

**‘THE INTERFACE BETWEEN EVIDENCE-BASED
MATERNITY CARE CLINICAL PRACTICE GUIDELINES
AND THE PREGNANT WOMAN’S AUTONOMY’.**

Thesis submitted for the degree of

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by

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'The interface between evidence- based maternity care clinical practice guidelines and the pregnant woman's autonomy.'

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ABSTRACT.

The importance of the pregnant woman's autonomy and the role of increased choice in decision-making relating to her maternity care have gained widespread recognition. This is borne out in the healthcare and bioethics literature, key initiatives in policy documents and clinical guidelines.

Although guidelines are a central feature of maternity care, little is known about how their recommendations are experienced by women and the impact on their autonomy. This thesis addresses that gap in knowledge.

The methods I used in this research comprised a literature review and an empirical study consisting of semi-structured interviews with 20 participants in an inner-city teaching hospital. Data collection, transcription and analysis were informed by adaptation of the Constructivist Grounded Theory approach (Charmaz: 2006).

My analysis generated two main thematic categories. First, women lack the appropriate in-depth pregnancy and birth knowledge to make decisions independently. Second, interactions with trusted professional carers were highly valued. Analysis suggested new insights, namely that the meaning of autonomy to women is more complex than self- government, a range of options and relational responsibilities can account for. Women felt empowered by being a genuine participant in the decision-making process. They expressed their autonomy by being invited to share their previous experiences, current expectations and concerns and request information in a manner consistent and timely with their own agendas. Women's responses were also shaped by considered reflection of the impact of their decisions on others.

My analysis revealed that some level of interdependence may be a precondition for women to exercise their autonomy. It is a paradox that the recommendation professionals should follow guidelines and be non-directive may result in the unintended consequence of women exercising their autonomy by in part reinstating authority to professional carers.

Interpretation of findings led to the development of my grounded theory, 'Choosing when to choose'.

Dedication.

I dedicate this thesis with love to my most dear late mother and father, Eleri and Ronald Ledward.

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ABBREVIATIONS

Abbreviation

Full Text

AIMS	Association for Improvements in the Maternity Services.
ALT	Alanine Aminotransferase Test.
CAQDAS	Computer- assisted qualitative data analysis software.
CCPC	Cochrane Pregnancy and Childbirth Collaboration.
CDMR	Caesarean delivery on maternal request.
CEMACH	Confidential Enquiry into Maternal and Child Health.
CINAHL	Cumulative Index to Nursing and Allied Health Literature.
CIS	Critical Interpretive Synthesis.
CMO	Chief Medical Officer.
CTG	Cardiotocography.
CTIMP	Clinical Trial of Investigational Medicine Product.
CVS	Chorionic villus sampling.
DCE	Discrete Choice experiment.
EBM	Evidence-based medicine.
GDG	Guideline Development Group.
GP	General Practitioner.
ICP	Intrahepatic cholestasis of pregnancy.
IOL	Induction of labour.
IOM	Institute of Medicine.
IRAS	Integrated Research Application Service.
IUGR	Intra- uterine growth retardation.
MADM	Mother's Autonomy in Decision- Making.
MF	Maternity forum.
MHHR	Maternity hand-held record.
MIDIRS	Midwifery Information and Research Services.
MPHIL	Master of Philosophy.
MRC	Medical Research Council.
MSAFP	Maternal serum alpha-fetoprotein.
MSLC	Maternity Services Liaison Committee.

NCC	National Collaborating Centre.
NCC-WCH	National Collaborating Centre for Women's and Children's Health.
NCT	National Childbirth Trust.
NDSCR	National Down syndrome cytogenetic register.
NHEL	National Health Executive Library.
NHS	National Health Service.
NICE	National Institute for Health and Care Excellence.
NIHR	National Institute for Health Research.
NRES	National Research Ethics Service.
NSC	National Screening Committee.
NSF	National Service Framework.
NT	Nuchal translucency.
PALS	Patient Advice and Liaison Service.
PHAC	Public Health Agency of Canada.
PIS	Participant Information Sheet.
PPI	Patient and Public Involvement.
PIIP	Patient and Public Involvement Programme.
PR	Proportionate Review.
RCM	Royal College of Midwives.
RCOG	Royal College of Obstetricians and Gynaecologists.
RCPCH	Royal College of Paediatrics and Child Health.
RCT	Randomised controlled trial.
REC	Research Ethics Committee.
SGA	Small for gestational age.
SIGN	Scottish Intercollegiate Guidelines Network.
TOL	Trial of Labour.
TTTS	Twin-to- Twin Transfusion syndrome.
UK	United Kingdom.
US	United States.
VBAC	Vaginal Birth after Caesarean.

Chapter One.

Introduction.

Statement of purpose:-

The purpose of this thesis is to gain an understanding of how the recommendations in maternity care clinical practice guidelines are experienced by pregnant women receiving maternity care and their impact on women's autonomy. The main focus is NICE (National Institute for Health and Care Excellence) guidelines. RCOG (Royal College of Obstetricians and Gynaecologists) and RCM (Royal College of Midwives) guidelines will also be referred to. The study will explore women's experiences of their care through the use of literature and an empirical research study. The research design comprises qualitative interviews with a sample of 20 pregnant women analysed in relation to relevant extracts from clinical guidelines using a modified grounded theory approach. I will show that, first, the meaning of autonomy for women frequently did not concur with the concept of the woman as primary decision-maker choosing freely from a range of maternity care options; second, women's ways of expressing their autonomy revealed new insights.

Chapter aims and objectives.

This Chapter provides the background to and rationale for the research study.

Section One provides background context to the study. Part (i) locates clinical guidelines broadly in context. Part (ii) provides a summary of the NICE clinical guideline development process. Part (iii) introduces debates within academic literature about professional control in medicine and the shift to enhanced patient autonomy and increased options. Part (iv) outlines

the concept of choice. Section Two explains what led me to undertake this research. Section Three explains the rationale for the research. Section Four outlines the potential benefits of the study for future practice and research. Section Five provides an Overview of this thesis.

SECTION ONE.

Background context to the research study.

Part (i) Guidelines.

Prior to clinical guidelines, there was widespread variation in opinion and practice on how to best secure a good pregnancy outcome. The EBM (evidence-based medicine) culture is premised on the belief that care should be based on tangible evidence, coupled with the healthcare professional's experience and the patient's wishes (Muir Gray: 1997). Specifically, in maternity care the evidence-based culture was activated by the landmark publications *Effective Care in Pregnancy and Childbirth* (Chalmers *et al*: 1989) and the Cochrane Pregnancy and Childbirth Database (Enkin *et al*: 1995) which provided published evidence on what is effective and what is not. It is relevant to this research that evidence-based practice is well developed in obstetrics (Audit Commission: 1997). More recently, the report *Standards for Maternity Care* has best evidence firmly rooted in its strategy for service improvement (RCOG: 2008). Translation of the accumulating body of research evidence into clinical guidelines has become a useful tool in practice. It would be impossible for healthcare professionals to carry out searches and critical appraisal of all the research literature. Medical textbooks quickly become outdated. Evidence-based clinical guidelines are a means of implementing EBM in practice.

Established in 1999, NICE has been responsible for the development of national guidance, its work including cancer service guidance, interventional procedures, public health interventions and clinical guidelines. NICE was introduced to reduce variations in care and maximise the cost-effectiveness of treatments in the NHS (National Health Service) in England contained in the policy document *The New NHS: Modern and Dependable* (Department

of Health: 1997) and *Clinical Governance: Quality in the New NHS* (NHS Executive: 1999). The cost-effectiveness of treatments will not be discussed in this thesis. Although important, the scope of the thesis prohibits meaningful debate in this area.

Since the 1990s, there has been considerable growth in the use of clinical guidelines (Tinsley: 2005).

NICE guidelines and public health guidance are regarded as good examples of evidence-based working (House of Commons Health Committee: 2008). Importantly, NICE guidelines are approved by the NHS.

Definition of clinical guidelines.

According to the IOM's (Institute of Medicine's) 1990 report, by definition clinical guidelines are 'systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances' (Field and Lohr: 1992: 27).

Guidelines are not synonymous with fixed protocols that must be followed. Their recommendations offer guidance to patients, their families and carers, healthcare professionals, managers and commissioners. However, although guidelines can take into account variations in clinical settings, they cannot respond to every patient's unique needs and should be applied using clinical judgement.

NICE clinical guidelines.

NICE clinical guidelines are recommendations based on the best available evidence on how healthcare and other professionals caring for patients should care for those with specific clinical conditions. They include a wide range of different forms of evidence and other relevant information. This could range from scientific research using a variety of different methods right through to testimony from practitioners and people using the services (The guidelines manual: NICE: 2014). Guidelines are developed by evidence-based scientific methods (van Everdingen *et al*: 2004). If there is insufficient available evidence the recommendations are based on the

collective viewpoints of the GDG (Guideline Development Group) and other expert advisers.

NICE intended their guidance to be used to improve patient care. Decisions should be made both in consultation with and the agreement of the patient and their carers if appropriate (Process and Methods Guide: NICE: 2012).

Part (ii) The NICE clinical guideline development process.

The development of NICE guidelines involves NICE, the NCCs (National Collaborating Centres), GDGs, the PPIP (Patient and Public Involvement Programme) at NICE, expert reviewers and stakeholders.

The GDG is composed of between six and eight healthcare professionals, technical experts and patients/ carers. Some GDGs have a Clinical Adviser with topic expertise. The Antenatal care GDG included two service –user representatives, one a Communications Manager at Down’s syndrome association and another from the NCT (National Childbirth Trust), two midwives, two obstetricians, a general practitioner, an ultra-sonographer and an MRC (Medical Research Council) funded public health research fellow(NICE:2008).

The GDG’s objectives are to develop guidelines based on current best evidence, helping people make appropriate decisions and doing what they can to empower patients with knowledge. For example, the wider recommendations of NICE maternity care guidelines are sensitive to maternal autonomy and choice and support healthcare professionals in providing care in partnership with women. Women’s care should take into consideration their needs and preferences and ensure that they (and their partners and families where appropriate) have the opportunity to make informed decisions about their care (NICE: 2014). Hence women’s care is underpinned by respect for their autonomy and choice. These objectives are significant to the overall purpose of my thesis.

The PPIP team at NICE includes patient and carer organisations who might have experienced the condition themselves or have a relative affected by the condition the guideline recommendations will include.

Registered stakeholders have an integral role in the development of NICE guidelines. They have an interest in the guideline topic or represent people whose professional practice or whose care could be directly affected by the guideline. Examples of these are The Health Care Commission and the Department of Health. Stakeholder organisations may also include both patient and carers groups and companies. An example of relevance to my thesis is AIMS (Association for Improvements in Maternity Services).

The main stages in the guideline development process.

The process of developing a NICE clinical guideline takes between 12 and 27 months , depending on the size and scope of the topic (The guidelines manual: NICE: 2014).

The scope.

NICE is presented with a short remit for each guideline by the Department of Health or the NHS Commissioning Board. The next stage in the development process is to clearly define the scope, that is what the guideline will and will not cover. The scope is assembled by staff at the NCC with the GDG Chairperson, the Clinical Adviser (if there is one), the guidelines team and the PPIP team based at NICE. Lay expertise may also be drawn upon. There may also be input from the evidence review teams, information specialist, systematic reviewer and economist. The group decide on key clinical questions to be addressed (The guidelines manual: NICE: 2014). For example, a guideline on the management of normal labour could potentially include anything that fell under the auspices of 'normal' birth, examples of which include a home birth or a water birth. Although these could be included in a sole guideline, the task of developing such a guideline would be very considerable. Therefore, there is a need to identify what should be included (and excluded) in order to define key

research questions to be addressed and to ensure that research questions are both clear and focused (The guidelines manual: NICE: 2014).

Draft scope

The draft scope is a brief description of the guideline topic, a summary of why the guideline is needed, ways in which it will contribute to healthcare and how the guideline links with other NICE recommendations and quality standards (The guidelines manual: NICE: 2014).

NICE then arrange a scoping workshop for all stakeholder organisations prior to public consultation on the scope (The guidelines manual: NICE: 2014).

For example, during the development of the Antenatal care guideline, *Antenatal care. Routine care for the healthy pregnant woman* (NICE:2008), Gloucester Hospitals NHS Foundation Trust stakeholder group commented that whilst it is appreciated that women need good evidence-based information in order to make informed decisions, many women complain that they are bombarded with information. This resulted in them feeling overwhelmed and consequently they don't read any of it. This stakeholder group requested that the GDG addresses first, what women really need to know and second, when it would be most timely to give that information. Their comments informed the guideline's development. The final version of the full Antenatal care guideline reads as follows:

'What, how and when information should be offered during the antenatal period to inform women's decisions about care during pregnancy, labour, birth and the postnatal period' (NCC-WCH: 2008: 37).

Guidelines that are consistent with woman-centred care reflect the importance of respecting women's autonomy and choice in their maternity care. We shall see the importance of this later in this thesis.

Consultation process.

NICE refine the draft scope which is posted on the NICE website for four weeks (Process and methods guide: NICE: 2012).

Final scope.

NICE compiles all stakeholder comments into a 'scope consultation table'. Comments could cover the general overall quality and content of the guideline, gaps in the evidence that the recommendations are based on and inconsistencies in and disagreements with the interpretation of the evidence. The NCC then finalises the scope in line with stakeholders' comments (Process and Methods Guide: NICE: 2012).

Finalising the guideline's scope after consultation.

The guideline Developer finalises the scope. It is signed off by a member of NICE staff responsible for quality assurance (The guidelines manual: NICE: 2014).

Review questions.

At the start of guideline development, key points highlighted in the scope may need to be translated into review questions which are the framework for the literature searches. They inform both the planning and process of the evidence review and act as a guide for the development of the guideline's recommendations (The guidelines manual: NICE: 2014).

The evidence review.

The key objective of an evidence review is to provide a summary of the relevant evidence (The guidelines manual: NICE: 2014).

Identifying the evidence.

NICE's objective is to identify the best available evidence to address a particular question (The guidelines manual: NICE: 2014).

Assessing the quality of the evidence.

Quality assessment is a very important stage in reviewing the evidence and might include, for example, quality assessment of systematic reviews, quality assessment of studies of interventions or quality assessment of studies on the views of people using the services, their families and carers, the public or practitioners (The guidelines manual : NICE: 2014).

In addition to a thorough assessment of validity, reliability and bias, sound interpretation of the evidence is paramount to inform the guideline's recommendations (The guidelines manual: NICE: 2014).

Writing the guideline.

The guideline's recommendations should be clear, understandable by the targeted audience without reference to the evidence reviews and based on the best available evidence (The guidelines manual: NICE: 2014).

The final stages of development include careful extraction and summary of the evidence into recommendations (The guidelines manual :NICE:2014).

Four versions of the guideline are published:-

- 1. The full guideline.** This sets out in detail the background to and evidence for the guideline, in addition to the recommendations. It is produced by the NCC or the NICE Internal Guidelines Programme.
- 2. The NICE guideline.** This sets out the guideline's recommendations, without information about methods and evidence.
- 3. The NICE pathway** is an online resource for professionals which contains the guideline's recommendations in addition to any other NICE guidance directly relevant to the topic.
- 4. Information for the public** summarises the recommendations in layperson's language for patients, their families and carers and the general public (Process and methods guide: NICE: 2012).

Updating.

When scheduling updates the main focus is on the scope of the published guidance but identified changes in practice are also taken into account (The guidelines manual: NICE: 2014).

Part (iii) Policy context.

There were other shifts in patient care relevant to the research study. During the 1900s, childbirth was increasingly medically supervised, reflecting a society that entrusted the medical profession with much authority. The 1960s and 1970s saw developments such as the women's movement and a culture that set out to shift control in decision-making from professional authority to the woman (Davis:2003). For many years, women had accepted a 'doctor knows best approach', but they began to question the merits of blindly following the medical profession. Two books in particular encouraged women, reminding them that pregnancy was not an illness and gave the impetus to question decisions about their healthcare, particularly relating to childbirth. One was *Our Bodies Ourselves* launched in the UK (United Kingdom) in 1978 (Phillips and Rakusen: 1989) and the other Sheila Kitzinger's *The Good Birth Guide* (Kitzinger: 1979). Both books were grounded on the principle of women's autonomy in healthcare matters. Kitzinger's work built on previous campaigns relating to rising rates of IOL (Induction of labour) and challenged other practices on the grounds of lack of firm supportive evidence. Her work suggested that women felt constrained by the organisation of hospital-based care 'My impression is that women often do not ask for what they would like and feel rather intimidated by the organization of the hospital, however kind the doctors and nurses' (Kitzinger:1979:15). This quote suggests the overall power of the institution (rather than professional carers) and the need for women to conform, despite the fact that the care was not always what they wanted.

In the UK, government recommendations that the health service should become more patient-orientated first appeared in the Griffiths Inquiry Report (1983). This stated that service-providers should explore patients'

experiences and perceptions about their care (Department of Health and Social Security: 1983). In maternity care, women complained about lack of information and involvement in decision-making (Jacoby and Cartwright: 1990). Other contributory factors were dissatisfaction amongst women about where and by whom childbirth should best be managed and fragmented patterns of care (Currell:1990).These criticisms fuelled a government- led enquiry during the 1990s which led to the publication of the House of Commons *Second Report on the Maternity Services* (House of Commons Social Services :1992). Its list of recommendations was extensive, but its main conclusion was that the woman and her baby should be the central focus of care and maternity services should be geared around them. Hence care should be 'woman-centred'. All four countries in the UK introduced policies for maternity services which carried a consistent message. These reports sought to structure a service where healthcare professionals build a dialogue with the woman, empower her by offering increased choice, involve her in decisions about her maternity care and tailor care to her needs as opposed to those of staff and managers (Welsh Office: 1991; Department of Health: 1993; Scottish Office: 1993; Department of Health and Social Services: 1994) (Waldenstrom and Nilsson: 1993; Newburn: 1994).

The House of Commons *Second Report* (House of Commons Social Services Committee: 1992) and *Changing Childbirth* (Department of Health: 1993) differed from past reports in two ways. First, they critically reassessed the role of healthcare professionals; second, they took into account the views and experiences of women and consumer organisations.

More recently, UK policy and practice has focused on choice. The *NSF (National Service Framework) for Children, Young People and Maternity Services* demonstrates this (Department of Health: 2004). *Maternity Matters* (Department of Health: 2007) focused on 'a wider choice in maternity care' and the 'need for flexible services with a focus on the individual'. The report's key objective was to improve the quality of service provision for women. This was to be achieved by four National Choice guarantees

available to women and their partners. These included choice of how to access maternity care, for example, directly through a midwife or GP (General Practitioner). Depending on individual circumstances, women were to be offered a choice of provider of their antenatal care, for example, midwife-led or shared between midwife and obstetrician. Other options were a choice of place of birth, for example, home, birth centre or hospital and finally a choice of postnatal care, that is, how to access postnatal care, for example at home or a health centre. Currently, one of the fundamental principles underpinning *Better births*- the national maternity review for England (NHS England: 2016) is supporting women's choices.

It appeared policy and practice were changing, the woman becoming more involved in decisions about her maternity care as opposed to being a passive recipient.

Different women want different things. Some empirical studies found that women were unhappy about a lack of continuity of care and carer (Williamson and Thomson: 1996) and waiting times in clinics (Brown and Lumley: 1994). Relevant to my research are studies which criticise women's lack of involvement in decision- making (Garcia *et al*: 1998; Proctor: 1998) and insufficient respect and sensitivity amongst professional carers (Brown and Lumley: 1994).

Part (iv) Choice.

The work of Kirkham (2004) demonstrates that the concept of choice has become predominant in maternity care. This was to give women (at least in theory) a sense of control about the options available to them (Symon: 2006). However, choice is complex. Raz (1986) suggests that choice requires having a range of alternatives from which to choose. As Frith (1998) says, choice should be seen as operating within the boundaries of achieving a good pregnancy outcome, that is, women's unfettered choice cannot be supported unconditionally and whilst choice is important, it is one element of good care. Furthermore, as Kukla and her colleagues say, the bioethics and healthcare literature frequently associates autonomy with the

availability of a wide range of options, but this fails to capture other issues that have importance and relevance. Examples of these are inadequate information about alternatives and lack of opportunity to implement choices (Kukla *et al.* 2009).

A limitation I identified in the literature about offering choice is the process by which options are presented to women. My empirical study will explore this point.

SECTION TWO.

What led me to this research study.

My choice of research topic arose from a theoretical Chapter entitled 'Evidence-Based Medicine and Women's options' in my MPhil (Master of Philosophy) thesis at the University of Liverpool. This Chapter helped my academic supervisors and me to identify an area that had a rich research-base with scope for further expansion.

As a former practising midwife I became increasingly interested in women's experiences of their care and how they made their decisions. The pregnant woman's autonomy is one of my long-standing research interests. It was these reasons, coupled with the growing use of empirical research in bioethics which contributed to my decision to conduct an empirical study.

SECTION THREE.

(i) Rationale for doing the research.

There are two main issues:-

(i) The impetus for the study arose from what is currently under-researched, that is pregnant women's experiences of their care based on recommendations in guidelines and the impact on their autonomy. One way of measuring the impact of guidelines in obstetrics has been through audit conducted by the RCOG. The development of audit based on the uptake of College guidelines is recognised as key in clinical effectiveness programmes (Templeton *et al.* 2001). However, there is a dearth of

research about evaluating the impact of evidence-based initiatives in midwifery practice (Spiby and Munro: 2009).

It is known that some women want information about the effectiveness of their care (Lavender:2008). Aslam (2000) maintains that many women would be disconcerted to discover that their midwife was unaware of the implications of the latest research findings related to their care. Furthermore, many women want to be informed about the relevance of the evidence that is the factual basis for clinical decisions on which to base their decisions (Entwistle *et al*:1996). Baker and her colleagues' study explored women's reasons for accepting or declining the invitation to participate in research. Their findings suggested that some women's decision to accept arose from their wish to be informed about the evidence- base which underpinned their maternity care (Baker *et al* :2005). Although women's responses were considered and revealed individual complexities, they were not asked specifically about experiences of their care. Therefore a key rationale for my study is the need to know more about women's experiences of their care recommended in guidelines and how these impact on their autonomy.

(ii) Women's views relating to their maternity care have been largely confined to studies about preferences and satisfaction with their care. Although some empirical studies briefly allude to clinical guidelines, women's experiences have not been analysed specifically in relation to their recommendations and the impact on their autonomy is left unaccounted for (Williams *et al* :2005; Grimes *et al* :2014).

Three studies which had some interest in women's experiences of care relating to recommendations in guidelines were identified in my literature search. I discuss them here as part of the rationale for my own study.

One study was Franco-Canadian. The work explored the experiences of a randomly selected sample of 8542 women drawn from the May 2006 Canadian Census. Women participated in a computer-assisted telephone interview conducted by Statistics Canada on behalf of the PHAC (Public

Health Agency of Canada) (Chalmers *et al.*: 2008). Interviews were conducted with women when their babies were between five and ten months old, hence the study's findings did not capture pregnant women's views. Findings revealed that a number of evidence-based practices, principally the considered use of interventions in accordance with guideline recommendations, were not being fully implemented. An example of this was higher than recommended use of interventions in childbirth. Hence the study's main findings exposed non-adherence to recommendations in guidelines. The study did not directly ask women about their experiences of care based on recommendations in guidelines and did not explore the effects of their care on their autonomy. My study builds on and adds to Chalmers and her colleagues' work.

Another small study was conducted in an inner-city university teaching hospital in the UK and related to evidence-based guidelines for midwifery-led care in normal labour. The first part, which will not be discussed here explored midwives' views, facilitated through group discussions (Munro and Spiby:2001; Spiby and Munro:2001). The second part explored women's views (Munro and Spiby:2003; Spiby and Munro:2004). It was designed in three parts. I will summarise each of these.

Part One comprised feedback from the MF (Maternity Forum) - the user group of the MSLC (Maternity Services Liaison Committee) on the first edition of the guidelines. They were enthusiastically received by the membership. Specifically, the MF welcomed the guideline's evidence- base and its woman-centred approach.

Part Two comprised two focus groups. Women who had had more than one normal delivery in the unit in the past four years were invited to participate. The rationale was that it might offer valuable information about changes in practice post-guideline. The research explored women's views on the information they received from midwives and how useful that was in helping them make decisions. However, due to the winter holiday period and adverse weather conditions, the focus groups were poorly attended. Only one woman attended the first group and two the second group. The woman

who attended the first group had had two births in the unit, the most recent three years previously. Although she did not think there was significant overall change, she felt that this time she was respected as a 'thinking person' and not simply 'a vehicle for birth'. She also commented that there was fuller explanation of vaginal examinations and that the absence of a CTG (cardiotocography) on admission made it 'less mechanical' (Munro and Spiby: 2003: 427). The two women who attended the second group had births two and four years previously. Both said they had been asked more about 'what they wanted to do' (Munro and Spiby:2003: 427). Although the findings are interesting, there are limitations in terms of numbers recruited. In their subsequent evaluation, the authors described attendance at the focus groups as 'disappointing' (Spiby and Munro: 2004). My study aims to expand on these deficiencies.

One year following the introduction of the guidelines, it was considered appropriate to think about updating them. The authors were aware of the limited data they held on the first edition of the guidelines. Part Three explored the views of 11 women attending antenatal yoga classes interested in giving their views on the guidelines by completing a questionnaire. All the participants thought that many women would be interested to know the level of evidence about topics seen to be 'missing' from the guidelines. An example was the use of the birthing pool. Most women commented that the language used in the guideline was 'slightly too technical' and might be incomprehensible to a layperson (Munro and Spiby: 2003:428). These findings concur with Sakala and her colleagues' report on a pilot project which involved consumers in the process of refereeing systematic reviews for the CCPC (Cochrane Pregnancy and Childbirth Collaboration) (Sakala *et al.* 2001). Munro and Spiby's findings make a small contribution to our understanding of the question to be addressed in this thesis, but it is impossible to generalise from them. It would have been more informative to have obtained a richer dataset from the focus groups and/or carrying out interviews with a sample of women. Another point in the authors' evaluation was that time constraints made it difficult to involve women in identifying the topic agenda or involving them as critical readers

during the guideline recommendations' development stage (Spiby and Munro:2004).

Building further upon service-users' comments on the guidelines which were intended to be used in one setting where the previous study's authors were based, a third edition was commissioned by the RCM. A booklet entitled *Evidence based Guidelines for Midwifery-led Care in Labour: Good Practice Points* was published by the RCM (Jokinen: 2005). On this occasion, there was significant increase in service-users' involvement. Members of national service organisations that work with service-users acted as peer reviewers. The authors' experience of involving service-users was that it offered useful feedback to the guideline developers. Their overall response was positive, although amongst the points they raised included a request for more information about how the recommendations were arrived at and further explanation of some concepts. An example was supporting women in labour. An important point was that the peer reviewers thought that women's experiences had influenced the guidelines (Spiby and Munro: 2009). However, there are no examples or quotations from the reviewers to substantiate this claim which limits its potential usefulness. In sum, although helpful and informative, women's responses were confined to a process of peer review of the guidelines. Peer review is valuable in helping achieve quality in the development of guidelines SIGN (Scottish Intercollegiate Guidelines Network: 2004). However, there was no formal interviewing process to explore women's experiences of their care based on recommendations in guidelines. The difference between Munro and Spiby's studies and my research is that I specifically asked women about their individual experiences about their care.

(ii) Impetus for the study approach.

The main impetus for my study arose from what is currently under-researched in the healthcare literature. As we shall see in this thesis, guidelines are sensitive to maternal autonomy and choice. Therefore, it is surprising that there is little research that relates specifically to women's experiences of their care based on recommendations in guidelines and the

effect on their autonomy. It is proposed that an in-depth analysis of women's first-hand accounts will contribute to the evidence-base by narrowing this gap and suggest directions for future practice and research.

Specific Focus of study:-

Research Question.

How are the recommendations in maternity care clinical practice guidelines experienced by pregnant women receiving maternity care?

SECTION FOUR.

Potential benefits of this research.

Findings from this research could potentially benefit women through :-

a) **Future Practice.**

A better understanding of women's experiences of their care could help further enhance woman/healthcare professional interactions and relationships. As Goldenberg (2005) says, qualitative research has the potential to help develop guidelines from women's experiences of their care. This may help healthcare professionals develop a better understanding of the most effective ways of interacting with women in order to capture women's perspectives and tailor information and care to the individual woman in the light of revised guideline recommendations.

b) **Future Research.**

The study's findings could serve as a useful evidence-base for further exploring women's experiences of their care in other locations during pregnancy. An example is community-based care among low-risk women and developing the most appropriate care for this specific group of women. Future exploratory work could inform further broad-based survey work that could generalise from my sample to a larger group of pregnant women.

SECTION FIVE.

Overview of the thesis.

I will now outline the structure of this thesis.

Chapter Two.

Literature Review.

This Chapter describes first, my literature search strategy. Second, it reviews and synthesises the benefits and limitations of guidelines; third, it introduces the debates on liberal and relational autonomy. It provides a critical analysis of some of the different ways in which autonomy has been debated in the healthcare and bioethics literature and provides some conceptual underpinnings for subsequent Chapters in this thesis. Based on my review of the literature on autonomy, I follow with a review of debates on decision-making in healthcare and trust between women and healthcare professionals. Lastly, I review a range of empirical research studies which my study builds upon.

Chapter Three.

Methods.

This Chapter sets out how the empirical study was designed and conducted in order to address the research question. It discusses the ethical review process, the development of the Participant Information sheet and the Interview Schedule /Topic guide, the sampling strategy, participant recruitment and the choice and justification of a qualitative methodology. It sets out the process of data collection, transcription and analysis which was informed by adaptation of the Constructivist Grounded Theory approach (Charmaz: 2006). The Chapter sets out an explanation of Constructivist Grounded Theory and refers to evidence supporting its use and consideration and learning from its use in other studies. The Chapter includes a section entitled 'Reflexivity and reflective analysis' which briefly considers my experiences during the research process.

Chapter Four.

Findings (i).

Pregnancy and birth: a time for new knowledge.

This Chapter presents findings from an analysis that explored 20 women's accounts of their experiences gathered via a qualitative interview study. My analysis suggested that based on women's limited pregnancy and birth knowledge, choosing between options in clinical guidelines presented a dilemma. With the help of trusted professional carers, understanding women's concerns is best facilitated by effective interactions as part of a process of shared decision-making.

Chapter Five.

Findings (ii).

Types of decisions.

This Chapter is about different types of decisions in pregnancy and childbirth and their variable effects on women's autonomy.

Chapter Six.

Findings (iii).

Screening for foetal abnormalities.

This Chapter is about antenatal screening for foetal abnormalities with a specific focus on the NICE guideline's recommendations on Down's syndrome (NICE:2008).

Chapter Seven.

Discussion and Conclusion.

This Chapter summarises the existing knowledge in the healthcare and bioethics literature, synthesising published theoretical work and empirical studies. Drawing these and the findings from the (primary) empirical study together, it explains the Grounded Theory my study generated and

articulates three propositions arising from it. The Chapter also discusses the study's implications, strengths and limitations, including the potential for methodological error and researcher bias, draws conclusions and makes recommendations for future practice and research. It also provides examples of how certain recommendations in clinical guidelines could be reframed, fully grounded in women's expressed views about their experiences in order to help make practice more finely tuned to individual women's needs.

The **Appendices** of this thesis include:-

- (i) PIS (Participant Information sheet).
- (ii) Participant consent form for the empirical study.
- (iii) Interview Schedule/ Topic guide.

and

- (iv) Analysis strategies.

For stylistic reasons, throughout this thesis I will be referring to the term 'healthcare professional.' This should be taken to mean predominantly doctors and midwives but includes all professional carers who contribute to the woman's maternity care.

Throughout this thesis, the extent to which I have utilised the work of others is that which is referenced in the text.

Chapter Two.

Literature Review

Introduction.

This Chapter is my literature review. Section One explains my literature search strategy. Section Two reviews and synthesises literature on the benefits and limitations of clinical guidelines. Section Three introduces debates on liberal and relational autonomy and demonstrates some of the different ways in which autonomy has been debated in the healthcare and bioethics literature. Based on my review of the literature on autonomy, there follows a review of the debates on decision-making in healthcare and the concept of trust. Section Four reviews selected empirical research studies which my study builds upon.

Since the literature is extensive, the aim of my review is to include a critical analysis of selected key texts which are most relevant to my research study. It is my intention to locate the study in the body of literature that has looked critically at clinical practice guidelines and autonomy and the empirical literature that explores women's views of their maternity care. The review aims to demonstrate how my work will contribute to the current evidence-base.

SECTION ONE.

Literature search strategy.

According to Shaw and her colleagues (2004), the aim of literature searching is to maximise the search's potential to identify relevant and exclude irrelevant material for a specific research question.

Developing a search strategy.

The work of Lefebvre *et al* (2010) says a search strategy is derived from the research question and contains a description of the terms to be used in the

search, the sources to be searched, for example, electronic databases and the search limits.

My literature search was conducted first, to review the available literature and second; to explore whether or not research had been undertaken that explored women's experiences of their care based on recommendations in guidelines and the effect on their autonomy.

My initial literature search was undertaken at the commencement of the study. Further reading and searching of relevant research became an ongoing feature of an iterative process, that is, the interpretation shifted as the review progressed, in line with grounded theory. The iterative process also helped ensure that references were kept up to date.

(i) Methods.

Choosing search terms.

Initially, I carried out a broad literature search. The database searches were performed using recognised search techniques using broad-based terms. These were derived from keywords in my research question and targeted a purposive selection of literature likely to be useful and relevant, for example 'clinical guidelines'. However, I did not commit to having clear definitions of the meaning of 'clinical guidelines' and 'evidence-based guidelines' used either individually or in combination which allowed me to make decisions about which sources to search and ways to structure searches within those sources. This became important in reaching a deeper understanding about guidelines.

Approach to the search.

The literature was searched in several ways. Initially, electronic searches were undertaken.

(a) Electronic databases consulted for the review.

CINAHL (Cumulative Index to Nursing and Allied Health Literature).

Cochrane library.

Expert documents and websites, for example, RCOG and RCM.

MEDLINE.

NHEL (National Health Executive Library).

Sage Journals online.

Social Science Abstracts.

UK Government websites.

I also searched databases for existing guidelines. An example is NICE.

- (b) Electronic searches were supplemented by manual searching of the indices in books to establish whether articles were missing.
- (c) Reference lists from relevant articles were used to identify additional papers, that is, 'back- chaining' from useful sources and other resources.
- (d) Hand-searching of selected journals was conducted as a supplementary search method. This was valuable as not all relevant articles are necessarily indexed under the appropriate keywords. An example of a journal I hand-searched was *Midwifery*.
- (e) Professional contact with my three academic supervisors who recommended journal articles and books as part of an iterative process.
- (f) Professional contact with a University- based subject librarian to make optimum use of library catalogues.
- (g) MIDIRS (Midwifery Information and Research Services). The Reference Database ranges from broad topics, for example, pain relief in labour to specialist interest topics, for example, the safety of home birth.

I found that a significant methodological challenge of literature searching was that qualitative studies were to be found in a range of social science and healthcare journals. Barbour and Barbour (2003) say this can be

problematic and it is important to make use of a range of databases to ensure adequate coverage.

Study selection criteria.

As researcher, I had to make decisions about which pre-existing studies would contribute to my literature review and subsequently the final analysis. Potentially relevant material was screened against the following criteria.

Inclusion criteria.

Criterion 1 Language – primarily restricted to work published in English.

Subsequently, in view of my educational background, I searched Pub Med for work published In French.

Criterion 2. Timeframe. Focus on literature published over the past 30 years, to include major changes in maternity care over that period.

Criterion 3. Methodology. Qualitative studies were the main focus, but in order to include all relevant material identified in the search, several quantitative studies were reviewed.

Criterion 4. Range of work to be included, that is, theoretical work, policy documents, clinical guidelines, surveys, editorials, letters to journals, stakeholders' perspectives and descriptive work.

Criterion 5. Studies were not to be confined to the UK.

I found clear screening criteria useful to see why some studies were included, whereas others were not.

(ii) Results.

The databases were searched and following electronic retrieval of articles, a preliminary review of the abstracts (where appropriate) was undertaken. I screened titles/ keywords of relevance to my research question. Searching broad topics, for example, 'decision- making in healthcare' resulted in the identification of over tens of thousands of records, many of which were irrelevant , that is, the largest body of literature was excluded first. As there

was considerable overlap of results with the remaining literature, screening of the titles and abstracts was conducted to assess their potential relevance with a view to further refining the search. Papers unrelated to the topic were removed. This further reduced the potential pool of literature to approximately 4150 references. Where abstracts appeared relevant, the full article was accessed and read. A further decision about whether to include the article was made on the basis of critical appraisal.

Copies of relevant articles, book chapters and reports were filed alphabetically by first author's surname. I retained a search history using index cards which enabled me to re-use earlier searches in new search strategies when appropriate.

This process resulted in a funnelling down of the literature to approximately 1380 references on the basis of those that related most closely to my research question.

There are occasions in this thesis when older texts have been used. This is when the more recent literature has not added any significant greater knowledge or where they have been used as a foundation for later work. An example is the work of Sheila Kitzinger (1979).

After removing duplications, a total of 987 relevant sources were retrieved and re-read. This process helped ensure that the relevant material had been identified and used. There are 511 references included in the final thesis.

SECTION TWO.

Literature Review.

The work of Benton and Cormack (2000) says that a literature review can be seen as systematically reading, critically appraising and then synthesising in a structured and coherent way. This is to illustrate similarities and variations and make connections in existing research relevant to the study topic (Coughlan and Cronin: 2016). Underpinning the

review is the researcher's understanding of the nature of knowledge and how knowledge is generated and used (the epistemological viewpoint).

The literature review is important because new insights can be developed by synthesising the literature. Such insights are not available without a literature review in a particular area (Aveyard: 2014).

My approach.

My data analysis is informed by the Constructivist Grounded Theory approach (Charmaz: 2006). There has been much debate about the place of the literature review in grounded theory research. Traditional grounded theorists (Glaser and Strauss: 1967; Glaser: 1998) advocate delaying the literature review until completion of the data analysis. They claim consulting literature prior to commencing fieldwork can lead to researcher bias during data collection and transcription. However, other grounded theorists have rejected delaying the literature review on the grounds that a researcher is unlikely to lack some familiarity with the literature (Clarke: 2005; Walls *et al*: 2010). The work of Giles and her colleagues (2013) says that preliminary review of the literature does not compromise the rigour of grounded theory research. Rather, it can enhance theoretical sensitivity and creativity. What is important is that researchers acknowledge the influence of previous work in their interpretation of what is emerging from their data (Giles *et al*: 2013). As Charmaz (2014) says, researchers typically have knowledge in their particular field when they embark on a research project. Although delaying the review encourages the researcher to articulate her/his ideas, it can result in rehashing empirical problems and disregarding the literature. The disputes, she says, seem to miss the point that the final review should be tailored to fit the specific purpose of the written report (Charmaz: 2014). Thus the purpose of the literature review goes beyond identifying gaps in the evidence to informing analysis of empirical data.

The aim of the review was to construct a critical analysis of an extensive and complex body of literature. Dixon-Woods and her colleagues (2005) have argued that conventional systematic review techniques have their

benefits and limitations. Benefits include synthesising certain forms of evidence in order to test theory about 'what works'. However, there are limitations when the aim is to use a large body of evidence in order to generate theory which is what I set out to do in this thesis.

I explored the work of Dixon-Woods and her colleagues (2006) which proposes the use of CIS (Critical Interpretive Synthesis). They claim that interpretive reviews are principally concerned with the development of concepts and theories which integrate the concepts of induction and interpretation, that is, the synthesis produces theory grounded in the studies included in the review. Although there is a tendency to use interpretive reviews to synthesise qualitative studies, it should be possible to apply this approach to all types of evidence. This is because theory building does not need to be based on one form of evidence. They go on to suggest that the approach is useful in modifying and refining the research question in relation to the findings from the retrieved literature, that is, it is part of the review process, unlike the standard approach of systematic review (Dixon-Woods *et al*:2006).

CIS prioritises the studies' relevance and potential theoretical contribution in assessing the quality of included studies as well as their methodological characteristics .Booth and his colleagues (2016) highlight its usefulness in critiquing bodies of literature from different disciplines, making it an appropriate method for my study.

The researcher is led from the findings in one research article to look for the next potentially relevant article so as to create a sampling frame, that is, literature searching, sampling, critique and analysis are all part of the process of searching and searching further based on what has been learned. CIS highlights the need for categories to be generated from the evidence and for these to be further reviewed as the review progresses, aiming to produce an account that is theoretically robust and well grounded in the evidence. It also states the need for constant reflexivity by the researcher (Dixon-Woods *et al*: 2006). Hence it draws on the principles of

grounded theory, making it an appropriate way of reviewing the literature in my study.

The general context to describe the current state of knowledge.

There has been extensive scholarly debate about guidelines and their place in healthcare (Eccles and Grimshaw: 2000; Goer and Romano: 2012; Weaver: 2015). This section explores some of the key literature.

Guidelines.

(i)Benefits.

Guidelines' beneficial effects are contingent upon a development process that is methodologically rigorous, including the best available evidence and successful implementation of the guideline (Graham *et al*:2002; Cook *et al*:2014).This lies in their potential to offer greater consistency and predictability, thereby reducing the risk that patients with identical clinical problems will receive inappropriately different care depending on the healthcare professional or location of care(Timmermans and Berg:2003; Arora *et al* :2016). Therefore, guidelines - at least theoretically, increase the likelihood that patients will be cared for in the same manner regardless of professional carer or location of care (Woolf *et al*:1999; Staff *et al* : 2013;Myatt *et al* :2014).However, it should be stressed that variations in care are appropriate if the evidence is not strong enough to justify consistency (Fox *et al* : 2003 ; Todd and Banerjee:2016).

One of the attributes of clinical guidelines concurs with the ultimate goals of healthcare that is to deliver optimal care based on current best available evidence. A central role of guidelines is to improve the quality of care and health outcomes through the promotion of interventions known to be effective and discouraging ineffective practice (Cuervo *et al*: 1999; Besevi and Lavender: 2006; Coates: 2010; Koster: 2010). Other authors have claimed they are a crucial instrument in providing safe and appropriate care by improving cross-practice care and enhancing the overall quality of care (Wilson: 2002; Loveday *et al*: 2014). This has particular symmetry with

government initiatives to promote EBM in order to establish greater coherence within the NHS. Recommendations in guidelines may also provide evidence to recommend that forms of care known to be ineffective should be abandoned (Allfirec *et al.*: 2013; Reveiz *et al.*: 2013; Smyth *et al.*: 2013). Guidelines formalise practice and may be part of an evaluation process to determine how their implementation influences quality of care. Specifically, maternity care guidelines that are rigorously developed and whose recommendations are based on strong evidence can improve the quality of care by reducing variations in practice, improving outcomes and encouraging further research (Lavender: 2008; Goer and Romano:2012). Potential benefits of guidelines to researchers is their ability to highlight areas where research is lacking (Lim *et al.*: 2008).

A common theme is that there are improvements in the process of care when evidence-based guidelines are followed (Lugtenberg *et al.*: 2009). There is also evidence that clinical outcomes improve when care is evidence-based (Dunning *et al.*: 1997; Koblinsky *et al.*: 2012; Souza *et al.*: 2013). Hence guidelines could be seen as authoritative recommendations, directing healthcare professionals to current best evidence-based clinical practice. For the purposes of this thesis, this is significant. Women and healthcare professionals share the common goal of securing a good pregnancy outcome. Women's perception of a good outcome is broader than the professionals' in that it includes not solely a good outcome in the physical sense, but also the feeling of feeling secure and cared for (Edwards:2005; Cheyney:2008; Boucher *et al.*:2009;Renfrew *et al.* :2014). My empirical study contributes by revealing ways in which women recount their previous experiences, current expectations and concerns that might be seen as unexpected.

