* 1997: 18). Baker and Rajasingam (2012), in their London-based study, suggest correctly that late booking means that women *may* not have the opportunity to benefit from screening tests, antenatal education and health advice, and that complications and conditions *may* not be identified until they have started to compromise the health of the mother or fetus. This is turn *can* have long term health consequences (my emphasis).

The picture is far from simple however. Timely and adequate antenatal care is generally acknowledged to be an effective method of reducing adverse outcomes in some pregnant women and their babies, but there is a lack of strong evidence (Alderliesten *et al* 2007, Lavender *et al* 2007). Dowswell *et al* ‘s (2010) Cochrane systematic review argues that antenatal care is a complex intervention, reflecting the Medical Research Council (MRC) definition of an intervention with several interacting components (MRC 2008). Although it is reasonable to assume that it does confer some health benefits, how it does so may be multifactorial and unclear. Similarly the definitions of ‘timeliness’ and ‘adequacy’ of care are far from clear cut in developed countries. As the NICE guideline for *Pregnancy and Complex Social Factors* states:

*“It is likely that early assessment of pregnancy needs and screening also lead to more appropriate antenatal care, which in turn would result in improved pregnancy outcomes, although there is little evidence to support this in income rich counties.”* (NCCWCH 2010: 41-42)

Many studies examining inadequate care do not differentiate between the timing of the initiation of antenatal care and the total amount of antenatal care received. One large UK birth cohort study did make this distinction, but found no relationship between delayed antenatal attendance (after 28 weeks gestation) and adverse pregnancy outcomes (Thomas, Golding and Peters 1991). Research demonstrates that a reduced frequency of antenatal appointments for low risk women has no influence on clinical outcomes, but does have a negative influence on women’s satisfaction with their care. The Cochrane review of reduced versus standard packages of antenatal care for low-risk pregnancy found that perinatal mortality was increased amongst those women randomised to a reduced number of antenatal visits, though the difference was only significant in low- and middle-income countries (Dowswell *et al* 2010). Gestation at booking was not considered however. There were no clear differences between the groups for the other reported clinical outcomes. However women in all settings were less satisfied with the reduced visits schedule and perceived the gap between visits as too long, and in one of the UK studies women were more worried about their babies and perceived them more negatively (Sikorski *et al* 1996). Downe *et al* (2009), in their meta-synthesis of barriers to antenatal care for marginalised women in high-income countries, suggest that these ‘low risk’ women might be expected to maintain a normal pregnancy, regardless of the number of antenatal visits.

However, as Philippi observes, in her US-based literature review of women’s perceptions of access to antenatal care (2009), the picture is complicated by the fact that most women who do not receive early and/or adequate antenatal care are in a demographic category that is associated with increased risk of poor pregnancy outcomes. There is sufficient data from repeated epidemiological studies that socio-economic deprivation is linked to both decreased access to antenatal care and increased maternal and fetal morbidity and mortality. There is less agreement however as to whether late, infrequent or non-attendance at antenatal services in particular is associated with adverse outcomes (Macfarlane and Mugford 2000, Rowe and Garcia 2003, Downe *et al* 2009).

Arguably these ‘high risk’ women have most to gain from antenatal care. The NICE guideline for *Pregnancy and Complex Social Factors* suggests that despite a lack of current evidence, *“it seems likely that facilitating early booking for these women is even more important than for the general population of pregnant women”* (NCCWCH 2010: 11). The US Department of Health and Human Services have previously estimated that up to 80% of women at high risk of having a low birthweight baby could be identified at the initial (booking) appointment (Roberts *et al* 1998). As a minimum, the potential to address women’s needs is greatly enhanced when antenatal care is utilised early and regularly (Lavender *et al* 2007). Holistic and bespoke approaches offering social support in addition to the antenatal ‘interventions’ proposed by NICE (NCCWCH 2008) have demonstrated positive outcomes in disadvantaged communities (both in the short and long term) for mothers, babies and families (Oakley, Rajan and Grant 1990, Leamon and Viccars 2007, Hollowell *et al* 2011). In terms of antenatal screening, inequalities in access to/uptake of screening may potentially disadvantage those most at risk, as these are the women most likely to have or to be carriers for the conditions being screened for, such as hepatitis or thalassaemia. Some researchers have argued that the system is therefore failing some women (Rowe *et al* 2004).

**1.1.3.1 Maternal wellbeing**

Numerous UK maternal mortality (CEMD) reports have suggested a link between late booking and maternal mortality, though the figures are complicated by combining initial and further attendance during pregnancy, and differing definitions of late booking. In the most recent report (Knight *et al* 2014), 9.3% of women who died beyond early pregnancy didn’t receive any antenatal care at all, and 22.5% of women had booked for care after 12 weeks. For a further 9.2% of the women this information was missing. 24.7% of women did not receive the minimum recommended level of antenatal care. In the previous report (CMACE 2011) 13% of the women who died had not booked by 18 weeks of gestation, did not seek care at all or actively concealed their pregnancies. Another 13% were poor antenatal attenders and for another 4% of women this information was missing. This is in contrast with the 4% of mothers found not to have booked with NHS maternity services by 18 weeks of gestation in a study undertaken by the National Perinatal Epidemiology Unit (NPEU) in 2006, covering the same period (Redshaw *et al* 2007). In preceding triennial CEMD reports, the percentage of women who died following late or no booking and/or poor attendance was 20%, 20% and 17% (Lewis 2007, Lewis 2004, CEMD 2001).

The 2014 CEMD report identifies that whilst direct maternal deaths have halved in the past ten years, maternal deaths from indirect (medical and psychiatric) causes have remained static. Seventy four percent of the women who died in the triennium covered were known to have pre-existing medical complications, whilst 17% were known to have pre-existing mental health problems (Knight *et al* 2014). Such women could have benefitted from early booking and appropriate referral for specialist care. The reports also continue to highlight that a disproportionate number of the women who die come from the most vulnerable and excluded groups of society: the poorest, often non-white, women living in the most deprived areas. The link between adverse pregnancy outcomes and vulnerability and social exclusion is clear, with the reports demonstrating that those women who need maternity services most use them the least. Vulnerable women with socially complex lives who died were far less likely to seek antenatal care early in pregnancy or to stay in regular contact with maternity services. Some of the women who died were let down because, although the initial referral was timely, they did not receive a ﬁrst maternity service appointment until they were around twenty weeks gestation; *“This delay denied them the opportunities that early maternity care provides for mother, baby and family”* (Lewis 2007: x).

**1.1.3.2 Fetal/neonatal wellbeing**

Lewis, in the 2004 CEMD report, suggested that children born to women from more vulnerable groups experience a higher risk of death or morbidity, with women facing problems with pre-term labour, intrauterine growth restriction, low birth weight and higher levels of neonatal complications. US Government figures from the 1980s and 90s suggested that for every dollar spent on antenatal care more than three would be saved in the first year of a baby’s life, in terms of reducing such growth restriction and infant mortality (Johnson *et al* 1994). Lavender *et al’s* (2007) systematic review of quantitative studies comparing early, late and no antenatal access found one study suggesting a link between late booking and increased perinatal morbidity (Petrou *et al* 2003), and others suggesting women who were unbooked to be at greater risk of perinatal morbidity and possibly mortality as well. However the findings were limited by a lack of prospective studies and UK evidence.

In one large cohort study based on 12 years of Finnish hospital register data, chorio-amnionitis or placental abruptions were more common complications of pregnancies of women ‘avoiding’ antenatal care (the authors’ language), and pregnancy outcome was impaired, even when adverse pregnancy outcomes were controlled for confounding factors (Raatikainen *et al* 2007). There were significantly more low birth weight infants in under- and non-attenders, more fetal deaths and more neonatal deaths. The authors conclude that even when birth takes place in hospital, non- or under-attendance at antenatal care carries a substantially elevated risk of severe adverse pregnancy outcome. A recent Belgian study, analysing the relation between specific elements of antenatal care and the risk of preterm birth (in comparison to consideration of the number of visits only) found a significant association between the content and timing of care and preterm birth, including initiation of antenatal care after 14 weeks gestation (Beeckman *et al* 2012).

Noonan *et al*’s (2013) review of data from a national (US) urban birth cohort study argues that whilst the evidence that early or adequate antenatal care has favorable effects on birth outcomes is limited, it is possible that it confers health benefits to the child that do not become apparent until after the perinatal period. They suggest that *‘routine health care encounters during the prenatal period could potentially be used more effectively to enhance children’s health trajectories’* (p189).

***1.1.4 How many women are accessing antenatal care late?***

Despite recommendations for early access, many women do not present early for antenatal booking. Studies have found hugely varying proportions of late booking women, but with varying definitions of late, most commonly between 18 and 22 weeks gestation. However the figures are further complicated by differing definitions of booking itself. Recently published NHS data showed a figure of 86.8%of women being *‘seen and assessed by a healthcare professional within 12 weeks and 6 days of their maternity’*, missing the 90% minimum target (DoH 2013). The 2007 Department of Health paper *Maternity Matters: choice, access and continuity of care in a safe service* quotes the percentage of women having their first hospital appointment after 20 weeks gestation for 2004-5 as around 16%, citing Hospital Episode Statistics (HES) (DoH 2007). A more recent publication from the Health and Social Care Information Centre presented HES data for 2011-12, which showed 13.5% of women being more than 19 weeks gestation at their ‘first antenatal assessment date’ (presumably their first hospital appointment). However with more than 27% being of unknown gestation at their first appointment, because it was not recorded (the author comments on the poor quality of data submitted by some NHS trusts), the figure could be considerably higher (HSCIC 2012). As hospital attendance statistics don’t take into consideration women who have already received antenatal care elsewhere, accurate figures are difficult to ascertain in this way.

Rowe *et al*’s (2008) cross-sectional study, using a postal survey of 839 antenatal women from 15 English hospitals, found the figure to be 2.5% booking after 18 weeks. Though the study was inevitably subject to response bias, the figure was significantly higher amongst certain ethnic and social groups. Similarly, though on a larger scale, the NPEU’s survey, *Delivered with Care: a National Survey of Women’s Experience of Maternity Care 2010,* was based on a postal survey of 10,000 randomly selected postnatal women (from birth registration data) aged over 16 years. It found that 2.8% of the 5333 respondents had not booked with NHS maternity services by 19 weeks, though there was significant regional variation (the figure was 6% in London) and that again certain social and ethnic groups were more likely to access care later (Redshaw and Heikkila 2010). This figure had fallen to 1.7% in the 2015 NPEU survey, though the response rate had also fallen overall to 47% (4571 women) (Redshaw and Henderson 2015).

Kupek *et als* (2002) analysis of the pregnancy records of 17,765 women from nine maternity units in Northern England and North Wales found 7% of women initiated care after 18 weeks. This contrasts with statistics from one London hospital which found that 31% of women in one financial year (2007-8) booked for antenatal care after 18 weeks gestation (Baker and Rajasingam 2012). An audit of 6 other London hospitals found between 8.2% and 22.5% of pregnant women booking after 22 weeks, though the author acknowledged that women transferring in after an initial booking elsewhere in the country were included in these numbers (Gaudion 2008). Statistics from the Jessop Wing in Sheffield showed that 6% of pregnant women booked after 19 weeks gestation in 2009-2010, though this figure was higher (8.7%) amongst women aged less than 20 years (NHS Sheffield 2010).

***1.1.5 Who are the late booking women?***

Table 1.1.5 summarises maternal characteristics associated with the late initiation of or reduced attendance for antenatal care, in UK and Northern European studies.

Rowe and Garcia’s 2003 systematic review of social class, ethnicity and attendance for antenatal care in the United Kingdom, confirms that evidence from outside the UK (Europe, USA and Australia) suggests that socio-economic factors - young age, ethnicity, low income, low education, unmarried status and high parity - are associated with late initiation of antenatal care and/or fewer antenatal visits. Other studies have confirmed this link to deprivation, marginalisation and low autonomy (Downe *et al* 2009). Rowe and Garcia comment that it is not clear how generalisable these are to the UK context however (p114). Their review of nine UK studies (selected from 1300 identified papers) assessing attendance for antenatal care according to social class, deprivation or ethnicity found that most studies were old and were of poor quality, involving small numbers, differing definitions of late booking and not taking into account confounding factors such as age and parity. They did suggest that women from manual classes were more likely to book late and/or make fewer visits, especially

***Table 1.1.5: Chronological summary of UK and European studies of maternal characteristics associated with later initiation of or reduced attendance for antenatal care***

|  |  |  |  |
| --- | --- | --- | --- |
| **Country** | **Author(s) and year** | **Type of study and number of participants** | **Maternal characteristics associated with later initiation / reduced antenatal care** |
| Europe | Delvaux et al 2001 | Case control study of 1283 women with inadequate care and 1280 women with adequate care, from 10 European countries. | Lack of health insurance,  Young age, High parity,  Non-European origin,  Low income,  Lower educational achievement |
| UK | Rowe RE and Garcia J 2003 | Systematic review of 9 UK studies assessing attendance for antenatal care | From manual classes,  Unemployed partner,  BME group (Asian origin) |
| UK | Rowe RE, Garcia J, & Davidson 2004 | Systematic review of 20 UK studies assessing offer or uptake of antenatal screening | BME group (South Asian origin) |
| UK  N England N Wales | Kupek E *et al* 2002 | Retrospective survey of records from 9 hospitals in 1 year: 20,771 women. | Young age,  Smoking,  BME group, particularly Pakistani |
| UK  national | Redshaw M *et al* 2006 | Postal questionnaire. 3024 postnatal women randomly selected from 1 week of birth registration data. | BME group (born in UK and not),  Living in deprived area,  Single |
| Finland | Raatikainen K *et al* 2007 | Cohort study: review of 27,776 births from patient data and antenatal questionnaires from 1hospital over 12 years. | Unmarried status,  Lower educational achievement,  Young age,  Smoking and alcohol use |
| Holland | Alderliesten *et al* 2007 | Prospective cohort study: postal questionnaire. 8267 pregnant women from midwifery practices and 6 hospitals, over 14 month period. | Poor language proficiency,  BME group,  Lower educational achievement, Young age (teenage pregnancy) |
| UK  England | Rowe RE *et al* 2008 | Cross-sectional antenatal survey. Postal questionnaire.  839 women from 15 hospitals. | BME group, No partner,  Never worked/unclassified employment status |
| UK  England | Raleigh VS *et al* 2010 | Postal questionnaire. 26,325 postnatal women from 151 NHS trusts. | BME group (inc. non-British white)  Single,  Lower educational achievement |
| UK  national | Redshaw M & Heikkila K 2010 | Postal questionnaire. 5333 postnatal women randomly selected from 2 weeks of birth registration data. | BME group (born in UK and not),  Young age,  Lower educational achievement,  Living in deprived areas |
| UK  London | Baker EC & Rajasingam D 2012. | Retrospective cohort study: review of medical notes of 5629 women in one London hospital in one year. | Young age (teenage pregnancy),  High parity (>4),  BME group (‘other’) |
| UK  London | Cresswell JA *et al* 2013 | Cross-sectional analysis of patient data for 20,135 women from 1 London hospital over 3 year period. | Poor language proficiency,  BME group (Non-British white, African/Caribbean),  Non-UK birthplace, Young age  Living in temp. accommodation |
| UK  national | Redshaw M & Henderson J 2015 | Postal questionnaire. 4571 postnatal women randomly selected from 2 weeks of birth registration data. | BME group (Black/Black British),  Young age,  Single,  Lower educational achievement |

if their partners were unemployed, and that Asian women were more likely to book late than white British women. They concluded that little good quality evidence existed on social and ethnic inequalities in antenatal attendance in the UK.

A further systematic review of social and ethnic differences in the uptake of antenatal screening (Rowe, Garcia and Davidson 2004) found equally poor quality papers but some suggesting women of South Asian origin were less likely to receive certain screening tests, and two studies linking late booking to lack of screening. This is significant as screening forms such an important part of antenatal booking. In Kupek *et al’s* (2002) study in Northern England and North Wales, maternal characteristics associated with late initiation were low maternal age, smoking and ethnicity, withBlack and Minority Ethnic (BME) women, particularly Pakistani, up to five times more likely to initiate antenatal care after 18 weeks than white women. In Rowe *et al*’s cross-sectional postal study (2008), black women were six times more likely to book late (9.6% as opposed to 1.6% of white respondents), though the authors admitted the numbers were small (four women); as were those women with no partner. Socioeconomic status was not significantly associated with late attendance, though women who had never worked or whose employment status was not classified were more likely to attend late. Compared to national data, there were fewer responders born outside the UK in this study, even though interpretation services were available for women to complete the survey. The authors suggested that the non-responders were more likely to be BME women and therefore more likely to attend late, so the 2.5% they found was likely to be an underestimate of the true proportion of women initiating and booking late for antenatal care.

Other UK surveys have had similar findings. A recent study at a large East London hospital found multiple predictors for late initiation of antenatal care, including non-British (white) ethnicity, poor English language skills and non-UK birthplace, African/Caribbean ethnicity, age less than 20 years and living in temporary accommodation (Cresswell *et al* 2013). The 2007 national Healthcare Commission funded survey of maternity services, with 26,325 respondents, found that BME women (including non-British white ethnicity), single women and women completing education at 16 years or earlier were more like to access antenatal care after the recommended 12 weeks gestation (Raleigh *et al* 2010). In the 2010 NPEU study Black women, both born in the UK and not, young women, those with lower educational achievement and those living in the most deprived areas (based on the Index of Multiple Deprivation) were significantly more likely to first see a health professional later in their pregnancies (Redshaw and Heikkila 2010). Secondary analysis of the data from this study found that after adjusting for age, ethnicity and parity, when compared to women living in the highest Index of Multiple Deprivation (IMD) quintile, women living in the lowest quintile were:

* 60% less likely to have received any antenatal care,
* 38% less likely to have been seen by a health professional before 12 weeks gestation, and
* 47% less likely to report being able to see a health professional as early as they desired in their pregnancy (Lindquist *et al* 2014).

Studies from Northern European countries, comparable to the UK in terms of their universal accessibility and encouragement of antenatal care, have also had similar findings. Raatikainen *et al’s* (2007) Finnish study found that under or non-attendance was associated with social and health behavioural risk factors including unmarried status, lower educational level, young maternal age, smoking and alcohol use. A large Dutch cohort study found all ethnic minority groups starting antenatal care significantly later. Poor language proficiency and education, and higher teenage pregnancy rates were major factors, however where no language barrier existed cultural factors (even after several generations) and attitude to pregnancy played a role in delaying access (Alderliesten *et al* 2007).

Attitudinal factors in relation to access to healthcare generally are well documented, with a suggestion that some lower socio-economic, ethnic or cultural groups may see health as being further from their control than others do, and are subsequently less able to make healthy choices (DoH 2004c). The influence of personal barriers such as attitude towards pregnancy, personal beliefs and lifestyle on the access to antenatal care is identified by studies, though mainly from the USA and most are 10-20 years old. These note a significant link between unplanned and particularly unwanted pregnancy, indifference to the pregnancy and delayed or non-attendance for antenatal care (Mayer 1997, McComb Hulsey 2001). Some studies however suggest that ‘planned ‘unplanned’ ‘mistimed’ etc. are not terms that women use when viewing their pregnancies, and there is debate about women’s acceptance of the concept of pregnancy ‘planning’ and the limitations of using such terms (Barrett and Wellings 2002). It has been estimated that as many as 50% of pregnancies in the UK are unplanned or mistimed (CMACE 2011). Unplanned pregnancy has been linked to lower socio-economic and educational status, young age and black ethnicity, also to negative health behaviours and attitudes. Links to poorer birth outcomes have also been identified (Barrett and Wellings 2002). Keeton and Hayward’s (2007) US cross-sectional study of pregnancy intention, using data from 48,000 births, cites ethnicity and particularly age as the most important factors influencing outcomes, though the authors agree that unwanted pregnancies are a reason for non-attendance antenatally, as well as poor socio-demographic and economic conditions.

**1.2 UK public health guidance in relation to health inequality and access to antenatal care**

Guidance on early access to antenatal care reflects the public health agenda and the focus of successive British governments to try to identify and tackle health inequalities and improve access to all healthcare. The publications are summarised in table 1.2. As the 2010 white paper *Equity and excellence- Liberating the NHS* (HM Government 2010) states*:*

*“Pregnancy offers a unique opportunity to engage women from all sections of society, with the right support through pregnancy and at the start of life being vital for improving life chances and tackling cycles of disadvantage”* (p17).

Policies reflect the influence of Tudor Hart’s ‘Inverse Care Law’ (Hart 1971, Appleby and Deeming 2001) and the findings of landmark health reports such as the 1980 *Report of the Working Group on Inequalities in Health* (Black report) (Department of Health and Social Security (DHSS) 1980) and the 1998 *Independent Inquiry into Inequalities in Health* (Acheson Report) (DoH 1998). The Acheson report in particular

***Table 1.2: Chronological summary of significant publications relevant to access to maternity care in England***

|  |  |  |
| --- | --- | --- |
| **year** | **Publication** | **Primary messages in relation to health inequality/access to healthcare/access to maternity care** |
| **1971** | **The Inverse Care Law** | *"The availability of good medical care tends to vary inversely with the need for it in the population served”* (Tudor Hart 1971: 405). Access to services also affected by the inverse care law: those who need healthcare least use the services more, and more effectively, than those with the greatest need (Appleby and Deeming 2001). |
| **1980** | ***The Report of the Working Group on Inequalities in Health*** (Black) | Improvement in overall health since the introduction of the welfare state, but widespread health inequalities, due mainly to economic inequality (DHSS 1980). |
| **1993** | ***Changing Childbirth: Report of the Expert Maternity Group*** (Cumberlege) | 3 principles of good maternity care, including *“Maternity services must be readily and easily accessible to all. They should be sensitive to the needs of the local population and based primarily in the community”* (DoH 1993). |
| **1998** | ***The Independent Inquiry into Inequalities in Health report*** (Acheson) | Existence of health disparities and their relationship to social class. Need to break the ‘intergenerational cycle’ of health inequalities and to prioritise the health of families, particularly pregnant women (DoH 1998). |
| **2004** | **House of Commons Health Committee report: inequalities in access to maternity services** | Unequal access still a significant issue. Further research necessary to establish the reason for inequalities and poor access to antenatal care (HM Government 2004). |
| **National Service Framework (NSF) for children, young people and maternity services** | Emphasis on designing a service to meet needs of all, especially vulnerable and disadvantaged women who experience poorer outcomes. Women should *“have easy access to supportive, high quality maternity services, designed around their individual needs and those of their babies”* (DoH 2004a: 4). |
| ***Every Child Matters: change for children in health services*** | National support to be provided to local agencies to assist them in implementing the NSF, as part of wider *Every Child Matters: Change for Children* programme (DoH 2004b). |
| **2006** | ***Our Health, Our Care, Our Say: a new direction for community services*** | Proposed a more flexible, personal service, tailored to the specific health or social care needs of individuals (DoH 2006) |
| **2007** | ***Maternity Matters: Choice, access and continuity of care*** | Need for *“high quality, safe and accessible services that are both women-focused and family-centred”* (p5). Unacceptable outcomes for some women, especially the vulnerable and disadvantaged (DoH 2007a). |
| **Health Inequalities Public Service Agreement (PSA) Target** (including infant mortality target) | Aim to reduce inequalities in health outcomes as measured by infant mortality and life expectancy at birth. Focus on helping families to access services and importance of early antenatal care (DoH 2007b). |
| **PSA 19: *Ensure Better Care for All*** | Specific target of increasing early booking and monitoring of access to maternity care (HM Gov 2007). |
| **2009** | **NHS Operating Framework Report for 2010-11** (and previous reports) | *“Ensuring that women access care by their 12th completed week of pregnancy enables the needs and choices of women and their partners to be met throughout the pregnancy…”* (DoH 2009: 18). |
| **2010** | ***Fair Society, Healthy Lives*** (The Marmot Review) | Evidence-based strategies for reducing health inequalities in England. Highest priority recommendation: to give every child the best start in life. *“Giving priority to pre- and post-natal interventions that reduce adverse outcomes of pregnancy and infancy”* (Marmot 2010: 22). |
| ***2010*** | ***Equity and Excellence - liberating the NHS*** | *“Extend maternity choice and help make safe, informed choices throughout pregnancy and in childbirth a reality… the right support through pregnancy and at the start of life being vital for improving life chances and tackling cycles of disadvantage”* (HM Government 2010: 17). |
| **2012** | **NHS Commissioning Guidance** | Importance of early booking for pregnant women, recommending *“a full medical and social risk assessment before the end of the 12th week of pregnancy”* (NHS Commissioning Board 2012: 20). |

identified the need to break the ‘intergenerational cycle’ of health inequalities and to prioritise the health of families, and particularly pregnant women. The recent review on health inequalities, *Fair society, Healthy Lives,* recommended *“giving* *priority to pre- and post-natal interventions that reduce adverse outcomes of pregnancy and infancy”* (p22) as part of its highest priority recommendation: to give every child the best start in life (Marmot *et al* 2010).

The 1993 report *Changing Childbirth* defined one of its three principles of good maternity care as *“Maternity services must be readily and easily accessible to all. They should be sensitive to the needs of the local population and based primarily in the community”* (DoH 1993: 18). Ten years later the House of Commons Health Committee’s report into inequalities in access to maternity services acknowledged unequal access was still a significantissue, and recommended further research to establish the reason for the inequalities and poor access to antenatal care (HM Government 2004).

The National Service Framework (NSF) for Children, Young People and Maternity Services (supported by *Every Child Matters: change for children in health services* – both DoH 2004) set out a ten-year programme for sustained improvement in children’s health and well-being, setting standards for the care of children, young people and maternity services. It reiterated the ideals of *Changing Childbirth*, promoting *“an individualised, flexible, woman-focused approach to care and support”* (p8) and emphasis on designing a service to meet needs of all, especially vulnerable and disadvantaged women such as refugees and asylum seekers, homeless women, substance misusing women, teenagers, and women experiencing domestic abuse. It acknowledged that some women, usually the most vulnerable, still miss out on services for pregnant women because they lack awareness of such services, and suggested that the disparity in uptake resulted in disproportionately poorer outcomes for women and babies.

One of the NSF standards stated that women should “*have easy access to supportive, high quality maternity services, designed around their individual needs and those of their babies”* (p4), and one of its ‘Markers of Good Practice’ stated that maternity services should be proactive at engaging all women, particularly those from disadvantaged groups and communities, early in their pregnancy and maintaining contact before and after birth. It identified that these women were significantly less likely to access services early or maintain contact throughout their pregnancies, factors which may affect the outcomes for their own and their babies’ health in the short and longer term. NHS maternity care providers and Primary Care Trusts (PCTs) (now replaced by Clinical Commissioning Groups (CCGs)) were required to plan their provision based on up-to-date assessments of the needs of the local population and involve local service users. They were also required to address the reasons why certain women find it difficult to access and maintain contact with maternity services, by designing services to overcome these barriers to care. This included ‘community-based continuity of care schemes’ for the most vulnerable, and targeted health promotion and education materials for pregnancy, encouraging early access to antenatal care.

A subsequent white paper *Our Health, Our Care, Our Say: a new direction for community services* (DoH 2006) set out the future for health and social care services. It proposed a more flexible, personal service, tailored to the specific health or social care needs of individuals. Following on from thisPublic Service Agreements (PSAs) were drawn up, with targets that set out the key public service improvements proposed by the government. The Department of Health established an infant mortality PSA target, one element of the *Health Inequalities PSA Target*, to reduce inequalities in health outcomes as measured by infant mortality and life expectancy at birth (DoH 2007a). A review of the target was established to consider why, despite a general improvement in infant mortality rates, significant health inequalities in infant mortality between different social groups remain. Recommendations included promoting the joined-up delivery of services, a strong focus on helping families to access services and the importance of early antenatal care, though it acknowledged the limitations of the evidence to support this:

*“there are interventions that… are likely to have an impact even without all the evidence, e.g. early booking and effective use of high-quality healthcare” (DoH 2007a:7).*

*“Early booking by 10–12 weeks gestation allows for antenatal diagnosis and planned management. Ensuring that women in the R&M group and black and ethnic minority groups book early and are able to access antenatal screening tests may help reduce infant mortality health inequalities” (ibid: 31)*

PSA19: *Ensure Better Care for All* (HM Government 2007) also had a key indicator relating to maternity services, and the specific target of increasing early booking and the monitoring of access to maternity care formed part of this indicator:

*“maternity service providers need to ensure that services are accessible to all women, including the vulnerable and excluded, so that a risk assessment can be completed, women can make informed choices about their care, and appropriate care and services are put in place to help improve life chances for children”* (HM Government 2007: 4).

The aim was that this would lead to the more flexible, responsive and accessible maternity services envisaged in the NSF. Again, it was proposed that ‘new and different types of care’ were designed to meet the needs of all women and their families who need additional support, such as outreach services for those who traditionally do not access maternity care early in their pregnancy, so that all pregnant women could benefit from early care:

*“women who are able to access maternity services for a full health and social care assessment of need, risk and choices by the 12th completed week of their pregnancy will have the full benefit of personalised maternity care and improved outcomes and experience for mother and baby”* (HM Government 2007: 5).

A specific target for increasing early access was introduced in 2008, withPCTs required achieve more than 90% of women booking by 12+6 weeks by 2010-11 (NHSIC 2008). As previously mentioned, this has not always been achieved. Although the PSAs have been abolished, this data is still collected as part of government transparency requirements.

The influential DoH maternity white paper *Maternity Matters: choice, access and continuity of care in a safe service*, also published in 2007, also highlighted the need for “*high quality, safe and accessible services that are both women-focused and family-centred*” (p5) and the unacceptable outcomes for some women, especially the vulnerable and disadvantaged, with increased maternal and infant mortality. It described a *“comprehensive* *programme for improving choice, access and continuity of care”* (p7) to be used by commissioners and providers of healthcare, as part of the government’s health reform agenda (DoH 2007c). Once again ‘improved access to services’ was cited as a key aim, and the need to understand what prevents some women from seeking care early in their pregnancies or maintaining contact with maternity services. Similarly, numerous NHS Operating Framework reports, most recently for 2010-2011, have identified early booking as an NHS priority (DoH 2009).

Though *Maternity Matters* is no longer government policy, the 2010 White Paper *‘Equity and excellence- Liberating the NHS’* has continued the focus on extending maternity choice and engaging women during pregnancy (HM Government 2010). Recent guidance for the new CCGs on commissioning maternity services has reiterated the importance of early booking for pregnant women:

“*Her midwife will help her develop a personalised plan of care for pregnancy including undertaking a full medical and social risk assessment before the end of the 12th week of pregnancy.* (NHS Commissioning Board 2012: 20)*”*

**1.3 The need to examine women’s perceptions and beliefs towards late booking**

The statistics and demographic information around late booking only tell part of the story. Feijen-de Jong *et al’s* (2011) systematic review of late and/or inadequate use of antenatal care identifies that many *retrospective* studies identify factors which are associated with late or poor antenatal care usage, but not the mechanisms associated with such usage. They suggest that further research, quantitative and qualitative, is needed to ‘disentangle’ such mechanisms. As Downe *et al* (2009), in their meta-synthesis of barriers to antenatal care for marginalised women in high-income countries, acknowledge:

*“Knowing that certain factors appear to influence outcomes does not tell us about the mechanisms and contexts in which these factors flourish. Interventions to address these factors cannot be devised unless the underlying mechanisms and contexts are understood and addressed”* (p519).

This suggests the need for a detailed exploration of women’s perceptions of antenatal care. Novick’s (2009) review of women’s experiences of antenatal care agrees, suggesting that despite decades of recommendations for women-centred approaches to antenatal care, women’s experiences are still relatively unexplored.

Oakley’s historical perspective on antenatal care (1982) identifies that concerns about antenatal non-attendance were raised even before widespread antenatal care was available in the UK in the late 1920s. She highlights women’s dissatisfaction with antenatal services as one of the strongest reasons why providers have been unable to reach all their potential clients. Garcia (1982), in the same publication, also notes that the need to gain women’s views about access to antenatal care has long been recognised. In 1949 the Royal Commission on Population, considering antenatal non-attendance, recommended that *“in the development of the maternity service… there is a special need for a close study of the woman’s point of view”* (RCP 1949 cited in Garcia 1982: 82).

Commenting on their delayed or reduced access to antenatal care, the authors of previous CEMD reports have questioned whether women died because they were unaware of the need for care, or unaware of the warning signs of problems in pregnancy, or because the services did not exist, or were inaccessible for other reasons such as distance, cost or sociocultural barriers (Knight *et al* 2014, Lewis 2004). Their recommendations have included that

*“The views of women who book late or fail to attend should be sought in helping to provide more appropriate services in future. The views of all women who use the services should also be sought on a regular basis”* (CEMD 2001, executive summary: 7-8).

The Government response to the House of Commons Health Committee’s *Inequalities in Access to Maternity Services report* in 2004also recommends further research:

*“If maternity services are to meet the needs of disadvantaged women, babies and families, the evidence base on which policy decisions and service developments are made must be expanded. We recommend that the Department commission programmes of quantitative and qualitative research so that an accurate assessment of the extent to which women who do not gain full access to maternity care can be made, the reasons for inequalities and inequities established and further action taken to address these inequalities”* (HM Government 2004: 10,51).

Asystematic review of access to antenatal care, by Lavender *et al* (2007),concludes that there is a general lack of both quantitative and qualitative research, particularly based in the UK, which addresses the phenomenon of late antenatal attendance or non-attendance. They argue that large scale audits are likely to produce superficial results, and suggest *‘pursuing work with known disadvantaged groups’* (p6) may be most effective, enabling a ‘layered approach’ to the complexities of the topic. Rowe and Garcia (2003), commenting on the poor quality evidence for late access to antenatal care, recommend the depth and detail of qualitative research:

*“Qualitative research is also needed to provide a better understanding of why some women book late for antenatal care or do not attend antenatal appointments”* (p118).

They advocate that non-attendance should be explored from a woman’s viewpoint as well as a professional/service perspective. This final point is significant in that it suggests both women and practitioners have a contribution to make to the understanding of late booking.

***1.3.1 My personal perspective as a midwife***

As a midwife I come from a profession which integrates biomedical, psychological and social perspectives in order to provide holistic care for women and their babies. I have a strong belief in the value of antenatal care. I want women to come for care early and regularly during their pregnancies because, like other midwives, I see it making a positive contribution. Though I acknowledge its limitations, I believe it makes a difference to women’s physical health and psychological wellbeing, to their experience of pregnancy and their preparation for parenthood, whether women are expecting their first or subsequent babies. I consider that some women, often women with difficult life circumstances, don’t prioritise their antenatal care because they don’t recognise its value, and that this lack of understanding may be the primary cause of late booking. My clinical experience leads me to acknowledge that there is an expectation that women *will* attend for care, but also that women are rarely asked for their opinions about the timing and content of the antenatal care they are offered. A drive to understand better women’s perceptions of antenatal care, and ultimately to improve access, underpins this research.

**1.4 Conclusions**

Antenatal care in the UK is a well-established and widely accepted programme of health screening, health education and social support, with national policies and clinical guidance encouraging early and regular attendance. It represents a significant element of contemporary midwifery practice, with antenatal booking the start of the midwife-woman relationship. The full impact of inadequate care during pregnancy, particularly late booking, is unclear, and complicated by many factors. Connections to health inequalities, in particular maternal, fetal and neonatal morbidity and mortality (especially amongst certain social and ethnic groups), have been made. Estimations of the number of women booking late vary widely, but suggest that a small but significant number of pregnant women do not attend early, many with risk factors for poor pregnancy outcomes. There is limited evidence to support the complex set of interventions that is modern antenatal care. However, women who book early are more likely to receive appropriate care and achieve better health, emotional and psychological outcomes (RCM 2012).

Many authors have identified the value of examining the attitudes and beliefs of late booking women, in an attempt to improve understanding, access to care and, ultimately, health outcomes. Gaudion and Homeyard's (2010) work with women of economic disadvantage in London considers that for professionals to develop true partnerships with such women, listening to their voices, however uncomfortable, *“provides the insight and learning to improve” (*p145). This has led to the development of a study to ‘listen to the voices’ of a group of late booking women, with the aim being to gain a deeper understanding of the reasons why some women present late for antenatal care. As part of this, chapter two will examine and synthesise the existing evidence in relation to perceptions and beliefs concerning the late initiation of antenatal care.

**Chapter 2: A literature review and critical interpretive synthesis of perceptions and beliefs towards late booking for antenatal care**

**2.1 Introduction**

The synthesis of research has been described as a process resulting in a ‘whole’ greater than the sum of its parts, pushing beyond the original data (in this case the literature on late booking) *“to a fresh interpretation of the phenomena”* (Barnett-Page and Thomas 2009: 15). It encompasses many approaches. Downe *et al* (2009) and others comment that there is a lack of UK-based qualitative research on access to antenatal care, and particularly delayed initiation (late booking). Preliminary literature searches confirmed this, but identified a small number of non-UK qualitative studies and a much larger number of quantitative and mixed method studies examining access to antenatal care, many including late booking as a focus. I decided therefore to search for a method of systematic review/synthesis that could summarise and integrate this diverse body of evidence.

The synthesis of qualitative healthcare research, most commonly using the principles of meta-ethnography (Noblit and Hare 1988), is recognised as a mechanism for producing theories with greater explanatory power than could be achieved in a narrative literature review (Seers 2012, Campbell *et al* 2003, 2011, Britten *et al* 2002). Synthesising qualitative research helps to ensure that patient/carer views and perspectives are incorporated into health service policy making and delivery. It can add new insight and value, and can identify common themes and any divergent views, as Ring, Jepson and Ritchie (2011) comment:

*“the strength of qualitative research is its ability to provide personal insight into the phenomenon being investigated but its perceived limitation has been the small number of participants and the inability to generalise findings. Being able to synthesise individual studies to produce a ‘stronger’ body of knowledge has, therefore, become of critical importance if the full potential of qualitative research to inform practice and policy is to be realised.”* (p388).

Meta-ethnographic techniques have been used solely with qualitative studies and small samples. A further challenge however is the comparison of a much larger and more diverse body of evidence, from a variety of sources, in a form that is useful in informing policy and that is empirically and theoretically grounded (Dixon-Woods and Fitpatrick 2001). Mays, Pope and Popay (2005) commentthat the complexity which surrounds clinical decision-making requires the synthesis of many different types of evidence.

Critical Interpretive Synthesis (CIS) is a relatively new method, developed in response to this challenge, by Dixon-Woods *et al* (2005/2006a,b), and originally used to synthesise evidence relating to access to healthcare by vulnerable groups. Its authors suggest the application and evaluation of CIS for use in challenging areas of health care. Responding to demands from policy-makers/managers for syntheses that are useful, rigorous and relevant, they argue that it should be possible (and is desirable) to include all forms of evidence in a synthesis. CIS has evolved from an attempt to use meta-ethnography and techniques from Grounded Theory to bring together findings from a large and methodologically diverse group of studies, moving beyond the limitations of interpretive syntheses confined to qualitative research (Barnett-Page and Thomas 2009, Campbell *et al* 2011, Heaton, Corden and Parker 2012). Flemming (2010) suggests it is the logical extension of qualitative syntheses. Both systematic and iterative in its approach, CIS is particularly useful for critical scrutiny of complex bodies of literature with the aim of generating new concepts, as well as recommendations for practice (Kazimierczak *et al* 2013).

Heaton, Corden and Parker (2012) suggest that CIS’s unique approach has distinct advantages, including the rejection of a ‘stage’ approach to review work and the promotion of a more flexible, iterative, dynamic and reflexive approach to synthesis. It enables researchers to engage critically with the assumptions underlying research, which help to shape and inform the results of studies, and *“can provide valuable additional knowledge, help to take stock of the current state of understanding and identify future research priorities and strategies”* (p8). It has the capacity to move beyond the aggregative understanding of conventional systematic review techniques and contribute to a more inclusive view of a topic (Talseth and Gilje 2011, Dixon-Woods *et al* 2006b).

It is an approach to the whole process of review, which is sensitised to the process of conventional systematic review methodology (summarising and theory testing), but draws on a distinctive tradition of qualitative enquiry and methods for interpretive synthesis (more theory generation): Noblit and Hare’s (1988) ‘integration’. Theoryin this context can be defined as an insightful and useful way of understanding a phenomenon which can be used to inform policy, practice and future research (Dixon- Woods *et al* 2005, 2006a). Dixon-Woods *et al* argue that CIS has the potential to go beyond a thematic summary of the literature, beyond accepting that the existing evidence base is the only valid way to understand a phenomenon, and insisting that it must fit under a rubric of ‘systematic review’ (Dixon-Woods *et al* 2006a,b).They suggest that CIS can

*“produce new insights and fresh ways of understanding the phenomenon… [it] offers the potential for insight, vividness, illumination and reconceptualisation of research questions, particularly in challenging areas”*(Dixon-Woods *et al* 2006a: 11)

CIS seeks to place literature within its context, to question its assumptions and to produce a theoretical model of a phenomenon. The theory is grounded in a comprehensive but not exhaustive body of evidence (Dixon-Woods *et al* 2005). It recognises the interpretive process required to produce an account of disparate forms of evidence, and is explicit about this, acknowledging the authorial voice in the process. The process starts with a clear but broad research question and uses transparent search and selection strategies, followed by an iterative process of synthesis to draw together conclusions from a wide range of research methodologies. As such it does not claim to produce a reproducible synthesis, but emphasises reflexivity and recognition that alternative accounts of the same evidence might be possible. However, the method reiterates that all accounts should be grounded in the evidence, and should be verifiable and plausible (Dixon-Woods *et al* 2006a,b).

**2.2 Method**

The CIS methodology links elements of conventional systematic reviews with interpretive approaches to analysis and synthesis of data typical of primary qualitative research (Kazimierczak *et al* 2013). An organic, creative and interpretive method, CIS has a relatively loosely defined set of processes for synthesising evidence (Greenhalgh *et al* 2005a). This flexible, ‘no stage’ approach includes question formulation and refining, searching, selection, data extraction, critique and synthesis, which proceed hand in hand in a dynamic and mutually informative way. This creates an iterative, inductive process rather than one that is fixed and sequenced, reflecting the influence of Grounded Theory (Barnett-Page and Thomas 2009, Heaton, Corden and Parker 2012). This adaptation is not unusual however; Ring, Jepson and Ritchie (2011) suggest that those synthesising qualitative research tend to adapt methods to suit their studies. The process focuses ultimately on fashioning a synthesising argument from available evidence, critiquing the quality of evidence, theory and assumptions made (Dixon-Woods et al 2006a). The method can be broadly divided into six interrelated and overlapping phases (table 2.2.1), though the boundaries become more diffuse as the synthesis progresses. I will explain these, briefly discuss their use in other studies and present the results of my synthesis.

***Table 2.2.1: phases of a critical interpretive synthesis***

|  |  |  |
| --- | --- | --- |
|  | **Formulating the review question, definitions and concepts** | Defining the review question, defining late booking for antenatal care |
|  | **Searching the literature** | Using search terms to search electronic databases, websites, also reference chaining. |
|  | **Sampling** | Using clear inclusion criteria to maximise relevance |
|  | **Determination of quality** | Using critical appraisal tools and modified checklists to assess quality |
|  | **Data extraction** | Using proformas to organise data from studies; presenting themes/constructs using language from the studies themselves |
|  | **Conducting the interpretive synthesis** | Synthesising the data, creating a synthesising argument from constructs within the data |

***2.2.1 Formulating the review question, defining late booking***

Not tightly focused or defined in advance, the aim of CIS is to allow a definition of the phenomenon being studied to emerge from the analysis of the literature through an iterative process, modifying/refining the question in response to search findings; the question *“more as a compass than as an anchor”* (Eaking and Mykhalovskiy 2003: 190). Traditional systematic reviews emphasise precise review questions, which lead to narrower, less iterative and inclusive results, more suitable for aggregative reviews rather than interpretive ones (Dixon-Wood *et al* 2005, Greenhalgh *et al* 2005a). The iterative, flexible approach reflects Noblitt and Hare’s (1988) meta-ethnographic approach, which involves *“identifying an intellectual interest that qualitative research might inform”* (p26) rather than a specific hypothesis or fixed meanings for concepts. Concepts may emerge late in the review and be a product of the review itself, particularly when the focus is hard to specify, such as access (Dixon-Wood *et al* 2005, Flemming 2010).

The question for the review evolved and was refined throughout the initial phases of literature searching and data extraction. The question became *“what perceptions and beliefs do pregnant and postnatal women express about delayed access to/initiation of antenatal care (‘late booking’)?”* There was a particular focus on barriers to early initiation, a common theme amongst all the literature.

Defining late booking/delayed access is challenging as there is no consensus of opinion, with definitions varying across the literature, from after the first trimester (Roberts *et al* 1998, Sunil *et al* 2010), 20 weeks gestation (Johnson *et al* 2003) to the third trimester (Harvey and Faber 1993, Nothnagle 2000, Heaman *et al* 2014). The Kotelchuck Adequacy of Prenatal Care Utilization (APNCU) Index, used in several US studies, defines inadequate care as booking after the 4th month of pregnancy (or receiving less than 50% of the American College of Obstetrics and Gynecology recommended number of antenatal visits) (Cook *et al* 1999, Johnson *et al* 2007). As all the studies define late initiation as being at or after the current NICE guidance definition of the limit of early booking as 12 weeks and 6 days gestation (NCCWCH 2010), and as the focus of the synthesis is perceptions and beliefs, I have chosen to accept the different definitions offered by the authors.

***2.2.2 Searching the literature and sampling***

The purpose of the literature search is to identify potentially relevant papers or ‘candidate studies’ to provide a sampling frame, from which evidence can be chosen to maximise relevance and theoretical contribution. Again reflecting Grounded Theory, other authors have identified that for a Critical Interpretive Synthesis literature searching methods may be iterative and purposive, using theoretical and purposive sampling based on key concepts identified early on, and aiming for conceptual robustness and to reach a theoretical saturation of literature, rather than identify all relevant studies (Dixon-Woods et al 2006a, Barnett-Page and Thomas 2009, Noyes and Lewin 2011). They suggest that the emerging theoretical framework, the development of inclusion and exclusion criteria and thematic categories, will inform the ongoing literature selection, accessing work that is not directly or obviously relevant (Dixon-Woods *et al* 2006a, Kazimierczak *et al* 2013). They propose a process which starts with highly structured searches of a range of electronic databases (for including nursing, medicine, sociology, psychology) using broad search terms to avoid missing relevant materials, stressing the importance of ‘adjacent literature’ and its important contribution to any theoretical arguments. This then would develop into a more organic process to fit the emergent/exploratory nature of the questions/concepts, with techniques such as website searching, reference chaining, hand searching of journals and expert contacts.

As sampling is concurrent with theory generation, the focus in an interpretive synthesis is on the development of concepts and theory rather than an exhaustive summary of data. Other authors have used a low threshold to maximise the inclusion and contribution of a wide variety of papers at the level of concepts, to give a maximum variation sample. This has included qualitative, quantitative, mixed method, editorial, review, and theoretical evidence, prioritising papers that appear to be relevant rather than by method/study type, limited by practical considerations. The notion of theoretical saturation for sampling could be perceived as problematic but reflects the ‘authorial voice’ and individualistic nature of a CIS, and reflects an approach which remains grounded in the evidence (Dixon-Woods *et al* 2006a,b, Kazimierczak *et al* 2013).

As the starting point for the synthesis the databases *MEDLINE* (via EBSCO), *CINAHL* *Complete* (via EBSCO), *PsycInfo* and *Maternity and Infant Care* (via OVIDSP) were searched using five key concepts, individually and in combination, using truncation and Boolean operators. The databases were chosen to represent medicine/health, nursing/midwifery and psychology. The concepts and subsequently the search were refined iteratively using key terms identified from papers in the initial search, which were incorporated into the list below as the search progressed:

|  |
| --- |
| **5 key concepts for literature search, and search terms used** |
| **1. Pregnancy**  *pregnan\* (pregnant, pregnancy, pregnancies)* |
| **2. Models of care**  *antenatal / prenatal / matern\* (maternal, maternity) / midwi\* (midwife, midwives, midwifery)* |
| **3. Human factors**  *attitud\*(attitude, attitudes, attitudinal) / belief\* (belief, beliefs) / percept\* (perception, perceptions) / accepta\*(acceptance, acceptability, acceptable )/ barrier\* (barrier, barriers) / behavio\* (behaviour(s), behavior(s))* |
| **4. Access issues**  *access\* (access, accessibility, accessible) / initia\* (initial, initiate, initiation) / delay\* (delay, delays, delayed) / late\* (late, later, latest)* |
| **5. (antenatal/late)** **Booking** |

As mentioned previously, several authors have identified the lack of UK-based research in this area (Downe *et al* 2009, Callaghan *et al* 2011). I decided therefore to search for studies from other countries with similar economic and cultural situations and levels of healthcare provision. The criteria for inclusion of evidence were as follows:

|  |
| --- |
| **Criteria for inclusion in synthesis** |
| **Published in English** |
| **Published between 1980 and 2014** |
| **Direct surveys of women’s perceptions and beliefs** towards delayed access to/initiation of antenatal care (‘late booking’), particularly barriers to care |
| Focus on or including discussion of the **initiation of antenatal care** rather than solely the continuation of antenatal care |
| **Studies in high income countries**: UK, Western Europe, USA, Canada, Australia and New Zealand |

The year 1980 was identified as a limit as, as Downe *et al* (2009) comment, this coincides with the publication of the Black Report and subsequent interest in health inequalities and access to healthcare.

The broad inclusion criteria for the synthesis necessitated a combination of different search methods. Other authors have identified the challenges of finding qualitative studies, due to inadequate indexing and titles which make it difficult to establish relevance (Dixon Woods *et al* 2007, Ring, Jepson and Ritchie 2011). In their systematic review of complex evidence, Greenhalgh and Peacock (2005b) found that only 30% of their primary sources were found by the traditional method of using a predefined search strategy, and recommended using other techniques. Twenty three (43%) of the studies included in this synthesis were found using the search terms and databases identified above. Database searching was supplemented with more informal snowballing methods of reference tracking, citation tracking and website searching (Greenhalgh *et al* 2005a, Greenhalgh and Peacock 2005b). Websites searched included NHS Evidence and NHS England, National Institute for Health and Care Excellence (NICE), The Cochrane Library and the National Perinatal Epidemiology Unit (NPEU), in addition to the use of general internet search engines such as Google and Google Scholar.

As the literature search progressed I developed a theoretical sampling approach to try to achieve ‘saturation’ on the subject of late booking, looking for evidence in relation to the range of women identified as most likely to book late: black and minority ethnic (BME) women, teenagers, substance misusing women, homeless women, women experiencing abuse, low income women in both urban and rural situations (Dartnall *et al* 2005, Lavender *et al* 2007, Raatikainen *et al* 2007). Studies that included women who received no antenatal care at all were included, however studies whose focus was a specific ethnic group in a specific location were excluded. The aim was to maximise the range of studies rather than including multiples of similar studies.

In order to cover the complete breadth of relevant research and research methodologies, qualitative, quantitative and mixed method studies were included, published in peer reviewed journals as primary research, as well as those published as policy documents. Quantitative and mixed method studies were included if they contained significantly detailed surveys of women’s perceptions and beliefs in relation to antenatal care, as opposed to one or two questions and socio-demographic data collection only. Reflecting the broad inclusion criteria for a CIS I also included systematic literature reviews/analyses/syntheses which met the inclusion criteria above, some of which had been undertaken as part of national clinical guidelines development and epidemiological reports. These reflect a detailed and considered view of the evidence relating to delayed access to antenatal care. Evidence that was UK based was prioritised for maximum relevance, even when methodologically weak. It was also decided to include studies identified in the search which contained both women’s and practitioners’ views, for further breadth. The search process is summarised in figure 2.2.2 and the database search histories can be found in Appendix 2.1.

***2.2.3 Determination of quality***

Dixon-Woods *et al* (2006a) argue that there is little consensus on how/whether to appraise papers for inclusion in interpretive reviews, and that there is no hierarchy of study design for qualitative studies, as there is for randomised controlled trials. Others agree: Barnett-Page and Thomas (2009) argue that meta-ethnography is less committed to the concept of quality appraisal, whereas Flemming (2010) suggests that the quality appraisal of qualitative research remains contentious. Dixon-Woods *et al* suggest that for an interpretive synthesis, evidence should be prioritised by relevance (likely contribution to theory development), the content and utility of findings, rather than methodology, with a low threshold for inclusion to maximise the variety of papers at concept level. They also suggest that the threshold of inclusion should be informed by expertise and instinct rather than being rigidly articulated *a priori*. Sandelowski,

***Figure 2.2.2 Literature search summary***

**7444 potential titles identified from four database searches**

(Medline: 3292, CINAHL: 872, Psychinfo: 1389, Maternity and Infant Care: 1891)

**Titles read, duplicates and non-relevant studies removed**

***151 studies remaining***

**151 abstracts read, 122 non-relevant studies removed:**

Containing/predominantly demographic data only 33

Focus on antenatal care in general 29

Limited to a specific ethnic group in a specific community 16

Focus on outcomes/intervention/service evaluation 13

Focus on pregnancy intention/behaviour change only 11

Review/discussion/opinion/commentary only 9

Satisfaction studies/focus on number of visits 3

Antenatal screening/testing/information giving only 3

Not in high income countries 3

Provider or partner views only 2

***29 studies remaining***

**37 additional titles identified from website searching, citation tracking**

**and reference chaining**

***66 studies remaining***

**66 studies checked for quality; 12 discarded as methodologically weak, having limited relevance or limited presentation of findings**

***54 studies remaining***

**54 studies included in synthesis:**

14 qualitative

19 quantitative

14 mixed method

7 systematic review, analysis or synthesis of literature

Docherty and Emden (1997) have argued previously that such expertise is essential to distinguish between ‘surface mistakes’ and more serious errors. Kazimierczak *et al* (2013) similarly argue that, though appraised for both, priority should be given to theoretical relevance, as opposed to methodological rigour.

Dixon-Woods *et al* point out that the process of synthesis involves ongoing critical judgements/interpretations of credibility and contribution anyway, suggesting that limited formal appraisal of methodological quality is appropriate. They identify that even some weak papers methodologically could have high relevance in terms of theoretical contribution, demonstrating comprehensive summary or breadth of evidence. As Talseth and Gilje (2011), in their CIS of nurses’ responses to suicide, comment:

*“all studies in the sample could contribute to an interpretive synthesis, even though they varied somewhat in their reported reliability/validity, trustworthiness and/or Jadad score”* (p 1653)

In this particular study the authors argued that quality scales such as Jadad have been criticised as being simplistic. They decided to weight all the reviewed studies equally, critically reflected on and then synthesised them into a conceptual understanding. In another the author used a quality appraisal checklist to score methodological quality but low scoring papers with greater relevance were included (Flemming 2010). Dixon-Woods *et al* (2005) suggest a need to consider and reflect on the credibility of the evidence (for example older research), both in terms of the quality (method) and their contribution to theory, but to exclude only those which are fatally flawed in methodology. They suggest this as a defining characteristic of CIS: a critical approach to the literature in terms of deconstructing research traditions or theoretical assumptions.

In this CIS I have tried to merge these different perspectives, utilising a transparent and pragmatic approach to balance relevance with rigour. I have used two methods of quality appraisal. The first involves the use of the UK Critical Appraisal Skills Programme *Critical Appraisal Checklists* for (1) qualitative research and (2) systematic reviews (CASP 2013), and (3) Boynton and Greenhalgh’s (2004) *Quality Checklist for Questionnaire Surveys*. These were used for (1) the qualitative studies and mixed method studies with a qualitative focus; (2) the literature reviews/analyses and (3) the quantitative studies and mixed method studies with a quantitative focus. These are presented in appendix 2.2. Secondly, I have used the criteria proposed by Dixon-Woods *et al (*2005)and Annandale *et al* (2007) for assessing all empirical papers, regardless of study type. These have been adapted from the National Electronic Library for Health criteria for the evaluation of qualitative research and are as follows:

|  |
| --- |
| Are the aims and objectives of the research clearly stated? |
| Is the research design clearly specified and appropriate for the aims and objectives of the research? |
| Do the researchers provide a clear account of the process by which their findings were produced? |
| Do the researchers display enough data to support their interpretations and conclusions? |
| Is the method of analysis appropriate and adequately explicated? |

Appendix 2.3 illustrates the application of these quality criteria for all the included studies. In accordance with the guidance of both of these authors, and other authors of Critical Interpretive Syntheses, I decided that a low threshold of quality was appropriate, particularly amongst studies from the UK, in order to maximise relevance and the conceptual contribution of the evidence to theory generation.

The final synthesis contained 54 studies: 14 qualitative, 19 quantitative, 14 mixed method, and seven systematic review, analysis or synthesis of literature. Five studies which contained both women’s and practitioners’ views (interviewed separately) were included. Thirty nine (83%)of the 47 primary research studies included in the synthesis were from the USA, four from the UK, two from Canada, one from Europe and one from New Zealand. The studies dated from between 1987 and 2014. A chronological list of the included studies, by study type, is presented in table 2.2.3.