Guidelines set out standards against which performance can be measured and many clinical audits are based on measuring care against guidelines. NICE guidelines are approved by the NHS. This carries an assertion of authority. As Gabbay and Lemay (2011) have demonstrated, there are many different clinical pathways, local guidelines, protocols, checklists and

Cochrane reviews that may be overridden by healthcare professionals. Guidelines make guidance more explicit and practice become more open to scrutiny, that is, guidelines have a surveillance function. It follows that practitioners and their employers should become more accountable for their actions (Atwal and Caldwell: 2002; Otto: 2016). Guidelines may also be helpful in raising compliance with good clinical practice.

(ii) Limitations.

There are several concerns associated with clinical guidelines. Common themes are that they may erode healthcare professionals' ability to use their clinical judgement, hence reducing practice to 'cookbook' medicine (Charlton: 1997 Bensing: 2000; Brush and Halperin: 2016). In this context, a major concern identified based on systematic reviews of RCTs (randomised controlled trials) is that EBM's values lie predominantly in population-based outcome measures, that is, the results focus disproportionately on the majority and are not always helpful to the individual patient (Kemmer:2006; Epstein and Street:2011; Greenhalgh :2014; Djulbegovic and Guyatt:2014). If we are agreed that a valid measure of 'woman- centred' care is 'care that is adapted to the mother' (Davis: 1997: 23), an important point is that guideline recommendations may sometimes be inappropriate (or at least inappropriate for certain individuals). Hence one benefit of guidelines, that is greater consistency and standardisation, may only be achievable at the expense of denying individual care for some patients. For example, guideline recommendations tend to follow a logical order so as to guide professional carers. Although there may be instances when this is appropriate, we shall see examples in this thesis of women's wish for personalised information and care to be given according to their own timely agendas.

Some authors have claimed that consistency and standardisation may only be achievable at the expense of curtailing some women's choice as RCTs do not address every situation in clinical practice (Jadad and Enkin:2007;Sandall:2008;Walsh:2008; Graham *et al* :2011). As we shall see in this thesis, women's decision- making is complex and sometimes cannot

be addressed specifically through guideline recommendations. Guidelines are also based on expert opinion, not just RCTs.

It could be countered that the accumulated evidence that forms the recommendations in clinical guidelines is not always rooted in the mental processes and behaviour of some healthcare professionals. Rather, it is in the minds of the guideline developers who are themselves distant from the clinical encounter (Berg *et al.*: 1997). The NICE guideline development process differs in this respect. As I noted in Chapter One, Section One, Part (ii) of this thesis, the GDG appointed for the updating process of the NICE Antenatal care guideline (2008) included six healthcare professionals and two consumer representatives. In addition, numerous stakeholder organisations submitted their comments on the draft and final guidelines. There is also evidence that stakeholders' comments influenced the wording of the guideline's recommendations. (NCC- WCH: 2008).

It could be argued that even good evidence from recommendations in guidelines could be seen as less than good practice and contrary to beneficence (do good) when applied in an unthinking way. The guideline's recommendations are based on population- based data, but care-giving is always contextual which may sometimes be inconsistent with the evidence-based paradigm (Thompson: 2004; Goer and Romano: 2012). As Naylor (1995) says, what is black and white on paper becomes grey in practice. It should also be stressed that women are not a homogeneous group as acknowledged in *Changing Childbirth* (Department of Health: 1993), *Maternity Matters* (Department of Health: 2007) and *Better births* (NHS England: 2016). Different women want different things and, as we shall see in this thesis, develop their own interpretation and understanding of medical information. Guidelines are composed of several elements and may appear coherent at first glance. However, clinical practice at the coalface is an untidy world which constantly presents challenges and disagreements (Gabbay and LeMay: 2011). Hence, there are instances in practice when there is a need for discretion based on clinical judgement.

A further point is that there may be tensions associated with healthcare professionals' interpretation of guidelines which affects some women's care (Chauhan *et al*: 2008; Upshur: 2014). An understanding of what affects the implementation of evidence into practice is complex and beyond the scope of this thesis. Making research evidence accessible and understandable in guidelines as a means of educating healthcare professionals is important in increasing their awareness about best clinical practice, but rarely does it overcome other barriers affecting practice (NHS Effective Care: 1999; Bal: 2017). Professional carers may sometimes resort to covert ways of practice. For example, some may feel compelled to practise in a certain way when a particular shift leader is on duty. They may have to succumb to others' rigid interpretation of the guidelines which might influence or even indirectly control the course of events when they themselves were willing to adopt a more flexible approach (Lavender: 2010; Goer and Romano: 2012). This would involve carefully weighing up the evidence in an individual woman's case and deciding whether it may be appropriate to depart from the guideline. In this respect healthcare professionals may experience decisional conflict (Kaimal and Kuppermann: 2010). On the one hand, the healthcare professional has a duty to act as woman's advocate. On the other, she/he may risk disciplinary procedures if they depart from the guideline. Assuming both woman and healthcare professional agree, there is no conflict. In these circumstances, the guideline may not feature prominently, or from the woman's perspective may be unnoticed.

There may be a case for saying that the guideline's recommendation may not be universally applicable. The Guidelines Manual makes clear the importance of professionals' need to think about the meaning of the recommendations in each case (NICE: 2014). Certain healthcare professionals and some women may mistakenly assume they are subjecting themselves to high risk by default when this may not be the case (Kotaska: 2011). There may be some leeway in less challenging cases. Kennedy and her colleagues (2009) identified the applicability of guideline recommendations as a challenge facing maternity care professionals. The guideline's recommendations should never be more important than the

patient; hence there is a need to exercise clinical judgement to determine when other forms of knowledge and reasoning may sometimes assume precedence.

My review of the academic debates on clinical guidelines, their place in healthcare and their relevance to my research question led me to conclude that there is a need for my empirical research study to explore women's experiences of their care based on recommendations in guidelines.

SECTION THREE.

The concept of autonomy.

Patient autonomy is frequently upheld as a cornerstone principle in health care (Schwartz *et al*: 2002; Gillon: 2003; Greener: 2009; Kearns *et al*: 2010). Autonomy has been variously defined but is broadly taken to mean self-determination and freedom from coercion (Jensen and Mooney: 1990).

Consent.

Respect for the woman's autonomy requires that the healthcare professional obtains her informed consent prior to performing an intervention. It is also a legal requirement (Beauchamp and Childress: 2013).

The following definition of informed consent is quoted and endorsed by the FIGO Committee for the study of Ethical Aspects of Human Reproduction and Women's Health (2007:14).

'Informed consent is a consent obtained freely, without threats or improper inducements, after appropriate disclosure to the patient of adequate and understandable information in a form and language understood by the patient on:

- a) The diagnostic assessment;
- b) The purpose, method, likely duration and expected benefit of the proposed treatment;
- c) Alternative modes of treatment, including those less intrusive, and

d) Possible pain or discomfort, risks and side-effects of the proposed treatment’.

My rationale for starting with autonomy as a problem arose from the drive to promote maternal autonomy and choice in the healthcare and bioethics literature, and policy documents. Many pregnant women want enhanced autonomy, increased choice and expect greater involvement in decision-making about their care (Weaver:1998 Lavender *et al* :1999; Vandevusse:1999; Hodnett *et al* :2010; Mander and Murphy- Lawless :2013). However, despite its importance and although maternity care guidelines are intended to be sensitive to maternal autonomy and choice, the word ‘autonomy’ is not referred to in NICE quick reference guidelines. This is despite the fact that these versions of the guidelines are frequently the only ones many people read (The guidelines manual: NICE: 2014). Rather, ‘autonomous’ appears in the full Antenatal care guideline recommendations ‘Screening for Down’s syndrome should start with the provision of unbiased, evidence- based information about the condition, enabling women to make autonomous, informed decisions’ (NCC-WCH:2008:155). However, what is meant by ‘autonomous’ is not explained. This lack of clarity is surprising, given the importance of autonomy in healthcare. Within the context of clinical guidelines these debates are significant because they shape the ways in which women are treated.

Debates on autonomy.

In this section I will present a critical analysis of the literature on autonomy in the context of maternity care so as to understand the various ways in which autonomy has been conceptualised in order to answer my research question. It will not be a critique of the conditions that are necessary for, nor the meaning of autonomy- although they are important in themselves. Rather, it presents authors’ positions and uses the debates first, to identify gaps in the literature that my empirical study will address and second to deepen our understanding of how clinical guidelines could be structured to enhance pregnant women’s autonomy. Lastly, drawing on CIS, I set out the

ways in which I related concepts which emerged from these debates to my empirical study and the subsequent development of my grounded theory.

My Grounded Theory is presented in Chapter Seven, Section Two, Part Two, subsections (a) and (b) of this thesis.

This process of critical analysis was informed by review and synthesis of theoretical and empirical studies on autonomy in the academic literature. I will present as follows:-

(a) The liberal model of autonomy.

(i) Theoretical debates on liberal autonomy.

(ii) Empirical study which includes liberal autonomy.

And

(b) The relational model of autonomy.

(iii) Theoretical debates on relational autonomy.

(iv) Empirical studies which include debates on relational autonomy.

(a) The liberal model of autonomy.

The liberal model of autonomy has its roots in the idea that providing others are not harmed, individuals should follow their own life plans according to their beliefs and values (Kymlicka:1989). This has been reinforced in the bioethics literature (Caplan:1992; Callaghan:1999; Gillett:2008). Liberal autonomy does not have a single meaning. Jackson's work (2001) on liberal autonomy has claimed that several ideas concerning self-determination, independence and freedom from constraints have crystallised around the idea that an individual's life may be enriched by being able to direct it according to her/his own values. Liberal autonomy may be characterised by the individual being the arbiter of choice. There are powerful reasons for this. The individual is in some sense free from the interference of others which is seen as profoundly valuable. Based on the liberal model of autonomy, professional carers assume responsibility for giving patients as

full as possible, unbiased information from which they should make their own decision about treatment options (Pellegrino and Thomasma: 1993; Latham and Norwitz: 2009). Refusal of information and treatment may be regarded as acceptable acts of patient autonomy.

(i) Theoretical debates on liberal autonomy.

The work of Young (1986) places autonomy and socialization in opposition to each other. Free will is distinct from social traits. Exercising autonomy means being able to free oneself from the constraining effects of the beliefs and values into which the individual has been socialised and acting upon what one *really* wants to do (Young: 1986). I suggest this account may depend on one's position on the liberalist spectrum. Autonomy should be considered in the light of the positive and negative effects of social forces on the individual. Granted that social relations can enhance or restrict an individual's autonomy, underlying this concept is the idea that women are individual decision-makers. How this might be interpreted in clinical guidelines is unclear. It is one thing to place the woman 'centre-stage' in her maternity care, but it would be inconsistent with recommendations in guidelines to suggest that she should be left to decide alone- unless that was what she wanted. A literal interpretation of Young's account would mean that social relations should be abandoned, or at best treated as potential candidates for interference with the individual's wishes. Another difficulty might be trying to determine whether the woman's autonomy was enacted during the moment she makes her decision or in the thought process that led up to the decision. However we look at it, the free will would need to navigate its way through what might be for some women an array of complexities. The model could have the effect of producing an unreflective patient, which is contrary to recommendations in guidelines.

There may, however, be instances in practice when the liberal model is appropriate. I suggest there is greater likelihood of its suitability in relation to options that have less far-reaching consequences. Furthermore, there may be grounds for saying that adopting the liberal model does not mean that all social relations should be abandoned. Rather, autonomy for some women

could mean enjoying such relations without restrictions on their decision-making. The relevance of Young's work and the potential theoretical contribution to my study it raises is the need for a better understanding of how guidelines could be structured to make clearer those options that might lend themselves to the liberal model.

A counter-argument to the relational model of autonomy might be that healthcare professionals are often unfamiliar with the woman and her family dynamics. Hence the liberal model presents an opportunity for the woman to shape her own care in the context of guidelines if that is what she wants.

There are other theorists who claim that a health-related decision is a rational calculation of the benefits and risks of an intervention, but concurrently minimise the importance of the social context that shape an individual's values, beliefs and preferences, claiming they are not intrinsic to autonomy. Dworkin's (1988) work focuses on the underlying ideas of independence that dominate an individual's thoughts, dialogues and actions. These include the ability to think independently, assess one's preferences and do what is in one's best interests in a rational manner.

There may be problems with Dworkin's account which tends to assume responsible use of medical information by the individual. Although Dworkin does not entirely remove any hint of influence or accountability by healthcare professionals, it may lead us to question whether, in his view, family, professional or a range of other issues run counter to an individual's autonomy. For Dworkin, the woman makes her decision based on unbiased, as full as possible understanding of the medical information with her preferences in mind. This would need to be achieved through value-free, non-directive counselling by her professional carers. But Dworkin's account may be inappropriate in the context of guideline recommendations because it leaves unanswered how spillage into other areas of the woman's life could be successfully contained.

Moreover, provision of objective information is at odds with the caring professions (Spoel: 2004) - although arguably forming the rationale for

evidence-based medicine. This might be problematic when women exercise their autonomy in seeking information and care which responds to their personal concerns. An example of this relevant to my study is the offer of antenatal screening tests for foetal abnormalities recommended in guidelines. Healthcare professionals would be obliged to tell women about the options, stand back and leave them to decide. The provision of objective information would be problematic when women do not wish to be given information without professional guidance. This would become more important still if the need arose to discuss further pregnancy management if a foetal abnormality was suspected. It could result in a narrow emphasis on informed choice, rather than enabling women to make their decisions. My study addresses this important point.

(ii) Empirical study which includes liberal autonomy.

A qualitative study by Vandevusse (1999) explored 15 low-risk primigravid and multigravid women's experiences of control in childbirth. Autonomy in this study was not narrowly conceptualised as self-determination. Rather, it was seen as a value concept (Maier and Shibles: 2010). In Vandevusse's work, the implications of its application in the context of birth are evaluated, that is women's expression of their autonomy was an active response to events in labour and their views of risk and responsibility.

Analysis of findings suggested increased empowerment when women were actively involved as primary decision-makers, in line with the self-governing decision-maker associated with the liberal model of autonomy. Other findings revealed some women were critical of their healthcare professionals and this was relevant in framing their perceptions of their care. An example of this is some professionals claiming they knew better than the woman when her baby would be born (Bergstrom *et al.*: 1997). Those who felt less cared for argued for an individualised approach in line with liberal autonomy. These perceptions were predictors of their autonomy. This interesting finding concurs with O'Neill's theoretical work (2002) in which she argues that a focus on liberal autonomy diminishes trust.

I concluded the study's findings might be explained by the different methods used in Vandevusse's study. The researcher purposefully oversampled women who had non-physician attendance during labour and delivery in order to maximise the range of experiences of control. The interviews had no specific focus and women were invited to talk about their birth stories in any way they chose. It is also plausible to think that women who are keen to discuss their births may typically have had a memorable experience (good or bad) and reflected on it- hence providing rich qualitative data.

The findings reflect to some extent women's expectations of being active participants in their care (Edwards: 2005; Mander and Murphy- Lawless: 2013). Liberal autonomy may be an appropriate model for decision-making in certain instances. Vandevusse's study drew out a further dimension, that is, autonomous decisions in this context did not reflect simple acceptance or rejection of options. This led me to think about how my research which used a sample frame from a range of pregnancy and birth experiences might generate empirical evidence for this and inform the development of my grounded theory. This was because I did not expect acceptance or rejection to be a one-off bifurcated process, but more complex and revisited and revised during pregnancy and birth.

Although Vandevusse's work is informative, no role is assigned to guidelines which would have been highly relevant to my study

(b)The relational model of autonomy.

Relational models of autonomy share with other accounts the understanding of autonomous as being one's own person and making one's own decisions (Entwistle *et al* :2010). 'Relational autonomy' does not refer to a single account. Rather, as Mackenzie and Stoljar (2000) put it, it is an 'umbrella term'. The work of Christman (2004) says that feminist writers draw attention to human interdependence that liberal critiques of autonomy tend to overlook or give only cursory attention. What distinguishes relational from liberal understandings of autonomy is that they give serious

consideration to the idea that individuals' identities are formed within a network of relationships and shaped by social determinants such as class and ethnicity. There are some disagreements as to what constitutes relational autonomy, most specifically the extent to which accounts state particular social conditions as necessary preconditions for autonomy. However, all agree on the significance of social connectedness and interactions with other people (Mackenzie and Stojar: 2000; Donchin: 2001; Sherwin: 2012; Maier: 2014). This might be, for example, between the pregnant woman and her foetus, partner, family and professional carers. Individuals and their wishes are seen as socially constructed by their personal relations and social structures which can exert varying influences and may promote or compromise women's choice of options. Sensitivity to others' needs and responsibility for taking care of others supports the relational theories described by Gilligan (1982), Surrey (1991) and Noseworthy (2013). Further points relevant to my research are how women's experiential knowledge interacts with healthcare professionals' knowledge in a relational sense in the decision- making process.

(iii) Theoretical debates on relational autonomy.

The work of Thachuk (2007) is a theoretical account of the relational model of autonomy. Thachuk says that during the woman's 'journey to motherhood' she experiences several relationships - with her foetus, doctor, midwife, partner, family and society as a whole. These relationships, whether helpful or constraining, will influence the decisions she makes about her maternity care. Thachuk acknowledges that not all women will have a plan of care or wish to actively participate in decisions about their care, but this may reflect the ways in which they situate themselves in the broader context of their lives (Thachuk:2007).

Thachuk is critical that 'much of clinical practice does not account for the social- situatedness of the individual' (2007:43). She claims that although in bioethics the role of relationships is not entirely overlooked in the decision-making process, nonetheless it is side-lined. Given these problems, she argues, there is a need to move beyond the liberal model of autonomy to an

approach which places greater emphasis on interdependence and includes a range of issues and values which may influence women's decision-making(Thachuk:2007). The concept of 'interdependence' in the context of guidelines made me think about how it might enhance or constrain women's autonomy and informed the development of my grounded theory.

Thachuk's account of relational autonomy, although informative, is theoretical and no role is assigned to guidelines. This exposed the need for my study to generate empirical evidence to further our understanding about interdependence and its impact on women's autonomy.

In her work on women's choice and prenatal screening, Seavilleklein's Canadian study (2009) argues that the liberal model of autonomy is confined to the woman's ability to accept or decline options but fails to incorporate other contextual influences which have an effect on her decision- making. Relational autonomy, she claims, has a broader scope than the liberal model. It includes decision- making in the antenatal clinic, but also the context in which options are offered. It is not solely the quality of the information that is important to women, but the type of options available, how they are framed and whether they are enabling or constraining. The relational model of autonomy, she claims, highlights how options may (or may not) cohere with women's values, not simply the range that is available (Seavilleklein: 2009).

In the context of my study, Seavilleklein's account leads us to think about autonomy in relation to antenatal screening options in clinical guidelines, that is, ways that concentrate less on the self- sufficient subject and have a greater focus on the woman's social context. Women are frequently motivated by reasons that are not solely attributes of the free will and can only be understood with reference to other people and have personal values which supersede what is subjectively desired. This concurs with the growing awareness in healthcare that many choices between treatment options are sensitive to individual preferences and values (Entwistle *et al*:2006). In addition, preferences and values may be shaped by medical interventions such as tests and also indirectly by guidelines themselves.

Although broadly supportive of relational autonomy, Seavilleklein presents some alternative arguments. She argues that neither the liberal or the relational models of autonomy serve women particularly well since neither promote or protect maternal autonomy. She claims this is the case whether autonomy is interpreted as a narrow conception of choice as informed consent or as a broad conception of choice as relational. Both, she says, raise problems in achieving what she refers to as 'adequate standards' of free informed choice. Central to her claim is that some women are being subtly directed to options they would not otherwise have chosen (Seavilleklein: 2009). The concept of being 'guided into complying' informed my research study. This is because although screening test options in NICE guidelines are clearly presented as offering women a choice, there is often greater emphasis placed on test procedures rather than enabling women to choose, thus shaping the ways in which women are treated.

Seavilleklein (2009) says there are factors which, although not hugely restrictive, might place constraints on the woman's ability to make a free choice about screening tests. These include the routine nature of the offer of screening tests to all pregnant women. However, Seavilleklein does not present the Canadian prenatal screening guidelines, hence it is difficult to judge whether they are sensitive to maternal autonomy and choice and limits what can be learned.

Seavilleklein's (2009) work suggests the need for a more inclusive approach that acknowledges women's wishes for participation in decision-making. We know that women value high quality interactions with healthcare professionals (Hunter *et al*: 2008; Nieuwenhuijze and Kane Low: 2013). Incorporating procedures routinely into women's care may restrict their participation. Clinical guidelines could be structured to involve more in-depth discussion on women's individual wishes about screening as an earlier part of the care process.

The concept of 'choice' about screening tests for foetal abnormalities informed my study. It led me to think about how the informed choice model of decision-making may not fit with the expansion of tests for all women.

However, Seavilleklein's work is theoretical and raises the need for my empirical study to better understand women's first-hand experiences.

There are authors who have taken the line of argument that although bioethicists frequently associate autonomy with having a large array of options, they do not enhance women's autonomy. Kukla *et al's* (2009) work is set in the context of women's options for the mode of delivery. They say the offer of a range of options often fails to capture other issues such as inadequate information about alternatives and lack of opportunity to implement choices (Kukla *et al*: 2009). Arguably, if patient autonomy is understood as increasing the number of available options from which to choose, then we would only need to increase those options to fulfil our ethical duty. But healthcare professionals have to appropriately balance women's autonomy with beneficence to the foetus (or sometimes both parties).The maternal/ foetal interdependence adds a further area of complexity. As Purdy puts it' Because of their location and state, foetuses are dependent on women in an unusually fundamental and continuous way' (1990: 279).Hence there are ethical obligations on the woman to promote beneficence to her foetus and options should be expanded within appropriate ethical boundaries.

Kukla and her colleagues argue that in the context of the mode of delivery, women should be informed not only about their options, but their own role in the decision- making process. Choices are shaped not only by women's sense of risk and responsibility, but their family commitments and expectations as well as existing knowledge and experiences. Hence Kukla and her colleagues present another way of thinking about the concept of 'choice' by highlighting the non- technical, self – defined knowledge contributed by women which is an interrelated and important component of their autonomy. This important point informed my study.

Kukla and her colleagues' concluding remarks ask what kind of guidelines, practices and conversations would help promote women's autonomy in a safe and positive birth process. This is highly relevant to my work and

raises the need for my empirical study to increase our understanding of these important issues.

There are those whose work has identified 'strong' and 'weak' versions of relational autonomy. Donchin's work indicates that some early relational theorists concentrate almost entirely on interpersonal relationships. However, more recently, authors have included in their writing relationships that extend beyond the personal (Donchin: 2009). I suggest that 'strong' autonomy adds an extra dimension which could help deepen our understanding of women's core values.

Strong relational autonomy, claims Donchin, extends beyond women's personal values to the social, political and economic forces which influence decision-making, that is, relational autonomy extends from personal and professional relationships to the very roots which influence the options available to women. Such accounts extend the concept of relational autonomy to include the supportive arrangements that may be a necessary prerequisite for exercising autonomy (Donchin: 2009). Maternity care guidelines infer, but do not specifically refer to 'support'. The NICE Antenatal care guideline recommendation states 'Be alert to any factors, clinical and/or social that might affect the health of the woman and baby' (NICE: 2008: 13). The work of thinking about 'support' and its application to guidelines and women's autonomy helped inform my grounded theory.

Strong relational autonomy encourages us to think of women as relational beings, but adds a layer that raises the need for healthcare professionals to further explore matters in order to determine not only the reasons for women's preferences, but the influences that underpin them. This particular onus places a greater responsibility on healthcare professionals in their interactions with patients (Greaney *et al*:2012) It may help build up a fuller picture if we have a better understanding of what lies beneath the surface which may be compelling, that is, women's choices may be intricately bound in other interests. These may concur with, compete against or diverge from her decisions in relation to recommendations in guidelines.

An understanding of strong relational autonomy in the context of guidelines suggests the need to build a broader vision about factors that may impact on women's decisions. Thus care may extend beyond clinical decision-making, so where necessary advice may be given about social care and support (Entwistle and Watt: 2013). It should be stressed that this is no easy task for healthcare professionals as their contact with women is confined to a professional relationship. This is not to argue that the act of exercising one's autonomy is socially elitist in any sense neither is it to enter into debate about health inequalities that may constrain healthcare provision. Rather, it is to make the point that a range of structures may enhance or restrict the options available to women. This has implications for guidelines. Good relationships based on trust between women and healthcare professionals will be important in order to tease out these issues.

Although Donchin's account offers additional insights, her work is theoretical. There is no role assigned to guidelines and women's accounts of their subjective experiences relating to their care are absent. My study aims to address that gap.

The work of Davies and Elwyn (2008) explores the potential negative effects of over-promoting patient autonomy, that is, calls for patient involvement in decision-making to be made mandatory. They identified two key limitations on the principle of mandatory autonomy. First was the failure to think socially about decision-making and second, the possibility of mandatory freedom to choose. The authors say there are problems in promoting mandatory autonomy because it may have the counter-effect of making patients feel constrained and unable to make an autonomous choice (Davies and Elwyn :2008).

Davies and Elwyn's work has addresses the effect of mandatory autonomy on patient access, cultural and social exclusion and communication and patient experience. I will focus on communication and experience which is most relevant to my study. Respecting patient autonomy means facilitating autonomous decision-making. However, when autonomy becomes mandatory, patients cannot elect not to choose and cannot elect to be

guided by healthcare professionals. Rather, interactions are substituted by informing patients about their options and carrying out their decisions. Patients would have to choose between options without guidance, despite being insufficiently informed and ill equipped to predict serious unforeseeable consequences in some instances. This might result in an (apparently) free but inappropriate decision (a decision that has an outcome that the woman has not intended). The work of Schneider (1998) claims that patients who have autonomous choice imposed on them may feel abandoned by their professional carers.

It is a paradox to impose mandatory autonomy onto patients who want to exercise their autonomy by deciding with others or by not making decisions. It is also contrary to beneficence. Guidelines are inclusive of maternal and foetal well-being and their recommendations promote reasoned decision-making. Davies and Elwyn (2008) propose that decisions are always made relationally, that is, interdependence and women's values are preconditions rather than compromisers of autonomy. This line of reasoning could be transferable to guidelines to enhance women's autonomy. As Lawson and Pierson (2007) say, women who are supported by their professional carers report feeling more autonomous compared to those who lack support. Women's needs can be complex and it is effective negotiation with healthcare professionals that can help develop their preferences to enable them to act on their intentions, but responsibly.

Davies and Elwyn conclude that knowledge of women's expectations for decision-making can inform optional autonomy. Fundamental to their arguments is the 'choice of not to choose' when appropriate. This in itself is a choice and informed my interpretation and explanation of findings leading to the development of my grounded theory.

(iv) Empirical studies which include debates on relational autonomy.

Analysing empirical data through a relational lens allows us to address issues which influence women's autonomy in consultation with their

professional carers. Guidelines are sensitive to patient autonomy and the provision of high quality information. Their recommendations promote effective interactions between women and healthcare professionals (NICE: 2008). However, their recommendations do not offer specific means of achieving this in practice which would be highly relevant to my work.

The work of Entwistle and her colleagues (2008) explored the experiences of 18 non- pregnant diabetic patients. Their study is an example of the dynamics of patient involvement in decisions about their care, that is, what made them feel involved (or not) and what involvement meant for them. The study's findings concluded that patients' expression of their autonomy was not simply based on information about treatment options. Relational autonomy advocates empowering the patient through a trusting relationship and consideration of the patient's full lived experience as well as the contexts in which these exist (Walter and Ross: 2014). It was through effective interactions with trusted professional carers, understanding of their experiences of health and illness, the invitation to participate and feeling empowered to raise issues of their choosing during the consultation that opportunities to exercise their autonomy were created (Entwistle *et al* :2008). It was thinking about the concept of 'trust' and the ways in which it related to my core question about autonomy that informed my study.

Communication problems were seen as disempowering, this being apparent when there were perceived power imbalances which frustrated patients' attempts to exercise their autonomy. This became particularly acute when there was a problem and patients felt they were not being listened to and their role in self- care outside the clinic was marginalised. (Entwistle *et al*: 2008). These issues suggest the need to explore the ways in which patients' autonomy is constrained and how recommendations in guidelines shape patients' perceptions of their care.

Entwistle and her colleagues' study is a non- obstetric example. Pregnant woman's experiences of their care and the impact on their autonomy are unaccounted for. However, as the authors point out, diabetic patients have experience of considering and revisiting different experiences and were

able to reflect on situations in which their participation was sought. This finding highlighted the importance of patients' reflective assessments in shaping their care which informed my study.

The work of Moffat and colleagues (2007) explored women's decision-making about TOL (Trial of Labour). Data collection included first, a thought keeping process recorded in a diary during pregnancy. Second, researchers recorded their observations of a clinical consultation between the woman and healthcare professional during the third trimester at which it was expected a final decision about mode of delivery would have been made. Third, women were interviewed at six weeks postpartum. Finally, the researchers maintained a field notes diary. The methods were chosen to provide insights into different stages and aspects of the decision-making process and provide an in-depth analysis of that process (Moffat *et al.* 2007).

Analysis of findings revealed that all women's initial thoughts about delivery were influenced by their previous delivery. As time went on, most women acknowledged that their decision could not be final as their clinical and social condition could change. Although all women stated a wish to be involved in the decision-making process, frequently this did not translate into the ways in which they exercised their autonomy. Women's wish for participation in the consultation varied. For example, in some cases healthcare professionals made strong recommendations for a particular mode of delivery. Other women described what they interpreted as inconsistencies, that is, the recommendations changed from one visit to the next. Because of the perceived uncertainties, some women thought the doctor should make the decision and they should not be involved. One woman felt pressurised to decide independently. Several were concerned about the level of responsibility associated with making the final decision. Another woman was adamant that she wanted a TOL and declined further meetings with her obstetrician to discuss her options (Moffat *et al.* 2007).

Two themes which emerged prominently and impacted on women's autonomy were the influence of their experiential knowledge and their

sense of responsibility vis- a –vis the decision they faced. I will discuss each of these.

Analysis suggested a consistent finding that there was a mismatch during women's previous pregnancy about what they had been led to expect and the actuality of the situation they experienced, that is their decision- making was shaped by being unprepared last time. This affected women's wishes to lay firm plans this time. This lack of perceived control meant that all but one of the study groups did not want to make a decision independently as with the liberal model of autonomy. Rather, despite the availability of choices which were evidence- based, they had limited usefulness to women's expectations, values and needs which emerged as clear defining features of the decision- making process. This suggests that women make choices underpinned by different rationales and not solely based on medical facts (Jomeen: 2012). Women's autonomy was influenced by knowledge from their previous birth experiences, their values and relationships with others. This finding concurs with the work of Sherwin (2012) who argues for the need to understand the relationships and social values that underpin women's decision- making in order to enhance their autonomy. The concept of women's 'experiential knowledge' and the importance of its role in their current pregnancy informed my grounded theory by its' ability to generate and support my interpretation and explanation of my findings.

The second point is about women's thoughts and understanding of the appropriateness of their role in the decision- making process. Analysis of findings suggested that the opportunity to be involved in decision- making enhanced women's autonomy. What was contentious in Moffat and colleagues' study was the degree of responsibility assigned to women, particularly during the third trimester when a decision needed to be made. Several women's accounts suggested that healthcare professionals assumed that the woman was a well- versed individual accustomed to making her own decisions independently, takes responsibility for the consequences and wants to choose. As Davies and her colleagues (2009) say, what this account calls into question is that these conditions are rarely

met in practice. This is because individuals have different and sometimes incompatible desires, some of which have to give way to others. Although respect for patient autonomy is a way of promoting patients' responsibilities, little is known about patients' potential responsibilities in decision- making and guidelines do not account for it.

The women in Moffat and colleagues' study suggested that their involvement in the decision about TOL should be built upon over time and a consensus reached based on personal context and joint responsibility. This suggests that relationship- based care enhances women's autonomy, particularly when maternal/ foetal relationships are associated with important outcomes (Alhusen *et al*: 2013).

The study's relevance is reflected in the methods of data collection which recognised the importance of women's views at different time points during pregnancy, childbirth and postpartum. Importantly, it made prominent that decision- making about childbirth cannot be final (Moffat *et al*: 2007). These findings made me think about the iterative nature of some maternity care decisions which informed my own study.

Women's autonomy was variable and exercised relationally. However, the study is confined to women's experiences of TOL and no role is assigned to guidelines. My work adds the further dimension of guidelines and a range of maternity care experiences.

A study by Noseworthy and her colleagues (2013) explored relational autonomy in the woman/ midwife relationship, most specifically how the midwife's influence impacted on women's autonomy. The authors take the line of argument that liberal ideas of autonomy and decision- making do not fit well with the context of decision- making in the woman/ midwife relationship.(Noseworthy *et al* :2013).

Eight women and midwife pairs were interviewed in the antenatal and postpartum periods about decision- making in childbirth and the third stage of labour in particular. There were three stages of data collection, namely an audio- recording of the discussion between the woman and midwife

about the management of the delivery of the placenta, followed immediately by an interview involving the woman and midwife with the researcher. Lastly, a postnatal interview with the woman and midwife was conducted (Noseworthy *et al*: 2013).

The antenatal interviews focused on the individual midwife's philosophy of practice and the social networks through which women choose their midwife. Examples include family, friends and previous experience, that is, women exercising their autonomy by doing their own research which helped secure their care provider. Analysis of findings revealed women's choice was shaped by the degree of ontological fit between the midwife's philosophy of practice and the woman's ideas about her childbirth experience. This led to feelings of security and trust at an early stage (Noseworthy *et al*: 2013).

A significant finding from the study was that women were in a stronger position to exercise their autonomy when they made decisions with others, most notably the midwife, suggesting the importance of relational trust (Noseworthy *et al*: 2013).

Analysis of findings suggested that relational trust becomes more salient when complications in childbirth occur or events do not proceed according to plan, increasing women's vulnerability and reducing their autonomy and choice. For example, when in pain or distress, anxiety may limit the ways in which information can be understood and negotiated. These findings are at variance with the work of Weaver (1998) who argued that the woman making the decision was the central issue of control in childbirth. But women's autonomy extends way beyond the moment a decision is actually made. Some of the women in Noseworthy and her colleagues' study suggested what mattered to them in time- limited situations was the midwife providing the most appropriate information and explanation, rather than simply providing information to women so they can make their own decision. This finding concurs with the theoretical work of Watkins and Weeks (2009) about the best ways of providing information to pregnant women and suggests that skilled interaction in a relationship of trust

enhances women's autonomy. Women's autonomy was better served by 'shared decision- making', a concept which is inferred, but not specifically referred to in guidelines. In this context, Noseworthy and her colleagues propose that the relational model of autonomy could address some of the concerns associated with the liberal model that I have discussed in subsection (a) of this Chapter.

The study concentrated primarily on the management of the third stage of labour. There is no reference to whether guidelines recommend a particular course of action. The audio recordings and antenatal interviews lasted only between five and 13 minutes each which limits what can be learned. My study is in –depth and includes a range of pregnancy and childbirth experiences.

A study which explored 18 low- risk primigravid women's experiences of delay in labour and its impact on women's choices was conducted by Armstrong and Kenyon (2015). The study draws on Mol's (2008) work on the logics of choice and care and the inherent tensions she sees between the two. Central to Mol's argument is that the 'logic of choice' assumes that healthcare professionals present patients with medical facts from which the patient makes her choice of desired outcome and the healthcare professional uses appropriate methods to deliver that choice. Mol claims that this is unhelpful as its focus is on an end product. Rather, care should be understood as an interactive process which is subject to re-evaluation and change (Mol: 2008). Armstrong and Kenyon use Mol's perspective to critically analyse the ways in which women understand and reconcile themselves when first, their labour did not progress how they would have wished; second, how they experienced constraints on their choices and the relative importance of choice compared to other childbirth outcomes and finally, how women's choices were made in a relational sense and the impact of their decisions on their autonomy (Armstrong and Kenyon: 2015).

Prior to labour commencing, women's accounts suggested that all options were open to them. Arguably, decision- making in pregnancy is well placed to include future planning, deliberation and reflection. As Galotti *et al* put it

'Few other important life decisions occur on such a well defined schedule' (2000: 320). However, as time progressed during labour, women's options became limited. Although upsetting, an overriding theme was that women in a situation of painful childbirth accepted that they faced unexpected and unavoidable situations in labour.

Fewer options in their revised situation led to women willingly ceding control to healthcare professionals. Some women's accounts suggested that they chose to segregate themselves from the situation, that is, there was a point at which they chose not to choose. (Armstrong and Kenyon: 2015). Their decisions were directly related to my core question about autonomy and informed the development of my grounded theory.

The study's findings suggested that women's decision-making and exercising their autonomy to defer to healthcare professionals was firmly bound up with their sense of responsibility to their foetus. This resulted in them re-evaluating the important end-product, that is, the focus shifted from an initial preference for a natural delivery to a safe outcome and healthy baby. The maternal/ foetal dyad adds a further layer of complexity and women's need for emotional security as well as physical safety (O'Brien *et al* :2017) Their qualitative work about women's understanding of informed choice concluded that women's autonomy should always be seen as relational. This fits in with several recommendations in NICE maternity care guidelines which are sensitive to maternal autonomy and choice.

Armstrong and Kenyon's study is confined to primigravid women's retrospective accounts about delay in labour. Guidelines are referred to but specific guidance is not quoted, hence we are unable to juxtapose women's experiences against the guideline's recommendations. My study takes that novel approach.

Further reading and searching of relevant research became an ongoing feature of an iterative process, in line with grounded theory. A quantitative study was reported by Vedam *et al* (2017) for which they developed and validated a new instrument, namely the MADM (Mother's Autonomy in

Decision- Making). The MADM scale measured a single construct- women's autonomy in decision- making in maternity care. The study's particular focus was women's ability to **lead** (*authors' emphasis*) decision- making, also whether women have sufficient time to consider their options and whether healthcare professionals respect women's choices. The authors say there are no validated scales that measure women's ability to lead decision-making in maternity care and quantitative measures of women's autonomy are 'sorely lacking' (Vedam *et al* :2017:12), thus raising the need for their study to increase understanding about these important issues. Guidelines are briefly referred to in the sense that pregnant women's autonomy and shared decision- making have been promoted by professional associations. Examples include NICE (2014) and the American College of Obstetricians and Gynaecologists Statement of Policy (2015).

To summarise Vedam and her colleagues' work, a convenience sample of 1672 women who were cared for in pregnancy and childbirth by a single healthcare professional were invited to complete an online survey which consisted of 31 items describing their preferences for and experiences of decision- making during pregnancy, childbirth and postpartum. Seven of these items specifically measured women's perceptions of their role when participating in shared decision- making. Women's responses were on a six- point Likert scale, range of scores between 7 and 42. Response options ranged between 'very important' 'important', 'somewhat important' and 'not important' (Vedam *et al*: 2017).

The study's results revealed that the majority of women, (90.8%) stated that it was *very important* or *important* that they lead decisions about their care. However, results showed some differences between different healthcare professionals and the level of autonomy women experienced. For example, women cared for by a midwife reported increased autonomy in decision-making when compared to those cared for by a doctor. This is consistent with findings from qualitative studies in the healthcare literature about women's experiences of midwife- led care during labour and birth (Maggioni *et al*: 2006; Fair and Morrison: 2012; Iida *et al*: 2012). Vedam and her

colleagues say the results may be explainable by the fact that doctors care for women with complicated pregnancies. The scope of the woman/ doctor consultation may leave little time to explore the normal processes of pregnancy and birth and fewer opportunities to participate in decision-making which impacts on women's autonomy. This result was consistent with Legare and colleagues' (2014) qualitative analysis of findings.

Autonomy in Vedam and her colleagues' study was presented as relational. This was because results demonstrated that women's experiences were defined by their relationships with their healthcare professional which in turn helped promote shared decision- making.

A salient feature of the study was that women experienced continuity of carer. The study's results add to the body of knowledge which suggests that first; relationship –based care enhances participation in decision- making (Elwyn *et al*: 2012; Nieuwenhuijze *et al*: 2014; Catling *et al*: 2016).The concept of 'continuity of carer' has implications for guidelines whose recommendations promote partnerships between women and their professional carers (NICE: 2008). In addition, the quality of the relationship and trust in healthcare professionals are key concepts in shared decision-making (Dhalen *et al* 2010; Stevens and Miller: 2012). Results also indicated the need for a more inclusive approach that acknowledges women's 'expectations' about participation. This was a concept which informed my grounded theory. This was because it highlighted the importance of gauging the woman's wishes about participation in the consultation prior to presenting her with options from which to choose.

The MADM scale is a useful instrument and relevant to my study. However, its results are limited to women who experienced continuity of carer; therefore it is unknown what the experiences of those who were cared for by more than one healthcare professional and the impact on their autonomy on the MADM scale would have been. My empirical study includes women who received predominantly hospital- based care and experienced several different caregivers.

My interpretation and synthesis of several debates in the healthcare and bioethics literature suggested that patients' autonomy may be better served by a process of shared decision-making rather than an individualised model. My iterative approach led me to look at the literature on decision-making following my review of the debates on autonomy.

Decision-making.

(i) Partnership.

Maternity care guidelines have responded to calls for greater patient involvement in their care. One of the wider recommendations in NICE guidelines is that women should participate in decisions involving their care:-

'Women should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals' (NICE: 2008:4).

However, guidelines do not explain what is meant by 'partnership' or how that guidance should be applied. Hence it is unclear what women's perceptions of partnership would be, or how professional carers should aim to achieve it. The *NSF for Children, Young People and Maternity Services Standards Three and Seven* also refer to women working in partnership with a healthcare professional, but what is meant by partnership is left unaccounted for (Department of Health:2004). To date, there has been little supportive evidence in the healthcare literature that women want to work in partnership with the midwife and further research is needed to clarify what is meant by partnership (Boyle *et al* :2016). This has implications for guidelines. Arguably, it is difficult to develop effective partnerships when what is required in terms of input between women and healthcare professionals requires clarification and explanation.

The work of Guilliland and Pairman (1994) proposes that midwifery should be seen as a partnership between woman and midwife and that equality

between the woman and midwife is the foundation for the partnership relationship. Additional theoretical concepts of the midwifery partnership are negotiation, shared responsibility, empowerment and informed choice. However, some authors have challenged the concept of equality, principally because the midwife has power over the woman and the principle of equality cannot be realised. Freeman and her colleagues (2004) explored women's opportunities to make decisions about their care during labour. Based on their qualitative work, they propose an approach which identifies how power can be shared without the need for equality, that is, by the woman and midwife working together through information exchange that helps enhance women's sense of empowerment. Similarly, Leap (2010) argues that equality cannot be realised. This is because women seek midwives' experience and knowledge and there is always an inherent power imbalance. Thus there is the need to balance the exercise of power with responsibility and, arguably, accountability.

Furthermore, Kirkham (2004) argues that the organisational context of maternity care makes developing partnerships difficult. Kirkham claims the concept of partnership does not reflect the realities of clinical practice. This is because several professionals may interact with the woman at different times in the decision-making process. It is outside the scope of this thesis to discuss systems of maternity care, for example, midwifery case-loads/teams or shared care between an obstetrician and a midwife which may mitigate against the woman and professional getting to know each other as a basis for a partnership to develop.

There are those who have claimed that although working in partnerships with women may be challenging and developing shorter-term partnerships may be beneficial, they may be limited to episodic antenatal care or care during labour. Such partnerships may be sufficient for some women to get a sense of shared experience as women and healthcare professionals work together towards the common goal of a good pregnancy outcome (Miller and Wilkes: 2015). This line of argument led me to consider its relevance to maternity care where women meet several healthcare professionals at

various time points- something which is not specifically accounted for in guidelines.

Other authors have taken a different line of argument. Salmon and Young (2005) claim that a partnership is something more than a set of interactions between a woman and her professional carers. Partnership in this sense implies a longitudinal relationship between the woman and her professional carers.