***T able 2.2.3 Summary of studies included in the synthesis, by type and chronology***

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **included studies** | **publication** | **year** | **country** | **study type** | **Sample size and characteristics** |
| **Qualitative** | | | | | | |
| **1** | Patterson ET, Freese MP, Goldenberg RL. Seeking safe passage: utilizing health care during pregnancy. | *IMAGE: Journal of Nursing Scholarship* | 1990 | USA | Qualitative grounded theory study. | 27 antenatal and postnatal women, who had accessed care during 1st/2nd/3rd trimester or not at all. Interviewed at prenatal clinics or on postnatal hospital wards, about pregnancy discovery and prenatal care. |
| **2** | Merchant V. Maternity services: antenatal care. The needs and experiences of some women living in two deprived areas of Lancaster. | *Journal of Advances in Health and Nursing Care* | 1993 | UK | Qualitative focus group study. | 18 women from Lancaster, interviewed during pregnancy and postnatally over an 18 month period; also an unspecified number of professionals from health promotion/ education, health visiting, midwifery, nurse management, academics and students. |
| **3** | Johnson Jl, Primas PJ and Coe MK. Factors that prevent women of low socioeconomic status from seeking prenatal care. | *Journal of the American Academy of Nurse Practitioners* | 1994 | USA | Qualitative Semi-structured interviews. | 15 low income postnatal women who had received no prenatal care. |
| **4** | Gazmararian JA, Schwartz KS, Amacker LB and Powell CL. Barriers to prenatal care mong Medicaid managed care enrolees: patient and provider perceptions. | *HMO Practice* | 1997 | USA | Qualitative Focus group study. | 6 focus groups with random selection of 42 enrolled women in 3 groups: recently pregnant, currently pregnant, no children (‘contemplators’). 4 focus groups with 22 providers in professional groups: doctors, nurse practitioners, nurses and medical assistants. |
| **5** | Mackey MC and Tiller CM. Adolescents’ description and management of pregnancy and preterm labour. | *Journal of Obstetric, Gynecologic and Neonatal Nursing* | 1998 | USA | Qualitative interview study. | 13 pregnant adolescents (14-19yrs) admitted to two obstetric antenatal units because of threatened preterm labour, interviewed in hospital and at home. |
| **6** | Peacock NR, Kelley MA, Carpenter C, Davis M, Burnett G, Chavez N, Aranda V and members of the Chicago Social Networks project. Pregnancy discovery and acceptance among low-income primiparous women: a multicultural exploration. | *Maternal and Child Health Journal* | 2001 | USA | Qualitative focus group study. | Purposive sample of 87 low-income postnatal women (birth in previous 12 months) from 4 cultural groups, in 8 community-based focus groups. |
| **7** | Milligan R, Wingrove BK, Richards L, Rodan M, Monroe-Lord L, Jackson V, Hatcher B, Harris C, Henderson C and Johnson AA. Perceptions about prenatal care: views of urban vulnerable groups. | *BMC Public Health* | 2002 | USA | Qualitative, focus group study. | 169 women and men in 18 focus groups: homeless women, substance-misusing women, male partners of these women, and members of a community with high infant mortality and poverty indices and low incidence of adequate prenatal care; including pregnant and postnatal women. |
| **8** | Sword W. Prenatal care among women of low income; a matter of “taking care of self”. | *Qualitative Health Research* | 2003 | Canada | Qualitative, grounded theory study. | 26 low-income women who were pregnant or had given birth in previous 2 years, from two areas of Ontario, interviewed in community settings. |
| **9** | Dartnall L, Ganguly N and Batterham J. *Access to Maternity Services Research Report.* | Department of Health report | 2005 | UK | Qualitative study. | 14 one-to-one in depth interviews with representatives from intermediary organisations, 28 one-to-one and 9 mini group interviews with pregnant women or those who had given birth in previous 18 months, from target audience. |
| **10** | Lutz KF. Abused pregnant women’s interactions with health care providers during the childbearing year. | *Journal of Obstetric, Gynecologic and Neonatal Nursing* | 2005 | USA | Qualitative, grounded theory study. | Convenience sample of 12 pregnant women who had disclosed abuse during pregnancy. |
| **11** | Daniels P, Noe GF, Mayberry R. Barriers to prenatal care among black women of low socioeconomic status. | *American Journal of Health Behavior* | 2006 | USA | Qualitative, focus group study. | 32 women who were currently pregnant or had attended particular prenatal clinics in the past 2 years, divided into 5 focus groups of either early, late initiation of prenatal care, or a mixture of both. |
| **12** | Callaghan M, Buller AM and Murray SF. Understanding ‘late bookers’ and their social circumstances. | *British Journal of Midwifery* | 2011 | UK | Qualitative, semi-structured interviews. | Non-random purposive sample of 20 ‘late booking’ pregnant/recently delivered postnatal women who booked after 12,22 or 28 weeks gestation in South-east London. |
| **13** | Roberts SCM and Pies C. Complex calculations: how drug use during pregnancy becomes a barrier to prenatal care. | *Maternal and Child Health Journal* | 2011 | USA | Qualitative, interview and focus group study. | Racially/ethnically diverse sample of 38 low-income women pregnant or had given birth in previous 2 years and using drugs and alcohol, in one California county. 20 individual interviews and 2 focus groups. |
| **14** | Nepal VP, Banerjee D and Perry M. Prenatal Care Barriers in an Inner-city Neighborhood of Houston, Texas. | *Journal of Primary Care & Community Health* | 2011 | USA | Qualitative focus group study. | 32 women aged 17-30 years with pregnancy experience in previous 5 years. From an underserved and predominantly African American inner-city neighbourhood in Houston, Texas. 5 focus group discussions around prenatal care experience held in community settings plus a brief survey. |
| **Quantitative** | | | | | | |
| **15** | Leatherman J, Blackburn D and Davidhizar R. How postpartum women explain their lack of obtaining adequate prenatal care. | *Journal of Advanced Nursing* | 1990 | USA | Quantitative: structured interviews. | Convenience sample of 44 newly delivered postnatal women identified as receiving inadequate care, including those with no care until 3rd trimester. |
| **16** | Kinsman SB and Slap GB. Barriers to adolescent prenatal care. | *Journal of Adolescent Health* | 1992 | USA | Quantitative: structured interviews. | 101 postnatal women aged <17 yrs, interviewed within 48 hours of birth at one urban hospital. |
| **17** | Reis J, Mills-Thomas B, Robinson D and Anderson V. An inner-city community’s perspective on infant mortality and prenatal care. | *Public Health Nursing* | 1992 | USA | Quantitative study with structured questionnaire | Convenience sample of 380 black adults – 231 women, 149 men – from inner-city Chicago neighbourhood, including 72% parents and 5% pregnant women. |
| **18** | Cartwright PS, McLaughlin FJ, Martinez AM, Caul DE, Hogan IG, Reed GW and Swafford MS. Teenager’s perceptions of barriers to prenatal care. | *Southern Medical Journal* | 1993 | USA | Quantitative: structured interview study. | 184 newly delivered postnatal women aged 17 or younger, interviewed in hospital. |
| **19** | Sable MR and Wilkinson DS. Pregnancy intentions, pregnancy attitudes and the use of prenatal care in Missouri. | *Maternal and Child Health Journal* | 1998 | USA | Quantitative: subsample from larger study of postnatal women. | 2378 women completing either 1) a postal questionnaire sent 3 months postpartum, 2) face-to-face interviews or 3) self-completed questionnaires, both on the postnatal wards of 5 hospitals. |
| **20** | Cook CAL, Selig KL, Wedhe BJ and Gohn-Baube EA. Access barriers and the use of prenatal care by low-income, inner-city women. | *Social Work* | 1999 | USA | Quantitative: cross-sectional descriptive study. | Convenience sample of 115 low-income newly delivered women on postnatal ward of a large urban hospital. |
| **21** | Fuller CA and Gallagher R. perceived benefits and barriers of prenatal care in low income women | *Journal of the American Academy of Nurse Practitioners* | 1999 | USA | Quantitative: cross-sectional descriptive study. | Convenience sample of 100 pregnant low-income women, interviewed at the initial prenatal appointment. |
| **22** | Mikhail BI and Curry MA. Perceived impediments to prenatal care among low-income women. | *Western Journal of Nursing Research* | 1999 | USA | Quantitative: structured interview study. | Convenience sample of 126 African American women who had given birth in preceding 12 months. |
| **23** | Braveman P, Marchi K, Egerter S, Pearl M and Neuhaus J. Barriers to timely prenatal care among women with insurance: the importance of pre-pregnancy factors. | *Obstetrics and Gynecology* | 2000 | USA | Quantitative: subsample of larger cross-sectional postpartum study. | 3071 low-income postnatal English and Spanish speaking women, interviewed during hospital stay. |
| **24** | Beckmann CA, Burford T and Witt J. Perceived barriers to prenatal care services. | *MCN, the American Journal of Maternal/ Child Nursing* | 2000 | USA | Quantitative study: Descriptive correlational study. | 110 pregnant women who sought prenatal care after 20 weeks gestation, at prenatal clinics. |
| **25** | Nothnagle M, Marchi K, Egerter S and Braveman P. Risk factors for late or no prenatal care following medicaid expansions in California. | *Maternal and Child Health Journal* | 2000 | USA | Quantitative study. | 6364 low-income postnatal women interviewed during their hospital stay in 19 large California hospitals. |
| **26** | Delvaux T, Buekens P, Godin I, Boutsen M and the study group on barriers and incentives to prenatal care in Europe. Barriers to prenatal care in Europe. | *American Journal of Preventative Medicine* | 2001 | Europe | Quantitative: Case control study: structured interviews. | 1238 recently delivered postnatal women with inadequate care, compared with 1280 control women, interviewed in hospital or by telephone. |
| **27** | Chandler D. Late entry into prenatal care in a rural setting. | *Journal of* *Midwifery and Women’s Health* | 2002 | USA | Quantitative survey study. | 176 pregnant women, in 5th-9th month of pregnancy, attending for prenatal care at 4 obstetric/ nurse-midwifery practices in a rural county of California. |
| **28** | Johnson AA, Nabil El-Khorazaty MN, Hatcher BJ, Wingrove BK, Milligan R, Harris C and Richards L. Determinants of late prenatal care initiation by African American women in Washington DC. | *Maternal and Child Health Journal* | 2003 | USA | Quantitative: Structured interviews. | 303 pregnant African American women interviewed at their first prenatal care visit, in a range of prenatal care clinics for low-income women. |
| **29** | Bloom KC, Bednarzyk MS, Devitt DL, Renault RA, Teaman V and van Loock DM. Barriers to prenatal care for homeless pregnant women | *Journal of Obstetric, Gynecologic and Neonatal Nursing* | 2004 | USA | Quantitative: Descriptive survey with written questionnaire | Convenience sample of 41 homeless pregnant women and 6 women who had given birth in previous 6 months whilst homeless, recruited through homeless agencies. |
| **30** | Johnson AA, Hatcher BJ, Nabil El-Khorazaty MN, Milligan R, Bhaskar B, Rodan MF, Richards L,Wingrove BK and Laryea HA. Determinants of inadequate prenatal care utilization by African American women. | *Journal for Health Care for the Poor and Underserved* | 2007 | USA | Quantitative: Structured interviews with postnatal women. | Convenience sample of 246 urban African American newly delivered postnatal women, in 5 Washington DC hospitals, classified as having adequate or inadequate care (Kotelchuck index). |
| **31** | Schempf AH, Strobino DM. Drug use and limited prenatal care: an examination of responsible barriers. | *American Journal of Obstetrics and Gynecology* | 2009 | USA | Quantitative retrospective cohort study. | 812 low-income recently delivered postnatal women in one hospital. |
| **32** | Sunil TS, Spears WD, Hook L, Castillo J and Torres C. Initiation of and barriers to prenatal care use among low-income women in San Antonio, Texas | *Maternal and Child Health Journal* | 2010 | USA | Quantitative survey. | 444 low-income 3rd trimester pregnant/postnatal women (birth within previous 6 weeks) interviewed at public health clinics. |
| **33** | Heaman MI, Moffatt M, Elliott L, Sword W, Helewa ME, Morris H, Gregory P, Tjaden L & Cook C. Barriers, motivators and facilitators related to prenatal care utilization among inner-city women in Winnipeg, Canada: a case control study | *BMC Pregnancy and Childbirth* | 2014 | Canada | Quantitative case control study. | Study of newly delivered women in 2 hospitals in Canadian city. Structured questionnaires with postnatal women, comparing those receiving adequate (n = 406) and inadequate antenatal care (n = 202), matched by neighbourhood. |
| **Mixed methods** | | | | | | |
| **34** | Poland ML, Ager JW and Olsen JM. Barriers to receiving adequate prenatal care. | *American Journal of Obstetrics and Gynecology* | 1987 | USA | Mixed methods study: structured interviews and review of medical notes. | Interviews with 111 recently delivered postnatal women who had received varying amounts of prenatal care, in one hospital in Detroit. |
| **35** | Chisholm DK. Factors Associated with late booking for antenatal care in Central Manchester. | *Public Health* | 1989 | UK | Mixed methods cohort study with structured questionnaire | 960 pregnant women in Central Manchester. |
| **36** | Lia-Hoagberg B, Rode P, Skovholt CJ, Oberg CN, Berg C, Mullett S and Choi T. Barriers and Motivators to prenatal care among low-income women. | *Social Science and Medicine* | 1990 | USA | Mixed methods interview study, with closed and open-ended sections. | 211 newly delivered women from areas with high poverty levels interviewed in 5 hospitals. |
| **37** | Kalmuss D and Fennelly K. Barriers to prenatal care among low-income women in New York City. | *Family Planning perspectives* | 1990 | USA | Mixed methods questionnaire study. | 496 postnatal low-income women, interviewed in selected hospitals, including those who received no prenatal care. |
| **38** | Sable MR, Stockbauer JW, Schramm WF and Land GH. 1990. Differentiating the barriers to adequate prenatal care in Missouri, 1987-88. | *Public Health Reports* | 1990 | USA | Mixed methods case-control interview study. | Interviews with 1484 newly delivered women on postnatal wards of 11 hospitals with higher than average inadequate prenatal care rates. |
| **39** | Aved BM, Irwin MM, Cummings LS and Findeisen N. Barriers to prenatal care for low-income women. | *Western Journal of Medicine* | 1993 | USA | Mixed methods study: patient interview survey and focus group discussion. | 69 recently delivered postnatal women who had received inadequate/no prenatal care, interviewed in 8 Californian hospitals. 7 obstetric doctors from same area. |
| **40** | Harvey SM and Faber KS. Obstacles to prenatal care following implementation of a community-based program to reduce financial barriers. | *Family Planning Perspectives* | 1993 | USA | Mixed methods study: structured interviews. | Postnatal interviews with newly delivered 236 women receiving inadequate care (including those initiating care in the 3rd trimester) and 246 women receiving adequate care, interviewed in hospital or at home. |
| **41** | Omar MA, Schiffman RF and Bauer P. Recipient and provider perspectives of barriers to rural prenatal care. | *Journal of Community Health Nursing* | 1998 | USA | Mixed methods study using descriptive survey and focus groups. | 61 pregnant women in 3rd trimester with at least 3 prenatal visits, recruited from prenatal clinics and childbirth education classes. Completed checklist at clinic or home.  15 providers of prenatal care in rural county. Focus group questions based on checklist given to women. |
| **42** | Roberts RO, Yawn BP, Wickes SL, Field CS, Garretson M and Jacobsen SJ. Barriers to prenatal care: factors associated with late initiation of care in a middle-class midwestern community. | *The Journal of Family Practice* | 1998 | USA | Mixed methods study with structured questionnaire | 813 pregnant women from two major clinics in Minnesota during a 6 month period, at their first prenatal appointment. |
| **43** | Teagle SE and Brindis CD. Perceptions of motivators and barriers to public prenatal care among first time and follow-up adolescent patients and their providers. | *Maternal and Child Health Journal* | 1998 | USA | Mixed methods interview study. | 250 consecutive pregnant adolescents from 5 prenatal clinics in one county of Arkansas, plus a convenience sample of 16 health providers working at the same clinics. |
| **44** | York R, Grant C, Tulman L, Rothman RH, Chalk L and Perlman D. The impact of personal problems on accessing prenatal care in low-income urban African American women. | *Journal of Perinatology* | 1999 | USA | Mixed methods study: questionnaire and semi-structured interviews | Postnatal data collection from 297 newly delivered African American women of low socioeconomic status, classified into 4 levels of prenatal care, from one hospital. |
| **45** | Napravnik S, Royce R, Walter E and Lim W. HIV-1 infected women and prenatal care utilization: barriers and facilitators. | *AIDS Patient care and STDs* | 2000 | USA | Mixed methods interview study. | Convenience sample of 3 women who had given birth whilst HIV positive and had received inadequate prenatal care (Kotelchuck index). |
| **46** | Houston Department of Health and Human Services. *Women of Worth: factors relating to prenatal care among women of Greater Fifth Ward: a qualitative and quantitative project.* | HDHHS, 2009, Houston, Texas. | 2009 | USA | Mixed methods: focus groups and structured questionnaire | 5 focus group interviews with 24 pregnant/ postnatal women with a child aged less than 2 years, from one ward of Houston, in community settings. |
| **47** | Corbett S, Chelimo C and Okesene-Gafa K, Barriers to early initiation of antenatal care in a multi-ethnic sample in South Auckland, New Zealand. | *The New Zealand Medical Journal* | 2014 | New Zealand | Mixed methods study with structured questionnaire, containing some open ended content | 826 women (including 137 late booking women) after 37 weeks gestation or less than 6 weeks postnatal, completing a questionnaire about antenatal care at appointments or home. |
| **Literature reviews/analyses/syntheses** | | | | | | |
| **48** | Perez-Woods RC. Barriers to the use of prenatal care: critical analysis of the literature. | *Journal of Perinatology* | 1990 | USA | Critical analysis of literature relating to beginning and remaining in prenatal care. | 45 papers published between 1966 and 1987. |
| **49** | York R, Grant C, Gibeau A, Beecham J and Kessler J. A review of problems of universal access to prenatal care. | *Nursing Clinics of North America* | 1996 | USA | Review of literature on prenatal care utilisation. | 32 USA papers reviewed. |
| **50** | Lavender T, Downe S, Finnlayson K and Walsh D. *Access to antenatal care: a systematic review – Report.*  Downe S, Finlayson K, Walsh D and Lavender T. ‘Weighing up and balancing out’: a meta-synthesis of barriers to antenatal care for marginalised women in high-income countries. | University of Central Lancashire.  *British Journal of Obstetrics and Gynaecology* | 2007  2009 | USA, UK and Canada  USA, UK and Canada | Structured review of qualitative and quantitative literature on access to antenatal care in developed countries.  Synthesis of qualitative studies from developed countries. | 7 quantitative papers (outcome and demographics only) from USA, UK, Ireland and France; 8 qualitative papers from USA, UK and Canada.  8 qualitative papers from USA, UK and Canada. |
| **51** | Philippi JC. Women’s perceptions of access to prenatal care in the United States: a literature review. | *Journal of Midwifery and Women’s Health* | 2009 | USA | Review of US literature on women’s perceptions of access to prenatal care within the United States. | 42 papers, including 19 with direct surveys of women. |
| **52** | National Collaborating Centre for Women’s and Children’s Health. *NICE Clinical Guideline CG110 - Pregnancy and complex social factors: A model for service provision for pregnant women with complex social factors.* | Royal College of Obstetricians and Gynaecologists, London. | 2010 | UK/USA/ Europe/ Australia/Canada | Literature reviews as part of National Institute of Health and Clinical excellence (NICE) guideline. | 64 papers from UK/USA/ Europe/ Australia/ Canada:  Migrant women: 28 papers  Substance misusing women: 10 papers  Young women: 10 papers  Abused women: 16 papers |
| **53** | Hollowell J, Oakley L, Vigurs C, Barnett-Page E, Kavanagh J and Oliver S. *Increasing early initiation of antenatal care by Black and Minority Ethnic women in the United Kingdom: a systematic review and mixed methods synthesis of women’s views and the literature on intervention effectiveness: Final Report.* | National Perinatal Epidemiology Unit, Oxford. | 2012 | UK | Mixed methods review and thematic analysis. | 72 studies of disadvantaged and vulnerable groups of women in the UK, with a subsequent focus on 36 papers relating to BME women for the thematic analysis and 21 papers for the synthesis. |
| **54** | Boerleider AW, Wiegers TA, Mannien J, Francke Al and Deville WLJM. Factors affecting the use of prenatal care by non-western women in industrialised western countries: a systematic review | *BMC Pregnancy and Childbirth* | 2013 | Europe/  Canada/ Australia | Systematic review of literature on non-western women’s experience in industrialised countries. | Synthesis of 16 articles from Europe, Australia and Canada - 12 qualitative, 3 quantitative and 1 mixed-method. |

***2.2.4 Data extraction***

Dixon-Woods *et al* (2006a,b) identify that all types of synthesis involve some summary of data and some interpretation, and that formal data extraction procedures such as proformas may be helpful but are not essential, and that their role in the synthesis of qualitative research requires formal evaluation. Like Flemming (2010), following a detailed reading and re-reading of the papers, and identifying recurring themes, I have created a proforma detailing the content of the included studies (appendix 2.4). This consists of:

|  |
| --- |
| Author, title, source, year of publication |
| Country of publication |
| Aim of study |
| Participants and setting |
| Key themes in relation to delayed/no access to antenatal care, using phrases presented by the women and the researchers. |

I have used qualitative data analysis methods to extract and summarise the key themes from each study, creating titles based on the themes and quotes presented in the results and discussion sections of the included studies (Pope*,* Mays and Popay 2007, Talseth and Gilje 2011).

***2.2.5 Conducting the interpretive synthesis***

The interpretive synthesis is concerned with generating concepts with maximum explanatory value, incorporating themes identified in primary studies into a more subsuming theoretical structure and potentially identifying concepts not found in the original studies, to help explain phenomena (Dixon-Woods *et al* 2005). The process and product are conceptual, aiming to move beyond the summarisation and aggregation of data (though this is part of the process of interpretation and synthesis) to produce a more insightful and generalisable way of understanding a phenomenon.

The process of synthesis therefore follows the following (simplified) sequence:

**data themes, constructs concepts synthesising**

**subthemes 1st/2nd/3rd order argument/**

**core concept**

**(theory/explanation)**

A ‘lines of argument’ (LOA) synthesis builds a general interpretation grounded in the findings of separate studies, with the most powerful themes recurring in the data identified by constant comparisons between accounts. Dixon-Woods *et al* (2005) suggest that a LOA synthesis enables a higher order analysis to be achieved, and is more appropriate for a large body of evidence, rather than the ‘reciprocal translational analysis’ (RTA, the extent to which concepts are translatable into each other) suggested by Noblitt and Hare (1988), which can dampen rather than promote the interpretive process. The synthesis method draws many influences from primary qualitative research: themes from original research become data, with the findings coded into themes and subthemes, which are then refined into constructs. These constructs can be generated initially with a low level of theoretical abstraction, for example through a taxonomy, then a more interpretive, sophisticated analysis to create concepts and theories (Dixon-Woods *et al* 2006a, Flemming 2010). The idea of first, second and third/synthetic order constructs reflect the interplay of *emic* and *etic* perspectives fundamental to qualitative research (Holloway and Wheeler 2010). They can be summarised as follows:

|  |
| --- |
| **1st order:** the everyday understandings of ordinary people (the quotes from the women). These may not exist/be presented in quantitative research. |
| **2nd order:** constructs of the social sciences: the themes identified by the authors of the studies, interpretations of 1st order constructs. |
| **3rd order/synthetic**: grounded in evidence but transformed into a new form, combining ‘new’ with ‘found’/2nd order existing constructs: build on the explanations and interpretations of the constituent studies (Britten *et al* 2002, Dixon-Woods *et al* 2006a, Barnett-Page and Thomas 2009). |

Talseth and Gilje (2011) talk about the spiral and unfolding/enfolding manner of this process: relating, translating, interweaving and synthesising of the subthemes and themes into constructs and concepts, through a dialectical and reflective process: “*the text began to illuminate an understanding…” (*p1665). This develops into a *synthesising argument*, which integrates themes from across the studies into a coherent theoretical framework: a network of constructs, combining both synthetic constructs developing through the process and the second order constructs already reported in the research and exploring the relationships between them (Dixon-Woods *et al* 2005,2006a, Heaton, Corden and Parker 2012).

The aim of the synthesis process is to provide ‘critical’ and ‘authorial’ voices: examining the context in which knowledge is produced, acknowledging reflexivity, questioning assumptions and lines of argument (Barnett-Page and Thomas 2009). The latter requires use of an element of Noblitt and Hare’s*refutational synthesis*to identify, characterise and explain contradictions, as part of the generation of the synthesising argument. Authors of CIS accept that because of the creative, interpretive processes involved, full transparency and reproducibility are not possible, but aim to generate a plausible, well justified, critically informed and meaningful theory (Dixon-Woods *et al* 2006a, Annandale *et al* 2007).

To develop the synthesis I have created a taxonomy of first, second and ‘synthetic’ constructs from the proforma detailing the content of the included studies (appendix 2.4). These included the original views and beliefs presented by the women, in their own words (1st order), themes identified by the researchers (2nd order) and 17 synthetic constructs (3rd order) developed through an in-depth comparison of the studies, relating to structural and practical, personal and motivational barriers to early antenatal care. I have focused throughout on themes relating to the initiation of antenatal care rather than continuing care, though this is not explicit in all studies. I subsequently developed a line of argument synthesis to ‘thread’ this network of constructs together, exploring the relationships between the constructs, the context of the themes and considering any contradictory or overlapping elements. This created the synthesising argument or core concept, an overarching interpretation of the findings (Heaton, Corden and Parker2012).

**2.3 Findings**

The summary of the constructs relating to late booking from the evidence is presented in table 2.3.1. This represents the views of the women (1st order), the interpretations of the authors of the 54 selected studies (2nd order), the integration of these into 17 ‘synthetic’ constructs (3rd order) and the resulting line of argument synthesis. Table 2.3.2 identifies the numerical occurrence of these constructs in the literature. The synthesis identifies **acceptance** **of personal and public pregnancies** as the core concept relating to late booking for antenatal care, which is explored in two parts in the following section.

First there is acceptance of the ‘personal’ pregnancy, which considers the influence of mindset in the recognition and acceptance of pregnancy. This acceptance is influenced by knowledge of pregnancy symptoms, pregnancy planning and desire, psychological factors associated with the recognition of pregnancy and the support of a woman’s immediate social network. Second, acceptance of the ‘public’ pregnancy considers women’s assessment of the social consequences of pregnancy, and the relevance and priority of antenatal care. This acceptance is influenced, amongst other things, by past experience, both positive and negative, beliefs about pregnancy and a consideration of life priorities. These two strands of acceptance are considered in relation to the selected studies, with those studies where the themes were represented most strongly referenced in the text. Brief comments are made, where relevant, of practitioner views in relation to the themes, from the five included studies of both perspectives.

***Table 2.3.1: Constructs and concepts relating to late booking from the literature: women’s perceptions and beliefs***

|  |  |  |  |
| --- | --- | --- | --- |
| **1st order: the women** | **2nd order:**  **the researchers** | **3rd order: synthetic** | **Synthesis:**  **concepts** |
| *“****I didn’t know I was pregnant”*** | Late recognition of pregnancy signs/symptoms | **knowledge of/ recognition of pregnancy** | **Acceptance of the personal pregnancy:** the pregnancy mindset |
| Delay in confirming pregnancy |
| Perceived risk of becoming pregnant |
| Lack of knowledge of pregnancy symptoms |
| No experience of pregnancy amongst peers |
| Being ‘a little bit pregnant’ |
| ***“I can’t do nothing but stick with it”*** | Unexpected/unplanned/mistimed pregnancy | **pregnancy intention/desire** |
| Unwanted pregnancy: hoping to miscarry/ considering termination |
| Non-acceptance of pregnancy |
| Negative attitude/feelings towards pregnancy |
| ***“Not thinking straight”*** | Depression, anxiety, stress | **emotional/ psychological factors** |
| Ambivalence, indifference |
| Guilt, regret |
| Fear of consequences of pregnancy |
| Embarrassment, shame, shock, anger |
| Denial |
| Isolation, lack of power |
| Stigma, self-stigmatisation |
| Feeling unprepared for pregnancy |
| ***“didn’t want to be bothered with me”*** | Lack of family, partner and friend support | **social support for pregnancy** |
| Not wanting to share the pregnancy |
| Negative attitude of others to pregnancy |
| Fear of family/partner reaction |
| ***“nothing in it for me”*** | Pregnancy a natural condition | **the necessity of antenatal care** | **Acceptance of the public pregnancy:** social consequences,  antenatal care relevance/ priority |
| No medical problems so not necessary |
| Friends/family support me instead |
| Early care not important/valued/ necessary |
| Weighing up pros and cons, motivation |
| Doctors not needed for a healthy pregnancy |
| Guarding private life/private pregnancy |
| ***“knew what should be done*** | Previous positive pregnancy experience | **previous experience** |
| Pregnancy a natural condition |
| ***“I feel fine”*** | Feeling fine, no need to go for care | **feeling well** |
| Accessing care in emergency only |
| ***“not up to going for care”*** | Continuing depression, anxiety, stress | **psychological and physical factors** |
| Fear of consequences of pregnancy |
| Feeling unwell, fatigue |
| ***“I can do this on my own”*** | Taking care of myself: active role in care. | **self-care/ reliance** |
| Taking care of myself: taking control/responsibility |
| Taking care of myself: the best choice |
| Being ‘a little bit pregnant’: self-care prior to formal care |
| ***“out of my hands”*** | Fatalism, acceptance of pregnancy | **fate, acceptance** |
| ***“not very important to those close”*** | lack of support/advice to access care | **social support for antenatal care** |
| others beliefs about pregnancy and healthcare, not valuing care |
| Others poor knowledge of antenatal care |
| Cultural norms/social norms |
| ***“need time, energy to deal with other problems”*** | personal problems | **other priorities in life** |
| others peoples problems |
| Time and other responsibilities |
| Other priorities/concerns: poverty |
| Other priorities/concerns : lifestyle, difficult/chaotic social circumstances |
| Other priorities/concerns: drug use |
| ***“no means”*** | Transport, distance | **practical/site related, system factors** |
| Childcare |
| Moving during pregnancy |
| Convenience: scheduling |
| Language, communication difficulties |
| Administrative failures |
| ***“the cost of getting care is too high”*** | Inability to afford care, insurance problems | **financial issues/ economic hardship** |
| Economic burden of pregnancy and care |
| ***“I already knew I was pregnant”*** | Poor knowledge of early care, screening | **knowledge of antenatal care / the 'system'** |
| Poor knowledge of maternity care, eligibility, access |
| Poor literacy/comprehension |
| Language/communication barriers |
| ***“like you’re a piece of meat”*** | Poor experience with health services generally | **previous healthcare experience, dislike of particular care** |
| Previous negative antenatal care experiences |
| Scheduling problems, communication problems |
| Lack of integrated care from different services |
| Negative attitudes, insensitivity, discrimination from staff |
| Perceived lack of concern and interest, lack of consistency, trust, confidence |
| Women’s lack of power/control |
| Negative attitudes towards providers |
| Cultural ignorance/insensitivity from healthcare professionals |
| Dislike/fear of medical procedures, examinations |
| ***“cultural and religious differences”*** | Dislike of interaction with males | **cultural factors** |
| Pregnancy a private experience |
| Preferring care/support from within own community. |
| Different healthcare experience in country of origin |

***Table 2.3.2: Occurrence of synthetic constructs relating to late booking in the literature: women’s perceptions and beliefs***

|  |  |  |
| --- | --- | --- |
| **Synthetic constructs** | **total no. of occurrences** | **study identity numbers (table 2.2.2)** |
| Acceptance of the personal pregnancy: the pregnancy mindset | | |
| **Knowledge of/ recognition of pregnancy** | **25** | 1,4,5,6,11,12,14,16,18,23,26,28,33,34,35,36,38,40,45,46,48,49,50,51, 52 |
| **Pregnancy intention/desire** | **33** | 4,5,6,11,12,14,15,16,19,22,23,25,26,27,28, 30,31,32,33,34,35,36,38,42,43,44,45,46,49, 50,51,52,54 |
| **Emotional/psychological factors** | **33** | 4,5,6,7,9,10,11,14,13,17,19,20,23,27,28, 30,31,32,33,35,36,38,39,40,43,44,45,48,49, 50, 51,52,53 |
| **Social support for pregnancy** | **18** | 3,6,7,11,13,14,15,18,20,23,27,31,34,45,46, 49, 50,52 |
| Acceptance of the public pregnancy: antenatal care relevance, priority | | |
| **Attitude towards care** | **26** | 1,2,3,8,10,11,16,17,22,26,28,30,31,33,34,35, 36,37,38,40,42,46,50,51,53,54 |
| **Previous experience** | **11** | 1,11,15,22,26,31,34,39,42,46, 51 |
| **Feeling well** | **7** | 1,15,34,36,37,39,51 |
| **Psychological and physical factors** | **34** | 3,4,6,7,9,10,11,13,14,17,19,20,22,23,28,30, 31,32,33,35,36,37,38,39,40,43,44,45,48,49, 50,51,52,53 |
| **Self-care, self-reliance** | **7** | 1,6,8,17,30,33,34 |
| **Fate, acceptance** | **3** | 9,53,54 |
| **Social support for antenatal care** | **10** | 14,17,22,25,31,36,45,49,51,53 |
| **Other priorities in life** | **23** | 7,8,9,12,13,20,22,27,28,30,32,33,36,37,38, 39,44,45,46,47,49,50,52 |
| **Practical/site related, system, convenience factors** | **38** | 2,3,9,12,13,15,16,17,20,21,22,23,24,25,26, 29,30,32,33,34,35,36,37,38,39,40,41,42,44, 45,46,47,48,49,51,52,53,54 |
| **Financial/economic hardship** | **27** | 3,13,14,15,16,17,18,21,23,24,25,28,30,32,34,37,38,39,40,41,42,46,47,48, 49,50,51 |
| **Knowledge of antenatal care/the 'system'** | **19** | 3,9,14,15,16,22,23,25,27,33,40,41,47,48,49,50,52,53,54 |
| **Healthcare experience, dislike of particular care** | **26** | 2,7,8,11,12,16,17,20,21,22,24,26,29,31,32, 34,36,43,44,45,48,49,50,51,52,53 |
| **Cultural factors** | **8** | 9,26,33,46,51,52,53,54 |

***2.3.1 Acceptance of the personal pregnancy: the pregnancy mindset***

**2.3.1.1 *“I didn’t know I was pregnant”* -** knowledge of/recognition of pregnancy

Poor knowledge and late recognition of the signs and symptoms of pregnancy contributed to delayed initiation of antenatal care in 25 studies, particularly those with a focus on younger women (Kinsman and Slap 1992, Cartwright *et al* 1993, Mackey and Tiller 1998), though one review identified this as young women not *wanting* to recognise the pregnancy (NCCWCH 2010). For some women this late recognition was due to the masking of pregnancy symptoms by irregular periods or psychological conditions such as stress and anxiety (Lia-Hoagberg *et al* 1990). For others it was because the expectation and perceived risk of becoming pregnant was low (Peacock *et al* 2001, Nepal, Bannerjee and Perry 2011).

Such women were not in a pregnancy mindset. One author identified the inability of women to place all their symptoms into a ‘meaningful whole’ and recognise the pregnancy, as a result of this lack of mindset (Peacock *et al* 2001). Other authors identified women’s poor knowledge of the symptoms of pregnancy, in some cases as a result of a lack of experience of pregnancy amongst their peers (Kinsman and Slap 1992, Delvaux *et al* 2001, Daniels, Noe and Mayberry 2006). This was reiterated by one group of healthcare practitioners as a lack of education and knowledge about pregnancy (Gazmararian *et al* 1997). Early pregnancy awareness was not always associated with early initiation however (Braveman *et al* 2000). Further delay in confirming the pregnancy followed a ‘letting it sink in’ phase of pregnancy; an in-between phase, sometimes lengthy, where women considered their options before making their pregnancy official by attending for care: being ‘a little bit pregnant’ (Patterson, Freese and Goldenberg 1990, Peacock *et al* 2001).

**2.3.1.2 *“I can’t do nothing but stick with it”* -** pregnancy intention, desire

Thirty three studies linked the late recognition of pregnancy and initiation of care to lack of pregnancy planning, with many identifying unexpected or mistimed pregnancies (Chisholm 1989, Braveman *et al* 2000, Daniels, Noe and Mayberry 2006, Heaman *et al* 2014). This resulted in feelings of ambivalence and negative attitudes, with some women struggling to accept the pregnancy and others going so far as to state that the pregnancy was unwanted (Poland, Ager and Olsen 1987, Kinsman and Slap 1992, Mackey and Tiller 1998, Napravnik *et al* 2000). In some cases women hoped to miscarry, in others women considered having a termination but were unable to go through with it, for time, financial or personal reasons (Sable *et al* 1990, Johnson *et al* 2003, 2007, York *et al* 1999).

**2.3.1.3 *“Not thinking straight”* -** emotional and psychological factors

A wide range of negative emotional and psychological issues were presented in the studies. This was the most common theme, identified in 33 studies as influencing the acceptance of pregnancy and access to care. Many women experienced depression, anxiety and stress, as a result of an unplanned or unexpected pregnancy or because of difficult life circumstances, often linked to poverty, social isolation and lack of power (Aved *et al* 1993, Cook *et al* 1999, Chandler 2002, Heaman *et al* 2014). Women experienced a range of emotions from ambivalence and indifference towards the pregnancy, to guilt and regret, embarrassment and the stigma of an unplanned pregnancy (Downe *et al* 2009, Houston Department of Health and Human Services (HDHHS) 2009, NCCWCH 2010). Many women described feeling angry and shocked, and unprepared for pregnancy (Mackey and Tiller 1998). Fear was widely expressed, particularly fear of the ‘consequences’ of pregnancy, whether this was the response of others, the necessary disclosure of risk taking behaviours or the need for official intervention in their lives (Lavender *et al* 2007). Fear of discovery of substance misuse in particular was highlighted by two groups of practitioners (Aved *et al* 1993, Gazmararian *et al* 1997), depression and the consequences of teenage pregnancy by another (Teagle and Brindis 1998). In some cases women acknowledged that these emotions led to the denial and resulting concealment of their pregnancies (Sable and Wilkinson 1998, Dartnall *et al* 2005, Daniels, Noe and Mayberry 2006).

**2.3.1.4 *“Didn’t want to be bothered with me” -*** social support for pregnancy

Eighteen studies identified the pivotal role of social support in the recognition and acceptance of pregnancy, whether from a woman’s partner, family or social network (Poland, Ager and Olsen 1987, Johnson *et al* 1994, Peacock *et al* 2001, HDHHS 2009). As previously mentioned, the fear of a negative reaction to the pregnancy from the father of the baby, family members or others close to them was highly influential (Milligan *et al* 2002). In some cases this resulted in women not wanting to accept nor share their pregnancies (Daniels, Noe and Mayberry 2006). One author discusses the notion of ‘temporarily limited’ support from a woman’s social network, as a result of lack of approval of a pregnancy (HDHHS 2009), that is available before pregnancy and postnatally, but not at the critical point of pregnancy acceptance.

***2.3.2 Acceptance of the public pregnancy: social consequences, antenatal care relevance and priority***

**2.3.2.1 *“Nothing in it for me”*** – thenecessity of antenatal care

The consideration of priorities and the weighing up of the benefits and risks of attending for antenatal care by pregnant women were documented in many studies. They identified that some women did not value care, viewing it as unimportant or unnecessary for a number of reasons, which impacted on their motivation to attend (Poland, Ager and Olsen 1987, Kinsman and Slap 1992, Harvey and Faber 1993). Women whose perception of prenatal care was that it was ‘less than very important’ were more likely to initiate care late, if at all (Roberts *et al* 1998). Some women explained that friends and family supported them, and therefore formal care was less important (Johnson *et al* 2003,2007, Heaman *et al* 2014). For other women it was the need to guard their private lives (and personal pregnancies), linked to the consequences of disclosure, that led them to conclude that the risks of attending outweighed the benefits (Lutz 2005). Women not valuing early care was identified by several practitioners as a significant influence on the initiation of care (Aved *et al* 1993, Gazmararian *et al* 1997, Omar, Schiffman and Bauer 1998).

**2.3.2.2 *“Knew what should be done” -*** previous experience

Negative perceptions of antenatal care were often presented by women with previous pregnancy experience. Eleven studies identified women using their previous positive pregnancy experience, both in terms of uncomplicated pregnancies and successful births, to assess their wellbeing and pregnancy priorities (Poland, Ager and Olsen 1987, Leatherman, Blackburn and Davidhizar 1990, Delvaux *et al* 2001, Daniels, Noe and Mayberry 2006). Some expressed a cynicism towards medical involvement in their pregnancies, stating that doctors were not needed for a healthy pregnancy or that they could not prevent some pregnancy problems (Schempf and Strobino 2009).

**2.3.2.3 *“I feel fine”*** - feeling well

Pregnancy was viewed by some women as a natural state rather than a condition requiring medical involvement. If the women felt well and had no medical problems then they saw no reason to attend, particularly during early pregnancy (Aved *et al* 1993, Philippi 2009). Women made contingency plans to access care in an emergency, but did not value preventative or routine antenatal care (Lia-Hoagberg *et al* 1990, Patterson, Freese and Goldenberg 1990), a point noted by practitioners in one study (Gazmararian *et al* 1997). This was particularly the case for multiparous women, especially those who were required to pay for care.

**2.3.2.4 *“Not up to going for care”*** - psychological and physical factors

In addition to psychological wellbeing, which was a significant influence on women’s initial acceptance of pregnancy, a small number of studies identified physical factors such as feeling unwell and fatigue as influencing women’s ability to attend for care. These symptoms were typical of those related to normal pregnancy, but were also the result of, and influential on, continuing stress, anxiety and depression related to difficult life circumstances and, as previously discussed, an unplanned or unwanted pregnancy (Harvey and Faber 1993, Johnson *et al* 1994, Cook *et al* 1999).

**2.3.2.5 *“I can do this on my own”* -** self-care, self-reliance

Seven studies identified women taking responsibility for their care (‘taking care of self’) as they perceived this to be the best choice for their circumstances (Poland, Ager and Olsen 1987, Sword 2003, Heaman *et al* 2014). This was described by one author as women taking an active role in their care, enough to promote ‘safe passage’ of their pregnancy, rather than simply a passive avoidance of care (Patterson, Freese and Goldenberg 1990). For some this was a temporary measure, part of being ‘a little bit pregnant’, prior to accessing formal, public care (Peacock *et al* 2001). For others it was a way of achieving at least some control over their pregnancies, when they felt they had little control otherwise (Merchant 1993, Sword 2003).

**2.3.2.6 *“Out of my hands”* -** fate, acceptance

Three studies focusing on women from BME communities highlighted cultural and religious influences in relation to women seeking antenatal care, particularly the role of fatalism and an acceptance of pregnancy. As such women were less interested in the screening offered in early pregnancy so were more likely to delay initiation of care (Dartnall *et al* 2005, Hollowell *et al* 2012, Boerleider *et al* 2013). Heaman *et al’*s (2014) study with a large number of indigenous Canadian women also suggested a reliance on self-care was part of this acceptance of pregnancy, as a normal state of health.

**2.3.2.7 *“Not very important to those close”* -** social support for antenatal care

Alongside the large number of studies identifying the pivotal role of social support in the acceptance of pregnancy, ten studies identified the influence of a woman’s social network in accessing antenatal care. Women were highly influenced by the knowledge, beliefs and attitudes relating to pregnancy and healthcare access (both positive and negative) of those around them; the cultural and social norms of their families and communities. Others lacked the social support and advice needed to access care or relied on others to accompany them (Daniels, Noe and Mayberry 2006, Hollowell *et al* 2012). Both of these experiences had the potential to influence women’s knowledge of antenatal care and whether it was valued and prioritised (Leatherman, Blackburn and Davidhizar 1990, Perez-Woods 1990, Mikhail and Curry 1999, Nothnagle *et al* 2000).

**2.3.2.8 *“Need time, energy to deal with other problems”* -** other priorities in life

Twenty three studies highlight the influence of other priorities in a pregnant woman’s life on her attendance for antenatal care. ‘Overwhelming life situations’ (York *et al* 1996) were identified by women and practitioners: personal problems and those of family and their social network, responsibilities that occupied their time, and other concerns in their lives which were a more important focus than healthcare (Gazmararian *et al* 1997, Dartnall *et al* 2005, HDHHS 2009, Heaman *et al* 2014). These, again, often related to complex, challenging and/or chaotic life circumstances as a result of poverty, and frequently lifestyle or health behaviour issues such as drug use (York *et al* 1999, Napravnik *et al* 2000, Milligan *et al* 2002, Callaghan *et al* 2011). In the most extreme situations immediate survival concerns inevitably took precedent (Lavender *et al* 2007), however for women from all backgrounds attendance reflected a consideration of life priorities.

**2.3.2.9 *“No means”* -** practical/site related/system factors

Practical and convenience issues were identified by the majority of studies (38), particularly in relation to transport, distance, childcare and scheduling of appointments, including three studies of practitioners’ views (Gazmararian *et al* 1997, Omar, Schiffman and Bauer 1998, Teagle and Brindis 1998). At first sight some of these appear to be unrelated to the initiation of care, however they were discussed in studies whose focus was late booking, often by multiparous women, as influential (Omar, Schiffman and Bauer 1998, Beckman, Burford and Witt 2000, Sunil *et al* 2010). Moving during pregnancy was also identified as a practical barrier to care (Chisholm 1989, Callaghan *et al* 2011, Corbett, Chelimo and Okesene-Gafa 2014). However practical considerations were only part of women’s consideration of convenience and priority. In one UK study poor women living close to the maternity hospital were more likely to book late for antenatal care than more affluent women living further away (Merchant 1993), in another administrative failures leading to delay went unchallenged (Callaghan *et al* 2011). The issues of practicality and convenience again reflected women’s assessment of their priorities and their commitment to receiving antenatal care.

**2.3.2.10 *“The cost of getting care is too high”* -** financial issues, economic hardship

In some US studies, particularly quantitative studies, the inability to afford antenatal care and insurance problems were presented as barriers to initial access (Philippi 2009). However the cost of attending for antenatal care was frequently discussed by women, including those eligible for free care, in the context of the increased economic burden of pregnancy rather than the cost of the healthcare *per se*. For example the cost of attending for care in terms of transport costs and time off work reflected another part of women’s assessment of priority (Reis *et al* 1992, Beckman, Burford and Witt 2000, Lavender *et al* 2007). This economic burden was also frequently linked to unplanned pregnancy and lack of familial support (HDHHS 2009).

**2.3.2.11 *“I already knew I was pregnant”* -** knowledge of antenatal care, the 'system'

Nineteen studies illustrated a poor knowledge and lack of understanding amongst some women about the content and value of early antenatal care, maternity care in general and access to it (Leatherman, Blackburn and Davidhizar 1990, Johnson *et al* 1994, Mikhail and Curry 1999). One group of practitioners shared this view (Gazmararian *et al* 1997). Some authors suggested this was a result of poor literacy and comprehension, due in some cases to language and communication barriers, others that it was the result of poor advice from others or social isolation (Dartnall *et al* 2005, HDHHS 2009, NCCWCH 2010). Without this knowledge and understanding women were unable to accept the need to attend for antenatal care and to prioritise it in their lives.

**2.3.2.12 *“Like you’re a piece of meat”*** - previous healthcare experience, dislike of care

Twenty six studies identified women’s poor experience with health services generally and negative antenatal care experiences as influential (York *et al* 1999, Daniels, Noe and Mayberry 2006, Callaghan *et al* 2011), though only one group of practitioners recognised this (Teagle and Brindis 1998). In the context of late booking these were expressed as direct experiences in previous pregnancies and indirect experiences from friends and family. Some women perceived a lack of relevance and poor organisation of care, for example with scheduling problems, communication difficulties and lengthy, poor quality appointments (Merchant 1993, Sword 2003). Others had negative attitudes towards healthcare practitioners, having experienced cultural ignorance and insensitivity, and articulated a lack of trust and confidence in them (Milligan *et al* 2002, Schempf and Strobino 2009, NCCWCH 2010). Women identified a lack of power and control in their experiences, which had a negative influence on their perceptions of the value and priority of care (Teagle and Brindis 1998, Hollowell *et al* 2012). For some this negative perception extended to a fear of specific procedures or examinations which led to women avoiding antenatal care.

**2.3.2.13 *“Cultural and religious differences”*** - cultural factors

Eight studies of BME women identified cultural factors as influencing their acceptance of antenatal care (Delvaux *et al* 2001, Dartnall *et al* 2005, NCCWCH 2010, Boerleider *et al* 2013). These were expressed in relation to direct healthcare experiences, for example the interaction with male healthcare staff, and the cultural norms relating to pregnancy, which were in conflict with the idea of attending for early care. The latter included consideration of pregnancy as private rather than a public experience to be shared with others, preferring care and support from within their own community, and differing experiences of healthcare in their country of origin (Hollowell *et al* 2012).

***2.3.3 Discussion***

Despite the huge diversity of women, in socio-demographic terms, and settings for the included studies, a simple argument has developed from the synthesis. For women to initiate antenatal care they must first recognise, then accept, their pregnancies, then accept the relevance and priority of antenatal care. This suggests the existence of two pregnancies: the intimate, ‘personal’ pregnancy of the woman (and possibly her immediate social network) and the ‘public’ pregnancy with its accepted norm of antenatal care attendance and its ‘social consequences’ (Peacock *et al* 2001, Daniels, Noe and Mayberry 2006, Lavender *et al* 2007). Late booking may result from the non-acceptance of either or both of these.

In terms of pregnancy recognition, the view of practitioners was one of primarily young, poorly educated women who lacked the knowledge and experience of pregnancy needed to identify that they were pregnant. This was borne out in a number of studies, particularly those with quantitative and demographic elements. However a more complex picture of pregnancy non-acceptance emerged overall, linked to lack of pregnancy planning and expectation and the influence of negative emotional and psychological factors, a result of these often unplanned and sometimes undesired pregnancies, and frequently combined with difficult life circumstances. The vigilance and support of a woman’s social network for the pregnancy, and the timing of this support, was also highly influential on a woman’s acceptance of her pregnancy. The influence of a positive pregnancy ‘mindset’ is suggested, both for the woman and those around her, in terms of recognition of signs and symptoms and acceptance of the personal pregnancy, the first part of a woman’s pregnancy journey. Where this mindset is absent, ambivalence and fear of the consequences of pregnancy mean that delayed acceptance of pregnancy is more likely. Mindset influences women’s consideration of time and the choices available to them, when accepting their pregnancies and traversing the boundary between the personal and public pregnancy, with the result being further delay in accessing antenatal care.

Once women have accepted their private, personal pregnancies there is a consideration of the public pregnancy and its social consequences; part of the creation of a ‘social pregnancy identity’ (Campbell *et al* 1995). Downe *et al* (2009) identify women’s consideration of their priorities, and a weighing up of the benefits and risks of attending for antenatal care, as a factor in ongoing care, rather than initiation (*“weighing up and balancing out”*). But the studies suggest it is also an important consideration for women at the beginning of their pregnancy journeys, particularly the majority of women studied who had complex and challenging life circumstances.

Practitioners expressed many of the same perceptions of late booking as the women. However, unsurprisingly perhaps, whilst many women didn’t perceive barriers to care or gave practical reasons for late or non-attendance, this was expressed by practitioners in labelling, negative terms. Women were seen as non-compliant, clinic ‘defaulters’, lacking the knowledge and understanding of the purpose and value of early care, which prevented them from prioritising care (Aved *et al* 1993, Merchant 1993, Gazmararian *et al* 1997). The women’s views suggested a different perspective. Some multiparous women made judgements about the relevance and priority of antenatal care in the context of their previous positive pregnancy experience and physical wellbeing, linked to views of pregnancy as a state of ‘wellness’ as opposed to a medical condition. Religious or cultural views of pregnancy were also influential for some BME women, in terms of the need for care. Fear of the consequences of a public pregnancy and the interventions of others in this also influenced a woman’s perceptions of control and whether she prioritised care. A natural extension of all these views was reflected in ‘self-care’: women taking control of their care, sometimes temporarily, as part of an ongoing consideration of priorities.

As with acceptance of the pregnancy, women’s psychological and physical wellbeing influence their judgements in relation to the priority of antenatal care, as well as their physical ability to attend. A woman’s social network and the social and cultural norms of its members can also be highly influential on her perceptions of the relevance and priority of antenatal care. All these factors however have the potential to influence a woman’s understanding and acceptance of antenatal care. Women’s acceptance of the priority of care is also linked to negative healthcare experiences and poor relationships with healthcare staff. These are widespread experiences, both direct and indirect, among many women in the studies, and they have a profound influence on the value placed on antenatal care and women’s desire to attend.

The overwhelming majority of research in the synthesis is from the USA (83% of the primary research studies), where there are significant differences in the organisation of healthcare. However, few women rejected the detailed content or format of antenatal care, but some rejected the overall relevance of the care: findings that cross national boundaries. Lavender *et al’s* (2007) systematic review of access to antenatal care acknowledges that many of the identified barriers to antenatal care in other countries, particularly the USA, may be pertinent to the UK, despite different models of healthcare provision.

Financial barriers reflect at first sight the strong US bias to the research, though in many studies women were eligible for free care. They also reflect the large number of studies with a quantitative, socio-demographic focus: statements such as ‘*the cost of getting care is too high’* were found in only three qualitative studies. However closer examination of economic and practical issues suggest that women’s views across the diversity of studies reflect a recognition of the full consequences of a pregnancy, including the costs, both personal and financial, direct and indirect, associated with attending for care. Again, past experience of antenatal care, particularly negative, influences women in early pregnancy. For many women from low-income backgrounds (the majority of studies), women with often complex lives and multiple commitments to their time and energy, cost and convenience represent significant considerations. Women in such circumstances demonstrate pragmatic decision making when prioritising their lives, accepting that antenatal care is not top of their priority list.

The issue of prevention suggests a contradiction to the theory of acceptance. A small number of studies, relating to BME women and particularly those recently arrived in a western country, have identified that there may be particular circumstances where preventative factors influence or even outweigh women’s acceptance of their need for care (Hollowell *et al* 2012, Boerleider *et al* 2013). For example, poor knowledge of antenatal care and ‘the system’ of care is associated with social isolation and misinformation, however there could be some circumstances where it results from language or comprehension difficulties. There may be a small number of women who are prevented from attending for care by practical issues such as financial restrictions or through administrative failures, if these are unchallenged. However the evidence suggests that even amongst these specific groups this is only part of the picture, and that knowledge and cultural factors, as well as practical considerations, influence women’s acceptance of the value of attending for antenatal care.

**2.4.3.1 Limitations of the CIS method**

The critical element of the CIS method requires a consideration of the nature of assumptions made in the studies. Different factors may influence antenatal care initiation and continuation, though any one factor may influence both (Leatherman *et al* 1990). Few of the studies sampled make a clear distinction between these factors, rather it is more a question of emphasis, a potential weakness in the review. The differing constructions of ‘late booking’ inevitably influence findings, with wide variation in the definition of late. Arguably women booking at 13 weeks gestation are likely to demonstrate differing attitudes towards their care than a woman booking at, say, 28 weeks. In addition, the inclusion of women who were unbooked in some studies represents another dimension of opinions, an extreme view of antenatal non-attendance perhaps, but one which was included to add further depth and completeness to the review.

The findings also reflect the diversity of women, contexts and the methods used. The range of ages (from 12 to 45) and backgrounds illustrate the full spectrum of life experience. Women interviewed postnatally, immediately after the safe arrival of their babies or several years later, will have a very different view of pregnancy challenges than those interviewed antenatally. Women interviewed in hospitals or clinics are likely to present themselves differently to women at home. Likewise, women singled out as ‘late bookers’ are likely to respond differently to women in more general surveys of antenatal access or participation.

The breadth and detail of the findings reflects the nature of the interviews and the freedom of choice women were given to respond. This ranged from the flexible interview guides of grounded theory studies (e.g. Sword 2003) to largely demographic data collection questions with a short list of possible barriers to antenatal care (e.g. Delvaux *et al* 2001) to complex questionnaires with more than 100 questions relating to health beliefs, barriers to care, pregnancy intention and support (e.g. Cartwright *et al* 1993, Fuller and Gallagher 1999). Even a well-constructed questionnaire has its limitations however, as Chandler (2002) illustrates:

*“we have little idea what was in the respondents’ minds when they said that they had ‘felt a great deal of stress’ at the time they found out they were pregnant”* (p33).

Several mixed method studies restrict their presentation of findings to demographic data and the fixed choice responses given by women, suggesting a preference for ‘hard’ quantitative elements to justify the validity of their findings (Kalmuss and Fennelly 1990, Teagle and Brindis 1998, Corbett, Chelimo and Okesene-Gafa 2014). Though the studies of women’s and practitioners’ views add another layer to the discussion, the comparison of such views is complicated by the different methods used to ascertain them, for example fixed or restricted choice questionnaires versus open focus group discussions. In addition, few researchers consider the influence of reflexivity.

The age of included studies is likely have some influence on the findings. However, although referral procedures and the location of care may have changed, the content of early antenatal care has changed little (in the UK at least) in the last 20 years. This is illustrated by Merchant’s 1993 description of the booking appointment, which (as now) included history taking, Body Mass Index (BMI) calculation, blood pressure and urinalysis, the offer of antenatal screening tests and ultrasound assessment of gestation.

There are limitations to any literature review, and inevitable summarising and subjectivity, however systematic the approach. Quality issues may weaken the nature of constructs emerging from the studies and subsequently their synthesis, however the CIS approach acknowledges the integral interpretation of both credibility and contribution (Flemming 2010, Annandale *et al* 2007). It embraces the authorial voice, using accepted qualitative research methods and a creative approach, to produce not simply a summary but a more conceptual reinterpretation of the evidence. In this case the somewhat limited voices of the women presented in quantitative studies contrast with the richness, and arguably the honesty, of the qualitative research. However all these studies have a contribution to make, forming an essential part of the evidence around late booking and contributing to the insight and usefulness of the synthesis. Similarly, incorporating other literature reviews and analyses adds to the body of knowledge, reflecting another layer of thinking about delayed access to antenatal care and helping to achieve a theoretical saturation on the subject.

**2.4 Conclusions, aims and objectives for the study**

CIS offers one approach to synthesis, one that is both systematic and iterative, and explicitly oriented to theory generation. This interpretive review of a large and methodologically diverse body of evidence around perceptions and beliefs towards late booking for antenatal care, identifies that antenatal care participation behaviour is extremely complex. However, an overarching theme develops, namely the acceptance of two pregnancies: personal and public. The personal pregnancy acknowledges that initial recognition and acceptance of pregnancy is the start of the pregnancy journey, and is influenced by knowledge, expectation and social support. The public pregnancy recognises that acceptance of the relevance and priority of antenatal care influences initial access to such care, the next step on the journey. This acceptance is shaped by a complex balancing of the positives and negatives of being pregnant, by a consideration of past, present and future factors: for some women late booking is a positive choice rather than a passive disengagement. The limited views of practitioners concur with many of those of the women, but universally express disapproval for late booking.

The review illustrates the limitations, in both breadth and depth, of research around late booking for antenatal care, as opposed to access to antenatal care generally. There is a lack of recent research about antenatal care initiation, a lack of UK based research and particularly research which is not London based. There is also a predominance of quantitative approaches. The findings, alongside the evidence presented in chapter one, demonstrate the need for further qualitative research around late booking.

A Health Services Research project was developed in Sheffield. The aim of the project was to understand the reasons why some women present late for antenatal booking; to contribute to an improvement in early access to antenatal care and ultimately to outcomes for pregnant women and their babies. To achieve this aim the project had two objectives:

**1. To interview pregnant women booking late for antenatal care in Sheffield:**

- to explore barriers to their early initiation of antenatal care;

- to explore their understanding of the importance of early antenatal care;

- to explore their experiences of pregnancy discovery and accessing care.

**2. To interview health and social care practitioners involved in the care of pregnant women in Sheffield:**

- to explore their perceptions of the barriers to antenatal care;

- to explore ways that antenatal access may be improved for ‘hard to reach’ pregnant women.

The focus, for the purpose of this thesis, is on the perspectives of the women. This study was the part of the larger project which I led as research midwife, including recruitment, data collection and analysis.

Findings from initial reviews of the literature and from the studies and publications in chapter one were used to refine the research question for the study, and to inform study processes such as the development of the interview guide and sampling.The following chapters, three and four, detail this refinement and the methodological considerations and qualitative methods underpinning the study. The interpretive synthesis itself was conducted subsequently, and separate to the data analysis for the Sheffield study. The intention was to maintain the originality of both the synthesis and the findings from the study, to avoid the imposition of *a priori* themes and ideas. These two parts are brought together later in the thesis, in the discussion and recommendations chapters.

**Chapter 3. The methodology for the study**

**3.1** **Determining the research methodology**

***3.1.1 Why qualitative research?***

## The research question

The previous chapters have given an introduction to the subject of late initiation of antenatal care (late booking). Chapter one has considered the reasons why late booking matters and who the women are who book late. Chapter two has illustrated the complexity of beliefs and behaviours in relation to antenatal care initiation and the limitations of existing research. The original aim of this study reflected a pragmatic health services research approach: to develop a better understanding of late booking in a UK setting, in order to influence future practice. This was in response to concerns about health inequalities in relation to pregnancy, and particularly the links between poor access to care and adverse outcomes. As with the literature review, the research question evolved from this aim and was refined throughout the initial phases of literature searching and data collection, alongside the multi-professional research supervision. The process of formulating the research question again echoes Eaking and Mykhalovskiy’s (2003) view of the questionas a compass rather than an anchor, opening up rather than restricting possible avenues of enquiry, framing the research in an answerable way, whilst aiming to avoid assumptions and pre-conceived ‘common sense’ answers (about late booking) (Green and Thorogood 2014). It is concerned with women’s experiences of late booking but also their beliefs in relation to this, and the particular significance of barriers to the early initiation of care. As such the overall research question has become *“what perceptions and beliefs do late booking women express about the delayed initiation of antenatal care?”*

The research question echoes chapter one, which considered that numerous studies and reports acknowledge that the statistics and demographic information around late booking are only one part of the story. The need to see beyond these, to understand women’s attitudes towards antenatal care and its initiation, in order to improve early access, has been expressed by both researchers and policy makers. This requires the application of research methods which allow a detailed examination of experiences and beliefs in relation to pregnancy and care. The challenges of researching a group of women who are potentially more vulnerable, and may be less articulate and confident, are considerable.

As chapter two has illustrated, a wide range of research methods can be used to investigate late booking, including both quantitative and qualitative approaches. Malterud (2001a,b) argues that such approaches are complementary rather than opposite, that they share underlying principles; it is the researcher’s role to choose *“the path of inquiry that will most adequately provide valid accounts of the actual study field”* (2001a: 399). The limitations of particular methods in achieving such ‘valid accounts’, particularly in relation to experiences and beliefs, are also acknowledged in chapter two. The use of quantitative methods, for example structured interviews and questionnaires, has many advantages, particularly the ability to survey large numbers of participants and cover a wide range of subjects. However, as some authors have reflected, such methods may be less personal, more superficial, and may fail to recognise the context of women’s lives. As a result they may generate results which are less honest and open, and which are unable to reflect the depth and detail of women’s views.

Both chapters one and two have considered the need for further research. However what is also evident from the literature review is the lack of a suitable template for the study of late booking in the UK. Unlike many of the US studies, there are no standard survey instruments available or appropriate to assess the adequacy or initiation of antenatal care. This necessitates a customised, purposive design rather than a standardised approach to answering the research question.

The title ‘qualitative research’ encompasses many forms of social inquiry, widely used in healthcare research, which focus on the way people make sense of their experiences and the world in which they live. In simple terms, whereas quantitative research focuses on questions such as ‘how often?’, qualitative research explores patterns of behaviour and subjective meaning, considering questions such as ‘why?’ and ‘how?’ (Pope and Mays 1995). They are largely interpretive approaches exploring behavioural processes and feelings, which allow for an in-depth exploration of attitudes, values and beliefs. As Holloway and Wheeler suggest, *“qualitative research is a coherent way of researching human thought, perception and behaviour”* (2010: 28).

Qualitative research has the ability to produce rich insights into human behaviour, social processes and complex issues, and as such it has been argued that it offers the potential for greater depth and validity than quantitative approaches (Murphy *et al* 1998, Bowling 2009). As Powell Kennedy (2011) argues, quantitative methods such as randomised controlled trials (RCTs), with their tight control over subjectivity and context, do not fully reflect the world of the individual and what is meaningful and relevant to them. Jenkinson (1997) acknowledges that qualitative methods have the capability to minimise the disparity between what people say they do and what they actually do.

The boundaries of qualitative research are sometimes less than clear: it has been described in terms of not being quantitative research (Pope and Mays 2006), but Bryman (2008) is also clear that it is not *“quantitative research with the numbers missing”* (p438). Qualitative researchers choose a variety of approaches and methods to achieve their aims. Denzin and Lincoln (2003) call these a *“complex, interconnected family of terms, concepts and assumptions”* (p3), and debates continue about the nature, purpose, status and methods of qualitative research (Murphy *et al* 1998, Paley and Lilford 2011). It is an approach, usually inductive in nature, which is not static but developmental and dynamic in character, with a strong focus on the process of the research as well as the findings. A flexible and emergent design, which evolves over the course of the research, reflects the desire for research to represent the realities and viewpoints of the participants, which may not be known at the outset of a study (Lincoln and Guba 1985). This is in contrast to the more rigid quantitative ‘testing’ of pre-determined ideas from the researcher’s perspective. As such, qualitative methods can access ‘challenging’ areas of social life that may not be open or amenable to quantitative research (Pope and Mays 2006). They have shown demonstrable advantages over quantitative approaches in situations (such as this) where there is little pre-existing knowledge and issues are sensitive and complex (Bowling 2009).

Qualitative methods for the study of health and health services are widely used and accepted as a legitimate method of attaining knowledge about practice issues (Hunter 2008). Their use reflects the dramatic changes in the ways in which health is understood and managed that have occurred in recent decades, beyond that which can be controlled, measured and counted (Malterud 2001a). As Green and Thorogood (2014) suggest, qualitative healthcare research is

*“conducted to understand more about a phenomenon rather than measure it, and to investigate health, illness or health services from the perspective of the communities and individuals affected, or the professionals who provide health services for them”* (p6)

It reflects the subtlety of beliefs and behaviours in health services and the influence of these. As Malterud (2001a) observes, *“clinical knowledge consists of interpretive action and interaction – factors that involve communication, opinions and experiences”* (p397). Qualitative approaches are specifically related to the consideration of these factors, in this study in the clinical context of antenatal care. They have the potential to focus on feelings, experiences and thoughts, but also consider change and conflict, for example issues relating to access and participation in services, and to evaluate changes in health service provision from the viewpoint of both patients and health professionals (Pope and Mays 2006, Holloway and Wheeler 2010).

Sword (1999) acknowledges that antenatal care utilisation behaviour is multifaceted and multidimensional, and that research must address this, but has failed to do so:

*“to date, knowledge about barriers to prenatal care has evolved largely through positivist research approaches… based on what service providers and researchers perceive as important factors… the use of traditional methodologies also may oversimplify the notion of barriers because they do not allow for the exploration of psychosocial processes that determine use.. qualitative methods are appropriate… because they elucidate personal perspectives and contextual meanings”(*p1174-5).

She argues that unlike other research methodologies qualitative research is able to facilitate an in-depth exploration of perceptions that are essential to understanding barriers arising within a given social context. Qualitative research is therefore essential to improve access to antenatal care:

*“if the situated experiences and perceptions of socio-economically disadvantaged women are not accessed to inform health care delivery, these women will probably continue to encounter significant barriers to prenatal care and relationships that reinforce positions of powerlessness”* (ibid p1175-6)

A qualitative approach was therefore considered highly appropriate for a study of women’s perceptions and beliefs, one with a Health Services Research focus, which aimed to influence (and improve) future practice through the development of ideas and interventions.

***3.1.2 Influences on the methodology***

Methodology can be defined as theprinciples and ideas, the theoretical framework, on which researchers base their procedures and strategies, i.e. their methods (Holloway and Wheeler 2010, Hall, McKenna and Griffiths 2012). It is important to explicate the ontological and epistemological principles which underpin the choice of methodology for any research. As Bondas (2011) argues:

“*An understanding of the epistemological roots of the method chosen in relation to the topic of interest may enhance the research process and, ultimately the quality and depth of knowledge that is subsequently developed.”* (p1).

In particular, good quality applied qualitative research must be theoretically informed. There are some very different theoretical, epistemological and political starting points in qualitative research, although many of them share a rejection of one or more of the elements of the positivist tradition (Green and Thorogood 2014). They reflect the inevitable tensions between rigour and originality, and the delicate balance of reflexivity with the voices of participants in the research. The desire to produce theories whilst reflecting the diversity of perspectives, and the need for systematic approaches whilst acknowledging the iterative and creative processes involved, are also manifest. All of these tensions are evident in this study.

The explication of the methodology begins with an acknowledgement that there is no single ‘superior’ approach to qualitative research, rather a number of complementary and overlapping approaches with more or less suitability for different research aims and settings. The qualitative methodology most appropriate to answer the research question is one which is:

1. Largely **Inductivist** in its approach: whereby theory is generated from the research data;
2. **Constructivist** in its ontological position, with postmodern and feminist influences; considering that behaviours and attitudes related to late booking for antenatal care are constructed as a result of interactions between people, rather than existing separately;
3. **Interpretivist** in its epistemological position: aiming to understand the social world of late booking women by examining how they interpret their world; using the concepts of ‘lifeworld’ and *verstehen* (empathetic understanding); and
4. Influenced by some of the principles of **grounded theory.**

These are explored in the following section.

**3.1.2.1 Inductivism**

With an inductive approach theory is the outcome of the research: drawing generalisable inferences out of observation, allowing what is relevant about the topic to emerge (or rather *be constructed*) from analysis. This is an iterative process of weaving backwards and forwards between data and theory, in clearly defined stages but not a linear process. This is associated with qualitative research methods and particularly grounded theory, and is in contrast to the *hypothetico-deductive* approach of most quantitative research, which involves testing or disproving hypotheses based round a pre-determined theory (Bryman 2008, Bowling 2009).

The study aimed to develop theories around late booking from the stories of women. The largely inductive approach, though informed by existing evidence, aimed to ‘keep an open mind’ rather than applying any predetermined theories about why women delay accessing antenatal care. This was reflected particularly in the data collection and analysis methods used in the study. However both qualitative and quantitative research can contain a balance of inductive and deductive elements, used for different purposes at different points in a study, and there is great potential (and necessity) for interplay and flexibility (Murphy *et al* 1998).As Sword (1999) comments:

*“most qualitative studies lie somewhere between a loosely structured, emergent, inductively grounded method and a deductive, confirmatory technique”* (p1175)

The generation of theories around late booking has entailed such combined thinking.

**3.1.2.2 Constructivism**

Constructivism is an ontological position *(ontology: the nature of reality or existence)* which views all knowledge as a compilation of human-made constructions, as opposed to an impartial discovery of an objective truth. Reality, or the world as we comprehend it, is therefore socially constructed. It is a product of social processes including context, time and culture, which can’t be separated out, rather than something external to us which is imposed. Individuals play an active role in the construction process, which influences perceptions and actions: ‘truth’ is therefore consensual (Murphy *et al* 1998, Bryman 2008). Lincoln and Guba (1985) suggest that the truth can be defined as the best informed and most sophisticated consensus, with the inquirer and inquired interlocked. Similarly participants, researchers and readers construct research through social interaction (Corbin and Strauss 2008, Holloway and Wheeler 2010).This is in contrast to positivist and objectivist/realist perspectives which suggest that there is one stable pre-existing reality out there waiting to be discovered. It has a strong tradition in qualitative health research where it plays a vital role in challenging assumptions or received wisdom and reading ‘beyond’ statistics (Green and Thorogood 2014).

Constructivism implies that social phenomena are produced through social interaction and are constantly being revised; the researcher’s own accounts are one part of this construction/reconstruction/revision, i.e. there is no single definitive answer. This suggests that knowledge is indeterminate, not fixed or inert; it may act as a point of reference but is always in the process of being formed (Bryman 2008). The categories we use to define and understand our world are social products – constructed in and through interaction, varying in time and place. Different social and cultural groups construct categories of meaning and behaviour in different ways (for example late booking): women’s views and doctors’ views are likely to be different. Particular meanings and connotations, for example negative or blaming, could be part of this construction, for example influenced by representation in the media (Bryman 2008).

Constructivism is allied to postmodernist views which reject the traditional view of absolute knowledge, stressing the plurality of perspectives and the importance of local context, and questioning the aspiration of objectivity and neutrality in research (Holloway and Wheeler 2010). Malterud (2001a) argues that postmodernist researchers are prepared to accept partial understanding of their topic and the identification of new questions as the outcome of their research, as opposed to definite answers. The postmodernist perspective also includes feminist views which suggest that‘knowledge’ is a masculine construction and that fundamentally men and women have different views of the world based on different experiences, which inevitably will influence research. Qualitative research is seen as more consistent with the values of feminism, avoiding a value-neutral approach and accepting the need for empathy and ‘conscious partiality’ (Mies 1993). Feminist thinking openly acknowledges the subjectivity required to engage with participants as real women in real life settings, to create research *of* women *for* women (Harding 1987, Bryman 2008, Green and Thorogood 2014).

The constructivist influence is reflected in several aspects of this study. Firstly, is the acknowledgement of my role as researcher in the construction of the findings with the women, of honesty regarding reflexivity and its influence in the research. The empathy between researcher and researched, and encouragement of all ‘participants’ to play an active part in this construction, also reflects feminist influences. There is a recognition that the findings have not simply emerged from the data but are as a result of social processes. The findings aim to reveal the diversity and detail of perspectives, influences and the social context for the study, rather than trying to find the definitive ‘answer’ about late booking; to create something original and relevant, with validity for Sheffield in the first instance.

**3.1.2.3 Interpretivism**

The positivist epistemological position *(epistemology: the theory of knowledge and its acquisition)* is centred around a belief in objective reality, which can be ascertained by the senses (empiricism), tested subject to universal laws and rules and is generalisable to all settings. Positivist research is largely deductive and quantitative in its approach, seeking causal relationships, focusing on prediction and control using ‘facts’ (the result of systematic observation and measurement) and using predetermined theories/hypotheses as the starting point for research. Key to the positivist perspective is the necessary distance between researcher and researched to avoid bias, and the use of ‘objective’ measurement systems. Positivist traditions shape much health and healthcare research, for example clinical trials and standardised surveys or structured interviews (Bowling 2009, Holloway and Wheeler 2010).

The 19th century views that led to the foundation of the positivist movement and the ‘scientific method’ are now viewed as simplistic, however many authors still identify the clash between positivism and hermeneutics *(the study and interpretation of human behaviour).* They argue that positivism is unachievable in research into human behaviour, being more concerned with facts, measurable behaviour and cause and effect, than context, feelings and subjective interpretations. Humans are different, they are complex and reflective, so a different approach to research is required (Bowling 2009, Green and Thorogood 2014). This echoes Alfred Schutz’s view from the 1940s of the fundamental difference between the natural sciences and the social sciences and the need for an epistemology that reflects this (Bryman 2008).

Interpretivism broadly encompasses many different non-positivist approaches. These approaches aim to interpret social phenomena, centring on the way that humans make sense of their experiences and attach meaning to them, and the importance of life context on these experiences. They focus on a reflective reconstruction and interpretation of other people’s actions and again mirror some feminist thinking (Pope and Mays 2006, Willis 2007). Max Weber’s concept of *Verstehen* reflects this, with an emphasis on empathetic understanding, a focus on internal, personal meanings rather than external influences/controls that have little meaning for ordinary people. It also recognises that understanding human experience is different to, but as important as, explaining it (Weber 1979, Bryman 2008).

Interpretivism is rooted in the philosophical approaches of phenomenonology and hermeneutics,whereby everything is subject to the acts of perception and interpretation. Research in such traditions aims to understand the ‘lifeworld’ of particular people: the world of unique but everyday experiences and meanings, putting aside, but not dismissing the influence of, existing prejudices, assumptions and theories (Bondas 2011). This lifeworld is created by those in it, through social interaction, and is not standardised across social and cultural groups, or existing separately to them (the objectivist view). It reflects Mead’s (1934) view of individuals as creative and thinking, exercising choice, not just reacting to external influences.

Interpretivist research focuses on discovering these social meanings, interpretations and subjective understandings, rather than an ‘objective reality’ (Green and Thorogood 2014). It requires multiple layers of interpretation: identifying people’s interpretations, interpreting these and then interpreting them again in terms of overarching concepts and theories. As Thome *et al* (2004) suggest, research aims to ask questions such as *‘what makes this lived experience what it is’* and *‘what is unique about this?’.* Because experiences are context and language bound, interpretive approaches recognise that the values and interests of all the participants (including the researchers) become part of the research process. This presents challenges as it suggests that complete objectivity and neutrality are almost impossible to achieve and that studies cannot be replicated. It is therefore essential to proceed in a well-structured and systematic way, taking into account one’s own position and influence in the research setting - reflexivity (Bowling 2009, Holloway and Wheeler 2010).

An interpretive approach is evident in this study, which attempts to examine the complexity of human behaviours and attitudes in relation to antenatal care initiation, rather than adopting an empirical approach to late booking as an ‘objective reality’. As evidenced in chapters one and two, late booking has many facets and definitions; perspectives around it are subtle and complex, requiring layers of interpretation in the analytical process. Trying to understand the lifeworld of late booking women necessitates acknowledging the unique context that led to delayed initiation of care, and demonstrating an empathetic recognition of the value of these perspectives for our understanding. A positivist ‘cause and effect’ methodology is thus potentially simplistic. Interpretivist and constructivist approaches share common aspirations, such as all participants actively contributing to the research process, which has been an important part of this study. There are also common tensions, reflected in the research: between the need to put aside preconceptions whilst acknowledging that these inevitably have some influence, and a balancing of the unique nature of the study with a systematic approach, to ensure validity (Braun and Clarke 2006).

### 3.1.2.4 The influence of grounded theory

The chosen methodology acknowledges the fundamental influence of phenomenology, with its emphasis on participation and the interpretation of multiple, socially constructed and context-bound realities. In terms of practical application however, the study has adopted a more structured approach to data collection than is usual in phenomenological research. This is in response to the pragmatic health service focus and the stated aims of the study to examine the attitudes and beliefs of late booking women, in an attempt to improve understanding, access and, ultimately, health outcomes. The study mirrors the pragmatic and interpretivist influences associated with action research but stops short of the explicit focus on practical methods and behaviour change. It also reflects the examination of late booking as a distinct point in women’s lives rather than as ongoing ‘lived’ experiences, typical of phenomenological and ethnographic research and often explored through observation.

Grounded theory is an approach to qualitative research which matches the aspirations of the study and its theoretical framework. It has provided a systematic structure, influencing many of the processes and output of the study. Glaser and Strauss (1967) developed grounded theory as an inductive method of qualitative research which allows social theory to be generated systematically from data (i.e. from the ‘ground’ upwards) rather than being defined in advance, through a systematic process of rigorous and structured analysis. They argued that through such an approach qualitative research could advance from description and interpretation to theory development. Grounded theory has been hugely influential in changing the way that qualitative research is undertaken. It is a useful method for research into human behaviour and attitudes, and the factors that influence these, especially when little is known about the area of interest (Hall, McKenna and Griffiths 2012). It is a particularly relevant approach for examining relationships in healthcare, for example in midwifery, as Hall, McKenna and Griffiths (2012) observe:

*“Grounded theory is an ideal research approach for exploring how midwives and women interact, and to examine the factors that mediate their decision making in clinical practice”* (p136).

Grounded theory has been called “*a compendium of different methods”* (Corbin 2009: 41); it can refer to a methodology, a method of inquiry and to the product of inquiry. It has grown and developed in different directions, however in essence it remains *“a set of flexible analytic guidelines that enable researchers to focus their data collection and build inductive… theories through successive levels of data analysis and conceptual development”* (Charmaz 2008: 204). Grounded theory emphasises the reciprocal relationship between data gathering, analysis and theory. Theories are not causal relationships but are built from multiple observations; they are generalisable ideas or concepts designed to express plausible relationships or testable propositions rather than absolute ‘truths’. At its most effective, grounded theory can provide rich, detailed interpretations; outcomes which reflect the aims of this study (Strauss and Corbin 1998, Pope *et al* 2006, Lacey and Luff 2007, Bowling 2009).

The process of grounded theory is a creative one, grounded in a scientific approach: part of its appeal has been the structured and detailed procedures it provides for the generation of theory from data (Lacey and Luff 2007). It is not a linear process but involves cumulative, frequent revisiting of the data and revision of the methods in the light of new analytical ideas that emerge as data collection and analysis progresses. Many different methods and interpretations of grounded theory exist. Charmaz (2006) suggests a constructivist view (more recently accepted by Corbin and Strauss (2008)), which has been influential in this study, arguing that theories are co-constructed by the researcher and the participants, rather than ‘emerging’ from the data as Glaser and Strauss first suggested; a mixture of induction and deduction, moving between data and theory (an ‘abductive’ approach of reasonable inference (Charmaz 2012)).

Effective grounded theory is a complex and creative process requiring ‘reasoned reflections’, ‘principled convictions’ and ‘aesthetic merit’ (Charmaz 2008). However, it has been recognised that grounded theory can be defined more broadly, and that there are many elements of the inductive grounded theory approach that are useful for *any* analysis of qualitative data. Even Strauss and Corbin in their most recent book (2008) define grounded theory *“in a more generic sense to denote theoretical constructs derived from qualitative analysis of data”* (p1). This and other practical considerations have been influential in its development (Green and Thorogood 2014). In practice, as in this study, researchers frequently use the analysis procedures outlined in grounded theory without taking on board the whole methodological approach to research design. As Charmaz (2012) comments: *“Most grounded theorists follow an iterative approach, many make comparisons, few construct theory. But the potential is there”* (p2). Some have described this as ‘modified grounded theory’ and have praised this as an evolution of the method, a flexible way of thinking (Charmaz 2006, Pope, Ziebland and Mays 2006, Holloway and Wheeler 2010). The influence of grounded theory is evident throughout the research, particularly the use of constant comparison method: the overlapping processes of data collection, analysis and theory development, each enhancing the other.

## *3.1.3 The main features of the methodology*

The essential features of the qualitative methodology are considered below and are explored in terms of the general conduct of the research. A more detailed consideration of influences on the study methods, including sampling, data collection and analysis, is presented in section 3.2.

### 3.1.3.1 Focus on the emic perspective

The research takes an *emic* perspective as its starting point, focusing on ‘the inside view’: the differing views of the people involved in the research rather than those of the researchers themselves. The aim has been not to adjudicate between accounts, but to uncover meaning and to understand how people interpret their experiences and behaviour, and the rules that govern their actions. There are two central tenets to the approach: face to face interaction and adopting an empathetic stance (Lofland *et al* 2006, Green and Thorogood 2014). The latter requires an empathetic understanding (reflecting Weber’s *verstehen*) of meaning, behaviour and intentions and a recognition that participants have a voice, which is there to be discovered, rather than imposing the researcher’s perspective and any prior assumptions they may have. Quantitative research has been accused of ‘riding roughshod’ over participants’ meanings, and of taken-for-granted assumptions distorting findings (Murphy *et al* 1998).

The study’s flexible methods, from sampling to data collection and analysis, reflect the desire to hear women’s ‘voices’ on late booking. They were developed in order to enable women to speak openly and at length about their experiences of becoming pregnant, about delays in seeking care, and their knowledge of antenatal care, and the influences on these, without superimposing preconceived ideas. They were also created to examine their perceptions and beliefs during pregnancy and how these impacted on their behaviour.

The *emic* approach also recognises that individuals are the experts of their own lives, both in terms of feelings and experiences, and that people make their own definitions of reality and normality which could be dynamic or changing. In health research this empathy is acknowledged as an essential part of changing behaviour, for example in terms of successful health promotion and education activities (Green and Thorogood 2014). A successful relationship between researcher and researched is thus close and equal, non-judgemental and honest, with participants having control over the research process. The researcher’s view (the *etic* perspective) emerges during the subsequent analysis and reflection process, with the researcher moving backwards and forwards between the two views (Holloway and Wheeler 2010).

### 3.1.3.2 Data has primacy

The research has attempted to produce rich, in depth, textual data, allowing for the description and interpretation of participants’ experiences; detailed portrayals of the processes underpinning social activity: context, behaviours and beliefs (Green and Thorogood 2014). This necessitated probing beyond the surface appearances often captured in quantitative approaches. As Denzin (1989) describes it: *“Deep, dense, detailed accounts… detail, context, emotion and the webs of social relationship”* (p83). This use of‘thick description’ (as expressed by Geertz 1973) enables researchers to go beyond the constructions of the participants, moving to a more abstract and theoretical level to generate new theories rather than testing existing ones. This reflects not simply a direct reproduction of the findings but an inductive process of selection and interpretation, of imbuing descriptions with theoretical assumptions; a process where the data has priority (Murphy *et al* 1998, Holloway and Wheeler 2010). This focus allows *‘the broader context of social behaviours to be delineated’* (Green and Thorogood 2014: 26), a merging of participants’ lived experiences and interpretation of those experiences (Ponterotto 2006).

This focus on creating something which is not merely observational, but also theoretical and analytical, and which ultimately has a purpose, is important. Denzin (1971) comments that social research should reproduce, in a rich and detailed fashion, the experiences, thoughts and languages of those studied, in an attempt to impose order on the social world. The study’s aim was to capture the depth and detail of women’s experiences, using these stories to interpret women’s experiences more broadly, constructing new theories about why women present late for antenatal care. This reflects pragmatic considerations in a process which aimed ultimately to influence future practice through the development of ideas and interventions which could be tested on a larger scale. This in turn reflects Medical Research Council (MRC) guidelines for the development of such complex interventions, which identifies key elements of the systematic development process, including

1. Identifying the existing evidence base through a systematic review of the literature; and
2. Identifying and developing theory, supplementing existing evidence and theory with new primary research, for example interviews with ‘stakeholders’ (MRC 2008: 9).

### 3.1.3.3 Context is important

The research methods have demonstrated a commitment to a holistic understanding of social behaviour through *naturalism* - studying people in context, in ‘natural’ or ‘real life’ environments. This is in contrast to the controlled, experimental or artificial conditions aspired to by many quantitative techniques. This allows the researcher a view of the‘real’ world of participants, an opportunity to see their point of view and how they construct situations. There is an acknowledgement of the need for sensitivity, to study people on their own terms and to respect context and culture. There is also a recognition however that true naturalism is somewhat idealistic, as the act of observation itself will impact on that being observed, and that what is produced is a ‘situated account’ (Murphy *et al* 1998). However, there is also a commitment to reflexivity and reflecting how the research setting has in itself had an impact on behaviour (Pope and Mays 2006, Holloway and Wheeler 2010, Green and Thorogood 2014). Data collection methods reflect the consideration of context, ‘natural’ settings and relationships, from both home and work. These recognise what is essentially an artificial encounter, whilst aiming to promote openness and honesty, and giving participants some ownership of the study. This context has the potential to influence the content and depth of the data collected.

### 3.1.3.4 Reflexivity and critical thinking are essential

Research is not value free, and investigators cannot be divorced from the cultural, social and political context of their topics; and because researcher and researched are part of same world, there can be no truly objective viewpoint (Bowling 2009). Reflexivity in qualitative research acknowledges this awareness of the impossibility of remaining outside of one's subject matter throughout the research process, and the researcher's potential contribution to the construction of meanings (Nightingale and Cromby 1999)*.* This recognises the constructivist view, acknowledged by Bryman (2008) who considers the role of the researcher as ‘part and parcel’ of the construction of knowledge. The values of a researcher can influence and inform every aspect of research, therefore it is essential for researchers to be self-reflective and exhibit reflexivity about the part such influence plays, considering how their own actions, values and experiences impact on the research setting, data collection and analysis (Gerrish and Lacey 2006, Bryman 2008). This is the opposite to the impartiality and objectivity of many quantitative traditions, with their goal of avoiding ‘bias’. Qualitative research is not simply subjective story telling: reflexivity is one of the ways qualitative researchers take subjectivity seriously and can validate their research practices; part of any strategy to maximise rigour and credibility. It is a continuous and integral process (Lambert, Jomeen and McSherry 2010, Green and Thorogood 2014).

It can be argued that researchers should approach reflexivity in two ways. Firstly, more strategically, they should reflect critically on the research itself, considering the broader political and social context of the research. This will help to unpack any assumptions that they have brought to the research, and to identify the ways in which this context might shape what they find, for example assumptions about what is correct behaviour. This might incorporate scepticism or rejection of received wisdom, of normative assumptions built into many research studies, for example the perception of ‘barriers’ or the value of an activity, in this study early access to antenatal care. Willig (2001) argues that there should also be an element of ‘epistemological reflexivity’,which encourages us to reflect upon assumptions we have made in the course of the research, and think about the implications of such assumptions for the research and its findings.

Secondly, more personally, there should be a consideration of the researcher’s role in data ‘production’ and analysis: who you are will shape findings. As Kuhn (1970) identifies, what we see depends on what we look at and what our previous experiences have taught us to see. This could be considered as helping us to ‘situate ourselves’ in relation to the data. There needs to be a critical reflection on what has been thought and done, an explicit self-awareness of the researcher and an awareness of the interaction between researcher, researched and the research itself (Holloway and Wheeler 2010, Green and Thorogood (2014). Lambert, Jomeen and McSherry (2010) argue that this reflexive engagement forms part of a positive process of knowledge acquisition, transfer and validation which can be applied to future practice, again reflecting the study’s pragmatic aims. Further consideration of reflexivity in relation to the study methods is presented in section 3.3.2.

### 3.1.3.5 A flexible research strategy

The research has used flexible and dynamic strategies which have adapted as the data has been produced and analysed, with an emphasis on capturing the process as much as producing the final ‘product’ (Bryman 2008). This is in contrast to the ‘input-output’ model characteristic of much quantitative research and is well suited to theory generation and discovery (Murphy *et al* 1998). In this emergent approach, stages have overlapped and informed each other, for example refining the research question or adding to the sample to give depth, a common approach in grounded theory research. Different methods have been used, reflecting the notion of the ‘*bricoleur*’ (someone who makes something from whatever materials are available) adapting and devising methods of inquiry for changing perspectives, emerging findings or utilising unexpected opportunities for data collection (Green and Thorogood 2014). This flexibility, adaptation and overlap were evident, in fact highly necessary, throughout the study, at different levels. Recruitment challenges and discoveries amongst initial data collection informed sampling methods. Also methods were modified during the study to facilitate more open discussions and achieve a greater depth and diversity of perspectives.

**3.2** **Determining the research methods**

*“the problem under investigation properly dictates the methods of investigation”*

(Trow 1957 cited in Bryman 2008: 468)

The research methods developed in response to the features of the qualitative methodology and the ontological and epistemological principles which underpin it, in turn reflecting the study’s aims and the research question. They represent the balance of theoretical, ethical and practical influences and decisions made prior to and during the research process.

## *3.2.1 Sampling*

Sampling methods reflect the qualitative methodology and the research question, in order to gain a full range of women’s perspectives on the subject of late booking. Sampling decisions were made early on in the research project, after the focus had been decided, reflecting the influence of prior knowledge from theoretical and professional sources. However they evolved and were modified as the study progressed, reaffirming the inductive and iterative nature of the qualitative approach.

### 3.2.1.1 Sample size and saturation

The sample size must reflect the qualitative approach to data collection, aiming to capture a wide variety of experiences and influences in detail, rather than obtain a representative sample or generate statistically significant findings (Hall, McKenna and Griffiths 2012). The number of participants is considered less important than the richness of the data, recognising that large samples are not necessarily better and might result in unwieldy amounts of data and a loss of depth (Murphy *et al* 1998, Patton 2002, Liamputtong and Ezzy 2005). As Sandelowski (1995a) points out, the process of choosing a sample size is complex: *"Determining adequate sample size in qualitative research is ultimately a matter of judgement and experience"* (p179). Researchers need to evaluate the quality of the information collected in light of the uses to which it will be put, and the research method, sampling and analytical strategies employed.

As such the sample size was not fixed, but an initial sample of 25 women was suggested, reflecting common sample sizes for diverse groups in qualitative research (Holloway and Wheeler 2010). Twenty five women was anticipated to be achievable in terms of practical considerations such as interviewer availability, and aimed to be large enough to answer the research question convincingly, and ultimately give credibility to the research (Green and Thorogood 2014).

Ultimately the question of sample size was left open, influenced primarily by a desire to achieve a point of ‘saturation’, interviewing until no new themes are generated from the data (Hall, McKenna and Griffiths 2012). This is an established method used in qualitative research (Bryman, 2008). However, achieving the ‘theoretical saturation’ of themes/categories identified in the data does not simply consist of stopping data collection when the stories in the data become repetitive. It requires careful sampling and a flexible and inductive approach to interviewing, to create *a “conceptually dense theoretical account of the field of interest in which all categories are fully accounted for, the variations within them explained and all relationships between the categories established, tested and validated”* (Green and Thorogood 2014: 122, Thornberg and Charmaz 2011). As Liamputtong and Ezzy (2005) have argued, saturation is highly subjective and context-bound, and additional data can always be found if the researcher allows the topic of the research to expand unchecked.

With this in mind, decisions about when saturation had been achieved were made through analysis meetings and supervisory discussion and feedback, and were based on the breadth of views required for the study. The broad focus of the research on late booking, in all its forms, and the resulting heterogeneous sample, required a larger sample than research with a narrow focus in order to achieve saturation (Guest, Bunce and Johnson 2006). This was achieved using a combination of sampling methods, informed by the literature but balanced with pragmatic considerations.

### 3.2.1.2 Sampling methods

Strategies for sample selection, like all other aspects of qualitative research, must be determined and judged in the context of the study, its purpose and rationale (Britten 2006). In this study, quantitative methods such as random or probability sampling were therefore considered inefficient and counterproductive, in terms of answering the research question. Sampling is influenced by theoretical and ethical but also pragmatic decisions, as difficulties with recruitment, for example a reluctance on the part of participants, may necessitate different approaches. Murphy *et al* (1998) talk about the idea of two levels of sampling decisions, initial and further, and the need to present a clear rationale and show evidence of systematic strategies for both. This was reflected in a combination of an initial pre-determined (purposive) method based on the research question and initial literature review, and adaptive (theoretical) sampling methods, to obtain a broad range of study participants (Bryman 2008).

**Purposive sampling** seeks to create rich, in depth information, yielding insights and in-depth understanding from a small sample size, rather than empirical generalisations. The term covers a wide variety of approaches but can be defined as a non-probability form of sampling: the researcher samples with certain research goals in mind, and thus inclusion or exclusion criteria for the study are essential. It is not a random sample or a convenience sample (simply available by chance to the researcher) but involves the selection of people with direct reference to the research questions being asked, the identification of a specific group of people who share characteristics and/or personal experiences, in this case late booking. Purposive sampling aims to select information-rich cases for studying a phenomenon in depth, to examine meanings, interpretations, processes and theory. It is a strategic approach in which participants are selected to ensure a good variety in the sample, to provide the best information and to best generate the desired data. Purposive sampling is more systematic than convenience sampling, and as such offers greater credibility (Liamputtong and Ezzy 2005, Bryman 2008, Bowling 2009, Holloway and Wheeler 2010, Green and Thorogood 2014).

Most sampling in qualitative research entails some kind of purposive sampling. Some authors have argued that all qualitative sampling is purposive; Patton (2002) presents a taxonomy of 15 different types of purposive sampling. The logic and power of purposeful sampling derive from its emphasis on in-depth understanding. What would be ‘bias’ in statistical sampling and therefore a weakness, becomes intended focus in qualitative sampling, and therefore a strength. However careful analysis is essential, as Patton (2002) comments:

*“Exercising care not to overgeneralise from purposeful samples, while maximizing to the full the advantages of in-depth, purposeful sampling, will do much to alleviate concerns about small sample size”* (p246).

**Theoretical sampling**, whereby cases are chosen to explore theoretical issues and maximise relevance (in this case the existence of particular socio-demographic groups amongst late booking women), was used alongside purposive sampling. Theoretical sampling has been called a dynamic process of gathering data to fill out tentative ideas, which encourages the researcher to sharpen their reflections, ask increasingly focused questions, seek answers and test the robustness of ideas as the research progresses (Bryman 2008, Charmaz 2012). It is an integral part of the process of constant comparison in grounded theory research and necessitates the interplay between existing literature, data collection, and the analysis and reflection on such data (Corbin and Strauss 2008, Bowling 2009, Hall, McKenna and Griffiths 2012). Such modification of the sampling procedure is seen as a rigorous way of ensuring thorough data collection: a strength in qualitative research (unlike quantitative methods), enabling adjustments and maximising the diversity and relevance of perspectives as data is collected, to achieve theoretical saturation (Holloway and Wheeler 2010, Green and Thorogood 2014).

## *3.2.2 Data collection*

The choice of data collection methods reflects the aim of the study and the need to answer the research question in the most effective way. The question sought multiple perspectives amongst a diverse group of participants, including vulnerable women, with a complex range of experiences and attitudes, and from a range of backgrounds. This necessitated the application of methods which were flexible enough to respond to this diversity, whilst detailed and individual enough to generate useful data in an ethical way, and practically feasible.

Interviewing is one the primary methods of gaining multiple perspectives used by qualitative researchers, and probably the most widely employed (Marshall and Rossman 2011, Green and Thorogood 2014). A flexible and powerful tool that can open up many new areas for research, qualitative interviews can be used to investigate research questions which would be difficult to investigate quantitatively, for example through the use of structured interviews or questionnaires. Such tools, as considered in chapter two, risk oversimplifying a complex subject and further alienating a group of women who, statistically, are more likely to be marginalised anyway. In contrast, qualitative interviews reflect a more personal approach, with greater potential to examine the social and psychological processes leading up to or following an event, in this case late booking for antenatal care (Bryman 2008). Interviews also create a specific focus and allow participants to reconstruct events and experiences in a way that is not amenable to alternative methods such as observation. Observation has greater potential to reflect the researcher’s (*etic*) perspective rather than the participant’s. It has greater relevance for studies of social interaction and on-going experiences, rather than the consideration of individual feelings and actions around a fixed point in the past, for example relating to pregnancy discovery and late booking (Liamputtong and Ezzy 2005, Holloway and Wheeler 2010).

Interviews, whether individually or in groups, give a voice to participants and provide a varied source of data which allows health researchers to see the world through their eyes, exploring and understanding peoples’ experiences, meanings, health behaviours and views towards care (Ziebland and Wright 1997, Hall, McKenna and Griffiths 2012). The type of interviewing and the techniques used to record and present the interview data are highly influential on any findings (Fontana and Frey 1998). The interview setting is also significant. The participant’s choice of setting reflects the ‘naturalistic’ approach fundamental to qualitative research, allowing the exploration of social events as experienced by individuals in their natural context (Malterud 2001a). Overall the flexibility and personal nature of interviews reflects the inductive approach of the study, and has the potential to generate rich, detailed data about the everyday meanings associated with pregnancy discovery and care initiation.

Semi-structured interviews are probably the most common form of qualitative research conducted in the UK and are widely used in health research where they frequently provide the basis for exploring both practitioner and client perspectives (Fox *et al* 2001, Holloway and Wheeler 2010). It is appropriate for a project such as this, beginning with a fairly clear focus, providing some structure in order to compare findings, whilst allowing for flexibility in the interview process (Bryman 2008). The use of pre-determined questions reflects the overall study design. In particular, the application of prior knowledge of the topic, principally in relation to the socio-demographic characteristics of the women gained through an initial literature review, the multi-professional study design and the pragmatic health services research focus (Ziebland and Wright 1997).

These *a priori* areas for exploration were intended to reflect the potential complexity of meanings and experiences of the participants, that could not be examined with a positivist methodology. Rather, the interviews reflected the interpretive approach, with its aim to analyse how participants interpreted the ‘world’ of late booking (Liamputtong and Ezzy 2005, Bowling 2009). The resulting *‘guided conversations’* (Lofland and Lofland 1995) used a flexible interview guide based around the research question, an initial review of the literature and discussion with a group of academics and health and social care practitioners involved in the care of pregnant women*.* This provided a framework for the semi-structured interview process and ensured some consistency in the data collected, reflecting the influence of the pragmatic health services research approach and research governance requirements, for example ensuring a useful contribution could be made by the research (DoH 2005).

Any interviewing risks imposing a potentially inappropriate frame of reference on people, and limiting their responses, which in turn limits the researcher’s view of their world. The flexibility and minimum structure of the semi-structured method creates opportunities for spontaneity but also for meanings which can be clarified and followed up. It encourages participants to reveal their point of view and talk honestly about what is important to them, not the interviewer, but also to suggest alternative directions for and ways of thinking about the research (Bryman 2008). The aim of the interview is to go below the surface of the topic being discussed, exploring what participants say to produce rich and detailed data, whilst being sensitive to the language and concepts used, but also to uncover new areas or ideas that are not anticipated at the outset of the research (Britten 2006). As Leininger (1985) comments, interviews are designed to elicit both definitive and unexpected kinds of information from the interviewee.

### 3.2.2.1 Individual interviews

*“As a researcher I sought to have people tell me about their lives from their perspectives rather than to force my preconceived interests and categories upon them. So I listened”* (Charmaz 1991: 275)

Individual semi-structured interviews have the potential to provide a natural, informal setting for people to talk about their lives and describe their personal experiences in their own words (Britten 1995). The approach is based on the fundamental qualitative assumptions that a participant’s personal perspective is meaningful and knowable, and that it should unfold as they view it (*emic*), unlike structured interviews where the balance of control lies with the interviewer (Fontana and Frey 1998, Patton 2002, Marshall and Rossman 2011). This reflects a feminist criticism of structured approaches which may separate people from the context that influences their choices, and impose a hierarchical (and potentially exploitative) relationship upon participants. In depth semi-structured interviews have been called the archetypal ‘feminist method’ (Kelly, Burton and Regan 1994).

The use of individual interviews as a method reflects pragmatic, methodological and ethical considerations. These include the availability of participants, but also the richness of the data desired, which may be compromised in a group setting, as well as issues of privacy and confidentiality. During individual interviews people’s responses are less influenced by the presence of others, so they may be more prepared to discuss sensitive matters. Such interviews may provide more detail about an individual’s understandings and experiences than can be gained through group interviews, particularly where participants are unconfident or reticent (Bryman 2008). These were the primary reasons for using the individual interview method.

However the individual interview method does have its limitations. Focusing on individual rather than social interaction, it may neglect context, and its focus on verbal communication may favour more articulate participants (Kvale 1996). It is widely acknowledged that all interviews are ‘situated’ rather than natural encounters, unique social situations that occur between the interviewer and interviewee, and as such cannot be replicated between participants. They are inevitably constrained by the context in which they are collected and the relationship between interviewer and participant (Murphy *et al* 1998). As such they represent personal, contextual accounts rather than literal descriptions. However this reflects the qualitative approach, which values motivations, thoughts and personal ‘truths’ rather than factual accuracy (Holloway and Freshwater 2007).

At their most negative, individual interviews could be perceived as threatening, abnormal interactions, with a mistrust of the researcher or ‘official’ involvement, and this may be reflected in some women’s reticence to talk about their experience. Even at its most positive, fundamentally the encounter is still one of strangers meeting, with a risk that it might generate opportunities for ‘impression management’ (Murphy *et al* 1998). This might result in ‘public’ accounts of socially acceptable views, rather than the more difficult to ascertain ‘private’ views, as a result of the interviewee making assumptions of what the interviewer wants to hear or find out. Whilst multiple interviews would alleviate this unfamiliarity and the potential lack of trust that accompanies it, the nature of the interviews as soon after booking as possible and concerning women’s experiences and decisions around a fixed point (i.e. booking), and challenges with recruitment, mean that this was not appropriate or feasible.

These challenges meant that the qualitative interviews required considerable skill and sensitivity to the complexities of interpersonal interaction, and reflexivity on the part of the interviewer (Marshall and Rossman 2011). As Ezzy (2010) argues, all interviews are emotional and embodied performances, and good interviewing is facilitated by a reflexive awareness of this. The interviewer is also an active participant in the interview process and takes part in co-constructing meaning from the resulting social interaction. Interviewers need to be honest about this, and must reflexively account for the interplay between the social positions of themselves and the participants in this construction (Britten 2006, Bowling 2009, Holloway and Wheeler 2010). Oakley (2004) argues that interviews, particularly those with women, are most effective when the relationship between the parties is non-hierarchical but also when the interviewer invests their own personal identity in the relationship *(‘no intimacy without reciprocity’* (p264)). This is discussed further in chapter four.

## *3.2.3 Data analysis*

There are many different qualitative data analysis methods, influenced by theoretical and methodological perspectives and the aims of the research, though fundamentally all qualitative data analysis is the search for general statements about relationships and underlying themes (Liamputtong and Ezzy 2005, Marshall and Rossman 2011). It is a process of “*discovering patterns, themes and categories in one’s data*” (Patton 2002: 453), bringing together “*components or fragments of ideas or experiences, which often are meaningless when viewed alone*” (Leininger 1985: 60). It seeks to generate and develop analytic categories and theoretical explanations, to describe and explain social phenomena, often from extensive data. It does not aim to quantify data or to present it as if it is statistically representative; as such, methods using counts or frequencies (such as content analysis) are inappropriate (Pope, Ziebland and Mays 2006).

As discussed earlier in the chapter, the inductive approach of grounded theory has been highly influential in this study. The process of coding and data analysis in grounded theory shares many of the characteristics of other qualitative methods, in terms of its search for themes and patterns across the entire data set. Green and Thorogood (2014) argue that there are many elements of the grounded theory approach that are useful for any analysis. However, the ultimate goal of a grounded theory analysis is to generate and/or develop a substantive theory (Polit and Beck 2012). This process of conceptualisation and abstraction of participants’ perceptions and actions moves beyond description, aiming to discover the ‘core category’ which links all categories or concepts identified in the data, arguably an objectivist approach (Bryman 2008, Holloway and Wheeler 2010). As previously mentioned, this may be achieved to a greater or lesser extent, and there is significant debate about the value of ‘modified grounded theory’ or what some have called grounded theory ‘lite’ (Braun and Clarke 2006). The aim of the study was not explicitly to generate theory, but rather to examine the full range of women’s views; presenting an inductive exploration of themes in relation to late booking. This reflects the pragmatic roots of the study, which weren’t aligned to any single pre-existing theoretical framework, and the likely diversity of perspectives, based on initial literature searches. Consequently, a decision was made to choose a method of analysis appropriate to the broad aspirations of the study.

Thematic analysis is a method which some have argued lacks a clear identity, but which is widely used in qualitative research. It is a process for encoding qualitative information, identifying common threads and facilitating the evolution of ‘simple’ interview data into more sophisticated codes, and subsequently into concepts and explanations that link the interviews together (Morse and Field 1995, Mays and Pope 2000). Some authors have argued that thematic analysis is not a distinct method of analysis, as the search for themes is an activity common to many if not all approaches to qualitative data analysis (Bryman 2008). Its use crosses different qualitative methods without being specifically described, and it has been referred to by many different names, such as ‘inductive analysis’ (Boyatzis 1998, Patton 2002). Other authors propose that thematic analysis should be considered as a method in its own right, as it has many advantages. For example, Braun and Clarke (2006) argue that it is an accessible and theoretically flexible approach to analysing qualitative data from different sources, in essence a foundational method for many forms of qualitative analysis, which allows for different interpretations of the data. Thematic analysis can summarise the key features of a large body of data and create results which are accessible and useful for informing policy development. It can be used to develop taxonomies or classifications, or to develop models or diagrams that express the connections between themes. The choice of thematic analysis reflects the study’s aim to articulate and understand these connections.

Thematic analysis has been presented as the simplest form of qualitative analysis used in healthcare research and the most inductive, although the reality is a mixture of both inductive and deductive methods, the latter particularly in the final stages of the analysis (Patton 2002, Liamputtong and Ezzy 2005, Pope, Ziebland and Mays 2006). It is a method which is highly appropriate for both the constructivist and interpretivist approaches which underpin this study. Thematic analysis mirrors many of the techniques of grounded theory: both seek to allow themes and explanations to develop from the data itself and to avoid the imposition of an explanatory framework by the researcher. Crawford, Brown and Majomi (2008) see this inductive approach being a key strength, in that the analysis is firmly anchored in the data and able to challenge existing theoretical presuppositions. Reflecting this, the analytical process is cyclical and iterative rather than sequential, and forms part of the process of constant comparison. This method results in the interweaving of theoretical sampling, data collection and the testing of emerging ideas as the study progresses, enabling the development of themes from the data itself (Murphy *et al* 1998, Liamputtong and Ezzy 2005, Pope *et al* 2006).

Thematic analysis takes a more inductive approach than other methods, such as the matrix-basedframework analysis (Ritchie and Spencer 1994). This is described as *‘a content analysis method which involves summarising and classifying data within a thematic framework’* (Green and Thorogood 2014: 218) and is widely used in health research. Framework analysis is a systematic and transparent process of organising qualitative data, with many strengths. Although partially ‘grounded’ in the original accounts of the people studied, it usually starts deductively from the aims and objectives of the study itself and *a priori* reasoning, reflecting, in part, its large-scale policy research heritage (Pope *et al* 2000, 2006, Gale *et al* 2013). Though Ritchie and Spencer argue that the framework approach is not a mechanical process and that dynamism and interpretive thinking are key features, critics have argued that this deductive focus has the potential to remove several key aspects of traditional qualitative analysis. This includes the induction of themes, flexibility in design and sampling, and an iterative approach, with the potential to constrain what is studied and suppress complexity (Donovan and Sanders 2005, Lacey and Luff 2007). Whilst the aims of the study and the prior knowledge of the research team have been influential on the study design, the process of data analysis has been conducted independently of this, and as such thematic analysis was considered more appropriate for this inductive approach.

Whilst a flexible method, the process of thematic analysis needs clear and concise guidelines (not simply ‘anything goes’), a clear statement of purpose and a systematic approach, to guide the whole process and maximise credibility and rigour (Wolcott 2009). Braun and Clarke (2006) argue that those undertaking thematic analysis need to make their assumptions explicit: what they are doing, why and how; theoretical and methodological assumptions need to be explicit too. The process aims to avoid a superficial analysis where data is simply organised rather than analysed, and/or criticisms of anecdotalism (Pope *et al* 2006, Bryman 2008). Validity is ensured through the provision of adetailed and descriptive narrative which offers insight into ‘what’s going on’ in terms of late booking, attempting to identify connections or relationships within the data and integrate these into existing theories around the subject (Ziebland and Wright 1997, Green and Thorogood 2014). Such analysis aims to represent data holistically rather than simply reduce it down to its component parts, demonstrating a consideration of different explanations for the findings, and presenting findings which reflect the breadth of participant views rather than one sided accounts (Murphy *et al* 1998).

To support this detailed analysis requires the ‘thick description’ discussed previously. However successful analysis requires even more than this: it is a complex and creative process which is difficult to prescribe and describe completely (Green and Thorogood 2014). As Corbin and Strauss (2008) comment, *‘something occurs when doing analysis that is beyond the ability of a person to articulate or explain’* (p9). Wolcott (2009) examines the difference between early ‘analysis’ – the description and examination of data using systematic and standardised measures and procedures – and ‘interpretation’ – a more intuitive and reflective activity which takes place later the process. He discusses how a well-balanced study should show evidence of both. Braun and Clarke (2006) propose a step-by-step guide to doing thematic analysis which attempts to articulate this balance. This echoes Leininger (1985) who proposed similar sequential conceptual steps for thematic and pattern analysis in relation to nursing studies; both reflect influential phenomenological approaches such as the method proposed by Giorgi (1985). This process is elucidated using (loosely) the six stages they propose in the following chapter, though the reality was less linear, and illustrates some of the tensions and complexities. Reflexive thinking formed part of this process of analysis, to try to avoid making premature assumptions about the data and the emerging analysis, as did independent data verification by the research team.

# 3.3 Considerations of bias and quality

## *3.3.1 Bias*

As Polit and Beck (2012) identify, in any study, whether qualitative or quantitative, it is the researcher’s role to:

* Use a variety of strategies to eliminate/minimise bias and strengthen study rigour as far as possible;
* To establish mechanisms to detect and/or measure bias, and
* To take known biases into consideration when interpreting any findings;

and the reader’s role to scrutinise and draw conclusions about whether bias exists and if it undermines the findings.

Careful consideration of appropriate methods for all aspects of the study, from sampling and data collection to analysis, was undertaken by the members of the research team at the outset of the project, using accepted protocols for research design, ethics and governance, to avoid design bias and systematic errors. The design and methods used were monitored and adapted throughout, as part of the project management and supervisory process, involving all members of the research team, to respond to possible bias and ensure the study methods were adequate to answer the research question. Purposive and theoretical sampling methods, and the use of triangulation, aimed to ensure comprehensiveness and reduce the potential for sample bias, whilst acknowledging the boundaries of the qualitative approach.

Recognition of the potential for interviewer bias has influenced my approach to interviews. I have attempted to convey a neutral and non-judgemental approach, using interviewing skills and empathy. The development and application of the interview guide for the study tried to avoid leading or biased questions and probing, and to be responsive to the participants. This and the naturalistic setting for the study aimed to encourage the participants to be as open and honest as possible, and to reduce the potential for reactive (Hawthorne) effects and social desirability bias. Being open with the participants, assuring them of anonymity, and not being directly involved in the care of the women interviewed, have also helped to reduce the potential for lack of candour. In addition, interviewing women as close to their booking appointment aimed to reduce the likelihood of recall bias (Bowling 2009, Tod 2010, Polit and Beck 2012).

I have acknowledged that my own subjectivity, based on my own experiences and expectations, has the potential to distort the findings of the study. Consequently, the recognition of personal biases, beliefs and assumptions, and if and when they have intruded into data collection and analysis, have formed a critical part of considerations of reflexivity, to be discussed further in the following section. Corbin and Strauss (2008) stress the importance of establishing enough distance between the interviewer and the research, in order to be able to think clearly and analytically, and to the need to reflect on and question everything, which I have attempted to do.