A health visiting perspective on the meaning of partnership was explored by Bidmead and Cowley (2005). They found similarities with the midwifery model, that is, supporting the woman and family through a normal life event in the community. They argue that there does not need to be a relationship of equality for partnerships to be realised. Rather, what is important is that the woman and healthcare professional work together to determine the woman's perspective and establish middle ground between the woman's choice and professional recommendations (Bidmead and Cowley:2005). If this is so, then partnerships may be more workable in the community, but still leaves unanswered what is meant by partnership and whether it is something women want. My empirical study is confined to a hospital setting where women meet several healthcare professionals. Although some women's accounts refer to community care, my work does not explicitly explore women's experiences about care in the community where there is a greater likelihood that professional carers would be familiar to them.

A review of the healthcare literature reveals three representative models of decision-making (Charles *et al*: 1999). These are paternalism, in which there is a sense of healthcare professional domination. Paternalism does not appear in maternity care guidelines and will not be discussed here, although there are instances when it may be appropriate for professional carers to take charge. The second is informed choice, when patients are given information to make their decisions and the third is shared decision-making, where information and responsibility are shared between patient and healthcare professional

(ii) Informed choice.

Informed choice is characterised by the patient being given information about her options (usually by a healthcare professional). The patient should be free to make her decision. However, as Charles and her colleagues (1997) say, although the informed choice model incorporates the idea of information-sharing between healthcare professional and patient, it does not necessarily lead to shared decision-making. It limits the role of the healthcare professional to one of transferring information to the patient. However, it does not exclude the possibility that women may consider information and advice given by others.

The concept of informed choice offers opportunity for professional carers to show respect for women as individuals, but tends to overlook the fact that some patients may make decisions with inadequate medical guidance. A further point is that some patients want information about care and treatment without the responsibility of making decisions (Beisecker and Beisecker: 1990; Ryan: 1992; Aune and Moller: 2012). Informed choice does arguably protect against unwarranted paternalism.

(iii) Shared decision- making.

There are those who have argued that there are patients who prefer not to take full responsibility for decisions in healthcare, but wish to have some say (Waldenstrom *et al.*: 2004; Gee and Corry :2012; Nieuwenhuijze and Kane Low:2013). Charles and her colleagues (1997) suggest that shared decision- making means that the woman should be willing to participate in the decision-making process. This means she should take responsibility for stating her preferences, asking questions, appropriately weighting the various options and making her decision. They suggest that patient and professional discuss and evaluate the various options and together they reach a consensus.

The wider recommendations of NICE maternity care guidelines state:-

‘Good communication between women and healthcare professionals is essential. It should be supported by evidence-based, written information tailored to the woman’s needs Care and information should be culturally appropriate. All information should also be accessible to women with additional needs such as physical, sensory or learning disabilities, and to women who do not speak or read English’ (NICE :2008:4).

‘Every opportunity should be taken to provide the woman and her partner or other relevant family members with the information and support they need’ (NICE: 2008:4)

The guidance captures the importance of effective interactions between women and healthcare professionals. However, as Charles and her colleagues say, what is less well recognised is that several healthcare professionals might provide input into the woman’s care. But this is not to suggest that each individual encounter cannot be shared. The challenge for guidelines is establishing the woman’s wish to share decision-making in different situations and at different stages during pregnancy and birth. Davies and Elwyn sum this up ‘Shared decision–making entails ascertaining patients’ understanding of their condition and where treatment ‘equipoise’ exists, it entails describing relevant options and supporting patients’ decisions to the extent they seek to exercise their choice’ (Davies and Elwyn: 2008:318). This is useful because women may exercise their autonomy and change their mind, or, as pregnancy is a time of change, their clinical condition changes which may enhance or restrict their options. Some decisions will need to be revisited and others will be more complex than others. We shall see examples in this thesis. As Miller *et al* (2011) and Prosser *et al* (2013) say, women’s perceptions of shared decision- making may vary for different treatments and interventions at different time points during pregnancy. For example, women may elect to participate in the decision- making process and then choose to avoid something they (originally) found acceptable. My argument is that the woman should be engaged in a discussion about her options with the healthcare professional,

not simply the act of choosing. This involves weighing up the risks/benefits and comparisons of an intervention, exploring the woman's concerns, inviting questions and eventually reaching a consensus. There may be a point during some discussions at which the woman wishes to defer to the healthcare professional on whose expertise she depends and decision-making is no longer shared. Part of the woman's autonomy is choosing to exercise her autonomy in a particular way. Enhancing a woman's autonomy might mean building a trusting relationship and ensuring her wishes are respected.

In maternity care, although shared decision-making has been advocated for over two decades, uptake has been slower than other medical specialties (Kaimal and Kuppermann :2010). There is evidence to suggest several benefits of shared decision-making for women which have implications for clinical guidelines. A Cochrane review demonstrated greater informed choice, improved communication with professional carers, enhanced involvement in decision-making, better knowledge and perception of clinical outcomes and no adverse effects on satisfaction (Stacey *et al*: 2011). A systematic review of the evidence for shared decision-making in maternity care demonstrated improved knowledge and increased perception of having made an informed decision, greater reassurance and satisfaction (Say *et al* :2011). There is also evidence to suggest that if women can share in decision-making at a level they are comfortable with it enhances their satisfaction with maternity care (Declercq *et al* :2013).

There are some limitations with shared decision-making. There is empirical evidence that not all women want to be primary decision-makers about their maternity care. My study builds upon these and other authors' work. For example, Kingdon and her colleagues' qualitative work (2009), although large-scale, focused solely on women's experiences of methods of delivery, that is vaginal delivery or Caesarean section. It did not ask women about their experiences of care relating to recommendations in clinical guidelines and was conducted prior to the guideline recommendations about CDMR (Caesarean delivery on maternal request) (NICE:2011). This guideline

might be interpreted as empowering women, that is, they can opt to deliver by Caesarean section in the absence of medical indications.

There is evidence to suggest that implementing shared decision – making in practice can be challenging. Astbury and her colleagues' (2017) in –depth qualitative study explored the process between parents and their health visitor. Findings suggested that despite strong relationships between the two, where supportive processes were absent, shared decision- making was difficult. The authors claim that for shared decision – making to be effective, there needs to be structured conversations, clarity and consensus about the issues that were affecting the child's well-being. Proposed interventions needed to be acceptable to parents and health visitors needed to better understand the dynamics within relationships in the family (Astbury *et al* :2017). The focus should be on engaging parents in order to explore their views and preferences including options for treatment/ management from their perspectives. Hence shared decision- making has a wide scope which may sometimes be difficult to achieve in practice.

A further problem is that some women have poor literacy skills which makes understanding of medical information and communication particularly difficult (Gaudion and Homeyard:2010 ; Cox: 2014). This may lead to difficulties in asking questions and expressing their concerns (Tharpe and Farley:2009; Balaam *et al* :2013). Less frequently discussed is that typically the healthcare literature refers to shared decision–making that involves in-depth discussions. An example is the option of vaginal delivery or Caesarean section. However, as Elwyn and his colleagues (2014) say, research on shared decision- making has not always recognised that some decisions, for example, whether to have surgery may not be episodic events. They could involve different healthcare professionals over a period of time which may make shared decision-making more difficult in practice.

What may be challenging for healthcare professionals working with guidelines is that they may not always recognise more routine and yet

important decisions as warranting the same kind of attention as invasive procedures. An example is maternal positions during labour and birth.

Clinical guidelines generally recommend that healthcare professionals should involve patients in decisions about their care (Barratt *et al* : 2004; Woolf *et al*: 2005 ;Thompson and Miller:2014). However, this is only one facet of service-user involvement. There is a lack of consensus as to the meaning of an extent to which 'patient involvement' can be seen as a useful concept. Greenfield *et al* define patient involvement in care 'within the context of the physician- patient interaction' (1985: 520). This is because it is in this context that patients can have the most impact on decisions relating to their care. For our purposes, this is a useful definition because as we shall see in this thesis, the woman/healthcare professional relationship is promoted in clinical guidelines and is very important in women's decision-making.

However, patient involvement in some cases goes beyond encouraging individual participation in decisions related to women's maternity care. One strategy is consumer involvement. As Winckler (1987) says, consumers have always been part of the organisational structure of the NHS, but as recipients of care. Consumer involvement brings into focus the importance of understanding the consumer's views and extends professional perspectives. It should include individuals and organisations in the evaluation of services at different levels. In this context, not only will the woman be involved in determining the appropriateness of her care and selecting her options, there may be those who are involved in the design, planning and monitoring of services. Examples might include the views of individual women who have the advantage of recent personal experience of maternity care, organisations such as the NCT or more formal longer-term arrangements such as a labour ward forum or Royal College forum (Phipps and Fletcher:2010).

To sum up, the extent to which a woman participates in decisions about her care should reflect her autonomous wish for involvement. As Thompson and Miller (2014:7) put it, there is little value in providing information and

involving patients when judged against an 'external standard' when patients themselves do not perceive they were informed and involved in the decision-making process. This important point has relevance to my study and my empirical research builds further on it.

Women's involvement in decisions about their care cannot be considered without talking about the relationships they have with their professional carers.

Trust.

According to Sachs (2004), there are two sides to a trusting relationship between patient and professional. First, professional competence and second, empathy and human kindness. A trusting woman/midwife relationship contributes to the woman feeling safe and reassured, both physically and psychologically. This may be more achievable when the woman is cared for by a familiar midwife, continuity facilitating the development of trust (Parratt and Fahy:2004; Wilkins: 2010;Sandall *et al* :2016; Astrup :2017). A study by Jenkins and her colleagues(2015) that explored ways in which women conceptualise continuity of their maternity care suggested that women characterised trust in terms of their healthcare professionals' familiarity with their circumstances or personal stories and not solely with the clinical aspects of their care. However, this is not exclusively the case. Leap and Edwards' theoretical work (2006) demonstrates that there are instances when the relationship has to be built up quickly and trust established instantaneously. Not all healthcare professionals work in situations which enable them to get to know women. An example of this is care during labour when the woman has not previously met her professional carers. Another example which is not time - limited can be found in Thorstensson and her colleagues' (2015) qualitative study of women's experiences of their midwives' support during pregnancy. Analysis of findings suggested that a trusting relationship with the midwife was often formed at the first meeting during pregnancy. Trust was facilitated

by the midwife's perceived professional competence in response to questions, taking time to offer reassurance and an interest in and understanding of the woman- all of which helped create a sense of security (Thorstensson *et al* :2015). What is important is that each interaction is treated as part of the care process and the caregiver listens to and interacts with the woman.

Some authors have claimed that trust between women and midwives is particularly important at vulnerable times during pregnancy and childbirth. Qualitative studies of birthing women suggested they needed to be able to trust their professional carers' judgement and it was good communication beyond that of simply receiving information that enhanced trust (Lundgren and Berg:2007; Goberna- Tricas *et al* : 2011). Although the crux of the matter is whether women can trust at times of vulnerability, my work builds further by showing that women's need to trust their professional carers at less crucial times during pregnancy is also important.

The trust of professional carers towards patients has been less extensively explored in the literature (Mogren *et al*: 2010). My empirical study contributes by including an account of reciprocal trust between a woman and a familiar midwife and how this shaped her experience of her care.

The theme of trust contributes to my final analysis as it was not anticipated at the start of the study. Rather, it was identified as a stage of concept development as part of my iterative process in line with grounded theory.

SECTION FOUR.

Empirical research studies.

Although there is a large body of empirical literature about women's views of their maternity care, as I set out in my rationale for the research study, there is little about their experiences of care based on recommendations in clinical guidelines. This thesis builds upon work already done, but takes it further by relating to women's experiences of their care to specific

recommendations in guidelines to highlight where autonomy is enhanced or compromised.

The views of healthcare service-users have frequently been dominated by the measurement of satisfaction (Hundley *et al* :2001). Several authors have claimed that women's sense of control about decision-making in pregnancy and childbirth is viewed as a significant determinant for their satisfaction with their care (Salmon and Drew:1992;Beattie:1995; Hildingsson *et al* 2010; Narney and Lyerly:2010; Larkin *et al*:2012). The work of Heatley *et al* (2015) revealed that participation in decision- making was a significant predictor of women's perceptions of the quality of care they received. These findings suggest that patient satisfaction is an integral part of high quality care and satisfaction ratings have a place in service evaluation.

However, the value of satisfaction as a determinant of care is complex (Sitzia and Wood:1997). One of the difficulties is the lack of consensus about its definition (Avis *et al*: 1995; Sawyer *et al* :2013). Although there is general agreement that satisfaction is a multidimensional concept, it is influenced by several factors. Examples of these are the care patients receive, their beliefs, values and expectations (Linderpelz:1982; Sitzia and Wood:1997). More recently, Srivastava and colleagues (2015) reported determinants of maternal satisfaction which covered all dimensions of care. Examples include structural aspects of care, for instance, a good physical environment, the process of care, that is, healthcare professionals' competence and interpersonal skills and pregnancy outcome. Hence the concept of satisfaction covers a wide spectrum, is complex to evaluate and difficult to relate to my core question about autonomy.

Williams (1994) found that generally, patients tend to respond positively and their responses do little more than provide an illusion of consumerism which produce results that merely endorse the *status quo*. Williams also suggests that patients may have a complex set of their own relevant beliefs which cannot be understood in terms of satisfaction. For the purposes of this thesis, this criticism of the shortcomings of satisfaction studies is

relevant. William's work also suggests that omitting patients' beliefs and values and the use of questionnaires literally enforce respondents to express themselves in terms which could be seen as alien to them, resulting in a picture that misrepresents service-users' actual beliefs. These shortcomings may limit what can be learned from this approach.

Specifically in maternity care, satisfaction is one of the most frequently reported measures of quality (Goodman *et al*: 2004). However, my review of the literature revealed that satisfaction is a contested concept. The reasons for this include factors such as previous experiences of care, choice of options about caregiver, place of delivery and women's difficulties in saying what they mean by satisfaction (Bramadat and Driedger: 1993; Rudman *et al*:2007; Ford *et al* :2009). Several authors have claimed that although women's expectations are thought to influence satisfaction, the association is weak (Wilcock *et al*: 1997; Staniszewska and Ahmed: 1999; Godlee: 2012). Others have claimed that measures of satisfaction are rarely adequate in measuring women's responses to care following an event such as birth (Oakley: 1983; McCourt *et al* :2006; Britton *et al*: 2010; Wilde-Larsson *et al*: 2010). As Lewis and her colleagues(2016) say, the concept of maternal satisfaction is challenging as women's and healthcare professionals' expectations and experiences can differ.

A qualitative interview study by Haines *et al* (2013) found that on the one hand, women were generally satisfied with their maternity care. On the other hand, when women were asked to reflect on specific experiences, there was a greater likelihood that they would state particular aspects of care that they liked or disliked. Although related to women's satisfaction with their care, the authors' line of approach highlights the need to carefully tailor the interview questions in order to explore women's specific experiences. This helped inform my empirical study.

The work of Jenkins and her colleagues(2014) was a large qualitative study that explored women's expectations and experiences of their maternity care. In- depth semi- structured interviews were conducted with 53 women experiencing maternity care in different hospital and community settings.

Guidelines are not alluded to. Findings revealed that women's satisfaction was rated primarily against staff and relational issues rather than facilities. Of particular interest were the differences in primigravid and multigravid women's accounts at different stages in pregnancy and from different locations. The authors conclude the need to include women with a diversity of experiences when trying to gain a better understanding of which aspects of care are most important to women and why this may be the case (Jenkins *et al* :2014). My empirical study explores primigravid and multigravid women's experiences of their care across a range of hospital-based antenatal clinics at different time points during pregnancy.

Some studies have also found that women's satisfaction with their maternity care, particularly during labour and birth has become important to healthcare professionals, managers and policy makers (Harvey *et al*:2002; Redshaw:2008). Harvey and her colleagues' quantitative work (2002) recruited 194 low-risk women into a RCT which compared midwife-led care (experimental group n=101) or obstetrician-led care(control group n=93). Protocols and guidelines for the midwife- led group are briefly alluded to, but there is no information about what these comprised. Redshaw (2008) suggests that asking women to sum up their experiences using general scales of satisfaction may be suited to audit, but falls short when exploring which aspects of their care. These studies are informative but offer no specific insights into women's experiences of their care based on recommendations in guidelines.

Harrison and her colleagues' work (2003) interviewed 47 women to explore their satisfaction with their involvement in healthcare decision-making during a high-risk pregnancy. Data analysis used constant comparative methods. The study found that some women wanted active involvement with decision-making, but not all did, the latter placing considerable reliance on healthcare professionals' judgement. Women's satisfaction with their care was congruent with how they wished to be involved in decision-making and what they actually experienced (Harrison *et al*: 2003). Although their work is informative, I suggest that the overall picture is more complex than

the study's findings suggest. Women have their own set of values and beliefs which are relevant and cannot always be demonstrated in terms of expression of their satisfaction with their care. Although there is a focus on the high-risk pregnancy, there is no information from guideline recommendations or even a professional treatment plan, much less how they may have affected women's autonomy. Women's accounts were confined to discussions with healthcare professionals about clinical facts which limits what can be learned. It was unsurprising that women's responses related to their understanding that foetal welfare was at risk and their corresponding responsibilities to their foetus. The study tended to overlook the fact that women are *also* already socially contextualised individuals with a network of family and friends and the effects of their decisions on their autonomy. Because it is important to distinguish women's experiences conceptually from satisfaction, my approach goes beyond surface accounts of satisfaction and encourages women's self-expression of their current and previous experiences of their care.

Another example of a satisfaction study is van Teijlingen and his colleagues' much quoted work (2003) which explored women's views via the Scottish Birth Study (1998). This consisted of a cross-sectional questionnaire survey completed by 1137 women. The main findings revealed that women were overwhelmingly satisfied with their antenatal, intra-partum and postnatal care. Predictably, reports of dissatisfaction were low. However, there were differences in satisfaction levels. For example, the greater continuity of carer the woman had in childbirth, the greater her likelihood of satisfaction. The authors suggest that a range of factors, for example, psychosocial, influenced women's responses. The authors concede that satisfaction studies have their limitations and problems may occur if surveys are used uncritically to shape future service provision. This is because women tend to value the *status quo* over options they have no experience of (van Teijlingen *et al*: 2003). In this study, maternity unit policy and its effect on the value women place on certain aspects of their care is referred to. For example, those with a policy of inviting women to record their birth plan directly in their maternity records were more likely to think it

was important. This suggests that the offer of an option such as this - when it is available, is important to women. The authors concede that satisfaction should not be separated from the actual care received, or from women's pre-existing wishes and expectations. Hence, they acknowledge that women's responses will be driven by what they previously experienced and what they have come to expect (van Teijlingen *et al* :2003). This goes part of the way to understanding that women's previous experiences of pregnancy and birth frequently influence expectations, hopes and fears in the current pregnancy. This is something we could benefit from knowing more about because as we shall see, experiential knowledge has variable effects on maternal autonomy.

The work of Larkin and her colleagues (2017) builds on van Teijlingen and his colleagues' (2003) work. The study took place in Ireland where there is a major focus on medicalised birth. Women who had experienced labour and had a healthy baby were invited to take part in a sequential mixed methods study (Larkin *et al* :2017). The initial qualitative phase consisted of ten focus group interviews. During the second phase, 531 accepted the invitation to complete a survey and were asked to state their preference for a particular aspect of care by choosing one scenario over another, that is the relative importance /unimportance of attributes for women's birth experiences. Analysis was in line with the DCE (Discrete Choice experiment). (This is a health economics tool which uses quantitative techniques to discover individual preferences for products or services). In this example. the DCE analysis using childbirth experiences revealed that although many women had not experienced a less medicalised system of care, nonetheless the care they received must be best, suggesting women value the *status quo* (Larkin *et al* :2017). Findings suggest that little has changed during the interim period.

The work of Hildingsson *et al* (2016) explored women's interest in different models of midwifery care. Women were recruited at their 17-19 week ultrasound scan and asked to complete a questionnaire. There were three follow-up points, at 32-34 weeks gestation, at two months and one year

postpartum. Findings revealed that although some women changed their mind over time, women were loyal to the care they had experienced, suggesting that women tend to most value what they have experienced, rather than options they have no experience of.

The work of Green (2012) emphasised the importance of women's views in large-scale studies which may be used as a basis for changing policies and practices of maternity care. In this respect, studies should first, explore why women hold specific views, second, recognize that women's views are complex and third, allow them to express their views. As Green says, satisfaction rating scales generally fail to include these three elements.

In summary, satisfaction studies suggest that women tend to value the *status quo* over options they have no experience of. Satisfaction is difficult to relate to my core question about women's autonomy and does not significantly increase our understanding about women's experiences of their care. This highlights the need to better understand what women value and the need for my empirical study.

Many studies have relied upon women's experiences expressed in satisfaction questionnaires and surveys. Others have taken the approach of exploring women's experiences of their care. Redshaw and Hockley's qualitative work (2010) explored women's experiences of delivery by Caesarean section. Women were invited to complete a questionnaire three months postpartum. The study concluded that there was a clear need for healthcare professionals to assume a greater listening role than is currently the case (Redshaw and Hockley: 2010). However, the study is confined to women's retrospective accounts of their care, the impact of their care on their autonomy is left unaccounted for and no role is assigned to guidelines.

A study that shows similar interest to my work was an exploratory study by Williams and her colleagues. Their qualitative work explored 14 women's experiences when offered first trimester antenatal screening for foetal abnormalities which took place in the context of an obstetric ultrasound scan (Williams *et al* :2005). A significant feature of this study is that it took

place following the time when a ministerial statement by the CMO (Chief Medical Officer) informed the NHS that a Down's syndrome screening test should be offered to all pregnant women, regardless of their age (Department of Health: 2001). Interestingly, the authors *do* refer to the NICE Antenatal care guideline (2003) which states that all pregnant women should be offered the option of screening for Down's syndrome. The authors regard this as highly significant. Prior to this guidance, there had been widespread variations regarding who should be offered testing and the methods to be used.

Previous research about women's knowledge about screening tests and the ways in which screening is offered questions the transparency of women's choice regarding testing (Faden *et al*: 1985; Marteau *et al*: 1988; Press and Browner: 1997). Williams and her colleagues' study had a particular focus on the scan in first trimester screening, some of the potential dilemmas and the ways in which women make their decisions about screening, in particular their role as 'moral pioneers'. This suggests that the guideline may have had a role to play in creating a situation whereby women who accepted the early scan assume a different status and are in some way 'leading the field'. One possible explanation for this may have been attributable to the chronology of events. It was they who experienced first-hand the policy shift following the guideline's recommendations. These findings should be interpreted in relation to the fact that the research was conducted post- policy change. New tests and novel medical technology may raise ethical dilemmas for some women.

The findings from Williams and her colleagues' work contribute to our understanding of the importance women attach to the first trimester scan. However, it leaves unanswered the effect on their autonomy. Nonetheless, the study does report that women gave careful consideration to their own beliefs and values prior to deciding (Williams *et al*: 2005). This finding highlights the idea to be built upon further in this thesis, that is, women rarely make their decisions as self- sufficient individuals and solely on medical information. Opportunities and constraints should be explored and

decision-making frequently takes place through interactions with healthcare professionals and others.

A later study which explored 15 pregnant women's and their partners' experiences of antenatal screening for foetal abnormalities pre and post screening was conducted by Watterbjork and her colleagues (2015). 15 interviews were conducted with women, six with women's partners and 16 with couples together. Data analysis used interpretive description, an inductive approach to gaining an understanding of how patients experience healthcare processes (Thorne :2008). Care was taken during analysis to ensure that women's accounts represented their experiences exclusively. The study is relevant and informative because it explored experiences of care pre and post screening. However, no role is assigned to guidelines. Autonomy is briefly referred to in the sense that on the one hand, screening may promote autonomous decision- making. On the other hand, in view of the perceived benefits screening offers, there may be pressure to accept the tests which may place constraints on an individual's autonomy (Juth and Munthe:2012). Data analysis and interpretation in Watterbjork *et al's* study does not specifically account for the effects of screening on women's autonomy, hence it does not increase our understanding of the concept. My study adds that further dimension.

An Australian study which used quantitative methods to investigate and gain an understanding about pregnant women's experiences of information –seeking behaviour and their needs was conducted by Grimes and her colleagues (2014). The study recruited 350 women at four months postpartum into a cross-sectional postal survey which comprised closed categories and open- ended questions. Frequency, percentages and means were used to describe the data (Pierson:2010) and responses to open – ended questions were analysed using content analysis (O'Cathain and Thomas:2004). Key findings were that women accessed information from a variety of sources, but the most frequently cited source of information was the midwife. The authors concede that their analysis of findings should be interpreted with caution and qualitative research may have given a deeper

understanding about the ways in which women seek information and the effect of not having their information needs met (Grimes *et al* :2014). Guidelines are referred to regarding the various systems of care offered to women, for example, midwife- led or shared care with an obstetrician (National Health and Medical Research Council, Department of Health and Ageing:2010). Directly relevant to the study is that provision of information to women is an important role of the midwife (Australian Nursing and Midwifery Council :2006). However, despite the aims and objectives of the study, we are not specifically informed about what the national guidance about women's information needs is, nor how it should be applied. The effect of women's met (and unmet) information needs on their autonomy is unaccounted for which limits what can be learned. These gaps raise the need for my empirical study

Conclusion.

The literature review in this Chapter raises the question why very little qualitative research relating to women's experiences of care based on clinical guidelines and their impact on their autonomy has been undertaken. This seems pertinent in a climate which promotes comprehensive information provision, evidence- based care, increased choice and enhanced maternal autonomy.

Guidelines.

Based on my interpretation and synthesis of the academic literature, guidelines present challenges for women and healthcare professionals. Although their wider recommendations refer to 'partnerships' in decision-making, they under-specify this concept and what it means to women. The concept of 'shared decision- making' between women and healthcare professionals is not directly referred to in guidelines. Based on my interpretation of the literature which revealed the importance of this concept, we need empirical evidence to understand its implications for guidelines and what it means in a relationship of trust for women's autonomy.

Autonomy.

My critical analysis of the literature on autonomy led me to reconsider how women understand and negotiate their decision- making with professional and informal carers. It orientated my thoughts to a relational model of autonomy which would allow me to interpret my study data through a social as well as a clinical or traditional bioethical lens.

Empirical studies.

My interpretation of the empirical literature on satisfaction revealed that it is an ambiguous concept that did not answer my core question about women's autonomy.

Effective communication between women and healthcare professionals was key and this included women's previous experiences not elicited in guidelines which miss this element of care. Information- giving often appeared to be one- way from healthcare professionals, but women have biographical information they wish to be taken into account which is important to their autonomy, suggesting the need for effective two- way interactions.

The review confirmed first, a gap in the research literature and second; in order to explore my research question, the appropriateness of undertaking the current research and the need for an empirical study to explore women's experiences of their care.

Chapter Three is my Methods Chapter and sets out how the empirical study was designed and conducted in order to address the research question.

Chapter Three.

Methods.

Introduction.

This Chapter sets out how the empirical study was designed and conducted. Section One, Part One entitled 'Research Methods' describes the ethical review process, the development of the Participant Information sheet, participant recruitment and sampling strategy. Part Two sets out the conduct of the study and the development of the Interview Schedule/Topic guide. Section Two entitled 'Research Methodology' sets out my choice and justification of a qualitative research methodology, data collection, transcription and analysis. This includes a section on the application of Grounded Theory, including how other studies informed my own research study. Section Three comprises a brief reflective analysis.

This thesis is exploratory (rather than based on a hypothesis). The focus is on applied research in order to draw conclusions and make recommendations for future practice and research.

SECTION ONE.

Part One.

Research Methods.

Study design.

(i) Ethical review process.

During the process of assembling my application, my responses to the filter questions generated via IRAS (Integrated Research Application System) indicated that my application was suitable for PR (Proportionate Review).

However, researchers should always be aware that studying sensitive/upsetting topics could affect a participant's well-being (Lowe and Gill: 2006). I anticipated that potentially distressing issues might be raised during the interviews. Hence, I requested full review by a REC (Research Ethics Committee).

Summary of the REC application process.

Patient and Public involvement.

Changing Childbirth (Department of Health: 1993); *Maternity Matters* (Department of Health: 2007) and *Better births* (NHS England: 2016) emphasised the need for maternity service-users to be actively involved in their planning, monitoring and review. In my study PPI (Patient and Public involvement) contributed towards the refinement and editing of the PIS and the Interview Schedule/ Topic guide.

As part of my methods, I referred to INVOLVE which is part of NIHR (National Institute for Health Research). INVOLVE defines public involvement in research as 'research being carried out **with** or **by** members of the public rather than 'to', 'about' or 'for' them'. An example of this is helping develop and commenting on patient information leaflets (NIHR: 2017).

Pilot work.

Development of Participant Information sheet.

I made contact with a former maternity service-user from an interest group at another hospital unconnected with the research study. She was a former high school teacher who had undergone fertility treatment and given birth to twins fifteen months previously. Hence not only did she have recent experience of the maternity services, her pregnancy warranted a high level of care. She kindly agreed to review the PIS and made comments which I incorporated into the draft version I submitted for the REC's scrutiny.

I asked the woman to comment on the justification for the research study, the timing of the interviews, the clarity of the PIS and any other views she had about the preliminary design.

The woman believed it was a worthwhile study and that the interval of between one to four weeks for women to decide whether or not to take part was appropriate. However, her comments brought to my attention issues that might otherwise have been overlooked. For example, she commented that whilst the layout of the PIS was clear, during pregnancy she received a lot of different information and there was a risk of becoming overwhelmed and consequently not reading any of it. Hence, she stressed the importance of keeping the information as succinct as possible. Her comments resulted in further editing of the PIS. She also enquired how women would be approached. She thought it was particularly important that women were approached face- to -face as copies of the PIS left randomly in the Antenatal Clinic waiting area alongside other maternity care literature could adversely affect recruitment to the study. Hence she drew on her personal perspective and her own working life and knowledge in order to highlight issues of importance. Her comments helped bring together her views and my thoughts to improve the PIS. The cumulative experience was helpful in understanding women's potential needs and wishes and contributed in a practical sense to further refinements of the scripts. (For a copy of the PIS, see Appendix (i)).

Chronology of events during REC application process.

My application was received on 12th July, 2012 and confirmed valid on 16th July. Meeting arrangements: I was to attend NRES (National Research Ethics Service) North West-Liverpool Central Research Ethics Committee on 1st August. The meeting was very brief and I was informed that I would receive written confirmation of the Committee's decision within a week. I received a Favourable Opinion letter dated 3rd August, 2012. REC Reference: 12/NW/0547.

26th September, 2012: I received a Letter of Access for Research and Research Passport from the NHS Trust Research and Development Manager. The Research study was registered on the Trust's Research and Development Database under the Reference: LWH 0940.

23rd October, 2012: I received confirmation of sponsorship from the University sponsor representative. Reference: UNOLE 0343.

Study setting.

The study was conducted in the Antenatal Clinic of a large inner-city teaching hospital in North West England. Approximately 8000 women give birth at the hospital annually. The hospital is university- affiliated and has a significant research culture. I felt that, pragmatically, this site would enable me to recruit women whose inclusion would be relevant to the research question.

Gatekeeper relationships within the NHS Trust were established following a meeting with my designated on-site clinical supervisor. Formal arrangements were made for me to attend different antenatal clinics, for example, Midwife-led, Diabetes and Hypertension, which run regularly on the hospital site.

Ethical considerations:

Consent: prior to the interview, I discussed the PIS with the potential participant, invited questions and clarification of issues. This took between ten and 20 minutes (depending on the woman's wish for information). I then obtained the woman's formal written consent to participate in the study in triplicate. One copy of the Consent form was given to the participant to keep and the second was filed into the participant's case notes by a member of the healthcare team. I temporarily retained the third and at the earliest opportunity took it for storage in a locked filing cabinet in Professor Richard Baker's office, Department of Health Sciences, University of Leicester. (For a copy of the Participant consent form, see Appendix (ii)).

Strategy in case of participant distress : there was a possibility that in some cases the interviews could raise something that the participant might find upsetting. An example is a previous negative birth experience. Specifically, I drew upon my previous experience as a clinical midwife and conducted the

interviews in what I hope was perceived as a sensitive and insightful way. If the participant became distressed, there were the options of taking a break or stopping the interview and seeking advice from the clinical care team and/or on-site clinical supervisor. Professional counselling services which were based externally were also available. Such situations did not arise.

Confidentiality: The NHS Code of Practice : Confidentiality (Department of Health:2003) was followed. Any information that left the hospital had the participant's name removed from it. However, there are instances when it may be ethical to breach confidentiality. For example, if the participant revealed information relating to safeguarding issues or illegal activity which suggested that individuals may be at risk, then I had a duty to escalate according to Trust guidelines. This situation did not arise.

Anonymity: each participant was initially allocated a study code number. Pseudonyms were subsequently used with direct quotations of what the participant said.

Physical security arrangements: After five years, I will destroy all data confidentially.

Concerns/ complaints relating to the study: In the event of a participant expressing concern about the study, in the first instance I would endeavour to rectify the problem. However, should the participant wish to communicate with someone independent of the research, she was to contact the Patient Quality Team based at the study site, whose contact details were noted on the PIS.

Table 3.1 Inclusion criteria.

<p>Primiparous or multiparous.</p> <p>20-36 weeks gestation.</p> <p>18-45 years old.</p> <p>Able to read, understand and communicate in English.</p> <p>Hospital attendees for the majority of their care.</p> <p>Facing a pregnancy-related decision of some kind.</p>

Table 3.2 Exclusion criteria.

<p>Less than 20 and more than 36 weeks gestation.</p> <p>Under 18 and over 45 years old.</p> <p>Inability to read, communicate and understand English.</p> <p>Those lacking capacity to consent to their involvement in the study.</p> <p>Those receiving most of their antenatal care in the community.</p>

(ii) Recruitment.

Potential participants were identified by members of their clinical care team by direct reference to their case notes and/or MHHR (maternity hand-held record). They were subsequently approached by members of the clinical team and given PIS which set out the aims and objectives of the study to take home and read. If they wished to obtain further information, had any questions, or decided they wished to take part in the study, they were invited to contact the researcher via her university email address or mobile telephone specifically designated for the study. Depending on the interval between antenatal appointments, the potential participant was given between one and four weeks to decide whether to take part. In order to minimise inconvenience to the participant, I was to arrange to meet her at her next antenatal appointment, that is, no additional appointments were necessary. These arrangements were to be finalised by a confirmatory email or telephone call one day prior.

Interviews were scheduled to take place in a private room in the Antenatal Clinic and with the participant's permission were audio-recorded. In the event of the need to re-contact the woman in order to check something she had said (*member checking*) (Barbour:2001), the participant's permission was sought. All participants agreed to this and provided a contact telephone number or email address. No further appointments were necessary.

Problems encountered.

Participant Information sheets were circulated amongst eligible women week commencing 5th November, 2012. Interviews commenced on 20th November. By mid-January, 2013, it became apparent that recruitment was very slow, that is, three participants only in two months. Taking into account the Festive period and unfavourable weather conditions, this was still seen as disappointing. Time pressures were cited as the main reason for declining to participate. Although disappointing, it made me realise that this

was not a straightforward process and that participant enthusiasm for the research study could not mirror my own interest. The experience taught me that my initial expectations were possibly too high and should be re-evaluated more realistically. In this respect, Silverman (2013) acknowledges the inevitable gap between the study design and the course of empirical work.

Following discussion with my on-site clinical supervisor, she suggested that in her experience, potential participants tended to respond more favourably to a face-to-face approach from the researcher in person. Shortly afterwards, I met with my academic supervisors and shared these thoughts. We agreed that I should request said permission from the REC. On 22nd January, 2013, a Notice of Substantial Amendment (non- CTIMPS) (Clinical Trials of Investigational Medicine Products) to the Protocol was submitted to NRES Committee North West-Liverpool Central to request permission to approach potential participants in person. REC permission was obtained in a letter dated 7th February, 2013. The new arrangements proved very workable. Up to and including 8th March, 2013, a further 17 women were interviewed.

(iii) Generation of sample.

Initial sampling involved selecting the group to study on the basis of their usefulness and relevance to address the research question appropriately, that is, their inclusion provided access in an interpretive sense to the topic being investigated and contributed to a developing theory (Mason:2002). As my research was inductive, that is, theory emerges as the data are collected and analysed, it was difficult to predict the number of participants that would need to be recruited. As Isaacs (2014) says, in qualitative research there are no formal criteria for determining sample size and the richness of the data is much more important than the number of study participants. However, the researcher still needs insight about the sample

size most likely to achieve the purpose of answering the research question. I sought advice from a senior qualitative researcher in my own university department who suggested I should aim for between 20 and 25 participants.

I adopted a theoretical sampling approach mostly used in grounded theory. I obtained more data in order to expand and explain the initial ‘thin’ categories I had identified, aiming to develop a well-saturated theory. As Babbie(2014) says, analysed data guides the areas to be explored and the focus of the sample needed to achieve this. Concurrently, a process of constant comparison of categories and observations was warranted as I sought to develop an understanding of the process I was investigating. In this respect, Josselson and Leiblich (2003) suggest that saturation is the best determinant of sample size. The sampling strategy was chosen not simply to generate categories which might produce data that supported the initial proposition, but also cases that cannot be accounted for by the explanation that I was developing. In order to demonstrate the range of variations of a concept in different situations, I included primigravidae and multigravidae across a range of clinic specialties. A focus on different cases is key in this process (Becker:1998).

(iv) The Sample. (Pseudonyms are used to protect participants’ anonymity).

Table 3.3 Study participants’ details.

Chloe Aged 40 White	Healthcare professional. Primigravida. 27 weeks gestation. Insulin dependent diabetic.
Lucia Aged 25 White	Qualified teacher working in a different role. Gravida 2. Para 1. 33 weeks gestation. Gestational Diabetic.

Alysha Aged 33 Non- white	Healthcare professional. Gravida 3. Para 2. 35 weeks gestation. Gestational Diabetic and Hypertension.
Sarah Aged 37 White	Housewife and mother. Gravida 9. Para 6. 35 weeks gestation. Uncomplicated pregnancy.
Georgia Aged 26 White	Working in a semi- professional role. Gravida 2. Para 1. 27 weeks gestation. Previous third degree perineal tear.
Jade Aged 28 Non- white	Former healthcare professional. Current postgraduate student. Primigravida. 28 weeks gestation. Uncomplicated pregnancy.
Raine Aged 27 White	Working in a semi-professional role. Primigravida. 29 weeks gestation. Twin pregnancy.
Catrin Aged 35 White	Working in a professional role. Gravida 2. Para 1. 37 weeks gestation. Gestational Diabetic and previous Induction of labour.
Rachael Aged 34 White	Healthcare professional. Gravida 3. Para 2. 23 weeks gestation. Previous severe shoulder dystocia.
Isabella Aged 45 White	Former healthcare professional. Current student Gravida 5. Para 3.(1 miscarriage) 27 weeks gestation. Uncomplicated pregnancy.

Holly Aged 24 White	Housewife and mother. Gravida 3. Para 2. 29 weeks gestation. Attending Bariatric Pregnancy Clinic.
Layla Aged 27 Non- white	Housewife and mother. Gravida 2. Para 1. 28 weeks gestation Attending VBAC Clinic.
Lauren Aged 30 Non-white	Student. Gravida 2. Para 1. 28 weeks gestation. Attending VBAC Clinic.
Nia Aged 27 Non- white	Working in a semi-professional role. Primigravida. 28 weeks gestation. Uncomplicated pregnancy.
Hannah Aged 28 White	Working in a semi- professional role. Gravida 3. Para 1. (1 intra-partum death). 31 weeks gestation. Attending Medical Specialties.
Lisa Aged 36 White	Housewife and mother. Gravida 2. Para 1. 28 weeks gestation. Attending hospital- based Antenatal Clinic for anti-D prophylaxis.
Charlotte Aged 29 White	Working in a managerial role. Gravida 2. Para 1. 33 weeks gestation. Gestational Hypertension.
Safia Aged 32 Non- white	Working in a manual role. Gravida 5. Para 4. 28 weeks gestation. Uncomplicated pregnancy.

Jasmine Aged 30 White	Working in a professional role. Primigravida. 30 weeks gestation. Intrahepatic cholestasis of pregnancy.
Rebecca Aged 29 Non- white	Housewife and mother. Gravida 3. Para 1. 30 weeks gestation. Uncomplicated pregnancy.

Part Two

Conduct of the study.

The interview.

I chose interviews as a means of generating data to answer the research question. Interviews present an opportunity for the researcher to enter into the participants' world, reflect upon and clarify issues so as to gain a deeper understanding of their experiences(Whitehead and Whitehead:2016).

Development of the Interview Schedule/Topic Guide.

The Interview Schedule was based on my literature review and developed according to the aims of the study. It was developed primarily in conjunction with my academic supervisors and later reviewed by my on-site clinical supervisor. The Interview Schedule/Topic Guide helped ensure that similar topics were covered in each interview. Prompts were there to remind the researcher in case these topics were not covered (Toles and Barroso:2017). I do not use the term 'autonomy' in the Interview Schedule. This is because the women's own terms for independence, choice and control were important.

Pilot work.

Patient and Public involvement.

I serve on a REC which regularly reviews qualitative research studies. A lay member of the REC also served on the local hospital information leaflets Reader Panel which reviews clinical information sheets for patients. She reviewed the Interview Schedule/Topic guide. The woman thought that the main interview questions were clear and consistent with the aims and objectives of the research study. However, her concern was that some women might be reticent about expressing their views. Hence she suggested the inclusion of some additional follow-up questions which she thought first, would help expand upon issues of real interest and second, would help women express their perspectives.

There were no formal pilot interviews prior to commencing the empirical study. As I had no previous experience of conducting interviews, I attended training sessions in Qualitative Methods at the University of Leicester and with Methods North West Doctoral Training scheme. Preparation involved research methodologies and participation in simulated interviews with group members.

The main topic for the interview was decision- making during pregnancy and women were guided to think about decisions they had made or would need to make. It was not possible to detail exactly what every question would be as some were developed concurrently with the flow of the individual participant's interview. In line with grounded theory, the interview questions were guided by my data analysis which allowed continuous adjustment of the interview questions in response to emerging themes.

The aim of the schedule was not to direct the interview process. Rather, it was to assist me as researcher to explore women's experiences of their care based on recommendations in guidelines. Women were encouraged to talk for as long as they wished. Probing was used when appropriate to

discover more detail and in some cases to clarify meaning. Hence, the interview offered a broad structure but was flexible enough to allow women to express their views and most importantly, expand on areas seen as important to them. (For a copy of Interview Schedule/Topic Guide, see Appendix (iii)).

I interviewed all 20 women face-to-face. The interviews ranged between 37 minutes and 1 hour 22 minutes, suggesting that women think about their experiences and express themselves in different ways. They were semi-structured and with the woman's permission, were audio-recorded. Structured interviewing can be restrictive, whereas unstructured interviewing can raise problems in maintaining a focus within the conversation. The semi-structured interview allows for a reasonably detailed interview schedule (Holloway and Wheeler: 2010). For example, I was able to ask the participant to talk through a specific incident, rather than what one would generally do in some prevailing circumstance. It also created some sense of excitement, reflecting the unique insights each participant brings (Rose:1994). Interviews have some disadvantages in that they are lengthy and time consuming (Rees: 2011). Nonetheless, they were an appropriate method for this study as they are an invaluable means of obtaining in-depth information from participants (Murphy *et al*:1998).

The lead question during the interviews was whether the woman had made or would be needing to make any decisions in pregnancy. I encouraged the woman to talk with minimal prompt or interruption for as long as she wished. I then asked her to elaborate further on events surrounding decisions she had had to make or would need to make in pregnancy. I asked participants to talk through their experiences in order to get a sense of the issues that featured most prominently. An example of this is antenatal screening tests for foetal abnormalities. I did not begin the study with the plan that this would be a major focus and result in a whole Findings Chapter, but women themselves raised it. In line with grounded theory it became part of a process and the Interview Schedule revised accordingly. This is an example

of how grounded theory works inductively, building theory from theoretical sampling and iterative analysis.