## *3.3.2 Quality*

There is much discussion of the relevance and adaptation of quality criteria for qualitative research. Many authors have argued that qualitative research, with its naturalistic approach, cannot and should not be judged by quantitative measures of validity, generalisability and reliability, though there is an acknowledgement that the application of such measures to research does not necessarily presuppose a positivist approach. Several authors have suggested that some definitions of rigour do not fit with an interpretive approach that values insight and creativity, and that qualitative research can be considered both an art and a science. This needs to be balanced with the consideration that the rejection of reliability and validity could suggest a lack of concern with rigour, which is naturally undesirable. They argue that there is a need for a balance between creativity and insightfulness and scientific excellence, producing research which is descriptively sound and explicit whilst also interpretively rich and innovative (Polit and Beck 2012).

Some authors believe that though there is no definitive set of quality criteria that can (or should) be rigidly applied to qualitative research, some quality criteria are fairly universal (Whittlemore, Chase and Mandle 2001). As Murphy *et al* (1998) observe, the hallmarks of high quality qualitative research, namely a commitment to rigour, clarity and systematicity, are the hallmarks of *all* good research. However, despite some broad similarities in purpose, the fundamental differences in the research goals and the knowledge each approach generates require that quality is assessed differently (Popay, Rogers and Williams 1998, Bryman 2008). As Spencer *et al* (2003) comment:

*“the concerns which lie behind customary conceptions of quality have relevance for qualitative enquiry but need to be reformulated – and assessed quite differently – within the domain of qualitative research… qualitative research should be assessed on its ‘own terms’ within premises that are central to its purpose, nature and conduct”* (p4).

Kisely and Kendall (2011) suggest rather that quantitative concepts such as reliability, validity, statistical power, bias and generalisability have qualitative equivalents such as triangulation, trustworthiness, saturation, reflexivity and applicability, which need to be explicit in any study.

The most cited quality criteria for qualitative research, Lincoln and Guba’s framework for developing ‘trustworthiness’ (Lincoln and Guba 1985, Guba and Lincoln 1994): identified five criteria, with parallels to standards of validity and reliability in quantitative research. These are:

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| --- |
| 1. **Credibility**: ensuring confidence in the truth of the data and any interpretations: carrying out study using methods to enhance believability, and demonstrating credibility in research reports; |
| 1. **Dependability**: demonstrating the stability and reliability of the data over time: ensuring the study could be replicated; |
| 1. **Confirmability**: giving a fair representation of the information and interpretations (not invented). Accurately reflecting the participants’ voices and the context of the study, not the researcher’s bias; |
| 1. **Transferability**: the extent to which findings can be transferred: providing enough data for readers to evaluate the applicability, for example using ‘thick description’; |
| 1. **Authenticity**: fairly and honestly showing a range of realities, reflecting participants lives, for example in terms of tone, mood and/or experience.   (cited in Polit and Beck 2012: 584-585). |

These are reflected in qualitative research appraisal tools such as CASP (2013), as used in chapter two. Several authors have reinterpreted Lincoln and Guba’s framework. Some argue that, there are two fundamental criteria, validity and relevance, which apply to both qualitative and quantitative research, but using different methods (Murphy *et al* 1998, Mays and Pope 2000, Malterud 2001b). Similarly, Whittlemore, Chase and Mandle’s (2001) synthesis of ten quality guidelines (including Lincoln and Guba) identifies validity as the overarching goal, including credibility and authenticity, but adding the need for criticality (critical appraisal of key decisions and self-reflection during the research) and integrity (on-going scrutiny of the validity of interpretations, ensuring these are grounded in the data). They provide supplementary benchmarks for quality relating particularly to explicitness and thoroughness, but also to vividness and creativity, many of which overlap with Lincoln and Guba.

Polit and Beck (2012) argue that such criteria may offer standards for readers to assess quality, rather than as a guide to researchers of how to do, but that the responsibility should rest with researchersto demonstrate the consideration of quality measures used *throughout* their research, providing evidence of rigour, integrity and trustworthiness. Mays and Pope (2000) agree with this comprehensive approach:

*“as in quantitative research, the basic strategy to ensure rigour, and thus quality, in qualitative research is systematic, self-conscious research design, data collection, interpretation and communication”* (p52)

This consideration is reflected in four key methods used: a commitment to multiple perspectives, triangulation, clarity of presentation and reflexivity; and an overall consideration of the relevance of the research, which are considered below.

**3.3.2.1 Commitment to multiple perspectives**

The study shows a commitment to the emic perspective, incorporating the views and experiences of a range of participants, contributing to the **credibility** and **authenticity** of the research. Several authors talk about the need for this ‘even handedness’ and ‘fair dealing’, to ensure that the research contains a wide range of different perspectives, so that the viewpoint of one group is never represented as ‘the truth’ (Murphy *et al* 1998, Mays and Pope 2000). The research attempts to present different sides of the discussion, including inconsistent and disconfirming evidence, which challenges accepted reasons for late booking and attitudes towards this (Polit and Beck 2012).

**3.3.2.2 Triangulation**

The use of multiple approaches is characteristic of qualitative research, and can be seen as a major strength, identifying patterns of convergence, enhancing the comprehensiveness of the findings and stimulating reflexive analysis (Mays and Pope 2000, Polit and Beck 2012). As Murphy *et al* (1998) identify, “*emphasis is on counter-balancing the distorting effects of any single approach… the aim is to establish the convergent validity of findings drawn from complementary approaches*” (P11).Data and investigator triangulation are key to **authenticity** and were achieved through the comparison of results from multiple data sources alongside independent reviews of the transcripts and themes developed during the analytical process, as part of the supervisory process, bringing a complementary blend of different perspectives. Such methods were used to examine patterns of convergence and to obtain a comprehensive understanding of the phenomenon of late booking, reaching a point of saturation, as discussed previously, and to reduce the risk of bias in the research (Polit and Beck 2012). However, the aim was to maintain a commitment to the context and complexity of the data, acknowledging the value of different contexts, rather than aiming for a single ‘master reality’ (Murphy *et al* 1998), an overall average where weaknesses or gaps in one set of findings might be balanced by strengths or areas of focus in another. There was also an acknowledgement that findings from different sources might corroborate and complement, rather than refute, each other.

**3.3.2.3 Clarity of presentation**

The clear exposition of methods and findings is critical to the **dependability** and **confirmability** of any study; Whittlemore, Chase and Mandle (2001) consider it key to a study’s integrity. I have sought to a provide a clear exposition of the study methods andthe appropriateness of these for the study’s aims, at all stages from recruitment, interviewing and transcription, to data analysis and the presentation of the findings, supported with evidence from previous research and literature (Liamputtong and Ezzy 2005, Kisely and Kendall 2011). The systematic approach adopted seeks to minimise any anecdotal interpretation of the data, and a detailed consideration of the language and presentation of the findings forms a key part of the analysis and interpretation. The complexities of the process and the challenges involved are articulated.

A clear description of how the development of a simple system of codes evolves into a more sophisticated structure of themes and subthemes is provided by the analytical process (Mays and Pope 2000). A credible account and an accurate representation of the phenomenon of late booking is given, attempting to provide a good match between the data presented and the themes and theories developed in the study, and displaying enough data to allow the reader to judge these (Hammersley 1992). Geertz’s ‘thick description’ encapsulates this idea: a comprehensive and vivid picture of the participants, their experiences and context, using verbatim quotes and lucid descriptions, is presented (Mays and Pope 2006, Kisely and Kendall 2011, Polit and Beck 2012). However, as Sandelowski and Leeman (2012) identify, description should be ‘thick’ not ‘heaped’ if qualitative research findings are to be understandable and usable. In practical terms, adherence to recognised research governance protocols, and particularly maintenance of a study site file, provide a clear and auditable trail for the project.

**3.3.2.4 Reflexivity**

All researchers must ensure that they do not overtly allow personal values or theoretical inclinations to bias the conduct of the research and its findings. However, reflexivity, an essential component of **credibility** and **confirmability** in qualitative research, requires a sensitivity to the ways in which the researcher and research process and strategies have shaped the data, including prior assumptions and experience, personal and intellectual biases. It recognises the potential for professional status to influence the data and the ‘distance’ between the researcher and the researched (Mays and Pope 2000, Green and Thorogood 2014).

I recognise that reflexivity has been an integral part of, and my personal connection to, the study. Evidence of the ways in which the data have been shaped by my presence and background is part of the transparencyof the study. Theoretical sensitivity forms a positive part of this reflexive approach. My knowledge and understanding of the subject of late booking and the participants’ world, from a theoretical perspective and professional experience, have informed the interviews and enhanced the analytical process. It influenced my ability “*to see the research situation and its associated data in new ways, and to explore the data’s potential for developing theory”* (Strauss and Corbin 1990:44). My personal and professional biases have been made explicit at the outset of the research, and I have attempted to be open and honest about the relationship between myself and the participants (Liamputtong and Ezzy 2005, Mays and Pope 2006). In method terms a balance has been sought between acknowledging my influence as a midwife and creating a research environment which was ‘value neutral’, to allow the participants to speak for themselves (Fox *et al* 2001). In terms of ‘situating myself’ in the data, all participants were made aware of my dual status as both midwife and researcher but I was not involved in the clinical care of the women.

Whittlemore, Chase and Mandle’s (2001)’s criteria of ‘criticality’ suggests rigour may be demonstrated through a critical approach adopted to research, exploring but also challenging taken for granted assumptions, for example about late booking. The critical approach has become part of the reflexive process, and an awareness that my identity and values, alongside the multidisciplinary influences from within the research team, inevitably influence any interpretation of the lives of the women, and the co-construction of the findings (Polit and Beck 2012). Critical thinking in relation to the study has involved situating the data within the context of the existing literature, and particularly the themes identified in the synthesis. My reflection has included a consideration of the status of the women in the study and their choices in relation to pregnancy; their assessment of risk and the relevance of care. Throughout the research there has also been a professional consideration (and reconsideration) on my part of the necessity and value of early antenatal care.

**3.3.2.5 Relevance**

The concept of relevance considers the extent to which research adds to existing knowledge about late booking, but is also linked to Lincoln and Guba’s **transferability**, the extent to which findings, though not statistically representative, can be generalised beyond the study circumstances, in empirical or theoretical terms (Murphy *et al* 1998). The interpretivist and constructivist thinking behind the study assumes a changing world socially and a multiplicity of ‘truths’, which inevitably influence the replication of any findings. In contrast topositivist or quantitative approaches, the study used sampling methods aimed at maximising diversity and which were contextually unique. As a result no real claims have been made about the generalisability of the findings to other settings. However, this is balanced with consideration of the purpose the study, which seeks in part to influence practice and policy generally, through new knowledge with the potential for wider applications (Fox *et al* 2001, Spencer *et al* 2003). The study aims for **authenticity**, representing the participants fairly and ethically, with the goals of producing findings with relevance and significance for both pregnant women and practitioners, to improve understanding and encourage change (Yardley 2000). To achieve this, the research has been presented with sufficient range and detail for the reader to judge if it can be applied elsewhere in similar settings; the rich accounts of ‘thick description’ and clarity of presentation considered previously. Also the use of theoretical sampling has ensured that the sample includes a full range of perspectives and contexts relevant to late booking, to consider as many factors as possible that might affect behaviour (Mays and Pope 2000, Liamputtong and Ezzy 2005, Mays and Pope 2006, Kisely and Kendall 2011).

# 3.4 Conclusions

There is no single ‘right’ way to do any research, but different approaches fit different research questions and generate different findings (Green and Thorogood 2014). A qualitative approach was chosen as best fitting the aims of the study; qualitative research is largely about understanding different perspectives, rather than explaining ‘reality’, in this case about late booking. It is about producing rich data for thoughtful and scrupulous analysis, insights from which may expose unexpected layers of complexity, rather than final answers(Ziebland and Wright 1997). Qualitative methodologies have the potential to generate sophisticated data on beliefs and behaviours in relation to healthcare use, and provide useful information to inform policy making and sensitise professionals to the views of health service users. This is essential if antenatal care is to become more responsive to the women it is designed for, and to influence the acceptance of personal and public pregnancies discussed in chapter two.

Green and Britten (1998) argue that the value of qualitative methods lies in their ability to pursue systematically the kinds of research questions that are not easily answerable from a quantitative perspective or more positivist epistemologies. The inductive, qualitative methodology chosen for this study rejects positivism for a more empathetic understanding (interpretivism) of late booking, and emphasises how pregnant women interpret and create their social world, and how this is constantly changing (constructivism) (Bryman 2008). The main features of the methodology reflect the need for honesty, flexibility and a partnership between researcher and researched.They acknowledge the influence of cultural and social contexts on both sides, whilst adoptingstrategies for maximising rigour and credibility during the collection, analysis and presentation of data (Bowling 2009). These are discussed further in chapter four.

**Chapter 4: Methods used in the qualitative study**

# 4.1 Introduction

Chapter three has considered the rationale for choosing a qualitative methodology to explore late booking for antenatal care among pregnant women, and the influences on this. This chapter provides a detailed consideration of the methods applied to the study. The methods chosen were systematic and rational, suitable to meet the aims of the study and to generate adequate and relevant information of sufficient quality (Holloway and Wheeler 2010). All qualitative research requires the skilful application of such methods, and an explicit and systematic approach, as Pope and Mays (2006) comment:

*“qualitative research involves the application of logical, planned and thorough methods of collecting data, and careful, thoughtful and, above all, rigorous analysis… requires considerable skill on the part of the researcher”* (p8)

An iterative process of concurrent sampling, data collection and analysis was undertaken during the study, with each ‘stage’ serving to refine and support the others.Methods reflected the theoretical background to the study, and aimed to address challenges presented during the research. The term ‘participant’ is used throughout to express the collaborative and equitable relationship between myself the researcher and the women researched, that was strived for during the study. Morse (1991) suggests this is in contrast to the passive response suggested by ‘respondent’ or ‘subject’. Qualitative methods are aligned with the health promotion (and feminist) ideology of empowerment (Sword 1999). The term participant reflects feminist influences on the research and better represents the active role played in such social encounters, emphasising a more egalitarian and reflective process for all involved (Holloway and Wheeler 2010). Fundamentally, the methods used aimed to generate rich insights from lay perspectives, in order to answer the research question *“what perceptions and beliefs do late booking women express about the delayed initiation of antenatal care?”*, rather than produce statistically significant or generalisable information (Bowling 2009).

# 4.2 Background to the study

## *4.2.1 Referring for antenatal care in Sheffield*

The Jessop Wing, part of Sheffield Teaching Hospitals NHS Foundation Trust (STH), is Sheffield’s only maternity unit, and approximately 7000 babies are born in the unit each year (NHS Sheffield 2010). The hospital offers both midwifery-led and consultant-led care antenatally, postnatally and during labour. It has a large neonatal care unit and feto-maternal medicine unit, and acts as a tertiary referral centre for complex pregnancies throughout South Yorkshire. The hospital has specialist multi-disciplinary teams working with women with complex medical needs such as endocrine, renal and cardiac disorders, as well as complex social and psychological needs, such as teenagers and substance misusing women. These teams work collaboratively with other medical and social care practitioners. Community midwifery teams, largely based in children’s centres, provide low and high risk care, working in conjunction with hospital-based services, GPs, health visitors, family support workers and social workers. There are some specialist community midwives, for example working with homeless and asylum women.

At the time of the research women were referred to the Jessop Wing by their community midwife or occasionally by their GP, by fax or letter, completed as part of their first ‘booking’ appointment at their local children’s centre, GP practice or home. This first appointment represents the initial pregnancy risk assessment (STH 2012a,b), when women are categorised into low risk (midwifery-led) or high risk (consultant-led) care, based on medical, psychosocial or obstetric history. Screening and lifestyle considerations are discussed and the initial completion of the woman’s handheld maternity notes is undertaken. As a result of the referral, women are sent an appointment to attend for the second part of their booking appointment, at the Jessop Wing, with a target date of 12 completed weeks of pregnancy for this appointment. At the time of the research, this first hospital appointment involved women having a dating ultrasound scan, antenatal screening tests including serum screening for infectious diseases, blood group and antibody testing and haemoglobinopathy screening, and the assessment of Body Mass Index (BMI) and smoking status. For high risk pregnancies this visit also includes attendance at an obstetric-led clinic to plan care for the pregnancy. All women are offered a detailed anomaly scan between 20 and 22 weeks gestation.

Some women booking after 20 weeks gestation are categorised as high risk, primarily because of other risk factors such as age, medical history or substance misuse. There are no criteria for late booking women with no other risk factors to be routinely defined as consultant-led pregnancies, and if a placental localisation scan at 32 weeks gestation is normal women are returned to midwifery led care. However some are categorised as higher risk and offered extra monitoring, partially as a result of the inability of later scans to accurately determine gestation. As with women who do not attend for multiple antenatal appointments, midwives are required to complete a Common Assessment Framework (CAF) assessment for the unborn baby with women who book after 20 weeks gestation (STH 2012c). This is shared with the woman’s GP and Health Visitor, and the city’s Multi Agency Support Team (MAST), who provide preventative and supportive services for vulnerable families, and may result in a referral to social care services.

## *4.2.2 Project management, research governance and ethical approval*

The study was conceived by Dr Georgina Jones at the University of Sheffield. The study documents can be found in appendix 4. A small pilot study was undertaken in Sheffield by Dr Jones, as principal investigator, and Mr Dilly Anumba, consultant obstetrician, in April 2005, to ascertain pregnant women’s opinions about the proposed study. The majority of women were supportive of the study’s aims and willing to participate. The organisation of the project followed recognised research governance procedures and is illustrated by the research project flowchart from the study’s sponsors, STH (appendix 4.6). An application for funding for the study was made to Sheffield Health and Social Care Research Consortium (SHSCRC) by Dr Jones, Mr Anumba and Dr Caroline Mitchell, also in April 2005. Funding was awarded by SHSCRC in July 2005, and a favourable scientific review of the proposal was also given by SHSCRC at this time. Ethical approval was sought for the study by Drs Jones and Mitchell and Mr Anumba, in October 2005. The NHS Central Office for Research Ethics Committees (COREC) application form was submitted along with the study protocol and all relevant study documents, including details of the investigators, interview schedules, participant information sheets and consent forms, to North Sheffield Local Research Ethics Committee. Following minor revisions to participant information and consent forms, particularly in relation to the recruitment of teenagers, it was approved in December 2005; further minor revisions were approved in June 2007. Research governance approval for the study was given by STH in January 2006, and by SHSCRC in March 2006.

The content of the study documents reflect the ethical principles underlying *The* *Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects* (WMA 1964 and subsequent amendments) and the DoH’s *Research Governance Framework for Health and Social Care* (2005). The latter brings together general principles of good research practice and promotes a *“quality research culture”* (p15), through the consideration of five key areas in relation to the conduct, monitoring and assessment of research. These are

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| **Ethics: ensuring the dignity, rights, safety and well-being of participants are protected.** Detailed clarification of the ethical approach to all aspects of the study and the ethical approval process were included. |
| **Science**: **ensuring a useful contribution can be made by the research and independent reviews of quality are undertaken.** Details of the justification for the research and the independent scientific review were provided. |
| **Information: ensuring free access to information and findings, and critical review through accepted channels.** Proposals for dissemination of the research findings, locally and more widely through presentations at conferences and publication, were provided. |
| **Health and safety: particularly priority to the safety of all research participants, and observation of health and safety regulations.** Consideration was given to the safety and wellbeing of all the participants during the study. |
| **Finance: particularly financial probity and compliance with the law, and provision for compensation if any harm caused.** Full transparency of the financial aspects of the study and compensation provision was provided. |

As part of research governance procedures a site file, using a template provided by STH, was established and maintained by Dr Jones throughout the project. The file contained essential study documents which permitted the evaluation of the conduct of the study and demonstrated the compliance of the investigator and the research team with standards for Good Clinical Practice in research (e.g. MRC 1998, 2012) and the DoH *Research Governance Framework* (2005). The file was available for audit as part of the research governance process, to confirm validity of the trial conduct, and contained documents relating to the study, including:

* The study protocol
* Evidence of independent scientific review
* Ethics committee approval
* Project registration
* Financial and project management
* Details of the research team
* Study related literature and documents, including those relating to participants: consent forms, records of interviews, all interview schedules and data collection information (including superseded versions)
* All correspondence relating to the study
* Confirmation of research governance compliance (STH 2004).

Detailed ethical considerations in relation to the study participants are discussed later in the chapter.

# 4.3 The study methods

The study is illustrated in figure 4.3.1, although this provides a somewhat simplified and linear view of what was a more complex process, which is detailed in the following sections.

## *4.3.1 Sampling*

Women were recruited to the study using a combination of purposive and theoretical sampling methods, to obtain a wide range of participants. The approach reflects the research question *“what perceptions and beliefs do late booking women express about the delayed initiation of antenatal care?”* and the overall goal of the research: to develop a better understanding of late booking (Bryman 2008). Initially, purposive

***Figure 4.3.1: flow chart for the study***

Purposive sample of late booking women approached to participate in the study. Women approached to participate at the time of attendance for first hospital antenatal booking visit, following confirmation of gestation by ultrasound scan.

Women informed of the study by midwifery or medical staff or the research midwife. Any woman interested in participating was given an information sheet to read about the study and signed a consent form agreeing to be telephoned in the first instance by the research midwife. All women were given a minimum of 48 hours prior to further contact.

Once telephoned, if they were happy to participate and be interviewed, written consent asked for, face to face, before the start of interview.

Individual, in-depth semi-structured interviews carried out and tape-recorded at the Jessop Wing, or at home or local children’s centre, at the woman’s convenience. Demographic data collected prior to interview.

Interviews continued until data saturation reached.

Qualitative analysis undertaken using a thematic approach.

Tape-recorded interviews transcribed verbatim and entered into NVIVO software. Independent verification of data. Data analysis commenced.

Theoretical sampling methods used to identify particular groups of women most likely to book late.

Broad sampling frame developed for initial purposive sampling of late booking women.

Potential participants identified through community midwife and GP referrals and co-ordination with specialist midwifery teams. Late booking defined as > 19 completed weeks gestation at first hospital appointment.

Development of taxonomy and thematic narratives. Findings written up.

Multidisciplinary analysis meetings for interpretive challenge

sampling was undertaken using decisions made prior to recruitment commencing, following an initial consideration of previous research and clinical guidance. Inclusion

and exclusion criteria were developed to create a sampling frame of all the women who might be sampled for the project, which is presented in table 4.3.2. Initial sampling was deliberately broad, to try to gain access to as wide a range of individuals relevant to the research question as possible, to obtain many different experiences of and perspectives on late booking. The inclusion criteria reflect widely accepted definitions of late booking but also essential ethical considerations such as informed consent and non-maleficence, which are considered in more detail later in the chapter. As previously discussed, the sample size was not fixed, however an initial sample of 25 women was suggested as appropriate for the study. Because audits of the 7000 women giving birth annually at the Jessop Wing demonstrated that at least 5% of women initiated antenatal care after 19 weeks gestation (NHS Sheffield 2010), it was anticipated that recruiting such a sample would be achievable.

***Table 4.3.2: sampling frame for initial purposive sampling of the women***

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| --- | --- |
| **Inclusion criteria** | **Exclusion criteria** |
| Pregnant women who had their first antenatal (booking) appointment at the Jessop Wing after 19 completed weeks gestation, as confirmed by ultrasound (dating) scan. | Pregnant women having their first appointment prior to 19 completed weeks gestation. |
| Women able to understand the project fully and give written informed consent to participate. | Women unable to understand the project fully and/or give written informed consent. |
| Women who had not received antenatal care elsewhere prior to this appointment, other than the initial referral appointment with their community midwife or GP. | Women who had received antenatal care elsewhere prior to their first appointment at the Jessop Wing. |
| Women with medically uncomplicated pregnancies. | Women where fetal abnormality had been diagnosed. |

More focused sampling methods were used alongside the purposive methods to identify women from these groups, developing and refining emerging ideas which in turn influenced further recruitment. This was an ongoing process throughout the research, developed through discussion with the supervisory panel and other members of the research team. Theories from existing studies, from this discussion and from initial interviews with women, were used to make predictions about women who were more likely to book late for antenatal care and their reasons for doing so. This included women who were potentially more vulnerable and hard to reach, including:

* Teenagers and young women
* Women with learning difficulties
* Women who were substance misusing
* Women who experienced homelessness or changing home circumstances during their pregnancies

This targeted approach to sampling, achieved in part with the support of specialist midwifery teams, also aimed to address difficulties with the purposive method and overcome the apparent reluctance of particular groups of women to participate in the study.

## *4.3.2 Recruitment*

Women were approached opportunistically to participate in this study (see figure 4.3.1) between September 2006 and August 2008 (interviews took place between October 2006 and July 2008). When I joined the study in May 2007, three women had already been recruited and interviewed by the previous research midwife. Late booking was defined as more than 19 completed weeks gestation when attending for the first hospital antenatal appointment. This was chosen as, although the end of the first trimester is widely considered the limit of early booking, from a clinical viewpoint 20 weeks is the gestation by which all antenatal screening tests should have been completed and is a widely accepted definition of late booking (NCCWCH 2008, 2010, EURO-PERISTAT 2013). As discussed in chapter two, different definitions of late will inevitably influence findings. Women booking at 13 weeks gestation are likely to demonstrate differing pregnancy experiences and attitudes towards their care than women booking at a more advanced gestation. The 20 week gestation was therefore also chosen to maximise the number of women making a deliberate choice to book late, rather than women whose discovery of pregnancy had been slightly delayed. Attendance at the first hospital booking appointment, rather than the initial referral appointment with the woman’s community midwife or GP, was chosen to examine whether external (such as administrative) as well as personal factors were influential in the delay.

Women were identified initially from the antenatal referrals faxed or posted to the hospital by community midwives or GPs. Women with an estimated gestation of approximately 20 weeks or more when attending for their first appointment were identified. Once this was confirmed by ultrasound scan at their hospital appointment I then spoke to them or arranged for the staff in the antenatal clinic to do so. As the study progressed and the process of theoretical sampling was developed, women were identified and approached following liason with midwifery staff working in antenatal clinic, particularly from specialist clinics such as the teenage clinic and substance misuse clinic.

Any woman who was interested in participating was then given an information sheet to read about the study and a consent form. Because initial attempts to recruit women found that they failed to send back consent forms, I obtained initial consent to participate and consent to contact the woman by telephone first before leaving the appointment. The women were then given a minimum of 48 hours to consider, before being contacted by telephone. Once contacted, if they were happy to participate and be interviewed, they were then asked for written consent, face to face, before the start of the interview, which was usually one to four weeks after the initial contact. Women who required the use of interpreters for their antenatal appointments were not recruited as there was no funding for this, however a few women whose first language was not English were recruited, where they were able to understand the project fully and give written informed consent to participate. One woman gave a joint interview with her husband. No financial inducements were made to participants, although reimbursements for any travel expenses incurred were offered.

Table 4.3.3 details the outcomes of the recruitment process for the women. If, after several attempts, a woman could not be contacted by telephone, a card was sent to their home address inviting them to contact me to arrange a time to meet. Many women (n = 39) were un-contactable after initially agreeing to be part of the study, and none of these returned the postage-paid cards that were sent out. Of the women that were contacted and agreed to participate, ten subsequently did not attend for interview and could not be contacted, and four declined to be interviewed. Recruitment stopped when, in discussion with the supervisory panel for the study, it was felt that theoretical saturation had been achieved. This resulted in a sample of 27 women.

***Table 4.3.3: outcomes of the recruitment process for the study***

|  |  |
| --- | --- |
| *Women recruited at the Jessop Wing, September 2006 – August 2008*  *Women attending for first antenatal (booking) appointment with gestation (confirmed by USS) > 19+6/40.*  *Potential candidates identified from referral letters by research midwife and through discussion with antenatal clinic midwives and specialist midwifery teams.* | |
| **Eligible women given information**  **pack and asked for initial consent for**  **research midwife to contact (n = 83)** | Not meeting entry criteria (n = 3) |
| **Contacted by telephone and/or post**  **by research midwife (n = 80)** | Unable to contact by telephone/post  (n = 39) |
| **Contacted by phone and interview**  **arranged in location of woman’s choice: at home, community children’s centre or next antenatal hospital appointment (n = 41)** | Did not attend for interview and unable to contact by telephone/post (n = 10)  Declined to be interviewed (n = 4) |
| **Interviewed at home, children’s centre or hospital (n = 27)** |  |

## *4.3.3 The interview setting*

It is recognised that in qualitative research, data collection approaches need to be sensitive to the social context in which data is collected. If not they risk being rigid, unnatural or unsympathetic, which could reduce the authenticity of the data (Topping 2010). Initially women were asked to come to the Jessop Wing specifically to be interviewed for the study. However, this proved to be ineffective as most women failed to turn up and this, in combination with women’s reluctance to participate, meant that initial recruitment was extremely poor. I recognised that to try to improve participation and eliminate barriers to attendance, I needed to understand the women’s lives better (again, a consideration of the *emic* perspective) and they needed to have some control over the interview process. As a result, interviews were subsequently conducted at the woman’s convenience, in her choice of location, either at the hospital to coincide with any further antenatal appointments, or at home or at another location of her choice, for example a local children’s centre. All women were interviewed antenatally, apart from one who was interviewed 48 hours after the birth on the postnatal ward.

It was quickly apparent that the setting for the interview affected its content and quality. Some authors have commented that it is usually preferable to interview people in their own homes or in a neutral location, reflecting the naturalistic approach of qualitative research. The rapport and trust between interviewer and participant is influenced not only by the language and body language of the interviewer but also the setting for the interview (Liamputtong and Ezzy 2005, Britten 2006). Therefore an interview in a private space that the participant has some ownership over is more likely to result in a relaxed atmosphere and a better rapport, and (by implication) richer interview data (Holloway and Wheeler 2010). This was certainly the case during the study, with the length and depth of the interviews varying considerably, depending both on women’s reticence to talk and the location. The interviews ranged in length from 16 to 63 minutes (mean = 32 minutes); women at home in general talked more openly and for longer.

It has been argued that a location related to a particular organisation, of which the interviewer is perceived to be a part (the NHS or hospital in this case), could be threatening. However, I wanted the participants to have some control over the process and particularly the choice of location. There was a trade-off between convenient settings for interviews (hospital) and more productive and trusting ones (home) (Green and Thorogood 2014). Some women did not wish to be interviewed at home, which seemed to be perceived as inconvenient or intrusive. This was reflected by the four women who were unavailable when I arrived at their homes to interview them, and other women who *were* interviewed but chose to do this at the Jessop Wing, prior to or following their next hospital visit. This resulted in convenient but somewhat time-limited conversations.

## *4.3.4 Collection of demographic data*

Prior to the interview women were asked to complete a demographic questionnaire, or it was completed for them if they had difficulties with reading and/or writing, and consent was obtained to access the women’s medical records if necessary (though this was not required). This data collection was designed to reflect the socio-demographic factors associated with late booking in the literature (see chapter one pages 11-15) and to provide contextual information for the interviews (Bryman 2008). The questionnaire is presented in appendix 4.12, and a summary of the results are presented in table 5.1.1, in chapter five.

***Table 4.3.4: Demographic data collected from the women interviewed*** *(factors associated with late booking in parentheses):*

|  |
| --- |
| **Home address** (living in areas with high deprivation indices) and **length of time at address** (temporary accommodation/recent arrival) |
| **Age** (older or young women) |
| **Ethnicity** (not ‘White British’ ethnicity) |
| **First language** (English not first language) |
| **Parity** (high and low parity) and **age when first pregnant** (young age) |
| **Educational level** of mother and baby’s father (low educational attainment) |
| **Relationship status and support** from baby’s father (lack of support, single parenthood) |
| **Occupation and employment status** of woman and partner (unemployment, low income) |

## *4.3.5 The interviews*

I carried out 24 of the 27 individual semi-structured interviews with the women in the study, between May 2007 and July 2008. The interview guide for these took the research question, *“what perceptions and beliefs do late booking women express about the delayed initiation of antenatal care?”* as its starting point, focusing on issues relating to late booking women’s experience, knowledge and beliefs. The flexible guide was designed to act as a prompt and a guide for discussion, without trying to limit participants’ responses. It was used to make interviewing more systematic and comprehensive, to provide a framework for the semi-structured interview process and to ensure some consistency in the data collected. However, there was a recognition that the standardisation of questions did not mean the standardisation of meanings for participants (Murphy *et al* 1998). The guide allowed for different interview patterns, individual interpretation and a degree of participant control. Its flexibility also allowed for modification during the research process (Bryman 2008, Holloway and Wheeler 2010).

The guide for the individual interviews was based upon four key areas relating to the initiation of and attendance for antenatal care. Its design reflected theoretical sensitivity, using professional experience and an exploration of existing socio-demographic studies of antenatal care attendance. It was developed through discussion with a group of academics and health and social care practitioners involved in the care of pregnant women. This included an academic social scientist, a GP, an obstetrician and a midwife. The initial interview guide (appendix 4.11) contained questions grouped around four main themes:

1) Reasons why the woman had presented late for antenatal booking;

2) The woman’s understanding of early antenatal booking and the health checks associated with this, and their importance;

3) Factors that might have prompted or helped the woman attend earlier for their antenatal booking visit and;

4) The woman’s plans for future care attendance and utilisation.

Again, reflecting the iterative approach of the research, the interview guide was designed to avoid prescription and preconceptions about why women might book late, which might limit the interview process. Questions were designed to be as open-ended and non-directive as possible, whilst still guiding; clear and at an appropriate level of understanding for the participant to enable them to tell their story. The interview guide consisted of a preliminary statement about the purpose of the study which was read to all participants, and simple questions, avoiding ambiguity, and using relevant language. It included some prompts and/or exploring questions to enable elaboration and allow different perspectives to emerge (Bryman 2008, Holloway and Wheeler 2010). Women were encouraged to consider barriers to their care because, as Melnyk (1988) identifies, *“the concept of barriers is of particular interest because it helps to define the interface between the consumer and the system”* (p196). There was no explicit consideration of possible solutions to late booking, though this was raised by some women.

The interview explored some general topics but was otherwise based around the way the participant framed and structured their responses. As women were interviewed other relevant themes began to emerge and the interview format was modified to incorporate these. Through the process of constant comparison the interviews were recorded and listened to afterwards to re-familiarise myself with the content, which in turn informed subsequent interviews. This revision, as research progresses, is a common part of iterative qualitative approaches. As Green and Thorogood (2014) argue, flexibility is essential when framing questions, using what works well in early interviews, what resonates with participants’ experiences, and removing what works less well. This was fundamental to not simply reflecting my own framing of the world but trying to reach the women’s, respecting the *emic* perspective by constantly returning to the data, rather than imposing preconceived ideas (Hall *et al* 2012).

In particular, modification of the interview guide resulted from some women’s general defensiveness with some of the questions, and a reluctance to talk openly about their late booking, which limited the initial interviews. The guide was modified, both in terms of the language used and the questions posed, to avoid the professional vocabulary that, on reflection, was evident, and to encourage women to tell the story of their pregnancy experience so far. In particular women were asked about discovering the pregnancy and their first thoughts and feelings. They were also encouraged to talk about how they made their initial access to antenatal care, and the influence of family and peers on the woman, her pregnancy and this initial access. Broad enquiry questions such as *“tell me about your experience of finding out you were pregnant”* were eventually used to start the interview, rather than questions about women’s late initiation of care. Patton (2002) suggests starting with simple, noncontroversial questions such as this, which encourage description, then moving on to opinions and feelings afterwards. He discusses how in qualitative interviewing the interviewee needs to become actively involved in providing descriptive information as soon as possible instead of becoming conditioned to providing short-answer, routine responses.

The interview guide was designed to create order and flow to questions, but with some flexibility. Charmaz (2002) distinguishes three types of questions which follow the flow and phases of an interview: initial open ended questions, intermediate questions and ending questions. These were used to encourage the women to elaborate on their experiences and their attitudes and those of the people close to them, but also to steer the conversation and to change subject. The flexible approach aimed to be responsive to participants, using the full range of questions, varying not only the content but the emphasis and order of the questions. This flexibility was also reflected in the timing and location of the interviews and the discrete use of taping. The guide was used less as the research progressed, as my confidence and skills, and familiarity with the interview process, grew. Some questions, for example relating to attendance for care in the future, were removed as they failed to elicit responses other than the expected *‘of course I will attend’*.

### 4.3.5.1 My relationship with the women

As my experience as an interviewer increased, I recognised the importance of my social and language skills in optimising the encounters with the women. My goal was to allow the women to tell their stories by providing a facilitative audience that was appreciative of their position. The flow of the interviews was further encouraged with positive body language, careful listening and rephrasing, trying to avoid interrupting and leading questions, using silences and gentle prompts to encourage elaboration (Bryman 2008, Hall, McKenna and Griffiths 2012). My aim was to demonstrate empathy and encourage the women to be *‘not passive respondents but active participants in an important social encounter’* (Holloway and Wheeler 2010: 97).

Using the participant’s descriptive experiences as a starting point allowed me to get into their world and encourage ideas familiar and known to them, to understand their perspective, to focus on concrete rather than abstract or theoretical issues (Green and Thorogood 2014). It enabled me to create a context for the discussion, and establish some rapport and trust with the women, to try to move away from perceived judgement and assumptions, for example that late booking was a bad thing that they should be ashamed of (Patton 2002, Liamputtong and Ezzy 2005). It enabled us both to take a step back from the research question, to ask about experiences and feelings directly and indirectly related to the woman’s late booking. Encouraging the women to tell their stories using their own language was particularly important, as it allowed them to express ideas as they knew them, and tried to avoid favouring the articulate. This encouraged the participants to feel more comfortable and at home with their ideas, rather than struggling with ‘research language’ from the outset (Leininger 1985).

This focus on the women’s perspective required several approaches, and a delicately balanced role, which reflects previous consideration of reflexivity in chapter three and is discussed further later in this chapter. The first was to recognise my effect as an interviewer, to try to generate the right data. This was achieved by taking an empathetic approach and trying to establish a rapport with the participants. Recognising people as the subjects not objects of research, with different perspectives and perceptions, and attempting to achieve a relationship of equality and mutual respect was the starting point for this (Bowling 2009, Holloway and Wheeler 2010). Encouraging women to be honest and open, and to feel some ownership over the research, required a flexible approach to the interview process. Whilst previous evidence informed the overall structure of the interviews, the aim was to avoid superimposing preconceived ideas. As an interviewer, this necessitated stepping back in conversations, using minimal prompting to encourage stories to be told.

I approached the interviews being honest about my status as a midwife, albeit one who was not involved clinically in the women’s care. There was a constant consideration of this relationship, also the aims of the interview and how these could be achieved throughout the study, in terms of elements such as the content and timing of interviews, listening skills and prompting used, with modification as the study progressed. There was also a recognition that social differences in the interview relationship, and their impact on the data collected, needed to be acknowledged, documented and included in the analysis (Holloway and Wheeler 2010, Green and Thorogood 2014).

Despite my honesty and empathy, for some women there was a reticence associated with the relationship. However, for others there was an appreciation of my status, a recognition that I understood their situation and could provide information and reassurance. In part this reflected women’s lack of antenatal care up to that point in their pregnancies. Consequently, many interviews were preceded and followed by questions and discussion around routine aspects of pregnancy and antenatal care. Oakley (2004) also observed this questioning in her study of pregnant women. She acknowledges that it is impossible to ignore this relationship between interviewer and participant, and that it is a positive part of a more egalitarian interview process.

### 4.3.5.2 Recording and transcribing

The interviews were tape recorded to help preserve the participants’ words as accurately as possible. This also enabled me to have eye contact and pay full attention to what participants said, enabling the dynamics of the conversation to be maintained with minimal disruption and distraction (Patton 2002, Holloway and Wheeler 2010). As Lofland *et al* (2006) suggest *“if conceivably possible, tape-record. Then you can interview… the process of note-taking in the interview decreases one’s interviewing capacity”* (p106). Because of the risk of making people self-conscious or alarmed by recording them, all participants were asked for permission to record; none refused however the presence of the tape recorder may have limited responses. Notes were also taken by myself, after the interviews, to support the analytical process, and reflected ethnographic principles of naturalistic observation which were influential on the study.

The interviews were transcribed verbatim to keep the interviewers and interviewees words intact and provide the most reliable record of the discussions (Green and Thorogood 2014). This was an ongoing activity throughout the research process, enabling me to develop an awareness of emerging themes that influenced further interviews. It reflected the iterative and inductive approach of grounded theory, which was influential throughout the study (Bryman 2008). Transcription was a challenging and time consuming process, in part because the basic recording equipment used resulted in poor quality audio files, but also the consideration of what to include and exclude (Poland 2002). The audio files were converted into digital files using *Audacity* software to make the transcription process easier**.**

The interviews generated large amounts of text to be analysed.Approximately one third of the interviews were transcribed by myself, the remaining ones were transcribed by a professional transcribing service. All interview transcripts were reviewed by myself while listening to a digital version of the original recording. This was to ensure accuracy, particularly the inclusion of pauses, expressions of emotion and colloquialisms which were important to the meaning of the conversation. It also became an essential part of the analytical process. As Lofland *et al* (2006) argue

*“it is in the process of transcribing that you truly ‘hear’ what the person has said and, as such, this is a period in which analytic insights are most likely to occur”* (p 107).

## *4.3.6 Ethical issues*

Ethical principles underpin all medical and social research, and the ethical aspects of research governance for the study have previously been discussed in section 4.3.2. Such principles have their roots in different models, with the focus on risks, benefits and outcomes in the medical model contrasting with the focus on respect, autonomy and process in social models. At the core of ethical research lies a commitment to integrity, quality and transparency (ESRC 2012: 2), and the principle that “*The dignity, rights, safety and well­being of participants must be the primary consideration in any research study”* (DoH 2005: 7). Fundamentally it has been argued that ethical practice is simply ‘doing the right thing’: conscience should be the researcher’s primary guide, with a responsibility to participants, researchers and potential users of the research (Green and Thorogood 2014). Consideration of ethical issues in qualitative studies involves a balance of responsibilities to these different ‘stakeholders’ and inevitable tensions, balancing conflicts of interest, the need to respect participant boundaries and privacy, benefits and risks, with a desire to tell their story. Homan (1991) argues that commitment to ethical practice is built on a recognition and understanding of such dilemmas. Ethical practice in qualitative research is achieved through honesty and negotiation with the participants, taking a holistic view of participants, their social and cultural context. Such ethical considerations are at the heart of reflexive practice (Goodwin 2006, Holloway and Wheeler 2010).

The abstract ethical principles of Beauchamp and Childress’ *Principles of Biomedical Ethics* (2008) are reflected in many research ethics frameworks (for example ESRC 2012), and the ethical considerations for this study. I recognised that the application of these in practice was likely be complicated. Some ethical issues were predicted, such as the need to protect confidentiality and obtain informed consent, however these (and others) developed during research, for example with the interviewing of teenagers and women with learning difficulties. In order to interview successfully and establish a rapport with the participants I needed both empathy and distance. I wanted to put myself in their place, but needed to be honest about my background as a midwife and could not completely detach myself from my professional role. This dual role was difficult to reconcile: I was not auditing good practice,or providing a caring role, but needed to acknowledge that safeguarding young women in particular was more important than confidentiality (Holloway and Wheeler 2010).

### 4.3.6.1 Informed consent and respect for autonomy

The principle of informed consent underpins all professional guidelines for conducting research (Green and Thorogood 2014). As Department of Health guidance (2005) states: “*Informed consent is at the heart of ethical research”* (p7). Informed, voluntary consent means that research participants are recruited appropriately, are fully informed about the research and the implications of participation, and give their voluntary agreement to participate in it. Participants are subject to neither implicit nor explicit pressure to do so (ESRC 2012, Holloway and Wheeler 2010). The principle of informed consent is linked to respect for autonomy and an individual’s right to self-determination, and is part of an ongoing process of honesty and collaboration throughout the research, so that participants understand they are able to withdraw at any time (Beauchamp and Childress 2008, Bowling 2009, Green and Thorogood 2014).

An opt-in process was used, whereby potential participants gave their initial consent to be contacted further to participate in the study. For the women, a participant information sheet (appendix 4.7) was given to potential participants, providing clear details about the research, the proposed interview, confidentiality issues, the opportunity to withdraw at any time and who to contact for further information or if they had any concerns. Accompanying this was a short consent form, giving me permission to contact the women by telephone to arrange a meeting, at their convenience. The information sheet, letters of invitation and consent forms formed part of the formal ethical approval process for the study.

Some authors have argued that making participants sign a form can deter and undermine the relationship between interviewer and participant, and this may be why some women chose not to participate. However, not receiving written consent is unrealistic in health research (Bryman 2008, Green and Thorogood 2014). For participants with a single involvement such as this study, Goodwin (2006) suggests that this sort of information sheet, outlining the research process, overall objectives and providing a clear statement about voluntary participation, is sufficient to obtain informed consent. She argues that the process of obtaining consent is complex however: *“obtaining informed consent in qualitative research cannot be accomplished by the mechanistic production of a consent form signed at the outset of the research”* (Goodwin 2006: 59). This was reflected in repeated opportunities confirming women’s willingness to participate prior to the interview.

All women were given background information verbally about the study, in addition to the sheet which they could take away. The information sheet aimed to provide significant information about the study, using clear, unambiguous language, without influencing participants behaviour by explaining *too* much about what I was looking for. Homan (1991) argues that there is a danger of contaminating people’s answers if too much information is given at the outset. All women were given the opportunity to read the information sheet and ask questions, prior to signing the consent form for initial contact by myself (appendix 4.9). All women were then given a minimum of 48 hours after signing the form before attempts were made to contact them, to give them time to consider. The subsequent telephone conversations gave a further informal opportunity for clarification and confirmation of consent to participate further. When meeting face-to-face, women were given a further opportunity to ask questions about the study and another consent form to sign prior to interview (appendix 4.10), including consent to be recorded, which was done overtly. Women were informed that they could refuse to answer questions and could also ask for their data to be removed from the study after the interview.

The process of obtaining consent adapted as the study evolved, reflecting the flexible and emergent nature of the research and the changing sampling methods used (Goodwin 2006). Particular care was taken when seeking consent from more vulnerable women, in particular the four teenagers aged less than 18 years and the three women with learning difficulties, to ensure that the study and participation was clearly explained and understood (DoH 2005). Green and Thorogood (2014) argue that researchers have a duty to represent such participants, whose voices are often not heard and who may be less able to be informed or to give true consent. Such women are over-represented among late booking women. As with medical treatment, the young women aged below 16 were not presumed to have competence to consent to participate in the research, however consent was obtained when it was felt that they had sufficient understanding and intelligence to understand fully what was proposed (sometimes known as 'Gillick competence' or the 'Fraser guidelines') (NSPCC 2014). This is in line with General Medical Council (GMC) guidance for research:

*“You must decide whether a young person is able to understand the nature, purpose and possible consequences… only if they are able to understand, retain, use and weigh this information and communicate their decision to others can they consent… the capacity to consent depends more on young people’s ability to understand and weigh up options than on age.”* (GMC 2007: 11-12, GMC 2010)

Extra time was spent with the women discussing the study and their part in the research, before asking for consent; particularly their understanding that participation was voluntary and that they had a right to refuse or withdraw from the research at any point. In some cases this discussion was in consultation with supporting adults. Particular attention was also made to the interview format and location for these more vulnerable women to try to put them at ease, for example giving them the option to be interviewed with a friend or family member present.

National guidance concerning research with children and young people recommends obtaining consent from a parent or carer with parental responsibility in addition to obtaining consent from the child or young person (Shaw *et al* 2011). Consequently an information sheet for parents was produced (appendix 4.8). However, three of the four women aged less than 18 who gave consent did not wish to involve their parents, which was respected, as it was that felt to do otherwise was to undermine their autonomy. The fourth woman, aged 17, who also had learning difficulties, requested to be interviewed with her mother present, though the mother did not participate in the discussion. The young woman signed the consent form and her mother received a copy of the parental form. Also in line with guidance, parental consent was obtained to conduct an interview with a 16 year old young women in her family home (Shaw *et al* 2011).

### 4.3.6.2 Right to privacy and confidentiality

Confidentiality and anonymity, particularly in relation to the appropriate use and protection of participant data, form a fundamental part of all stages of any research project, as recognised by the ESRC *Framework* for *Research Ethics* (2012) and DoH*Research Governance Framework* (2005). The aim was to uphold confidentiality and anonymity as far as possible, making clear the limits of confidentiality at the outset of the study (Green and Thorogood 2014). This was reflected in the wording of the participant information sheet which noted that *“All reasonable steps will be taken to ensure confidentiality… we would like to emphasise that it will not be possible to identify you from any report of this study”* (appendix 4.7). Access to the data was limited to myself, the principal Investigator for the study and the supervisory panel, for independent verification and interpretive challenge.

The process of confidentiality started with me disclosing my background as a midwife but reaffirming my role as a researcher, independent of their antenatal care. I recognised the importance of honesty with participants but also of not researching women in my care, because of the potential perceived power imbalance and the possible disclosure of sensitive information which might affect our relationship (Butler 2003). Achieving privacy for the interviews was another essential part of this confidentiality, in terms of location and the presence of others, but was balanced with the participant’s choice. Two women chose to be interviewed with other people present: as previously mentioned, one young woman with learning difficulties was interviewed with her mother, although she did not participate in the conversation; another woman whose English was limited was interviewed with her husband, who did. This was a pragmatic way of gaining the women’s perspectives, but one which subsequently included the views of the family member.

The anonymity of participants throughout the study, during data collection, analysis and writing up, was maintained by removing all identifiable content and allocating participant numbers to the women. Other steps were taken to ensure the confidentiality of information, such as not using local transcription services. Tapes, transcriptions and notes were stored without identifying details and separately to demographic details; all were stored securely in accordance with the research governance guidance for the study.Collection of data only occurred during planned interviews, and there was no informal collection, quoting or referencing of confidential documents such as medical notes or personal details. Information about participants was discussed anonymously during supervision and analysis but was not disclosed in other settings. Participants were made aware that others had limited access to the interview tapes for peer review, as part of the analysis process, and consent was obtained to quote them directly but anonymously.

### 4.3.6.3 Non-maleficence and beneficence

Bryman (2008) argues that doing no harm to participants is the litmus test of ethical research, but also that *“virtually all social research is intrusive and exploitative to some degree”* (p129). There is an argument that qualitative research has the potential to be more intrusive than quantitative research, and as such requires particular sensitivity and good communication skills to minimise the risks, the emotional consequences, to any participants (Holloway and Wheeler 2010). Interviews were conducted in as quiet and supportive environment as possible, with the participant’s choice of location and timing, recognising the sensitivity of the topic for the women particularly and the possibility of distress or anger. My approach towards the interviews intended to build a supportive relationship and to convey respect for participants’ (*emic*) perspectives and concerns, rather than my own, allowing their stories to be told honestly but also in a positive way.

### 4.3.6.4 Fairness and justice

A fair and just approach to the research was reflected in the research governance of the study and all the study methods discussed above, and particularly the honest, collaborative approach adopted towards recruitment and interviewing.The exclusion of non-English speaking women from the study reflected this commitment, as women could not be represented fairly and truthfully without the use of interpreters. It was also reflected in the consideration of my own safety when interviewing in people’s homes. This responsibility to the participants has continued during the writing up of the research, in terms of attempting to represent them fairly.Fairness was also reflected in the presentation of the findings, avoiding imposing interpretations that were not shared by the participants themselves, which would have reflected an unequal and hierarchical relationship (Bryman 2008). Green and Thorogood (2014) identify the risks of any analysis and interpretation; they argue that a balance must be struck between moving thinking forward and representing participants faithfully.For me, the exact reproduction of the words of the women particularly, through verbatim transcription and quoting, was part of this fair representation.

## *4.3.7 Analysis of the data*

The data was analysed using a thematic approach, as discussed in chapter three. Braun and Clarke (2006) propose a step-by-step guide to undertaking thematic analysis which attempts to articulate the balance between analysis and interpretation suggested by Wolcott (2009). I have attempted to elucidate the process below using (loosely) the six stages they propose, though the reality was less linear, and illustrate some of the tensions and complexities inherent in the process. Critical to all stages of the analytical process was the interaction between myself and the research team, through research meetings and academic supervision, providing independent verification of the data and critical challenge.

### 4.3.7.1 Stage 1: becoming familiar with the data

As discussed previously, the analytical process began with the transcription of the interviews and the checking of the audio files to ensure accuracy. This was done repeatedly to examine all relevant data and get a clear picture of the participants’ language and views (Ziebland and Wheeler 1997). Transcripts were read and re-read and initial notes were made summarising each woman’s story (table 5.1.2, chapter five). These were compared with notes made after the interviews, to start to build an overall picture of the women’s views and to begin the process of coding the data. Members of the supervisory panel were involved in verification of the data during this initial process.

### 4.3.7.2 Stage 2: generating initial codes

Called the heart of thematic analysis (Liamputtong and Ezzy 2005), initial coding of the data involved identifying, sorting and organising data, labelling interesting features of the interview data in a systematic fashion, line by line. This inductive process was completed across all the data, collating data relevant to each code, using only codes originating from the interviews themselves (‘in vivo’) rather than imposing predetermined categories. The process of initial coding of the data involved the use of a computerised analysis package for qualitative data: NVIVO 8, which enabled the creation of hierarchies of codes and the ‘attachment’ of interview data to these. An illustration of the coding of the data in NVIVO is presented in appendix 4.13. NVIVO offered an efficient way of handling and organising the data. Its use improved the management of the large amount of interview data generated, and improved the transparency and rigour of the analysis. However, NVIVO acts to facilitate the process rather than carrying it out and does not help with complex skills like coding decisions or the interpretation of findings (Murphy *et al* 1998, Bryman 2008). Lofland *et al* (2006) comment about such software that

*“at best they expedite and expand data organisation, storage, and retrieval possibilities, but they cannot do the hard work of data analysis, which requires certain intellectual and creative skills that, to date, only the analyst can bring to the enterprise”* (p204).

It has also been argued that the use of such software may distance the analyst from the data, blunting the sensitivity which is central to the data analysis process (Murphy *et al* 1998). This was evident in my experience. NVIVO was a useful organisational tool, however dividing the data into coded pieces led to some fragmentation and loss of context and narrative flow.

The coding process considered not only what was said but also how it was said, some of which was lost during transcription. The coding of long narrative and discursive accounts was particularly challenging, as they included several themes in a coherent sequence, which required multiple, overlapping codes. As a result of these factors the analytical process required a combination of methods, including repeated comparison of the complete transcripts, the coded data in NVIVO and in some cases the audio files. This was supported by the production of memos and analytical diagrams describing the data, initial codes and theories and ideas for further sampling, reflecting the influence of grounded theory.

### 4.3.7.3 Stage 3: searching for themes

Refinement of the initial coding process gradually led to the creation of hierarchies or patterns of codes. Many codes were generated initially, which were then combined and recombined into recurrent themes. This reflects grounded theory’s ‘axial coding’: looking for relationships and putting the fractured data back together. The original research question was central to this process, which tried to identify, using the language of the participants themselves, the essence of women’s reasons for late booking. The themes, ‘meaningful sequential units’ (Leininger 1985), reflected differing levels of complexity and abstraction (DeSantis and Ugarizza 2000), as Boyatzis (1988) notes:

*“A theme is a pattern found in the information that at minimum describes and organises the possible observations, and at maximum interprets aspects of the phenomenon”* (p4)

The process was undertaken systematically and repeatedly for all the interviews, as I became more familiar with the data and the software. Again, the aim was to allow the themes to be found in the original data itself, using a careful and rigorous process, rather than superimposing pre-existing ideas onto the data and using ‘cherry picking’ methods to find supporting evidence of their existence (DeSantis and Ugarriza 2000, Green and Thorogood 2014). Although *a priori* considerations of the women who might be recruited for the study had been made, based on the surveys discussed in chapter one, there was no such influence in relation to the thematic analysis. As discussed in chapter 2, the literature synthesis was undertaken following data collection, and separate to the thematic analysis for the Sheffield study. This contributed to maintaining the originality of the findings.

### 4.3.7.4 Stage 4: reviewing and refining themes

Pope, Ziebland and Mays (2006) discuss how a stronger analysis moves beyond simple description to examine the interconnection of themes. A process of reviewing, reorganising and refining themes was undertaken for all the interviews in the study. This involved drawing thematic maps and tables of the data, exploring relationships between the themes, subthemes and the codes within them, and checking the coded extracts; looking for repetition, omissions, similarities and differences (Ryan and Bernard 2003) (Appendix 4.14). This reflects Wolcott’s (2009) description of the more intuitive process of ‘interpretation’ which started to take place at this point. Leininger (1985) calls this interpretive process a ‘synthesis’ of themes, to obtain a comprehensive and holistic view of the data.

### 4.3.7.5 Stage 5: defining themes, developing theories

As the analytical process progressed I started to focus on developing more theoretical ideas in relation to the data. The themes, their boundaries, hierarchy and the language used to define them, were refined further. As the pattern of themes became more defined visual mapping methods were used, as illustrated in appendix 4.15, to give an overall graphic picture of the data and aid the analytical process. Lofland and Lofland (1995) suggest that at this stage in the analytical process the themes or ‘elaborated codes’ as they call them *‘begin to assume the status of overarching ideas or propositions that will occupy a prominent place in the analysis’* (p192). A taxonomy of themes and subthemes relating to late booking was developed and went through many transitions, with interpretive challenge provided during analysis meetings from the supervisory panel. As this developed I started to consider the overall story that the analysis was telling, whilst trying to ensure that it remained honest to its component parts: the individual accounts from the women. This was a challenging and complex task, as Leininger (1985) discusses:

*“Much creative thought and analytical ability is needed to literally “put the pieces together” so that a theme or pattern of behavior is formulated that is congruent to the people being studied*” (p60)

Differing depths of analysis are appropriate for different studies (DeSantis and Ugarizza 2000). The study’s aim was to gain a broad understanding of the attitudes and beliefs of late booking women, to improve access and health outcomes, rather than exploring language in detail, such as in discourse analysis. The process of thematic analysis provided an analytical method with breadth but also an attention to detail, variation and ‘deviant’ cases, to provide a credible and thorough account of the data, beyond the taxonomy (Green and Thorogood 2014).

### 4.3.7.6 Stage 6: presenting the findings

Braun and Clarke (2006) identify the writing up stage as the final opportunity for analysis, the creation of a ‘big picture’, whose parts fit logically and meaningfully together. This final stage reflects Sandelowski’s (1995b) ‘qualitative interpretation’, a creative process that produces something new that is different from, whilst faithful to, the data in its original form. The end point of the analysis aimed to be both descriptive and theoretical about late booking; to create something that could have the potential to influence policy or practice interventions.My aim was to present a taxonomy of themes relating to late booking (a common method of ‘measurement’ in qualitative research (Pope and Mays 2006)). However, I also wanted to create a story (Giorgi’s (1985) overall ‘structure of experience’) around the voices of the women, a narrative representation of the accounts but one which was anchored (grounded) in the words of the participants.

This narrative attempts to reflect common but also unique and striking themes in the data, alternating description and analysis with illustrative quotes (Holloway and Wheeler 2010). As it was recognised that the sample was not representative of the whole population, and because of the flexibility in the interview process, I felt it was misleading to report relative frequencies of responses. However, simple numeric indicators were used in some cases to give an overall flavour of the data (Ziebland and Wright 1997). The language of the themes aims to be consistent with the interpretivist approach and feminist influences on the research itself, particularly in terms of being respectful of the participants’ perspectives, not labelling or blaming. The narrative attempts to develop explanatory theories, in order to provide a comprehensive view of late booking that has depth and breadth, and to answer the research question.

# 4.4 Conclusions

Methods were chosen to complement the goal of the research, to develop a better understanding of late booking, and specifically to answer the research question *“what perceptions and beliefs do late booking women express about the delayed initiation of antenatal care?”* Such methods reflect the chosen qualitative methodology, the conventions and quality criteria of qualitative research, but also ethical and practical considerations. The methods were iterative: as described, compromises and adaptations were made as the study progressed, largely as a result of recruitment challenges and interview limitations. As Bryman (2008) observes however, such compromises are a normal part of the research process as *“all research is the coming together of the ideal and the feasible”* (p27). The methods enabled the collection and analysis of detailed and personal stories of late booking, from pregnant women’s perspectives. The study has rejected the ‘value-free’ claims of positivist research and acknowledges the influence of context and reflexivity in the construction of the findings, through the systematic yet creative process of thematic analysis. These methods are designed to present the findings with sufficient clarity and detail for the reader to judge their transferability: their potential application elsewhere in other contexts and with other groups. This reflects in part the study’s pragmatic roots: to contribute to improving access through strategies for wider application (Polit and Beck 2012, Green and Thorogood 2014). The findings are presented in chapter five.

**Chapter 5: Results from the qualitative study**

**5.1 Introduction**

This chapter presents the results of the thematic analysis of the data from interviews conducted with 27 pregnant women who booked for antenatal care after 19 completed weeks gestation. The interviews were conducted in women’s homes, community children’s centres and hospital antenatal clinics in Sheffield, between January 2007 and July 2008.

***5.1.1 The characteristics of the women***

Table 5.1.1 summarises the characteristics of the women. The full demographic table can be found in appendix 5.1. The sample was theoretically informed by an initial literature review and supervisory discussion, and was diverse, particularly in terms of age, parity and educational level. The mean age of the women was 26 years (range 15-37 years) and parity ranged from zero to four; 15 women were nulliparous and two had had previous children removed for adoption, as a result of child protection procedures. Twenty one women were White British, however women from six other ethnic groups were also interviewed. The women reported a range of occupations from professional and managerial to manual and service positions; 16 were not employed, including seven who were school and college students. Educational level included up to postgraduate, 13 were educated to secondary school only and 3 had self-declared learning difficulties. Whilst women were interviewed from a range of locations across the city, a large percentage lived in Sheffield neighbourhoods with high deprivation indices, as determined by the English Index of Multiple Deprivation Score (Department for Communities and Local Government 2011, Office for National Statistics (ONS) 2010).

***5.1.2 Overview of the thematic analysis***

The inductive process of thematic analysis, detailed in chapter four, identified emergent themes and subthemes relating to late booking. Table 5.1.2 presents a narrative summary of each of the interviewed women’s stories. A taxonomy of these

***Table 5.1.1: Socio-demographic characteristics of the women interviewed (n = 27)***

|  |  |
| --- | --- |
| **Age at interview** | |
| Mean age (range) | 26 (15-37) |
| **Marital status** | |
| Married  Cohabiting  Single | 10 (37%)  7 (26%)  10 (37%) |
| **Ethnic origin** | |
| White  Mixed White/Caribbean  Pakistani  White European (Dagestani)  Black African (Eritrean)  Other (Mexican, Saudi) | 21 (77.8%)  1 (3.7%)  1 (3.7%)  1 (3.7%)  1 (3.7%)  2 (7.4%) |
| **Parity** (2 women had previous children removed and placed for adoption) | |
| 0  1  2  3 or more | 14 (52%)  7 (26%)  2 (7%)  4 (15%) |
| **Educational level** (3 women had learning difficulties) | |
| Up to 16 years (secondary school)  Further education  Higher/university education  Unknown | 13 (48%)  7 (26%)  5 (19%)  2 (7%) |
| **Occupation**(ONS 2000) | |
| None  Student  Housewife  Elementary occupations  Personal service occupations  Sales and customer service  Professional occupations/managers | 3 (11%)  7 (26%)  6 (22%)  1 (4%)  5 (18%)  2 (8%)  3 (11%) |
| **Deprivation ranking of home address (2010)**(ONS 2010) | |
| Living in lowest 5% of English neighbourhoods  Living in lowest 20% of English neighbourhoods  Living in lowest 50% of English neighbourhoods | 9 (33%)  15 (56%)  20 (74%) |

themes and subthemes was developed through this analytical process; this is presented in table 5.1.3. A chart mapping the themes and subthemes and their frequency can be found in appendix 4.15.

The women presented a complex variety of often interrelated personal and organisational reasons for not accessing antenatal care early in their pregnancies, and attitudes towards their late booking. Three major themes emerged from the women’s interviews: women not realising or believing they were pregnant and therefore not accessing care (not knowing), women knowing they were pregnant and avoiding or postponing antenatal care (knowing) and women being prevented from accessing care by others (delayed). As the thematic chart (appendix 4.15) and the women’s narratives shown in table 5.1.2 illustrate, most women had primary and secondary reasons for late booking. For example, late diagnosis of pregnancy was sometimes compounded by system or professional failures and/or personal avoidance, resulting in further delays. The themes are presented in detail below, with the words of some of the interviewed women to illustrate.

***Table 5.1.2: brief narratives for the 27 women interviewed***

|  |  |
| --- | --- |
| **1** | The woman didn’t accept that her symptoms were pregnancy, as she attributed them to existing health problems. When she did find out she was pregnant she was ambivalent about an unplanned/unwanted pregnancy and acceptance was delayed while she considered whether to have a termination. Finding herself in advanced pregnancy after initial mis-estimation of her gestation led to the eventual acceptance of the pregnancy and access to care. |
| **2** | Pregnancy was unexpected by the woman due to contraceptive use. She initially didn’t have any of the cardinal symptoms of pregnancy. Learning difficulties affected her ability to recognise and accept her symptoms, such as fetal movements, as pregnancy. |
| **3** | The woman initially didn’t recognise the symptoms of an unplanned pregnancy and attributed them to other things in her life. Changing locations led to cancelled appointments and delay in accessing primary care: she was working away and wanted to come back to Sheffield to ‘get things sorted’. |
| **4** | The woman didn’t recognise an unplanned pregnancy due to irregular periods and weight loss. |
| **5** | This was an unexpected pregnancy, with delayed appointments in primary care adding to the overall delay, due to the woman and her partner working away from Sheffield and waiting to book here. This woman had a previous concealed pregnancy as a teenager, and admitted to being more relaxed about not receiving early care because of this. |
| **6** | Learning difficulties impacted on the woman’s ability to recognise pregnancy symptoms (which were recognised by a parent eventually). The woman also did not accept that she could be pregnant: she attributed amenorrhoea to a previous medical condition. |
| **7** | An unplanned teenage pregnancy which wasn’t accepted or confirmed due to the stigma feared by the woman. She demonstrated denial and the avoidance of antenatal care; she wanted to be in control and used her knowledge and experience from college to monitor her pregnancy and undertake antenatal self-care. |
| **8** | A previous traumatic birth led the woman to experience ambivalence about an unplanned pregnancy, and fear about her ability to cope with another child. She considered a termination but couldn’t go through with it. The indecision eventually led to delayed acceptance, which resulted in postponement of care. |
| **9** | Delayed scheduling of the woman’s antenatal appointments wasn’t challenged, due to lack of knowledge of the ‘system’, and also feeling well and receiving positive support from friends and family. |
| **10** | The woman didn’t experience the cardinal symptoms of pregnancy, which were masked by irregular periods and her not expecting to be pregnant, which affected her acceptance of the pregnancy. This was compounded by delay with the scheduling of appointments. |
| **11** | The woman had been away from the UK for several months and had felt well. She admitted being in denial about being pregnant initially. Her religious beliefs and positive previous pregnancy experience all influenced her acceptance of an unplanned pregnancy as ‘normal’ and not requiring intervention until returning home. |
| **12** | A lack of classic pregnancy symptoms and an initial misdiagnosis of menopause by the woman’s GP resulted in the lack of a pregnancy ‘mindset’. This was compounded by the delayed scheduling of antenatal appointments. |
| **13** | Delayed scheduling of antenatal appointments was compounded by a lack of knowledge and misinformation given by the woman’s midwife. The woman’s positive relationship with her supportive midwife influenced her acceptance and rationalising of the incorrect advice. |
| **14** | The woman was ambivalent about the pregnancy, leading to initial denial, delayed diagnosis and acceptance. |
| **15** | An unplanned pregnancy, an initial lack of cardinal symptoms and delayed scheduling of appointments due to mis-estimation of the woman’s gestation led to delay. |
| **16** | The woman attributed symptoms to irregular periods (her ‘normal’) and lifestyle changes: professional failures compounded this. This was an unplanned pregnancy and the woman admitted she did not have a pregnancy mindset. Others recognised the pregnancy but were ignored. |
| **17** | The woman had no prior experience of pregnancy and was not expecting to get pregnant so quickly due to her age. She admitted she did not have a pregnancy mindset. |
| **18** | Initially ambivalent about an unplanned pregnancy and coping with another child, delayed access was due to the woman waiting to return to the UK following a prolonged holiday in her home country. The delay was also influenced by the woman’s later acceptance of the pregnancy, due to religious beliefs and a positive past experience of pregnancy. |
| **19** | A delayed scheduling of appointments plus feeling well, and some language difficulties, led to a lack of challenge by the woman, and subsequently to delay. |
| **20** | A recent arrival in the UK from Eastern Europe, the woman was waiting to move into more permanent accommodation and get settled before attending for care; combined with some other practical problems accessing care. She felt well and accepted the pregnancy; her previous positive pregnancy experiences (and a previous late booking) also influenced the delay. |
| **21** | The young woman’s symptoms were masked by irregular periods and a lack of knowledge about pregnancy – she did not accept that she was pregnant. Eventually peers diagnosed her pregnancy. |
| **22** | The woman was not expecting to become pregnant due to her Polycystic Ovarian Syndrome (PCOS), so didn’t accept her symptoms as pregnancy. She also experienced misdiagnosis, with her pregnancy not picked up on two ultrasound scans. |
| **23** | The woman was frightened of her family’s response to pregnancy. She also had other priorities in her life which prevented access and influenced her acceptance of the value of care. |
| **24** | This young woman didn’t think she could get pregnant due to previous cancer and her contraceptive use. She didn’t have any cardinal symptoms initially so didn’t accept that she could be pregnant; acceptance was also delayed whilst she considered a termination. |
| **25** | Delayed diagnosis and acceptance were due to an unexpected pregnancy and a lack of symptoms as a result of drug use. The woman’s ambivalence and fear (as her previous children had been removed) following confirmation of the pregnancy led to her avoidance of antenatal care. |
| **26** | The woman protected and concealed her pregnancy from her partner, who wished her to have a termination. She accepted the pregnancy and felt well, so rationalised her need to delay booking, undertaking self-care until beyond the termination limit. |
| **27** | Pregnancy was unexpected by the woman due to contraceptive use. She had booked late in her previous pregnancy: learning difficulties affected her recognition of pregnancy symptoms such as fetal movements, nausea and vomiting. This was compounded by initial lay hindrance. |

***Table 5.1.3: taxonomy of themes for late booking***

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **NOT KNOWING** | **Realisation** | Delayed confirmation of pregnancy | Lack of cardinal symptoms of pregnancy |  |
| Symptoms masked by irregular periods |  |
| Women’s misinterpretation/ misdiagnosis of symptoms | Attributing to other life event | ‘Mindset’ |
| Attributing to past/current medical condition |  |
| Lack of reproductive knowledge / pregnancy experience | Learning difficulties |
| Influence of others | Lay hindrance |  |
| Rejection of lay influence |  |
| **Belief** | Age affecting fertility |  |  |
| Past illness affecting fertility |  |  |
| Using contraception |  |  |
| Not planning, expecting to be pregnant | ‘Mindset’ | Ambivalence |
| **KNOWING** | **Avoidance** | Fear and ambivalence | Delay in confirming pregnancy |  |
| Fear of ‘consequences’ of pregnancy | Fear of removal of child |
| Fear of stigma, judgement |
| Ambivalence towards pregnancy and antenatal care |  |
| Coping mechanisms | Denial, concealment | In control of decision |
| Antenatal self-care | Using knowledge, experience |
| **Postponement** | Fear and ambivalence | Fear of the ‘consequences’ of pregnancy | Fear of judgement, reaction |
| Convenience |
| Denial |
| Coping with another child |
| Previous traumatic childbirth |
| Fear of blood tests |
| Considering termination | Indecision resulting in delay |
| Unplanned, unwanted pregnancy |
| Pressure to have a termination | Protecting the pregnancy | In control of decision |
| Early antenatal care not a priority | (Good) past experience of pregnancy | Previous concealed pregnancy/late booking |
| Feeling well |
| Acceptance | Fatalism, religion |
| Antenatal self-care | Control |
| Being ‘on the move’ | Lack of understanding of portability and timing of care |
| Waiting until ‘home’/in place of trust/safety |
| Other priorities |
| Practical difficulties accessing care |
| **DELAYED** | **Professional failures in primary care** | Misdiagnosis, misinformation |  |  |
| Mis-estimation of gestation |  |  |
| **System failures** | Delay in referral process/ scheduling of appointments |  |  |
| Lost appointments |
| **Women’s knowledge and empowerment issues** | Not challenging the system | Lack of knowledge of the antenatal care system | ‘Mindset’ |
| Rationalising the delay | Trusting healthcare professionals |  |
| Feeling well, care not important |  |
| Influence of family and friends |  |

**5.2 Themes**

***5.2.1 Not knowing***

The majority of the women interviewed (n=19) had said they had not known they were pregnant for weeks or sometimes months, which had contributed to the delay in them accessing care. As previously mentioned, this was often compounded by other factors (as appendix 4.15 illustrates) leading to further delay. Women had not realised that they were pregnant and/or did not believe that they could be pregnant: a lack of pregnancy planning and a pregnancy ‘mindset’ was evident in many cases.

**5.2.1.1 Realisation**

***5.2.1.1.1 Delayed confirmation of pregnancy***

The women who had not realised that they were pregnant were divided into those who said that they didn’t have any of the typical symptoms of pregnancy, and those who had symptoms but didn’t recognise them as pregnancy. Ten women reported that they had felt well and/or that they had not noticed any of the ‘classic’ [cardinal] symptoms of early pregnancy, for example nausea, vomiting, lethargy and amenorrhoea, particularly primigravidas:

*“I didn’t have any feelings whatsoever, I weren’t having any movements from baby, I was still having proper periods and my belly were flat because I’ve always been slim, so it were just flat and you know, like, sometimes you can get cravings and stuff, can’t you, and I ain’t got any cravings really, so, I had no idea.”*

(#24, G1P0, age 15)

*“I didn’t actually have any sort of signs in my stomach or breasts, so there was no signs there.”*

(#1, G1P0)

*“I didn’t find out until I was 23 weeks, I was still having periods all the time, a month before, February, and then I missed a month, so that’s when I went to the doctors a month after. So I just didn’t know really, that’s why I never went. Thinking about it they weren’t as heavy, but I was still on the same amount of days, the same time every month, no different.”*

(#10, G1P0)

For eight women, both primigravid and multigravid, irregular or non-existent periods were normal for them. In one woman’s (#25) case the amenorrhoea was a result of long-term substance misuse but for most of these women irregular periods were something they had grown up with and accepted as a normal part of their lives. This cycle irregularity masked their perception of the key symptom of pregnancy and for this reason they did not realise they were pregnant, which affected a woman’s ability to confirm the pregnancy early and delayed access to antenatal care.

*“I don’t get periods so, that’s why I didn’t think I were pregnant.*

*I: Right. When did you last have a period?*

*Years and years ago.”*

(#25, G4P3, on methadone)

*‘I were having, like, they weren’t regular periods, they were just like on and off but I’d been having trouble with my periods like since I started them, so, I didn’t really think nothing of it.”*

(#21, G1P0, age 15)

*“To be honest, my periods aren’t regular so I didn’t know how many weeks I were. I can go without periods for six months... So I don’t find out while I’m three months anyway if I’m pregnant, because they’re not monthly, they’re every two months. And because of my periods I suppose it took a while before I knew I was pregnant for definite.”*

(#8, G3P2)

One woman commented how she had been encouraged by her GP in the past to consider her irregular periods as normal for her and therefore nothing to worry about, so didn’t consider amenorrhoea at that time as anything to be concerned about.

*“I: Did you have any periods in this time?*

*No. But that’s not unusual at all, so… since I was 14, I could go a year and not have one every month and then I could go a year and have maybe two or three and they said we’ll put you on the Pill, which I’ve been since I was 16 and I still never had regular periods after that really and they said ‘oh it’s just the way you are, not to worry’.”*

(#16, G1P0)

***5.2.1.1.2 Women’s misinterpretation or misdiagnosis of symptoms***

Some women, in retrospect, recognised that they had experienced some classical pregnancy symptoms but had misinterpreted/misdiagnosed these early symptoms and signs for a number of reasons, often because they had not planned or expected to become pregnant.

*“I never contemplated being pregnant and then I started feeling really tired and I had got no energy, I was feeling sick and then I was bleeding really heavy… so I went to the doctor’s about this because I was quite concerned and they thought I was going through the change… And it was only after I had the blood test at the doctors that I realised I was pregnant.*

(#12, G4P3)

**Attributing symptoms to other life event, past or current medical condition**

Some multigravid women and one primigravid woman attributed symptoms such as nausea to stressful/other life events or weight change due to lifestyle issues (a lay explanation that in one case was reinforced by the woman’s family). As a result the women rationalised their symptoms and didn’t consider pregnancy initially, so didn’t access care.

*“I had a bleed and I thought I’d just had a period. We were opening this pub and it was just really stressful and I thought I was feeling sick because we weren’t eating; we were like working from ten in morning until two or three at night. So I just thought I was run down”*

(#5, G2P1)

*“I went to see the doctors Tuesday, and she said you’re about 22-24 week. I just thought it was wind, because I’d lost loads of weight, I’d lost three stone in weight. All of my family they normally look at my face and know, but because I’d lost weight I’d lost it in my face. So nobody knew at all.”*

(#4, G3P2-1)

*I just started putting on loads of weight, I thought coz it was from eating rubbish.”*

(#3, G2P1)

For six women, the classical symptoms of pregnancy that they were experiencing were misinterpreted for a current medical problem, for example a water infection or related to their Polycystic Ovarian Syndrome (PCOS):

*I thought I had a water infection, cos when I had a water infection my stomach swelled like that before. That’s what I thought were probably up with me and it wasn’t. It was pregnancy”*

(#6, G1P0, learning difficulties)

*“My belly had been swelling up a lot, because I’ve got polycystic ovaries so they said that I couldn’t have kids yet, because I’m not coming on every month. So I thought ‘right, that’s it’, my belly was swelling but I ain’t been to toilet, I felt constipated”*

(#22, G1P0)

**Lack of reproductive knowledge or pregnancy experience**

In some instances, women (particularly primigravid but also including one multigravid woman) did not realise they were pregnant because of a lack of reproductive knowledge and experience of what to expect when pregnant. Some women acknowledged this lack of knowledge had delayed confirmation.

*“not many of my friends have got children, and I think because, you know I mentioned before I’m adopted, so, and that was because my adopted mother couldn’t have children, she’d had a hysterectomy, so I’d never got to, spoken to her about it because obviously she’s never been through everything that happened. So, no, I didn’t really know what to expect or anything really.”*

(#17, G1P0)

*I know bits and pieces from school and that but not really that much... probably if I knew, like, a bit more about it then I’d have, like, realised a lot sooner”*

(#21, G1P0, age 15)

It was only when the pregnancy had been confirmed in other ways, e.g. with a positive pregnancy test, or when symptoms were explained to them, that women realised what they had been experiencing.

*“I just remember it were right low down and it felt like flutter, I said ‘feel it’, I didn’t think he’d be able to feel it and he felt it more than me…..[it felt] like trapped air bubbles and then I found it was kicking!*

(#22, G1P0)

*“I were getting butterflies and that but I just, like, thought, didn’t think nothing of it, like, when I did the test I actually realised what it were,”*

(#21, G1P0, age 15)

*“I do now because she told me when I went to the doctors, she told me what it [fetal movements] were like and I were like ‘yes’”*

(#10, G1P0)

Key groups for whom this was the main reason they didn’t realise they were pregnant, were those women with learning difficulties and teenagers, both primigravid and multigravid.

*“I found movements moving about in my stomach and I wondered what it were, so I went to see my GP….[I didn’t have] no sickness or owt like that, er I went to see my GP, he examined me and said I could be like six months pregnant.”*

(#2, G2P1, learning difficulties)

*“I found out when I had the pregnancy test, the two lines come up, when I went to the GP. I couldn’t believe it, I was gutted. I didn’t even know”* (#6, G1P0, learning difficulties)

*“I: you said you didn’t have any [periods]?*

*No, I didn’t have none.*

*I: So did you think that was strange, that you didn’t have any periods?*

*No, cos normally I usually get stomach pains to tell you when you’re coming on to your period, I didn’t even get none of them.*

*I: So what did you think was happening then?*

*Nothing, I thought nowt’s happening yet so fine, just wait.”*

(#27, G2P1, learning difficulties)

***5.2.1.1.3 The influence of others***

**Lay hindrance**

Women’s acceptance of their pregnancies, and the need to access care, was influenced by their peers and family members, in both positive and negative ways. Lay hindrance was identified as a barrier in some cases: some women did not realise they were pregnant because family, friends and partners had also attributed the classical pregnancy symptoms to another reason. This was most evident in relation to symptoms of nausea and vomiting, where explanations such as food poisoning or stomach upsets were given as the cause of the problem rather than pregnancy.

*“I were being sick a few times but my mum said ‘it’s just something you’ve ate’”.*

(#15, G1P0, age 16)

*“Even M didn’t think owt to it. We all just used to be sat there and I‘d go to the toilet and M used to say ‘she’s got upset stomach’. That’s all she used to say, that’s all we put it down to, just upset stomach, we didn’t think of owt else.”*

(#27, G2P1, learning difficulties)

In one young woman’s case her pregnant step-mother who she lived with didn’t recognise the pregnancy either, despite them spending time together and having lots of information about the subject:

*“My step-mum, she were pregnant, well, obviously she were pregnant at the time that I was so, like, I read a lot of stuff with her and that and, like, it just didn’t make any difference at all. It’s like my step-mum would be reading it and, like, I’m with her most of the time, so it was like reading it and looking at it together and that, didn’t really trigger anything at all.”*

(#21, G1P0, age 15)

**Rejection of lay influence**

In other cases it was family members or close friends, particularly women who had experience of pregnancy, who played an important role in ensuring women *did* eventually access antenatal care; noticing the pregnancy before the woman herself and urging her to seek care. Women did not always listen to their advice however, and only acknowledged their recognition significantly later, leading to further delays in accessing care.

*“The only person that kept suggesting it was my sister-in-law and both her sisters had had children last year and she kept saying ‘I think you’re pregnant, I think you’re pregnant’…*

*I: And when you know what to look for –*

*Exactly, it can be very obvious. But if you don’t know what to look for, it’s very different.”*

(#16, G1P0)

*“My tummy started to get a bit bigger and everyone kept saying to me ‘you’re pregnant’, ‘no, I’m not!’*

*I: So how long had your friends been saying - ?*

*About a month or so, two months”.*

(#25, G4P3, on methadone).

*“Me dad had an idea that I could be pregnant because I was a bit swollen. He says “you’re pregnant”. I says “I haven’t got a bloody idea”. He says “I think you ought to go and get checked”. So a fortnight later I went and checked, I went back home and said “Dad, you’re right, I am pregnant”. He went “I told you I were bloody right didn’t I?”*

(#6, G1P0, learning difficulties)

*“J used to like, lay with his head on my stomach and it used to just kick and we never thought nowt of it until it went right hard on his head, kicked his head off me stomach. And that’s when he said “you’re bloody pregnant!” and I said “I’m not!”*

(#27, G2P1, learning difficulties)

*“it’s just that everyone was getting on at me and I thought ‘well right I’ll do a test to prove to you all that I’m not’ and then, so I did the test and it come back that I were, so I did two and it come back that I were and I was, like, oops – they was all saying it, like, way before that but, like, everyone’s been saying ‘we know your body better than you do’, I was, like, ‘well yes you do’.”*

(#21, G1P0, age 15)

**5.2.1.2 Belief**

***5.2.1.2.1 Age affecting fertility***

Some of the women who accessed antenatal care late did so because they didn’t believe they could be pregnant and so did not have a pregnancy ‘mindset’, in some cases even when experiencing cardinal symptoms of pregnancy such as amenorrhoea. Two women in their thirties assumed age would more significantly adversely affect their fertility than was actually the case. One primigravid woman assumed it would take her a long time to conceive, when in reality the opposite happened:

*“when I came off the Pill, I thought it was going to take ages to get pregnant and I think because, and like I said as well before, because I would have like to have had, ideally had a baby earlier, I was, it meant so much to me that I was almost setting myself up for failure before I started, if you know what I mean, so I was almost saying to myself ‘well, you might never be able to have children, don’t count on it, it might take years’, you know, all those sort of things were running through my head so to think that, actually, it probably only took 3 months, that was the least likely scenario that I thought would happen”*

(#17, G1P0, age 31)

This woman acknowledged that being adopted by someone who was unable to have children had irrationally affected her own expectations about conceiving, and resulted in her creating a barrier to accepting she was pregnant:

*“because I’m adopted and my adopted mother couldn’t have children, for some reason, I don’t know why, but I thought that the same thing would happen to me, which is silly [laughs], really silly but, again, that was in the back of my mind, I thought ‘well the same thing might happen to me, so I have to prepare myself for that… it was the fact that I just didn’t honestly really think that I was having a baby and then I was… I think it was me that put the barriers there”*

(#17, G1P0, age 31)

Another woman in her late 30s, presenting with symptoms of fatigue and irregular bleeding, accepted her GPs initial diagnosis of menopause rather than pregnancy, because of her age, despite having had four children previously. She admitted that the diagnosis and focus on her age had influenced her to a point where she had not considered pregnancy as an option:

*“when they said ‘I was going through the change’ I thought ‘well could I be?’ because like 37 I thought ‘well I might be’ because you hear women go through it earlier than I did and I think I got that into my head more than anything and I never contemplated that I were pregnant.”*

(#12, G5P4, age 37)

***5.2.1.2.2 Past illness affecting fertility***

Some women didn’t believe they could be pregnant because they had existing medical conditions that meant that it was more difficult for them to conceive, or they had been ill recently or in the past and thought this would affect their fertility. For example, two women described how they had attributed amenorrhoea to conditions such as polycystic ovarian syndrome or even recurrence of a cancer rather than pregnancy, and another to how childhood cancer had influenced her expectations of being able to conceive.

*“My belly, like’s, fluttering, like trapped air and he went ‘you’d better go and get a test’, I’d say ‘I don’t need one, I don’t need one, I’m not pregnant, I can’t be’.”*

(#22, G1P0, PCOS)

*“I didn’t think I could have any, and that was the problem. Because of what had happened to me in the past. The pituitary tumour… I knew I weren’t coming on but I thought it was the tumour growing back, or something like that. Obviously, with what I’ve been through in the past.”*

(#6, G1P0, learning difficulties)

*“I had a feeling, though, I had a feeling before that I were always thinking to myself, oh well I wonder if I can have children when I’m older and stuff, because of the cancer.”*

(#24, G1P0, age 15)

***5.2.1.2.3 Using contraception***

Eight women, both nulliparous and multiparous, were using contraception when they conceived, most commonly taking the contraceptive pill, which significantly affected their acceptance of pregnancy. Consequently, these women did not believe that they could be pregnant and amenorrhoea was attributed to the contraception, and in some cases to their ‘normal’ (i.e. irregular) cycle.

*“I was on depo injections so I didn’t think I could get caught on that.”*

(#2, G1P0)

*“I were on the pill at the time. So obviously we didn’t think that anything would come of it.”*

(#7, G1P0, age 18)

*“I took contraceptives I did them continually, Microgynon, so not to have a period”*

(#1, G1P0)

*“I: So they never did a pregnancy test or even suggested it to you?*

*No, no, no, and I’d been on the Pill so it wasn’t something I’d thought about and I’ve never had regular periods so it didn’t occur to me to check back or anything”*

(#16, G1P0)

*“But protection was used”*

(#24, G1P0, age 15)

For one woman with learning difficulties, this was her second late booking pregnancy and she had experienced contraceptive failure with both.

*“Last time were alright, it were just weird because I went for the Depo and they told me I were 25 weeks pregnant. I got caught on the Depo and I didn’t know that, and I took the pills and I got caught on the contraceptive pill this time with… and I didn’t know with this one.”*

(#27, G2P1, learning difficulties)

Another multigravid woman assumed breastfeeding would probably provide her with enough contraception. Her pregnancy was unplanned but not unexpected:

*“I was breast feeding and I know it’s not a full protection but I thought oh, you know, it’s something. I thought I’ll just see what happens.”*

(#11, G4P3)

***5.2.1.2.4 Not planning, expecting to be pregnant***

Seventeen of the 27 women in the study stated that they had not planned to become pregnant, and for another six this was implied. Other women suggested that their pregnancy was intended but mistimed. As such, many of these women did not have a pregnancy ‘mindset’ so were not expecting the symptoms of pregnancy and expressed ambivalence towards the idea of being pregnant. This, in combination with a lack of pregnancy knowledge and experience amongst primigravid women, had affected how long it had taken some of them to confirm they were pregnant:

*“I think if I had wanted to have a child as well I probably would have been looking for the signals as well, but I think even now why didn’t I know, that was the last thing”*

(#1, G1P0)

*“I think sometimes you might have symptoms or things change, you can say it’s just the way I am, you might not associate that with being pregnant, even though we wanted to start trying and it was something that, it was in the forefront of my mind in the next months this is something that was going to happen anyway, it didn’t even occur to me in, maybe not knowing the signs, that could be something you’ve got to look for”*

(#17, G1P0)

### *5.2.2 Knowing*

A large group of women in the study knew that they were pregnant at an early gestation however, for a variety of reasons, delayed accessing antenatal care. These women fell into two groups: i) those that wanted to avoid care and ii) those that intended to postpone their antenatal care until a future, more convenient, date. In some cases this was a passive avoidance or postponement, in others women actively chose to conceal their pregnancies or delay access, though few women concealed their pregnancies from everyone. The boundary between avoidance and postponement was sometimes indistinct: the number of women avoiding antenatal care was small (five), however for some of these women what started as avoidance became postponement, as their pregnancy progressed and more people became aware.

### 5.2.2.1 Avoidance

***5.2.2.1.1 Fear and ambivalence***

**Delay in confirming the pregnancy**

In some cases women expressed ambivalence about confirming their pregnancies, with some stating that they had been in denial about their situation. With all of these women there was the suggestion that this had contributed to a delay in accessing care, whether by avoidance or postponement.

*I: “How did you find out you were pregnant?*

*I just thought cos I were putting on a lot of weight and I wasn’t feeling very well. So I just thought that I’d just do it myself.*

*I: So did you do a pregnancy test?*

*I didn’t, no, because I didn’t want to think about it.”*

(#7, G1P0, age 18)

*“I had an idea about two months before, but I did a pregnancy test and that didn’t work, it didn’t say negative or positive, just no result come up. I did two [pregnancy tests] and they weren’t positive.*

*I: They were both inconclusive?*

*Yes… So then I just put it to the back of my mind, and my mum mentioned it again in a little while and I did another pregnancy test and that worked.”*

(#14, G1P0, on methadone)

*“I think just in denial really. I don’t think I was – I didn’t really want to be pregnant at that time I don’t think. I was trying to lose weight and it was like selfish reasons really… in the back of my mind I always knew really but at the same time I didn’t want to say anything to anyone, I didn’t want to think about it”* (#11, G3P2)

**Fear of the ‘consequences’ of pregnancy**

Women experienced a huge range of emotions when discovering they were pregnant. Fear and anxiety about a frequently unplanned pregnancy were common and influenced a woman’s ability to access care. Some women chose to avoid antenatal care, having no clear plans to access it. This process of avoidance lasted from weeks to months, though whether this was a passive or active process was sometimes unclear. The primary theme associated with avoidance was fear, with some women fearful of the social consequences of the pregnancy. One substance-misusing woman, whose other children had been removed and adopted, feared the response of professionals such as her GP and removal of the baby by social services. She avoided antenatal care until being admitted at 33 weeks gestation with a suspected Deep Vein Thrombosis.

*“I was scared at first, because of what happened before [three previous children removed]. It was a bit of a shock, you know what I mean, when, when I sort of, like, really knew, the shock, I was scared.”*

*“Some doctors are nice, some are horrible. Just suppose they know you take drugs, treat you nasty, not very nice.*

*I: Do you feel like people are judging you?*

*Yeah.*

*I: Has that ever put you off going to see the doctors before?*

*Yeah… it does stop people from going to the doctors when they’re like that.”*

(#25, G4P3, on methadone)

Some younger women were concerned they would be judged and labelled as irresponsible after becoming pregnant unexpectedly. For three young women, all teenagers, it was the reaction of their families that they were fearful of, combined with the worry of the stigma and the negative stereotypes that exist surrounding teenage pregnancy, that led to them to avoid accessing antenatal care. In some cases this led the woman to conceal her pregnancy for a significant length of time:

*“Probably when I was seven months pregnant, it came out. I didn’t want to tell my mum. It was very bad [her mum’s reaction].”*

(#5, G2P1, previous concealed pregnancy aged 17)

*“I keep it a secret at first, from my Mum, then I told her. She’d go mad at first. And my Grandad, my Grandad and my Mum”*

(#23, G1P0, age 17, learning difficulties)

One young woman put her delay in accessing care (she finally booked at 36 weeks gestation) down to a combination of this fear and having other things going on in her life:

*“I knew you had to go for all the tests and things like that, but I just couldn’t go. Cos I was only 17, just thought I couldn’t tell anyone, thought people’d look at me like…I don’t know, just like I was, irresponsible, yeh”*

*“I didn’t want to think about it. So I thought I’d just put it to the back of my mind, cos I was at college and I am in my last year and had quite a bit to do, so I thought I’d just forget about it… It were finding the right time to tell her [mum], cos I were at college… I didn’t know how she’d take it.”*

(#7, G1P0, age 18)

**Ambivalence towards pregnancy and antenatal care**

Another reason for some women avoiding antenatal care was the significant ambivalence they described feeling towards the pregnancy and towards antenatal care. Consequently, there was active avoidance of antenatal care despite early symptoms being apparent to the pregnant woman and sometimes friends and family, who tried to influence them. These women were often from the most vulnerable groups i.e. women with a history of substance misuse and learning difficulties:

*“I didn’t go see no-one, because I went with A to his house, in Chesterfield.*

*I: Did you have an appointment to go?*

*Yeah, I missed them, just didn’t want to go… I was with my boyfriend and I couldn’t be bothered to go.*

*I: Right, so there’s nothing that we could have done, or anybody else could have done, that would have made you go and see the midwife sooner?*

*No (laughs).”*

(#23, G1P0, age 17, learning difficulties)

***5.2.2.1.2 Coping mechanisms***

**Antenatal self-care**

Alongside the denial and concealment demonstrated by some of the women in the study as coping mechanisms, a process of antenatal self-care was evident amongst a few women who avoided and postponed their antenatal care. One young woman, though a primigravida, described an intuitive process of ‘do it yourself antenatal care’ as a personal coping strategy, and a substitute for conventional care. This included self-checks, for example observing the baby’s growth and movements, and was based on her theoretical knowledge of pregnancy from college and her experience from observing other family members.

*“I did look on posters and things like that and my cousin had just recently had a baby as well so I was looking at how she was with her pregnancy, things like that, how she coped with it… Because I knew quite a bit anyway I kept referring to my books and just checking and thinking ‘oh yeh it’s alright’ so there was nothing bad. Bits I’d got from college and things like that, so obviously I was thinking I can feel this so I don’t think there’s anything wrong”.*

(#7, G1P0, age 18 years)

This particular woman admitted that she had made an active decision to conceal her pregnancy, and had decided to that she wanted to be in control about when to disclose the pregnancy to her family.

*“He [baby’s dad) did give me advice and things like that but I just thought well, I’ll do what I want to. He were going on at me all the time to tell my mum and everyone. I just said I’ll tell them when I want to tell them.”*

(#7, G1P0, age 18)

### 5.2.2.2 Postponement

The number of women postponing their antenatal care until a future date was larger than those avoiding care (11 women), with a broad range of themes emerging, including both passive and active postponement of care. For this group of women, it was evident that although they didn’t access antenatal care on time, their intentions were to always access it ‘at some point’ in the future.

***5.2.2.2.1 Fear and ambivalence***

**Fear of the ‘consequences’ of pregnancy**

Like the women who avoided care, fear and ambivalence were prevalent themes amongst the postponing women, presenting in different ways, as women considered the consequences of their pregnancies. Some planned but then postponed antenatal care as they struggled with the consequences of the pregnancy for themselves, and feared the reaction and potential judgement of family members. Again, unplanned or mistimed pregnancies planning were common amongst this group of women. For example, one woman admitted her ambivalence towards an ‘inconvenient’ pregnancy, discovered just before a long family holiday. She acknowledged that she had been in denial and felt that official confirmation of the pregnancy would influence her physical and psychological wellbeing, as she would start ‘feeling’ pregnant and this would spoil her holiday.

*“I went on holiday abroad for three months and while I was there I was having these sort of symptoms but everyone kept saying ‘oh have a test, have a test’ and I said ‘no, because if I know I am then I’m going to start feeling ill and I just want to enjoy my holiday, get home and then I’ll find out for sure’. I could tell I was [pregnant] but at the same time I was trying not to think about it”*

(#11, G3P2)

Two other women considered how they might cope with another baby, having recently given birth.

*“It was still going in my head: what am I going to do? How am I going to cope? It’s too hard to cope with tired toddlers. I don’t know, it just took me ages to go to the GP.”*

(#8, G3P2)

*“I was really in a bad state, depressed, we’d just moved here and looked for work and we are planning to go back home for a holiday, two months, and I’ve got some plans about studying and you know, when I found something was… I was depressed for three weeks, it was like you know, run around, I lost my appetite, I stopped eating… how can I be, my life with two children just being, you know, being close to each other, yes and I have to study hard to join the university, it’s so difficult.”*

(#18, G2P1)

For one of these women an unexpected pregnancy also brought back disturbing memories of recent traumatic childbirth:

*“It was going through my head what am I going to do, how am I going to cope, because my last was a c-section. A caesarean, and it was terrible… I just couldn't go before, I was so frightened, I didn't want to think about it… I knew I should go but I just couldn't, I just kept saying 'I'll go next week' and then the weeks went by and I was busy with the children and I just put it to the back of my mind, I didn't want to think about it, because of last time, because it was so horrible. I wasn't ready for another baby I think. I didn't know how I was going to cope.”*

(#8, G3P2)

Another woman explained how it was her fear of blood tests which had contributed to her postponement:

*“I mean I’m scared of having my blood taken, I’m petrified, I wouldn’t have gone if I’d had to have that took.”* (#2, G1 P0)

***5.2.2.2.2 Considering termination***

Another key reason for women postponing access was because they were considering termination. Four women planned to have a termination but couldn’t go through with it for a variety of reasons. For three of them it was because they were already at quite an advanced gestation when they found out that they were pregnant. This led to a delay in accessing antenatal care whilst women considered their options: women only ‘booked’ when the decision to continue with the pregnancy had been made. This resulted in an almost passive acceptance of antenatal care, as when the pregnancy became ‘inevitable’ women felt that they had no choice but to access care.

*“[going to the GP] were to get things sorted and that and, like, see what the options were but, obviously, there weren’t any options at all.”*

(#22, G1P0, age 15)

*“so I went to the hospital and they did a scan and actually said that I was eighteen weeks so it was quite a surprise and even then having done that I was actually going to go for a termination and the difficulty came when they said they couldn’t do the termination because I was too far gone, I was over eighteen weeks and the stop is 18 weeks unless there is medical problems so they gave me a number to phone and I started getting quite upset about the situation because by the time the termination could have taken place in London at one of the clinics I would have been one day off 24 weeks… I said I don’t think I can go through with it and that took like couple of weeks umming and aahing to myself so then I went to my official Ante Natal appointment it would have been week 22 and there I had all the assessments and I thought I couldn’t have gone through with it”*

(#1, G1P0)

*“I didn’t know how I were going to cope, so I were going to go have an abortion. I couldn’t go, I couldn’t go ahead with it. I thought, fine, I won’t be able to cope now, but when a few years have gone I will regret it. I was thinking about it a lot, whether it’s a boy or a girl… so I thought I can’t do it. I can’t, it’s killing something inside you, and I thought no I can’t.”*

(#8, G3P2)

*“I were just waiting for, to find out my options and stuff but, bit late on to get rid of it and I ain’t got heart to put it up for adoption”*

(#24, G1P0, age 15)

***5.2.2.2.3 Pressure to have a termination***

**‘Protecting the pregnancy’**

For one woman there was active postponement of her antenatal care until she was ‘safe’ from a perceived obligation to have a termination, after a negative response to the pregnancy from the baby’s father. This woman admitted that she didn’t want to be forced into a decision but wanted to choose for herself whether to carry on with the pregnancy. She acknowledged that she had taken responsibility for the pregnancy and would accept the consequences of her decision, even the judgment from healthcare professionals she met.

*“I knew that S, my husband, didn’t really want one, so I kept it to myself for a while hoping that maybe it was wrong in one way and in another way it wasn’t, but, and then when I did tell him, he wasn’t happy at all and we went back to the doctors... I cancelled the appointment because I really just did not want to go through with it and then I just kept putting off going back to the doctors and going back to the doctors thinking, I’ve put it off that long, they’re not going to be able to do anything about it and we will have to carry on… I really think it should be my decision, not just his, that’s why I didn’t present til later. I’ve thought about it and if the baby is born and there is anything wrong with it then it is my fault, but there again, it was what I had to do to keep this baby. It was a hard decision but it were one that I had to do. So, maybe they do look down on you but, there again, it’s my choice, my body and my baby.”*

(#26, G2P1)

***5.2.2.2.4 Early antenatal care not a priority***

**A good past experience of pregnancy**

For some of the postponing women their perception of the value and priority of early care, and ultimately convenience issues, affected their decision to access care. For many this was influenced by past experience, with some multigravid women feeling well antenatally and therefore choosing to seek care at a time convenient to their own perceptions about the appropriate timing of antenatal care. An acceptance of or fatalistic attitude towards the pregnancy meant some were in no hurry to access antenatal care, usually influenced by a good past experience of pregnancy. For many of these women, it appeared that underlying this postponement was the belief that antenatal care was only needed if they felt unwell. For example, one woman trusted her considerable past experience of normal pregnancy:

*“they’ve all been normal thank God and I think if there were any previous problems with them I would have probably, you know, found out but I just felt healthy, I felt OK, you know, I just felt normal basically and I suddenly saw my belly getting a bit bigger and my clothes weren’t fitting as much as when I first arrived there. That’s it basically… I thought hopefully when I get home everything is going to be all right… they’d all gone all right thank God so I just assumed I’d be all right.”*

(#11, G4P3)

Several other multiparous women also expressed confidence in and acceptance of their pregnancies, based on previous knowledge and experience and their general wellbeing.

*“I was thinking about after the baby was born. Because I’d got experience of being pregnant so it’s probably, it’s ok… I knew about everything to do with pregnancy.”*

(#19, G2P1)

*Partner: “There wasn’t any reason, we just didn’t go! (discussion in Russian) She felt very well, that’s why. She’s got experiences, it’s going to be fine… She was worried about the baby but because she felt very well, that’s why she didn’t go (discussion in Russian)… whatever was going to happen, it will happen, that’s why… According to her experience, because it wasn’t the first one.”*

(#20, G4P3)

*“if I’d have felt that there was something wrong I would have probably have gone, but because I felt alright in myself, I thought I was better off waiting that little bit longer… I knew what to look for and stuff, like I said, if I’d have been worried I’d have gone”*

(#26, G2P1)

**Previous concealed pregnancy/late booking**

Four women reported booking late in a previous pregnancy and hence had not (and in one case never) experienced the recommended early antenatal checks. Two of the women said their previous experience had made them more relaxed about what to expect in early pregnancy and about not needing care.

*I: “this time you’re twenty weeks now when you’re having your first appointment, was it so late with the other boys?*

*partner: Yes, no, with the second one it was the exact…*

*woman: Third one.*

*I: The third one?*

*partner: (laughs) Ah yes, the third one was the same (both laugh)… he was six months I think!*

*I: really!*

*partner: Yeh, or eight months!”*

(#20, G4P3)

*“Yes… I didn’t actually tell anybody I was pregnant, that’s probably why I wasn’t so worried about it in the early stages”*

(#5, G2P1, previous concealed pregnancy age 17)

In addition, three other women had direct family experience of late booking and/or concealed pregnancies.

**Acceptance**

For five women this acceptance of the pregnancy reflected their instinct, a perception of pregnancy as a ‘normal’ healthy state of being, and their religious beliefs. This was usually, but not exclusively, associated with previous pregnancy experience. These women suggested that they were less interested in accessing early antenatal care because antenatal screening for foetal abnormality, a significant part of this, was less important to them.

*“We are Muslims so we are not allowed to have abortion. But after 40 days from the pregnancy it’s not allowed for you, and before the 40 days you should have some serious problem like your heart’s not good or the baby is very damaged, so it’s not just, I don’t want it, because I have already one child or like that, so I didn’t think about that at all. I have to accept that really and thank God for it.”*

(#19, G2P1)

*“I’ve never had that [screening] before. I don’t think I’ve ever chosen to have that before. Maybe with one of them but because of, you know, religious reasons and everything I just feel that if there is a disability then it won’t change my mind about having a baby or anything… I just believe that if it was going to happen then I’d get through it. I just hope that everything’s all right, you know, everything’s healthy. About them tests, I’m not that really bothered.”*

(#11, G4P3)

*“And I would say to myself, I shouldn’t worry even if I don’t have the test. That because I feel so well I should expect to have a healthy baby, and in some way I felt sometimes in the past they didn’t have all these tests”*

(#9, G1P0)

**Antenatal self-care**

Another woman, with previous pregnancy experience, described her antenatal self-care, which again included self-monitoring, observing the baby’s growth and movements, and staying ‘well’ and healthy. For this particular woman the care was perceived as a temporary measure, a coping strategy and means of control, promoting and monitoring the healthy progress of the pregnancy until she felt able to access conventional care, when the termination her husband wanted was no longer possible.

*“I’d done everything that I could possibly do myself because obviously with having A, I knew what you could eat, what you couldn’t eat, this that and other, so I followed everything religiously, took my Pregnacare every single day, made sure I drunk plenty, had plenty of rest, so I carried out what I knew, but obviously I’d had no checks to make sure everything was progressing alright, I’d had movement, I noted down when I’d had movement and things like that, so I’d done all I could … [friends] did try and say to me ‘go and see the doctor’ and I kept saying ‘no I’m fine, I’m doing everything that I should be doing’,”*

(#26, G2P1)

**Being ‘on the move’**

In some instances, being ‘on the move’ and not in a familiar environment or stable place acted as a barrier to women accessing antenatal care on time. For five women this was the primary reason for their late booking. Women described practical difficulties and convenience issues in making appointments, work pressures and the social isolation of being away from home. Overall, the responses suggested a lack of understanding of the 'portability' and timing of antenatal care and its value in general.

For example, a few women were travelling abroad or working elsewhere in the UK and described waiting to access antenatal care until they felt settled in a place of trust or safety: ‘home’. One woman, on a three-month family holiday to her husband’s country, had admitted a reluctance to confirm her pregnancy. She expressed a distrust of foreign hospitals and preferred to wait until returning to the UK.

*“It was such a long way away, I don’t know, I just prefer here and I trust the hospitals here and everything. I just didn’t want to ruin my holiday feeling ill with morning sickness and things like that, so I just left it… I was pretty sure but I just wanted to know for definite, but not there… I just trust these hospitals because I’ve had all three of them here. Maybe if I lived over there, you know, of course I would have gone but I thought no, I’m coming home soon so everything should be all right.”* (#11, G3P2)

For one Arab woman home now was the UK, where her first child had been born. She acknowledged that she had considered accessing care whilst visiting family in her home country, but that it was inconvenient.

*“I was thinking about it but because it was like a holiday, visiting, doing camping, lots of social activities, so there was no time, but I was really thinking about doing a scan.”*

(#18, G2P1)

Another woman, working in another city temporarily, described the isolation and stress of her working situation and how this had impacted on her ability to access care. She was reluctant to access care in a place she didn’t know and when she knew her baby would be born in Sheffield, so had waited to return home.

*“I didn’t know York, I didn’t have no transport when my partner was out at work every day. I didn’t know where buses used to go… I think if I was in Sheffield at the time I probably would have [accessed care]. Because I wouldn’t have been working all the hours of the day. We were working and just totally stressed as well because we didn’t know anybody in the area.”*

*“I didn’t want to change my doctor, because I’m going back home to my own house. I wanted to have my baby in Jessops, I didn’t want to have my baby in a town that I didn’t know. I weren’t registered, I weren’t going to live in York. I was coming back.”*

(#5, G2P1)

Similarly, a woman moving to another northern city from Sheffield, and back again in early pregnancy, identified delays caused by changing locations and GPs as the reason for booking late.

*“It were because I moved to Manchester, I was child-minding and then found out I was pregnant but I’d just changed doctors to that one and then I came back to Sheffield and I had to mess about changing doctors and stuff all again and things. That’s why it were a bit late”*

(#3, G2P1)

For another woman, whose family were recent migrants living in temporary accommodation, there was an expressed need to ‘get settled’: to sort out their home and locate local services before adding the additional complexity of antenatal clinic appointments in different locations across the city.

*(discussion in Russian between woman and partner)*

*Partner: “she was going to come, soon, because we changed a few places and we didn’t know where we were going to stay… we were waiting to move to this temporary accommodation, where we live at the moment, and she was going afterwards when we got this house, she was going to visit.”*

(#20, G4P3)

The same woman was the only person interviewed who mentioned practical difficulties which had further influenced her ability to access antenatal care. These were linked to the family’s changing location but also language limitations and the necessity to attend appointments with their three young children.

*“Partner: I wanted her to go to see a doctor, but for some reasons she always, she wanted to go but something happens then… it’s difficult, because when you go with the whole family, children, it’s very… (discussion in Russian) and there is no place to leave them, in nursery or somewhere, to come. This is the problem… she doesn’t know where to go, how to get there.”*

(#20, G4P3)

***5.2.3 Delayed***

**5.2.3.1 Professional failures in primary care**

The delayed group of women had been aware from a relatively early stage that they were pregnant and were willing to engage in timely antenatal care. However, due to a combination of reasons they had booked late. One reason for this was perceived professional failures which occurred within primary care. For nine women, both primigravid and mulitiparous, there were examples of GP/nurse misdiagnosis in primary care which contributed to a delayed presentation. For example, attribution of pregnancy symptoms to urinary tract infections or other lifestyle/medical causes led to several primary care consultations before pregnancy was confirmed for one woman:

*“I began to feel really sick and really unwell and lo and behold I was pregnant. But I’d gone to the doctors and I’d gone to see the nurse and I’d gone back repeatedly and they said because you’ve stopped drinking, stopped smoking it’s just all the toxins and such like coming out so nothing to worry about… they’d convinced me because I had a completely new lifestyle, a new job and nothing to worry about so –*

*I: How many times was this that you’d gone to see them feeling unwell?*

*Och, maybe five or six times… the doctors had been feeling my stomach all the way up until the last time and they never… they’d just said I had a kidney infection.”*

(#16 G1P0)

This misdiagnosis was subsequently compounded by the opinion of the local midwife who insisted that the woman wasn’t pregnant, despite a positive pregnancy test, causing fear and anxiety.

*“I went to see her, she said ‘oh you’re not pregnant’, she says ‘I can’t feel anything, the doctors don’t know what they’re talking about’, she says ‘I don’t even know why you’re here’… And she said ‘oh I don’t know if you are actually pregnant, are you sure’ sort of thing. Maybe a young girl making it up? I don’t know, just the impression I got. I’d left my first midwife appointment and I thought ‘well maybe, there’s something wrong maybe, It’s a tumour’, you know, you begin to think about, the doctor can feel something in your stomach and you’ve been feeling very unwell.”*

(#16, G1P0)

For one multigravid woman, in her late 30s, it was the GPs suggestion of menopause rather than pregnancy that delayed diagnosis and referral for antenatal care:

*“I went to the doctor’s about this because I was quite concerned and they thought I was going through the change… they did all these blood tests and that to see if I was on the change or was I diabetic or things like that.*

*I: So they didn’t really know either?*

*No, they didn’t know”*

(#14, G5P4, age 37)

One primigravid woman with PCOS had ovarian ultrasound scans arranged by her GP when she was, in fact, six weeks and four months pregnant. The pregnancy was apparently not detected, which the woman remained incredulous about:

*“I just hadn’t been on for six month, so they went and did that internal scan, but I must have been pregnant when they first did that and they’ve not known and then I went back again to have another one and they didn’t see ‘owt then, they just saw, like, little eggs they said. And I must have been, what, last one I had I must have been four month pregnant and they’d not found out. That's what we can’t get over now, I’m just like thinking, aaaahhhh, How could they not have known?”*

(#22, G1P0, PCOS)

In one young primigravid woman’s case the midwife had not attempted to ascertain how many weeks pregnant she was, despite being uncertain of her dates. As a result the midwife underestimated the gestation and the woman received a routine appointment approximately eight weeks after the initial pregnancy test, booking eventually at 20 weeks gestation

*“I: how many weeks was it from doing the pregnancy test to actually going to the hospital and having your first scan do you think?*

*About two months.*

*I: when she [community midwife] saw you here or at the GP’s, did she say how pregnant she thought you were?*

*No.*

*I: And did you tell her how pregnant you thought you were?*

*No, I just said I didn’t know how long.*

*I: Did she feel your tummy or do anything?*

*No.*

*I: Right. But you weren’t showing at all?*

*No.*

*I: Right. So she didn’t say ‘oh I think you’re three months’.*

*No, nothing like that”.*

*I: She came to see you two weeks later?*

*Yeah.*

*I: And when she came to see you at home did she feel your tummy or see how pregnant you were?*

*No.”*

(#15, G1P0, age 16)

Another woman, who’d chosen not to access care to protect her pregnancy from her partner who wanted her to have a termination, mentioned that her midwife had known she was still pregnant but had decided not to do anything to encourage her to book for antenatal care.