Learning how far to probe was a balancing act. Care was taken to remain sensitive to participants' concerns. I found I had to think quickly about what had been covered and that the use of an aide-memoire with topic headings and brief note-taking were invaluable. In order to explore participants' experiences in greater depth, there were instances when I invited the participant to elaborate further 'Could you please tell me more?' Hence, interviewing obliged me to constantly make decisions about what to ask next, whether to explore further or move on, that is, steering the interview in a way consistent with the research question.

SECTION TWO.

Research Methodology.

A quantitative research approach to the study was seen as inappropriate for the exploration of participants' experiences. Pregnancy is a process with many features that cannot be quantified. Oakley's work (1990) criticised research which concentrated on one measurable and quantifiable aspect of pregnancy and childbirth to the detriment of other factors which may have equally important, but nonetheless less measurable features. Greenhalgh (2014) clearly describes the limitations of quantitative research and the merits of qualitative research in 'seeking a deeper truth'.

Other researchers have taken a different line of argument. Where hypothesis testing is the aim and this is tested by studying the effects of independent on dependent variables using statistical methods, quantitative research methods can enable the researcher to use numerical data to answer research questions and draw inferences from their results (Shields and Smyth:2016).

When insight into the research topic is not well established, qualitative methods allow a fuller exploration of participants' experiences (Morse:1997). This is directly relevant to my study as little is known about women's experiences of their maternity care based on recommendations in guidelines. Qualitative methods also allow the relative importance of certain issues to emerge and can reveal strength and depth of feelings. The researcher uses qualitative methods in order to get a deeper and more nuanced understanding of the topic and to see it in novel ways (Kelly:2010).

(i) Choice of research methodology.

A method was sought which not only acknowledged the ontology of the individual's perspective, but also to inform further information- gathering and interpretation from which theory could be generated. As Silverman says 'There are no right or wrong methods. Rather, there are methods which should be appropriate to the research topic and the model within which the researcher is working' ((Silverman 2005:112). The chosen method should acknowledge that individuals in apparently similar circumstances may have hugely different experiences. Grounded Theory is a qualitative methodology developed by Barney Glaser and Anselm Strauss (1967). The principles underpinning grounded theory were considered the most appropriate and form the basis for my data collection and analysis. I also considered Phenomenology, an outline of which is set out in subsection (a) which follows. What is crucial is that the researcher understands the methodological approach and is able to demonstrate how the data were gathered, transcribed and analysed.

Selecting between phenomenology and grounded theory was challenging. Each methodology shared certain values and relevant pointers for the empirical study. As Braun and Clarke (2006) say, the question of epistemology is usually determined when a research project is conceptualised as it helps adopt a critical stance to the literature being reviewed. It may also have relevance during analysis when the research

focus may shift to different aspects of the data that is differences between research findings are explainable through critical thinking about the assumptions that underpin the research. The research epistemology, then, guides what the researcher can say about the data and how meaning is theorised. In this sense, it was helpful to think about the theoretical perspective behind each methodology and what epistemology informs the theoretical perspective.

(a) Phenomenology.

Phenomenology can be defined as a methodology which aims to understand and interpret the 'lived experience' of individuals. The type of problem best suited to this approach is one in which it is important to gain an understanding of several participants' common or shared experience of a phenomenon in order to discover the core essence of a concept (Polit and Beck: 2008). As with other qualitative approaches, there is no single method which produces a phenomenological study. Researchers who draw upon this approach credit the influence of one or two key German philosophers, namely Husserl and his student Heidegger who developed Husserl's ideas in an alternative direction (Hermeneutic Phenomenology). Husserl's work concentrated on describing the experience of a phenomenon. The emphasis is a descriptive approach to the lived experience, that is 'what' the participants themselves experienced and 'how' they experienced it (Moustakas:1994). The researcher is encouraged to 'bracket out' (*epoche*) that is, identify and set aside her or his own beliefs so these do not influence the data collection and interpretation. This is to achieve an accurate description and a novel perspective of the phenomenon under investigation. There is scholarly debate about whether or not 'bracketing' is achievable (Burns and Grove :2009; Gelling:2010). Further debate exists relating to the process the researcher should adopt when attempting to bracket (Hamill and Sinclair:2010). Those following Heidegger's approach do not bracket. The focus is the study participants'

experiences and where some prior understanding of the topic is an essential part of the researcher's interpretation of the phenomenon.

My own position is that :- in order to answer the research question, the researcher needs to critically analyse the data to determine what it is about the phenomenon that needs to be described. My reasons for rejecting phenomenology were twofold. First, it might result in the field of enquiry being narrowed down solely to the participants' experiences. Whilst I am aware that this is the main focus of the study, as a former midwife 'bracketing out' would have been unworkable. Second, it is important – in order to allow ideas to flow freely, not to feel confined by them. Hence , former professional experience influenced my decision. My research specifically focused on the relationship between women's experiences and clinical guidelines, so I would regard this as the main justification for considering phenomenology but rejection in favour of Constructivist Grounded Theory. In addition, my interest in autonomy partially directed the focus of my enquiry, while at the same time allowing women to tell me what autonomy meant to them.

(b) Grounded Theory.

The term 'grounded' refers to the fact that the theory to be developed emerges from the empirical data and is related to thinking and behaviour. It emphasises the analysis of a basic process the researcher discovers in the literature and data. Grounded Theory methods aim to develop theory inductively from the data using a strategy termed the constant comparative method (Glaser and Strauss:1967). Data which are gathered, coded and analysed are directed at drawing out the properties of a category and discovering relationships between the emerging categories as a process with theoretical sampling being a key feature. Grounded Theory saw further developments in the 1970s when Glaser further elaborated on the data coding process by making distinctions between substantive coding and theoretical coding. During the 1980s, Strauss, in collaboration with Juliet

Corbin introduced several new concepts into the original theory, namely the use of axial coding, a paradigm based around context, conditions and consequences in which text is converted into concepts. The term 'grounded' refers to the fact that the theory which emerges from the empirical data makes it particularly suitable as a method that directly relates to participants' thinking, perceptions and behaviour (Arber:1993). It is the researcher's analysis and interpretation of the data which results in the development of a theory (Morse:1997; Dey:2004).

I sought a methodology to explore the individual participant's view, but also from which a theory could be generated to inform further data collection and interpretation. I chose grounded theory because it does not sacrifice creativity for prescriptive methods of data gathering and analysis. Grounded Theory shares commonalities with other qualitative approaches because it is an emergent process, that is, the data have primacy and facilitate the development of ideas and theories through rigorous analysis. According to Glaser, grounded theory is 'enjoyable, meaningful, informative and empowering' (Glaser:1998: 19). A further attribute is that it guides the researcher through an analytic process, aiming to develop a deeper meaning by studying and interpreting the data. It is a suitable method when a theory is unavailable to explain a process (O'Donoghue:2007). For example, a theory may be needed to explain how people experience a phenomenon and the grounded theory that the research produces will help provide a framework. Grounded theory is useful to novice researchers as it 'provides a frame for qualitative inquiry and guidelines for conducting it' (Charmaz : 2009:127).

(c) Constructivist Grounded Theory.

1. Appropriateness of Constructivist Grounded Theory for my research study.

The theoretical perspective or philosophy that informs and guides the process of enquiry (Jeon:2004) relates to the researcher's ontological, epistemological and methodological position. Ontology refers to the nature of reality, whereas epistemology is the relationship between the researcher and what is known (Denzin and Lincoln: 2005). According to Mills and her colleagues (2006), researchers should first identify their ontological and theoretical positions. This is because they need to indicate which grounded theory is best suited to their process of inquiry. Constructivist Grounded Theory was particularly appropriate for my study because the specific process I was interested in was women's decision-making related to guidelines underpinned by women's social context and relationships.

Theoretical sensitivity.

Glaser and Strauss (1967) refer to theory as emerging from the data and separate from the researcher. I will not be drawing on their approach, but on the work of Kathy Charmaz (2006 ; 2014). Charmaz is a leading proponent of the Constructivist Grounded Theory approach. She reminds us that Glaser and Strauss (1967) encouraged researchers to use grounded theory strategies in a flexible way. At the root of Constructivist Grounded Theory is the belief that neither data nor theories are discovered. Rather, Charmaz argues, we are a part of the world we study and the data we gather. We construct our grounded theory through our own past and current involvements, our interactions with research participants, their perspectives and our research practices, a theoretical perspective she terms 'symbolic interactionism' (Charmaz:2014 : 262).

The constructivist researcher begins with a desire to understand more about a particular substantive area and has some preconceived questions which can be used flexibly and modified in relation to the development of the interview. Charmaz emphasises the need for the researcher to become

immersed in the data to increase theoretical sensitivity. Hence, developing Constructivist Grounded Theory means seeking both participant *and* researcher meanings through the development and subsequent refinement of and interrelation of concepts. This means that participants and researcher co-construct experiences and meanings from the data (Charmaz:2014). In my study, the analytic process included identifying relationships between relevant extracts from guidelines as well as women's quotes and this occurred in an iterative manner, similar to the constant comparative process.

Literature.

The issue of reviewing the literature – that is how best and when to review and utilize existing literature in the research study has been repeatedly debated (Bryant and Charmaz: :2007). Glaser and Strauss (1967) advise researchers to write the review after completing data analysis so as not to risk contamination of findings. Corbin and Strauss (2008) maintain that there are always new discoveries to be made – hence a literature review prior to commencing the study is unnecessary. Bryant and Charmaz (2007) however, maintain a literature review is warranted in order to situate the current study within the context of related literature and provide a way forward, thus ensuring that cumulative evidence builds and new findings are relevant and meaningful for policy and/ or practice, rather than banal. As I demonstrated in Chapter Two, Section Two, I undertook a substantial part of the literature review prior to commencing the empirical study and the academic conceptual debates about autonomy informed my emergent theorizing.

Data analysis.

Data are collected and analysed through interaction between participants and researcher together and an interpretation of reality is co- constructed (Charmaz:2014). She stresses the need to go beyond the surface in

searching for meaning in the data. It is this process that helps enrich data, deepens analysis and generates a theory that reflects participants' experiences and the context in which they are situated. This is part of the process of developing analytic categories which facilitate data comparison in order to allow new ideas to emerge. Constructivists study *how* and *why* participants express their own possible meanings and actions. The researcher aims to get in close proximity to the participants' experiences, whilst recognising they are something that can never be fully replicated (Charmaz:2014). It follows that the emerging theory cannot stand independently of the researcher's views, experiences and interpretations.

Constructivists aim to understand the assumptions underpinning the data by piecing them together. For example, participants in the empirical study consistently reported their maternal obligations to the foetus as a self-evident fact. However, it is not until they are specifically asked what these mean, that is, what vision, hopes and fears these obligations generate do they start to develop a form and content that has explanatory power.

I constantly asked questions of the data until I produced the theory. As Charmaz (2006) says, Constructivist Grounded Theory lies firmly within the interpretivist approach in qualitative research. Grounded Theory need not be prescriptive and a focus on meaning furthers rather than limits interpretive understanding. My data analysis explored how women's experiences related to my specific focus of recommendations in guidelines. This was because both were part of the framework being studied. Analysis is invariably contextually situated in time and place. For example, my findings about new choices and dilemmas relating to antenatal screening for foetal abnormalities evolved from my analysis of the data, reading the literature and critical analysis of guidelines.

Reflexivity.

One of the challenges faced by researchers is remaining mindful of their own preconceived ideas and how they might impact on the research.

Charmaz(2014) says that researchers should continuously reflect about their own actions, values and perceptions. Reflexivity is important because the researcher's stance has an impact on the research setting and can affect data collection and analysis. Section Three of this Chapter comprises a brief reflective analysis of my study.

2.Previous use of Constructivist Grounded Theory and the ways in which it informed my research study.

Grounded Theory has informed different disciplinary areas and has wide applicability as a research methodology (Morse:2009).

The following studies provided precedents and transferable learning, demonstrating the value of Constructivist Grounded Theory for my own study. They were selected because of their theoretical significance, their ability to generate and support the researcher's interpretations and explanation leading to the development of the grounded theory.

In this section, I discuss salient features in studies that have used Constructivist Grounded Theory as a methodology and explain how these informed my own study.

I will primarily draw on :-

(i) The works of Charmaz on chronic illness and disability (1995;2002;2009).

And, specific to maternity care

(ii) The work of Kamal *et al* (2005).

(iii) The works of a) Carlsson *et al* (2009) and b) Carlsson *et al* (2012).

(i)Charmaz has published extensively, most notably on self and chronic illness (1990;1991;1995;1999;2000;2002;2006;2009;2010). Other scholars in nursing, midwifery and psychology have used grounded theory underpinned by a constructivist paradigm (Corbet Owen and Kruger:2000; Madill *et al* :2000; McCann and Clark:2003; Dodson and Dickert:2004; Carlsson *et al* :2009; Carlsson *et al*: 2012). All these authors draw upon Charmaz' work (1995; 2000 ;2006) in making a case for using Constructivist

Grounded Theory in their own work and these studies have a common focus on participants' experiences.

Charmaz (2000) says that Constructivist Grounded Theory is both possible and desirable because data do not provide a window on reality. Rather, the 'discovered' reality arises from the interactive process and its temporal, cultural and structural contexts.

Charmaz' work challenges researchers to think about the nature of their relationship with the study participants and their representation of them and their accounts, that is, it offered a way of thinking about the data with the aim of conceptualizing it (Charmaz:2009). For example, in my study, data collected from women receiving hospital-based care based on recommendations in clinical guidelines reflected the influence of that particular setting on their experiences. It also reflected the researcher's experience as former midwife of caring for women in a hospital setting.

Another point is that Charmaz' work includes not only the context of the interview, but participants' experiences of chronic illness in their lives and the contextual aspects of the research question. In this sense, she treats the interview not simply as an individual's account of their experience of their care, but a story that unfolds as the participant and researcher explore the topic. For example, Charmaz (2002) talks about the merits of using participants' expressions from their own experiences to frame research questions. She refers to participants' expressions of 'good days' and 'bad days' and how these are interpreted.

- Tell me what a 'good' day is like for you.
- Do you feel better about yourself on a 'good' day?

The first question invites the participant to share their experiences.

The second question might elicit a 'Yes'/'No' response.

These examples show that the ways in which the interview questions are framed affects participants' responses and the subsequent development of theory.

In my own study participants sometimes expressed themselves in metaphor. An example of this is referring to 'applying the brakes', thus ceding control.

A further point is that Charmaz says in order for participants to create meaningful realities, it does not mean that their experiences beyond the interview cannot be tapped into and become part of the analysis. An example of this is Charmaz'(1995) work on the chronically ill, who experience their illness regardless of whether or not they participate in interviews. These ideas helped me think about how the woman's social relationships and contextual factors which were a part of her life- world prior to becoming pregnant might affect the options available to her and impact on her autonomy.

Maternity care studies.

(ii)Kamal *et al* (2005) draw on the guiding principles of grounded theory in their exploration of healthcare professionals' experiences of factors influencing delivery by repeat Caesarean section. The publication commences with a review of the literature on health care professionals' views and practices on VBAC(vaginal birth after Caesarean). Interviews were for the purpose of developing a deeper understanding of the topic (Charmaz: 2006; 2014).

Kamal *et al* (2005) offer the reader a clear and concise account of their use of the constant comparative method based on a methodological process. In accordance with grounded theory, every part of the data, that is, the emerging codes, categories and different parts of the data are constantly compared with other parts of the data. This is to explore variations, similarities and differences relating to the research question. Hence data collection and analysis occur simultaneously. The first step Kamal and colleagues describe is how data is compared with data. Second, 'open' codes were generated, refined and subsequently developed into thematic categories. Their analysis makes clear how each part of the data,

including codes, categories and other dimensions, that is contextual factors, are constantly compared as part of a methodological process in order to ground the final theory in the participants' experiences. These points usefully informed my own study. As Charmaz says, other qualitative methods do not provide clear directions about how researchers should proceed, whereas grounded theory provides 'explicit guidelines' (Charmaz: 2006:3). Like Kamal *et al's* study, my analytical interpretation of the data helped direct further data collection and the data eventually saturated the emerging categories. It also ensured that the codes and categories were grounded in data. In line with Charmaz' work, this approach provides novice researchers with 'heuristic devices' to 'get started, stay involved and finish the project' (Charmaz:2006: 2). Constant comparison between codes, categories, memos and literature helped ensure that consistency in methods was maintained throughout the process. Kamal *et al* provide a clear exposition of their methods which persuaded me of the value of a grounded theory methodology.

(iii)(a) Carlsson *et al's* (2009) work explored women's experiences of being admitted to hospital during the latent phase of labour in order to gain an understanding of how women who seek care at an early stage experience the latent phase. The primary source of data were transcripts of data with 18 women, including primigravidae and multigravidae with uncomplicated pregnancies. The aim was to contribute to knowledge through the development of theory in relation to the research question. Hence a method was needed which specifically explored the phenomenon from women's perspectives.. The authors identify a clear gap in knowledge- no previous studies have explored women's experiences of the latent phase or women's reasons for seeking care during this phase of labour. This inductive approach, which involved exploring a topic with no predetermined theory or framework, analysing data and the use of literature to structure the analysis was clearly related to my own study.

The particular value of Carlsson and colleagues' work in relation to my study was their clear and concise definition of the problem to be explored. The researcher was a clinical midwife and her previous knowledge and experience of the study context enhanced the theoretical sensitivity during data collection, analysis and theory development. As Schwartz –Barcott and colleagues (2007) say- such knowledge assists in conceptualising the data and offers a vital link to theory development. This resonated with my own experience as a former clinical midwife.

In line with Constructivist Grounded Theory (Charmaz : 2006: 2014) there was a particular focus on what the women in Carlsson and her colleagues' study said. They were encouraged to talk freely and listened to actively. Attention was also given to other topics raised by the woman and identified as important by her. This approach is in line with Charmaz' constructivist approach which relates to exploring issues of importance in participant's individual situations, context and time which reflect the participant's way of thinking . This is what Charmaz and an applied example of the constructivist approach has to offer other qualitative researchers.

The authors' exploratory approach generated rich data grounded in women's experiences. For example, 'Could you please tell me about your experiences after you arrived at the hospital?' (Carlsson *et al* :2009:174). Women were able to influence the direction of the research and focus on what was important to them. This approach informed my own interview schedule.

The constructivist researcher develops the emerging theory which reflects both researcher and participants' viewpoints. 'Handing over responsibility' to professional carers emerged as the central theme in the data. Together with the central theme, five categories formed a conceptual model of women's experiences (Carlsson *et al* :2009:175). The authors provide a clear exposition of women's experiences of early labour and what it meant to women admitted to hospital during the latent phase. Thorough analysis of the data revealed new insights which contributed to the body of knowledge

and could improve women's care. Although guidelines are not alluded to in Carlsson and her colleagues' work, nonetheless it provided me with a structured framework to conduct my study. It was potentially transferable because it explored women's experiences of their maternity care about a phenomenon that was previously unknown using a constructivist approach.

(iii)(b) Carlsson *et al* (2012) build further upon their (2009) work. The authors' (2012) study explored how women who remain at home during the latent phase of labour experience the period from the onset of labour until admission to labour ward. It aimed to understand how early labour is experienced and coped with without professional support. 19 primigravid women with uncomplicated full-term pregnancies and spontaneous onset of labour were purposively selected for the study from the birth register postpartum.

The interviews commenced with open ended questions, for example 'Could you please tell me your thoughts and feelings when you noticed your labour had started?' This was followed by another question 'Could you please tell me what you did?' (Carlsson *et al* :2012: 87). Each interview was fully transcribed manually before the next one. In line with grounded theory, this meant that data analysis commenced straightaway -something which informed my own study. It meant that as my analysis was conducted, new questions emerged and could be followed up in subsequent interviews, thus providing me with a sense of direction for the next interview.

In line with Constructivist Grounded Theory, the authors used initial, focused and theoretical coding as well as memo -writing (Charmaz:2006). The authors constructed a 'core' category, 'Maintaining power' that is, the central part from which all other categories can be subsumed. 'Maintaining power' meant that women could elect to remain in their home environment with the associated freedom that would have been denied them in hospital (Carlsson *et al* :2012). These stages in the analysis were useful to my study, but my analysis generated two main thematic categories which were

interrelated, that is, I slightly adapted Carlsson and her colleagues' methods to fit my analysis of findings.

What was particularly valuable about Carlsson and her colleagues'(2012) study was its' power to evaluate Constructivist Grounded Theory by credibility, originality , resonance and usefulness (Charmaz:2006; 2014). The following points were useful in my own study:-

(A)Credibility.

In order to be credible, analysis of findings should demonstrate "intimate familiarity' with the topic being investigated '(Charmaz: 2006:181). Carlsson and her colleagues (2012) achieved credibility by adhering closely to the method, that is, using all coding steps and collecting data to saturation point. As Charmaz (2014) says, one of the advantages of grounded theory offering guidelines is knowing how to proceed- something that is valuable to a novice qualitative researcher.

(B)Originality.

Grounded theory is frequently chosen when little is known about the research topic. In this respect, Carlsson and her colleagues (2012) say that most previous research has focused on women's experiences of their care during labour and birth. The authors make clear that the originality of their work is a better understanding of the ways in which women cope without professional help before going to labour ward, that is, the period spent at home is of great interest. This is because if women are encouraged to remain at home during this time, then more knowledge of how to best support them is needed (Carlsson *et al* :2012). They make a clear link between their analysis of findings, the implications for practice and the need for further research in this area. Their framework helped inform my study.

(C)Resonance.

Charmaz suggests that credibility and originality in grounded theory lead to resonance (Charmaz:2014). As Carlsson and her colleagues(2012) say,

because their study's findings are grounded in data and their categories include a full range of meanings, resonances are highlighted. This helped me understand the importance of including a range of women's experiences fitting the categories until data saturation was achieved and the subsequent grounded theory I was seeking to develop.

(D)Usefulness.

Grounded theory should produce a theory that is useful. Carlsson and colleagues' (2012) suggest their findings could inform antenatal education offered by public health services. Charmaz (2006) suggests that a useful grounded theory offers interpretations that can be used in people's everyday lives. This made me think about how my analysis of findings could help inform recommendations in guidelines to improve women's care. In addition, consideration should be given to how they might impact on clinical practice and their contribution to future research. An example of this is an exploration of low-risk women's experiences of their care based on recommendations in guidelines in a community location.

Together with original work by Charmaz, these applied examples of Constructivist Grounded Theory show that this is a method well suited to gaining an understanding of what is going on in social processes and keeping the participant's story to the forefront. The method also acknowledges subjectivity, that is, the findings are interpreted through the researcher's interaction with the social context as well as the participant's views(Charmaz:2006).

(d)Objectivist Grounded Theory.

Objectivist Grounded Theory differs from the Constructivist approach in that it treats the data as real and eliminates from the analysis the social context from which the data emerge and the researcher's influence. It presupposes an unbiased researcher, who, in the conceptual sense, assumes that the data are representative of objective facts from which the

researcher discovers and develops a theory , that is, it contrasts with my interpretivism. In the systematic process of Strauss and Corbin (1990; 1998), the researcher seeks to develop a theory that explains a process or action on a topic. Although it has limited flexibility, it places less emphasis on personal values, assumptions and hidden realities than on the research methods. Nonetheless, the findings of a grounded theory study are not definitive. Rather, they are verified throughout the course of the research study (Strauss and Corbin:1998).

I sought a theory that was less prescriptive but addressed multiple realities. The theory should also aim to include in the analysis the complexities of participants' experiences, whilst the researcher maintains an (inevitably) non-neutral but nonetheless not separate stance. It was for these reasons that I rejected the Objectivist Grounded Theory approach.

My empirical study data.

(ii) Data collection.

With participants' consent, the interviews in my research study were audio-recorded. One of its advantages is that there are no limits on the number of times the researcher can return to the data in its original form. It also enabled me to maintain eye contact with the participant throughout the interview. I made the decision to stop after completing 20 interviews. This was because after 18 interviews, no new themes were emerging. This is termed theoretical saturation (Stern:2007). It was not related solely to sample size. Rather, the data collection needed to be sufficiently comprehensive in terms of breadth and depth to generate and support my analysis.

(iii) Data transcription.

The interviews were transcribed *verbatim* in full by myself. Throughout the process of data collection, transcription was completed at the earliest opportunity. This is thought to contribute to data integrity and minimize

perceptual bias (Sacks:1992). I was able to note and subsequently explore nuances of meanings and processes that might be overlooked by another person. For example, emphases of certain points, pauses, expressions of emotion and occasionally even anger were noted. It also enabled me to get a sense of the data for analysis at an early stage.

(iv)Data analysis.

Charmaz's Constructivist approach places greater emphasis on participants' views and experiences than on research methods. Nonetheless, she describes the process of collecting data, coding, writing memos and the use of theoretical sampling (Charmaz:2006).

I chose to carry out the process of transcription, coding and analysis manually. There are debates within qualitative methodological studies about the use of CAQDAS(computer- assisted qualitative data analysis software) and its advantages of speed, consistency and capacity to support the researcher's own cognitive efforts. However, as Macmillan and Koenig (2004) say, although a program may facilitate the user's development of a theory, it is the program's user whose responsibility it is to analyse the data and develop theory.

Stages of analysis.

Stage One. Early coding.

The transcribed data were stored in file folders with index cards. The initial stages of the process consisted of reading and re-reading the interview transcripts word by word, line-by-line and applying initial codes. This is defined as 'open coding' (Berg:1989). Coding is the pivotal link between gathering data and eventually developing a theory to explain the data. This was the first step in defining what was in the data and thinking about what it might mean in the context of recommendations in clinical guidelines.

During the early stages of my analysis, I treated this as a task, but after four interviews it became apparent that certain themes were emerging. Hence my preliminary data analysis began early. The intention at this stage was to start creating categories which I anticipated would need to be re-worked and refined at a later stage. As Charmaz says 'Initial codes are provisional, comparative and grounded in the data. They are provisional because you aim to remain open to other analytic possibilities and create codes that best fit the data you have' (Charmaz: 2014: 117). Line-by-line coding gave initial insights on the data and was the process by which I made some inroads into defining and categorising my data. Line-by-line coding forced me to keep studying my data, interact with it, consider its relationship to recommendations in guidelines and remain attuned to participants' experiences.

Modifying Grounded Theory. My methodology.

My analytical process went beyond collection, transcription and analysis of interview data. Rather, my distinct approach was the juxtaposition of recommendations in clinical guidelines with individual women's quotes. The aim was to conceptually link the recommendations in guidelines with my research question and explore women's experiences of their care. The rationale for my approach was to ensure that my analysis was conducted *with* the guidelines and not about them.

Melia (1997) has argued that in all probability, no-one employs a grounded theory approach in a pure sense. Constructivist Grounded Theory promotes a flexible adaptation of grounded theory processes in which the contributions of participants and researcher help develop and construct a theory (Charmaz:2006).

There were challenges to be negotiated. Prior to commencing data collection, I had not considered the use of recommendations in guidelines as an interpretive possibility. I had conducted a substantial part of my

literature review prior to commencing data collection and the literature informed my process of enquiry. However, after the first few interviews, I found the guidelines prompted ideas which provided a specific focus for my analysis. I then developed a coding frame in order to enhance the analytic potential of the data.

The initial stage of analysis identified 95 codes that arose from coding imprecisely. Clearly, 95 was an unworkable number of codes. The process needed to become more sharpened and focused in order to be useful analytically. A further point is that I named the codes which carried a risk that my own preconceptions might cloud my judgement. The Constructivist approach aims to develop an understanding of participants' views and experiences (and involves delving much further than coding alone). With this in mind, it was very important to remain open-minded to emerging themes and scrutinize the data for possible meanings.

Stage Two. Focused coding.

The next step consisted of careful re-reading of the data to ensure that the main categories covered the original codes. This is to ensure that the researcher develops an understanding of and the meaning of the data as part of the methodological process (Silverman: 2005; Polit and Beck :2008). Many of the 95 codes became superfluous at this analytical stage. This was not solely because they did not recur several times across the dataset, but because after deliberation they were irrelevant, or sometimes they replicated something that had been better articulated elsewhere, that is, they did not add to my analysis. An example of this is something I classed as the wider effect of the guideline. For instance, some women were closely monitored which warranted frequent hospital attendances. One participant expressed her frustration about car parking congestion on the hospital site, but suggested that when weighted against what she regarded as expert care, the issue ceased to matter. I reduced, refined and subsequently re-combined the categories that produced my grounded

theory. 'Focused coding' Charmaz suggests, requires the researcher to make decisions about which of the initial codes will make the most significant contribution in an analytical sense (Charmaz:2006).

Throughout, I tried to remain alert to what each category was intended to represent, that is, trying to define what was happening in the data and its relationship to recommendations in guidelines. Drawing upon the constant comparative method aligned with grounded theory, not only did I need to think about the relationship between slices of data to explore similarities, variations and differences, but also the relationship between my data and guidelines. Hence the main challenge was to integrate them as part of an iterative and dialectical process. I treated the codes as building blocks from which explanatory frameworks could be constructed. It followed that I had to think particularly hard about condensing the numerous codes into categories and subcategories. This step in the process involved labelling sections of text, their relationships with each other and recommendations in guidelines. An example is women's different ways of expressing their wish not to make decisions independently and the wider recommendations in guidelines that women should have the opportunity to make informed decisions in partnership with professional carers (NICE:2008).

I condensed and juxtaposed data with recommendations in guidelines. The advantage of this approach was that it gave me an early sense of the direction in which my research might progress through a new analytic lens. As the interviews progressed, adapting guideline recommendations as part of my analytical process helped further structure my coding and subsequent analysis of the categories derived from the initial codes. In line with grounded theory, I identified emergent themes and refined subcategories with the overall objective of developing a theory. This led eventually to a reduction in the codes from 95 to between 20 and 30 and after further deliberation to two main thematic categories and their associated subcategories.

Stage Three of the process forced me to think again about what had emerged from my main thematic categories and subcategories and how they might be linked. For instance, I identified codes in the subcategories that shared commonalities. (An example is included in my Analysis Strategies, Appendix(iv)). This led me to think about further refining the main thematic categories which led to my final theory.

My process of adaptation of Constructivist Grounded Theory brought into focus the relevance of the guidelines' recommendations and enabled me to ask a wider range of questions about the data which helped shape my analysis.

SECTION THREE.

Reflexivity and reflective analysis.

I referred to the role of reflexivity in Section Two (c) of this Chapter.

Observations recorded in a research diary.

During the initial planning stages and throughout the interviews, I made written notes about my personal experiences. Returning to the clinical arena with a new role of researcher had its own advantages, problems and pitfalls.

Prior to and throughout the interviews, I made formal memos and notes in a fieldwork diary. A diary which documents events and concerns as they arise is seen as a *bona fide* method of enhancing the research process (Graneheim and Lundman:2004; Silverman and Marvasti:2008). As part of the reflective process, the account should be sufficiently detailed to demonstrate the researcher's engagement with the research, involving self-criticism and self-appraisal (Hall and Callery:2001). The diary helped not only to reflect upon and address any problems, but became a meaningful source of data which contributed towards my analysis.

In Section One, Part One of this Chapter, I alluded to the initial slow recruitment experienced during my early days at the study site. During that time, I was reliant upon members of potential participants' caring team to initiate approach for the research study. There were days when I was seated in the clinic which was an opportunity to make observations. Observation commenced before the data collection and analysis, although this was largely unrecognised at the time.

I became quite interested in what Strong (1979) refers to as the 'ceremonial order' of the clinic. Although there were several educational resources relevant to pregnancy and birth on display, I observed that few women – even those attending unaccompanied, used them. Most appeared focused on healthcare professionals and – interestingly - volunteers identifiable by a simple tabard and name badge. There seemed to be a strong culture of what could be summed up as 'You lead, I follow', that is, order was very apparent. Retrospectively, during data analysis, I found that this organisational culture pervaded the rubric of women's care. An alternative explanation might be that women were merely behaving courteously and they attach importance to an efficient appointment schedule and being seen in timely fashion.

As a former midwife, I was reasonably well accustomed to talking at some length to pregnant women. This gave me some sense of 'insider-ness', despite the fact that I had never practised as a midwife in the NHS Trust hosting the research. However, there were occasions during the first few interviews when I felt there was a risk of losing focus by becoming immersed in thoughts about practice issues and it was difficult to pull the interview back on track.

Most women offered detailed and illuminating accounts. Others were more reticent. This is understandable, in the face of an interview with a stranger in a hospital environment. Rapport needed to be developed very quickly, so

as to try to maximise participants' responses. Notably, for both participants and researcher, an interview could be seen as an unnatural situation when compared with a clinical consultation, the latter of which has a therapeutic function (Birch and Miller:2002). The interview is for the advancement of knowledge and is unlikely to benefit the participant. Women were more likely to engage in dialogue if a particular issue had importance and relevance for them. Some participants' accounts were about particular healthcare incidents. Inevitably, this had implications for the general focus of the interview and I had to balance an understanding of the participant's account with the task in hand. It sometimes became necessary to steer the course carefully as the narrative tended to meander, but there were instances when this led to something that was relevant, interesting and even unexpected. Premature interruption would have disrupted the flow of the woman's account .

There were instances of women providing what could be seen as socially acceptable answers to questions. Silverman warns against 'identity work' in which the researcher presents a particular persona - maybe as a response to the identity presented by the researcher or the perceptions the participants have of the researcher (Silverman:2006). Issues can arise from participants' perspectives. For example, it was one woman's perception that I was 'from the government' and that my academic supervisors were 'government officials'. Despite reassurances to the contrary, she seemed anxious that she might give incorrect answers and I felt her hesitancy restricted the flow of the interview.

Conclusion.

This Chapter has set out the methodological approach underpinning the study. I have tried to identify and explain what I perceived were the strengths and limitations in the procedural steps I followed and have set out my epistemological and ontological positions.

I have tried to justify my choice of research methodology. This included the application of Constructivist Grounded Theory and how other studies informed my own research study and how my adaptation of grounded theory would provide the theoretical underpinning to explore women's experiences of their care based on recommendations in guidelines.

My reflective analysis demonstrates how my own position and interactions influenced my interpretation of the study data.

As we shall see, my analysis and observations frequently do not rely on spectacular accounts (although there are some compelling and poignant participants' quotes which form a rich source of data). Rather, what could be seen by some as apparently obvious acquires new meaning. Chapters Four, Five and Six of this thesis will present an in-depth analysis and my interpretation of the 'Findings' from the empirical research study.

Chapter Four.

Findings (i).

Pregnancy and birth: a time for new knowledge.

Introduction.

The purpose of this thesis is to gain an understanding of how the recommendations in maternity care clinical guidelines are experienced by pregnant women and their impact on women's autonomy. This Chapter is the first of three findings Chapters which presents findings from an analysis which explored women's accounts of their experiences gathered via a qualitative interview study. The analysis relates these experiences to extracts from guidelines that were relevant to particular themes in the data and provide interesting revelations about how women express their autonomy.

Pregnancy and childbirth are significant life experiences and a time for new knowledge for women. Two main thematic categories emerged from my data analysis. First was women's limited pregnancy and birth knowledge. The subcategories of making sense of the unpredictable, needing to feel cared for, the need for personalised information, taking things as they come and asserting will help explain it further. Second was the importance of women's interactions with trusted healthcare professionals. This is interconnected with the knowledge asymmetry between women and their professional carers. The subcategories of the need for timely information, deciding together, the difficulty in resolving a dilemma and the need to confer and confirm will help explain this finding further.

Pseudonyms are used when quoting from the data. I will support my arguments with reference to the relevant literature. I aim to show how my interpretation is reasonable and meaningful. As I explained in Chapter

Three, my analysis is informed by adaptation of the Constructivist Grounded Theory approach (Charmaz:2006).

Updated guideline recommendations.

*Amongst other guideline recommendations, this Chapter refers to guidance from the following:-

1. *Diabetes in Pregnancy. Management of diabetes and its complications from preconception to the postnatal period.* NICE Clinical Guideline 63 (2008).

This guideline was updated in 2015. Its title is unchanged and the current version is NICE Guideline NG3. The guidance I have quoted and juxtaposed against **Extracts 4.1, 4.2, 4.5, 4.6 and 4.7** relate to the recommendations at the time of conducting the empirical research study in 2013.

The current guidance has been slightly amended. For reference, it is documented as {**NEW 2015**} and quoted following the 2008 guidance.

2. Green-top Guideline Number 29. *Third and Fourth Degree Perineal Tear Management.* (RCOG:2007).

This guideline was updated in 2015. Its title and number are unchanged. The guidance juxtaposed against **Extract 4.12** is unchanged.

3. *Intra-partum care. Care of healthy women and their babies during childbirth.* NICE Clinical Guideline 55 (2007).

This guideline was updated in 2014. Its title is unchanged and the current version is NICE Clinical Guideline 190. The guidance juxtaposed against **Extract 4.19** is unchanged.

Research question to be explored:-

How are the recommendations in maternity care clinical guidelines experienced by pregnant women receiving maternity care?

Data analysis.

My analysis revealed two main thematic categories:-

- 1. Women's limited pregnancy and birth knowledge.**
- 2. The importance of interactions with trusted healthcare professionals.**

1. Women's limited pregnancy and birth knowledge.

My analysis revealed a knowledge asymmetry between women and their professional carers. Knowledge covers a wide spectrum which includes not only information, but understanding and intuition relating to the physical and psychological aspects of care (Narney and Lyerly: 2010). Had women possessed and been able to apply that knowledge to their own situation, there is a likelihood they would have been able to exercise their autonomy more meaningfully. Unsurprisingly, my analysis suggested that this occurred most frequently when women were asked to make important decisions during pregnancy and childbirth. My analysis suggested that women's limited knowledge was strongly related to their need to confer with trusted healthcare professionals who were seen as able to help secure a good pregnancy outcome.

The five subcategories which emerged from the main category 'Women's limited pregnancy and birth knowledge' were :-

- (i) Making sense of the unpredictable.
- (ii) Needing to feel cared for.

- (iii) Need for personalised information.
- (iv) Taking things as they come.
- (v) Asserting.

Making sense of the unpredictable.

Women report finding pregnancy and birth unpredictable. The work of Norton(1975) suggests that uncertain events contain one or more of the following dimensions-vagueness, lack of clarity, ambiguity, unpredictability, inconsistency, probability (or lack thereof), multiple meanings and lack of information. I will show how unpredictability affected some women's decisions and how this impacted on their autonomy.

The following retrospective account was selected because it comprehensively illustrates the main category of women's limited pregnancy and birth knowledge and its effect on maternal autonomy. The woman's use of metaphor adds a deeper layer of meaning to the analysis.

The Guidelines Manual states that guideline recommendations should reflect the strength of the evidence. For example, a recommendation that should (or should not) be used should be framed in directive language such as 'Offer' (or 'Do not offer') 'Advise, 'Measure' or 'Refer' (NICE :2014). My analysis suggested it was the offer of a choice of options that contributed to this woman's dilemma.

Participant:- Catrin.

Gravida 2. Para 1. 37 weeks gestation. Gestational Diabetic. Previous IOL .

Guideline.

Clinical Guideline 63. Diabetes in Pregnancy. Management of diabetes and its complications from pre-conception to the postnatal period (NICE:2008).

Guidance:-

Offer Induction of labour after 38 weeks if the baby has grown normally (NICE:2008).

***For reference, the updated guidance reads as follows:-**

Diabetes in Pregnancy. Management of diabetes and its complications from pre- conception to the postnatal period. NG3 (NICE:2015).

Guidance:-

Advise women with gestational diabetes to give birth no later than 40+ 6 weeks, offer elective birth (by Induction of labour or by Caesarean section if indicated) to women who have not given birth by this time {NEW} (NICE: 2015).

Background to the 2008 guideline's recommendations.

Gestational diabetes is characterised by hyperglycaemia which presents for the first time in pregnancy. It is associated with an increased risk of macrosomia, shoulder dystocia, hypoglycaemia, Caesarean section and future maternal type 2 diabetes (Langer *et al*:2005). There is also an increased risk of stillbirth associated with gestational diabetes (Schmidt *et al*: 2001). However, as screening, diagnosis and treatment have developed, the link between gestational diabetes and perinatal mortality has become less clear. When considering the best time for delivery to improve perinatal outcomes, the risk of stillbirth should be appropriately weighted against the risk of infant mortality and morbidity.

Extract 4.1

Researcher: *You were induced at term last time?*

Catrin: *Yes, It was this slope I was on, I think. I knew with Induction of labour, there's one intervention, then another – this slippery slope and I thought going in there I'd have to do a little more than put the brakes on here and there. So it was a little bit disappointing to me that I found myself not in as much control as I thought I would be in. I feel there's nothing I could have done other than what I did and what the hospital recommended. They made me feel I was in good hands.*

I will make the starting point of my analysis what the metaphor of the 'slope' means for maternal autonomy. The woman's use of metaphor suggests she feels insecure and has a deeper meaning to convey than could be expressed in simple language. As Patton (2000) says, metaphors can have a powerful effect and convey great depth of meaning in a single phrase. The woman shows awareness of the interventions that might impose constraint and suggests she broached the subject tentatively. Her account suggests she perceived the slippery slope as a downward spiral that could slip out of her control. Her expectations concur with objective probabilities, as there is a likelihood she will experience medical intervention which she seems to equate with loss of control. This is illustrated in her referral to applying the brakes which suggests an assertion of her autonomy.

The offer of IOL creates a dilemma, but she concedes that the consequences of relinquishing her wish for spontaneous labour are not hugely disappointing. The processes women go through when offered a choice of alternatives about their care are complex. As Tracy (2006) says, when women are offered an intervention such as induction of labour, they are not routinely informed of what might lie within that option. **Catrin** had not experienced the intervention and the problem was understanding what

may lie within the option and its consequences. However, even if she had those assurances, she would be unable to predict what might or might not be directly applicable. As Kirkham says ‘Coping with uncertainty is a major issue in reproductive health and is emotionally demanding Some questions cannot be answered or cannot be answered at the present time’ (Kirkham: 2009:236). This has implications for guidelines which stress the importance of thinking about the meaning of the recommendations in individual cases (The guidelines manual: NICE:2014). My analysis suggests that the woman defined her own priorities from the offer of induction. It became *less* a struggle to preserve autonomy and *more* a concern of where the procedure might lead.

In Chapter Two, Section Three I outlined first, the liberal model of autonomy in which the decision-maker is characterised as a self- governing agent and second, the relational model of autonomy in which the decision-maker is characterised in relation to her social context and her relationships with others. **Catrin’s** case demonstrates deference to healthcare professionals- although the woman refers to them as ‘the hospital’. Nonetheless, her account suggests that professional input was at least as important as her own wishes.

However, it was not her expectation that events *would* proceed according to plan.

She continues:-

Extract 4.2

Catrin: *There are other people you talk to, other women, friends who are pregnant – everyone has their own experience. Foul stories. Great stories. Nobody’s pregnancy it seems goes according to plan. I guess- that was the only thing I expected – it turned out to be true, but everyone goes in with a plan and the plan never really goes as expected.*

It is a striking feature of her account that the only thing she expected was that things would not turn out as expected which suggests that she may not have pitched her expectations particularly high. Autonomy is not a fixed concept and difficult to maintain. As Lindley puts it 'To be perfectly autonomous is impossible for a finite intelligence'(1986:69). Decision points during pregnancy and birth require a revisiting of past decisions or new decisions depending on the progress of events.

The following retrospective account was selected because it has a different focus in relation to my research question. It grounded the woman's uncertainty with the timing of events associated with IOL which for her was challenging.

Participant:- Charlotte.

Gravida 2 . Para 1. 33 weeks gestation. Gestational Hypertension.

Guideline.

Clinical Guideline 107. Hypertension in Pregnancy. The management of hypertensive disorders during pregnancy (NICE: 2010).

Guidance:-

For women with gestational hypertension whose blood pressure is lower than 160/110 mm.hg. after 37 weeks, with or without antihypertensive treatment, timing of birth and maternal and foetal indications for birth should be agreed with the woman and senior obstetrician (NICE:2010).

Background to the guideline's recommendations.

Hypertensive disorders in pregnancy are associated with risk for the woman and foetus. They may result in maternal morbidity and maternal death in some cases. A UK study found that a third of severe maternal morbidity was the result of hypertensive disorders (Waterstone *et al*:2001).

It has been reported that 1 in 20 (5%) stillbirths in babies without a congenital abnormality occurred in women affected by pre-eclampsia (CEMACH:2009) (Confidential Enquiry into Maternal and Child Health). Furthermore, SGA (small-for-gestational age) babies (less than the tenth centile of birth weight for gestational age) which occur because of placental insufficiency occur in 20-25% of preterm deliveries and 14-19% of term deliveries in women affected by pre-eclampsia (Ramussen and Irgens :2006).

Extract 4.3

Researcher. *Is there any likelihood of induction this time?*

Charlotte. *Probably.*

Researcher. *How do you feel about that?*

Charlotte. *(Sighs) All right about it. I just think, it's such a long process being induced, and if it doesn't – it took three days for my waters to break last time and it's such a long process to go through all those contractions and actually be - have your labour started. I think that's long- a bit of a weary thought - like- that's how I feel. Hopefully, it will just come on its own, but I would go with the right decision at the time for whatever's going on. So if it was my blood pressure or the indicators for pre-eclampsia, I think – yes, and somehow that baby has to come out - because it's detrimental to my and its health, so I would **never** (Woman's emphasis) go against a*

*decision that's going to harm one of us; that I **totally** (Woman's emphasis) understand.*

Questions about IOL are complex. This is reflected in the guideline 'Induction of labour' which explains that induced labour may be less efficient and more painful than spontaneous labour. This is because synthetic hormones are needed to start labour and keep contractions going. There is also a greater likelihood of epidural analgesia and assisted delivery (NICE:2008). These factors may affect women's experiences. **Charlotte** suggests it is not so much the appropriateness of the induction, but her perception of the effectiveness of methods of induction which is challenging, that is, she refers to her decision to accept induction culminating as a 'weary thought'. This forms the starting point of my analysis. She visualises her progress in labour in terms of her expectation of the length of time that could be involved. However, experience gained last time cannot resolve the uncertainty she feels. My interpretation is that it leads us to ask whether there is a mismatch between women's and professional carers' perception of time, or whether the woman wants her labour to be more closely monitored by healthcare professionals.

The woman calculates risk in terms of danger/safety rather than on statistical evidence in guidelines. She is clear about the risks associated with pre-eclampsia and is adamant she would not put foetal or maternal welfare at risk. She does not refer to the process of induction itself being risk-laden. Rather, she questions the procedure's effectiveness and if she has a wish, it is to make sense of the timescale involved. The Hypertension in Pregnancy guideline's recommendations refer to the timing of birth (NICE:2010). This refers to the idea of planning in advance which contrasts sharply with the woman's perception of time which makes her autonomy difficult to maintain at a constant. Just as questions surrounding IOL are complex, women's previous experiences can inform the decisions they make.

Autonomy for this woman is not a relentless pursuit of her own goals. No-one can guarantee the length of labour. However, although labour is unpredictable, it would be nonsensical to believe that Caesarean section is problem-free. The woman suggests it is not so much the decision that eliminates risk so much as the decision that minimises risk as she perceives it.

She continues:-

Extract 4.4

Charlotte: *I think people are a lot more mindful about pushing people down one particular route than another, so I think healthcare professionals might go- 'Try x-y-z, you choose sort of thing', rather than saying- 'This is the best option and you're going to have to go along with that'. That said, with the pain relief in labour you have to have some drugs at certain times, so you have to rely on the midwife or doctor to tell you. You're having the physical symptoms in your body and you're also living through it... Erm, whatever happens, happens. I quite like hospitals, they're good, because I feel looked after. You rely on these people when the time comes.*

Needing to feel cared for.

My analysis suggested that women seem to understand that their autonomy will be compromised when in a situation of painful childbirth. The longevity of events and analgesia in labour adds to **Charlotte's** dilemma. She may feel that it will be difficult to reconcile what she thought when pregnant, what she wanted when pregnant and what occurs in labour. She refers to 'living through it' –portraying a sense of labour being very personalised. This raises the need for personally tailored information and decisions which may be warranted in view of her revised situation, that is her autonomy is not a constant. On the one hand, her referral to 'x-y-z' suggests she perceives

she has a choice. On the other hand, her account suggests an awareness that certain restrictions on drug therapy during labour are warranted- hence the need to revisit her decision if appropriate and defer to professional help.

In Chapter Two, Section Three, I suggested that there is inherent ambiguity about how partnership in the wider recommendations in NICE guidelines translates into women's experiences of their care. The woman suggests she associates safe passage with healthcare professionals who have authoritative status. We may infer that part of feeling cared for means that the healthcare professional should explore with and capture the woman's individual perspective of time. This may reveal new insights on the information formally documented in the woman's case- notes and provide a more meaningful basis for decision-making.

My interpretation of **Catrin and Charlotte's** accounts suggested they shared the same stance, that is, they knew on a subjective level that IOL might be required. Belenky *et al* (1986) refer to this as 'connected knowing'. This is characterised by drawing upon others' experience and knowledge. Through a process of interaction with their professional carers, women can start the process of measuring personal knowledge against others' authority and develop their own constructed (or reconstructed) knowledge of childbirth based upon personal lived experience. Arguably, if women are open to alternative explanations at the outset, then the change in circumstances represents less a threat to autonomy.

It also leads us to question whether partnership decision-making recommended in guidelines can be realised. There are women who unwittingly surrender control early in pregnancy. For example, a healthcare professional confirms the pregnancy and arranges the initial Booking-in appointment. Some women want this to happen. There are also grounds for saying that the decision both women face is one of several options, that is, this is not the first occasion they have been asked to choose. For

example, they have already chosen whether to accept or decline antenatal screening tests. Their illustrative experiences suggest that if they have a wish, it is that professional carers respect and explore their individual concerns in response to changing events. These are some of the complexities inherent in guidelines. The situation women find themselves in demands some degree of reasoning that tests out any prior expectations and concerns, that is, women do not enter pregnancy with a blank slate. My analysis suggests that women's autonomy is at risk if they are denied the opportunity to build these fully into their deliberations. The woman's autonomy can be enhanced by drawing on her experiences and expressing her views, that is, engaging in the decision-making process, not simply the act of choosing.

My analysis suggests IOL raised further concerns which women had to factor into their deliberations. **Catrin** is a gestational diabetic. Arguably, induction was not chosen by her in the same way as, for example, a woman chooses a home birth. This is an important point in understanding autonomy and choice. Home birth is an option frequently chosen because it includes specific elements of care that women like. Examples include familiar surroundings and the freedom to invite people of their choosing to attend the birth. Women do not choose IOL for these reasons. The woman's decision to accept induction was not a self-selected option willingly *chosen* by her. Rather, she was guided into complying, based upon her understanding that it was clinically warranted. However, her acceptance is part of her autonomy.

Her situation had the potential to change several times- hence her referral to the 'slope', where it might lead and the impact on her autonomy. Induction might previously have been distant, but it became a strong possibility. Her thoughts turn to a revised set of goals.

She continues:-

Extract 4.5

Catrin: *I mean - I went into the whole pregnancy process thinking it would all be as natural as possible, so I felt like I needed to ask - 'Am I being pressurised into this?' I wanted to know exactly – 'Is this something that was going to be in the best interests of me and my baby?' I needed information in order to make a rational decision and (I'm kind of babbling on about this) - but I felt that's what I wanted. It's a very emotional thing-pregnancy, and you want to do the best for the health of this little creature – but it's difficult. But I felt trusting of them (healthcare professionals). I felt I made the best decision I could - that we could have made together.*

Her account suggests she is aware of restrictions on her autonomy, 'Am I being pressurised into this?' The 'slope' may be particularly troubling, but arguably, there are situations when no amount of information and planning will clarify the process. She reaches a turning point at which articulating her wishes becomes difficult. Her account suggests that her autonomy is variable and literally see-saws in response to the events that may (or may not) present themselves. She becomes aware that today's decision will become tomorrow's care. Greer (1999) suggests it is at salient points such as these that women find themselves on a conveyor belt and once on board it becomes increasingly difficult to get off. However, she does not resist the challenge presented to her. Rather, it was mostly tolerated which suggests that potential risk was a powerful lever in her decision.

The woman refers to trust in her professional carers. This usefully ties in with the second main thematic category to be presented in this Chapter. The work of Bluff and Holloway (1994) and Berg *et al* (1996) suggests that the need for women to trust their carers is most apparent during labour. However, **Catrin's** account suggests the importance of her interaction with

the doctor in a less acute situation. Her trust rested on a shared value, that is a good pregnancy outcome.

She continues:-

Extract 4.6

Catrin: *I eventually read through the guidelines regarding this, searching out information and so when I met with the doctor she said – ‘Well, yes, there is a choice, but there is a slight risk of stillbirth regarding people with gestational diabetes, so we feel it’s very safe for you to wait until term, diet controlled, but we don’t really have that much information to go on, considering- if you were to decide to go beyond term. So of course, most women decide that they don’t want to take even a very small risk and that it’s best to do this’. So, how can I ignore that?*

The woman suggests her response to the prospect of induction was to exercise her autonomy and conduct her own research. Nonetheless, despite reading the guidelines, she describes her interaction with the doctor in a way that shows she links trust with safety. There is evidence to suggest that as a society we have come to expect expert knowledge from healthcare professionals about pregnancy and birth (Stapleton:2004; Martin *et al*:2014). Even what might be seen as a simple matter in seeking information reflects a deeper confidence in the doctor, despite the fact that she alludes to gaps in scientific knowledge.

As the woman very neatly puts it:-

Extract 4.7

Catrin: *What I’m looking for is a more authoritative view. I need someone medical to parcel up the information for me.*

Need for personalised information.

It is significant that she says 'parcel up the information for me'. This reinforces the need for authority, thus ceding control. Her request suggests a sense of feeling overwhelmed if the information is incomprehensible. This finding supports the wider recommendations in guidelines 'Good communication between healthcare professionals and women is essential. It should be supported by evidence-based, written information tailored to the woman's needs' (NICE:2008:4). Information should be orientated towards the woman making an informed decision through a process of interaction with professional carers.

Other women expressed similar sentiments.

Participant :- Nia.

Primigravida. 29 weeks gestation. Uncomplicated pregnancy.

Extract 4.8

Nia: I've never been in hospital before, been healthy all my life. They always ask my views, but I've no idea what to expect and find it hard to ask questions.

Nia suggests that seeking her views, which is consistent with the wider recommendations in guidelines was a good thing, but should be tempered by the fact that pregnancy is a new experience and she has limited knowledge. She suggests that this makes it more difficult to exercise her autonomy.

Participant:- Jasmine.

Primigravida. 30 weeks gestation. ICP (Intrahepatic cholestasis of pregnancy).

Extract 4.9

***Jasmine:** The care I've been having feels right. It's been completely thorough, but then again I'm a complete beginner who doesn't have a clue about what she's supposed to be doing. When you're there for the first time you **are** (Woman's emphasis) quite child-like - you've got no reference, so... But this isn't just me, it's this little person we have to look after and it comes with a responsibility, doesn't it? I need to feel well for her (foetus) to be well. I'm having weekly blood tests to check my ALT (Alanine Aminotransferase Test) levels – they must know that's enough time if my levels start to increase - but if it meant coming in every day, I would be happy to do that. But they've been completely transparent and they do involve you. 'This is what your blood test is this week'. I'm a figures person, so I've been able to kind of map in my head how much up or down we are which for me is really comprehensive.*

Jasmine's account clearly expresses the theme of the maternal- foetal unit as one and her understanding of her own well-being relating directly to her foetus'. She refers to the personal usefulness of an enumerative blood test result. This was something that helped supplement her limited knowledge and contributed to her overall understanding of her situation. It was *less* any perceived inconvenience associated with weekly hospital visits and *more* this information that was important. Her compliance with the blood test regime may be an expression of her autonomy because the information she gleans is something she wants.

Participant:- Layla.

Gravida 2 Para 1. 28 weeks gestation. Attending VBAC clinic.

Extract 4.10

Layla: *Only when you're pregnant do you really experience what it's like not knowing. It's a good idea to have some idea of what you're talking about.*

Taking things as they come.

My analysis suggested **Catrin** re-evaluates the perceived risks and as part of a process creates new parameters. Negative aspects are to some extent overshadowed by getting a step closer to her dream, that is a healthy baby. This is part of her autonomy. She no longer attempts to steer through potential minefields and learns to do without previous wishes. The doctor's account became very legitimate and previous expectations surpassed. She arrives at a perceived point of safety with the security that she is being cared for.

The woman's revised, unspoken ideal becomes induction as an extension of the pregnancy process that is already managed. There is language in her account which suggests unease, but not resistance. The outcome of her deliberations falls within what she sees as reasonable proximity of her expectations and her autonomy is less affected. She has been guided into complying, but for justifiable reasons and does not express a wish for alternative arrangements. It may be that she has 'put the options to the test' and an awareness that she *could* have made an alternative decision preserves her autonomy. She may feel guided into thinking she has made her own decision. Of course, there is no way of determining the point at which a woman reaches her decision, that is, decision-making is not simply the act of choosing. She could continue to think about the situation, whilst acting outwardly as though a decision had been made. It may be her way of expressing her autonomy.

What lay ahead was for the most part 'unknowable' and my analysis suggested that the woman appeared resigned to this. She moves forward,

but in a way that feels safe to her, accepting that she cannot become an expert. For her, being in safe professional hands is preferable to asserting her autonomy. Her acceptance becomes part of a foregone conclusion – that one is controlled, at least to some extent by factors beyond one's control and this is necessary in the transition to motherhood.

From my own observations and listening to **Catrin's** account, it was my interpretation that she had almost lost herself - it might even be a form of retreat. Any previous expectations were unvoiced and ceased to matter greatly. It was my interpretation that a sense of calm followed which was an outcome not originally sought after. It is interesting that this was achieved in a hospital as opposed to a community location where there is more likelihood that healthcare professionals will be familiar to the woman. Her account suggests the need to maximise the effectiveness of each encounter during the care process. Options open and close. Retrospectively, if things go well, it may *become* the intervention that will not have mattered greatly, but that is something for the woman to determine.

It was not *all* women who typically approached IOL tentatively. This case was chosen because the woman gives alternative perspectives based on a previous negative experience:-

Participant :- Sarah.

Gravida 9. Para 6. 35 weeks gestation. Uncomplicated pregnancy.

Guideline.

Clinical Guideline 70. Induction of Labour (NICE:2008).

Guidance:-

Women with uncomplicated pregnancies should be offered Induction of labour between 41 and 42 weeks to avoid the risks of prolonged pregnancy. The exact timing should take into account the woman's preferences and local circumstances (NICE:2008).

Background to the guideline's recommendations.

There are several clinical circumstances which may indicate the need for induction of labour. These include, for example, postmaturity, pre-eclampsia and IUGR (intra-uterine growth retardation). Ultimately, the decision rests on whether it would be in the best interests of the woman, her foetus (or sometimes both) to continue with or end the pregnancy (Oleson *et al*: 2003; Caughey *et al*:2007).

Extract 4.11

Sarah: *Well, you always trust healthcare professionals – sort of. My last – I didn't like the care I received during my last delivery. I thought it was absolutely diabolical to be honest with you.*

Researcher: *Can you tell me more about that?*

Sarah: *Right, I was induced.*

Researcher: *Why was that?*

Sarah: *Well, because my waters had broken, I came in for a post-date appointment and was sent to delivery suite and the midwife said after examining me – 'You can come back tomorrow and be induced'. I had come to the point where, like most women, I just wanted it out and I'd never*

before been induced. They send you home with a thermometer. Had I known what it (the induction) was like I probably wouldn't have. It was absolutely awful. At first the drip didn't seem to be working - so she put it on the fastest it can go - to the max. I was only in labour for 50 minutes, so it was quick, but the pain isn't like a normal labour. Normally, it builds up which makes it more tolerable and you know it's going to get worse, but this just hits you full force ten on the pain scale. You don't get that build up - it was just horrible. I remember two surgeons came in and said 'Turn the drip off now or she's going to have to have a Caesarean section'. They turned it right down and I had him, but the pain of that..... I'm alright with pain, don't usually have much in the way of pain relief, but that..... I hated it with a passion and am dreading it. Although they discussed pain relief with me, so I wasn't ill informed, I just don't think they can tell you how painful quickly it's going to be. But you might go into labour naturally, so they're not going to put that fear into you. I have made up my mind, absolutely determined. In fact, it was the first thing I told my friend when I first found out I was pregnant. **Short Pause...** Obviously, I know there comes a point where your placenta is going to fail, so I'll soon be going into waiting mode, but at full term, I'll start. I will be doing everything in my power- running round the block, bouncing on the trampoline to get that baby out if I go over this time to avoid 'that'. **Further Short Pause...** I know there's other things they can do, but I don't want that. I'm sure I'll be fine, just fine- mine usually are.

Asserting.

Sarah knows there is a choice, that is, she has an *expectation* that induction may be warranted, but a very clear *preference* to avoid it. It was a focused event on her personal calendar that had a lasting impact and contributed to her need to assert some sense of control over events. For example, 'absolutely diabolical' and 'doing everything in my power' strongly suggest the need to take control of the situation.

A key point is that the natural rhythm she associated with her previous labours has been massively swamped by medical intervention. As she puts it:-

Extract 4.12

Sarah: *All the others perfect, but this.....*

Intervention resulted in a very rapid labour and delivery. Concurrently, as Nettelbaldt and colleagues (1976) say, she makes a distinct association between her past experiences and present situation influencing her experience of pain in childbirth. Her adverse experience exposed the inadequacy of the information she had been given, resulting in some degree of mistrust in healthcare professionals.

A significant feature of her account is her use of the metaphor 'waiting mode' and what that might mean. It suggests preparation is involved, namely her own expectant management with which she associates a sense of control. She is vehemently opposed to induction. When she says 'I'll start' it may be her way of putting into action a process that she has thought about with a view to getting closure, that is safe passage for her baby and herself. Some women want to exercise their autonomy to choose, but this may not be confined exclusively to options in clinical guidelines. She makes what Meyers (1989) terms a decision that is in harmony with her authentic self. This interesting finding needs further explanation. It does not mean that she makes her decision as a self-governing individual as in the liberal model of autonomy. Rather, in a relational sense she realises her goals through a life-plan and becomes the kind of person she wants to be. As Meyers says, the life-plan could include one's goals and interests, the relationships one wants to have and how one becomes the person one wants to be in realising those goals. This can be both episodic and programmatic (Meyers:1989). I suggest this is episodic, where the woman faces a specific situation and in response acts accordingly. It matters deeply

that she avoids an unpalatable situation. But an additional feature of Meyers' account is that the agent moves beyond introspection and considers how her behaviour may be interpreted by others (Meyers:1989). This is an important point as it is effective interaction between women and their professional carers that reveals the significance of the guideline's recommendations and the way in which it might impact on a woman's autonomy.

A further point is that she does not blanket all healthcare professionals as experts. Her comments suggest that her faith in her maternity care has been shaken as a result of a bad experience last time. An interesting feature of her account is that she states that healthcare professionals cannot adequately explain to a woman the intensity of the pain she may experience during labour, although she enumerates it as 'full force ten'. Although she expected pain, this suggests her labour was considerably more painful than anticipated. She wanted to be able to plan her actions. Even though this was beyond her control, had she been better prepared, her autonomy would be less affected.

Main thematic category.

2.The importance of interactions with trusted healthcare professionals

My analysis suggested that interactions with trusted healthcare professionals were highly valued by women and seen as a means of empowerment. Although not new in healthcare, my analysis ties this main thematic category in specifically with pregnant women's experiences of recommendations in guidelines. My analysis suggested the need to interact closely with professional carers was frequently related to women's limited pregnancy and birth knowledge, but there are other complexities which reveal new insights.

The four subcategories which emerged from the main category 'The importance of interactions with trusted healthcare professionals' are:-

- (i) Need for timely information
- (ii) Deciding together.
- (iii) Difficulty in resolving a dilemma.
- (iv) Need to confer and confirm.

The following case was chosen because it is a good example of a choice of alternatives and non-directiveness in the wording of the guideline's recommendations, which created a dilemma for the woman.

Participant :- Georgia.

Gravida 2. Para 1. 27 weeks gestation. Previous third degree perineal tear.

Guideline.

Green-top Guideline Number 29. Third and Fourth Degree Perineal Tear Management (RCOG:2007).

Guidance:-

All women who have an obstetric anal sphincter injury should be counselled at the booking visit regarding the mode of delivery and should be clearly documented in the notes. If the woman is symptomatic or shows abnormal anorectal manometric or endoanal ultrasonographic features, it may be advisable to offer an elective Caesarean section (RCOG:2007).

Background to the guideline's recommendations.

The risk of obstetric anal sphincter injury is 1% of all vaginal deliveries. Obstetric anal sphincter injury includes both third and fourth degree perineal tears. There are no systematic reviews or randomised controlled trials that indicate the optimum mode of delivery (RCOG:2007).

Extract 4.13

Researcher: *Have you had to make any choices in this pregnancy?*

Georgia: *Yes.*

Researcher: *Can you tell me about these?*

Georgia: *I had a third degree tear with my first pregnancy. They recommended I have a Caesarean section this time. They've offered it, so it's for a good reason, they don't do it for the fun of it. They haven't pushed it on me or anything, **it's all been left up to me.** (Woman's firm emphasis). So I have to weigh up whether to do it naturally again, or what to do. I'm 27 weeks now and I'm starting to get anxious. I haven't been told a great deal about it yet. I've read some leaflets and 'bumpf' (sic.) about all kinds of random things but I want them to go through it properly with me – details; what's going to be involved - things like that. I just want to know - will she (baby) be coming to me, or will they take her to do things? I just want to know what's going to happen, so I have it in my head. I have an appointment with the obstetrician at the end of the month, so I assume they're going to go through it all with me. I don't really know a lot about what's going to happen.*

Researcher: *Is that so you can mind map it, as it were?*

Georgia: *Erm..... Yes, but at the end of the day you have to concentrate on the baby and get on with it. It's been mentioned at most of my appointments, but there's been no pressure about doing it either way. I would like to think I could take a mid-line position – decide with the doctor, but I tend not to stand up for myself as maybe I could.*

Georgia is being asked to make a decision about the mode of delivery without the requisite knowledge of the finer details about Caesarean section. Women have previous experiences, existing expectations and their own wishes which provide the bedrock onto which any new information will fall. Beyond this, as my analysis has suggested, women draw out their own priorities for the birth. The offer of a choice - in this instance between vaginal delivery or Caesarean section is more complex than being presented with the option and invited to choose. Arguably, however, the woman has to deliver by one route or another and cannot exercise her autonomy by creating an alternative. She has read some information about Caesarean section, but her autonomy fluctuates when faced with uncertainties about what she might encounter. Her limited knowledge about Caesarean section is not the only issue. The wider recommendations in guidelines state that 'Every opportunity should be taken to provide the woman and her partner or other relevant family members with the information and support they need' (NICE:2008:4). However, the woman may have to exercise her autonomy in asking for it which her account suggests may be prohibitive.

The main issue is the decision to be made. Paradoxically, she says that Caesarean section has been recommended, then says the decision has been left entirely to her. The fact that professional carers have good reason is her justification of trust in her carers or it may be that she needs that belief in order to justify her decision and claim that decision as her own. The

crucial point is that supporting a woman *on her terms* - which may enhance her autonomy, differs from informing her about the available options and leaving her to make a decision as with informed choice outlined in Chapter Two, Section Three. O'Connor *et al* (2009) suggest that the idea that patients should be enabled to make informed decisions could be seen as a right step in encouraging their understanding of healthcare interventions and helping them exercise their autonomy. I suggest there is greater emphasis in guidelines on offering women opportunities to make decisions and less on enabling. Enabling women to choose places greater demands on professional carers' skills and time which is not always reflected in guidelines.

Need for timely information.

The woman's account suggests that not only does she want personalised information about treatment options, but in a timely fashion. At 27 weeks gestation she is starting to become worried. She has read what she refers to as 'bumpf', but what is absent is an explanation which responds to her specific concerns about Caesarean section which may be the very elements she needs to enable her participation in the decision-making process. This finding echoes **Catrin's** wish for personally useful information (**Extract 4.7**). **Georgia** suggests she wants the information now, but is obliged to wait until the end of the month. The point is that she would feel empowered if she was given the information she seeks according to *her* timely agenda. My argument is that her autonomy will be enhanced or restricted depending on the ways in which the skills of the healthcare professional can recognise and respond to the intricacies she raises. Such interactions help shape a different woman/ professional carer relationship.

Deciding together.

The woman's referral to a 'mid-line position' she associates with professional input is significant. Her account suggests she has relevant

questions which could be answered with a face-to-face discussion with the doctor. However, the prospect of being sole decision-maker and making a choice when she is inadequately informed seems overwhelming and may pose a threat to her autonomy. The work of Coulter (1999; 2002) claims that patients may either experience conflict regarding the decision or may feel abandoned by their professional carers which may compromise their trust in them. There is also a greater likelihood that they will regret their decision. The offer of a choice has perhaps legitimized the importance of the woman's perspective, but this should be tempered against her expectation of what in her view should *not* happen, that is herself as sole decision-maker.

Furthermore, the woman concedes that she finds it difficult to assert herself. Although there is no compulsion for her to decide, her emphasis that it had been left up to her suggests that her perception was that there was an expectation amongst healthcare professionals that she would want to decide for herself. Another explanation is that she is reticent about voicing her concerns about feelings of isolation because she assumes her views will not be tolerated, much less welcomed. Nonetheless, her perceived bewilderment suggests that taking control of the decision may alienate a woman in need of support.

The woman suggests she sees professional carers as authoritative figures with appropriate knowledge. However, there is nothing to suggest that she would want to enjoy equal status with them as some partnership models endorse. Far from being empowered, she suggests feelings of bewilderment which could be alleviated by professional involvement. However, it seems unlikely she would prefer to have *no* say and defer to the doctor. As set out in Chapter Two, Section Three, there are authors who have argued that some patients prefer to share decisions with their clinicians, that is, they consider the risks/ benefits/ comparisons of treatment options, state their preferences, ask questions and eventually reach a consensus (Gee and Corry: 2012; Nieuwenhuijze *et al* :2014). The

implications for healthcare professionals working with guidelines is to understand the different situations and time points during pregnancy when shared decision- making may be appropriate.

My contribution is understanding that promoting this woman's autonomy is not confined to building a trusting relationship and enabling her to make a shared decision with the doctor. Rather, because of her specific wish for timely information, it means thinking about the decision. Far from being a single detached decision, it is likely to involve a series of actions which current guidance does not capture. This could include formally inviting the woman's request for information, information- giving, exchange of views, responding to her concerns and the opportunity to deliberate between options. Furthermore, guidance does not make clear that the organisational context of maternity care means that the process may involve several professionals over a period of time. Therefore, in order to enhance the woman's autonomy, what is important is that each clinical encounter is recognised as part of an ongoing process (as opposed to episodic) and utilised to maximum effectiveness.

The categories that emerged about the importance of interactions with health care professionals and the need to share decision- making were reflected in other women's accounts. Women referred to their relationships between healthcare professionals in ways which show they rely on them and link trust with safety.

Other women summed up their experiences and hopes about their care by expressing a wish for healthcare professional involvement in their decision- making.

Participant:- Lauren.

Gravida 2. Para 1. 28 weeks gestation. Attending VBAC clinic.

Extract 4.14

Lauren: They've been really good here, looked after me. They've always asked us (partner and self) how we feel about things. That's what's made it a smooth pregnancy and I'm hoping that will translate into a smooth delivery. If the doctor comes round and says 'We need to do an emergency Caesarean section for a-b-c reasons', I'll be like – 'Whatever you need to do to make sure the baby's safe'. At the end of the day, I always have the baby in mind, so whatever's good for the baby, even if it annoys me, just put up with it.

Lauren's account suggests she attributes her 'smooth' pregnancy to the ways in which she has been cared for, principally that she and her partner were consulted and she was not sole decision-maker. Her wishes, however, are less important than foetal welfare. Her account suggests she values such interactions, and by implication the exchange of information which they included.

Participant:- Jade.

Primigravida. 28 weeks gestation. Uncomplicated pregnancy.

Extract 4.15

Jade: It is clearer from some knowing person, GP or midwife, need to confer with them.

Participant:- Safia.

Gravida 5. Para 4. 28 weeks gestation. Uncomplicated pregnancy.

Extract 4.16

Safia: *My opinion is face-to-face with the midwife, because in my experience, it's good.*

There were other examples of the importance of women's need to interact with their professional carers:-

This case was chosen because it comprehensively illustrates a woman's experience of some of the complexities associated with shared decision-making and how relational responsibilities can enhance or restrict the range of available options.

Participant:- Rachael.

Gravida 3. Para 2. 23 weeks gestation. Previous severe shoulder dystocia.

Guideline.

Green-top Guideline Number 42. Shoulder Dystocia (RCOG: 2012).

Guidance:-

Either Caesarean section or vaginal delivery can be appropriate after a previous shoulder dystocia. The decision should be made jointly by the woman and her carers (RCOG:2012).

Background to the guideline's recommendations.

Shoulder dystocia is a form of obstructed labour where, following delivery of the head, the anterior shoulder cannot pass through or needs considerable manipulation to pass through the symphysis pubis (Resnik:1980). It is an

obstetric emergency and is associated with significant perinatal mortality, neonatal morbidity and maternal morbidity (Gross *et al*: 1972).

Extract 4.17

Researcher: *Have you had to make any decisions in this pregnancy?*

Rachael: *Not so far, but I know I'm going to have to, whether it's going to be a Caesarean section or a natural birth.*

Researcher: *Can you tell me why?*

Rachael: *Well, in my second pregnancy, my baby was 10lb 5oz, so it was a traumatic birth and very large, considering my first one was 6lb 4oz. When I had (second baby) she was so big the consultant said to me if I was to have any more 'Unquestionably it would have to be a Caesarean', so when I found out I was pregnant this time I thought Oh, it has to be a Caesarean section, but then when I came to see a different consultant this time she said 'No, not at all, you do have the choice and if you wanted to have a Caesarean section, that's fine and we'll book you in if that's your preference'.*

Researcher: *How many weeks pregnant were you then?*

Rachael: *Probably about 15, so she said they could arrange that if I knew that I wanted a Caesarean section as my first choice, she was happy to arrange that, but she also laid down the options. She said they could give me sizing scans and if the baby was going to be so big, then we could make a decision together later on - as to whether it would be safe to have a vaginal delivery. She also gave me another option which I'd never been aware of - they could bring me in earlier to induce me, so the baby wouldn't go so big..... so that just gave me – I thought there was no choice in it at all. When I spoke to the consultant and she explained the various*

options, it was' Okay, and we'll just wait and see then' – because a Caesarean wouldn't have been my first option, although if it was down to safety then I would be happy to have a Caesarean. If they can address things to make natural birth a safer delivery then..... It's down to personal choice, I suppose. Both sets of delivery have got their risks. I personally feel, to put the baby through – although it's harder in some terms, it just feels more natural than the thought of just having my stomach cut open and the baby took out. Somebody rummaging around in there doesn't feel special to me, not to me, but then in terms of the convenience of having it booked and then you're going to have it, especially when I've considered the fact that I might have to have a section, I think well, I'll know when I'm coming in, I'll know the date, I'll be able to get (two daughters) looked after. Usually, you're a bit like - Oh, when am I going to go? 2:00am when your children's friends are staying over and you go into labour, so you ship your children off to other people . In a way, at 2:00am it's all part of the excitement, but I can see why it's inconvenient for some people (Laughs).

Difficulty in resolving a dilemma.

The wider recommendations in guidelines are sensitive to maternal autonomy and choice and include family values.

'The views, beliefs and values of the woman, her partner and her family in relation to her care and that of her baby should be sought and respected at all times' (NICE:2008:4).

Furthermore, the RCOG (2012) guideline's recommendations coloured the interaction between **Rachael** and the obstetrician in that it created several options, one of which the woman was unaware existed. The offer of different options was challenging, as her expectation was that there was no choice. The choice is not limited to 'doing something versus doing nothing' as the baby has to be delivered one way or another. My contribution is that despite the guideline Developers and writers working diligently, they cannot

factor into the recommendations women's expectations and what they do not expect to be told. The guideline does not include a clause which states that the recommendations may be surprising to some women who had previously understood they would not have a choice of options about mode of delivery in their current pregnancy.

She continues:

Extract 4.18

Researcher. *You've still got a fair bit of time to think about it.*

Rachael: *(Spoken slowly and quietly) Hmm... Yes. A natural birth would be my first option, but I wouldn't hesitate having a Caesarean section if the consultant felt that it would be safer because I was so traumatised after the last one. I was like, sitting there. (Husband) had been in and out of the room, I had consultants all around me and I can't even remember half of. The consultant last time told me they tried five different things to get (baby) out and when she came out she was grey and they took her over to resuscitate her and the midwife was holding my hand and I just said 'What's happening?' and she said 'I don't know'. I remember sitting there thinking 'How can I tell people the baby's dead?'- and it was **just the most awful feeling** (Woman's strong emphasis) and I thought I would do anything to avoid that in future. But I don't care what my choices are- whatever they say to me, if they say this is going to be a big baby and we feel that Caesarean section would be safer, I'll go for that really, because I wouldn't want to put myself or the baby or (husband) through that, nor (daughters). The thought just terrifies me (Emotional). **Short pause...** and I've done it all again to myself (Laughs).*

The woman suggests her autonomy has elements which have to be tempered against one another, that is, being autonomous *and* relational. As Douche succinctly puts it '.....decisions around childbearing form part of a

tapestry that weaves together the temporalities of a woman's past, present and future as well as her relationships with others' (Douche :2007: 161). She rationalises her family commitments and is willing to forfeit some of her autonomy, that is her wish for vaginal delivery. For her, the stakes rise. Previous obstetric problems should be immediately apparent to the healthcare professional from the woman's case-notes. However, my analysis suggests other factors which impact on her autonomy may be less apparent. The woman is already socialised into her own situation. As Kitzinger(1992) says, the woman's life world was there well before any knowledge she acquires during pregnancy. It is something that is unique to the individual, but is shared with others. The woman's account suggests she does not find her autonomy liberating.

The guideline's recommendations offer structure to the woman and consultant's planning of her care which is one of the benefits of guidelines set out in Chapter Two, Section Two, subsection (i). The consultant's suggestion that they make the decision together at a later date might be seen as a stabilizing factor. My analysis suggests that the woman perceives the consultant as knowledgeable and able to draw upon relevant clinical factors. An example of this is estimated foetal weight, which in view of the woman's previous traumatic experience, is consoling. But of course, except in the most isolated of cases, healthcare professionals are not the only sources of support for women. The challenge presented here is the close tailoring of the guideline to the woman's autonomous *and* relational needs, that is, there may sometimes be a tension between the individual aspect and the relational aspect which addresses the person connected to others. Thiele sums this up 'We don't just 'fall' pregnant or 'give' birth or 'have' children, we do so in a process that is multifaceted and complex; biological, cultural and historical aspects are integrated and mutually transforming' (Thiele:1989:10).The woman refers to the baby and the potentially traumatising effect on her husband and daughters, but never to herself in terms of labour pain nor the prolonged recovery period post- Caesarean

section. Personal fulfilment associated with vaginal delivery is subordinated by her relational responsibilities.

The offer of options in guidelines is available to her, but the actual *delivery* of the said options takes place amidst a complex web of relationships. As Kearns *et al* say 'The spinning coin between autonomy and relational responsibilities might fall on the relational side and inhibit a patient's autonomy' (Kearns *et al*: 204: 2010). It is surprising that Kearns and his colleagues suggest that if the woman decides on a relational basis, it diminishes her autonomy in some way. First, the woman's decision might concur with her family's; second, she might wish to put them first, despite the fact that Caesarean section was not her first choice.

In this Chapter, I have discussed cases where there was a need to discover the deeper meaning of options presented to women in guidelines. Arguably, not all decisions during pregnancy have profound consequences. However, for some women, their limited knowledge and the interconnected theme of trust in healthcare professionals to help secure a good pregnancy outcome were still apparent. This case was selected because it illustrates these points.

Participant:- Lisa.

Gravida 2. Para 1. 28 weeks gestation. Uncomplicated pregnancy. Attending hospital- based Antenatal clinic for anti-D prophylaxis.

Guideline.

Clinical Guideline 55. Intra-partum Care. Care of healthy women and their babies during childbirth (NICE:2007).

Guidance:-

Women should be encouraged and helped to move and adopt whatever positions they find most comfortable throughout labour (NICE:2007).

Guideline.

Evidence- based guideline for midwife- led care in labour.

Women often 'choose' to do what is expected of them, and the most common image of the labouring woman is 'on the bed'. Midwives therefore need to be proactive in demonstrating and encouraging different positions in labour (RCM 2010 cited in RCM Evidence- Based Guidelines for Midwifery-Led Care in Labour: 2012).

Background to the RCM guideline's recommendations.

Although there are significant advantages to assuming an upright position during labour and delivery (Lawrence *et al*: 2009), lying down remains the most frequently used position (RCM:2010).

Extract 4.19

Researcher. *So yours is a normal pregnancy. Do you have any particular wishes for the birth?*

Lisa: *Yes, I have. For instance, if I came in and without any medical evidence I was made to labour on a bed lying down, I would definitely challenge that because I don't think I could do that. But it's still difficult. You're not medically trained, you're not sure if there might actually be a genuine decision about clinical care by people who know better about this.*

There's a certain level of confidence you have to have if they're doing certain things, then it's for the well-being of you and your baby.

She continues:-

Lisa: *I don't really anticipate a problem, but it's something I need to tick off in my mind. Being allowed is one thing, but I have a slight fear of not being attentive enough myself to what was going on..... and things might fall through the cracks. You are less confident than those treating you - or that's what you feel like anyway.*

This case is an example of a woman stating that she would exercise her autonomy by refusing to labour recumbent on the bed. However, despite her initial assertion, **Lisa** suggests that it would be difficult to *sustain* her autonomy. She cannot predict what might happen during labour and the possible need to reconsider her options. Her account suggests a safe haven created by professionals where she can feel shielded from harm. Arguably, the woman herself is in control of the decision to hand control to the healthcare professional. However, she suggests that the healthcare professional's authority overrides her previous wishes. Although it is probably incorrect to say that autonomy did not matter to her, her account does not persuade that it was important.

Need to confer and confirm.

It might be expected that this type of decision would be pursued more rigorously than those with major consequences. However, there are similar trends to the cases discussed in this Chapter, reinforcing the idea that a trusting relationship with the midwife is fundamental to safety (Lemay: 1997; Noseworthy *et al* :2013). Both guidelines are clear that women should be offered a choice of alternatives, but *even so* the woman expresses her misgivings. Her account suggests that although she feels able to make a

decision, what she lacks is the appropriate knowledge and experience to decide for herself.

The healthcare professional was seen as a means of reducing the tension between the guidelines' recommendations and the woman's deliberations. There is a further attempt to seek reassurance which might be attributed to the fact that the woman herself has raised the subject of positions during labour. Her autonomy is somehow subordinated into a negation of her concerns relating to the legitimacy of her choice. Autonomy for this woman includes the ability to judge when a professional carer may know better.

The birth is the fulcrum of the woman's pregnancy journey. Cosslett (1994) and Miller (1998) identified how women internalize both 'medical' and 'natural' views about birth, the combination of which suppress their own personal wishes. The woman tries to counterbalance her autonomy with her uncertainty which results in a confusing picture. It might be inferred that some women are *glad* to defer to professional control, that is, there are instances when women relinquish their autonomy and it did not matter greatly anyway. The uncertainties they experience will only be resolved by giving birth, which will present a new set of uncertainties associated with becoming a new mother.

Conclusion.

- **Healthcare professionals.**

My analysis suggested that the presentation of findings reflect not only what women value about their pregnancy and birth experiences, but what it is they value about healthcare professionals' approach. Women draw into their deliberations their foetus, partner, family, professional carers and, as I have shown, the changing circumstances at different time points during pregnancy and birth which they report as unpredictable. These resulted in them revisiting and revising their decisions with varying levels of impact on

their autonomy. Findings suggested this often requires a certain confidence in their ability to interact as a genuine participant which has an impact on their autonomy. Findings also suggested that an understanding of women's concerns is best facilitated by interactions between women and their professional carers as part of a process of shared decision-making.

- **Personalised information.**

I suggest that a limitation in guidelines is that they do not necessarily reflect all the intricacies in the transition to becoming a new mother. My analysis suggested women's autonomy could be enhanced by exploring and supplementing their need for personally tailored information. This should be based upon their reflective assessments and any expectations they have which cannot be accounted for by recommendations in guidelines.

- **Timely information.**

Discussions should also include an in-depth exploration of the woman's expression of uncertainty and respond to her wish to obtain information and revisit/expedite/defer decisions in ways more timely with her own agenda whenever appropriate.

My analysis suggested that women's autonomy was not expressed as a relentless self-directed pursuit of a wide range of options. Rather, although most women had great trust in their caregivers, analysis suggested that their autonomy could be enhanced by a more fluid relationship with healthcare professionals.

Although my analysis does not suggest that there is a distinct optimal response to any of the cases I have presented, nonetheless the centrality of the concepts identified in women's accounts help contribute to an understanding of the kind of interventions in guidelines that could benefit

women. The following two Chapters build further on my analysis of findings in this Chapter.

Chapter Five.

Findings(ii).

Types of Decisions.

Introduction.

This is the second findings Chapter which explores how the recommendations in maternity care clinical guidelines are experienced by pregnant women and their impact on women's autonomy. In this Chapter, I continue with the two main thematic categories of women's limited pregnancy and birth knowledge and the importance of interactions with trusted healthcare professionals. I build further on these to deepen my analysis and reveal further insights relevant to my research question.

My analysis showed there were different types of decisions. The purpose of this Chapter is to relate these to specific guidelines, selected because they were relevant to particular themes in the data and provide interesting revelations about women's autonomy. This is the gap in knowledge the Chapter will address.

Section One of this Chapter explores decisions with a clear role for women's autonomy in interpreting the medical evidence and applying it to their own situation. This included decisions such as lifestyle choices, principally smoking during pregnancy. I will also include short extracts where subcategories had relevance to other women.

Section Two explores a decision in which a woman's expression of her autonomy was clearly articulated. The woman's reflective assessment was relevant to securing what mattered to her.

Section Three explores how a woman experienced several birth options and what this reveals about the significance of a range of options for a woman's autonomy.

Section Four explores how a woman understood and came to terms with having few realistic options. Rather than striving for a sense of control, information as open communication and authority were shared between the woman and doctor.

Background.

During the interviews, much of what women said about their experiences focused on decisions for which healthcare professionals are gatekeepers. An example is IOL. My analysis suggested the need for a better understanding about women's limited knowledge and their need to share decision-making with their professional carers.

My analysis suggested there were different types of decisions in maternity care. Whitney's theoretical work (2003) about shared decision-making groups decisions according to their importance, that is, major, important, routine and minor decisions. Whilst this is useful and informative, my analysis suggested that in order to address my research question, these should be thought about in a different way. An alternative framework might be to think about the types of decisions and the role the woman might autonomously choose to adopt. My analysis suggested there are relatively few major incidents in maternity care but important decisions are frequent. When women are treated as individuals, they have greater involvement in decision-making. The wider recommendations in guidelines are sensitive to the fact that women's decisions are not simply fact-based, but personal. It is difficult to understand how such decisions could be seen as routine. An individual woman has her own experience of care, so she cannot perceive routine-ness. My analysis revealed women rarely referred to minor decisions, for example, purchasing small items of baby equipment. This may suggest that such decisions were not recognised as decisions, were seen as insufficiently important to raise during the interview or were something to be discussed at more appropriate times with professional carers, family and friends.

Following data analysis I grouped the decisions (to be treated as headings) as follows:-

Types of decisions.

- **Decisions with moderate importance.**
- **Independent decisions.**
- **Important decisions with several variables.**
- **Important decisions with limited options.**

I will explore each of these in relation to specific guidelines.

SECTION ONE.