*“she’d [community midwife] put me to the back of the pile thinking that, well she’ll come and get in touch with me, and she did say ‘I’d just about given up that you were going to come.’”*

(#26, G2P1)

Some women experienced bleeding in early pregnancy which had led either to the assumption of complete miscarriage or mis-estimation of gestation by health professionals. This consequently led to slight delays in referring for antenatal care. However, these typically occurred very early within the first trimester and once the pregnancy was confirmed timely presentation to antenatal care could have been achieved.

*“I didn’t know I was pregnant, so, and I couldn’t know because I was still having some kind of bleeding, so I thought it was probably my period. I had the first visit to the GP. After eight weeks, it was the first days of week nine I guess, and I was asked to have another appointment for the next week to have a test to verify that I was pregnant. Or that I was still pregnant because of the light bleeding. It could probably be a miscarriage”*

(#9, G1P0)

*“I started with some bleeding and I had about a week of continuous bleeding, went to my GP and explained that I had done a test, he didn’t do another test, he just said ‘have you done a test?’ I said ‘yes’, explained the bleeding and he said ‘well I think you have probably miscarried so there is nothing we can do at this stage, come back when you are seven weeks pregnant‘, which would be another couple of weeks”* (#13, G1P0)

**5.2.3.2 System failures**

Eight women were delayed by the referral process in primary care, sometimes as a result of delays between GP and midwife appointments, slow referral procedures or professional failures. This often compounded delays due to late initial diagnosis of pregnancy. Some of the women interviewed were highly aware of what needed to be done and expressed frustration at the bureaucracy of the ‘system’ and the resulting delays, and its impact on antenatal screening:

*“And with me having to change doctors and stuff and mess about and have to wait too… then you have to go and see a midwife and then get referred to a GP and then go and have a scan, and they have to write to hospital and they have to write to you, and it does take a long time, it took three weeks from when I seen my midwife to going to have a scan.”*

(#3, G2P1)

*“I eventually did see the midwife and she worked it out I was 18 weeks pregnant, at that point. So if she knew I was 18 weeks pregnant at that point why didn’t she phone me through for a quick scan, instead of waiting 3 weeks in the post for it to come back here? So when I came here I was 22 weeks. I was really upset then because I couldn’t have a proper scan. And it seems like these weeks have been wasted through bureaucracy, rather than getting to the point of it all.”*

(#5, G2P1)

*“When I asked for the appointment and they said it was Monday the 13th I knew it was too late for blood… I just knew when I was at the appointment that these two blood tests – Spina bifida and Down’s Syndrome – were not possible any more because it was too late.”*

(#9, G1P0)

Other system failures also occurred in secondary care, for example wrongly scheduled appointments or letters not being sent and/or received, despite the efforts of GPs and midwives.

*“I got it within that two week period, which would have been between about week 11 and about week 13, but it came through with the date and the date was actually - I can’t think of the date, I have got it in my diary, but it was exactly 21 weeks on that day - it were a Tuesday and it made me exactly 21 weeks”*

(#13, G1P0)

*“they did try and she said ‘we want to do it as quick as possible’ and then I didn’t hear anything, so I phoned her back to see if I had missed them or - and she said that they were still trying to get me an appointment, she tried to fax it through, because I was so far on, but I were 27 weeks before I even had my first scan… they had sent me a letter out, well they said they had sent me a letter out but it had basically gone - I hadn’t got the letter”*

(#10, G1P0)

**5.2.3.3 Women’s knowledge and empowerment issues**

The women affected by these failures in primary and secondary care were primigravidas or in one case a multigravid woman who had booked late before. Despite these being system and professional failures a key theme underlying the reason for delay was empowerment, as many of the delayed women were relatively passive in accepting delayed appointments and typically did not challenge health professional misdiagnosis of early pregnancy symptoms. Though often acknowledging that something ‘wasn’t right’ about the delayed appointment, the women had a lack of knowledge of pregnancy and the antenatal care ‘system’ and appropriate scheduling of appointments, or language difficulties which prevented them from challenging delays. Some women openly admitted their lack of knowledge:

*“I had been a little bit concerned but I had never had a baby before, we hadn’t really got any babies in my family and my mum’s next door neighbour she had three children and she didn’t seem to think it was very strange at all that I had not had any [appointments]”*

(#13, G1 P0)

*“I didn’t see anybody until seven month [in previous pregnancy] so I don’t know what they did in early pregnancy.”*

(#5, G2 P1, previous concealed pregnancy)

*“I aint got a clue [about antenatal care]! It’s me first one so I wouldn’t have a clue.”* (#6, G1 P0, learning difficulties)

*“I didn’t know how these things work here.”*

(#9, G1P0, Mexican)

Where they did challenge the delay, two women expressed acceptance of the reasons given primarily due to lack of knowledge and an inherent trust in the professional’s (wrong) opinion on the delay. They subsequently appeared to rationalise the delay that had occurred.

*“I thought ‘well this seems a long time away’… I said ‘but I have got my appointment, but it is this date, actually it does actually make me quite late’ and she said ‘oh, that’s a little bit strange, I am not quite sure why that is, there must be a big influx of people at the moment’ and she said ‘well don’t worry about it, you are supposed to have a scan early on and then one at 20 weeks, now obviously you will have missed that, but what I would think they will do is give you a detailed scan when you go in and it is 21 weeks’… I kept thinking ‘well it seems a long time for me not [to be seen]’… I could have pushed it more at week 15 if I had thought about it, if I had had more knowledge, but I foolishly thought because I had been given the date that that was it. I wasn’t as on the ball as I would have been and to be fair, I trusted the midwife”*

(#13, G1P0)

*“I told her that according to the information in the book and leaflets, the blood tests, I needed two blood tests, one that week and then another in the later weeks, but I was not going to be able to have those on time. She [the midwife] told me that even if the tests were a bit later I was going to be able to have them. And I said well maybe this is not the optimal time to have them, but I am still having the possibility of having those tests. So I tried to leave that. Maybe I could have those tests later, but maybe they were not the optimal time to have them but that it was possible.*

*I: Did you feel reassured by what she said?*

*Yes. I didn’t feel worried about them. I thought ok, this is just going to be later.”*

(#9, G1P0, Mexican)

Another reason for some women’s acceptance was because they felt well and felt that there was no need to challenge the delay, or they were influenced by advice given by friends:

*“Something that prevented me to do something was that in some way I have felt fine, I haven’t had any kind of nauseous or problematic symptoms. I feel almost as normal, except for my tummy’s growing. I felt really well. And I would say to myself, I shouldn’t worry even if I don’t have the test. That because I feel so well I should expect to have a healthy baby and in some way I felt sometimes, in the past they didn’t have all these tests… they [friends with babies] always told me that it’s a very good signal that I don’t have these symptoms and that it would be very likely for me to have a very healthy… well at the end you don’t know but they sort of gave me this positive messages and in some way I also believed. I also thought that there was no problem about having the tests a little bit later, as far as I had them, it was going to be ok. I never thought that this delay would affect or impact on something.”*

(#9, G1P0, Mexican)

*“Yes, I think I wait three months [for an appointment]. I ask the GP why long two months and they sent the paper from this hospital on 28th January. I think I’m healthy, I’m ok, just I’m wait for the 28th January, because I’m ok, I’m alright.”*

(#19, G2 P1, Eritrean)

Two women also rationalised their acceptance of the delay by acknowledging that because the pregnancy was unplanned or mistimed they were not in a pregnancy mindset and not as well prepared for pregnancy as they might have been. This had affected them focusing on the number of weeks they were pregnant and what care they should have been receiving:

*“I didn’t maybe focus on it perhaps as a mum who had been planning her baby for two years and it arrives and she is absolutely spot on and she has read every book that there is. I think probably if I had I would have been thinking ‘hang on a minute I should have had this at 12 weeks’.”*

(#13 G1P0)

*“I guess if you’re planning a pregnancy then you get all the information beforehand and you can read in a book about it, and think “well yes I need to go to the doctors then, then, then”, but that weren’t pinpointed in my brain. If I’d been planning I would have known what to do”.*

(#5, G2P1)

***5.2.4 Triggers for accessing care***

**5.2.4.1** **The influence of mothers**

For many of the primigravid women, particularly those avoiding care, it was their mothers who were decisive in helping them confirm the pregnancy and organising care. Sometimes the women saw this as a positive thing, however others were fearful of a negative reaction or annoyed with something they saw as interference:

*“She [her mum] just asked me if I thought I were and I said I weren’t sure, so she went and got a pregnancy test for me… my mum did, she went through it with me. Just what to expect really.”*

(#14, G1P0)

*“My mum did think but she didn’t want to say anything, because she didn’t want it, for me to feel like I were anything bad, or just like to insult me or anything… But she just couldn’t ask me so she kept putting it to the back of her mind and then one day she just thought I need to know so she just came and asked me… It’s a positive thing and I thought they were going to be horrible but she’s not, she’s been really good about it, she’s really excited”*

(#7, G1P0, age 18)

*“I didn’t want to tell my mum. It was very bad [her reaction]. I had to tell her because I was just going out of my brain really.”*

(#5, G2P1, previous concealed pregnancy)

*“My Mum telled me to keep going, she were getting on my nerves.”*

(#23, G1P0, learning difficulties)

**5.2.4.2 Needing positive/official confirmation of pregnancy**

For the women who postponed their care, it was the women themselves who eventually decided that they needed antenatal care, and particularly confirmation that everything was well with the pregnancy. There were key triggers for access: two women acknowledged that feeling the fetus moving made the pregnancy ‘real’ for them and therefore antenatal care more urgent.

*“I: So when did the baby become real then, do you think?*

*After making movement. When I went to my country. About 2 weeks there I felt some movement”*

(#18 G2P1)

*“I was curious and wanted to know everything was alright, and I started to feel the baby moving, so I went to the GP.”*

(#8, G3P2)

Other women became worried that they might become too late for any care, that they needed to get into ‘the system’ and make their pregnancies official:

*“I’d done what all I could, but I just thought, I’ve got to go now otherwise it’s going to be too late, as in to get any care.”*

(#26, G2P1)

*“I thought if I am quite late then they might not give me anything. I didn’t know what they were going to do. I thought if I’ve missed the twenty weeks period they might not offer me a scan and I really wanted that… I was so worried thinking this time what if I’m really far and what if I go into labour before even the hospital has registered me or anything?... I did start to get a bit worried, I thought no, I need to know for a fact that that baby’s in there and it’s got a healthy heartbeat and get me on the register”*

(#11, G4P3)

***5.2.5 Attitudes towards having booked late***

Women expressed a range of attitudes towards their late booking. Most of the women interviewed were aware of the optimum time to access antenatal care and were clear that they would have booked early if they had known. This included young women and primigravidas. Many expressed regret at not accessing care earlier. Several of the women, both those who had known they were pregnant and those who hadn’t, and one woman’s husband, acknowledged the desirability of attending for early antenatal care. They were clear about what they would have done if circumstances had been different.

*“If I had known I would have come virtually the first couple of weeks I knew, if you know what I mean, but as I say, I had no clue, no idea. I would have gone straightaway, yes, I would advise anybody to do that straightaway, yes.”*

(#12, G5P4)

*“If I did know and if I did keep it, then I would have gone to see someone at two to three months, but I didn’t know”*

(#24, G1P0, age 15)

*“When you first find out really, if you find out early on, that’s the best time [to go]. Around eight weeks? Probably it is when the baby starts to develop and things.”*

(#14, G1P0)

*“The best time to find out is about 12 weeks, something like that, or a bit earlier, before that. There’s some find out about that week, don’t they? They have a scan about 12 weeks, and they find out a bit earlier. But I didn’t even know how far I were.”*

(#6, G1P0, learning difficulties)

One multiparous woman suggested this was particularly important when pregnant for the first time:

*“When you realise that you are pregnant, you should go, immediately, because first times, in general, pregnancy I think it’s something you should take care about… you might discover something that you might regret after.”*

(#18, G2P1)

There was further recognition of the accepted convention of early care, as opposed to its intrinsic value:

*“I’d go straight away. If I’d have found, if I’d have known, if I’d have had regular periods and I’d have missed one, I’d have gone straight away and then I’d have done it from then. I think it, I just, I think it’s because that’s what everyone does, isn’t it? From when they first find out, that’s when it all starts, isn’t it.”*

(#22, G1P0)

*Partner: “But she should have gone earlier I think, because, anyway, four months is late, you need to go earlier to see what, what’s correct.”*

(#20, G4P3)

Another woman expressed her view of accessing antenatal care as the reassurance of ‘getting things sorted’ and making the pregnancy ‘official’.

*“I would have gone straight away. As soon as I found out I was pregnant I would have gone. That’s just me, I just like it, I like to start from the beginning, let them talk me through it and get everything sorted…get me on the hospital register and things like that. I think it's nice just to have that regularity.”*

(#11, G4P3)

However, as one of them observed, their understanding of what was theoretically ‘correct’ and desirable in terms of antenatal care might bear little relation to what had happened in their own pregnancy and the choices they had made:

*“I would advise anybody who knew to go. I just don’t take my own advice!”*

(#26, G2P1)

**5.2.5.1 Guilt, regret**

Many women expressed feelings of guilt and regret at accessing care late. Some were concerned about care that they had missed, particularly screening, and changes to their lifestyle that they could have made in preparation for pregnancy.

*“I’m more annoyed with myself, because I didn’t, because I, like I say, I put up all those barriers straightaway, because then I was still, like, drinking and probably not eating that healthily and that kind of thing”*

(#17, G1P0)

*“It’s a worry, it still is a worry, I’m pleased, you know, that I haven’t been drinking or smoking at all, but then, you know, there’s things I think oh if I had my time again, if I’d known, what would I have done differently? I feel like I’ve missed out on a lot of care, a lot of things I feel maybe could have been doing at that time.”*

(#16, G1P0)

*“I thought I’m leaving it too late, I should go now in case there is something wrong… I missed out on folic acid; I regret that very much. I took it with my other children. In some ways I think I let this baby down, I didn't give it what the others had, but I just couldn't go. I feel guilty about that.”*

(#8, G3P2)

*“The only thing I’m upset about is that I just couldn’t have my 20 week scan. And that’s it… Just knowing that baby’s healthy really. Just knowing that, that if I did have that scan…”*

(#5, G2P1)

**5.2.5.2 Pleased to have ‘missed’ early pregnancy**

Regret was not a universal response however, to a delay in making the pregnancy ‘official’ by booking for antenatal care. Some women who had not known they were pregnant were pleased to have ‘missed’ part of the pregnancy: impatience for the pregnancy to be over and their baby to arrive was expressed by several women and their partners.

*I: “how did you feel about the fact that you were quite a bit further along?*

*Alright. I were loving it. I were going out buying baby stuff, I were loving it already. I were loving it.”*

(#27, G2P1, learning difficulties)

*“it was good, it was really good because I thought I won’t have to wait as long, because nine months is a long, even now, I feel like it’s been such a long time.”*

(#16, G1P0)

*“I were right excited, because I missed everything, [the] worst bit. I’m right impatient, so if I’d have found out when I were first it would have dragged, cos it’s felt ages now… I’d rather do this way again!”*

(#22, G1P0)

Another woman was happy with her decision and pleased to be in an advanced gestation. She was disappointed not to be even further on in her pregnancy:

*“I didn’t feel guilty at all because it wasn’t my fault, I’d been on holiday, I couldn’t help the fact that I’d been, you know, I’d planned to stay there quite a long time so I didn’t feel guilty at all… I was really hoping that I was quite far on and then when she said ‘oh no, I think that’s right’ and she measured it and everything so I was a bit disappointed with that.”*

(#11, G4P3)

**5.3 Conclusions**

Chapter five has presented the themes and sub-themes emerging from the analysis of interviews with a diverse sample of 27 women who booked for antenatal care after 19 weeks gestation. The interviews were undertaken to gain a deeper understanding, to answer the research question *‘what perceptions and beliefs do late booking women express about the delayed initiation of antenatal care?’*

Three major themes emerged from the women’s interviews. These were women not realising or believing they were pregnant and therefore not accessing care (not knowing), women knowing they were pregnant and avoiding or postponing antenatal care (knowing), and women being prevented from accessing care as a result of professional and system failures (delayed). Sub-themes relating to individual circumstances, including pregnancy expectation and women’s knowledge and experience of pregnancy and antenatal care, but also empowerment and socio-cultural factors, were significant. Such influences were frequently overlapping and interrelated. In addition, women expressed a wide range of attitudes towards their late booking. These themes are discussed in the following chapter, in the context of previous research around antenatal access and women’s perceptions of care.

**Chapter 6: Discussion of the findings from the qualitative study**

**6.1 Introduction**

The purpose of this qualitative research was to gain a deeper understanding of the reasons why some pregnant women delay booking for antenatal care. It was undertaken to consider the women’s perspective, to provide insights into the perceptions, behaviours and social processes surrounding late booking, in a way that would not be possible using quantitative methods. This purpose was reflected in the overall research question underpinning the study: *“what perceptions and beliefs do late booking women express about the delayed initiation of antenatal care?”* Twenty seven late booking pregnant women were interviewed individually, using a semi-structured interview format. From the thematic analysis a taxonomy (table 5.1.3) of themes and sub-themes relating to late booking for antenatal care was developed, with three major themes: ‘not knowing’, ‘knowing’ and ‘delayed’, and explanatory sub-themes relating to individual circumstances, empowerment and socio-cultural factors. These include the recognition of pregnancy and the influence of a pregnancy ‘mindset’, the perceived value of antenatal care and the influence of previous pregnancy experience. Other sub-themes include avoidance and postponement strategies and the acceptance of delay.

As appendix 4.15 illustrates, the taxonomy is not always mutually exclusive, with all women having primary and secondary exacerbating factors which resulted in late booking. These interrelated, and sometimes sequential, factors acted as barriers to early antenatal care, delaying, curtailing or preventing access. They can be divided up into those which were primarily practical or organisational (for example the delayed women) and those which were personal (realisation, belief), motivational or attitudinal (avoidance, postponement) (Dartnall *et al* 2005, Downe *et al* 2009, Callaghan, Buller and Murray 2011). It appears that the timing of initial access to antenatal care is determined by a spectrum of choices, influenced by women’s acceptance of their personal and public pregnancies, as first mentioned in chapter two, from acceptance through a more passive non-acceptance to an active rejection of the pregnancy and/or the need for antenatal care. This suggests a linear process, however in some cases the reality is less structured, reflecting a ‘web’ of these choices, bound up with preventative factors. This process is influenced by a complex interaction of psychological, social and demographic factors, which must be negotiated prior to a woman’s first antenatal appointment. By the time she sees a midwife or doctor, a woman has already overcome the majority of common barriers to antenatal care (Downe *et al* 2009, Philippi 2009).

Whilst for the majority of pregnant women, the convention of early access to maternity services is an accepted ‘norm’, a different, and more complex, picture exists amongst those women who have been identified as vulnerable or ‘hard-to-reach’. As Dartnall *et al* (2005) comment, groups such as teenagers, women with learning difficulties, substance misusing women and those from outside the UK, may access services at different points and for different reasons. These women formed a significant part of the Sheffield study. However, there were also other women, from a range of ages, parities and backgrounds, who would not be considered vulnerable, who were also interviewed, as part of the inclusive approach to recruitment and the maximum variety sample for the study. Many themes associated with late booking found in previous studies of marginalised women are evident amongst these women, across the social, educational and cultural spectrum. The women demonstrated a wide range of attitudes and experiences, and reveal a view of pregnancy and antenatal care not usually considered.

The similarities and differences between existing research and the Sheffield study are examined in the following discussion, and the concept of personal and public pregnancies is explored in relation to the themes identified from the data. The majority of the high quality studies (see chapter two, section 2.2.3 for consideration of quality appraisal) of antenatal access cited are from urban settings within the USA; consequently studies from the UK, Canada (CAN) and Europe (EUR) are identified as such throughout this chapter for clarity.The US studies share an urban context with the Sheffield study, however the different health and social care systems that exist in the UK and USA mean that caution is required when making comparisons. However, as previously acknowledged in chapter two, there are common themes across the countries, and evidence that many of the barriers experienced by American women may be transferable to the UK (Lavender *et al* 2007).

**6.2 Not knowing: accepting the personal pregnancy**

Acceptance of pregnancy, and the need for antenatal care, begins with a woman’s internal recognition and acknowledgement of her personal pregnancy. This is linked to a woman’s intention and expectations of becoming pregnant (her pregnancy ‘mindset’) and her ability to recognise the pregnancy itself. The latter is influenced by a woman’s knowledge, her physical and psychological wellbeing, but also potentially by those in her immediate social network. Such acceptance may not be an immediate response to pregnancy discovery, but may follow a prolonged period of uncertainty and reflection, as discussed later in the chapter. The major theme of ‘not knowing’ from the Sheffield study illustrates this non-acceptance of the personal pregnancy. The study found two key sub-themes amongst women who had not known that they were pregnant, leading to delayed confirmation of pregnancy and access to antenatal care. These related to women’s **realisation**: their (non) recognition of pregnancy signs and symptoms, but also to **belief**: their expectation of becoming pregnant and the influence of a pregnancy mindset. Central to this mindset was a lack of pregnancy planning, a theme running throughout the study and influencing women’s acceptance of both their personal and public pregnancies.

***6.2.1. Recognising the pregnancy***

‘I didn’t know I was pregnant’ was a common explanation for late entry into antenatal care. The majority of the women (22 out of the 27) interviewed in the Sheffield study said that they had not known they were pregnant for weeks or sometimes months. This had delayed them accessing care. This was expressed as women not realising that they were pregnant and women not believing that they could be pregnant (for most of the 22 women a combination of these two factors was evident). Several other studies have identified delayed confirmation of pregnancy as a major factor in preventing early initiation of antenatal care (Harvey and Faber 1993, Rogers and Schiff 1996, Peacock *et al* 2001). Sable *et al’s* (1990) study of low income women in Missouri USA found those who did not recognise their pregnancies in the first four months were nine times more likely to have received inadequate care. This is particularly apparent amongst young women (as identified by Leatherman *et al* 1990, Gazmararian *et al* 1997, Mackey and Tiller 1998); all seven women aged 20 years or less in the Sheffield study expressed some degree of delay in recognising and confirming their pregnancies.

This study suggests that for some women ‘not knowing’ that they are pregnant is a combination of lack of recognition, acknowledgement and acceptance of the signs, symptoms and consequences of pregnancy. It is influenced by several factors, such as a woman’s knowledge and experience of pregnancy, both personally and amongst a woman’s social network. Her physical health but also her psychological wellbeing, including stress, anxiety and/or depression, alongside her expectation of becoming pregnant, are also influential. Peacock *et al’s* (2001) qualitative study of low-income women in Chicago USA recognised this interplay of realisation and belief, and the involvement and influence of others in the process of a woman ‘knowing’ she is pregnant:

*“Recognition of a pregnancy can be a complex and sometimes protracted process that includes assessing pregnancy risk, perceiving and correctly interpreting pregnancy signs and symptoms, seeking confirmation, accepting (or denying) the pregnancy”* (p110)

The concept of ‘knowing*’* in this context suggests identification and understanding; an acknowledgement of the physical and social consequences of the pregnancy from the woman and potentially those around her. Whilst some acknowledge pregnancy recognition as an influence on access, few studies, particularly quantitative ones, have demonstrated the complex relationship of influences and the importance of this pregnancy mindset.

**6.2.1.1 Lack of reproductive knowledge**

The pregnancy mindset is influenced by many factors. Lack of reproductive knowledge, in all its facets, is a thread running through the results from the study, and has been identified as a major factor in the delayed initiation of antenatal care in many other studies. These facets include a lack of recognition of early pregnancy symptoms; lack of knowledge of antenatal care and its value; lack of pregnancy planning and contraceptive failure. It was most evident amongst nulliparous women and women with risk factors such as learning disabilities, substance misuse and for whom English was not their first language; often those identified as most at risk in previous UK maternal mortality reports (Lewis 2007, CMACE 2011 (UK)).

Women’s apparent poor knowledge and awareness of pregnancy, and their failure to recognise many early signs and symptoms, were common themes in this study and have been widely reported in a range of qualitative studies from the USA (Gazmararian *et al* 1997, Mackey and Tiller 1998, Peacock *et al* 2001, Daniels, Noe and Mayberry 2006). This lack of knowledge and/or skills relating to pregnancy has been identified as linked to low educational achievement (Braveman *et al* 2000) and was particularly (though not exclusively) evident amongst younger women and women with learning difficulties. Peacock *et al* suggest that thispotentially demonstrates *“a lack of understanding of the processes underlying conception and pregnancy”* (2001: 112). Whilst a lack of reproductive knowledge is evident, to label women as ignorant would be simplistic and judgemental. For example, how much understanding of her body, let alone the realities of pregnancy, might a young woman of 15 or 16 be expected to have? Brubaker’s (2007) US study of BME teenagers found that before they became pregnant, formal health care and knowledge about health, sexuality and pregnancy were largely absent from their experience, resulting in delays in disclosing sexual activity and pregnancy, and subsequently the initiation of care.

Perhaps more significant however were the eleven women, six of whom were primigravidas, in the Sheffield study who considered that they had not experienced any pregnancy symptoms at all. Some authors discuss a point at which the pregnancy becomes physically ‘apparent’, to women, suggesting this is when fetal movements are felt or the pregnancy is visible (Gazmararian *et al* 1997, Callaghan, Buller and Murray 2011 (UK)). However many of the women in the Sheffield study confirmed their pregnancies well after the time when these symptoms would have been evident and, it could be argued, obvious. This is in contrast to Browner and Press (1996), who discuss women’s use of ‘embodied knowledge’ (the subjective knowledge derived from a woman’s perceptions of her body and its natural processes) in antenatal decision-making. Rather, these findings suggest a lack of knowledge or self-awareness, or that denial or some other personal perceptions were influential.

**6.2.1.2 Misinterpretation**

Several women in the Sheffield study misinterpreted pregnancy symptoms and attributed them to other events in their lives, such as stress, exhaustion or weight gain or loss, or to medical conditions. It was common to attribute even multiple symptoms to causes other than pregnancy, especially when their perceived likelihood of becoming pregnant was low, for example for age, health or contraceptive reasons. Other authors have acknowledged this attribution of pregnancy symptoms to medical conditions, but only in relation to irregular periods. In contrast, bloating and heaviness were attributed to Polycystic Ovary Syndrome (PCOS) and a water infection by two women in the Sheffield study. This suggests another level to women’s interpretation of physical symptoms. Recognition of the similarity of pregnancy symptoms with those of stress and physical illness and psychological distress, leading to misinterpretation and delayed recognition, *has* been noted elsewhere (Lia-Hoagberg *et al* 1990, Peacock *et al* 2001). This was identified by several of the women in the study.

Some women also experienced irregular or absent periods, which were a normal part of their lives and which impacted on their ability to diagnose pregnancy. Other authors have recognised this as a contributing factor (Chisholm 1989 (UK), Lia-Hoagberg *et al* 1990), often in combination with other factors such as a lack of expectation of becoming pregnant. As in other studies, women with unplanned pregnancies were much less likely to be aware of amenorrhoea, potentially a significant symptom of pregnancy. In Napravnik *et al*’s (2000) qualitative study of HIV positive women, they considered this symptom as not significant, as they weren’t thinking about having children. Lack of periods, as a result of substance misuse, was a significant factor in one woman’s case in the Sheffield study, though there was no admission of the effects of intoxication on pregnancy recognition, as seen elsewhere, such as Dartnall *et al’s* UK study of ‘hard to reach’ groups (2005).

Some women in the Sheffield study, especially those experiencing irregular periods, dismissed a missed period as an unreliable indicator of pregnancy. Women created their own ‘normality’: one woman said that she had been encouraged by her GP to see irregular periods as normal for her, others expressed acceptance of the situation, so did not consider amenorrhoea as unusual. In addition, women were more likely to consider any bleeding as a normal event not associated with pregnancy, potentially masking the pregnancy further. This personal ‘normality’ forms part of a woman’s embodied knowledge and suggests women’s acceptance of their bodies, which may contribute to explaining why some of the women said that they had not noticed any pregnancy symptoms at all.

***6.2.2 Planning the pregnancy***

*“whether or not a woman intends to get pregnant and how she feels about the pregnancy appear to be central elements in the obtainment of prenatal care*” (Sable *et al* 1990: 554).

The majority of women in the Sheffield study had not planned to become pregnant at the time they did and therefore had not made any preparations for pregnancy. Seventeen of the 27 women stated that they had not planned to become pregnant, and for another six this was implicit in their reaction to pregnancy discovery. Other women suggested that their pregnancy was intended but mistimed. This lack of planning affected women’s mindset and in some cases influenced recognition of their pregnancies, which delayed confirmation and subsequent care.

It has been suggested that lack of pregnancy planning or intention plays a significant part in delayed attendance for antenatal care (Peacock *et al* 2001), but this is usually discussed in the context of the fear and ambivalence women feel after a pregnancy is confirmed, rather than the initial recognition of pregnancy signs and symptoms. As Braveman *et al* (2000) found, in their survey of more than 3000 low-income women in California, women who were consciously planning to become pregnant were likely to be much more vigilant about potential pregnancy signs and symptoms during the first trimester. In their studytwo-thirds of pregnancies were unplanned, and they concluded that the greatest risk factor for ‘untimely’ care was an unwanted or unplanned pregnancy.

Research suggests that unplanned pregnancies are particularly prevalent amongst low socio-economic status women, who may feel a lack of control over their health, lives and futures (Sable *et al* 1990, DoH 2004c (UK)). This in turn may influence their use of contraception, but also their possible acceptance of a pregnancy as ‘inevitable’. Downe *et al’s* (2009) meta-synthesis of studies from the USA, UK and Canada suggests that indicators of pregnancy are more likely to be missed in unplanned and unexpected pregnancies among (primarily young) women, because of ‘youth and physiological naivety’, learning difficulties and the lack of a pregnancy ‘mindset’. However, numerous US studies suggest that ambivalence and negative views of pregnancy are major factors in delayed access to antenatal care for women across the social spectrum, and in large part are linked to lack of pregnancy planning (Lia-Hoagberg *et al* 1990, Sable *et al* 1990, Mayer 1997, Roberts *et al* 1998, Nothnagle *et al* 2000, Johnson *et al* 2003, Sunil *et al* 2010).

Multiple factors influence a woman’s perception of the likelihood of her conceiving. Contraceptive use and its influence on a woman’s acceptance of pregnancy has not been mentioned in other studies but was highly significant in this study. The shocked comments of the eight women using contraception suggest a combination of factors. Perhaps a lack of knowledge about conception and the risks of pregnancy whilst using (incorrectly perhaps) oral or other forms of contraception, but more importantly a lack of belief in becoming pregnant.Other factors influenced this mindset, including the two women who thought age would influence their chances of becoming pregnant. Callaghan, Buller and Murray (2011), in their London-based qualitative study, interviewed one woman who thought she was too old to conceive, but again it is a subject that has been largely unreported in studies of late booking.

As Peacock *et al* (2001) comment, acknowledging pregnancy is as much about a woman’s attention to as well as her knowledge of pregnancy signs and symptoms. The shock, confusion and potential anxiety of conceiving outside of optimum conditions, for example where a pregnancy is unplanned or unexpected (i.e. the majority of women in this study), may have resulted in an inability to place pregnancy symptoms into what they call a *‘meaningful whole’*, leading to misinterpretation and delay. Many women in the Sheffield study described that they had not put all their symptoms together to build a picture of themselves as pregnant; they had not created a pregnancy identity. It was only after a trigger, for example a test result or an explanation of symptoms they had been experiencing, that the pieces of the puzzle fell into place.

Recognition of an unplanned pregnancy led to feelings of fear and ambivalence amongst some women in the study, particularly related to the consequences of the pregnancy. This resulted in denial, avoidance and delayed entry into the maternity care system. This mirrors the picture widely reported in US research, both qualitative and quantitative (Harvey and Faber 1993, Roberts *et al* 1998, Mackey and Tiller 1998, Peacock *et al* 2001, Daniels, Noe and Mayberry 2006, Downe *et al* 2009, Philippi 2009). The ambivalence women felt meant that they were more likely to ignore or deny early signs and delay confirming their pregnancy, despite first trimester awareness. This was also noted by Chisholm (1989) in Manchester (UK) as a reason why women had delayed seeing their GP. As Lia-Hoagberg *et al* (1990), in their mixed-method study in Midwestern USA, comment:

*“many women may be denying or repressing the reality of an unplanned and often unwanted pregnancy. Seeking early prenatal care would only confirm and force them to confront what they did not want to recognize or acknowledge”* (p491).

As in other studies, some late initiators of antenatal care were, at best, indifferent, if not distraught, at becoming pregnant, with feelings of depression, psychological stress and pregnancy rejection that led to denial and concealment, and hindered access (Hulsey 2001, Daniels, Noe and Mayberry 2006, Johnson *et al* 2007). As Downe *et al* (2009) comment:

*“In contrast to the delight experienced by many women when a pregnancy is planned, the recognition of an unplanned pregnancy can be devastating. Many women recalled struggling to accept their situation”* (p521)

These are themes identified amongst different groups of women, including multiparous women and adolescents (Chisholm 1989 (UK), Mackey and Tiller 1998, Teagle and Brindis 1998, Hulsey 2001), the latter in sharp contrast to the common perception that teenage pregnancy is a lifestyle choice. This was evident with two of the postponing women in the Sheffield study, as they struggled with the idea of coping with another child.

Many quantitative and mixed method studies from the USA have documented this lack of motivation and low mood resulting from an unexpected pregnancy, with women not feeling ‘up to’ going for care (Kalmuss and Fennelly 1990, Leatherman *et al* 1990, Oberg *et al* 1990, Cook *et al* 1999, Pagnini and Reichman 2000, Sunil *et al* 2010). Johnson *et al’s* (2003) study of BME women in Washington DC found that unhappiness with being pregnant was linked to low self-esteem and was identified as making women ‘not think straight’, suggesting its influence on women’s judgements about their need for care. Other US studies suggest that this personal distress resulted from the combination of a stressful life situation and lack of support and encouragement, with an unintended pregnancy, which made attending for care seem too difficult, particularly amongst young women (Mikhail 1999, Napravnik *et al* 2000, Luecken *et al* 2009). Dartnall *et al’s* (2005) UK study of hard to reach groups also discusses the importance of this support, in combination with women’s acceptance of their pregnancy and an understanding the role of the maternity services, on women’s engagement, again almost like pieces in a puzzle which need to fit together. Lack of support was not particularly evident in the Sheffield study however.

A small number of the women interviewed had considered having a termination, which led to a delay while they considered their options. This has been a common theme in other research and linked to stress, ambivalence, indecision and, again, lack of support (Lia-Hoagberg *et al* 1990, Sable *et al* 1990, Mayer 1997, Teagle and Brindis 1998, Napravnik *et al* 2000, Johnson *et al* 2007, Callaghan, Buller and Murray 2011 (UK)). Johnson *et al* (2003) found that considering abortion was the most important factor in delayed initiation of care,particularly amongst younger women. In the Sheffield study this factor was evident amongst a range of women, aged between 15 and 36 years.

Some women in the Sheffield study expressed ambivalence towards their pregnancies, particularly those who had considered a termination, and those who felt most likely to be judged, such as teenagers and substance misusing women. As Peacock *et al* (2001) note in their qualitative Chicago-based study, ambivalence, even when pregnancy is desired, is a common reaction to the discovery of an unplanned pregnancy, amongst women, their partners and families, and has the potential to lead to significant delay in accessing care. However, as Hulsey (2001) comments, unwanted and unintended pregnancies are quite different things, though both may be associated with an initial indifference, influencing initiation of antenatal care. A woman’s attitude is also likely to change during pregnancy; wantedness of a baby is not the same as wantedness of pregnancy (Sable *et al* 1990). Ambivalence was not a common theme in the Sheffield study, and far less prevalent than in other studies. This may partially be a characteristic of the women who were prepared to be interviewed, but also the effect of being interviewed by a midwife, even one not involved in their care: women are unlikely to admit that their baby is unwanted to such a person.

Whilst studies suggest that young and other vulnerable women, and particularly teenagers, are more likely to not know that that are pregnant, this study and others shows it is amore complicated picture than simply lack of knowledge,with young women fearful both of finding out they were pregnant themselves and of others finding out(Leatherman *et al* 1990, Mackey and Tiller 1998). The relationship between a pregnant woman and others influences the ‘discovery’ of a pregnancy, the boundaries between not knowing and knowing, the creation of a woman’s pregnancy identity and her public or ‘social’ pregnancy, which is discussed further in the next section.

Such boundaries, between not knowing and knowing, recognition, acknowledgement and acceptance of a pregnancy are far from clear however. The concept of knowing in this context suggests identification and understanding, an acknowledgement of the physical and social consequences of the pregnancy, from the woman and also potentially those around her*.* As diagram 6.2 suggests, based on the findings from the Sheffield study and previous research, it is not a fixed point in the pregnancy. There is the potential for prolonged periods of ‘consideration’ before the pregnancy and the need for care are accepted and care is sought. This consideration and rationalisation, and ultimate resolution (however protracted), also creates overlapping boundaries between a woman’s personal and public pregnancies.

***Diagram 6.2: A diagram to illustrate the initial stages of pregnancy recognition, acceptance and care seeking***

**Stage Response**

**Not pregnant** *I’m not pregnant*

**T I M E**

**T I M E**

**In between** *Something’s happening?* ?

**n**

**o**

**t**

**k**

**n**

**o**

**w**

**I**

**n**

**g**

**p**

**e**

**r**

**s**

**o**

**n**

**a**

**l**

**p**

**r**

**e**

**g**

**n**

**a**

**n**

**c**

**y**

**r**

**i**

**v**

**a**

**t**

**e**

**p**

**r**

**e**

**g**

**n**

**a**

**n**

**c**

**y**

Pregnancy **possibility** *Could I be pregnant?* *recognition of symptoms?*

*do a test?*

**k**

**n**

**o**

**w**

**i**

**n**

**g**

Pregnancy **discovery** *I am (a little bit) pregnant* !

Pregnancy **consideration** *Ok, so now what?* *do something?*

*tell someone?*

Pregnancy **acknowledgement** *I am pregnant and I need what to do?*

**p u b l i c**

**p r**

**e g n a n c y**

*to do something about it* *who to tell?*

Pregnancy **consideration** *Ok, so now what?* *do something?*

*tell someone?*

Pregnancy **acceptance** *I am pregnant and I want I’ve told…*

*to keep the baby -*

*I need to act.*

or **non-acceptance** *I am pregnant and I don’t I’ve told…*

*want to keep the baby -*

*I need to act.*

Pregnancy **‘official’ -** *I’m having a baby*. *I’m* *there’s no going*

accessing care (public *going for care.**back…*

**knowledge)**

**6.3 Knowing – accepting the public pregnancy**

Acceptance of the need for antenatal care, and accessing the care itself, also requires a woman to acknowledge that their pregnancy exists beyond the personal, to open up their pregnancy to the outside world and make it ‘official’. This ‘public’ pregnancy stems from an acceptance of the social consequences of the pregnancy and the creation and development of a woman’s pregnancy identity, with its accepted norms and potential consequences. However, it also reflects a woman’s acceptance of the purpose of antenatal care, and potentially the relevance and value of such care. Such acceptance may not be an immediate response to pregnancy confirmation, but may once again follow a period of reflection, a weighing up of priorities, linked to previous experience, her current life circumstances and personal perceptions of health and healthcare.

The major theme of ‘knowing’ from the Sheffield study illustrates a non-acceptance of this public pregnancy. The study found three key sub-themes amongst women who knew they were pregnant but did not access early antenatal care: avoidance, postponement and being delayed by others. Avoidance and postponement were themes emerging from 14 of the 27 interviews. Whereas women avoiding care had made no plans to access care, women who postponed their care intended to access care ‘at some point’ in the future. **Avoidance** suggests a denial or rejection of the pregnancy and its consequences, **postponement** suggests a reluctant acceptance or at least some consideration of the pregnancy. Both were linked to feelings of fear and ambivalence for some women, though the boundary between avoidance and postponement was sometimes indistinct. For some of these women what began as avoidance became postponement; in some cases a passive avoidance or postponement, in others women actively chose to conceal their pregnancies or delay access. These themes are discussed in the context of social influences on women’s acceptance of pregnancy, and their perceptions the relevance, value and priority of antenatal care.

***6.3.1 The ‘social pregnancy’***

*“Pregnancy discovery and acceptance… is a complex process… pregnancy exists as a socially constructed phenomenon as well as a biological reality”* (Peacock *et al* 2001: 113-4).

Pregnancy is a social and cultural as well as physiological phenomenon, which exists for women at private and public levels; the concept of ‘being pregnant’ is complex, with many consequences and parties involved (Peacock *et al* 2001). Society as a whole interprets and gives meaning to this ‘natural’ event, which has changed from a purely private to a far more public experience through history, bringing with it whole new range of meanings and interpretations (Symonds and Hunt 1996). Women need a certain amount of approval and social support before the need for antenatal care, can be acknowledged and accepted, both by the woman herself and her social network (Lia-Hoagberg *et al* 1990, Johnson, Primas and Coe 1994, Peacock *et al* 2001, Daniels, Noe and Mayberry 2006). The dynamics of this negotiation between a pregnant woman and others influence both the ‘discovery’ of a pregnancy and the creation of a woman’s pregnancy identity and her ‘social pregnancy’. The notion of a social pregnancy moves beyond the individual and includes her family, partner and peers, extending to a network involving a woman’s community and to antenatal care providers as well (Daniels, Noe and Mayberry 2006). All of these become influences in the process of pregnancy acceptance. Access to antenatal care is heavily influenced by a woman’s willingness to embrace her pregnancy and particularly these social aspects of the pregnancy (Dartnall *et al* 2005 (UK)).

Supportive relationships within a woman’s social network can strongly influence the coping mechanisms of women, and reduce and prevent delay in accessing care. As Schaffer and Lia-Hoagberg (1997) argue in their US study of low income urban women, the perception of being loved and valued is a significant part of the process of initiating and continuing antenatal care. For many women, once they are able to share their pregnancies it becomes easier to seek support and access care. As with other studies, families, partners and peers of the Sheffield women played an important role in their pregnancies and attitudes towards seeking antenatal care; offering support, information and advice, and acting as a significant motivator (Lia-Hoagberg *et al* 1990, Napravnik *et al* 2000, Daniels, Noe and Mayberry 2006). For many primigravid women, pregnancy, and the need for care, was often recognised by someone else. Particularly amongst the younger women in the Sheffield study, it was their mothers who were pivotal in confirming the pregnancy and ensuring they access antenatal care. These were similar findings to Mackey and Tiller (1998) who found pregnant teenagers in the Southeastern USA tended to let their mothers manage their pregnancies.

The social and cultural norms of a woman’s primary reference group could also be highly influential on a woman’s acceptance of care in both positive and negative ways, potentially contributing to *“a continuing cycle of women ranking prenatal care low on their list of prioritie*s” (Daniels, Noe and Mayberry 2006: 196). Studies from the USA and UK suggest these cultural norms might reflect a more fatalistic outlook towards pregnancy and/or a rejection of mainstream services, of which antenatal care is a part (Johnson, Primas and Coe1994, Milligan *et al* 2002, Dartnall *et al* 2005 (UK), Daniels, Noe and Mayberry 2006). This applied to many of the ‘postponing’ and ‘delayed’ women, several of whom talked about family and peer influences.

**6.3.1.1 Fear of consequences**

For some of the avoiding and postponing women in the Sheffield study pregnancy acceptance was linked to their initial disclosure of the pregnancy to family and friends and whether they received support and approval. For some women this relationship was a positive one, but for others it was less so. Several women admitted that they had ignored suggestions (which were perceived as interfering or irrelevant) that they might be pregnant and/or should access care, sometimes for weeks or months. Others talked about the negative influence of partners and families on their acceptance of the pregnancy and the choices they made, for example the fear of parental reactions and partner disapproval of a pregnancy. Where support was perceived to be lacking there was a reluctance to reveal the pregnancy, and thus to access care, for fear of disapproval, rejection, or other ‘consequences’.

A lack of support and approval within a woman’s social network, for example from the baby’s father, or stressful home circumstances, will inevitably influence a woman’s acknowledgement and acceptance of her pregnancy and the need for antenatal care. The resulting isolation has been identified as a barrier to care. In one US study of low-income urban women, those who did not want family and friends to know about their pregnancy were nearly five times more likely to receive inadequate care (Cook *et al* 1999). As Peacock *et al* (2001) comment

*“when a woman conceives outside of circumstances that are considered acceptable within her social context, and particularly without an adequate support network, she may perceive pregnancy as a situation too threatening to contemplate”* (p114)

Lutz’s (2005) US study of women experiencing domestic abuse discusses the idea of pregnancy as ‘public life’: an external, idealised view of the woman’s life, pregnancy and family. A pregnancy becomes public property once disclosed and made official, for example, by booking for antenatal care. As such many women may feel the need to assume a role which presents a positive image of themselves as capable, pregnant women, happy to be pregnant. This may not be the reality of the situation. Booking for care also crosses a line of inevitability, and demonstrates publicly a commitment to the pregnancy. As several women in the Sheffield study indicated, fear of judgement, stigma, scrutiny or even the consequences of the pregnancy, such as coping with another child, meant that they were not ready to take this step, leading to avoidance or postponement of care. As Young *et al* (1989) comment in their US literature review of access to antenatal care:

“*the process of acknowledgement and acceptance of the pregnancy often was prolonged and filled with conflict… women frequently appeared reluctant to assume the roles of expectant mother and prenatal patient**by their denial of symptoms of pregnancy and their subsequent failure to participate in an organized prenatal care program” (p243).*

This delayed acceptance contrasts with Jomeen’s (2006) UK study of women’s choices in early pregnancy, which found that following pregnancy confirmation women adopted a ‘pregnant woman identity’, which “*imbues women with an immediate personal responsibility to their foetuses”* (p e198) and ownership of the pregnancy. Women did eventually reach this point but for some it was not an immediate response to pregnancy discovery, reflecting the unintended nature of their pregnancies. Some talked about the motivation to ‘get things sorted’ when their bump began to show and the pregnancy could no longer be hidden from their social network.

As with other studies, the fear of judgement and the consequences of pregnancy was particularly apparent amongst vulnerable women. Fear, whether fear of tests, examinations or doctors, or a fear of others discovering the pregnancy and the consequences of this, has been identified as a common factor for delayed attendance amongst pregnant adolescents, but also other women, in many US studies (Leatherman *et al* 1990, Lia-Hoagberg et al 1990,Mikhail 1999, Rogers and Schiff 1996, Teagle and Brindis 1998, Young *et al* 1989). Dartnall *et al’s (*2005) UK-based qualitative study of hard to reach women identifies particularly vulnerable groups such as substance misusing women and teenagers as lacking the confidence to engage fully with services, for fear of being labelled or facing discrimination and unwanted intervention. This was borne out in the Sheffield study, though other identified groups such as women with learning difficulties and recent immigrants did not articulate this fear. One of the teenagers in the study expressed her fear of the stigma of teenage pregnancy, which led to her avoiding care, a theme also identified by Callaghan, Buller and Murray (2011) in their UK study of late booking in London.

As Roberts and Pies (2011) acknowledge, in their qualitative study from California USA, the situation with substance misusing women is a particularly complex interaction of individual, interpersonal and system factors, which creates multiple barriers. Substance misuse can act as an influence on the acknowledgement and acceptance of both pregnancy and the need for care, due to the impact of intoxication and the resulting chaotic lifestyle on women’s choicesand priorities (Gazmararian *et al* 1997, Milligan *et al* 2002, Downe *et al* 2009). Many women recognise the potential harm to their fetus and the consequences of any intervention resulting from their pregnancy. This fear can prevent women accessing antenatal care but women may also be isolated from supportive networks as a result of their addiction. Whilst the latter point was not evident in this study, both of the substance misusing women in the study demonstrated avoidant coping strategies. One woman expressed ambivalence, avoiding confirmation of the pregnancy for several months. The other stated that she was frightened when finding out that she was pregnant, suggesting her recognition of the potential consequences of the pregnancy: the required disclosure of her substance misuse, which had resulted in the removal of her previous children. She also suggested that previous negative healthcare experiences, and particularly fear of judgement from her GP, had led her to delay confirmation of the pregnancy and accessing care.

These are common themes in many other US studies relating to substance misuse and antenatal care attendance (Kalmuss and Fennelly 1990, York *et al* 1996, Gazmararian *et al* 1997, Mikhail 1999, Napravnik *et al* 2000, Milligan *et al* 2002, Lutz 2005). Such women, struggling to cope with difficult personal circumstances and/or lacking the confidence to cope with the complexities of a pregnancy and the involvement of others in their pregnancies, are particularly likely to delay access. However, as this study illustrates, many ‘ordinary’ women also have other challenges, other priorities in their lives, which impact on their ability and willingness to engage with the ‘public property’ of their pregnancy and the care that goes with it.

In some cases the anxiety resulting from pregnancy discovery led to an initial denial and ongoing concealment which continued for a significant proportion of the pregnancy, for two women until well into their third trimester. This secrecy about pregnancy was particularly significant amongst young women in the Sheffield study, reflecting a common theme in other studies (e.g. Leatherman *et al* 1990, Mackey and Tiller 1998). However, it would be wrong to assume that women concealed their pregnancies completely from those around them (only one woman concealed her pregnancy in the true sense). Most women told other people close to them but concealed their pregnancies from ‘official’ confirmation and involvement, indicative of their fear of the consequences of disclosure. Women were highly selective about who they *did* tell, choosing friends or the father of the baby initially, people who were removed from their immediate family, followed eventually by ‘layers’ of revealing to those in their social network. In several cases avoidance became postponement, as more people became aware of the pregnancy, a prolonged process resulting in a passive non-acceptance rather than an active rejection of antenatal care, where initial *“avoidance seemed easier than engagement”* (Callaghan, Buller and Murray 2011: 9 (UK)).

***6.3.2 The pregnancy identity***

Pregnant women must make many psychological adjustments as part of a transition to motherhood. Though often discussed in the context of postnatal experiences, some authors argue that the process has the potential to start early, at the point at which pregnancy is still unconfirmed, with an initial period of huge adjustment in the first trimester (Carver and Ward 2007). Oakley’s UK-based qualitative research found considerable discrepancy between women’s expectations and the reality of different aspects of motherhood, including pregnancy (2004). The dominant metaphor was ‘shock’. She suggests *“a process of emotional recovery is endemic in the normal transition to motherhood”* (p266). Mercer argues that the first stage of this transition is a commitment to the pregnancy and becoming a mother: beginning the creation of a maternal identity, a *‘new conception of self’* (2004: 226); something all-encompassing in a woman’s life rather than a role which can be stepped in and out of. Rubin’s US study of maternal adaptation talks about ‘becoming’: a process of *‘taking-on, taking-in, letting-go’* (1967a: 240), considering the latter as part of a process of grieving for a former (non-pregnant) identity.

This process of adjustment and adaptation is influenced by a woman’s social, economic and personal situation, cultural beliefs and knowledge. Successful adaptation is associated with positive pregnancy experiences such as supportive relationships and self-esteem, whereas stress, depression and lack of support all have a negative effect on a woman’s ability to make this commitment, with ongoing consequences throughout pregnancy and after birth (Nichols, Roux and Harris 2007). This process of adaptation is not exclusive to primigravid women. Nichols, Roux and Harris’s (2007) US study identifies the differing characteristics and needs of primigravid and multigravid women antenatally, which are rarely acknowledged, and argue that multigravid women may face as many challenges in this adjustment as primigravid women.

Such pregnancies may not be a positive experience, and the burden of a woman’s pregnancy identity may be felt keenly. Shock and surprise at becoming pregnant was evident amongst many of the women in the Sheffield study.This was reflected in women’s choices around accessing antenatal care, particularly among the postponing (predominantly multiparous) women, as they considered the consequences of another pregnancy, which was often unplanned or unexpected, and the adaptations they must make. Jomeen (2004) argues that pregnancy can be a distressing event that affects a woman’s quality of life, with intense negative feelings of loss. The transition to motherhood is associated with a mixture of emotions, including fear, anxiety, responsibility, discomfort, exhilaration and guilt; a process of adaptation that may be hindered by an idealised society or media view of motherhood which women may not share or may feel unable to achieve (Burke 1985, Winson 2003). The adjustment to motherhood requires women to behave differently, some have argued less selfishly, suggesting again the influence of the ‘public pregnancy’, with its view of a pregnant woman and how she should behave (Bailey 1999). Jomeen (2006) agrees, suggesting that women feel that they are required to act responsibly and comply with convention in order to avoid public criticism, but acknowledges that women *do* take ownership of their pregnancies and aspire to present themselves as responsible, making the right choices to safeguard their babies. This was evident in the study, though was not an immediate response for some women, as previously discussed.

**6.3.2.1 ‘A little bit pregnant’**

Rather than an outright rejection of the pregnancy, avoidance in the study reflected a woman’s refusal to consider the pregnancy and its consequences. In contrast postponement reflected a period of ambivalence about and evaluation of the pregnancy, as women considered their choices and priorities, prior to an open acceptance of the pregnancy and initiation of care. Other studies have considered this ‘phase’ of a pregnancy after initial recognition, whether through self-diagnosis or by taking a test, reflected in both avoidance and postponement of care. Peacock *et al’s* (2001) US qualitative study discusses the idea of being ‘a little bit pregnant’: an in-between, liminal or transitional state, neither pregnant nor ‘unpregnant’, between pregnancy discovery and pregnancy acceptance, when women would make the pregnancy ‘official’ and take action. Pregnancy discovery and pregnancy acceptance form part of the timeline illustrated in figure 6.2. For some women in the Sheffield study, failure to acknowledge their pregnancies by refusing or ignoring a pregnancy test was clearly part of this ‘little bit pregnant’ phase, and suggested an avoidant coping strategy.

This avoidance of pregnancy confirmation suggests women were unwilling or not ready to take full ownership of their pregnancies at that time**.** Patterson, Freese and Goldenberg’s (1990) qualitative study in Alabama USA talks about a ‘letting it sink in’ phase, lasting from days to months, while women considered whether to continue or terminate the pregnancy, and the process of active or passive delay that ensued. This was clearly evident amongst some of the postponing women in the study, following pregnancy confirmation, and once again reflects their consideration of pregnancy as a social phenomenon, with a public status and consideration of ‘consequences’. Several women identified this ‘needing to think about it’ period and the passage of time that resulted: women struggled with their identity and ownership of their pregnancy, with its associated responsibilities.

***6.3.3 Valuing care***

**6.3.3.1 Prioritising antenatal care**

The concept of prioritising antenatal care, particularly amongst vulnerable pregnant women, has been discussed at length by many authors (York *et al* 1996, Downe *et al* 2009, Phillippi 2009). Few suggest that women place a low value on antenatal care, however numerous studies, in the UK and elsewhere, have demonstrated that beliefs about the importance of antenatal care are not always predictive of behaviour and do not account significantly for lack of use (Sword 2003 (CAN)). For example, in Chisholm’s (1989) Manchester (UK) study, more than 80% of women who booked late thought antenatal care very important and more than 50% thought early booking important. Similarly, in another (US) study, more than 95% of women receiving inadequate care thought antenatal care very or considerably important; this figure was 75% amongst women receiving no antenatal care at all (Aved *et al* 1993).

Although lack of knowledge about the value of early care, and others not valuing care were contributing factors in other studies (Harvey and Faber 1993, Nothnagle *et al* 2000), these factors were not found amongst the women interviewed in Sheffield. Almost all the women demonstrated some knowledge of antenatal care. Most stated that antenatal care was ‘a good thing’. Many had a clear picture of the importance of early antenatal care, some its purpose and positive effects. In Omar, Schiffman and Bauer’s (1998) US study of low-income rural women, whilst all women perceived antenatal care to be important, only half thought that barriers had prevented them from accessing antenatal care, suggesting women perceived their late attendance as an inconvenience or something to be expected, rather than feeling that they had been prevented from accessing care. This suggests that professionals and women define barriers to care quite differently (Sword 1999 (CAN)). This was evident amongst postponing women in the Sheffield study, and reflected the active choice of some women to delay care, from a considered and experienced (rather than uninformed) perspective.

Many women in the study demonstrated their understanding of the convention of attending for antenatal care, using expressions like, *“it’s because that’s what everyone does, isn’t it?” and “you need to go earlier to see what, what’s correct.”* Other studies found this to be a frequent reason for attending for antenatal care: because it was *“the thing to do”* or *“I knew I was supposed to”* (Lia-Hoagberg *et al* 1990). This was articulated more clearly than an understanding of the value or purpose of antenatal care, suggesting women felt a sense of duty to attend, a wish to accord with a social norm rather than a rational and empirical belief in the importance of antenatal care.

This suggests that most women accept the importance of antenatal care ‘in theory’. For it to be acceptable ‘in practice’ however it needs to be appropriate, a good ‘fit’ to the woman. This echoes Penchansky and Thomas’s (1981) definition of access as the degree of fit between the patient’s characteristics and expectations and the characteristics of providers and services within the healthcare system. All these characteristics can inhibit the initiation and continuation of antenatal care (Sword 1999 (CAN)). Women’s perceptions of convenience, and thus attendance, are influenced by their view of the *relevancy* of the care to themselves and their lives (Sword 2003 (CAN)), part of the ‘patient-centredness’ identified by Tandon, Parillo and Keefer (2005) as so valued by Hispanic women. Findings from the Sheffield study suggest that women made their own judgement of this ‘fit’/relevance in relation to antenatal care, and their priorities reflected this.