- **Decisions with moderate importance.**

The three subcategories which emerged from my analysis to be presented in this section are:-

- (i) Influence of medical evidence.
- (ii) Actioning medical evidence.
- (iii) Effect of personalised information.

Kirkham (2004) suggests that when women are presented with options which are important but less challenging than, for example, IOL, there remains the need for adequate information and consultation with professional carers to assist women to make informed decisions.

Guideline.

Public Health Guidance 26. Quitting smoking in pregnancy and following childbirth (NICE:2010).

Recommendation 1.

Identifying pregnant women who smoke and referring them to NHS Stop Smoking Services – action for midwives.

Guidance:-

Provide all women with information (for example, a leaflet) about the risks of smoking, including smoking by partner or family members. Address any concerns she, her partner or family may have about stopping smoking (NICE: 2010).

Background to the guideline's recommendations.

My findings revealed that women are strongly motivated to do everything possible to ensure a good pregnancy outcome. Many are receptive to information and willing to make changes arising from their understanding of the adverse effects of smoking during pregnancy. For example, the causal links between smoking, low birth-weight and perinatal deaths are well documented (Donaldson and Donaldson:2000; Royal College of Physicians:2000). Pressure is brought to bear on pregnant women to give up smoking, the tone of which could be seen as authoritarian. For example, Bourne (1975) claimed that smoking 30 cigarettes a day almost certainly causes physical and mental retardation in late childhood and women must not smoke during pregnancy. For those who accept professional help to make appropriate lifestyle changes, the work of Smith (1997) suggests that smoking cessation programmes for pregnant women have been effective. The majority of women who discontinue smoking in pregnancy do so spontaneously (Chapple: 2006). However, over a quarter of pregnant women who smoke continue during pregnancy in the UK (Coleman: 2004).

This case was selected because it is a good example of a woman exercising her autonomy and illustrates the deeper meanings associated with a decision that has moderate importance.

Participant:- Georgia.

Gravida 2. Para 1. 27 weeks gestation. Previous third degree perineal tear.

Extract 5.1

Researcher: *Do you smoke?*

Georgia: *I quit first time.*

Researcher: *I see. Was that a pregnancy-related decision?*

Georgia: *Yes.*

Researcher: *Have you ever resumed smoking?*

Georgia: *Flirtatious with it.*

Researcher: *What motivated you to stop?*

Georgia: *Simply being pregnant. I'd been thinking about it and I'd cut back, but when I found out I was pregnant I just stopped straightaway. I didn't smoke again until my little girl was about 18 months when I went outside and had a cheeky one. When I'd tried to quit before it hadn't really worked, so for the baby – you know the damage it can do.*

Researcher: *Did you need the doctor or midwife to spell out the risks?*

Georgia: *No. Everyone knows the risks really. You know it's bad for the baby.*

Researcher: *Yes. Were you stopping smoking for yourself as well?*

Georgia: *Erm... Yes, trying to. When I fell pregnant I just stopped and it was fine.*

Influence of medical evidence.

Georgia suggests her decision to discontinue smoking was hers solely, without the formalities of guideline recommendations and healthcare professional input. She has the option to reduce, quit or continue to smoke and can accept or decline specialist help offered to her. However, I suggest that the situation is more complex than it appears.

The woman's account suggests a level of confidence in her convictions. There is no neutral trading of convenience, that is, the decision to reduce or quit smoking versus the decision to continue which goes way beyond

reading a leaflet recommended in guidelines. It is not my aim to demonstrate beyond doubt that decisions such as this are inherently complex in every case. Rather, I develop the idea that a superficial understanding of an *apparently* straightforward decision may overlook certain complexities.

The woman's decision to discontinue smoking *will* unquestionably receive healthcare professional approval. There is a safety element, but less one of dependence. Her decision to discontinue smoking dovetails neatly with those of the guideline's recommendations and healthcare professionals' advice and she takes control. Furthermore, it may be important to her that there are *some* decisions in pregnancy that *can* be made at *her* own pace and in *her* social milieu. Healthcare settings after all, are not what she is used to. *Prima facie*, her account appears consistent with the liberal model of autonomy set out in Chapter Two, Section Three. It depicts the woman as sole decision-maker, rationally choosing from the options of continuing to smoke, reducing or discontinuing smoking. She has her autonomy in so far as she has effectively circumvented the guideline and has the power to protect her foetus from the detrimental effects of smoking.

The woman suggests that smoking reduction is something that can be achieved independently of medicine. The question is whether maternal autonomy was exercised or it is simply a case of 'doing the right thing', which suggests she is toeing the party line. The woman constructs her own therapeutic action which may be the simplest way of exercising her autonomy. It is the body of respected medical evidence that helps her make her decision which is reflected in favour of the benefits of discontinuing smoking in pregnancy. The guideline and healthcare professional advice are there, but the woman is attuned to her own body of knowledge. However, concurrently, in making her decision she could impose a constraint on what she may perceive as the positive benefits of smoking. This is not so much her way of choosing. Rather, it may be her way of exercising her autonomy in order to meaningfully *engage* with a constraint

on her desire to smoke (as opposed to a constraint being imposed upon her).

The outcome of her decision falls within established clinical norms. There is no language suggesting resistance and she does not express a wish to be free of any kind of influence. On one level, she relies upon her own resources to make her decision. On another level, she draws into the equation *what is known in the scientific sense* about the detrimental effects of smoking in pregnancy. As Graham succinctly puts it 'If she smoked she rejected medical claims, if she didn't smoke, she accepted them' (Graham:1976: 401), that is, it is her *acceptance* of the medical norms which form the backbone of her decision. Autonomy had some relevance, because she used her knowledge and did not express a wish to confer with healthcare professionals. This case diverges from the ways in which women react when faced with a decision for which they have insufficient knowledge. Examples are **Catrin (Extract 4.1)** and **Lisa (Extract 4.19)** whose accounts suggested knowledge asymmetry between themselves and their professional carers.

The woman could choose to reject the evidence. As Gillies and Wakefield put it 'Professional advice and information about smoking must also compete with the powerful influence of family and friends, many of whom have had normal pregnancy outcomes despite being smokers' (Gillies and Wakefield:1993: 159). There are some women who do not perceive low birth-weight and other co-morbidities associated with smoking as problematic.

Despite the fact that healthcare professionals working with guidance may not actively engage in facilitating this objective in a formal sense, there is nonetheless a pull towards what might be seen as some level of influence. In this case, the woman suggests she is sufficiently knowledgeable to make her own decision.

Actioning medical evidence.

The woman's account suggests she treats smoking more seriously when pregnant than non-pregnant, that is, she has an impetus to discontinue. The apparent spontaneity with which she discontinued may not translate neatly into preference-seeking behaviour as it is made during pregnancy and without healthcare professional input. Nonetheless, the science on which she bases her decision is something widely accepted. Because it is directly applicable to her, it assumes new meaning. Although *a priori* her decision, it is strongly influenced by medical ways of securing a good pregnancy outcome, that is, it was the medical arena (in an informal sense) that proposed the agenda which she followed. Her decision is desirable in itself and an expression of her autonomy. It could be more meaningful if she did not have an expectation at the outset that there would be certain decisions that she herself would be able to make. Giddens sees this as 'a protective device against anxieties' (Giddens: 1991: 98). It is her interpretation of medical science (without formal consultation with a healthcare professional) that makes it more autonomous.

The woman's account suggests she has compelling reasons to take remedial action against smoking, that is, she takes control. Her talk in metaphor 'Flirtatious with it' suggests a compromise between her attitude and behaviour related to smoking when pregnant and non-pregnant. She suggests that such behaviour - whilst not ideal, falls within the boundaries of acceptability when non-pregnant but is prohibitive in pregnancy. It suggests an element of enjoyment associated with smoking, so it might be inferred that discontinuing in pregnancy was not something she really *wanted* to do (and if there were no harms associated with smoking in pregnancy she would have continued). Rather, it is what she felt she *ought* to do. Autonomy in this respect means developing a personal action plan.

Other women offered their thoughts about discontinuing smoking in pregnancy.

Participant:- Lauren.

Gravida 2. Para 1. 28 weeks gestation. Attending VBAC Clinic.

Extract 5.2

***Lauren:** Oh, giving up smoking. The moment I found I was pregnant, I completely went off cigarettes because I knew it wouldn't be good for the baby. Psychologically, I was tuned in to stop.*

***Researcher:** How did you make the decision?*

***Lauren:** Just like that (Gesticulates a rapid click of her fingers). The only motivation was the baby. There was no doctor or midwife involved in it.*

Participant:- Isabella.

Gravida 5. Para 3. (1 miscarriage). 27 weeks gestation. Uncomplicated pregnancy.

Extract 5.3

***Isabella:** I don't smoke, stopped smoking with my first child. It wasn't difficult, never went back to it. Same thing with coffee - decaffeinated.*

Although **Lauren** and **Isabella** suggested they found it relatively easy to discontinue smoking in pregnancy and to confidently articulate their actions, arguably it was not they who controlled the agenda that contributed to their decision. In a sense, their spontaneity draws parallels with the work of McKinlay who points out that 'consumer enthusiasm for the innovation is generally the very last piece in the puzzle and must be constructed by and receive impetus and direction from professional interests that are already committed to it' (McKinlay:1982:243). Although there is no direct professional involvement, *it is women's acceptance of the 'evidence'* that is key. Given the type of decision, they feel able to navigate their way around what is scientifically known, although for some women it demands a high degree of self-management . However, as Kukla says, ongoing self-care is

not totally independent of healthcare monitoring. Not only are practices recommended by professional carers, women themselves are held accountable for them (Kukla: 2005). Nonetheless, for women taking responsibility frequently means acting in accordance with trusted scientific and/or professional knowledge. Some women may willingly choose to be guided by her carers. Hence their decision has a relational element. It may be useful to compare this with, for example, a procedure where the woman is 'done to'. For example, a midwife takes an intravenous blood sample from a woman. Unlike the cases in Chapter Four where women reported pregnancy and childbirth as unpredictable, the smoking example is less a struggle to understand what is happening. Women's response is to exercise their autonomy accordingly.

Georgia's quote (**Extract 5.1**) 'Everyone knows the risks really' leads us to ask *Whose* voice are we party to when the woman says she has discontinued smoking? The work of Arney (1982) claims that women are subjected to constant surveillance. In view of the fact that risk factors are more generally known about, they become the vehicle whereby monitoring (in a less formal sense) is not confined to healthcare professionals and finds its way into the public domain. If her decision merely concurs with society's view of the way in which a pregnant woman should behave and she makes the appropriate changes through fear of public criticism, then it seems doubtful that autonomy is very meaningful to her as the perceived power lies in the public domain. This process of subjectification is argued by Lupton and Schmied (2013) in their work on women's concepts of embodiment at the time of birth. They found that women who delivered by Caesarean section felt disembodied from the 'pivotal moment of birth', instead relying on professional carers, suggesting that professionals should include not only the physical and emotional, but also the ontological aspects of care. This may have implications for guidelines.

Effect of personalised information.

So far, I have confined my analysis to the general scientific knowledge about the adverse effects of smoking in pregnancy which **Georgia**

accepted. Graham (1976) found that many women preferred information given to them personally, that is, there was a stronger likelihood that women would accept and adhere to advice given on a face-to-face basis than information derived from books, pamphlets and television. This theme shares commonalities with women's wish to supplement their own lack of knowledge by conferring with healthcare professionals. As I argued in Chapter Four, this is very apparent, despite the wide range of information available today. If we relate it to Graham's (1976) work, it suggests that little has changed during the interim. Furthermore, it could be countered that the very wording of the guideline is designed to influence maternal behaviour which impacts on their autonomy.

Participant:- Sarah.

Gravida 9. Para 6. 35 weeks gestation. Uncomplicated pregnancy.

Extract 5.4

Researcher: *Have you made any lifestyle decisions in pregnancy?*

Sarah: *Yes, I smoke which I know is bad, but I've cut down because you don't want your placenta to come out grey and in bits, or whatever, because they know, don't they? **What it did for me** (Woman's emphasis) I'll tell you. In one of my previous pregnancies, I must have smoked quite a lot(I think it was my third) and they asked 'Do you smoke heavily? We can tell by your placenta'. **That clinched it.** (Spoken emphatically) **I felt bad.***

Sarah moves beyond the existing traditional perspectives about smoking. She vividly portrays the image of the placenta 'Grey' and 'in bits', that is, what was concealed during pregnancy is revealed at delivery. From her account, it is the ultimatum in determining correct and incorrect maternal behaviour. The woman creates a causal relationship between foetal welfare and smoking.

Arguably, the information women discover and receive might be applicable to others - or at best a combination of general and personalised - the

woman selecting what is most appropriate to her. It is established that smoking in pregnancy can result in placental infarcts, that is the healthcare professional's message to the woman is consistent with the current body of knowledge. Nonetheless, it leads us to specifically consider the woman's reaction to the condition of her placenta. By her account, she found it compelling. It became the lens through which her decision was filtered and has withstood the test of time as her current pregnancy is her seventh. She cites the condition of the placenta as *the* motivational force, which by no means novel *per se*, for her was important. She makes a clear interplay between the risks associated with an unhealthy placenta and her decision. By constructing her own personal yardstick, the woman constructs an assessment of the situation, based on that particular experience. She suggests that the placenta's pathology, in terms of its appearance, and any comparisons with normal placentae provides the information she seeks. It is the woman who has broadened the scope of what could be thought of as personalised information. She has the security that her knowledge is firmly located within the boundaries of medical science. It becomes the point from which her decision becomes her own - and more autonomous.

Her account suggests general information did not suffice. If we reject her understanding of events, we place a constraint on her autonomy. Although it did not involve deep-seated thinking, there is no inference that her knowledge was in some way more legitimate than the medical facts. Rather, it is something that confirms and strengthens her convictions. The woman's shared thoughts on the placental imagery demonstrate her ability to conceptualise the undesirable consequences of smoking during pregnancy. Her use of the metaphor 'in bits' highlights something which she can legitimately claim as hers. She voices quite powerfully '***That clinched it***', thereby strongly expressing her convictions. The effects of placental malfunction could be seen as accepted evidence, but her use of metaphor suggests it can be better understood in personal terms, that is, its meaning should be understood by her interpretation and understanding. She has discovered experientially what matters - a process driven by what she cares about and not solely about abstract factual information. It gives specific

reasons for acting and it is in this context she exercises her autonomy. We are unable to predict whether she would have reduced smoking had she not been given personalised information. Her expression of autonomy is unique and contextually situated.

As I have shown, some of the information relating to smoking in pregnancy is taken for granted and unremarkable. A richer understanding is how the woman's account was not simply coincident with different sources of information, *but is related specifically to the ways in which she herself defines the problem and exercises her autonomy in direct response*. This finding usefully ties in with and deepens my analysis in Chapter Four which suggested women's need for personalised information. Examples of cases include **Catrin (Extract 4.7)**, **Jasmine (Extract 4.9)** and **Georgia (Extract 4.13)**.

Healthcare professionals are generally unfamiliar with women's relational identities, and have to rely upon each woman's own assessment. **Sarah** suggests this was considerably more influential than the independence so prized by the liberal view of autonomy, that is, presenting the options - 'Go ahead and choose for yourself'. As set out in Chapter Two Section Three, based on the liberal model, professional carers should give appropriate information, respect and not interfere with her decisions. But matters are more complex. Those involved in developing and writing the guideline do so diligently with the best available evidence, but they are unable to refine the guideline to accommodate factors which are important for some women.

However, it could be argued that the decision has relational elements in that the healthcare professional instigated it by taking control. Furthermore, it supports the theme of trust in healthcare professionals, that is, **Sarah** trusts the midwife to make a correct assessment of her placenta. This diverges from her account of her negative experience of IOL in a subsequent pregnancy in which her trust in professional carers was compromised (**Extracts 4.11** and **4.12**), highlighting the range of women's unique experiences in different pregnancies.

My contribution is that some women's accounts suggested that their autonomy depended not only on their acceptance of the medical evidence, but also on what was directly relevant to them.

There were other women whose accounts suggested they were able to exercise their autonomy in making lifestyle choices.

Guideline.

Clinical Guideline 63. Diabetes in pregnancy. Management of diabetes and its complications from pre-conception to the postnatal period (NICE:2008).

Guidance:-

Gestational diabetes

Give information and advice on:

Diet, body weight and exercise, including weight loss for women with a BMI over 27kg/m²(NICE:2008).

***For reference, the updated guidance reads as follows:-**

Guideline.

NICE Guideline NG3.Diabetes in pregnancy. Management of diabetes and its complications from pre-conception to the postnatal period. (NICE:2015).

Offer women advice about changes in diet and exercise at the time of diagnosis of gestational diabetes {NEW 2015}.

Advise women with gestational diabetes to eat a healthy diet during pregnancy and emphasise the foods with a low glycaemic index should replace those with a high glycaemic index {NEW 2015}.

Refer all women with gestational diabetes to a dietician. {NEW 2015}.

Participant:- Lucia.

Gravida 2. Para 1. 33 weeks gestation. Gestational Diabetic.

Extract 5.5

Lucia: With the gestational, I've had to change my diet a lot. I've been more strict with the baby inside me than if I had diabetes for myself and I wasn't pregnant. It's definitely made me more careful. I haven't seen a dietician this time around. They give you the information sheets, but you have to read them. Saying that, my parents are both diabetic, so I was aware of what to do anyway.

Lucia suggests that her decisions were made in the context of family relations, that is, independently of professional input but still involved her assessing and weighing the scientific information. She is not an isolated agent reflecting solely on her own dietary wishes. Her parents' support network has helped shape her decisions.

Participant:- Alysha.

Gravida 3. Para 2. 35 weeks gestation. Gestational Diabetic and Gestational Hypertension.

Extract 5.6

Alysha: I'm so amazed. I'm diabetic now and I really love drinking 'Coca-Cola'. There are options, that's what I like, because I can still drink 'Coke', so long as it's 'Diet' or 'Diet Zero'. There's support from the dietician. She asked me what I really liked to eat and she gave me a booklet with options, so the choice of what is most compatible with my taste buds is mine. There were plenty, never deprived me of anything I wanted to eat, but they don't force you to do it. It's good to know.

Alysha suggests she received helpful care and trusts the process by which the decision to include the information in the booklet was made. She has exercised her autonomy to take control of her eating regime. However, the information tended to support her choices and was derived from a

respected professional source that shapes her decisions. Her account draws out the relationship between what goes on inside the clinic setting and the responsibility for implementing her decisions which is placed in her hands.

SECTION TWO.

- **Independent decisions.**

The two subcategories which emerged from my analysis to be presented in this section are:-

- (i) Trust in familiar procedures.
- (ii) Trust in hospital staff.

The healthcare literature reports the importance of independence and its significance for childbearing women (Gibbins and Thomson: 2001; Larkin *et al*: 2009). These themes can be usefully applied to the choice of birth location (Cunningham: 1993; Viisainen: 2001).

Participant:- Rebecca.

Gravida 3. Para 2. 30 weeks gestation. Uncomplicated pregnancy.

Royal College of Obstetricians and Gynaecologists/Royal College of Midwives Joint Statement:-

Guidance:-

The RCM (Royal College of Midwives) and the RCOG (Royal College of Obstetricians and Gynaecologists) support home birth for women with uncomplicated pregnancies. There is no reason why home birth should not be offered to women at low risk of complications and it may confer considerable benefits to them and their families (RCM/RCOG :2007).

and

Guideline.

Clinical Guideline 55. Intra-partum care. Care of healthy women and their babies during childbirth (NICE:2007).

Guidance:-

Women should be offered the choice of planning birth at home, in a midwife-led unit or in an obstetric unit (NICE : 2007) .

Background to the guidelines' recommendations.

Changing Childbirth (Department of Health: 1993) recommended that women should make informed decisions about their care, including the choice about where they wanted their baby to be born. This marked a departure from government policy aiming for all babies to be born in hospital (Ministry of Health: 1959; House of Commons Social Services Committee: 1980). The outcomes of home births in the healthcare literature indicate that those attended by appropriately skilled practitioners are safe for healthy women and babies (Ford *et al*: 1991; Campbell and Macfarlane: 1994).

This case was selected because it is an example of the woman's autonomy being clearly articulated in relation to her decision to give birth in hospital.

Extract 5.7

Researcher: *Have you had to make any decisions in this pregnancy?*

Rebecca: *The midwife told me that as I don't have problems, I could have the baby at home if I wanted. Is that true? Is that coming in the future?*

Researcher: *Actually, it's not a new thing.*

Rebecca: *Really!!! (Expresses great surprise). I don't like it. The midwife said - would you like to have it that way and it was up to me.*

Researcher: *So what have you decided?*

Rebecca: *Hospital (Spoken firmly).*

Researcher: *Can you tell me why you decided on a hospital birth?*

Rebecca: *Because it's good. (Spoken purposefully). There's more help. When the woman is pregnant, they're helpful. When you have the baby, they help you, they keep asking about the child and before you go home they check – but when you see the GP or something like that, there's really no help. Last time my small boy had a cough. I saw my GP three times. He sent me home each time - 'Give him Paracetamol and water and he'll be fine'. The final visit, he was unconscious by the evening and we had to have an emergency ambulance to Children's Hospital.*

Researcher: *Is he quite well again now?*

Rebecca: *Yes, but he was in there for four weeks. I think when you are pregnant there's more care really, more care - maybe it is because you are two persons. You are the mother and the child is in you, maybe that's it. Although she (midwife) told me about it (home birth), I didn't want to know, but you don't need to argue with them because they don't push you. To me, the girls (midwives) have plenty of knowledge and they're fine and friendly. They treat me well. I like them.*

Researcher: *Are you happy to accept the midwife's advice on pregnancy matters?*

Rebecca: *Yes (Spoken emphatically). Because she told me, of course.*

Trust in familiar procedures.

Rebecca's account suggests that hospital was the sole location for her to give birth. She has accepted without question that maternity care is centralised during her two previous pregnancies and has not exercised her autonomy in seeking alternatives, much less explored them herself. This concurs with van Teijlingen and his colleagues (2003) and Larkin *et al* (2017) whose work suggests that women tend to prefer the type of care they are accustomed to. Furthermore, Madi and Crow suggest that although women wanted to be informed about the various options, those planning a hospital birth were 'protective of their planned pace of delivery' ((Madi and

Crow: 2003:333). Arguably, it is difficult to express a preference for one type of care over another when unaware that alternatives existed and without previous experience of one or the other (or both) of them. There is a possibility that one might over-emphasise the benefits/risks or tend to play them down. The woman's account suggests she has been influenced by the somewhat discredited assumption of greater safety in hospital (Murphy and Fullerton: 1998; Olsen and Jewell: 2001). However, she had never compared the two as she was unaware that the option of home birth existed.

Trust in hospital staff.

The woman draws out positive features about hospital birth, but not in the sense that she associates it with the availability of technology. Rather, she cites a *non-obstetric* example of community-based care which she deemed as substandard, even fraught with danger. She suggests a strong trust placed in hospital-based midwives and a mistrust of community-based staff. Her young son's episode of illness features prominently, re-iterating a point made in Chapter Two, Section Three that women do not make decisions based solely on medical facts, nor entirely for themselves. Although she has no hesitation in declining home birth, *it is relational considerations that lead her to the point of decision-making*. She is both autonomous *and* relational.

She compares the availability of help in hospital with feelings of frustration and fear she associates with community-based care. She was unable to convince her GP about the legitimacy of her concerns about her son. Although not a parallel situation with her son, the woman may draw out similarities which make the option of home birth prohibitive. It has been well documented that women who choose hospital birth do so because they are concerned with safety (Soderstrom *et al*: 1990; Chamberlain *et al*: 1997). A hospital birth most closely supports the woman's views and is a means of avoiding a shaky start to motherhood.

It is interesting that the woman sought confirmation with myself as researcher about the perceived novel option that the trusted midwife had presented to her. Her account suggests that the decision was made well nigh instantaneously and not on the basis of good information. She does not indicate that the decision was left open in any sense, with time to deliberate and arrive at a deferred decision- which would have been entirely acceptable. This differs from my analysis of findings in Chapter Four where women suggested the need for timely information, professional carer involvement and the opportunity to think about their options. Examples are **Charlotte (Extract 4.3)**, **Lauren (Extract 4.14)** and **Jade (Extract 4.15)**. **Rebecca** expresses a preference *not* to have been informed. She *cannot* undo and effectively reverse what the midwife has offered. The guideline's focus is on choice for women with uncomplicated pregnancies which makes it an appropriate option for her. However, the guideline does not include a clause for women who are faced with a discrepancy between the care they expected and the care they were offered. This could impact on their autonomy. In this respect, the case has similarities with **Rachael (Extract 4.17)** who was presented with options she had not anticipated, but unlike **Rebecca**, **Rachael** exercised her autonomy by considering their possibilities. The implication for guidelines is that the Developers and writers cannot predict what the individual woman's current understanding and expectations of her care might be.

Rebecca *can* decline what she does not want and has the security of a trusted alternative which she likes. What mattered to her was not a choice of options, rather, it was her perception of safe care. Although some women experience various constraints when trying to arrange a home birth (Edwards: 2004), whoever heard of a woman being denied a hospital birth? It is a moot point whether her decision would have differed had she been in possession of the relevant information. Her decision is in a sense incomplete - she may have little (if any) understanding of the values that underpin home birth. The issue is being presented with a choice. Her outright refusal suggests that her autonomy was meaningful - and she used the opportunity to exercise it without fear of reprisal. Her refusal will not

jeopardize her care, nor her good relationship with the midwives. Her questions to myself as researcher *may* suggest an element of curiosity (but not a wish to explore further). Rather, there is a wish for closure.

SECTION THREE.

- **Important decisions with several variables.**

The three subcategories which emerged from my analysis to be presented in this section are:-

- (i) Several options.
- (ii) Forward planning.
- (iii) Fear.

Kukla and her colleagues claim that when a woman is faced with a number of variables it may have the effect of undermining her autonomy by making choices 'unproductively difficult' (Kukla *et al.*: 2009:6). They maintain that if women's autonomy is understood as informed choice and increasing autonomy is a matter of expanding women's options, *prima facie*, this is a step forward in enhancing women's autonomy. They argue that this understanding of autonomy fails to recognise women's concerns which fall outside this discourse (Kukla *et al.*: 2009).

Participant:- Raine.

Primigravida. 29 weeks gestation. Twin Pregnancy. Attending Multiple Birth Clinic.

Guideline .

Clinical Guideline 129. Multiple Pregnancy: The Management of twin and triplet pregnancies in the antenatal period (NICE: 2011).

Guidance:-

Discuss with women with twin and triplet pregnancies the timing of birth and possible modes of delivery early in the third trimester (NICE:2011).

And

Guideline.

Green-Top Guideline Number 51. Monochorionic Twin Pregnancy Management (RCOG:2008).

Guidance:-

It is appropriate to aim for vaginal birth of monochorionic twins unless there are accepted specific clinical indications for Caesarean section, such as twin one lying breech or previous Caesarean section (RCOG: 2008).

In monochorionic twin pregnancies, discussion should take place as to the mode of delivery and intra-partum management at 32-34 weeks gestation (RCOG:2008).

Background to the guidelines' recommendations.

There is lack of consensus about the management of twin pregnancies generally, also their mode of delivery. TTTS (Twin-to-Twin Transfusion Syndrome) is a major potential complication. Accordingly, many units routinely deliver all monochorionic twins by Caesarean section because of the 10% risk of acute transfusion during labour. However, in preterm labour with a cervix at least 5 centimetres dilated and cephalic presentation of the first twin, vaginal delivery may be considered (Duncan: 2005).

This case was selected because it comprehensively illustrates the woman's dilemma of facing an important decision complicated by several variables .

Extract 5.8

Researcher: So what are your thoughts about delivery ?

Raine: *You have to look at the pros and cons of natural birth and Caesarean section. I'm the type of person who likes to know, so when I found out I was expecting twins, I've been doing a lot of reading up. If I was having a single pregnancy I'd be more comfortable with the thought of a natural birth, but because I'm having twins and they've got a shared placenta as well and there's the risk of TTTS. I'm..... In my head I'd be more comfortable having a Caesarean section, but there's obviously the after-care to think about, the fact it's major surgery and looking after twins after you've had the surgery, so it's something I've been giving a lot of thought to and I've been quite indecisive over. At the moment they're both head down which means they're in a good position for a natural birth, but they might move **Short pause** ... It's (Caesarean section) not something I want, but it's something I just feel deep down would be the best thing to do, just because I feel it would be more safe for the babies. **Pause**..... I'm 29 weeks now. I'm worried what would happen if I went into labour early and you can't discuss it until you're 33 weeks. You need to prepare for it, so it would be better to know. But it's too soon for the hospital to put that (mode of delivery) in my notes. Also, I'm just worried that if I went into labour early, **there's two** (Woman's emphasis). **Pause**.....But it might not be my decision - if the one at the exit's breech, I've got to have one (Caesarean section).*

Several options.

Raine's account suggests she reasons within a framework that could be seen as 'twofold'. This is because she has monochorionic twins and her understanding of their potential complications, notably TTTS and the risk of premature labour. She perceives Caesarean section as a safer option for her foetuses, symbolic of some semblance of order and a means of controlling events. The alternative of vaginal delivery incorporates many aspects that could result in deferred decision-making and revised plans. Although singleton pregnancies are not exempt from complications and revised strategies of care, her twin pregnancy is something she has elevated to a different status. She acknowledges the potential problems associated with surgical delivery and the short to medium-term

disadvantages in terms of self-recovery which she is prepared to undergo for the long-term benefits to her babies. The guideline states that 'Maternal views will be important in reaching a conclusion about the best method of delivery' (RCOG: 2008: 7). However, it is less clear that she finds the various alternatives liberating.

The woman's account suggests her expectation is less a question of whether she will require the help of medical technology, but rather the extent to which intervention will be warranted. If the problems she associates with vaginal delivery become notoriously burdensome, then it may be that delivery by Caesarean section is no worse in so far as it takes care of her foetuses and reassures her, even though it is not what she *wants*. Hence Caesarean section becomes not so much a matter of choice, but a *means of* delivering the two babies safely. She might find respite in believing that twins provided her with greater justification for Caesarean section which makes the option more compelling.

Forward planning.

The woman's account suggests she feels responsible for knowing about and planning her options. Her ability to engage in discussion about a complex decision such as this is restricted by her understanding that the mode of delivery cannot be formally discussed until 33 weeks gestation. Although she can request further information beforehand, I suggest that the decision will be better informed and more autonomous if it is raised by a healthcare professional and the woman's participation invited, rather than one that is made solely on the basis of her request for information. Entwistle and Watt (2006) claim that close attention by healthcare professionals to the sequence of decision-making makes patient involvement more recognisable. One benefit is the 'knock forward' effect. An example is patients' involvement in problem recognition and clarification of issues which will help contribute to subsequent evaluation of their options and their decision. These authors claim patients who misunderstand their options may be inclined to resist involvement in their care. The woman's wish for

information ahead of recommended times and her expression of uncertainty about premature labour is not reflected in the guideline's recommendations.

She continues:-

Extract 5.9

***Raine:** I think it could be quite distressing to have a long labour and then to have a Caesarean section after it and one worry is that you might have one natural and one by emergency Caesarean – they say it's about 5% of cases. My partner says it's up to me, but he's talked about it and said 'Why would you want one?' I'm just a bit scaredIf it (Caesarean section) needs doing, I'm more than happy to have it done. I've had great care here and I know I'm in good hands.*

The woman is presented with a number of variables, but it cannot be assumed that they will enhance her autonomy. If that were the case, we would simply need to expand the available options and we would fulfil our ethical duty, if autonomy is understood as informed choice and a range of alternatives. The woman draws out the uniqueness of each twin's birth, but this is marred by the potential scenario of one twin delivered vaginally and another surgically. This amounts to something of a win and lose situation which she tries to make sense of amidst a disorderly context. Even if she were to 'choose' vaginal delivery, at best she can only *attempt* a vaginal delivery (and this remains constant for all women), but it is *more* challenging for her amongst several alternatives. Furthermore, it is not so much chosen by her. Rather, it is something into which she feels guided into the rightness of, that is the guideline offers choice, but it is less facilitative in drawing out the intricacies imposed by unpredictable circumstances. Her account suggests that being told she had that choice gave her some control - but for her the mode of delivery was not an obvious choice. It is difficult to favour a particular mode of delivery because circumstances can change and decisions have to be revisited. Autonomy is not a constant. She still experiences ambiguity about surgical delivery of the second twin,

depending on the presentation of her foetuses and the progression of events in labour.

Fear.

The woman's account suggests fear which concurs with the healthcare literature (Fisher *et al.*: 2006) and the term 'emergency Caesarean' is frightening to women (Redshaw and Hockley: 2010). The woman has tried to decipher and ultimately determined for herself the degree of risk she is prepared to accept. Such a decision often requires deferring to healthcare professionals. Nonetheless, this could be an expression of her autonomy if she took responsibility for it. Rather than increasing options, promoting autonomy might include guiding the woman's attempts at, for example, risk assessment and sharing responsibility for her decisions. If, as the guideline says, maternal views should be sought, then the woman's account would draw out the ambiguities of the situation, something which makes expressing her autonomy in terms of a preference difficult. This is because, assuming the woman elects to attempt a vaginal delivery of both babies, depending on the progress of events, she will not face the final decision until she is in labour.

The breech presentation of the first twin is seen as confirmation of the need for Caesarean section. The woman sees the situation as 'absolute,' that is, vaginal breech delivery of the first twin becomes prohibitive. Obstetricians have claimed that certain clinical conditions are 'hard and fast' and it logically follows that a Caesarean section is clinically warranted (Kamal *et al.*: 2005: 1056). It is perhaps no coincidence that their account concluded with an indication that it would remove the ambiguities currently faced. If we interpret **Raine's** account as subordination (which could be accompanied by some sense of relief) she retains her autonomy (despite the fact that she has not *chosen* the mode of delivery herself). She suggests she would feel secure that she has 'done the right thing'. Alternatively, because care becomes more directive by healthcare professionals than deliberative on her part, she still has autonomy in so far as she has prepared for all eventualities which is the maximum she could have done. It is not that she

does not want her autonomy. Rather, she wants guidance to enable her to exercise it appropriately. An account of liberal autonomy understood as self-determination fails. Relational autonomy is more relevant and helpful and should be taken to include a sharing of the decision-making process with professional carers. This case is an example of a decision which will need to be revisited and may involve different professional carers at different time points in pregnancy, something that is not reflected in the guidelines' recommendations.

SECTION FOUR.

- **Important decisions with limited options.**

The three subcategories which emerged from my analysis to be presented in this section are:-

- (i) Caught up in labour.
- (ii) Need to renegotiate.
- (iii) Dependence on trusted healthcare professionals.

Deber and colleagues argue that most patients want to defer to trusted health care professionals when the situation is important and has a single correct solution (Deber *et al*: 1996). My analysis shows that with skilled healthcare professional input the decision need not have clear-cut professional authority.

This case was selected because it illustrates that despite several constraints, the woman's feeling of being enabled adds to a literature which tends to focus on information about treatment options, that is women are told, but not always sufficiently involved.

Participant:- Catrin.

Gravida 2 .Para 1. 37 weeks gestation. Gestational Diabetic. Previous IOL.

***This case should be seen as a continuation of Catrin's account in Chapter Four (Extracts 4.1 4.2 and 4.5- 4.7).**

Guideline.

Clinical Guideline 132. Caesarean section (NICE:2011).

Guidance:-

A pregnant woman is entitled to decline the offer of treatment such as Caesarean section, even when the treatment would clearly benefit her or her baby's health. Refusal of treatment needs to become one of the woman's options. (NICE:2011).

Background to the guideline's recommendations.

The law places no additional restrictions on a woman by virtue of the fact she is pregnant and the principles relating to her informed consent do not differ from other areas of medicine. The law upholds the individual woman's right of autonomy to make decisions relating to her care, and the foetus has no legal personality (Montgomery: 1997:400-401).

Extract 5.10

Researcher: *Could you tell me about what happened next during your labour?*

Catrin: *At that point the baby's heart rate started to dip down every time I had a contraction, then eventually went beyond normal limits. It was terribly worry-some just to be thinking, is he still okay, is he still there? I was thinking - this wasn't part of my plan and it was serious surgery. I thought, well, I'm on the iv. drip, I've got an epidural, I've already progressed along this route and I'm only dilated about one centimetre and then having the Caesarean section is one final thing - one final intervention. **Short pause...** I was just.... I felt overwhelmed. I guess I needed to hear it from somebody, someone to tell me authoritatively- 'This is necessary now you know, either you're at risk or my baby's at risk'. I needed somebody to say 'Listen - this is needed and it isn't an option'.*

Researcher: *What was your response?*

Catrin: *You really have to do it. Looking back at the process, it was scary. Based on the information I had, I couldn't have done it any other way that wouldn't have added to the risk and my baby.*

Caught up in labour.

Catrin's account suggests she found herself in a cul-de-sac. She has already consented to intravenous syntocinon and an epidural (interventions she had not originally wanted). These interventions increase surveillance of the labouring woman and can cause labour to stall (Diniz and Chacham: 2004). The pending Caesarean section narrows her options further still. Her contractions were failing to progress her labour and foetal distress exacerbates matters to crisis point. An interesting feature of her account is her directive questioning about her foetus' survival *in utero* which relate to her underlying concerns about the complications of gestational diabetes (**Extract 4.6**). Examples are neonatal hypoglycaemia and the risk of stillbirth, problems sufficiently important to take appropriate action to safeguard her foetus (however prescriptive and contrary to her plans it may be). Another feature of her account is that she has already progressed (albeit in a minimal sense) along this route. Her stunted progress reflects the extent to which she can reasonably expect to go. Effectively, her hopes had been dashed. Her account shares similarities with Armstrong and Kenyon's qualitative work about uncomplicated primiparous women's delay in labour. The authors refer to a 'tipping point' at which the situation changes from women considering their preferences to a situation where there were few options. Women who accepted their revised situation did so on the basis of trust in their professional carers (Armstrong and Kenyon: 2015:9).

The woman refers to the Caesarean section as 'final' - inferring that post-operatively there can be no further interventions. Her account suggests the theme of finality accompanies feelings of safety she associates with it. At no time does she actively resist the intervention. Her account is consistent

with findings from studies in the healthcare literature exploring women's feelings about undergoing both elective and emergency Caesarean section deliveries. Redshaw and Hockley's(2010) work explored women's accounts of delivery by Caesarean section . Women were selected at random by birth registrations in England, invited to complete a questionnaire three months postpartum and their responses analysed using qualitative methods. Many women in Redshaw and Hockley's study reported feelings of relief, because having the Caesarean section either averted or terminated the labour process. Only a small number were very disappointed they had not had a natural delivery. The study concluded that there was a clear need for professional carers to assume a greater listening role than is currently the case (Redshaw and Hockley: 2010). Tully and Ball's qualitative study found that women who underwent an unplanned Caesarean section derived some reassurance from knowing that their efforts during labour went part of the way towards the final outcome, even if the mode of delivery was not what they originally wanted (Tully and Ball: 2013).

Autonomy in this instance may mean expressing a wish for her labour to end. She has exhausted all other routes. Faced with ambiguities, she points to the need for authoritative information.

She continues:-

Extract 5.11

***Catrin:** I rested for a couple of hours with the epidural. I had the feeling of not being able to move my legs at all and feeling very trapped in my own body.*

Need to renegotiate.

The woman suggests that her protracted labour has raised the need to rethink and renegotiate her plans. Correspondingly, her autonomy is not a constant. Although she was trapped in a physical sense, the gradual realisation brought about by intra-partum events was congruent with the doctor's advice. As Thoits (1983) says, unexpected and unpredictable

events are frequently the most onerous to cope with. Although not hoped for nor wanted, the progress of events collectively sent out warning signals that all was not well and the resting period provided an opportunity to reconcile her thoughts. These findings diverge from the work of Malacrida and Boulton (2014) who claim that, in view of the time pressures on women in hospital delivery suites, it is unlikely they would have the opportunity to step back and recompose their thoughts. Although not a clear-cut situation that required *immediate* action, the woman was resigned to walking a fine tightrope in order to re-balance her thoughts in a situation of great tension which makes resisting medical interventions difficult. However, she exercises her autonomy to renegotiate what she sees as the *only* remaining option. She was confined in a real sense and as Berg (1992) says, if she were to step outside the regime, there is an implication that the action would have to be explicitly renegotiated. She understands that a major change of plans specifically to meet her wishes does not exist. If she were to resist, she would endanger her foetus and there are no advantages in diverging from what has become a prescribed route of care.

In her revised situation, the woman has defined the upper limit to which she can aspire. She retains her ability to consider what, for her, has become the protective element of a Caesarean section. Her autonomy is not expressed openly as a choice as her previous wishes are obsolete. Neither is it expressed as outright resistance. Gregg (1995) suggests that women draw upon 'little strategies' to exert 'minor influence' on a system that generally subordinates them during the very early stages of their pregnancy journey. It is the nature of something such as this which becomes the cornerstone of her decision-making, the yardstick against which she can exercise her autonomy in a situation of unpredictable childbirth.

Dependence on trusted healthcare professionals.

There was an emerging sense that, just as healthcare professionals had controlled the management of her labour up to this point in time, there was a need (and an expressed wish) for them to take control again. It was

respect for and trust in professional carers that helped empower the woman.

Extract 5.12

She continues:-

Catrin: *I wanted to know **exactly** (Woman's emphasis) that it (Caesarean section) was going to be necessary, if it was going to be in the best interests of me and my baby and thankfully the doctor was very patient and explained the reasons - what I could do if I wanted to wait a bit longer, what the consequences of that course of action would be – so I felt that I was getting..... I needed information so as to confirm my thoughts, so I wanted to know I was not making a decision based on fear, based on pain - because the life of this little creature is in your hands. I felt I was able to do that.*

*At that point you have to put your trust in professional people. For me, the trust comes from feeling this person's giving me the information I need to make a decision. I don't want to feel I'm totally out of control. I want to feel I can put my trust in that person - I need them to help with the handover of authority. At a certain point you want to be reassured that these people know more and they're caring about my health and my baby and that's the primary concern. I think when they have experience with a number of different cases they can predict the concerns people will have, just kind of deal with people's fears even before they arise and I think at that level , concerns and questions that you might have, maybe don't even think about asking because you're in **such** (Woman's emphasis) a tight situation. I think that's when you feel you're having better care, because this person is saying - 'Here is the evidence we have for the situation you're in. You might be wondering about this or that - but here are the kind of things you might have questions about '- and just kind of predict. Sometimes they're advising a course of action and they're seeking your consent to do something - and you in reality have no idea about it. But - how can I refuse that? **Short Pause...** I wanted to experience childbirth, but I could foresee an operation.*

The woman's account suggests she understands what was realistic which strongly influenced her revised expectations. Given her situation, it is particularly important to strike an appropriate balance with information. She states emphatically 'I wanted to know **exactly** that it was going to be necessary'. This suggests she needs assurance that the situation really was an emergency and indicates a need to be clear about what women really need to know and when. The implications for guidelines is that this may be more important still in an emergency when women are in a situation of painful childbirth.

During her interaction with the doctor, the woman can test out the boundaries she has constructed, resulting in a more coherent stance as there is little remaining to compromise. Having composed her thoughts, the woman articulated the need for the doctor's input, *which may have been the maximum she could do*. As Enkin puts it 'Objecting to the risk management approach to childbirth is difficult, because the idea of risk management is a product of the culture we live in. It is so basic to maternity care today that it is difficult to imagine any other model of care' (Enkin: 1994:133). The woman speaks with near certainty of the Caesarean section delivery. As Cosslett (1994) says, any further attempts to control would only lead to some illusive range of possibilities which are beyond her reach. Having autonomy permitted her to grapple with her own situation. Importantly, she has the reassurance that there is no misfit between her expectations and the doctor's response which was supportive rather than controlling. The 'small space' in which she exercises her autonomy reveals the need for negotiation consistent with shared decision-making. It reinforces her perception of the doctor as expert and her need to share information and authority with him. Concurrently, safety appeared to encompass not only foetal well-being, but her own psychological security which helped empower her. She needed to avert her worst fears, that is, a compromised or dead baby. Risk becomes the lens through which her decision was eventually made to accept the Caesarean section as there is no less intrusive means of protecting her foetus.