Daniels, Noe and Mayberry (2006) comment, in their focus group study of low-income BME women in Atlanta USA, that some women view antenatal care as important, but not as important as other issues in their day to day lives. Utilisation of antenatal care must be viewed in this context; the complexity of coping or surviving in vulnerable situations, often related to low income and instability. This may overshadow the pregnancy and the need for antenatal care (Mayer 1997, Napravnik *et al* 2000, Milligan *et al* 2002, Gaudion and Homeyard 2010 (UK)). Several American authors talk about motivational reasons for inadequate care, with women needing time and energy to deal with a variety of family and personal problems, linked to chronic economic strain, that discourage or take priority over the initiation of care (Leatherman *et al* 1990, Kalmuss and Fennelly 1990, Lia-Hoagberg *et al* 1990, Sable *et al* 1990). However, although most women in the Sheffield study lived in neighbourhoods with high deprivation indices and in low income households, many would not have been considered ‘vulnerable’. Few expressed any practical reasons why they had been unable to access care, suggesting that they were well supported. Rather, they illustrated a different set of priorities, a consideration of convenience and an assessment of the value of early care, linked to location, health and past experience.

This perception of inconvenience has also been noted as a significant factor for non-attendance for antenatal care in other studies (Leatherman *et al* 1990, Johnson *et al* 2003, Bloom *et al* 2004). Sword (2003)(CAN) and Lutz (2005) similarly discuss that women’s access to healthcare and health-seeking behaviour is determined by a perception of value, convenience and priority, a process of what Downe *et al* (2009) call a **‘**weighing up and balancing out’ of the situation, and of the risks and benefits of any action. This echoes Levy’s (1999) (UK) concept of women balancing or ‘maintaining equilibrium’ antenatally. Women’s experiences within the health care system generally may be influential, including the direct and indirect effect of poor experiences, for themselves, their family and friends. Studies from the USA and Canada have identified that some women considered their antenatal appointments to be a routine that did not provide them with any important benefits, or were more of a burden than a benefit (Reitmanova and Gustafson 2008, Sword 2003 (CAN)). Raine *et al*’s (2010) London-based study found different coping strategies amongst women in responding to poor antenatal communication. Where women perceived a stressful situation was unalterable, when the benefits of engagement were unclear, or where they had been rebuffed in previous encounters, one coping strategy was disengagement, most commonly amongst white women with limited education and non-English speaking women.

Though poor care or communication was not articulated explicitly by any of the women in the Sheffield study, as in other studies antenatal care was identified by many as important but not an immediate priority, something that could be postponed (Lia-Hoagberg *et al* 1990, Daniels, Noe and Mayberry 2006). Women’s consideration of the relevance and priority of care in their lives is significant. Antenatal care is grounded in a biomedical paradigm that focuses on individual determinants of health, rather than a more holistic, socioecological view of care which acknowledges a more complex range of influences (Sword 1999, Oakley 1992). Sword’s (1999) qualitative study in Ontario, Canada, argues that antenatal care reflects an ideology of practice that gives power and precedence to the knowledge and expertise of health care professionals and precludes consideration of women’s experiential knowledge and shared decision-making. As such it has the potential to be less sensitive and responsive to the needs of low income women particularly, creating an unbalanced relationship which in turn has the potential to alienate them (Oakley 1992). This may be reflected in the low priority given to care by the multiparous women in the study.

**6.3.3.2 Pregnancy as wellness**

Many studies, from the UK, USA and Canada, have identified that some women consider pregnancy a natural, normal life event, a state of ‘wellness’ rather than a medical condition requiring immediate attention, and would only attend for care if unwell, thus rejecting the convention of early antenatal care (Kalmuss and Fennelly 1990, Lia-Hoagberg *et al* 1990, Aved *et al* 1993, Omar, Schiffman and Bauer 1998, Mikhail 1999, Callaghan, Buller and Murray 2011 (UK), Heaman *et al* 2014 (CAN)). Leatherman *et al’s* (1990) US study notes that feeling well was a significant reason for delayed attendance amongst older women, suggesting higher parity and greater pregnancy experience and confidence in their bodies. This was borne out in the Sheffield study, with four women, all with previous pregnancy experience, saying that they felt well and that subsequently antenatal care was less important to them, but that they would seek help if problems arose.

For some women booking for antenatal care is an act of engagement with a model of care based on surveillance and testing, an interventionist approach to pregnancy which they may not subscribe to (Carolan and Cassar 2008, Callaghan, Buller and Murray2011 (UK)). Some studies of BME women have suggested that certain ethnic and religious groups are more likely to share this view; resulting in different patterns of health seeking behaviour and different expectations for healthcare (York 1996, Carolan and Cassar 2008, Reitmanova and Gustafson 2008). Such women may use a different frame of reference to make sense of pregnancy, viewing it as a normal and expected event, and particularly early antenatal care as unimportant. Choté *et al’s* (2011) study in the Netherlands argues that some (BME) women may feel early care is less relevant given its focus on behaviour change in relation to activities such as smoking and drinking alcohol, which aren’t applicable to them. Another Dutch study (Alderliesten *et al* 2007) found perceptions amongst ethnic groups were influential on access to care even after several generations.

In some (non-western) cultures a pregnancy doesn’t become real until fetal movements are felt. Dartnall *et al’s* (2005) UK study found that Muslim women with more traditional beliefs were likely to access care at the time they were due their second ultrasound scan (20-22 weeks gestation) as they were fatalistic and did not see the need for early intervention. The women expressed a strong belief that the course of pregnancy would be decided by God or fate, therefore medical intervention was inappropriate and seen as interference. Similarly, a London-based study identified that women from different cultural communities conceptualise pregnancy in different ways, influencing their engagement with antenatal care (Cresswell *et al* 2013, Hatherall 2013). The study found some women changed their last menstrual period (LMP) date in order to avoid induction of labour and other interventions; interference in what they saw as the ‘natural’ process of pregnancy. In the Sheffield study three of the four women discussed previously were Muslim and in two cases these were women who said that early screening was not needed and therefore attendance for antenatal care was less important. These and other cases suggest a fatalistic view of pregnancy, and a positivismlinked with a feeling of wellbeing, which led to women either not trying to access early care or not challenging delays.

This may also suggest influences beyond religion: an acceptance by the women of their bodies and pregnancies, creating a non-medicalised but positive pregnancy identity. Such women were taking control of their pregnancies, in some cases utilising such positivism as a protective strategy against what they perceived as unnecessary interference. This reflects some of the women’s views from the Bristol (UK) Antenatal Care study of less care as positive, less interference:

“*I’m not ill, I’m pregnant. Just let my body get on with it, it knows what it is doing.”* (Sanders 2000: 172).

**6.3.3.3 Previous pregnancy experience**

The influence of previous pregnancies was evident amongst some postponing women, with several women expressing a relaxed, accepting attitude towards their pregnancies and late booking, or who didn’t challenge delay. Authors have identified that some women accept pregnancy as a state of ‘normality’ and familiarity, stemming from previous pregnancy knowledge and experience. The Bristol Antenatal Care Study found women with at least one previous normal pregnancy considered antenatal care less important than primigravid women (Jewell, Sanders and Sharp 2000). A Swedish survey of women’s expectations on the number of antenatal care appointments found that a preference for fewer appointments was associated (amongst other things) with parity, age, obstetric history and previous positive birth experience (Hildingsson, Waldenstrom and Radestad 2002).

Many other studies from the US and UK found that multiparous women, particularly those of high parity, were more likely to book late, or in some cases to not book at all, because they perceived care to be more of a burden than a benefit, with perceived ‘losses’ outweighing ‘gains’ (Chisholm 1989 (UK), Lia-Hoagberg *et al* 1990, Sable *et al* 1990, Aved *et al* 1993, Braveman *et al* 2000, Hulsey 2001, Nothnagle *et al* 2000). Daniels, Noe and Mayberry’s (2006) US qualitative study found all women agreeing antenatal care was important, but late initiators were more likely to say it was less important in their current pregnancy, suggesting the influence of previous pregnancy experience. The authors suggest (not entirely positively) that women believed that

*“because they had experienced prenatal care in the past they did not need to seek early or any prenatal care”* (Daniels, Noe and Mayberry 2006: 193).

Women’s perceptions of convenience and value, and thus attendance, reflect again their view of the *relevancy* of the care to themselves and their lives (Sword 2003). Women with previously uncomplicated pregnancies are likely to have received routine antenatal care which may have been perceived as less relevant and appropriate in subsequent pregnancies. This may be linked to poor continuity of care, a cornerstone of UK maternity policy. For example, *Changing Childbirth* (DoH 1993) identified the need for continuity of care within an ongoing relationship with a lead professional, whereas *Maternity Matters* states that *“every woman will be supported by a midwife she knows and trusts throughout her pregnancy”* (DoH 2007: 5). However, as Kirkham (2010a) observes, this continuity remains elusive, and the majority of women experience a very fragmented maternity service, with women’s surveys describing a conveyor belt process, rather than receiving care within which a relationship between woman and midwife can flourish.

From a medical, rather than midwifery perspective, Browner and Press’ (1996) study in California (USA) found that multiparous women felt they had received a variety of conflicting and unhelpful advice in previous pregnancies, resulting in ambivalence towards antenatal care. Such women were more likely to act independently, referring back to previous experiences, particularly when these were associated with positive outcomes, and their own knowledge. Women used this ‘embodied knowledge’ and experience as a standard against which to assess the validity of clinical recommendations, rejecting medical recommendations they could not easily incorporate into their ongoing daily life circumstances. This again echoes Levy’s (1999) ‘maintaining equilibrium’, where women dealt with information in order to protect and keep in balance the interests of themselves, their baby, family and others, and ultimately retain control over their pregnancies. Part of this process involved avoiding information if they regarded it to be irrelevant and unhelpful.

Docherty, Bugge and Watterson (2012) argue that whilst *access* to antenatal care may not necessarily be influenced by the socio-economic background of pregnant women, *engagement* is. Their Scottish study suggests that this can be defined in terms of less evidence of personal connection to their own care, poorer communication and less opportunity for shared decision making amongst low income women. This reflects the unequal power relationship previously considered, between healthcare provider and pregnant woman, which may hinder the communication of a woman’s needs and influence theirbeliefs and decisions about what actions to take to enhance their health (Carver, Ward and Talbot 2008). The impact of this relationship has influences beyond the current pregnancy to future healthcare access (and by implication to future pregnancies).

However, in contrast to the studies above, no women in the Sheffield study identified poor experience with previous antenatal care specifically, though one substance misusing woman discussed the judgemental attitudes of her GP, a factor seen in other research (Napravnik *et al* 2000). This study (and others) suggests rather that women were less motivated to attend where they had a good past experience of pregnancy (Leatherman *et al* 1990, Mikhail 1999). Roberts *et al* (1998), in their study of middle-class women in Midwestern USA, found that antenatal care was seen as less important by older, multiparous women, due to their previous positive experience, suggesting that the delay was because women felt care made little difference to the course and the outcome of the pregnancy. There was a suggestion amongst multiparous women in the Sheffield study that they were more relaxed about missing early care, because of their previous pregnancy experience, and that antenatal care was particularly important for first pregnancies, when women had more to learn.

Several multiparous women in the Sheffield study also expressed a trust in their pregnancy knowledge and experience, a suggestion of expertise and an ability to make their own choices. Evidence of this non-participatory approach in pregnancy - women making their own decisions - was also found by O’ Cathain *et al* (2002), in their study of informed choice in maternity care. They found that multiparous women, but also women from manual occupations and with lower educational attainment (many of the women in this study) were more likely to express a preference for not sharing decision-making with health professionals, but were likely to express that they had made an informed choice antenatally.

Though not specifically related to antenatal care, Dixon-Woods *et al’s* (2006) idea of ‘candidacy’ suggests that access to healthcare is not simply a question of utilisation but reflects a dynamic process of negotiation, influenced by people engaging in defining their own understanding of what is appropriate medical attention and intervention for themselves. They argue that there are multiple influences on this, including personal characteristics, social context and the macro level organisation of services. The Sheffield study suggests these influences are evident in antenatal care, as some of the pregnant women made these judgements in relation to the timing of antenatal care, in the context of their previous pregnancy experience, their beliefs and their acceptance of pregnancy. The social context includes the experience and influence of other mothers which was also evident in their choices. Many received advice and information, and a number of women in the study had experienced late booking within their families, reflecting (again) the influence of mothers and peers as models for maternal role taking (Rubin 1967b), and the significance of social and cultural norms in relation to late booking.

**6.3.3.4 Location of care**

Only one of the women interviewed expressed any problems relating to their home circumstances or financial background that had prevented them from accessing care. In contrast, a large number of studies, primarily from the USA but also one from the UK (Dartnall *et al* 2005), identify practical barriers to access such as distance or transport and the time and cost involved, *‘the ease with which one gets connected to care’* (Bloom *et al* 2004: 433), as highly significant in influencing access. However, in many of the studies no distinction is made between initial access to care and continuing access, so it is difficult to assess their significance to late booking. Also many of the studies are quantitative, giving the women no opportunity to explain their situation or attitudes further (e.g. Lia-Hoagberg *et al* 1990, Cook *et al* 1999, Schaffer 2002, Bloom *et al* 2004, Johnson *et al* 2007, Sunil *et al* 2010).

Travel as a practical barrier to care is not a universal finding however. Chisholm (1989) found a higher proportion of late bookers in Manchester (UK) living near to the hospital, whilst other authors from the USA and Canada suggest that practical barriers, particularly distance and transport, are far less significant than women’s attitudes to care and how they prioritise it (Omar, Schiffman and Bauer 1998, Nothnagle *et al* 2000, Sutherns and Bourgeault 2008). Similarly, although Dartnall *et al (*2005) found that changing locations impacted on GP registration and therefore on access (as illustrated by one of the women in the Sheffield study), such practical barriers were primarily linked to ‘mindset’: a lack of understanding of the role and value of the services themselves and subsequent lack of priority.

This concept of mindset is well illustrated by the women who were ‘on the move’ in the study, whose responses are suggestive of a differing set of priorities: a consideration of convenience and the value of early care, linked to location, health and past experience. There is little discussion in the literature of women’s mobility during pregnancy and its impact on access to care, though transient lifestyles were identified previously by Mackey and Tiller (1998) and this was a contributing factor for one woman in the Sheffield study. Callaghan, Buller and Murray*’s* (2011) London-based qualitative study acknowledged that urban populations are diverse and mobile, and that travel during pregnancy is now common. Late booking was strongly associated with moving during pregnancy in the Sheffield study.

In Callaghan, Buller and Murray*’s* study the late booking women who had travelled while pregnant all received antenatal care outside the UK, so would not have met the criteria as late bookers in the Sheffield study. In contrast, in Sheffield five women chose not to attend for any care until ‘home’: a place of perceived trust, familiarity and safety. Some women were able, but chose not, to access early care where they were, choosing other priorities in their lives. One woman recounted a negative experience abroad which had influenced her decision not to access care until back home, despite a prolonged period outside of the UK. The women’s stories illustrated again how perceptions of the value and convenience of antenatal care affect women’s attitudes towards its acceptability, in terms of timing, portability and necessity. They also identified the importance women place on a familiar environment for such care; reflecting their desire for home based care which is a good ‘fit’ to their lives: local, familiar and trusted.

**6.3.3.5 Taking control, protecting the pregnancy: self-care**

The Bristol Antenatal Care Study found both primigravid and multigravid women considered ‘the way you look after yourself in pregnancy’ to have the greatest influence on pregnancy outcomes; suggesting internal control and a lack of association with the belief that antenatal care makes a difference (Jewell, Sanders and Sharp 2000). The authors acknowledge that women do have opinions about their care:

*“some women, even at the beginning of their pregnancy, will hold clear views about the type of antenatal care they wish to receive”* (Sanders 2000: 173)

or, by implication, care they do not wish to receive. As Browner and Press (1996) identify, women seldom follow medical advice uncritically: they reflect and evaluate, pick and choose, using and discarding advice according to internal and external influences (the ‘weighing up’ considered previously).

In the Sheffield study, where women had other priorities and had made the decision to avoid or postpone antenatal care, they demonstrated differing strategies to deal with their decision. For some women it was simply denial, a refusal to acknowledge publicly their pregnancy, a passive acceptance of delay or ‘hoping for the best’ based on instinct (“*I just assumed I’d be all right”).* However, others demonstrated a more active, considered approach to their pregnancies, engaging in a process of self-care. Authors have suggested differing views of this process. Sword (2003 (CAN)) suggests it underpins all the decisions a woman makes about her pregnancy:

*“taking care of self is the overarching concept used to described the basic consideration inherent in women’s decision making regarding prenatal care use”* (p330)

Also, as Peacock *et al* (2001) observes, pregnant women engage in a wide variety of self-care behaviours, even prior to accessing care. Two women in the Sheffield study expressed a confidence in managing their pregnancy themselves, not needing mainstream antenatal care. They undertook what could be described as ‘DIY antenatal care’, an active process of monitoring the progress of the pregnancy and staying well, as a substitute for conventional care, until they were at an advanced gestation. For these women self-care provided a coping strategy, a way of avoiding or bypassing the ‘social pregnancy’, but for very different reasons. For one woman it formed part of a very private concealment of pregnancy and avoidance of antenatal care. For the other it was openly described as a temporary measure until she was able to access conventional care, while she waited for a ‘point of safety’ in her pregnancy, when the termination her husband wanted her to have was no longer possible.

Peacock *et al* (2001) and Callaghan, Buller and Murray (2011 (UK)) both discuss other cases where women resisted perceived pressure to have a termination, resulting in their delay to access antenatal care. In all these cases women feared the judgement of others and particularly someone else’s choice being forced onto them, and wished to take control of and ‘protect’ their pregnancies from outside influence. For one of the women mentioned above ‘protecting’ involved creating a safe space away from the threat (her husband) and waiting. As discussed in chapter five, the two women explicitly (and others implicitly) used their experience of pregnancy, both direct and indirect, to make sophisticated assessments of the progress of their pregnancies. This self-reliance was seen as a positive, purposeful thing by the women, who were determined to take control, stay well and informed, and make their own choicesabout the pregnancy: as identified in previous literature (Omar, Schiffman and Bauer 1998, Roberts *et al* 1998).

Some authors have presented this self-care in negative terms, as passive non-attendance based on ignorance. Johnson *et al* (2007) suggest that it is a barrier to care, linked to not valuing antenatal care and an attitude of being able to take care of one’s self, seeking emergency care only if necessary. A traditional perspective of pregnant women ignorantly assuming self-care to be sufficient is given by Mayer (1997), who states that women

“*may have correctly considered pregnancy to be a normal and healthy process, but incorrectly concluded that this obviates the necessity of preventative care”* (p250)

This study suggests a more positive view, echoing Sword’s qualitative research (2003 (CAN)), who describes this care as a means of self-reliance, part of a strategy for women to take control of their pregnancies, making choices themselves, when they feared this control and choice would be removed. She identifies that women perceived this to be the best choice, given their particular circumstances. In contrast to many other authors, Sword argues that women take an active rather than the assumed passive role in their care, and make choicesfrom an informed, rather than ignorant, perspective.

*“In contrast to beliefs about these women as passive non-users of the health care system, the notion of taking care of self positions them as self-determining individuals who make purposeful and rational choices about use of programs and services”* (p331)

This positions such women as active participants in their pregnancies (again, reflecting Jomeen’s (2006) view of women taking personal responsibility for their pregnancies), in contrast to Kirkham’s view of pregnant women as ‘consumers’ of maternity services: *“still a relatively passive role for life’s most creative act”* (Kirkham 2010a: 3).

Similarly, Patterson, Freese and Goldenberg’s(1990)US qualitative study describes this as part of a process of women ‘waiting’, and ‘seeking safe passage’ for their pregnancies, and suggests that *“women did what they believed was adequate to promote safe passage”*  (p30). The concept of ‘ensuring safe passage’ for themselves and their babies during pregnancy is also expressed by Rubin (1984), as an important task in the creation of a woman’s maternal identity. This included gaining knowledge from different sources, self-monitoring, self-care and contingency planning if there was any perceived threat to the pregnancy, with women assuming personal responsibility for their pregnancies and taking an active role. This was particularly evident amongst multiparous women, who decided early care was not needed as they were healthy; avoiding practical difficulties with accessing care and making their assessment based on previous pregnancy experience, despite a fear of being reprimanded. Omar, Schiffman and Bauer (1998) agree, if in a somewhat qualified way, suggesting that multiparous women may have been empowered to determine their own self-care needs during this pregnancy based on past experience, and “*may have been able to make their own decisions about when to access ‘the system’”* (p246). For the women in Patterson, Freese and Goldenberg’s study this ‘waiting’ was often ended by others (sometimes reluctantly), or if the woman had physical symptoms or needed information and/or reassurance. These reasons were also given by many of the postponing women in the Sheffield study, who expressed considered views about what was appropriate care and when they would seek it. This again reflects women’s rationalisation and normalisation of their pregnancy experience, and their considerations of ‘candidacy’ for antenatal care.

This process of self-care presents women making choices from a considered perspective, associated with the belief that pregnancy is a natural state that does not require early professional intervention. From some women’s perspectives, taking control or charge of the pregnancy may be identified as an active and considered rejection of the ‘status quo’ of antenatal care, a positive rather than negative choice. This thoughtful process of self-determination echoes that seen elsewhere in healthcare research, such as Pound *et al’s* (2005) notion of ‘resistance’ to medicine taking, with non-compliance not simply a passive failure but the result of active engagement and decision-making by patients, demonstrating ingenuity and energy. Such resistance in pregnancy similarly represents a hidden or concealed process, a modification of the ‘norm’ in response to what Pound *et al* see as the coercion of traditional approaches (which could include antenatal care). Similarly, Brubaker (2007) observed a process of ‘embracing and resisting’ formal pregnancy care by pregnant teenagers; small assertions of autonomy over aspects of care, part of what Kendall *et al* (2005) call ‘asserting adulthood’. This concept of women challenging orthodoxy, in choosing to trust their own instincts about maintaining good health in pregnancy, requires further examination as it suggests a link to women’s health beliefs and/or a possible cynicism about the medicalisation of the ‘normal’ process of pregnancy.

**6.4 Delayed: barriers to care, accepting delay**

Some cases in the Sheffield study have highlighted the lack of a coherent approach between primary, community and secondary care towards the management of early pregnancy. A significant number of women in the study experienced administrative and professional failures. These were sometimes as a result of misdiagnosis of pregnancy or mis-estimation of gestation, or a result of the incorrect scheduling of appointments, leading to and exacerbating other delays. However, there is little evidence of these factors in other studies, and where it exists the authors make no distinction between initial access and subsequent appointments, so it is difficult to assess its significance. York *et al* (1996) and Hulsey (2001) in the USA acknowledge that the lengthy enrolment process in some publicly funded care led to unavoidable delays in entering care for some women. However, as Callaghan, Buller and Murray (2011) observe, there is little acknowledgement in the UK literature that late booking does not always originate within women’s decisions or indecisions. Their London-based qualitative study identified several women who had been delayed by administrative failure, but made no reference to women’s attitudes to this delay.

The idea that women are prevented from attending for their initial antenatal care is a complex one. Common factors act to prevent women from accessing care, in terms of direct, practical prevention, but also indirectly through an influence on their acceptance of their pregnancy and understanding of antenatal care. Although for six women, professional and system failures were the primary reason for late booking, there were no cases where there were no other contributing factors (see appendix 4.15). Whilst initially appearing to have been prevented from attending for care, many of the ‘delayed’ women expressed other, more subtle opinions relating to their acceptance of the value, timing and portability of antenatal care.

Most significant in this study was women’s acceptance and lack of challenge of delays. On first examination this appeared to be because of a lack of reproductive knowledge, particularly relating to the antenatal care ‘system’ and the appropriate timing of care, and primarily amongst primigravid women. Eleven of the 14 delayed women were primigravidas, two women were non-native English speakers and one multiparous woman had not experienced early care in her first pregnancy. As discussed in chapter five, lack of knowledge and misconceptions about antenatal care and what to expect were evident, and contributed to delayed access. Many US studies identify a limited understanding of the purpose, value and even location of antenatal care (Leatherman *et al* 1990, Harvey and Faber 1993, Johnson *et al* 1994, Teagle and Brindis 1998, Mikhail 1999), particularly amongst young women in their first pregnancies.

The Sheffield study, like others, demonstrates that a lack of familiarity with health care services, sometimes linked to difficulties with language, is a significant influence. Whilst not always a primary reason for delayed access, it may exacerbate barriers to care by compounding a lack of knowledge and limiting a woman’s ability to challenge delay (Kalmuss and Fennelly 1990, Schaffer 2002, Dartnall *et al* 2005 (UK), Tandon, Parillo and Keefer 2005). This has also been identified by several authors in relation to BME women and other marginalised groups (Firdous and Bhopal 1989 (UK), Gazmararian *et al* 1997, Dartnall *et al* 2005(UK)), who acknowledge that a poor understanding is linked to a greater likelihood of inadequate care. Language proficiency affects the active and passive acquisition of essential information, including the exchange of experience with other pregnant women(Alderliesten *et al* 2007).

However, primigravid women’s acceptance of the delays they encountered was also linked to other significant factors, namely their ‘mindset’ and preparedness for pregnancy, their relationship with healthcare professionals and the trust they placed in their professional opinion. The lack of empowerment and passive acceptance of professional opinion forms a significant part of the complex relationship of beliefs and behaviours identified in the study. One woman explained that she had built up a trusting relationship with her midwife in early pregnancy, so did not consider challenging her (incorrect) advice. Lack of knowledge was not a universal characteristic of the delayed women however, as several were well educated about pregnancy and antenatal care, either through experience or reading, particularly the detail of the content of care. Although antenatal care was seen as valuable, life circumstances and personal perceptions of their health and the necessity of care, sometimes as a result of past experience or the views of others, influenced women’s opinions of the timing of care and their acceptance of delay. This suggests that acceptance was as much a significant factor in women’s late attendance as prevention.

**6.5 Strengths and limitations of the research**

Women’s views are a fundamental part of research into maternity care, and as such researchers must ensure that women’s voices are heard. They should not be thought of as stand-alone extras to ‘hard’ clinical outcomes, but integral, having an impact on such outcomes and playing a key part in their assessment (Jomeen 2006, Green 2012). However, Novick (2009) suggests that despite decades of recommendations for women-centred approaches to antenatal care, women’s experiences of antenatal care are still relatively unexplored. Goldenberg, Patterson and Freese (1992) expressed similar views, in relation to antenatal access:

*“it appears that far more emphasis must be placed on understanding the woman’s motivation for seeking care, the psychological characteristics associated with failure to obtain that care, and the actual sequence of events or pathways a woman travels to enrol in care”* (p147).

Since the Sheffield research commenced in 2007, there have been several systematic reviews published of the literature around antenatal access and initiation (for example those presented in chapter two), though these are dominated by quantitative research from outside the UK and a focus on antenatal access in general. In addition to the Sheffield study (Haddrill *et al* 2014), only one other UK-based study has been published recently concerning women’s perceptions of antenatal access, and in particular the initiation of antenatal care: the London-based qualitative study by Callaghan, Buller and Murray (2011). The qualitative findings of another London-based (mixed methods) study remain unpublished (Cresswell *et al* 2013, Hatherall 2013). There are many similarities between the two published studies, and they share many of the same findings. However, the sample size was larger in the Sheffield study, which only included women booking for care from 20 weeks gestation; in comparison to women booking after 12, 22 and 28 weeks in the London study, but which also included women who had received early care elsewhere.

The Sheffield study has listened to the voices of a group of late booking women, considering their status and their choices in relation to pregnancy; their assessment of risk and the relevance of care. The explicit focus of the research has been the women’s perspective, in contrast to many quantitative studies of late booking which have been driven by the perspectives of professionals (Carver and Ward 2007). Sword (1999) comments on the limitations of such research:

*“To date, knowledge about barriers to prenatal care has evolved largely through positivist research approaches and, therefore, is based on what service providers and researchers perceive as important factors… their views may not be congruent with those of women… fails to provide insight into the social context of meanings associated with behaviour”* (p1174-5).

A US mixed methods study on non-attendance for antenatal and postnatal appointments found that women had more complicated and emotional reasons behind their missed appointments, such as embarrassment, than those identified on the quantitative survey (Quinn, Detman and Bell-Ellison 2008). The authors argue that women’s reasons for not accessing care are complex and subtle. Cognitive barriers about the perceived value of care may outweigh structural barriers, but reporting structural barriers may be easier or the only option provided in a fixed-choice survey. This emphasises further the strength of qualitative research in relation to healthcare attendance.

Qualitative methods can enrich our knowledge of health and health care and are aligned with the health promotion ideology of empowerment and the emancipatory focus of much feminist research (Sword 1999, Mays and Pope 2000, Willis 2007, Bryman 2008). At the heart is pragmatism. As Strauss and Corbin (1998) argue, the theories that result from inductive methodologies, such as those influenced by grounded theory, can be used not only to explain reality but to provide a framework for action. Sandelowski and Leeman (2012) talk about translating thematic statements into the language of intervention and implementation, to enhance the accessibility and utilisation value of the findings. This was always the intention for this study. Throughout the research there has been a professional consideration (and reconsideration) on my part of the necessity and value of early antenatal care, and of ways of improving access. As a midwife I have a strong belief in the value of antenatal care. I want women to come for care early and regularly during their pregnancies because, like other midwives, I see it as a positive health intervention. Though I acknowledge its limitations, I believe it makes a difference to women’s health and wellbeing, to their pregnancy experience and their preparation for parenthood, whether it is their first or subsequent babies. But I want women to come for care because they value care that is relevant to their lives, not because they feel compelled or threatened to attend by others, or by the need to accord to a social norm. This view has underpinned the research and has driven the suggestions for strategies to reduce late booking which are presented in the following chapter.

The aim of the Sheffield study was to understand the reasons why some women present late for antenatal booking. The intention was to create a study whose findings were believable, and might ultimately contribute to improving early access to antenatal care and outcomes for pregnant women and their babies. The study has used multiple techniques to reflect these aims and to ensure its quality and rigour. These are illustrated in appendix 6.1, which presents a critical appraisal of the Sheffield study, using the CASP Qualitative Research Checklist (CASP 2013). Previously utilised to appraise the evidence in the literature synthesis of chapter two, the intention was to subject this research to the same critical analysis. The techniques are also shown in table 6.5, using Lincoln and Guba’s framework for developing ‘trustworthiness’ in qualitative research, as previously discussed in chapter three (Lincoln and Guba 1985, Guba and Lincoln 1994).

In terms of the study’s credibility, transferability and dependability, a consistent approach has been demonstrated throughout. This is evident in the clear articulation of recognised qualitative methods, the presentation of findings from multiple perspectives and the interpretation of these in relation to previous research. These were developed through a multi-disciplinary process of supervision, independent verification of the data and critical challenge. Additionally, detailed presentation of the findings reflects the important concept of ‘thick description’, as previously discussed in chapter three. The accurate representation of the women’s data, for example using direct quotes and including contextual information, aims to give a sense of women’s ‘whole’ lives and contributes to the study’s confirmability and authenticity. This detail and transparency allows the reader to assess all aspects of the study and creates a vicarious experience of women’s late booking.

***Table 6.5 Techniques used in the study to ensure quality***

(using Lincoln and Guba’s framework for developing ‘trustworthiness’ in qualitative research - Lincoln and Guba 1985, Guba and Lincoln 1994, Shenton 2004)

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | | **Techniques used in the study** | | | | | | |
| **Criteria** | **Definition** | Use of recognised qualitative research methods | Interpretation of the findings, developed through a multi-disciplinary process of supervision and debriefing | Presentation of multiple perspectives and the interpretation of these (data triangulation) | Clear articulation of methods, findings and interpretation, to demonstrate consistency (audit trail) | Detailed presentation of findings and comparisons with previous research, using ‘thick description’ | Considerations of reflexivity – promoting honesty and openness | Accurate representation of data, e.g. using direct quotes from women and including contextual information |
| **Credibility** | Is the study believable? |  |  |  |  |  |  |  |
| **Dependability** | Could the findings could be replicated with similar participants and context? |  |  |  |  |  |  |  |
| **Transferability** | Could the findings be extrapolated to other settings/groups/contexts? |  |  |  |  |  |  |  |
| **Confirmability** | Does the study give an accurate representation of the data and its interpretation? |  |  |  |  |  |  |  |
| **Authenticity** | Does the study give a fair and honest reflection of the range of women’s lives and experiences? |  |  |  |  |  |  |  |

Such techniques also enable the reader to evaluate the relevance of the findings to other groups or settings. However, this evaluation must acknowledge qualitative research’s recognition of the changing nature of phenomena and participants, and the interpretive and constructivist perspective that understanding is co-created. Therefore the context and findings of each study are unique and are not generalisable in a quantitative sense. Both the quotes and the interpretations of the findings are open to further interpretation by the reader (Jomeen 2006). Such research therefore provides insight, one layer of interpretation, whereby the reader may judge its transferability.

## *6.5.1 The women*

The challenges of conducting a study about lack of engagement with antenatal care in a population of women stereotypically seen as ‘hard to reach’, e.g. vulnerable and socially disadvantaged, must be acknowledged. There were many difficulties associated with recruiting women to the study. Women’s reticence, differing priorities, but also the clear opportunities to withdraw from the study, were reflected in the low response rate amongst the women after initial consent to participate. Challenges with recruitment have prevented the ‘member checking’ that could have been valuable for validating the study’s findings, though there are many criticisms of the method (Polit and Beck 2012).

Achieving a truly diverse sample ethnically was not possible, as non-English speaking women were unable to participate due to the lack of interpretingprovision. The views of the very small number of women in Sheffield each year who did not receive any antenatal care at all were also excluded, as these women declined to participate. This would have added another dimension to the results. However, recruitment took place over 22 months during which snowballing methods and active engagement with key health and social care practitioners were undertaken. This, in combination with some women’s reluctance to participate, lengthened the recruitment phase and has inevitably influenced the findings. However, the overall diversity, size and exclusivity of the sample, within the context of qualitative research, suggest a rigorous and largely successful process.

The focus of this study has been the diversity of views of late booking women across the social spectrum, in comparison to most previous studies which have targeted low income or vulnerable women from specific communities. As table 5.1.1 illustrates, the women in the study were diverse in terms of age (from 15 to 37 years), parity (zero to four) and socioeconomic status; including occupation (students, unwaged and those in a range of jobs, including service and professional occupations), educational attainment (from secondary only to university graduates) and the deprivation ranking of their home address. This may be considered a strength or a weakness. Gestation at hospital booking, rather than the initial community-based appointment, was chosen to examine whether external as well as personal factors were influential. This has contributed to the diversity of the sample, including those for whom pregnancy discovery was delayed, those who initiated care later and those who were delayed by ‘the system’, and has provided a range of perspectives and experiences not usually recorded. There have been many (unexpected) overlapping views across the sample. Many of the women would have been considered low risk antenatally, had they not booked late, and therefore arguably are of less concern to maternity policy makers. The study has not focused on pregnancy outcomes. As discussed in the introduction, Downe *et al* (2009) suggest that these ‘low risk’ women might be expected to maintain a normal pregnancy, regardless of the number of antenatal visits. However, all the late booking women missed the opportunities provided in early pregnancy for screening and/or support. This has the potential to influence women indirectly; as a minimum it may be linked to reduced breastfeeding and poorer psychological status, and difficulties with newborn attachment.

***6.5.2 The interviews***

One major strength of the study was interviewing women antenatally, shortly after their first booking appointment, in contrast to 35 of the 47 primary research studies included in the synthesis which interviewed women postnatally or both antenatally and postnatally, in some cases several years after the birth. As Novick (2009) observes, women are unlikely to criticise their antenatal care postnatally, after the safe arrival of their baby; also women’s recollections of early pregnancy will change over time.

The study’s flexible and iterative methods of data collection and analysis were informed by the inductive approach of grounded theory, and were, in many situations, effective at generating rich data about attitudes towards antenatal care. This process continued, as previously discussed, to a point of data saturation. The individual interview method aimed to minimise power imbalances in interviews, and the location of interviews was also influential in this respect, encouraging women to talk openly and honestly about their experiences. This was reflected in the findings. Women interviewed in their homes, particularly those who had not realised they were pregnant, were generally open and happy to talk in detail and at length about not accessing care. Similarly, women who had experienced professional or system failures were angry or frustrated and keen to tell their story.

However, there was a need to know not just what the women thought and did, but also why, that was not always fully explored, due to a lack of depth in some of the interviews (Green 2012). Recognising the complexity of women’s views and allowing them to be expressed completely was challenging, given many women’s reticence and my inexperience as an interviewer. This lack of experience was particularly evident when interviewing women who had postponed or avoided care. A poor exploration of the influence of previous pregnancies and antenatal care, amongst multiparous women, is a particular limitation to the study. It is also inevitable that my own background and position, as a midwife, was influential. There are challenges with the relationship between any researcher and participant, but arguably even more so between health professional and ‘client’, as some women would have perceived the relationship. Hennings, Williams and Haque (1996) also argue that there is an assumption that a female researcher has an automatic affiliation with female participants by virtue of their shared gender, but that this may be the only characteristic shared. These influences, combined with the interview environment and its timing, came to the fore in hospital-based interviews. Women interviewed in clinic, often the women who had concealed their pregnancies, were reluctant to talk about non-access, being quite closed and defensive in their responses. This suggests that they felt that they would be judged and/or criticised by me as a midwife, or by the healthcare ‘establishment’ in general, for making the wrong choices (Kirkham 2010a, Jomeen 2012).

The use of field notes taken at the time of (and immediately following) the interviews, was underdeveloped, in part due to my inexperience with qualitative methods. Such notes should represent the interviewer’s *“efforts to record information and also to synthesise and understand the data”* (Polit and Beck 2012: 548) but were largely descriptive, rather than analytical, and lacked detail: the ‘thick description’ previously mentioned. The notes were, with hindsight, of limited value. Note taking could have been used more effectively to complement the interview data and to support the inductive process of thematic analysis, providing a greater contribution to the more conceptual and analytical memos and diagrams that were created subsequently.

***6.5.3 Reflexive considerations***

As discussed previously, the perspective of the researcher shapes all research. My background, and the multidisciplinary influences of the supervisory team, have been influential. However, as Malterud (2001b) comments, *"Preconceptions are not the same as bias, unless the researcher fails to mention them"* (p484). Considerations of reflexivity are evident in the methods used, the presentation of the findings and the interpretation of these, and are a significant influence on the study’s authenticity and credibility. I have attempted to acknowledge both aspects of reflexivity (as suggested by Schwandt 2007), and provide an honest interpretation of the findings, by

1. acknowledging my part in the phenomenon of late booking and its Sheffield context;

2. self-reflecting on my own biases, preferences and involvement in the research, and theoretical inclinations , throughout the study.

I recognise that my background as a midwife in Sheffield, albeit not one involved in the clinical care of the women interviewed, has played an integral part in the construction of the findings from this study. I have attempted to establish a relationship of openness, trust and mutual understanding with the women in the study, whilst being honest about my role and the ‘distance’ between myself and the participants. I have never obscured my status and, as previously discussed, this has had both positive and negative effects on my relationship with the women interviewed. It may have influenced women’s responses and their need to present themselves as the ‘responsible pregnant woman’ previously discussed.

I have tried to be aware of my prejudices and how they might be influential. Certainly my view of late booking at the beginning of the research was very different to many of the women interviewed. This grew into a deeper understanding of women’s priorities and choices as the study progressed; reflexive thinking acknowledges that the potential influence works in both directions (Lambert, Jomeen and McSherry 2010). However, my intention has always been to ensure, as far as possible, that the study’s findings reflect the experiences and perceptions of the participants, rather than my own characteristics and opinions. Overall, the research has sought to focus on listening to women and critical thinking beyond the accepted conventions about antenatal care attendance (Smythe 2011), whilst remaining sensitive to its context as health services research. As discussed in chapter three, I have reflected both on the status of the women in the study and the choices they made, but also on the necessity and value of early antenatal care from a professional perspective. These factors, alongside the methodological and theoretical openness, a consideration of the influence of the social setting, and an awareness of the wider context of the research evident in the thesis, allow the reader to judge its trustworthiness and potentially its value in enhancing practice (Green and Thorogood 2014).

**6.6 Conclusions**

The findings of this study, considered alongside previous research into late booking, suggest that the timing of initial access to antenatal care is determined by a spectrum of choices, from acceptance through a more passive non-acceptance to an active rejection of the pregnancy and/or the need for antenatal care. Cognitive, emotional and personal factors and environmental influences are all interacting determinants, operating within different domains and at multiple levels (Sword 1999). Chaotic lifestyles, lack of knowledge and economic deprivation all influence women’s perceptions of their healthcare needs and priorities. The themes from this study suggest a different emphasis however, across the social spectrum. Whilst vulnerable groups are strongly represented in this cohort, women do not always fit a socio-cultural stereotype of a ‘late booker’. Rather, many women illustrated a different set of priorities regarding antenatal care, relating to its relevance, convenience and familiarity. They used their previous pregnancy experience and embodied knowledge, and good health, and take an active rather than passive role in their pregnancies to ensure wellbeing. There was also greater emphasis on the lack of a pregnancy ‘mindset’ relating to the expectation of becoming pregnant, which influenced women’s acceptance of their personal pregnancies, and the creation of a woman’s pregnancy identity as part of her ‘social pregnancy’. All these factors are linked to women accepting delay, even when this originates from professional or administrative failures.

Inevitably, comparisons with other research, particularly from outside the UK, need to be undertaken with caution. Distinct, whilst overlapping, factors will influence antenatal care initiation and continuation, though these are not differentiated in some studies. The overwhelming majority of research conducted into antenatal attendance is from the USA (83% of the primary research studies in the synthesis in chapter two), where there are significant differences in the organisation of healthcare. The influence of models of care based around privately funded rather than universal antenatal care provision has been significant, with some studies demonstrating a considerable financial element to women’s non-attendance (Philippi 2009). Additionally, a recent comparison of USA and UK low-risk antenatal guidance found only 56% of quality indicators were the same, suggesting differences in practice and professional norms (Bollini and Quack-Lötscher 2013). This is likely to be reflected in women’s attitudes and patterns of attendance. The medical focus of maternity care, and the lack of midwife-led care in the USA and in some European countries could also be influential. This is only mentioned generally in other research, in the context of women, usually BME women, preferring female carers during pregnancy.

However, despite differences in care provision between the USA and UK, Bollini and Quack-Lötscher (2013) acknowledge that antenatal guidelines (and others from Europe and Australia, as discussed in chapter one) have the same recommendation for early booking, ideally before ten weeks gestation. Several US studies have surveyed women in receipt of free antenatal care (Gazmararian *et al* 1997, York *et al* 1999, Braveman *et al* 2000, Nothnagle *et al* 2000) to exclude financial barriers, finding negative attitudes towards unintended pregnancies a common theme. Delvaux *et al’s* (2001) study in ten European countries found convenience issues and cultural barriers, alongside unintended pregnancies and women feeling that medical care was unnecessary, rather than the direct cost of care, were most significant. This suggests that differences in health service structures and care provision between countries may be a less significant influence on late booking than at first appearance.

The women’s reflections on their late booking have emerged as an additional area of interest from the study data. For example, the perception amongst some women that delayed access was a positive thing, with an impatience for the pregnancy to be over as soon as possible, has not previously been identified. These findings reveal another layer of attitudes and behaviours influencing access, further pieces in the late booking ‘jigsaw’, which merit further consideration. Ultimately, booking for antenatal care is an act of engagement with the NHS maternity system, an approach to pregnancy and a model of care which women may or may not understand, may embrace or accept as convention only, or may even not subscribe to. Care must be responsive to such a range of acceptance. Women place importance on feeling accepted when attending for appointments, however acceptance works on both sides (Carolan and Cassar 2008). Professionals need to accept women’s embodied knowledge and experience and use this to individualise care, whether physical, psychological or educational. In turn, women need to be enabled to recognise the value and relevance of such care to their pregnancies.

In *The Woman in the Body* (1989), Emily Martin considers the complex interaction of the biological and the social components of women’s health, and the need for an integrated understanding of the relationship between them. She gives the example of the baking of a cake, the contribution of the ingredients together rather than individually and the processes that transform them. Whilst the factors contributing to late booking can be identified individually it is the consideration of their interaction and integration that holds the key to improved access to early antenatal care. Chapter seven considers this interaction and integration and how the findings of the study may influence future maternity care policies and practice, alongside suggestions for future research around the subject of late booking.

**Chapter 7: Recommendations to reduce late booking and for further research**

**7.1** **Introduction**

The aims of this thesis are pragmatic; namely, to try to understand delayed access to antenatal care from the woman’s perspective, and ultimately to contribute to improvements in early access to antenatal care and outcomes for pregnant women and their babies, by encouraging changes in practice and policy. Reflecting these aims, chapter five has presented the findings of a qualitative study undertaken in Sheffield to ascertain the perceptions of late booking women. Chapter six has considered these findings and discussed them in relation to existing research around pregnancy, antenatal access and attitudes towards care. To conclude the thesis, chapter seven will consider strategies to reduce late booking for antenatal care, and possible directions for further research around the subject.

Antenatal care originates from models developed in Europe in the early decades of the 20th century (Oakley 1982). It has been argued that the content of antenatal care is more ritualistic than rational and the evidence for its benefits is far from clear, particularly for low risk women (Enkin *et al* 2000, Dowswell *et al* 2010). Late initiation of antenatal care is associated with poor maternal, fetal and neonatal outcomes, but with many complicating factors, as discussed in chapter one. However, at its simplest, contact with a midwife early in pregnancy has the potential to give women more time to make informed choices about their care, and to ensure they can take advantage of all the support and screening available. Evidence suggests that this will improve the likelihood of women receiving appropriate care and achieving better health, emotional and psychological outcomes (Shribman 2007, National Childbirth Trust (NCT)/RCM/ RCOG 2012).

For healthy, low risk women this support can be as significant as the prevention of pregnancy complications, through health education and promotion and lifestyle advice, reducing the risk of conditions such as antenatal and/or postnatal depression and increasing the likelihood of breastfeeding, with its concomitant health benefits. Research has also found longer term benefits, because the experience families have during pregnancy and postnatally influences their long-term health, wellbeing and their use of health services in general (NHS Commissioning Board 2012, Cresswell *et al* 2013). Women who have positive experiences with antenatal care are more likely to be socialised into the ‘system’ of family health and health surveillance, for example attending baby and child clinics and accessing preventative services such as contraception, immunisations and developmental assessments (Tandon, Parillo and Keefer 2005, Quinn, Detman and Bell-Ellison 2008). For young women and women from outside the UK this may be particularly important, as pregnancy may be the first time they access regular healthcare.

The pragmatic aim of the Sheffield study (and this thesis) follows ethical principles for research, which argue that researchers should not take sides but rather ask what potential contribution they can make to solutions (Green and Thorogood 2014). As other authors have identified, there is a need for culturally sensitive, patient-centred and appropriate interventions to improve early and consistent access to antenatal care (Cresswell 2013). However, determining the dimensions and detail of such interventions is challenging. As Jomeen (2012) observes, pregnant women are not a homogenous group; they are individual, complex and multi-dimensional. Access to care is a dynamic process, involving the interplay between a woman, healthcare professionals and the setting for care (Phillippi and Roman 2013). As discussed in the previous chapter, the timing of initial access to antenatal care is determined by a spectrum of choices, from acceptance through to a more passive non-acceptance and at the extreme an active rejection of the pregnancy and/or the need for antenatal care. This suggests a linear process, however the reality is often less structured, a combined ‘web’ of these choices bound up (in some cases) with organisational and practical barriers to care.

This reflects the multiple interrelated influences on women’s acceptance of their personal and public pregnancies, and their decision to access early antenatal care. An interaction of psychological, social and demographic factors must be negotiated prior to a woman’s first antenatal appointment (Downe *et al* 2009, Philippi 2009). As this research and previous studies have identified, logistical/practical barriers during pregnancy appear to play a relatively limited role in the late initiation of care (Bloom *et al* 2004). Rather, the findings suggest that late booking is linked to reproductive knowledge and pregnancy expectation, anxieties about the consequences of pregnancy and considerations of the relevance and priority of antenatal care. Understanding the complexity of this decision-making process and the priorities women set during pregnancy is essential, in order to consider any interventions to improve access to antenatal care (Sunil *et al* 2010).

There is a widespread recognition of the need for an integrated ‘life course’ approach to optimising women’s health; an approach which maximises collaborative opportunities and ‘joined up’ thinking (Willems van Dijk, Anderko and Stetzer 2010, RCOG 2011). One of the RCOG’s stated steps to achieving this is

*“removing financial and healthcare provider barriers to seamless integration of services across the interconnected phases of a woman’s life including contraception, preconception, antenatal and postnatal stages”* (RCOG 2011: 6)

The Marmot Review (Marmot *et al* 2010) shares this recognition of the need for action across the life-course, both antenatally and postnatally, to reduce adverse outcomes of pregnancy and infancy. As the Sheffield study has also shown, the way in which women decide what they want from their antenatal care, and the choices they make, are not straightforward. They are influenced by many factors such as past experience, personal commitments, family influence and the care setting (Hirst *et al* 2003). Improving early booking and birth outcomes (and thus reducing infant mortality) therefore requires a comprehensive focus on all of the *“social, environmental, biological, and behavioural determinants of health”* (Willems van Dijk, Anderko and Stetzer 2010: 99). As suggested above, solutions need to be tailored to different situations, with multiple approaches from different directions. This again has been acknowledged by the RCOG in its consideration of women’s lifelong health:

*Changing health behaviour… requires long-term, multifaceted strategies involving cross-sectoral agencies and recognition that a ‘one size fits all’ approach is unlikely to succeed.”* (RCOG 2011: 4)

Antenatal guidance focuses around providing women with care appropriate for their gestation, rather than encouraging them to attend in the first place. There is an underlying assumption that women will attend (NCCWCH 2008, RCOG 2008). Any care provided at a woman’s *initial* attendance is therefore an influence on whether she, or other pregnant women she knows, will prioritise such care in future pregnancies. The complexity of the challenge concerning late booking is reflected in the focus not on solutions but on targets and monitoring, as evident in NICE guidance and local strategies for reducing infant mortality, with their recommendations to establish regular reporting systems and ‘achieve’ levels of early booking (NCCWCH 2010, Greig and Burrows 2012). Arguably this is only part of the solution.

This study has identified three overlapping themes amongst late booking women: those who did not know that they were pregnant (not knowing), those who knew but chose to avoid or postpone care (knowing), and those who were delayed by professional and administrative failures (delayed). Lack of pregnancy intention or expectation was an overarching factor amongst all three groups of women. Recommendations to reduce late booking reflect these themes, the pragmatic Health Services Research focus to the study and my professional expertise as a midwife. Three interacting recommendations are proposed, resulting from the consideration of existing policies and previous research, in addition to the findings of the Sheffield study. These aim to consider, and influence, both women’s personal and public (social) pregnancies. They reflect general priorities identified by NICE for women with complex social factors, namely improvements in

* service organisation,
* care provision,
* training for healthcare staff,
* information and support for women, and
* woman-centred care (NCCWCH 2010).

The recommendations are intended to work concurrently and collectively, and be integrated across education, health and social care services. Whilst the focus of these proposals is improving initial access to antenatal care, there are many suggestions which apply to care throughout pregnancy and postnatally too, given the potential influences on both current and future pregnancies. The three recommendations are:

1. **To address unintended pregnancies**: developing strategies for improving reproductive knowledge (including contraception, the recognition of pregnancy signs and symptoms, and the value of early antenatal care) amongst women, their families and peers;
2. **To facilitate easy access to care**: streamlining and clarifying processes for access to early antenatal care; and
3. **To provide woman-centred antenatal care:** care which women perceive as relevant and valuable, and are willing to prioritise. This entails the provision of individualised and flexible care which reflects women’s needs during pregnancy.

These are discussed in detail in the following section.

**7.2 Three recommendations to reduce late booking**

***7.2.1 1. Addressing unintended pregnancies***

The recommendation to address unintended pregnancies considers ways of improving women’s reproductive health literacy, including knowledge of pregnancy prevention and planning, but also a woman’s recognition of pregnancy and the value of early antenatal care. Such health literacy has the potential to influence a woman’s pregnancy mindset, related to her intention and expectations of becoming pregnant, but also her attitude towards accessing care. As discussed in the previous chapter, lack of pregnancy planning and expectation are the most common factors related to the late initiation of antenatal care. Research from the USA suggests that an estimated 49% of pregnancies are unintended (defined as mistimed, unplanned or unwanted) (Finer and Zolna 2011). Links between unintended pregnancy and negative maternal and child health outcomes have been identified; consequently reducing unintended pregnancies has been adopted as a national goal in the *Healthy People 2020* campaign (Grindlay and Grossman 2013). Similarly, figures of 40-50% in the UK have been cited (CMACE 2011, RCOG 2011), and *“preventing unplanned pregnancies”* identified as a challenge for clinical commissioners (NHS Commissioning Board 2012: 12). In the Sheffield study the proportion was even higher, with 17 of the 27 women stating that they had not planned to become pregnant.

There are some difficulties with the concept of pregnancy planning, as there is considerable variation in the definitions of a planned pregnancy. Some authors have identified that pregnancy planning is not part of how women view their pregnancies, is not used by the majority of women and is resisted by some. As Barrett and Wellings (2002) note, pregnancy planning is more than just stopping contraception, but linked to agreements and wider preparations. Kendall *et al* (2005) argue that becoming pregnant ‘accidentally’ enables a woman and her partner to avoid the decision of whether to deliberately enter parenthood, and may be a conscious choice. The authors also consider a ‘planned pregnancy’ to be a middle class concept, foreign to many women, primarily because it assumes women are the locus of control for such decisions, but also because of lack of reproductive knowledge, economic disadvantage and social or cultural norms. The language of any health messages needs to reflect this focus on pregnancy intention rather than planning.

Many authors consider reducing barriers to effective family planning to be an integral part of any solution to unintended pregnancies (Braveman *et al* 2000). Contraceptive use, like late booking, is multi-faceted, with many factors affecting women’s preferences and their ability to use contraception or to postpone a pregnancy. As the Sheffield study illustrates, women *“present a complex story to support their childbearing decisions”* (Kendall *et al* 2005: 310)reflecting multiple circumstances and desires. Again, a more holistic view of a woman’s reproductive health, through her life course, and reproductive health targeting, needs to be adopted to reflect this complexity. A key recommendation in the most recent UK maternal mortality reports is for pre-conceptual discussion/education as an integral part of routine maternity services, for women with pre-existing medical conditions, but ideally for all women planning a pregnancy (CMACE 2011, Knight *et al* 2014). However, the 2011 report acknowledges that given the large proportion of unintended pregnancies there is a need for opportunistic reproductive health reviews and education, and contraceptive counselling in community settings.

As the Sheffield study suggests, for a small number of (potentially the most vulnerable) women preventative factors may influence their acceptance and decision-making in relation to pregnancy. Lack of reproductive knowledge could be part of this. Teenage pregnancy rates in England, though falling, remain the highest in Western Europe (Dugan 2014). Some women, particularly young women, may have little knowledge and experience of formal health care, and limited knowledge about sexuality and pregnancy, prior to becoming pregnant (Brubaker 2007). To address this therefore requires educational interventions prior to conception as well as in early pregnancy.

Such women need access to flexible reproductive health services and information. Most important is the dissemination in primary care of clear and concise health promotion and education messages about reproductive health, including the limitations of contraceptive methods. However the existence of lay hindrance and a lack of active engagement in care seen in this study suggest a need for improved promotion of the value and relevance of early antenatal care generally in the population, not simply among women who might become pregnant. This reflects the influence of a woman’s social network on her pregnancy, as previously discussed. It necessitates adopting a broader approach, across health, social care and education settings. This would include (where appropriate) key messages for pregnancy preparation, the signs and symptoms of early pregnancy, access to early antenatal care and the models of care available to women, stressing the importance of early booking (RCOG 2002). In combination with the wider use of pregnancy testing kits, in all settings, this may facilitate earlier recognition of pregnancy and access to care. The RCOG (2011) has also acknowledged the significance of peer influences on women’s health behaviours: *“Behaviour change is more likely if it is part of greater health literacy involving exchange of information between peers, rather than from the top down.”* (p4). Reaching others is key to addressing the social and cultural norms of late booking that were evident amongst some women in the study.

NICE antenatal guidance (NCCWCH 2010), particularly aimed at women from outside the UK, recommends that women should be provided with information about pregnancy and antenatal services, including how to find and use them, in a variety of formats, settings and languages. Information about all aspects of reproductive health needs to be aimed not only at women across the childbearing spectrum but also their families, partners and peers, with different messages tailored to different groups and communities. There is a role for community-based information and advice campaigns about early pregnancy symptoms and care, particularly targeting areas with higher than average late booking. Early access to maternity services in Sheffield has improved following a targeted communications campaign informed by a health equity audit (NHS Sheffield 2010) and influenced by the findings of this study (Greig and Burrows 2012). This echoes RCOG guidance (2008), that campaigns and materials should be targeted towards women in groups and communities who under-use maternity services or who are at greater risk of poor outcomes. Such information needs to use a variety of methods, locations and both low and high technologies to reach new audiences, to ensure health services are responsive to all women’s needs (Gaudion, Godfrey and Homeyard 2009, RCOG 2011).

Formal education has a part to play in this reproductive health literacy. The government’s *Sex and Relationship Education Guidance* (Department for Education and Employment 2000) for schools identifies that the key task for schools is, through appropriate information and effective advice on contraception and on delaying sexual activity, to reduce the incidence of unwanted pregnancies, particularly teenage pregnancies (Long 2014). There have been criticisms of inadequate teaching in a large number of schools however, particularly those not following the National Curriculum, and comments from health campaigners that better teaching around consent, relationships and sexual health would contribute to safer and healthier young people (Burns 2014). In relation to pregnancy the guidance mentions addressing *“the consequences of one’s actions in relation to sexual activity and parenthood”* (p10), providing young people with information about how they can access local sources of advice, and the benefit of using other young people, such as teenage mothers, as peer educators. With a change of emphasis all of these could be employed, alongside preventative strategies, to provide key messages around early pregnancy recognition and the purpose and accessibility of antenatal care previously mentioned.

Highlighting the value of early care is important for multiparous women too. For such women, an improved emphasis on their six or eight-week postnatal appointments, particularly for those women at risk of or who have experienced poor pregnancy outcomes, such as giving birth prematurely or to a low birthweight baby, or who have booked late previously, may be effective. Such appointments are currently under-valued and poorly attended, again as women weigh up the benefits of attending, in terms of time, inconvenience and the potential costs involved (Quinn, Detman and Bell-Ellison 2008). They have the potential to highlight the value and relevance of early antenatal care for subsequent pregnancies, and offer opportunistic reproductive health reviews and education. The RCOG (2011) has recognised the need for such a joined-up approach to reproductive healthcare, which could have had a significant impact on many of the women in the late booking study:

*“A life course approach implies the need for greater integration of services across different sectors, both horizontally and vertically… For example, the traditional separation of contraceptive services and antenatal services hinders delivery of effective preconception care and postnatal contraception, both key to achieving control of fertility and healthy pregnancies and children. Through these services, women have multiple encounters with nurses, midwives, general practitioners and obstetricians who are well placed to deliver consistent health messages and more holistic care. Although about 40% of pregnancies are unplanned, contraceptive consultations can provide an important opportunity for discussion of preconception issues”* (p 5)

This might require taking such appointments out to the women, in the home or community setting, perhaps linked to the use of lay health workers. These have recently been identified in a Cochrane review (Glenton *et al* 2013) *“as a different and sometimes preferred type of health worker”* (p2), with a positive role in the development of services that recipients perceive as relevant, and in improving access to maternal and child healthcare. All these strategies have the potential to improve health literacy and women’s mindset around pregnancy and associated care. They may also contribute to enabling women to challenge misdiagnosis and delays in their care; a significant factor in the Sheffield study.

**Addressing unintended pregnancies**

**Recommendations for maternity care commissioners and providers:**

• Development of education campaigns around recognising pregnancy and the value of early antenatal care, aimed at all members of the community, to be located in GP practices, children’s centres, libraries, community centres, secondary schools and colleges. Use of a range of languages and formats, developed collaboratively with local groups from BME communities.

• Developing links with third sector organisations involved in sexual health, pregnancy and parenting, particularly those aimed at young people, such as Brook and Best Beginnings. This could include the development of mobile phone Apps relating to contraception, pre-pregnancy and early pregnancy health, with potential links to the national *1001 Critical Days* campaign (Best Beginnings 2015) or global WHO affiliated *1000 Days* campaign (1000 Days 2015).

• Prioritising of pre-conceptual discussions with GPs, and opportunistic counselling around contraception and pre-conception health in primary care.

• Formalising of postnatal follow-up for all women, but particularly those who have experienced complex pregnancies, poor outcomes or previous late booking – strengthening the handover from midwife to health visitor, practice nurse and GP**.**

• Trialling of lay health workers to work with postnatal women in relation to maternal and child health issues (again as part of *1001 Critical Days* campaign), particularly reproductive health (Glenton *et al* 2013).

***7.2.2. 2. Facilitating easier access to early antenatal care***

Facilitation is a key (external) aspect of the access process: optimising a woman’s ability to enter and maintain antenatal care. It has been argued by others that improvements to the clinical environment are integral to such facilitation (Phillippi and Roman 2013). Though the physical environment for care had little influence on women’s late booking in the Sheffield study (being more linked to USA studies of continuing care), broader influences on the clinical environment, in terms of deficiencies in the information offered and referral procedures, were evident influences. Improving the clinical environment, in its broadest sense, also connects to strategies for improving community-based information and advice on pregnancy and contraception, as suggested in recommendation one.

There is significant guidance in the UK aimed at facilitating access to early antenatal care. As mentioned in the previous section, NICE antenatal guidance (2010), particularly aimed at women from outside the UK, recommends that women should be provided with information about pregnancy and antenatal services, including how to find and use them. This echoes one of the RCOG’s *Standards for Maternity Care* (2008) which identifies that

*“Maternity services should be proactive in engaging all women, particularly women from disadvantaged and minority groups and communities, early in their pregnancy … Antenatal care should be readily and easily accessible to all women and the option for all women to access a midwife as the first point of contact should be widely publicised”* (p14)

Direct access to maternity care, and to midwives in particular, has been championed as beneficial in improving early access. This is evident in the NHS *Vision and Strategy: an Approach in Midwifery Care* (2012) which aspires to make midwives the first point of contact for pregnant women within ‘accessible maternity services’, with direct access to maternity services and booking by 12 weeks gestation. It has been reflected in many local initiatives. Sheffield’s *Early Access to Maternity Care* target includes the need to ‘establish and promote timely referral into maternity services’ (Greig and Burrows 2012). A pregnancy helpline/textline has been established, influenced by this research, as part of the community-based information and advice campaign about early pregnancy symptoms and care. Others schemes include fast-track booking in the West Midlands, linked to free pregnancy testing in pharmacies (DoH 2007b), NHS Bradford and Airedale’s *Direct Access to a Midwife* campaign (Bradford Teaching Hospitals 2011), and the establishment of central booking lines across Scotland to facilitate early access to antenatal care. Such schemes have been linked not only to improved access but also to an improvement in ‘health behaviours’: reduced smoking and substance misuse, and increased breastfeeding rates (RCM 2014: 8). This is in contrast however to research from the USA. A review of 10 years of national pregnancy survey data found mandated direct access to maternity care had not resulted in improvements in maternal health behaviours or infant health outcomes (Durrance and Hankins 2011). The authors recommend a focus on alternative policies.

In addition, the improved management of early antenatal care, a more ‘joined up’ approach which was identified as missing by several women in the Sheffield study, is required. Improved communication and co-ordination between community midwives, family doctors and reproductive and sexual health services, but also health and social care services that are outside of the NHS, could help to ensure the transfer of appropriate information, and the referral and follow up of women in early pregnancy. This could also minimise system and professional failures, but also provide the essential information and advice women need to encourage them to challenge any delays. Automatic pregnancy testing in primary care for women with unexplained symptoms could help to facilitate early access to antenatal care in some situations.It would have prevented the misdiagnosis and delay experienced by several women in the Sheffield study. The *NICE pathway on pregnancy and complex social factors* (NICE 2014) offers guidance for ‘enhanced care delivery’, and recommends that at the first contact between a pregnant woman and any healthcare professional, the need for antenatal care should be discussed. If the woman is continuing with the pregnancy a booking appointment in the first trimester should be offered, ideally before 10 weeks. New technologies are being employed to improve referral procedures and facilitate this joined up approach to early care, including the use in Sheffield of electronic referral systems and the prioritising of scheduling of booking appointments by gestation rather than receipt.

**Facilitating easier access to early antenatal care**

**Recommendations for:**

**Local Authority public health/health promotion and NHS care providers:**

• Explore best practice in terms of development of direct access to antenatal booking schemes, related to pregnancy health education and health promotion activities. To complement existing access routes through primary care services. Continued development of a range of formats, including phone and online services, for women of all ages and communities.

**Maternity care commissioners and providers:**

• Continued improvement of referral procedures within NHS, but also streamlining procedures and improving pregnancy confirmation, information giving and transfer when pregnant women present outside of maternity services or primary care. For example, pregnant women presenting to social care, Accident and Emergency or walk-in centres, sexual health and pregnancy/abortion services such as 3rd sector organisations such as British Pregnancy Advisory Service (BPAS) and Marie Stopes UK.

***7.2.3. 3. Providing woman-centred antenatal care***

Such practical proposals, focusing on education and easier access, are perhaps only part of the answer to the challenge of late booking.Any discussion around improving access to antenatal care needs to consider the care itself, its quality and focus. There needs to be some acknowledgement of the potential influence, direct and indirect, that the content and delivery of care has on attitudes and behaviours in relation to antenatal booking. This consideration also reflects my background: as a midwife I am concerned with the care women receive, and whether it meets their needs, not only in physical but also psychosocial terms. Such care needs to be truly woman-centred, a phrase widely used in maternity care but which, like informed choice, risks becoming a theoretical description or ideal, rather than the reality of care.

Phillippi and Roman’s (2013) theory of antenatal care access argues that motivation must come first, as it is the most cited reason that women fail to begin prenatal care: *“a woman’s drive for care must be present to begin the access process”* (p511). This motivation is reflected in a woman’s acceptance of her (personal) pregnancy and the need for antenatal care (her public pregnancy), which in turn is reflected in her engagement with antenatal services.For women to attend for antenatal care, it must be perceived as relevant and valuable to their lives and pregnancies. As discussed in the previous chapter, bridging the gap between perceptions of the importance of antenatal care in theory, and its acceptability in practice, requires care which is a good ‘fit’ to the woman. Early pregnancy is acknowledged as a time when many women have a particular need for information and reassurance(Sanders 2000). However, for low risk, particularly multiparous, women, the benefits of early antenatal care may not be immediately obvious, and subsequently not a priority. This was evident in the Sheffield study. As mentioned previously, by the time they see a midwife or doctor, women have already overcome the majority of common barriers to antenatal care (Downe *et al* 2009, Philippi 2009).

The challenge therefore, to improve both engagement and potentially outcomes, is both direct and indirect: to create responsive maternity care which influences women in current and future pregnancies, but also changes general perceptions about the purpose and value of antenatal care amongst women and those around them. This necessitates providing care which matches women’s lives and expectations. It requires the reconceptualisation of antenatal care, to make care relevant to all women from all backgrounds, particularly young primiparous women but also multiparous women and women whose experience of healthcare comes from outside the NHS (RCOG 2002). As Kirkham (2004) suggests, women need to be at the heart of such changes:

*“If we are to develop better ways of taking decisions and women are to be involved in their childbearing on their terms, profound change is called for in the organisation and resourcing of maternity services”*(p 287).

Raine *et al’s* (2010) London study of antenatal communication discusses the need to *“encourage empathetic interactions that promote constructive provider-user relationships, and encourage women to engage effectively and access the care they need”* (p590), but this is arguably easy to say, hard to do.

The process begins with acknowledging that blaming women is unhelpful. An undercurrent of opinion that women who don’t access care are ignorant and need to change, a paternalistic view favouring ‘expert’ opinion and western models of care, still remains (Mayer 1997, Johnson *et al* 2007, Carolan and Cassar 2010). This has the potential to distract from the real issues around late booking, as Braveman *et al* (1993) comment:

*“A widespread and convenient belief has emerged that places the blame for poor prenatal care on irresponsible behaviour by pregnant women… blaming the women themselves diverts attention and resources away from effective solutions that would simultaneously address financial, systems and personal obstacles to receiving high quality care”* (p1289)

As the Sheffield study found, asking women questions that were perceived as judgmental and blaming, such as “*why did you book so late?”* resulted in defensive, closed responses. As the interviews progressed this question became modified to *“tell me about your experience of finding out you were pregnant” and “what was it that made it difficult for you to book for antenatal care?”*, opening lines of communication. And as Bloom *et al* (2004) identify, opening up communication begins the process of involving women in finding solutions to late booking.

So what might this woman-centred care look like? Antenatal care that

* provides individualised and flexible care
* is focused on listening to women (like this research)
* provides psychological as well as physical care
* treats women as active partners in their care, and
* facilitates real choice and autonomy for women

is likely to be effective and accepted care that women are prepared to prioritise, to attend early and regularly for throughout pregnancy, and to recommend to friends and family. It is care that is likely to have a positive influence on women’s decision making and access in current and future pregnancies. These qualities are explored in the following sections.

**7.2.3.1 What does ‘woman-centred’ mean in the context of antenatal care?**

Surveys of women’s attitudes towards antenatal care inevitably focus on the women who *do* attend; often white, educated and articulate women, rather than those who do not. Authors have acknowledged the challenges of reaching ‘hard to reach groups’, such as teenagers, low income and BME women (Hirst *et al* 2003). But there is an acknowledgement that there are some fundamental commonalities in what women want: to understand and be understood and respected, to be able to express their wishes and choices. Any solutions therefore start with the aim, as in this study, of understanding women’s views of pregnancy and antenatal care, and their needs, and placing them at the centre of care. The NHS *Vision and Strategy: an Approach in Midwifery Care* (2012) identifies key priorities around woman-centred care, including working in partnership with women, their partners and families and developing social models of care with women at the centre of the experience.

In recent history women’s needs in pregnancy have been defined by health professionals, within the context of a biomedical model (Carver, Ward and Talbot 2008).In the 1920s the primary focus of antenatal care was considered to be the surveillance and supervision of women’s health (Oakley 1982); arguably little has changed since then. Antenatal care has been described as primarily “*a way for women to integrate into the medical/obstetric care system”* (Feijen-de Jong *et al* 2011: 904), and a *“process of medical socialization”* (Browner and Press 1996: 144). Pregnancy may thus be viewed as a medical ‘problem’ needing ‘expert’ attention: relying on such experts to define experiences that historically women have understood better themselves. Kirkham (2010a) argues that despite reports from the 1990s concluding that a medical model of care should no longer drive maternity services, the proliferation of monitoring and surveillance in maternity care, in a risk conscious, medicalised society, defines women as needing medical procedures to have a ‘normal’ pregnancy, and makes an assumption that normality has to be continually proved. This has the potential to target women’s insecurities and anxieties about their bodies and their ability to have a normal pregnancy, resulting in fear and contributing to the convention of attending for care. Recent research on women’s emotional journey through pregnancy indicates that the first trimester is one of the most anxious times for women (NCT/RCM/RCOG 2012). Women are required to be responsible pregnant women/‘mothers-to-be’ and behave appropriately: the public pressure to do this is another powerful influence (Edwards 2004, Jomeen 2012).

It is argued that current models of antenatal care are still dominated by health professionals and ‘experts’ views of need, and focus particularly on physical aspects of health, even if these offer neither improved outcomes nor satisfaction: *“the needs of pregnant women, as expressed by the women themselves, have received little attention in the provision of health care programs during pregnancy”* (Carver and Ward 2007: 98). As such women’s experiences and subjective knowledge, and their resulting needs, may fail to be incorporated into the antenatal care system (Carver, Ward and Talbot 2008). Kent (2000) argues that many midwives support ways of working and advising women that incorporate this biomedical model of pregnancy and birth. Consequently they may need further encouragement to facilitate woman-centred care and choices, particularly amongst the most disadvantaged, whose lives (and pregnancies) may be viewed as more ‘problematic’ (Brubaker 2007). This is borne out in analysis of the findings from the 2010 National Maternity Survey, which highlights the need for a change in the culture and attitudes of health professionals towards women from lower socio-economic groups particularly (Lindquist *et al* 2014).

As discussed in chapter three, trying to understand the lifeworld of late booking women necessitates acknowledging the unique context and individual perspectives that led to the delayed initiation of care. In order to respond to women, to engage and inform rather than judge and stigmatise, midwives need to begin with a realistic view of women’s circumstances and life experiences (Radcliffe 2011). This research contributes to providing such a view of late booking women, which may be used to inform midwifery practice. As discussed in the previous chapter, the research was most effective when women were interviewed at home. Such an approach takes a holistic perspective, seeing individuals within their social environment and demonstrates how the research agenda can be shaped by the researched as well as the researcher, as partners and equals (Hennings, Williams and Haque 1996). There is a need to reflect this influence of context and equity if the goal of holistic, woman-centred maternity care is to be achieved. For example, information provided and its format, women’s background and experiences, the people around them and the timing and location of any encounter, are all significant components of individualised care (Green 2012). This care needs to be built around the premise that antenatal care makes a positive and welcome addition to women’s pregnancies, and is care that women want to come for, rather than feeling coerced or frightened into attending.

**7.2.3.2 Providing individualised and flexible care**

*“quite simply, clinicians should ask women directly about their own needs and preferences, and modify care accordingly”* (Novick 2009: 235).

If all women are to receive optimal care during pregnancy, antenatal care attendance needs to be viewed not simply as convention, but as valuable and relevant to individual women. Many women in the Sheffield study weighed up the value and relevance of antenatal care in relation to their personal circumstances, deciding what was best for them. They favoured care in a familiar, personal setting. Considerations of priority were influential for all women across the social, educational and cultural spectrum, not just vulnerable and low-income women. Relevance and acceptability stem, in part, from care which is individualised, tailored to each woman, and flexible enough to meet their needs (Clement *et al* 1996, RCOG 2002). Effective midwifery care requires a balance of this individualisation with credible evidence-based clinical guidelines (Viccars 2009). The differing characteristics and needs of primigravid and multigravid women antenatally, evident in this study, suggest the need for tailored care beyond the physical components (Nichols, Roux and Harris (2007).

Official guidance identifies that antenatal care should be sensitive to the needs of individual women and the local community (RCOG 2008, NICE 2014). However, as Kirkham (2004) suggests, many policies, procedures and guidelines for evidence-based care are derived from randomised controlled trials, and apply to the ‘average’ childbearing woman. Rather, there is a need to recognise women as individuals; to respect their need for control of their situation and to nurture individuality to improve outcomes. Jomeen argues that care should be flexible and individualised, not rigid or fixed in a way which imbues women with the need to aspire to some *“blanket criteria of normality”* (2006: e199): the convention of antenatal access previously considered. Sandall, in her recent report on continuity of midwifery care for the RCM (2014), identifies that personalising women’s care contributes to building better relationships between women and midwives. A midwifery outreach scheme in Lambeth and Southwark, London, reflects this, noting that *“reductions in the number of unbooked women show what can be done through provision of responsive individualised services”* (DoH 2007b: 80).

Additionally, there are suggestions that a good relationship between a woman and her midwife could reduce the need for care. Clement *et al’s (*1996) Bristol Antenatal Care study found women satisfied with reduced schedules of antenatal care were more likely to have had a supportive caregiver (a midwife presumably) and were less likely to be depressed in pregnancy. This suggests individualised/personalised care has benefits for all concerned. What is required is to provide midwives with the resources to offer women the individualised and relevant support they need during pregnancy, not simply screening (which women might not want) and physical assessments. Individualised care can only be provided where there is continuity of care and carer; a key recommendation from the recent UK study examining utilisation of maternity care and outcomes for women from low socio-economic groups (Lindquist *et al* 2014). The benefits of such continuity are widely recognised; for example the Cochrane systematic review of midwife-led continuity models of care identified several benefits for mothers and babies, and no adverse effects when compared with models of medical-led care and shared care (Sandall *et al* 2013). The authors conclude that most women should be offered such care. However, such approaches require time, appropriate midwifery caseloads and facilities.

**7.2.3.3 Focused on listening**

*“it is important that we listen to the needs of women across the stages of pregnancy and that the ‘voice’ of pregnant women be as influential as that of ‘experts’ in informing policy… and the provision of care which meets individual women’s needs”* (Carver, Ward and Talbot 2008: 77)

Understanding women’s lives and meeting their needs requires sensitivity and flexibility, and the ability to listen (Levy 1999). Page (2006) argues that one of the fundamental steps to sensitivity in evidence-based practice is *“finding out what is important to the woman and her family”* (p360). As Gaudion and Homeyard have observed in their research with disadvantaged women:

“*It is essential to begin with the woman’s view of the world, not the professionals… finding out what the woman’s individual needs are and working with her to make a holistic plan”* (2010: 157)

The value of listening to women’s opinions about their healthcare is evident in strategies such as the Friends and Family test, already used for antenatal services: *“This kind of feedback is vital in transforming NHS services and supporting patient choice”* (NHS England 2014). Women’s opinions about their care have great potential for influencing their own future care decisions, but also those of others. NICE’s *Pathway on Pregnancy and Complex Social Factors* (NICE 2014) and RCOG guidance on reducing maternal mortality (2002) suggest that involving women in their antenatal care is key to improving service organisation and encouraging women to access antenatal services. They suggest this is to be achieved by ensuring women are asked about their satisfaction with the services provided and using this information to guide service development, but also involving women in determining and meeting local needs, engaging representatives of vulnerable groups in the planning of services. Both strategies have the potential to influence future access, however listening to women’s views needs to begin during rather than after pregnancy.

Pregnant women gather their experience and knowledge of maternity care in different ways. This may be limited, or framed by social influences, and contrasts with healthcare practitioners’ lengthy education and socialisation into the practice and values of their profession. Consequently, midwives have a different view of pregnancy and risk to women. This has the potential to create an imbalance in expertise and power, which can hinder the midwife focusing on the individual voice and needs of each woman. Such a relationship may be centred around one way communication, resulting in care which is not individualised or relevant (Kirkham 2004). Docherty *et al’s* (2012) study of antenatal engagement found poor perceptions of care amongst low income women, including a perception that care was less personalised and an imbalanced relationship where midwives did not assess women’s prior knowledge and directed their antenatal decisions. Edwards (2004), in her study of women’s choices around homebirth, observed that many women found their care to be lacking in flexibility and depth, never really scratching the surface.

A woman-centred approach requires an acknowledgement of women’s understanding and priorities; it is not simply about knowledge (or lack of it). Women make pragmatic decisions. Reviews of women’s views on antenatal care, including the comprehensive national surveys conducted by the NPEU, suggest that key aspects of care valued by women include convenience (Redshaw *et al* 2007). ‘Need’, like risk and safety, is subjective and socially constructed. Kirkham and Stapleton (2004) describe the focus in midwifery practice of a routinised process of ‘checking not listening’ and argue that if midwives are to learn about women’s knowledge, values and preferences they must start by listening: *“when women are listened to, they voice many ways of seeing maternity care and many definitions of safety”* (p142).

Edwards (2008a,b) has similarly argued that pregnant women have a much wider view of caring and safety than healthcare professionals, with family and relationships at its centre, and which involves the continuing physical and mental wellbeing of their whole family, in the present and future. As such, ‘safety’ is both relative and limited, and *“may be defined differently depending on one’s beliefs, values and circumstances”* (Edwards 2008b: 19). She also talks about the emergence of a ‘telling not listening’ culture, steering women to make the ‘correct’ choices, and the need to be willing to listen and keep listening (Edwards 2004). This reflects RCOG guidelines aimed at reducing maternal mortality, which identify the need to overcome dismissive staff attitudes and enhance the status of listening to all women (RCOG 2002). The report, also echoed by Raine *et al* (2010), recommends exploring ways to provide all women with the opportunity to discuss their experiences, with local training programmes for midwives and obstetricians in 'listening skills', including ‘active listening’.

Such active listening, and greater emphasis on the personalisation of care, may help to eliminate any lack of depth and equality. There is a need to strike a balance within antenatal care between the two perspectives: the midwives’ expert knowledge (with its professional boundaries) and women’s knowledge of their own needs (Carver, Ward and Talbot 2008). This acceptance and compromise on both sides is significant in the provision of care which has relevance and value for pregnant women. This balance of views is necessary across midwifery. This study has not focused particularly on women from outside the UK or for whom English was not their first language, though these were included. Language proficiency affects the acquisition of healthcare information directly and indirectly, although integration into a culture relates to more than language proficiency. The Sheffield study and other research suggests that differing attitudes, particularly towards health surveillance and testing, cultural differences and the different organisation of healthcare in a woman’s home country are likely to be significant reasons for late booking. Any effective interventions to encourage minority groups to engage with maternity services must reflect such differences as part of this process of acceptance and compromise (Cresswell *et al* 2013).

Carolan and Cassar’s (2008) study of immigrant women in Australia found a gradual ‘trajectory of adjustment’ towards pregnancy and the priority given to it; to valuing antenatal care. They note that *“women assimilated continuous pregnancy care into their understanding of how things should be during pregnancy”* (p195).This suggests a somewhat paternalistic view of the ‘right’ way to manage a pregnancy, i.e. the Western model of care, and that women were expected to change. However, the authors do acknowledge women’s struggle to conform to Australian expectations, but also the reaching of compromises, and the co-existence of old and new beliefs. They argue that acceptance works on both sides: professionals accepting women’s embodied knowledge and experience, women accepting the value and relevance of care. This needs to be reflected in antenatal provision.

**7.2.3.4 Targeted care**

Targeting may form part of the process of individualising care. The US Department of Health and Human Services have previously estimated that up to 80% of women at high risk of having a low birthweight baby could be identified at their initial antenatal appointment and, by implication, offered individualised care and support (Roberts *et al* 1998). Docherty *et al* argue that the first trimester may be an important period in terms of initiating and sustaining engagement and that the early identification of those women at risk of non-engagement may facilitate *“the development of a more equitable antenatal service”* (2012: 126). Antenatal guidelines identify that women who fail to attend should be actively followed up (RCOG 2002, NCCWCH 2010), however targeting women prior to booking is a greater challenge.

Evaluations of targeted, non-standard models of antenatal care, seem to suggest they offer some benefits to women at increased risk of poor pregnancy outcomes, both in the short and long term. Willems van Dijk, Anderko and Stetzer (2010) reviewed data from more than 10,000 low income women at high risk of poor pregnancy outcomes, who received Prenatal Care Coordination (PNCC). PNCC is a widely available service in the USA supporting women who receive Medicaid to access antenatal care and other health, education and social care services (such as nutrition and smoking cessation) through outreach and advocacy. They found women who received such tailored care, based on a holistic view of their needs, an ongoing relationship and bespoke interventions, were at significantly reduced risk of poor birth outcomes, including low birth weight and prematurity. The authors argue that such care is cost effective but needs to be part of wider family healthcare; that targeted high-intensity antenatal care for women at risk

“*should be delivered within a comprehensive, broad-based system of care for families and young children to ensure the greatest long-term outcomes for creating a healthy population”* (Willems van Dijk, Anderko and Stetzer 2010: 107).

A systematic review of 36 tailored antenatal care programmes to reduce infant mortality and preterm birth in socially disadvantaged and vulnerable women found several interventions, all from the USA, including increased frequency of care, group antenatal care, improved continuity and health education (including maternal care coordination), which seemed to indicate beneficial effects (Hollowell *et al* 2011). However the authors consider that it is unclear whether the findings could be generalised to other disadvantaged populations or healthcare systems. They conclude that there is insufficient evidence of an adequate quality to suggest that interventions involving alternative models of organising or delivering antenatal care are effective at reducing infant mortality and preterm birth, and recommend further research and ‘robust evaluation’.

Allen *et al’s* systematic review of models of maternity care for adolescents found *“growing evidence that the model of maternity care can make a significant difference to those at risk”* (2012: 62), with tailored care resulting in improved childbirth outcomes. The most established programme of support for such women is the Family Nurse Partnership (FNP). In existence for 30 years in the USA and 7 years in the UK, and underpinned by an extensive evidence base, it offers prolonged, targeted, individualised information and support for pregnant young women (aged under 19 years) who are at a high risk of poor life chances. It aims to recruit the majority of young women before 17 weeks gestation, and has demonstrated improved health, social and educational outcomes in the short, medium and long term. The scheme is currently being extended in England (NHS FNP 2014).

As discussed in the introduction, women with reduced or delayed antenatal care have poorer birth outcomes, particularly in terms of preterm birth, but the focus of previous research has been largely on the quantity *or* timing of antenatal care, rather than its content in relation to timing. Recent Belgian research suggests a minimum ‘appropriate’ level of care, in terms of 3 key antenatal interventions (blood pressure, ultrasound and blood sampling) through pregnancy, has the potential for a significant reduction in preterm birth (Beeckman *et al* 2012). Part of any flexibility in antenatal care could enable women at low risk to receive such a minimal level of physical care and intervention. Although this scheme still recommends booking by 13 weeks gestation, this ‘low key’ approach could be attractive to low risk women, though whether this is defined as in the NICE guidance as a ‘*healthy woman with an uncomplicated singleton pregnancy’* (NCCWCH 2008) or in some other way, requires further consideration.

So targeting care may make sense, both at the very beginning and throughout pregnancy. All types of individualised care, perhaps making use of new technologies to facilitate interactions between pregnant women and their healthcare providers, offer the potential for increased relevance and value (Raine *et al* 2010). However, such care relates to women who have already booked for antenatal care; it is arguably more difficult to reach women prior to booking. The challenge is to get the targeted care to women in early pregnancy so that it can have most benefit and contribute to positive experiences and outcomes. These will in turn influence future pregnancies, for women, their peers and families, creating models of care that women are prepared to prioritise. As discussed in section 7.2.1, it requires broad education and promotion across health, social care and education settings, and joined up thinking and opportunistic contraceptive and preconception care, to address both current and future pregnancies.

**7.2.3.5 Providing psychological as well as physical care**

*“the provision of sympathetic listening support through continuity of care, which is what women have been requiring whenever anyone has thought to ask them, is a more effective way to promote their health and that of their babies than most of the medical interventions carried out in the name of ‘antenatal care’* (Oakley 1992: 327)

As the Sheffield study has illustrated, social and psychological support is integral to initial access to antenatal care. Schemes such as the FNP and PNCC (and Oakley’s *Social Support and Motherhood* study quoted above (Oakley 1992)) suggest that such support, through advocacy and relationship building during pregnancy, leads to improved outcomes, as much as physical care. This reflects both lay and professional influences. Furber *et al* (2009) discuss how antenatal depression, like late booking, is associated with preterm birth and low birth weight babies. This correlation may be worthy of further investigation, especially given this growing evidence of the benefits of individualised antenatal care which offers holistic and sustained psychological support for women.

Midwifery care should form part of this support. The *NHS Vision and Strategy: an Approach in Midwifery Care* (NHS 2012) identifies providing ‘holistic, responsive and compassionate’ midwifery care as a priority. Numerous authors and antenatal guidance discuss the need to offer improved psychosocial as well as physical care: an empathetic, sensitive and non-judgemental approach that builds a relationship and provides support for the psychological period of adjustment to motherhood (Clement et al 1996, Docherty *et al* 2012, NICE 2014). Such an approach acknowledges the significance of the ‘social pregnancy’ and the recognition that birth is a collective social enterprise (Kirkham 2010b). However, the emphasis on physical care, for example in the NICE antenatal guidelines (NCCWCH 2008), reflects the medical dominance of pregnancy with its risk management approach. Current midwifery remains focused on the physical (arguably easier) aspects of care; a process frequently of form filling and box ticking, which is arguably disempowering and de-individualising (Stephens 2004). This process, for low risk women at least, has the potential to ignore or sideline more important psychological elements of antenatal care, which are messy and harder to quantify.

Booking has been identified as linked primarily to antenatal screening (Rowe *et al* 2008), but there is little discussion about women who decline screening, and far less emphasis on the other roles for early booking, such as support and health education/promotion. Many existing measures focus on the quantity of antenatal care women receive, but do not measure the quality of such care. This is perhaps not surprising, given the challenges of such measurement. Feijen-de Jong *et al’s* (2011) systematic review of late and/or inadequate use of antenatal care identifies the need to examine both the content and quality of prenatal services. As the previous section describes, evidence that enhanced, ‘patient-centred’ care can lead to improved birth outcomes is increasing. Tandon, Parillo and Keefer’s (2005) study of Hispanic women suggests patient-centredness in a maternity context stems from what is communicated and how, women’s relationships with healthcare practitioners and the provision of culturally and linguistically sensitive care. This presents challenges for healthcare providers capturing and coding tasks for payment however, as antenatal care becomes defined as a set of tasks and tariffs into which ‘relationship’ doesn’t fit (Kirkham 2010a).

Choté *et al*’s (2011) Dutch study examining ethnic differences amongst late booking women, suggests that some, particularly BME women, may feel that early care is less relevant to them, given its current focus on screening and behaviour change in relation to activities such as smoking and drinking alcohol**.** Despite visions and strategies, in the present risk and financial model of antenatal care there may be little left for women (and midwives) beyond the physical aspects of care and the behaviour change messages. Any reconceptualisation of antenatal care must therefore address the continuing challenge (amongst others) of marrying official policies and clinical guidelines with the complexity of social and emotional care (Kirkham 2004).

**7.2.3.6 Women as active partners in care**

Marmot’s report on the promotion of health equity identifies the need to encourage a partnership approach to healthcare; working together to empower the most disadvantaged and to provide individualised care (Marmot *et al* 2008). Research suggests this partnership is valued by those using healthcare too. Entwistle *et al’s* (2012) synthesis of 77 studies of patients’ experiences of health care delivery found that patients wish to feel respected, contribute to their care and experience reciprocity. Alongside the provision of improved information for women about the pattern and purpose of pregnancy care, there is a need for recognition that women can be experts in their own pregnancies and can take an active role in their care. Effective antenatal care *“needs to meet their expectations and support them to be in control of their childbirth experience”* (Viccars 2009: 265). Sandall’s recent report for the RCM (2014) talks about optimal maternity care supporting “*women’s own innate capacities*” (p3), Docherty *et al* (2012) about using strategies such as shared decision making and the recognition of prior knowledge. Involving women more actively in their care requires women to take more control and for midwives to relinquish some control, whilst maintaining a partnership. In order to develop and sustain engagement, health professionals need to recognise all women’s prior knowledge and experience, balancing women’s wishes with organisational and professional requirements (Kirkham 2010b). Arguably the most vulnerable women, such as teenagers, need this partnership and reciprocity, and degree of decision making power, to reduce stigma as much, if not more, than other women (Brubaker 2007).

Many of the knowing women in the Sheffield study assumed such an active and thoughtful role. Kirkham (2010a) argues that childbearing women have become relatively passive ‘consumers’ of maternity services, but could be active and equal participants. It is difficult to identify those women wishing less care (Clement *et al* 1996, RCOG 2002), however shifting the balance of control antenatally may be feasible, even if it requires thinking ‘outside the box’. Influential health consultancy McKinsey voiced a controversial suggestion in 2012 that the majority of antenatal care could be delivered by women themselves (Dowler 2012). Though the RCM’s response was that the McKinsey view was simplistic, treating maternity care like a production line, the principle of self-care merits further consideration, particularly given that nearly 50% of women are classified as low risk, even at the end of pregnancy (Sandall 2014). As Patterson, Freese and Goldenberg (1990) suggest, for low risk women in particular,

*“it seems appropriate to begin to think about what aspects of prenatal care might be transferred to women to manage themselves”* (p31).

Such self-care is found elsewhere in the NHS. The *Expert Patients Programme* was established in 2002 by the Department of Health to put patients with chronic conditions at the centre of their health care, teaching ‘self-management’ and monitoring (ORCIC 2013). Such schemes have recognised the benefits of self-management, giving patients some control over their health, both in physical and psychological terms, and the resulting economic benefits. Although pregnancy is not a chronic condition, there are many circumstances where women take control of aspects of their antenatal care. This study and others have acknowledged that the majority of women do take responsibility for their pregnancies, for seeking ‘safe passage’ for themselves and their babies, taking steps to protect the pregnancy, undertaking self-care in the form of monitoring and lifestyle changes, and accessing care at a chosen point. Ultimately the majority of late booking women want to be seen to be ‘doing the right thing’ and do take ownership of their pregnancies and responsibility for their babies, though this may not be an immediate reaction to pregnancy discovery, as women struggle with their pregnancy identity.

This expertise and personal responsibility, whether it includes women declining care, should come from an informed perspective and a realistic view of what antenatal care entails. This builds upon women’s health literacy, which begins with good communication and the provision of relevant educational information across families and communities, as discussed in section 7.2.1 (Docherty *et al* 2012). O’ Cathain *et al’s* (2002) view of non-participative decision making by pregnant women is that if decisions were made from a position of power and understanding then they should be respected and followed. If such decisions stem from a position of resignation or ignorance this needs tackling educationally. However, sensitivity and flexibility are needed to meet women’s needs. Health professionals, with their differing views of needs and risk, may be guilty of judging women as passive and ignorant rather than making informed decisions to delay access. Women shouldn’t be demonised for not wanting early care or screening, which may be the case when women are referred to social care as a result of late booking. Self-care (as opposed to no care) deserves recognition and respect, in the context of individualised and holistic care; care which tries to balance both women’s and midwives’ needs. However, as Beeckman *et al* (2012) suggest, this partnership and dialogue around a minimum effective level of care should begin ideally in early pregnancy. Such an approach goes hand in hand with improvements in health literacy and access.

**7.2.3.7 Facilitating real choice and autonomy**

The concept of informed choice has become a mantra in maternity care. Sandall’s report for the RCM (2014) identifies that high quality maternity care is *“women and family centred, which involves facilitating informed decision making”* (p3). The *Changing Childbirth* (DoH 1993) and *Maternity Matters* (DoH 2007) reports both explicitly state that women should be the focus of maternity care, with an emphasis on providing choice, easy access and continuity of care. Such reports and the NICE guidance for antenatal care that has followed them argue that the views, beliefs and values of women should be sought and respected at all times (NCCWCH 2008). The suggestion is however that informed choice is something that women can only make with professional guidance: *“having discussed matters fully with the healthcare professionals involved”* (NCCWCH 2008: 6).

There are arguments that despite this ‘discourse of choice’ it remains merely a maternity buzzword,with a lack of evidence to suggest that choice is a reality for many women accessing maternity care (Jomeen 2006, Carver, Ward and Talbot 2008). Kirkham (2010) argues that choice has become a big issue in maternity care but that the service provider controls the menu of ‘choices’: a series of predefined options. With the powerful professional concept of the ‘right choice’, options are limited for many women. She suggests that any autonomous action, arguably some of the late initiation of care seen in this study, is seen as a deviation from the pathway laid down by the ‘experts’. Kirkham and Stapleton (2004) previously argued that what women exhibit is ‘informed compliance’ rather than informed choice, perhaps reflected in womenaccepting the convention of antenatal care rather than choosing to attend because they valued its contribution to their pregnancy. Many late booking women in the Sheffield study were highly aware of the convention and expectation of early care and most expressed feelings of guilt and remorse. This reflects women feeling the need to be perceived as responsible pregnant women, fearful of making the ‘wrong’ choice and being labelled as bad mothers or problematic for choosing a different path, or declining care (Anderson 2004, Jomeen 2006, 2012).

Choice is a messy and complicated process, subject to many influences. As O’ Cathain (2004) comments, perhaps the most striking difference between maternity care and other settings is the sheer number of decisions that need to be made. As consumers and recipients of care, pregnant women are caught in the middle between a medical model of risk and safety, and a midwifery model of normality (Jomeen 2012). Edwards identifies that choice *“unravels rather rapidly into a series of complex processes, rather than a thin, linear, unproblematic ‘shopping list’’* (2004: 4); an interaction of interests, concerns and constraints. Attendance for antenatal care is predominantly women balancing these priorities and choices - in terms of benefits, risks and consequences - as measured by themselves; and maintaining control. This is evident in the thoughtful, rather than passive, process of ‘*weighing up and balancing out*’ of Downe *et al* (2009), and Levy’s (1999) ‘*maintaining equilibrium’* with its tightrope balancing metaphor. As Novick comments:

*“some women may perform something similar to a cost-benefit analysis… may decide that the benefits of receiving prenatal care do not outweigh the expenditure of time and resources required to obtain care. These women, who may sometimes be viewed within the health care system as noncompliant or passive nonusers of care, may in fact be making rational choices”* (2009: 233).

Facilitating informed choice itself is complex, with information and education (associated with the concept of health literacy perhaps) seemingly relatively ineffective compared to context and social influences (O’ Cathain 2004). Midwives need the sensitivity to acknowledge these influences and to have a good understanding of the choices women make. They need the skills and knowledge to provide women with real rather than theoretical alternatives to prevalent models of care if women are to attend and engage with care that they perceive has relevance and value; care that they are willing to prioritise (Edwards 2004, Levy 2004). Choice should be *“less about presenting a predetermined menu and more about providing opportunities which enhance women’s autonomy potential as they engage with decisions*” (Edwards 2004: 23).

**Providing woman-centred antenatal care**

**Recommendations for commissioners of maternity research:**

**Understanding what works**

• Evidence uncertainties remain about effective antenatal care programmes, particularly for socially disadvantaged and vulnerable women in the UK. Further robust evaluation is required (Hollowell *et al* 2011, NICE 2011).

• Evidence suggests the benefits of continuity models of care (Sandall *et al* 2013) and the wider health benefits of investing in antenatal care. However, there needs to be greater evaluation of the long term impact of models of care and antenatal interventions; for example broader health status, access to healthcare generally and in subsequent pregnancies, as well as short term morbidity and mortality.

**Understanding what women want**

• To commission studies of women and their families’ views about antenatal care, in terms of what they want from their care, perceptions of the value and relevance of such care, in terms of meeting both physical and psychological needs. This needs to be across the socio-demographic spectrum and amongst both nulliparous and multiparous women, seeking beyond the broad interpersonal questions about interactions with healthcare professionals assessed in questionnaires such as the NPEU’s National Maternity Survey (Redshaw and Henderson 2015).

• Such ‘conversations’ may involve engagement with community-based organisations working with women and families, also midwives’ perspectives.

**Recommendations for commissioners and providers of maternity care:**

**Refocusing care - providing choice and continuity**

• To use research findings to drive the development of high quality, individualised care; care that women are willing to prioritise. Such care could be based around the default concept of pregnancy as wellness and the status of women as ‘active partners’ in their pregnancies; where women are well informed and well supported in their choices. This might include offering minimal patterns of care for low risk, multiparous women, innovations in targeted and shared care, and alternative choices such as group antenatal care.

• Antenatal guidelines also need to acknowledge the full range of potential benefits of attending for antenatal care; recognising the influence of psychological, emotional and social support during pregnancy, alongside physical assessments of wellbeing, and the time required for such holistic care.

• Continuity is at the heart of providing such woman-centred care; flexible care based on women’s needs. There needs to be sustained development and evaluation of such models of care, in particular for the most vulnerable women and families. These could be targeted around geographical areas with poor access and engagement with healthcare, or towards women with socio-demographic, physical or psychological risk factors for poor pregnancy outcomes, or towards all nulliparous women.

• Models of care need to provide midwives with manageable caseloads based around risk and need, providing care which is truly integrated between midwives, GPs, health visitors, family and social support services and 3rd sector organisations. Such models could incorporate the use of lay health workers (Glenton *et al* 2013).

**7.2.3.8 Conclusions**

Creating a model of antenatal care which encourages women to book early presents particular challenges, as women are attending for the first time, not returning for subsequent care. Initial attendance is influenced by women’s acceptance of their personal and public pregnancies, which are in turn shaped by their knowledge of pregnancy and antenatal care, but also prior experiences, direct and indirect, and external influences. As some of the women in the Sheffield study demonstrate, accessing care is not simply about knowing that it exists and its purpose, but considerations of its value and priority, its timing and portability. This relates to where care fits into women’s lives, for example the convenience and familiarity of the home setting, the relationship with previous pregnancies and perceptions of screening. Encouraging women to book early is therefore not simply about telling women the risks associated with non-attendance or making attendance a convention: fear and obligation are not good foundations for engagement. Health promotion and education messages about the purpose and benefits of antenatal care need to co-exist with care that women feel belongs to them, that they are encouraged to be actively involved in and that is tailored to their needs and experience. It is this combination of high quality information and advice around conception and early pregnancy, with easily accessible and individualised antenatal care, that is likely to be most effective at reducing late booking.

***7.2.4 Financial incentives***

The role of financial incentives to improve access to antenatal care deserves brief consideration. A systematic review of the effectiveness of financial incentive interventions for encouraging healthy behaviour change, such as smoking cessation and attendance for screening (excluding antenatal screening), found that they were effective for encouraging healthy behaviour change, both in the short term, and to a lesser extent, in the longer term (Giles *et al* 2104). The authors argue that financial incentives may be a useful addition to the behavioural change toolkit and should be considered across the spectrum of healthy behaviours, of which antenatal attendance could be considered part. A recently published Scottish RCT has demonstrated the successful application of financial incentives for smoking cessation in pregnancy, with nearly three times as many women in the incentives group quitting (Tappin *et al* 2015).

NOurishing Start for Health (NOSH) is a National Prevention Research Initiative funded project exploring the potential of offering women financial support to breastfeed, in order to improve breastfeeding initiation and duration in areas with low breastfeeding rates. The project authors acknowledge that the impact of financial incentives for women on breastfeeding is a relatively unexplored area, but cite effective schemes in North America (University of Sheffield 2014a). A pilot study in 2013-14, designed by researchers and local healthcare professionals to complement existing breastfeeding support, tested the feasibility of the incentive scheme (University of Sheffield 2014b). Satisfaction with the scheme was high among both mothers and health-care staff participating in the scheme, which saw a modest increase in women breastfeeding at 8 weeks postnatal. A large scale randomised controlled trial testing the effectiveness of the scheme is now planned (Relton *et al* 2014).

Regulation limits the type and value of incentives that can be offered to women receiving Medicaid in the USA. However, a study in Las Vegas by Rosenthal *et al* (2009) found that an incentive of $100 given to 1436 women of low socioeconomic status, to initiate antenatal care in the first trimester and maintain regular visits, led to an increase in the uptake of early care from 14% to 76%. The incentive also contributed to a reduction in neonatal admissions and spending on paediatric health in baby’s first year, but had no influence on birth weight. Smaller incentives have shown less success in influencing women’s behaviour however (Laken and Ager 1995).

Several European countries, including France, Finland, Hungary and Luxembourg, have offered women financial incentives for the early initiation of antenatal care (McQuide, Delvaux and Buekens 1998). As mentioned previously, a country comparable to the UK in terms of its universal accessibility and encouragement of antenatal care,Finland’s incentive is in the form of the Maternity Package. This parcel of newborn essentials, packaged in a box which doubles as a cot, is given to all pregnant women who attend for antenatal care before five months gestation. Part of Finnish culture, the package has been in existence for more than 75 years and its provision has accompanied a dramatic fall in Finland’s infant mortality to one of the lowest levels in the world (Lee 2013). The difference between this and pregnancy incentives currently available in the UK is its universal availability, part of the engraining of early access to antenatal careinto the culture, at a time when universal benefits such as Child Benefit and the Health in Pregnancy Grant (previously given to all pregnant women) in the UK have been removed or reduced.

It is likely that such incentives would have an influence on women’s short term behaviours and perceptions of the priority of attending for antenatal care, but perhaps not on their perceptions of its relevance or value. However, in combination with the provision of high quality, individualised care, it could have longer term influences, for example on subsequent pregnancies. The universality (like Finland) of an incentive would ensure maximum effect. However, targeting towards the groups identified in chapter one as most likely to book late and experience adverse outcomes may be most cost effective. As with the NOSH or Scottish smoking cessation studies, perhaps attaching financial incentives to key targets, such as the minimum antenatal care interventions identified by Beeckman *et al* (2012) in section 7.2.3.4, may be worthy of further exploration.

**7.3 Future research**

As chapter one has identified, and this study has confirmed, late booking women are a diverse group. Such a diversity of backgrounds is reflected in the range of experience conveyed by the women, and the interacting influences on women’s acceptance of their personal and public pregnancies presented in chapters five and six. This diversity needs to be reflected both in solutions but also in future research, requiring the ‘layered approach’ to the complexities of the topic suggested by Lavender *et al*‘s (2007) systematic review of access to antenatal care. As Feijen-de Jong *et al’s* (2011) systematic review of late and/or inadequate use of antenatal care also identifies, further research, both quantitative and qualitative, is needed to ‘disentangle’ the mechanisms associated with poor antenatal care usage (and, by implication, with poor pregnancy outcomes). Part of this disentangling requires the examination of influences on both early antenatal booking and ongoing access to care throughout pregnancy. Both contribute to maternal and neonatal health and wellbeing.

Though not exclusively, social and economic disadvantage were common themes throughout the group of women interviewed in the Sheffield study. It is likely that, given the poorer outcomes associated with such disadvantage discussed in chapter one, targeting such women by *‘pursuing work with known disadvantaged groups’* (Lavender *et al* 2007: 6) may be the most effective strategy for future research around late booking, and likely to have most impact. The NICE guideline for pregnant women with complex social factors (NCCWCH 2010) has identified three key research priorities relating to antenatal access, and pertinent to late booking. These are explored below, in relation to the findings from the study.

**1. Training for healthcare staff**

Evidence presented in the NICE guideline suggests that women facing complex social problems are deterred from attending antenatal appointments, including booking appointments, because of the perceived negative attitude of healthcare staff. Though a common theme in the literature synthesis this was not evident amongst the women in the Sheffield study. Lindquist *et al*’s (2014) recent analysis of UK maternity survey data found pregnant women living in the poorest areas not only less likely to book early but also significantly less likely to report that they were ‘*able to see a health professional as early as desired’* (p5). Though somewhat ambiguous, this suggests external barriers to early care that were only briefly identified in this part of the Sheffield study, related to difficulties with appointments and the negative perceptions of healthcare staff, as mentioned by NICE. Staff attitudes and behaviours are integral to providing antenatal care that women perceive as relevant and valuable. The subject is being explored in the other part of the study, looking at health and social care practitioner perceptions of late booking, which may be influential in developing further research.

**2. The effect of early booking on maternal and neonatal outcomes**

As chapter one has discussed, pregnant women experiencing social and economic disadvantage are known to book later, on average, than other women, and to experience poorer maternal and neonatal outcomes, but the evidence linking the two factors is limited. As NICE comment about facilitating early booking:

*“It seems likely that facilitating early booking for these women is even more important than for the general population of pregnant women. There is, however, no current evidence that putting measures in place to allow this to happen improves pregnancy outcomes for women with complex social factors and their babies.”* (NCCWCH 2010: 11).

Further research is therefore needed to evaluate the impact of improving early access to antenatal care, for vulnerable groups in particular, and may include both quantitative and qualitative components.

**3. Different models of service provision and interventions**

Evaluation of the effectiveness of interventions to address late booking and poor antenatal attendance is also required. The examination of different models of antenatal care reflects the need for further research and ‘robust evaluation’ around tailored antenatal care programmes, to reduce infant mortality and preterm birth in socially disadvantaged and vulnerable women, as identified by Hollowell *et al* (2011) in their systematic review. NICE identify that, for example in relation to substance misusing women,

*“It seems likely that making it easier for these women to attend antenatal appointments and providing tailored care will improve outcomes, but at present it is not clear how this should be done”* (NCCWCH 2010: 13).

Further research is needed to develop and examine the effectiveness of targeted care and antenatal (and/or postnatal) interventions, to discover which are most effective at encouraging early and regular attendance. Such interventions could apply to both initial access to antenatal care, as discussed earlier in the chapter, and subsequent care, and could include financial incentives. NICE suggests that it is unclear what models of service provision exist in the UK and how these models compare, both with each other and with standard care, in terms of outcomes. It needs to be determined what data should be collected, and how, as well as how it is shared, in order to assess the quality of and allow comparisons between different models of care.

Comparisons of maternal and neonatal outcomes between women, for example those receiving standard or targeted care, could be made using quantitative techniques. However, it is also essential to ensure that women’s voices don’t get lost along the way. Further qualitative research is neededto examine women’s experiences of different models of service provision or antenatal interventions, especially considering their potential influence on women’s current and future decision making around antenatal care. The University of East London’s Institute for Health and Human Development is currently undertaking National Institute for Health Research funded research evaluating a complex intervention package to improve equity of access amongst low income and particularly BME women in East London, using both qualitative and quantitative methods (Hatherall 2014, personal communication). The intervention aims to address the multiple barriers identified by previous research regarding perceptions of the purpose, value and nature of antenatal care, and factors within maternity service organisation, which may delay the early initiation of antenatal care in diverse communities (Hatherall 2013).

**The characteristics and perceptions of late booking women**

However, there are other aspects to late booking which merit further exploration.The themes identified in the Sheffield study challenge over–simplistic perspectives concerning the reasons why women present late, such as socio-demographic adversity, concealed pregnancy and denial, and the view of late bookers as passive and ignorant. The study participants included many ‘low risk’ women, who may be forgotten in a story of late booking which focuses wholly on vulnerability and deprivation. As mentioned previously, potentially all late booking women will be disadvantaged by the reduced care they receive antenatally. It may be that these low risk women represent a larger group than previously identified. If stereotypical categorisation is to be challenged this requires further study, in a larger scale cohort study, comparing late and early booking women, in terms of outcomes, but also maternal characteristics and perceptions of care. The unique and distinct differences between primigravid and multigravid women in the study suggest that both research and interventions tailored to each are required (Nichols, Roux and Harris 2007). The influence of women’s experience in previous pregnancies was underexplored in this study and may be highly influential on the choices women make antenatally.

Women’s views of the value and convention of antenatal care are significant, and further exploration of the influences on women’s perceptions of care necessary. Women’s reflections on their pregnancies and their own late booking, perceiving it in both positive and negative ways, have emerged as an additional area of interest from the data. The study suggests that the likelihood of repeated late booking is associated with women’s direct and indirect experiences of late booking, and that there are social and cultural norms in relation to pregnancy and antenatal access, and differing views of risk amongst groups of women. This deserves further examination, in particular women’s perceptions of time and risk in relation to pregnancy, and their prioritising of antenatal care. Women’s opinions on solutions to late booking will also form an important part of any future research, as this important subject was omitted from the Sheffield study.

This study has also identified aspects of reproductive knowledge and beliefs relating to contraception, and particularly contraceptive failure and the likelihood of conceiving, which need further exploration. Hindering and facilitating factors relating to lay and professional involvement have also been identified. These require further investigation and analysis, in terms of what makes women present for pregnancy care both initially and regularly, and the relationship between pregnant women, those around them and the health and social care professionals who care for them. The study suggests that it is not only women’s views but those of peers, families and professionals, that are influential and worthy of further examination. Multiple methodologies are required to contribute to a greater understanding of the multi-faceted nature of late booking.

**7.4 Conclusions**

Antenatal care in the UK is a well-established programme of health screening, health education and support, and offers many benefits to pregnant women and their families. Sandall (2014), in her RCM report into continuity in midwifery care, identifies that both the model of care and the place of birth are important influences on a range of outcomes for mothers and babies.Heaman *et al*‘s (2014) Canadian study agrees, suggesting that

*“prenatal care can contribute to a decrease in maternal and perinatal morbidity and mortality by screening for potential risks, treating medical conditions, and helping women address behavioural factors that contribute to poor outcomes”* (p817)

Such a description provides compelling reasons for promoting timely and regular antenatal care. However, it ignores the other significant aspect of care that, at its best, antenatal care offers psychological, social and emotional support for women during pregnancy and beyond, with direct and indirect benefits which are harder to quantify. Arguably, this aspect of care is as valued by women as the physical checks that confirm their pregnancies are progressing normally. It is a fundamental part of individualised care which has relevance for women, their friends and families; care which women are willing to prioritise.

There is an underlying assumption that pregnant women will recognise the benefits and attend for early care, however a small but significant number of women do not attend early, many with risk factors for poor pregnancy outcomes. The Sheffield study has contributed to a greater understanding of this late booking, and to the debate around strategies to improve early access to antenatal care and outcomes for pregnant women and their babies. Evidence from this study and others, both qualitative and quantitative, suggests that antenatal care initiation behaviour is extremely complex, and is influenced by the interaction of cognitive, emotional, social and environmental factors. A woman’s mindset and particularly her acceptance of her personal pregnancy, the social consequences of the pregnancy and the need for antenatal care (her public pregnancy), are reflected in her relationship with antenatal services. This study shows that there *are* common themes, such as unintended pregnancy, and prevalent groups who book late. However, it also highlights a different perspective on late booking, one rarely seen in previous studies. This demonstrates that women across the social spectrum exhibit thoughtful and purposeful engagement with their pregnancies, outside of mainstream maternity care, also comparable attitudes and priorities relating to the relevance and value of such care. Consequently, stereotypical definitions of ‘late bookers’ are unhelpful. Solutions to late booking and poor antenatal engagement must attempt to balance such commonalities with the evident complexity and diversity of women’s experiences. They must also acknowledge that acceptance works on both sides.

Any approach to improving maternal health equity, in terms of access and outcomes, requires co-ordinated action. Reducing late booking necessitates reaching out to places where women access all forms of education, health and social care, using a range of methods and media, but also reaching out to women personally. The three recommendations from this study acknowledge this. Ultimately women, their friends and families, need to be better informed about all aspects of reproductive health. Antenatal care needs to be readily accessible but also relevant to women’s lives and needs. To do this, such care needs to be flexible and focused on the individual, with more emphasis on a woman’s choice, and with psychological support having parity with physical assessment. It is this combination which will promote the provision of timely, but also effective, antenatal care for all women**.**

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