Women can still exercise their autonomy with skilled professional interactions. There may be a point when some women wish to defer to their professional carers and the decision is no longer shared, but the decision to defer can be an expression of their autonomy.

Another woman voiced feelings that could be seen as finite in her decision to undergo Caesarean section, suggesting a willingness to be guided to comply.

Participant:- Chloe.

Primigravida. 27 weeks gestation. Insulin dependent diabetic. Attending Diabetic Pregnancy Clinic.

Extract 5.13

Chloe: *I'll be having a pre-booked Caesarean section (Spoken definitively). I don't care what I go through, it's what's best for the baby. (Spoken emphatically).*

Catrin's account raises another complexity - that the proposed surgery combines childbirth with an operation (**Extract 5.12**). Taken as separate entities, these generally provoke different emotional responses. There is a tendency for family and friends to become so absorbed by the baby that they overlook the mother's physical and psychological distress (Lobel and De Luca: 2007), whereas those who have surgery for reasons unconnected with pregnancy tend to expect and generally get sympathy (Rosenberger *et al*: 2006).

The woman's account suggests that Caesarean section was a way of assisting her to give birth in order to minimise compromise, but not in the sense she had hoped for. She suggests she had to focus on the pending operation - with the experience of natural childbirth thrown into oblivion. She tries to make sense of segregating the two - surgery representing a transition into motherhood taken out of her hands and placed firmly in the healthcare professionals' domain. The way in which she captures it suggests that natural childbirth may be a metaphor for some level of control

and surgical delivery a metaphor for loss of control. She neatly draws the distinction between the two which she sees as a mechanism of separating her own views about childbirth from the sterile environment of the operating theatre. Although the surgical procedure was clinically warranted, Adams(1994) refers to the 'machine/physician' entering the woman by way of needles and monitors. In the woman's mind this may have been the polar opposite of a low-technology birth when there was (at least theoretically) increased scope for exercising her autonomy.

Conclusion.

My analysis suggests the effect of recommendations in some guidelines can be powerful in shaping women's care. Correspondingly, this suggests a need to re-evaluate the thresholds of the types of decisions women expect to be informed about and involved in.

Types of decisions.

- **Decisions with moderate importance.**

Depending on the type of decision, some women's previously acquired knowledge, that is their acceptance of the medical evidence, was seen as empowering. My analysis builds further on my findings in Chapter Four that just as personalised information tailored to the woman's situation given by a healthcare professional can help promote her autonomy, some women's self-constructed information based on medical evidence and their personal experiences are relevant and can provide further impetus to exercise their autonomy.

- **Independent decisions.**

A woman's reflective assessment and not medical information was most relevant in enabling her to express her autonomy outright.

- **Important decisions with several variables.**

Decisions, particularly complex ones, are frequently in need of re-evaluation. The process should be treated as ongoing with greater weight placed on the woman's timely agenda and corresponding need for information rather than the chronology recommended in guidelines. The woman's participation should include ensuring she understands the information and take account of her concerns about her revised situation. Autonomy is not maintained as a constant but can be enhanced in this way.

- **Important decisions with limited options.**

There was a case when the guidance of trusted professional carers helped preserve maternal autonomy. In cases of intra-partum decisions where options are limited, my analysis suggested the need for an increased focus on ongoing provision of information and support. The importance of maternal choice receded but autonomy was not diminished.

What emerges is a complex decisional playing field at several levels. The findings to be presented in Chapter Six build further on those presented in this Chapter.

Chapter Six.

Findings (iii).

Screening for foetal abnormalities.

Introduction.

This is the third findings Chapter. Its focus is on antenatal screening for foetal abnormalities. The purpose of this Chapter is to specifically relate women's experiences to the guideline's recommendations for Down's syndrome (NICE: 2008) in order to understand how women exercise their autonomy when choosing to accept or decline the offer of antenatal screening tests.

The quotes extracted from women's accounts that I present in this Chapter were selected because in relation to my research question they provided interesting revelations about women's autonomy. They also build further upon my two main thematic categories, that is, women's limited pregnancy and birth knowledge and the importance of interactions with trusted healthcare professionals.

I will show that the offer of antenatal screening was experienced in diverse ways by women. Reasons given by women for accepting or rejecting the offer of screening revealed the subcategories of the importance of reciprocal trust in decision-making, compelled to choose, restricting options, eager to choose and little concept of choice.

It should be pointed out that although ethical issues about disability and abortion are inevitably raised during the presentation of findings, they are not the main focus of the Chapter.

This Chapter arose directly from my grounded theory methodology. This is aligned with my interview methods that allowed women to discuss what was important to them.

Background.

Second trimester screening for neural tube defects and Down's syndrome is a well established part of antenatal care. Informed choice was a central concept behind screening, which is borne out in the foreword to the Second Report of the UK NSC (National Screening Committee). This emphasises 'the need to be absolutely clear and explicit about the risks and limitations of screening. There is a responsibility to ensure that people who accept an invitation to be screened do so on the basis of informed choice' (Department of Health:2000). In 2001 a ministerial statement by the CMO informed the NHS that a Down's syndrome screening test should be offered to all pregnant women, regardless of their age (Department of Health:2001). Screening is based on the assumption that it is reasonable for women and their partners to choose to prevent a life with Down's syndrome. Although Down's syndrome affects relatively few families, internationally each year it is discussed with millions of women (Alderson: 2001).

Prior to 2003, there were wide local and regional variations in the timing of and methods to be used for Down's syndrome screening (Pilnick *et al*: 2004). In 2003, there was a significant shift in policy, that is screening for foetal abnormalities; particularly Down's syndrome became a routine part of antenatal care to be offered to all women. Prior to this, there were no national guidelines for screening in the UK, other than those issued by the RCOG which stated that all units should have a written statement of their policy(Lane *et al* : 2001). Previous established criteria such as age could be seen as conflicting with respecting all women's wish to undergo Down's syndrome screening, that is, not all women were offered the test. I set out in my literature review in Chapter Two, Section Two that one of the perceived benefits of guidelines was to offer greater consistency and predictability in healthcare (Woolf *et al*: 1999 Staff *et al*: 2013; Myatt *et al* 2014). The Antenatal care guideline's recommendation was to offer all women the option of screening (NICE: 2003). Women identified as having a baby with Down's syndrome can be offered care and support to either continue their

pregnancy or termination of pregnancy if that is their decision(Harcombe and Armstrong:2008).

The guideline also stated that 'Pregnant women should be offered screening for Down's syndrome with a test which provides the current standard of a detection rate above 60% and a false-positive rate of less than 5%' (NICE: 2003).This could be seen as a potential shift to first trimester screening procedures which are able to achieve that level of accuracy. Maternal serum (HCG + PAPP-A) and NT (nuchal translucency) screening in weeks 11-13 takes place in the context of a detailed ultrasound scan. Through a combination of these two parameters with the pregnant woman's age, an overall risk figure for foetal abnormality expressed as a probability may be calculated. Results are usually expressed numerically, for example, a 1/250 chance that the woman has an affected foetus (NCC-WCH: 2008). The woman will usually be offered a diagnostic test, either CVS (chorionic villus sampling) following a first trimester test or amniocentesis following a second trimester test. When the woman is offered diagnostic testing she should be informed about the risks. These include a risk of foetal loss of approximately 1% compared to women who did not undergo diagnostic testing (NCC- WCH: 2008). NT refers to the measurement of the fluid between the foetal neck skin and the cervical spine. An increased NT is associated with trisomies 21 (Down's syndrome), 18 (Edward's syndrome) and 13 (Patau's syndrome). An increased NT is also associated with a range of other genetic syndromes (Nicolaidis *et al*: 2000).

Down's syndrome is a congenital syndrome in which the baby has an extra copy of chromosome 21 (Patterson: 2009). Without antenatal screening, about 1:700 babies would be affected. The incidence of Down's syndrome in England and Wales was 1.1 per 1000 live births in 2005. This figure represents 753 live births NDSCR (National Down syndrome cytogenetic register).Down's syndrome causes learning disabilities which may be profound, but the majority of affected children learn to walk, talk, read and write, although they will meet their developmental milestones later than their

peer group. There is also an increased incidence of congenital malformations (particularly cardiac and gastrointestinal abnormalities). Around half of children with Down's syndrome have congenital cardiac defects which require surgery, but survival rates are high. The average life expectancy for someone with Down's syndrome is between 50 and 60 years (NCC-WCH: 2008).

Several difficulties have been associated with antenatal screening. There is limited understanding about the best way to present information to women (Say *et al.*: 2011). One of the problems is that healthcare professionals are somehow 'expected to slip seamlessly' between being more directive about certain issues, for example, smoking cessation, to being non-directive when giving women information about screening for foetal abnormalities (Williams *et al.*: 2002a:231). This is borne out in clinical guidelines which promote informed choice based on non-directive counselling (NICE: 2003; NICE: 2008). This has the effect of transferring authority to women with variable effects on their autonomy. Further problems are difficulties raised by healthcare professionals when trying to explain to women different aspects of the screening process. One example of this is the distinction between screening and diagnostic tests (Williams *et al.*: 2002b). Furthermore, not all abnormalities can be detected and no screening test can guarantee a healthy baby (Pilnick: 2004; Heyman *et al.*: 2006). A report co-authored by the RCOG and the RCPCH (Royal College of Paediatrics and Child Health) states that 'A screening test is one which identifies an increased risk or likelihood of a foetal abnormality. A diagnostic test confirms or refutes the existence of an actual foetal abnormality in those at increased risk' (RCOG&RCPCH: 1997:5). Such difficulties are set in a context where the offer of screening may be interpreted by some women as a recommendation and can conflict with informed choice (Press and Browner: 1997). Other published studies in the healthcare literature have shown that despite a high uptake rate, women did not feel they were being offered a choice about screening and did not feel their decision was informed (Ritchie *et al.*: 2004). This concurs with Green and her colleagues' work whose review included 106 publications from 12 countries and concluded that most

women are not making informed decisions (Green *et al* : 2004). These are some of the dilemmas which may impact on women's autonomy.

Guideline.

Clinical Guideline 62. Antenatal care. Routine care for the healthy pregnant woman (NICE: 2008).

Guidance.

First contact with a health care professional:-

Give specific information on:

All antenatal screening, including risks, benefits and limitations of the screening tests.

Booking appointment (ideally by 10 weeks):-

Offer screening for Down's syndrome.

Offer early ultrasound scan for gestational age assessment and ultrasound screening for structural anomalies.

Key priority for implementation:-

Screening for foetal anomalies.

The 'combined test' (nuchal translucency, beta-human chorionic gonadotrophin, pregnancy-associated plasma protein-A) should be offered to screen for Down's syndrome between 11 weeks 0 days and 13 weeks 6 days. For women who book later in pregnancy the most clinically and cost-effective serum screening test (triple or quadruple test) should be offered between 15 weeks 0 days and 20 weeks 0 days (NICE:2008).

The recommendations in this guideline were selected because of their relevance to the main thematic categories and subcategories that emerged from my analysis. As I set out in Chapter Three, Section Two, drawing upon the constant comparative method aligned with grounded theory, not only did I consider the relationship between slices of data, but also incorporated

selected elements from guidelines into my analysis. My aim was to conceptually link the recommendations with my research question and explore women's experiences of their care.

Five subcategories emerged from the two main thematic categories. These were:-

- (i) The importance of reciprocal trust and familiarity in decision-making.
- (ii) Compelled to choose.
- (iii) Restricting options.
- (iv) Eager to choose.
- (v) Little concept of choice.

The importance of reciprocal trust and familiarity in decision-making.

In this thesis, my analysis has revealed the importance to women of trusting their professional carers to enhance their feelings of security and empower them. I set out in Chapter Two, Section Three the importance of a trusting relationship to feeling safe and reassured, both physically and emotionally. This may be more achievable when women are cared for by a familiar midwife, continuity facilitating the development of trust (Parratt and Fahy: 2004; Wilkins: 2010). However, there have been instances when trust was established immediately (Leap: 2010).

The importance of midwives trusting the women they care for to know what is best for themselves may not always be considered (Thorstensen:2000).

This case was selected because it demonstrates not only the woman's trust in her midwife, but the midwife's trust in the woman to make her own decision and the effect of a trusted environment in helping her feel cared for. This is an example of a grandemultigravida, despite her considerable experiential knowledge, needing to trust her midwife as screening for foetal abnormalities was new for her. The case brings into focus the importance of guidelines recognising and responding to women's changing needs in subsequent pregnancies.

Participant:- Sarah.

Gravida 9. Para 6. 35 weeks gestation. Uncomplicated pregnancy.

Extract 6.1

Researcher: *Have you had to make any decisions in this pregnancy?*

Sarah: *The only thing about the pregnancy which has been different to the previous pregnancies is I've never had the blood test for Down's syndrome before, but because of my age I saw my community midwife (who I know really well). She said 'Don't get me wrong, it's not our place and we can only advise and it's not our place to say whether you should or shouldn't, but you read the information and you make the decision for yourself'. It was more based on my age (37 years) and obviously the older you are, the greater the risk of Down's syndrome. I just thought it was better to err on the side of caution. I knew you couldn't miss the slot. The new test is where you have the blood test and nuchal fold the same day together and they send the information off. My youngest is aged six. I don't know where they send the information to - some sort of research centre and they put both sets in - the blood test and the scan results and you come back more clear probability of Down's syndrome . I've never had the blood test before, that's the only thing I've done differently this time.*

Researcher: *So the tests were initially presented to you by your community midwife?*

Sarah: *Yeah, I'm very lucky, she's been my midwife for all my children, so I know her anyway. She's a fab.(sic.) midwife; she's lovely. She made it perfectly clear, 'It's up to you anyway whether you have the blood test'. It was my decision whether I should have it and I even said to her 'What do you think I should do?' but she said 'It's not for me to tell you what to do, it's just that. Read this and if you feel you want it, have it and if you don't, then don't'. Obviously because I've had so many kids for me to read the entire pregnancy information pack would be a bit daft. I did read it 17 or 18 years ago but I haven't read it since because for me it obviously comes with*

experience. I pretty much know certain things from previous pregnancies – and everyone gives you a little bit of advice. However, I did read through the thing about the procedure and because of my age I thought it was best to have it, so I did. It made things different for me this time. (Sighs). But mine are always fine.

Healthcare professionals need to trust the women they care for to exercise their autonomy in a responsible way (Kennedy:2000). **Sarah's** account suggests the midwife's recognition that she is able to make her own decision. Although the woman is clear about the purpose of screening, her account suggests that making a decision was not an easy step, but a trusting relationship can help.

In Chapter Two, Section Three I referred to Boyle and her colleagues' claim that partnership in decision- making recommended in guidelines lack adequate explanation and clarity and may not be attainable(Boyle *et al* :2016). This is because professional carers have authority over women (Leap:2010) and the organisational context of care often prevents woman and professional getting to know each other (Kirkham:2004). However, as Bidmead and Cowley (2005) claim, partnership may be more achievable between women and their familiar professional carers in the community. The woman suggests that she and her midwife established common ground based on reciprocal trust, but it was the woman who made the decision. This has implications for guidelines, that is, reciprocal trust between the woman and a familiar midwife may not only enhance feelings of security but may help promote partnership recommended in guidelines. My contribution is that current recommendations do not make a distinction between partnerships with familiar or unfamiliar professional carers and do not refer to locations of care. Both these factors could impact on the woman's autonomy.

The woman uses the rationale of her age expressed in personal terms, that is, she is 37 years old to justify her decision to accept the combined antenatal screening test. She has read the relevant information. This differs from her previous pregnancies and her account suggests she has given the

tests due consideration. This runs counter to the much quoted US (United States) study by Press and Browner (1997) on MSAFP(maternal serum alpha –feto protein) testing in low -risk women. Their line of argument is that women are frequently unaware that there is a decision to be made or that testing is optional. Green and Statham's(1996) UK study found similarly that women assumed that routine tests were necessary and appropriate. The more recent work of Webster (2007) suggested similar findings. My analysis suggests that in this instance the guideline recommendation has achieved its objective, that is, the woman *is* aware she can accept or decline the combined test and understands the procedures. Nonetheless, she has conferred with a familiar and trusted midwife whose non-directive approach is in accordance with guidelines. Arguably, the test had previously not been salient to the woman, but this time it has new meaning. She stresses the point that this pregnancy is different and demonstrates to her midwife that she sees the responsible course of action to consider screening.

Although screening is frequently an accepted part of antenatal care, for this woman it is anything but a formality. She has had six good pregnancy outcomes. However, she is aware that the tests must be performed within a defined time-span which may add 'cost' in personal terms as it exacerbates a tentative situation. As Santalhati *et al* (1998) say, although presented as a choice, it is a difficult one because women have to make several decisions within what could be seen as a prescribed and limited time- frame. These include whether to accept antenatal screening, if an increased risk is suspected, whether to have diagnostic tests and what to do if an abnormality is confirmed. Her account, in stressing the distinction between this pregnancy and others, harkens back to when there was no such impetus to choose. The woman's expression of autonomy is to pursue the matter in an informed way.

The ultrasound scan and serum screening could be interpreted as more congruent with the medical objectives of the procedure, that is, searching for foetal defects, as opposed to obtaining reassurance about foetal welfare. This is the antithesis of what the woman perceives as normal, firmly shaped

by her six previous pregnancies. We are unaware as to whether, or in what ways testing was presented to her in previous pregnancies, that is, whether it somehow obscured the need to make a decision - hence the woman's autonomy was unaffected because she was not burdened by the prospect of having to choose. Her greater responsibilities are mitigated by the trusting relationship with her midwife whose approach encourages the woman's perspective. The woman links her sense of control to her midwife whose support helped her make a decision.

Extract 6.2.

Researcher: *Could you tell me the outcome of the screening tests?*

She continues:-

Sarah : *Oh yes, it came back low risk . It comes back as a percentage risk , more of a ratio. I can't remember what it was, but it was extremely low, so that was fine. I didn't need any further investigations, but she (community midwife) made it perfectly clear that it was my choice, she didn't try to sway me in either direction. Some people never have it. I've never had it before, it was because of my age and I thought that's a guideline as well. I was just fitting into that category. I'm looking at it on the wall now (Points towards a chart displayed in the Antenatal Clinic Interview Room) and there's the risk. When you're under 25, it's really low, that's why I've gone for it this time.*

The guideline's recommendations shaped the woman's care in ways that are subtle but significant. Her account suggests she is aware that accepting the test may result in the need to make further decisions, that is, whether or not to accept diagnostic tests. She does not articulate whether or not she would terminate her pregnancy (or maybe she had not thought that far ahead) and had chosen to take each stage of the process in a logical order. She was unable to recall the test result in numerical terms, which suggests she places limited value on laboratory data and more on her much-trusted community midwife's interpretation of the statistics. Hence, although guidelines promote greater involvement in decision-making, it was her evaluation of personalised information *and* trust in her

midwife, rather than solely the numerical cut-off point which reassured and empowered her. Autonomy was associated with information the woman understands, coupled with the assurance that no further investigations were warranted. This finding builds further on **Catrin's** wish for personalised information (**Extract 4.7**). **Sarah's** perception of low- risk and her midwife's appear to correspond, that is, the midwife's interpretation of foetal well-being translates into the woman's personalised understanding of foetal welfare. The context of reciprocal trust suggests that the woman is a judicious user of the information she was given. Her account suggests her autonomy depended on what was directly relevant at the time.

She continues:-

Extract 6.3

Sarah: *I have to be honest, because I'd opted to have a nuchal fold scan, I thought it was nice to be booked in by my midwife rather than the doctor, and there's geography as well as I happen to live in the same road as the Sure Start Centre. I liked it that you had all your blood tests - iron count and that - she did those there and then and sent them off. When I came to Hospital which is where I'd be coming to have the baby if the tests are alright - 'cos (sic.) I know I can't have a home birth as I'm a high risk for haemorrhage - it (the scan) was quick. **Pause.....** With it being different this time around, that's definitely the way I'd have chosen to be treated. There's a lot of children in my house and I didn't want to bring them with me or have to get childcare. They'll find out soon enough. It was completely different this time. It might not have been very pleasant and could have turned chaotic, so for me it was a much more sensible way of doing things.*

The woman's account suggests she attaches considerable importance to her care being provided by a familiar midwife in the community. This concurs with the Antenatal care guideline's recommendations. 'Antenatal appointments should take place in a location that women can easily access. The location should be appropriate to the needs of women and their community' (NICE:2008:12). Although national guidelines do not take into

account the availability of services such as Sure Start, the woman's expression of security is influenced by local service provision. Although the guideline shapes her experience, her account suggests a deeper meaning than simply geographical convenience. Principally, she avoids attending hospital and she suggests feelings of security in local services which enhance her autonomy. She describes the ultrasound scan as 'quick' and does not hint at any sense of excitement or pleasure at visualising her foetus for the first time. There are several qualitative accounts in the healthcare literature which suggest there is compelling evidence that women attach considerable importance to being able to 'see their baby' (Campbell *et al*: 1982; Villeneuve *et al*: 1988; Green *et al*: 1992). Rather, the woman's account suggests she tried to maintain a distance from her foetus and the scan was something to be endured which further endorses the fact that she took seriously the offer of screening and did not see it as a formality. Getz and Kirkengen's work written in the context of the discovery of an increased risk of foetal abnormality being disclosed and explained to parents, refers to the situation as a 'profound and private moral dilemma' (Getz and Kirkengen: 2003: 2054).

I suggest this woman's dilemma was realised when she seriously considered the need to make a decision. Her wish to temporarily conceal her pregnancy from her children suggests anxiety and in the event of a high-risk result there may be challenges to her autonomy. I suggest it is the *absence* of talk of what action she might take in the case of a suspected abnormality that contributes to her private dilemma. Other researchers have taken a similar line of argument. Baillie and her colleagues (2000) suggest that the situation may be further exacerbated by what they refer to as the most relevant statistic to the individual pregnant woman, the population base of one-herself. The woman's account suggests this is her way of making sense of her personal risk and privatising responsibility for preventing the birth of a disabled child. Her response suggests her reticence to share confirmation of her pregnancy with others. Her assessment of risk prior to her test results governs future foetal life, that is the decision of whether to undergo further diagnostic tests.

The issue of responsibility has particular consequences relating to the woman's autonomy and recommendations in guidelines. In this context, there are those who have interpreted the UK guideline on first trimester antenatal screening in diverse ways. Harris and her colleagues claim that first trimester screening technologies place an emphasis on the individualised risk model of pregnancy, whereby pregnant women become responsible for self-government (Harris *et al* :2004). Arguably, the act of making the option available promotes in some women a sense of responsibility. Just as presenting for antenatal care demonstrates women's responsibility to their foetus, screening tests are very much a part of that care. However, it does not follow from this that women act independently at the point of decision-making.

The woman suggests that part of the process of accepting the test involved thinking about the effect of a Down's syndrome child (or a child with other disabilities) on her existing children. This is an example of the effect of the guideline's wider implications on women's families. At no time does she point to any foreseeable burdens she might experience. My analysis suggests she attaches less importance to the test procedure *per se*, but great value to its ability to provide her with personalised information. Just as her pregnancy progresses, she sees a situation that could potentially escalate. If she were to decline testing, her decision might conflict with her relational responsibilities, and the woman has connections to others. It may be a complex web of relationships in which she herself is embedded (Granovetter: 1985). This does not suggest that she accepted solely for her family's sake, rather that the offer of screening was not perceived as neutral. Women are frequently motivated by reasons that can only be understood with reference to other people and their decisions need to be determined in the context in which their beliefs and values were formed. The impact of the guideline is that it is not simply an instrument to reach a certain goal. Rather, it is socially attuned to the ways in which options are understood and acted upon within a relational context.

The decision moved from the individual paradigm the woman associated with her previous pregnancies and further into its relational context. Many decisions in pregnancy are based on whatever is the safest option for the foetus - *but this one differs*. The option of screening alone is inadequate to capture the woman's concerns that have a major influence in her life. She broadens and effectively shifts her decision- making framework. The guideline is facilitative in that its recommendations say she can include others in her deliberations.

She continues :-

Extract 6.4

Sarah: *I'm an old hand now and for me obviously the information pack they give you is a bit general, so I haven't read it. But with the nuchal fold this time I did and everything that I wanted covered was covered.*

The option of screening takes place in the space between the clinic and the woman's life circumstances. The impact of the guideline is that some degree of responsibility for future foetal life is effectively transferred to the woman. It is an interesting feature of the woman's account the she refers to the information pack as 'a bit general'. Nonetheless, it met her specific need for information about NT screening. This finding suggests there are instances when women themselves can choose to exercise their autonomy by segregating specific information from the general and applying it to their own situation in an informed way. It also demonstrates to her midwife that she was informed about her options and able to exercise her autonomy to manage a complex decision.

Compelled to choose.

Another woman's account suggested that the offer of a choice *did* compromise her autonomy. This extract was selected as an atypical case and a specific example of the midwife's directive approach.

Participant:- Jasmine.

Primigravida. 30 weeks gestation. ICP.

Extract 6.5

Researcher: *When you were offered screening tests, was it made clear to you they were optional?*

Jasmine: *Yes it was. I had the one slightly later on - the triple test. By the time we came in and I was scanned she (foetus) was already 16 weeks, so she'd hidden herself for a while, so it was too late for me to have the earlier one. I had this triple test and although it was presented as an option, at the Booking-in session, the midwife - I don't want to use the word 'forceful', but she was far more encouraging about having it than not. **Pause.....** I didn't want it particularly, but my husband did and I was kind of booked in for it - not against my will - I'm not going to say it was against my will because I had the right to say 'No, this isn't for me', but the reason I was not for having the test was because when it actually came down to it, nothing was ever going to change for me. Termination was never an option, so really, in my opinion, what was the point because it was never going to change anything for me. But yes, I remember – the one thing I remember being said to me was – 'Well, you're only 30 – there's a 1:900 and something chance of Down's syndrome - you're really low risk , you may as well 'and I think that stuck with me.*

Jasmine's account suggests that although she understood the tests were optional, she was influenced by her husband and the midwife. As Donovan (2006) puts it, although screening tests increase 'options' they decrease 'choice' in the sense of freely made decisions. It is also relevant that she thought through the usefulness of the risk ratio from which she sets out her value commitments with reference to future pregnancy management based on reasons she understands.

The interesting feature of her account is the positive encouragement by the midwife to accept the test. The midwife's directive approach was inconsistent with guidelines. Authority was somehow transferred from the woman to the risk ratio presented to her. This is not to infer that guideline recommendations are based solely on preventing a child with Down's

syndrome or other abnormality from being born. Rather, the woman experienced it not so much as an option but as a recommendation by her midwife which guided her into complying. Her account concurs with Nicol's work (2007) who found that when women are in a stressful situation, they comply with what they perceive is their healthcare professional's recommendations. Her wish not to be tested has been compromised by professional authority.

Restricting options.

A woman suggested she placed her own restrictions on screening tests. She exercised her autonomy to make her decision based on what was relevant to her. This case was selected because it exemplifies how the woman's experiential knowledge and relational values influenced her decision to decline the tests.

Participant:- Isabella.

Gravida 5. Para 3. (1 miscarriage). 27 weeks gestation. Uncomplicated pregnancy.

Extract 6.6

Researcher: *Have you had to make any decisions in this pregnancy?*

Isabella : *There's only the screening and things. For my age (45 years), the high risk of Down's syndrome.*

Researcher: *Did they make clear to you it was optional?*

Isabella: *Yes, they did. On your Booking-in appointment they go through everything - what your options are and it's in your notes for you to look at, that you've declined or not declined. I think it is made clear to you and as an older mum you inform yourself and find out about these things more maybe than if you were younger and I think that goes for a lot of things.*

Researcher: *So, regarding the screening tests, what did you decide?*

***Isabella:** I didn't have the screening for Down's syndrome because the only way it's 100% certain is the amniocentesis to guarantee and there's no way I'd have that. I don't believe in abortion, that's my choice. I'm not saying it's everyone else's and what is the point in knowing if the only benefit of knowing is if it would make any difference at the birth, but that won't really because you have all the specialist care here, so if the baby is born with difficulties, the care's here anyway. They're fabulous here, the way you're treated. You do matter. It's important and it's your baby. I'm not opting for home birth, so I don't need to know for that reason. I don't need a test to come back - the chances are it's going to come back high risk because I am - so why have your pregnancy ruined? Also, I'm scared with my history of miscarriage. I just wouldn't put myself through it, what with the miscarriage last year and the risk of miscarrying again. It does take the enjoyment out of your pregnancy and you're working in weeks, not months. I've gone past that. We've only just gone into maternity, prior to that it was just getting to the next appointment, that's why I haven't chosen any of those tests. A few weeks ago, I had the scan when they look at the whole baby's body and it looked fine. They tell you there and then which is brilliant. I think that's the important thing. Why have the tests unless you choose to end that pregnancy?*

The offer of maternal serum screening and nuchal translucency are presented in guidelines in terms of expanding choice for all women (NICE:2008). Concurrently, the literature for women and healthcare professional counselling about antenatal screening gives some indication of the likelihood of foetal abnormalities. In accordance with the guideline, **Isabella** is clear that she may accept or decline and her account suggests that she was able to make her own decision. She sees as a foregone conclusion that her risk probability is, by virtue of her age, 'high'. She also indicates her grasp of the limitations of screening tests and the definitive nature of amniocentesis. She does not wish to resort to testing and laboratory data to confirm her risk factor. This in itself is a choice. She has her autonomy and chooses to exercise it to decline. As Beck-Gernsheim (1995) says, healthcare professionals have a duty to inform women about

the available options, so even women who decline screening are unable to do so until they have given the process some thought. Although the woman does not indicate any sense of compulsion to deliberate between the available options, she could not elect *not* to be given the *offer* of screening. Rather, it was a part of her care over which she had little control. She has experiential knowledge and it was unsurprising to her that it was offered; she had been drawn into the expectation of a screening culture. Moreover, she might have questioned had the option of screening been overlooked or abandoned.

However, she feels some need to justify her refusal. Her recent miscarriage was something *not* previously experienced – her former faith in her reproductive abilities has been put to the test and any previous certainties have been markedly challenged. She concedes that ‘We have only just gone into maternity’, suggesting that she had endured several precarious weeks when there was a greater risk of miscarriage. She suggests she has reached a significant milestone in pregnancy and enters ‘maternity’ in a formal sense. Her initial recognition of the current pregnancy and her feelings now differ widely, perhaps indicating a quantum leap. Yet she faces a dilemma. On the one hand, the woman is asked to take due care of her foetus, and be willing to abort. On the other, she has the offer of tests, but her response is to reject them. My contribution is that it may seem a confusing picture that the woman’s autonomy is enhanced not by expanding, but limiting her options.

My analysis suggested that the option of tests has aggravated an already fraught situation. Any perceived pressure to accept would have placed constraints on the woman’s wish to decline. If she were to seek information over and above that provided by the obstetric ultrasound scan as reassurance, there is a price to be paid - and it is one that may place her on the pathway of needing to make further choices about amniocentesis. She fears invasive testing may result in the very thing she autonomously wishes to avoid, namely a miscarriage. When weighted against the primary goal of avoiding miscarriage, testing may ultimately result in the very antithesis of

that goal. Testing will raise more fears than it will allay. This finding concurs with the literature on the recognised downside of screening, that is, the worried well and creating anxiety (Shickle and Chadwick:1994). She does not have a strong case for testing. Rather, in her calculus she has a far better one to avoid it. If a central tenet of screening is the offer of a choice, then one of the available options must be that the woman may opt out if she wishes. The implication for guidelines is that professional carers need to be alert to women's specific concerns and the ways these might be interpreted and limit their options. The consequences of tests for some women extend way beyond the application of technology such as ultrasound scans.

She continues:-

Extract 6.7

Isabella: I've got a friend with a daughter who's 15 with Down's syndrome and I'm actually studying Educational Needs of Children with Disabilities at the moment – so I'm sort of prepared if that happens. It's not the worst, there's worse things than that.

The woman has some acquired knowledge of Down's syndrome which she attributes to her friend's child and the course of studies she is enrolled on. She does not refer to information she received in consultation with health care professionals, rather the information she herself sought out and personal experience. The information given to women about the conditions for which testing is offered tends to be brief (Marteau *et al*: 1992; Murray *et al*:2001). This contrasts somewhat with the screening process *per se*. The decision to accept or decline is more complex than clinical content alone. Women are both autonomous *and* relational. Relational factors featured prominently in her account and she exercises her autonomy accordingly.

It is perhaps ironic that the woman's account suggests she places great trust in professionals providing her maternity care (**Extract 6.6**). Williams and her colleagues found that although information relating to screened for conditions appeared to be balanced, practitioners lacked a grasp of *what it meant* to live with a child with Down's syndrome (Williams *et al* :2002a),

that is, the very system the woman regards as expert may be falling short in this respect. This is because a general background about the lived reality of the condition should be made part of the training of those offering screening tests (Tyzack and Wallace :2003; Fuchs and Peipert : 2005). There is an inference that healthcare professionals lack specific knowledge about day to day functioning, care and responses to treatment of those affected by Down's syndrome (Parens and Asch:2000). The woman's account suggests she has a vision of how an affected child might affect her lifestyle and has decided this is not something she strenuously wishes to avoid. She concedes that 'It's not the worst', suggesting that there are conditions she would rate as infinitely worse than Down's syndrome. Her own research and personal acquaintance with a Down's syndrome child influenced her decision, although her experience is confined to one particular case. It could be argued that she was not as fully informed as possible and this compromised her autonomy. Nonetheless, her focus is not on potential problems associated with Down's syndrome – which is variable, that is, she is not a quality controller of her pregnancy. Rather, she is the safe-guarder of her foetus, to whom she perceives she owes maximum protection. For her, autonomy depended on what was most relevant to her.

There were some women for whom the recommendations on screening tests for Down's syndrome in guidelines were perceived as superfluous or even burdensome. This was based on their previous experiences. These extracts were selected because they are examples of how the offer of screening to all pregnant women in guidelines can be unhelpful for some women.

Participant:- Hannah.

**Gravida 3. Para 1. (1 intra-partum death) 31 weeks gestation.
Attending Medical Specialties.**

This case was selected because it is unusual. It comprehensively illustrates the subcategory of restricting options.

Extract 6.8

Researcher: *Have you any hopes or expectations for this pregnancy?*

Hannah: *From my previous experience, just a live, healthy baby to me is fine - not bothered about the gender. I'm not even concerned if - touch wood, the baby was to have any kind of defects or anything. I would love the baby anyway, and that's something I've learned through losing a healthy child to the unfortunate substandard care that was provided to me (sic.).*

Researcher : *Were you given the offer of screening tests?*

Hannah: *I was, but because of my previous experience, I didn't have any.*

Researcher: *Could you tell me more about your decision to refuse the tests?*

Hannah: *I've come to a point, because of what happened to me in my first pregnancy, it's made me look at having babies in a completely different light. In the beginning I would have followed the stereotypical – Well, if I've got a Down's syndrome baby, they'll find out. **Pause**..... Because I lost my child, that ignorance left me and if I so long as my baby's alive, I don't care what form it comes in as opposed to – if it hadn't happened to me , I might have been - It's got Down's syndrome; Oh, terminate it. I would **never ever** consider terminating a baby ever - never in any situation (Spoken emphatically). Anyone who's had a traumatic experience, it opens your eyes. On the second as well as this pregnancy - not bothered, they (screening tests) don't need them, don't want it.*

She continues:-

Extract 6.9

Hannah: *And even the midwives would be like – it was obviously the norm, everybody wants to know if there's anything up, any detrimental effects - even if there is, they want to terminate it and then I come along. If I was to have a baby, I'd still love the kid exactly the same as if it was a healthy baby, I would personally. Whether I could say that before I don't know, and*

that's just me being honest, but now - Yes, certainly I do and straightaway I said I'm not interested - don't want it, especially when there's things linked to where it can miscarry after the test and things. In the beginning, (first pregnancy) I would just go along with it. Midwives, doctors, consultants, surgeons, they were always right.

*What's the point in putting them there in the first place and then, yeah, you have these tests, but we're only 85 or 75 % sure? Well, I'm quite an analytic person and I just think that's ridiculous - if anything's up with your baby regardless we can find out - but it might not be. For example, I've got a sister-in-law who was told her three children were at risk of Down's syndrome. Every single one of those children were perfect and absolutely gorgeous looking kids as well. It didn't ruin her pregnancies, but if she was another person who would have said – 'Oh, get rid of them', she's just lost the chance to have three gorgeous little boys by listening to something that was frightening to her. Fair enough, if they've got 100% evidence that it is. (Spoken angrily). **Pause.....** (Recomposes herself.) It's the same when you go for your gender. Do you want to know? Yeah, but it might not be - right, then what's the point in telling you in the first place? Is it the case that they haven't studied it enough? Wishy washy. I work in banking and it's highly monitored - very precise. (Sighs deeply). But I suppose everybody's different. I am the rare case.*

Hannah's response to the tragic events of her first pregnancy suggests a long-term reaction which, unsurprisingly, has influenced her second and current pregnancies. It has resulted in her not so much having a need to know, but rather no need to confirm nor refute the presence of a detectable foetal abnormality. The offer of a choice helped facilitate her refusal, but her account suggests it was an additional burden during a very tense pregnancy. Hence the offer of tests conflicts with her wishes. Antenatal screening tests that might place her in a high- risk category could be seen as superfluous as they would not be actionable by her. The guideline's recommendation that all women should be offered the tests cannot be framed in terms of the woman's self-selection or rejection of the option.

Rather, it is something that results from it being set out as a recommendation. The guideline creates a dilemma in that she cannot choose not to choose. The concept of 'choosing not to choose' is not something new. The work of Kitzinger(1987) and Leap and Edwards (2006) refer to it within a framework where control was less important to women. This might be, for example, because they were unaccustomed to asserting themselves or want their professional carer to decide for them. My findings challenge these authors' work as the woman's account suggests that control is a salient issue for her.

My contribution is that there is no opportunity in the guideline's recommendations for women not to be offered screening tests. Hence, the main purpose and perceived benefit of the guideline, that is to make the option available as a deliberate act, is problematic for some women. However, it is the healthcare professional's duty to inform women about the available options. Women who decide they wish to reject screening cannot do so until they have considered these options. For some women it is a recommendation which undermines the notion that some women prefer not to consider the option of screening tests.

Consistent throughout is the woman's expressed wish to avoid antenatal screening tests. Her decision to decline the tests has arisen from a previous intra-partum death which has markedly changed her outlook. Similarities may be drawn with Lundgren's work (2005) on intra-partum care in which she talks about women being in an unavoidable situation, that is, labour – which changed the women and was also a platform for empowerment. **Hannah's** account suggests how much *more* must the tragic events have changed her perspective and her wish to exert control over events during the antenatal period - something that might be her only means of controlling her fate. Her decision to decline vociferously is relational, but not in the sense that it is linked to trust in professional authority. Rather, it is part of the woman's personal values, hopes and fears which are strongly influenced by her past experiences. Her autonomy is exercised within that framework. This case differs markedly to the accounts from **Sarah**

(Extracts 6.1 6.2 and 6.3) and **Isabella (Extracts 6.6 and 6.7)** where there was established trust in professional carers.

The woman suggests that her own experiential knowledge is key and that the knowledge asymmetry between professional carers and herself may not be very significant. Her reasoning differs markedly from cases which suggested knowledge asymmetry. Examples are **Catrin (Extract 4.5)**, **Georgia (Extract 4.12)**, **Lisa (Extract 4.18)** and **Catrin (Extract 5.12)**. The implication for guidelines is that professional carers should explore and give serious thought to her specific concerns and how they impact on her decision to decline.

The woman's account suggests she has unrealistic expectations about the screening tests, that is, they should give definitive results. However, this is not new. Enkin and Chalmers (1982) suggested that the marked improvements in obstetric outcomes since World War Two have literally encouraged expectations to rise to the extent that achievements are unable to keep pace with them. Given the complexity of the tests, it is unsurprising that there is a corresponding unwillingness to tolerate uncertainties. Maternity care has become more complex during the interim, with a broadening of the target population for antenatal screening and an expansion of options. My analysis suggests that her account differs from **Raine's, (Extracts 5.8 and 5.9)** where there were ambiguities about the various alternatives, but nonetheless a commitment to weighing them into the balance.

It is not **Hannah's** expectation that these tests will, in some unspecified way, contribute to a good pregnancy outcome. Rather, it is their perceived controversial nature, coupled with her previous experience that makes her reject them outright. It mattered deeply to her that the guideline says she can decline and she exercises her autonomy in so doing.

Another woman expressed a wish not to be informed about the offer of screening tests.

Participant:- Rebecca.

Gravida 3. Para 2. 30 weeks gestation. Uncomplicated pregnancy.

This case was selected because it is characteristic of 'strong' relational autonomy in decision- making.

Extract 6.10

***Rebecca:** Because I'm Muslim, although they told me about them (screening tests) , I didn't want to know. They didn't push me, it's up to me.*

Rebecca's decision to decline the tests is relationally situated in that it reflects her religious beliefs. As I set out in Chapter Two, Section Three, 'strong' relational autonomy is not only about relationships with other people. Rather, there is another layer which includes personal beliefs and values that have shaped the woman's identity (Donchin:2009). Again, in accordance with recommendations in guidelines, the woman cannot elect not to be informed about the screening tests and is unable to reverse the fact that the midwife offered them, that is, the guideline has a powerful effect in shaping her care . Arguably, it could be said she was no better nor worse off. This is despite the fact that perceived key benefits of the guideline are to offer all women the option of screening. The very act of refusing was important to her in that she did not simply go along with what she was offered. She exercises her autonomy by refusing which in itself is a choice.

However, it was not all women offered antenatal screening tests who faced doubts. Analysis suggested that the offer of screening tests surpassed their expectations but did not have the effect of overwhelming them.

Eager to choose.

These cases were selected because their extracts concur with the objectives of the recommendations in guidelines.

Participant:- Lisa.

Gravida 2. Para 1. 28 weeks gestation. Uncomplicated pregnancy. Attending Hospital-based Antenatal Clinic for anti-D prophylaxis.

This case is an example of the woman's perception of being invited to choose and treated as a genuine participant in her care.

Extract 6.11

Researcher: *Did you have the offer of antenatal screening tests?*

Lisa: *Yes. I had my first baby in France in 2009 and coming from somewhere else you have no idea of what to expect. I opted to have the screening for Down's syndrome because it meant there were no implications - I mean in physical terms - for the foetus. If the screening tests had shown up an anomaly I wouldn't have gone on to the other tests which might have caused miscarriage, which is what happens next. So I was offered and it was clear it was optional, particularly in the literature – it was quite clear it was optional. The literature took quite a bit of ploughing through, actually. There are several booklets and things, all these arrive in the mail. You get a lot of information and some of it is quite complicated. I remember making an effort to sit down with it and it was actually quite a task.*

She continues:-

Extract 6.12

Lisa: *Yeah, one of the things I found quite interesting was the long letter saying 'Even if you do the screening tests that doesn't necessarily mean that they know your baby is or isn't going to be Down's syndrome'. It was the same with the scans - that it won't pick up on everything, whereas the experience I had previously in the French system was they just did things and tell you the results. There seemed to be no worry whether or not there might be some degree of..... you just sort of got told – 'You've got a 1:330,*

but the baby's not positive for Down's' and it's just left there (Laughs); whereas the letters I got this time, the two or three – like - It may or not be and we can pick up on most things and these are the percentiles. There wasn't any of that in France at all. They do the scans and they tell you' Oh, the baby looks normal' and that's it. I went on to have a perfectly healthy child. You don't have that sort of breakdown. In France, I think it's routine procedure to do it. They can be quite clinical - a 'doctor knows best approach'. There's an appointment made for you. Turn up for it! (Laughs). It was my first pregnancy and I think I'd like to have been a bit more closely monitored, whereas this time around.....

Lisa's previous experience is shaped by the French antenatal care system. It is the very act of offering tests in the current pregnancy that appears to have exceeded her expectations and extended her control. She is the mother of a healthy child and her account does not suggest tension about what the tests may or may not detect. Rather, her account suggests that her new found involvement has given her an unexpected sense of control. This is an example of the guideline enhancing the woman's autonomy.

The woman suggests that the knowledge she gleaned and the invitation to choose whether to accept or reject the screening tests shifted her expectations. Drawing upon her previous experience, it may not have been her expectation that her views would be sought. What is significant is that the screening process is commenced early in pregnancy and this in itself may have (in some unspecified way) altered her expectations of her maternity care as a whole.

She defines the tests in her own terms, that is, if she accepts screening, the chances are she will get good news. If not, she makes the connection between testing and selective abortion and her acceptance of the screening tests will not translate into actionable behaviour. She wants the information that screening provides to be used as standalone knowledge about her foetus.

The guideline coheres with her values in that it encourages her participation. In certain respects, her sentiments draw parallels with Harrison and her colleagues' study. Their work explored the experiences of 47 women with pregnancies threatened by hypertension or pre-term delivery. A major theme in their work was 'wanting to do it differently next time', that is, to be more active. Participants' accounts suggested that in decisions relating to their care, their passivity bore relation to their doubts and vulnerabilities and healthcare professionals' influence (Harrison *et al*: 2003). Their qualitative work is interesting, but the sample is confined to high-risk pregnancies and guidelines are not alluded to. Rather, the main focus was on women's satisfaction with their involvement in maternity care decisions. For our purposes, this raises the question as to whether **Lisa**, following the uncomplicated pregnancy and birth of her first baby, even considered that she would want to approach her care differently in subsequent pregnancies. On balance, it may be that her newly found empowerment is related more to the comparisons she inevitably draws between the French system and care offered in her current pregnancy and somewhat less to the offer of a choice in recommendations in NICE clinical guidelines. The French guidelines which were operational in 2009 read as follows:-

FRANCE.

Screening for Down Syndrome.

The current policy for prenatal (*sic.*) screening of (*sic.*) Down's syndrome in France includes:-

- Nuchal translucency measurement as a matter of routine between 11 and 13 weeks of (*sic.*) gestation.
- Maternal serum screening between 14 and 16 weeks, which should be systematically proposed to all women as stated by a law implemented in January 1997 (de Vigan: 2004).

In this respect, it would be interesting to turn the equation around and ask – had the woman been cared for in England last time, whether her perception this time would have differed, or whether she would have accepted her care without question. The gateway to a different system of care this time enhances her autonomy- but arguably it is within that very system. Her account suggests that it was more difficult to opt out last time. The wording of the French guideline makes no reference to a choice and it is interesting that the woman's perception of what she perceived as routine *is* borne out in the guideline's recommendations. The woman's account concurs with Vassy's (2006) research which found that most women in France did not make informed decisions to be tested which affected their autonomy.

The wording of the NICE guideline (2008) is more facilitative than the French. The woman does not verbalise whether she accepted routine testing as a clear message of approval during her last pregnancy, but this time her care assumes new momentum. For her, there has been a conscious effort to offer testing within the context of informed choice in accordance with guidelines. Her account suggests that being in England this time made her feel more in control than in France.

Another woman's account suggested she exercised her autonomy to accept the tests.

Participant:- Charlotte.

Gravida 2 .Para 1. 33 weeks gestation. Gestational Hypertension.

This case was selected because it is an example of a woman who welcomed the offer of screening tests.

Extract 6.13

Researcher: *What about screening tests for abnormalities, was it made clear they were optional?*

Charlotte: *Yes, it was and I think the screening programme is a very good screening programme.*

Researcher: *Why is it good?*

Charlotte: *Knowing you can make decisions about things and if something isn't quite right, then you've got choice. I think the fact it gives people choice and empowers them is really good, because not everybody can cope with the different things or want to face the extra challenges some babies bring and I think the fact that you can arbitrate these days is a good thing.*

Researcher: *How did you feel about choosing?*

Charlotte: *I was keen to choose. I wanted to have everything that was available to me, all the different screening tests, so every single one that was available to me I wanted to have, so I was well informed of any potential problems or abnormalities that were there. I'm the one carrying the baby, so I've got someone else to take care of. I wanted that information so I could make a choice if the pregnancy was to continue or not.*

Charlotte's thought process appears clear in that she goes beyond the mechanics of testing and refers to the end point when termination of pregnancy might become necessary. Her account suggests she places a reliance on the screening tests offered to her. This thought is based on the assumption that healthcare professionals' expertise and the information the tests generate would in some way provide information about foetal welfare or lead to a decision to terminate her pregnancy. Her account concurs with Muller *et al* (2006)and Garcia *et al* (2008) whose work concluded that women's reasons for accepting screening tests included reassurance and being prepared in the event of the need to consider further options such as diagnostic tests. She suggests that the option of screening tests is a good thing and if we were to place limitations we may compromise her autonomy. Care is offered in accordance with the guideline which has the effect of making her think about the usefulness of the service which has empowered her.

Little concept of choice.

Other women's accounts suggested that the offer of antenatal screening tests had no meaningful impact on their autonomy. These extracts draw out the routine nature of testing.

Participant:- Safia.

Gravida 5. Para 4. 28 weeks gestation. Uncomplicated pregnancy.

Extract 6.14

Researcher: *Were you offered antenatal screening tests?*

Safia: *Yes, I had the scan and blood test. I don't mind anything (Laughs). Whatever's going – exactly. Down's syndrome they test for is it? I forget about this word. (Laughs again).*

Safia accepts the tests that she views as unproblematic. Screening is sending out a clear message of approval which is woven into the matrix of what is expected in that it is routine, not questioned and hardly experienced as a choice. This is not in accordance with recommendations in guidelines. Her account suggests she did not fully understand what had been offered to her. Although she had a decision to make, she suggests she had not gone through the process of thinking about what might happen with a high-risk result. The woman's autonomy is maintained at a constant.

Participant:- Holly.

Gravida 3. Para 2. 29 weeks gestation. Attending Bariatric Pregnancy Clinic.

Extract 6.15

Researcher: *Were you offered antenatal screening tests?*

Holly: *I said 'No' straightaway. I just didn't want it. It's as simple as that. I've never had it with the other two kids either.*

Holly refers to her two previous pregnancies, suggesting the routine nature of her refusal. Her account suggests that although she exercises her autonomy spontaneously, it was but a formality on her part to decline testing. In this case, what is presented in the guideline as a recommendation of informed choice is seen as a routine act. This draws out the regularity of the context in which some women make their decisions.

Conclusion.

This Chapter has demonstrated that the introduction of new guidelines with the offer of first trimester screening presents new dilemmas which impact on some women's autonomy. The implications of wider testing suggest a mixed picture.

- **Reciprocal trust and familiarity.**

A trusting relationship can enhance the woman/healthcare professional relationship and help create the context for care that is recommended in clinical guidelines. Giving trust to the woman, particularly from a familiar professional carer with knowledge of the woman's previous experiences and family dynamics can help enhance her autonomy and promote partnership decision-making recommended in guidelines.

- **Compelled to choose.**

We have seen an example of not so subtle pressure being placed on a woman to accept antenatal screening. Although not directly attributable to the guideline's recommendations, the rhetoric of objective information which led to her decision may seriously compromise a woman's autonomy.

- **Restricting options.**

We have seen an example of a woman who exercised her autonomy by placing her own restriction on her options. It is ironic that the expansion of antenatal screening tests in guidelines is perceived by some women as placing a restriction on their autonomy.

We have seen examples of women who chose not to choose. The idea that in offering screening the guideline is giving women a choice is not quite correct. This sometimes has the counter-effect of limiting rather than increasing women's options. Increasing choice does not always correlate with women's wish to make decisions that encompass their own values because they would have preferred not to have been offered the choice in the first place.

Guidelines seek to reconfigure authority to the woman, but in a subtle way women may be directed down a path they would not otherwise have chosen under the rhetoric of objective information and informed choice.

- **Eager to choose.**

There were women who equated the offer of tests with a sense of control. One woman perceived that the results would equip her to make other choices if appropriate. This is an example of the empowering effect of guidelines.

- **Little concept of choice.**

There were other women who accepted or rejected the tests as routine—almost a corollary to being pregnant.

In sum, information about screening conceptualised as neutral may ultimately lead to interventions which are value-laden and impact on women's autonomy. In accordance with guidelines, professional carers appeared to use a particular approach. Such care may or may not recognise women's specific needs and preferences.

Chapter Seven.

Discussion and Conclusion.

Introduction.

Aims and objectives.

The purpose of this thesis was to gain an understanding of how the recommendations in maternity care clinical guidelines are experienced by pregnant women and their impact on women's autonomy.

The main impetus for the enquiry arose from what I found was under-researched in the healthcare literature, that is, few previous studies specifically asked women about their experiences and analysed their responses in relation to their care based on recommendations in guidelines. Building upon what is already known; it was proposed that an in-depth analysis of women's experiences in an empirical research study would help address the gap.

The thesis explored women's accounts about their maternity care experiences and the extent to which these concurred with or raised challenges for guidelines. Based on my findings, I make proposals for reframing certain recommendations in guidelines

SECTION ONE.

Research question:-

How are the recommendations in maternity care clinical practice guidelines experienced by pregnant women receiving maternity care?

SUMMARY.

(i) Methods.

The methods I used to investigate this question were:-

- The literature review in Chapter Two in which I critiqued a selection of the healthcare and bioethics literature relevant to the study.

and

- Face-to-face semi-structured interviews with a sample of 20 pregnant women were conducted in the Antenatal clinic of an inner-city teaching hospital and audio-recorded. Data collection, transcription and analysis was informed by adaptation of Constructivist Grounded Theory (Charmaz: 2006).

(ii) Findings.

Women's expression of their autonomy was often more complex than suggested by either a liberal or relational model of autonomy.

Women expressed their autonomy by sharing their previous experiences, current expectations and concerns as well as being supported with information in a manner consistent and timely with their own agendas.

(iii) Implications of findings.

- The meaning of women's autonomy has been debated in the academic literature and choice is advocated within health policy broadly and in guidelines. My findings indicate some level of interdependence may be a necessary precondition for women to exercise their autonomy.

- Healthcare professionals need to better capture and understand women's previous experiences and current expectations, so information flow is two-way.

- Recommendations in guidelines should be reframed to reflect the study's findings.

(iv) Chapter Summary.

This Chapter's main focus is on my discussion, acknowledgement of the study's limitations, conclusions and recommendations.

Section One will briefly summarise the current state of knowledge about the topic under investigation. It will then briefly summarise the findings from the

published theoretical and empirical studies in the healthcare literature in order to establish gaps or tensions.

Section Two, Part (i) will briefly summarise the main findings from the primary research (empirical) study.

Section Two, Part (ii) (a) will explain the Grounded Theory generated from my study and (b) articulate three propositions arising from my theory.

Section Three is a discussion of the study's findings. It is integrated with my grounded theory and refers to extracts from the study data to illustrate theoretical points. The implications of the study's findings in relation to pregnant women, healthcare professionals and the existing thinking in the healthcare and bioethics literature and consideration of the implications of the study's findings for guidelines will be discussed.

Section Four will discuss the strengths and limitations of the study and the potential for methodological error and bias. Drawing together the study's implications, strengths and limitations, recommendations for future practice and research are suggested. The Chapter ends with a short final conclusion.

Overview.

(a) Policy context.

The 1960s and 1970s saw developments such as the women's movement and a culture that set out to shift control in decision-making from professional authority to the woman (Davis:2003). Since then, policy has increasingly emphasised patient participation in decision-making. In the UK, the landmark *Changing Childbirth* report introduced policies for 'woman-centred' services that supported women to make informed choices and exercise their autonomy (Department of Health: 1993).

Subsequent documents, namely the *NSF for Children, Young People and Maternity Services* (Department of Health: 2004) and *Maternity Matters* (Department of Health: 2007) have reinforced these objectives. Currently,

one of the fundamental principles underpinning *Better births* (NHS England: 2016) is supporting women's choices.

(b) Guidelines.

In Chapter One, Section One, Part (ii), I referred to the updating process of the recommendations for Down's syndrome screening in the Antenatal care guideline, noting the composition of the GDG included both professional and lay members (NICE: 2008). Their objectives were to develop guidelines based on best available evidence, help make appropriate decisions and do what they could to empower women with knowledge. These objectives should be regarded as significant in relation to the overall purpose of my study.

Maternity care guidelines are sensitive to women's autonomy and choice. This is evidenced in their wider recommendations, 'Women should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals' (NICE: 2008:4).

(c) The concept of autonomy.

As set out in Chapter Two, Section Three, patient autonomy is frequently seen as a cornerstone principle in healthcare (Schwartz *et al* :2002; Gillon:2003 ; Greener:2009; Kearns *et al* :2010).

The literature review that preceded my analysis concluded that autonomy is a contested concept. Many women want enhanced autonomy, increased choice and greater involvement in decision-making about their maternity care (Weaver: 1998; Lavender *et al*: 1999; Vandevusse: 1999; Hodnett *et al*: 2010; Mander and Murphy- Lawless: 2013).

However, there is also empirical evidence that not all women want to be primary decision-makers. Some authors have argued that although women wished to be involved in decisions about their care, they did not necessarily want the final say (Bluff and Holloway: 1994; Kingdon *et al*: 2009; Nieuwenhuijze and Kane Low: 2013). This suggests the need for a more nuanced understanding of how pregnant women express and negotiate

autonomy. The literature also indicates that guidelines may present new and difficult choices and may require further updating to take account of women's experiences of decision-making.

Findings from the literature review.

(i) Theoretical studies.

In Chapter Two, Section Three, I outlined two key theoretical debates about autonomy that shape how women are treated.

The liberal model of autonomy is underpinned by the assumption that individuals exercise freedom to make rational choices. Ideas concerning self-government, independence and freedom from constraints have crystallised around the idea that autonomy is a priority in healthcare (Jackson: 2001). The concept of the individual as independent decision-maker is seen as profoundly valuable by many authors working within this model (Young: 1986; Dworkin: 1988).

The liberal model of autonomy presumes that patients value information that allows them to rationally deliberate from a range of options and freely choose between them. Critics of liberal theories have claimed that they do not explicitly account for the social situated-ness of the individual (Mackenzie and Stoljar: 2000; Donchin: 2001; Sherwin: 2012). Thachuk (2007) argues there is a need to think beyond the liberal model of autonomy and consider an approach which includes a range of issues which may influence women's decision-making. The wider recommendations in guidelines are inclusive in this respect 'The views, beliefs and values of the woman, her partner and her family in relation to her care and that of her baby should be sought and respected at all times' (NICE:2008: 4).

In this thesis, I argued that healthcare takes place in a complex web of relationships. Women cannot exist in a vacuum with needs that can be satisfied without reference to others' interests. Christman (2004) argues that feminist writers in particular have claimed that the idea of autonomy should be reconfigured so as to be more sensitive to relationships of care and

interdependence that define our lives. I concluded from my literature review that relational autonomy does not refer to a single concept. As Mackenzie and Stoljar(2000) put it, it is an ‘umbrella term’ based on the premise that ‘persons are socially embedded and that agents’ identities are formed within the context of social relationships and shaped by a complex of intersecting social determinants, such as race, class, gender and ethnicity’. My argument is that women are both autonomous *and* relational, that is, they are self- governing but simultaneously connected to others.

(ii) Empirical studies.

As set out in my literature review in Chapter Two, Section Four, many empirical studies relating to women’s experiences about their maternity care have relied upon accounts expressed in satisfaction surveys and interviews (Hundley *et al* : 2001).

However, the value of satisfaction as a determinant of healthcare has been contested. Specifically in maternity care, Bramadat and Driedger (1993) claim that satisfaction can be difficult to define and evaluate. This is because it has multiple influencing factors (Rudman *et al*: 2007; Ford *et al*: 2009). This limits its usefulness in increasing our understanding about women’s experiences about their care.

As I noted in Chapter One and as the literature review demonstrated, there have been few empirical studies which specifically explored women’s experiences of care and their autonomy in relation to recommendations in guidelines.

In summary, on the basis of the context set out in Chapter One, I critically examined a selection of theoretical and empirical work published over the past 30 years, the majority in English and some in French. I concluded that pregnant women’s decisions are shaped by multiple relationships and values which impact on their autonomy. I found that autonomy is frequently expressed as a result of interactions between women and healthcare professionals. I concluded that women’s autonomy need not necessarily be expressed outright. For example, the term ‘autonomy’ was never explicit in

women's accounts, that is, they expressed it using their own words. My analysis drew on women's accounts of their experiences, focusing in particular on what they said about decision- making. I used theory to interpret what this meant in terms of autonomy.

SECTION TWO.

Part (i) Summary of the main findings from the empirical study

My rigorous analysis shows from that for the most part, women were happy to accept the care offered and were usually unwilling to challenge it. This is reflected in guidelines which state that women should be given the opportunity to accept or decline an intervention (NICE: 2008). Multigravid women's reflective assessments frequently helped them express their autonomy, that is, their experiential knowledge was empowering. Several primigravid women indicated they had nothing with which they could compare, which suggests they found it more difficult to articulate their thoughts. Although my analysis suggested most women tend to assume that the care they were offered had been well thought out by experts, at least one woman could recall a bad experience of her care.

My analysis suggested women's expectations were pragmatic and realistic. Despite the choice of alternatives in guidelines, no-one wanted a proliferation of options. Rather, one woman suggested that, faced with a complex decision, several alternatives were confusing. Some women chose to restrict their options.

Findings frequently suggested a divergence from the drive for maternal autonomy and increased consumer choice. A good pregnancy outcome was in some way achievable by sharing or even handing over control to professional carers.

Principal Findings.

The first main finding from the empirical study revealed that women frequently lacked the appropriate pregnancy and birth knowledge to make

decisions independently, suggesting their autonomy was not a constant. Decision-making was shaped not only by the offer of treatment options, but the whole clinical encounter and the woman/ healthcare professional relationship. This finding highlights how women's autonomy is influenced by multiple factors.

The second main finding was the importance for women of interactions with trusted healthcare professionals. They placed their trust in professional carers' abilities to provide a safe and caring service to help ensure a healthy baby, which was seen as crucial. My analysis suggested women's concept of safety was broader than healthcare professionals' benchmarks of mortality and morbidity. Rather, women's concept of safety encompassed personal feelings of reassurance and security.

Part (ii) (a) An explanation of my Grounded Theory.

Several recommendations in maternity care guidelines promote discussion between women and healthcare professionals to help women make their decisions (NICE: 2008; NICE: 2014). Findings suggested one of the most important mechanisms which can potentially enhance women's autonomy is effective interactions between women and healthcare professionals. However, establishing the level of involvement the individual woman may want in the decision-making process across a range of pregnancy and childbirth decisions is challenging for women and healthcare professionals.

To summarise, my data were transcribed, coded and categorized using the constant comparative method which forms the basis of grounded theory. The categories were arrived at through exploration of women's accounts, the use of literature, extracts from clinical guidelines. and rigorous data analysis. In this way the interview components were put into context, grounded in the whole dataset and analysed with the existing literature to develop a coding framework, that is, an explanation which integrated the related concepts. This process drew together the ways in which the categories functioned together and led to the emergence of the theory. My grounded theory is '*Choosing when to choose*'.

It should be noted that theory is not an absolute truth. Rather, it is the explanation of a phenomenon (Ezzy: 2013). Its main objective is to provide a deep and nuanced understanding of participants' experiences (Harding and Whitehead: 2016). Constructivist Grounded Theory 'explicitly provides an interpretive portrayal of the studied world, not an exact picture of it' (Charmaz: 2002: 678). In line with Charmaz (2000), my theory offers a practical and flexible approach which is based on my interpretive understanding as researcher of the study participants' accounts of their experiences.

'Choosing when to choose'.

The theory generated suggests aspects of the decision- making process that enable women to feel supported by healthcare professionals. The theory rests on my two main thematic categories, that is, the knowledge asymmetry between women and their professional carers and the importance of interactions with trusted healthcare professionals.

Analysis of findings suggested that women experience difficulty in making a range of decisions about their care, particularly when choices were difficult. Accordingly, women chose to defer to healthcare professionals for advice and professional guidance, not solely about healthcare, but according to experiential factors, relational factors, time and context. This leads us to consider how interactions between women and healthcare professionals shape women's involvement in their care based on recommendations in guidelines.

The theory of 'Choosing when to choose' is not confined to the point of decision- making. Rather, it has broader application and is part of the woman/ healthcare professional relationship, the clinical encounter, contextual and relational factors. Findings revealed that first; exercising their autonomy had different meanings for women. Second; the very act of choosing between options in guidelines was frequently women's main concern. There were several examples across a range of women's pregnancy and childbirth experiences. Guidelines do not include the option

of choosing when to choose. My theory leads us to consider ways in which achieving the appropriate balance of information and care should help enhance maternal autonomy.

Clinical guidelines *are* sensitive to maternal autonomy and choice. Their approach promotes women's involvement in decision- making on the grounds that it is preferable for women to choose. By contrast, if women were asked *when* they wanted to choose, they could choose to opt out of active choosing- which in itself is a choice. However, 'Choosing when to choose' is not a simple rejection of options. Rather, it should be seen as a woman's response as part of a process. This approach could help enhance women's wish to choose when *they* deemed it appropriate, rather than undermining their preference not to do so.

In Chapter Three, Section Two, I referred to Carlsson and her colleagues' (2012) study using the Constructivist Grounded Theory approach and its' power to be evaluated by credibility, originality, resonance and usefulness.(Charmaz:2006;2014). These criteria were applied to my own study as follows:-

(A)Credibility.

Credible grounded theory should produce a theory that is closely grounded in data. I tried to ensure any claims I made were sufficiently grounded in the study data. This meant constantly referring back to the initial codes and categories. This process helped ensure a systematic and rigorous analysis and maintained strong links throughout the analytic process between the data collected and women's accounts of their experiences in subsequent interviews.

(B)Originality.

Grounded theory is chosen as a methodology when little is known about the study topic (O'Donoghue:2007).This made it an appropriate methodology for my topic. The originality of my work is a better understanding of women's experiences of their care based on recommendations in

guidelines. I made a connection between the gap in knowledge my study addressed and the need for my analysis and an explanation of the emergent theory.

(C) Resonance.

Charmaz (2006) says that the most important test of resonance is whether the grounded theory resonates for others who are in similar situations. It is envisaged that my theory could be applied or adapted across a range of maternity care clinical situations.

(D) Usefulness.

Grounded Theory should produce a theory that is useful. As Charmaz says, a useful grounded theory offers 'interpretation that people can use in their everyday worlds' (Charmaz: 2006: 183). Guidelines are a central feature of women's care. My analysis and interpretation of findings and suggestions for reframing certain recommendations in clinical guidelines provide direction to improve women's care.

(b) The three propositions the theory leads us to consider.

The propositions have been developed directly from applying conceptual findings into a three -step process. The process is practical but not prescriptive. 'Choosing when to choose' identifies priorities that enable women to feel supported and assisted to choose between options, or to decline that opportunity, if that is their wish. Application of the theory could help shape healthcare professionals' ways of supporting the woman according to her previous experiences, current expectations as she defines them and changing events during pregnancy and childbirth.

1. Setting the agenda.

The theory of 'Choosing when to choose' suggests healthcare professionals should explore women's wishes in advance of the consultation, whilst concurrently keeping open the possibility that women's responses may change during the clinical encounter. Arguably, unless women have actively stated that their particular preferences and *why*, then

healthcare professionals cannot know what they want and are unable to prioritise them. Adopting this approach should help healthcare professionals gauge women's expectations of the consultation and the degree of professional involvement that is most appropriate in decision-making. This contributes to the development of trust and reduces the risk of making mistaken judgements about what women want.

The point is that some women choose when to choose, or would do so if they were asked and this is part of their autonomy. Hence there is a need to explore the woman's wish for involvement and to offer an indication of the process and timing of decision-making. This should include developing an awareness *at the outset* that each consultation may be affected by previous consultations and there may be relevant clinical factors (and deliberation) during the interim unknown to the healthcare professional that may enhance or restrict women's options. This is because findings revealed that there were some situations in which women chose not to choose *unless* healthcare professionals participated in a process of shared decision-making. An example of this is the choice between VBAC and an elective Caesarean section delivery in which women's choices were sharpened by a heightened sense of the inherent risks, their experiential knowledge and relational issues. An agenda can help make the process more transparent and provide direction for women and healthcare professionals.

2. The importance of an awareness of context.

The wider recommendations in NICE clinical guidelines state that women should be given information regarding the risks/ benefits/ comparisons of different options available to them (NICE: 2014). However, in order to provide a fuller picture, there is a need to place the decision in context, that is, non-biomedical factors and outcomes should also be targeted. Analysis of findings suggested that pregnancy and childbirth affects women in several ways, that is, physically, socially and emotionally. When healthcare professionals showed interest in and concern about women's psychosocial issues, it helped promote their involvement in decision-making. It is proposed that a discussion of these issues becomes a more formal and

integrative part of the consultation process and included as a recommendation in guidelines. The information gleaned could provide insights into why and in what circumstances some women choose when to choose, increase understanding between women and professional carers and improve their care.

3. *Direction of communication between women and healthcare professionals.*

The theory of 'Choosing when to choose' suggests the need for healthcare professionals working with recommendations in guidelines to be clearer about what individual women equate with being directive/ nondirective in the consultation and decision- making process and when these approaches may be appropriate. Hence there is a need to configure the options in guidelines that suggest the adoption of these approaches and how the healthcare professional might support each woman best. On the one hand, if the woman chooses not to choose only because she lacks sufficient information, a clear agenda and context (above) may help set the scene for information –giving/exchange which is tailored to her specific needs. On the other hand, if the woman does not want information about, for example, home birth, then her wish not to know plays an important part in the decision- making process.

In Chapter Five of this thesis, I referred to the conceptual framework that includes different types of decisions and their impact on women's autonomy. Guidelines do not reflect what constitutes such decisions. Findings suggested that in making some decisions, for example, smoking reduction/ cessation in pregnancy, women place little reliance on the healthcare professional, that is, they choose when to make their decision to continue to smoke, reduce or discontinue smoking. Nonetheless, there is a need for the healthcare professional to be directive about the risks of smoking in pregnancy. This holds true despite the fact that the woman makes her own decision. However, healthcare professionals do not always understand women's health beliefs and values. Their involvement may

mean gaining a better understanding of these which would help guide the consultation process- something currently underscored in guidelines.

There is a need to specifically present certain decisions as negotiable between women and healthcare professionals. An example of this is IOL. This approach should help circumvent women's accounts of recommendations in guidelines offering choice but not accounting for their individual needs and preferences. It is during two –way information- giving that healthcare professionals can explore women's wish for negotiation and gauge the appropriateness of a directive or non-directive approach.

There may be instances when the consultation moves backwards and forwards between a closed, directive approach to a more open, non-directive approach and that process needs to be fluid. For example, my findings suggested that healthcare professionals might give a woman information about the benefits of healthy diet in pregnancy, that is, making the woman aware that various options exist. Once informed, the woman is supported to explore her individual preferences in a non- directive way. It is she who will make her decisions in timely fashion.

There may also be instances during the consultation when women do not wish to make their own decisions, but additional information and/ or discussion with healthcare professionals alters their perspective. In this respect, a previously uninformed option can move towards an informed decision, and a wish not to choose may be reversed. This is part of the woman's autonomy.

Applications for practice.

The three propositions are interconnected, provide further insights into my grounded theory and direction for recommendations in guidelines. The theory could have explanatory power across a range of maternity care situations. It is recognised that care will need to be constantly re-evaluated and re-shaped to meet women's specific needs and wishes throughout pregnancy and childbirth. Effective interactions with healthcare professionals guided by the three propositions outlined should help reveal

that if a woman chooses when she wants to choose, she is not removing herself from the decision – making process. My theory points to the importance of the nature of the decision and the individual woman with whom it is being made.

SECTION THREE.

Discussion of findings.

My analysis suggested important divergences from, and some consistencies with the drive for increased choice and the promotion of maternal autonomy in the healthcare and bioethics literature, policy documents and recommendations in guidelines.

My discussion will focus on first, whether my findings concurred with or raised challenges for guidelines and second, what my grounded theory suggested based on the three propositions set out in subsection (b) and their application for practice.

Main thematic categories.

1. Women’s limited pregnancy and birth knowledge.

The first of two main thematic categories was women’s limited pregnancy and birth knowledge to make decisions independently. When considered in relation to the overall purpose of the study, this is very significant as it is acquired knowledge from both formal and informal sources that is a major contributory factor in decision- making.

Findings (i). Pregnancy and birth: a time for new knowledge.

My analysis suggested clear conceptual links between women’s limited knowledge and their wish to defer to trusted healthcare professionals. This is important as knowledge relates not only to appropriate information, but understanding and the ways in which knowledge is relevant to women’s own situation (Proctor: 1998; Pairman: 2006). Also important were the ways in which women use their knowledge that could be seen as unexpected to construct their own explanations in order to make sense of their situation.

(i) Making sense of the unpredictable.

As we have seen with the example of **Catrin (Extract 4.1)**, her referral to the 'slope' suggests she equates IOL with loss of control. Her referral to application of 'the brakes' was her way of expressing her autonomy in a situation she perceived could escalate out of control. Her deference to the hospital staff suggests she needs to feel cared for and rounds up her decision. She suggests she tried to justify her decision in order to make sense of it and this may be an implicit way of expressing her autonomy.

Maternity care guidelines state that women should have the opportunity to make informed decisions in partnership with healthcare professionals (NICE: 2008). However, the guideline is unclear how partnership translates into women's experiences. In my literature review in Chapter Two, Section Three, I referred to Leap's (2010) work which argues that partnerships may not be attainable because professional carers have authority over women. If partnership means that women and their professional carers are equals in the decision-making process, my analysis of women's experiences revealed that professional support was crucial for women to participate when choices were difficult, much less take control themselves. This was because women drew out their own priorities from the offer of a choice of alternatives and struggled when presented with solely a package of care. This meant they attached more importance to the course of events that took place and their consequences than the offer of a choice.

My grounded theory of choosing when to choose suggested three points. First, there is a need for healthcare professionals to explore women's wishes in advance of presenting them with options from which to choose. Although sometimes caught between previous expectations and their current situation, and there were some inferences in words and gestures that women might prefer to accept or decline a-b-c, assertions such as 'definitely want' or 'don't want' were infrequent, that is, women were unwilling to challenge. Second, some women were unwilling to make decisions without professional support. Hence inviting women's *participation* in the decision was a measure of promoting their autonomy and sharing

their concerns with a trusted healthcare professional was an expression of their autonomy. Third, exercising their autonomy meant being given the opportunity to rethink their options in view of their revised situation. My grounded theory suggested that women's responses may change during the consultation, leading me to conclude that their autonomy was not a constant, but needed to shift accordingly. The woman trusts her professional carers and decides in a relational sense. These findings concur with the work of Entwistle and her colleagues (2008) who found that diabetes patients judged their autonomy not in terms of the range of options, but the nature of the dialogue they had with their professional carers and the ways in which they gauged that their carers respected their hopes and fears. As Entwistle and her colleagues say 'Participants associated involvement with practitioners making it easy for them to discuss their problems, inviting questions, really listening, answering their questions thoroughly, providing relevant information and explaining things well' (Entwistle *et al* :2008:367).

In their qualitative study that explored ten women's retrospective experiences of complicated childbirth, Berg and Dahlberg (1998) found that what women wanted most was to be recognised and affirmed as genuine participants. Choices about obstetric interventions were seen as less important. If the woman has a wish for *some* involvement in making decisions, the idea that it is through skilful negotiation in a shared sense that the professional can help her make a difficult decision is appealing. She can still choose what to do and claim the decision as hers. The implication for guidelines is that some degree of interdependence may be a necessary precondition for women to exercise their autonomy in situations such as painful childbirth when choices are difficult.

My findings generally support Entwistle and her colleagues and Berg and Dahlberg's work. However, I extend these authors' implications through highlighting a paradox that guideline recommendations concerning healthcare professionals' non- directive practice may result in the unintended consequence of some women exercising their autonomy by in

part reinstating authority to their professional carers. These findings differ from the work of Vandevusse (1999) who reported increased satisfaction when women were actively involved as primary decision-makers during childbirth, resonating with the self-governing decision-maker associated with the liberal model of autonomy. My own study, however, used a sample frame of a range of pregnancy and birth experiences.

(ii) Taking things as they come.

Some women found security in taking things as they come when faced with a difficult decision and ceding some degree of control. My analysis suggested the need for trust and significantly, more in-depth interactions between the woman and her professional carers than is currently accounted for in guidelines. This has been shown to be more facilitative when women are cared for by a known midwife with whom they have established a relationship of trust (Edwards: 2010; Wilkins: 2010). Edwards' and Wilkins' qualitative work was community-based. Although it was beyond the scope of this thesis to present a critical analysis of different types of maternity care, my findings for the most part did not suggest that women differentiated greatly between community and hospital-based care. Women suggested they secured a trusting relationship with several hospital-based professional carers. My grounded theory suggests that healthcare professionals should treat each interaction as part of the ongoing care process, regardless of care- provider or location of care.

(iii) Need for personalised information.

Catrin's account about information- giving (**Extract 4.7**) suggests three points. First, the need for a parcel of information suggests she would feel overwhelmed if the information was incomprehensible; Second, her need goes beyond that of generalised information. Third, her quote reinforces the need for authority, thus ceding control. There is an implication that guidelines need to reflect these measures My grounded theory suggests the need for a more formal process in guidelines to integrate these measures.

This could help increase healthcare professionals' understanding of women's individual needs.

(iv) Asserting.

Not all women who were offered IOL placed unquestioned faith in healthcare professionals. The option provided the impetus for a grandemultigravida to take an active role in her current pregnancy. In view of her reflective assessment of a previous negative experience of her care, her account suggested that she expressed her autonomy outright. (See **Sarah's** account **Extract 4.10**).

This finding was consistent with Brown and Lumley's (1994) work which suggested that multigravidae are more affected than primigravidae if they are excluded from decision-making, indicating that there is greater potential for affronts to their autonomy, although we should be cautious about drawing general conclusions from a single study. My analysis suggested that multigravidae's experiential knowledge (as well as their preferences and values) should be taken seriously by professional carers. Although **Sarah** has an awareness of the risks of declining IOL, it is doubtful they were sufficient to override her autonomy. This is reflected in the fact that she does not directly refer to what her revised decision would be if these measures failed. It is experiential knowledge and faith in her own reproductive abilities that help her express her autonomy.

The implications for guidelines is that reflective assessments of their previous experiences empower some women and create an opportunity to specifically articulate their plans. In this situation, **Sarah** was able to express her autonomy explicitly, making prominent the idea that it is *she* who will give birth and take main responsibility for her baby.

My grounded theory suggests that the woman should have opportunity to talk about her particular preferences. It is through effective interactions with healthcare professionals that it will be revealed that her decision goes way beyond a simple rejection of a recommendation about IOL in guidelines. Application of my grounded theory could help shape healthcare

professionals' ways of supporting the woman according to her previous experiences and current expectations.

Main thematic category.

2. The importance of interactions with trusted healthcare professionals.

There were women who faced concerns about foetal welfare and experienced little problem in deferring to their professional carers. This became apparent when a woman was given a choice of vaginal delivery or elective Caesarean section when she had previously been led to believe there would be no choice – a situation she had accepted, suggesting that her autonomy was not very important. (See **Rachael's** account Extract **4.17**).

The implication for guidelines is that the recommendations do not include a clause which states that they might be surprising to some women who understood they would not be given a choice. My grounded theory suggests that setting an appropriate agenda for the consultation reduces the risk of making mistaken assumptions about what women understand.

My adaptation of Constructivist Grounded Theory led me to revisit initial categories and extracts from guidelines and re-group them so as to interpret further. I concluded that although women decide whether information is personally useful, my analysis suggests the need for a greater focus on information about the process of, for example, Caesarean section (not solely the rationale for performing it). My analysis suggested that women would feel more empowered if they were given a clearer indication of how treatments may feel, for example, the degree of discomfort they might expect. The implication of my findings is that women feel empowered by the act of *sharing* the decision, that is, they exercise their autonomy by being invited to voice their concerns, being listened to and sharing difficult decisions with their professional carers. This is because professionals were perceived as being able to draw out the various contingencies in the available options. However, there is nothing in the recommendations in

guidelines which encourage women to think about which aspects of maternity care are most useful to them. My contribution is that guidelines should be more explicit about the need to do this.

An active role in decision-making was not important for all women. Some suggested that the transition to motherhood was accompanied by constraints and in certain instances hampered by factors beyond their control. My analysis suggested that some women may have been unable to articulate their wishes which may lead us to ask why this might have been the case.

One woman's account suggested that she felt overwhelmed by the prospect of deciding between vaginal delivery or elective Caesarean section.

(i) Deciding together.

Georgia's account (**Extract 4.12**) suggests that she has a set of pertinent questions and a fear of being left to decide alone. Paradoxically, she says that Caesarean section has been recommended, but the decision has been left entirely to her. The guideline is non-directive in this respect. The fact that the caring team have good reason for their actions is her justification of trust in her carers *or* it may be that she needs that belief to justify her decision and claim it as her own. The crucial point is that supporting a woman *on her terms* – which may enhance her autonomy, differs from informing her about her options and leaving her to make a decision in line with informed choice outlined in Chapter Two, Section Three. **Georgia's** account is an example of her wish for shared decision-making with the doctor. The implication for guidelines is that this understanding will place greater demands on professional carers' time and skills. My grounded theory suggests that maximising the potential of interactions by gauging women's wishes for involvement in decision-making will help women feel cared for and more able to express their autonomy.

There was also evidence of a woman's wish to confer with professional carers on decisions that had less far-reaching consequences, for example,

positions in labour. (See **Lisa's** account **Extract 4.19**). The implication for guidelines is that the importance (or otherwise) of such decisions is something to be decided by the woman herself. My grounded theory suggests a better understanding is needed based on the woman's wishes and perceptions of her care about the different situations when she might prefer a more directive approach in order to support her best.

These findings support and add to Page's work (2006) – that women need an understanding of the system they are in and the process they are undergoing to maintain control.

Findings (ii). Types of decisions.

My analysis suggested there were different types of decisions, that is, those with moderate importance, independent decisions, important decisions with a range of variables and important decisions with limited options.

Decisions with moderate importance.

(i) Influence of medical evidence.

Some decisions, for example, smoking in pregnancy were seen as an aspect of care in which women were able to exercise their autonomy based on their reasoned understanding of the scientific evidence about the adverse effects of smoking during pregnancy. The guideline recommends that information is given to women about the risks of smoking in pregnancy (NICE: 2010). Findings revealed that some women discontinued smoking prior to making contact with healthcare professionals or without knowledge of recommendations in guidelines. This may suggest that their autonomy was constrained by medical evidence. However, my analysis led me to reinterpret further and I concluded that the evidence encouraged them to reflect upon their wish to smoke when weighted against the adverse effects of smoking in pregnancy and they can *still* choose what to do. These findings diverge from Graham's work (1976) who found that there was a greater likelihood that women would adhere to advice given on a face-to-face basis by a healthcare professional, rather than information derived

from books and pamphlets. Although the scope of my study does not allow me to infer whether or not women adhere to advice, it is fair to say that much of women's self-management during pregnancy takes place outside the clinic boundaries. This provides an example of the effect of the guideline with a lesser focus on healthcare professional input. Arguably, however, the effects of policy may go beyond patient and healthcare professional interactions. Women's preferences are influenced by public health messages that often use social marketing techniques to achieve behaviour change.

Foetal welfare became the lens through which the decision was made, indicating a clear conceptual link between them, that is, women are autonomous *and* relational.

(ii) Effect of personalised information.

Sarah's account (**Extract 5.4**) combined her own story based on her previous experience of a badly infarcted placenta with the evidence and professional advice, creating a personal layer to her decision to reduce smoking. This fits with Christman's claim (1991) that the personal element is something that makes a decision more autonomous. It could be countered that personalised information creates additional responsibilities, but it is the woman who chooses to accept them, emphasising my point that the woman's autonomy is a richer concept than simply her ability to accept or decline an intervention in line with informed decision-making. Although her values shape her decision, she is the author of her own actions. This deepened my analysis and led me to conclude that autonomy in this instance meant that she was able to define her own meanings from the scientific evidence.

This influence of medical evidence broadened to other lifestyle decisions, for example, dietary considerations. My conclusions diverge from research in the healthcare literature which found that women were prepared to let the midwife make the decision with options women perceived as relatively unimportant. An example of this is episiotomy (Drew *et al*: 1989); although

it could be countered that performing an episiotomy sits firmly in a midwife or obstetrician's sphere of practice. This might explain women's willingness to defer, whereas smoking reduction/cessation is something women can action themselves. My conclusions add to the debate about choice in relation to the type of decision to be made and my analysis has deepened from initial assumptions. There are two implications for guidelines. First, advice about smoking may need to be presented as part of an awareness of potential choices to be made and negotiated. Second, decisions such as smoking cessation should be treated less as routine and more as personal. Based on my interpretation of findings, my grounded theory suggests the need for healthcare professionals to develop an awareness of women's health beliefs and values and how these impact on their decision- making.

Independent decisions.

One low- risk woman's account suggested she felt able to exercise her autonomy explicitly with the offer of an option to which she felt vehemently opposed. An example was the offer of a home birth. (See **Rebecca's** account **Extract 5.7**).

(i) Trust in familiar procedures.

My analysis suggests **Rebecca's** decision was as maximally autonomous as possible and consistent with her wish to have a hospital confinement. Interestingly, it was an uninformed decision as she did not explore the option. However, the guideline recommends that women at low risk of complications should be given the option of home birth (NICE: 2007). In overall relation to the study, this is significant. My analysis suggests that some women can exercise their autonomy without an array of options and make an uninformed decision, that is, it is plausible to conclude they were not a prerequisite for their autonomous choice. This is something which diverges from the drive for offering women a range of options set out in the healthcare literature and policy documents. Her reasons for outright refusal are firmly grounded in my empirical study data. She recalls what she perceived as substandard care from her GP when her son was ill and

indicates great trust in hospital-based staff to help ensure a good pregnancy outcome. Her account concurs with the work of Porter and Macintyre (1984), van Teijlingen *et al* (2003) and Larkin *et al* (2017) that is women tend to prefer the type of care they are accustomed to, the chronology of which suggests that little has changed during the interim.

My analysis concluded that not only did the woman want to retain a service that was familiar and trusted; she expressed a wish not to have been given the option in the first place. The implications are that the woman's direct voicing of her concerns was not only an expression of her autonomy, but sent a message to her midwives that the hospital birth environment was something she regarded not only as safe, but empowering - and this arose from two uncomplicated deliveries. My contribution is that these findings differ from what has previously been understood in so far as the woman uses a non-obstetric example to illustrate her resistance to home birth.

My conclusions diverge from Edwards's (2005) detailed study of home birth, the findings of which concluded that home birth included those very elements that contributed to birthing autonomy. For the women in Edwards' study, home birth was a way of protecting their autonomy and self-esteem. For many of them, a sense of control was lost when admitted to hospital and for some maintaining control meant having a home birth, suggesting that exercising their autonomy in hospital was prohibitive. Another possible explanation for my findings is that some women do not expect to be given a choice.

There are two implications for guidelines. First, when interpreting the options available to women, there may be a need to take greater account of how women's experiences of healthcare shape their perception of place of birth. Second, some women express their autonomy outright despite being uninformed.

My grounded theory suggested that that if the midwife had explored the woman's preferences with her at the outset, **Rebecca** could have expressed a wish not to choose which in itself is a choice.

Important decisions with several variables.

One woman's account suggested that she did not find the offer of several alternatives liberating. (See **Raine's** account **Extracts 5.8 and 5.9**).

(i) Several options.

My analysis suggested that in complex cases, women struggled with the various contingencies which were confusing or even frightening, that is, they might have the effect of restricting their ability to participate in decisions about their care. This does not suggest that professional carers should withhold information. Rather, the implication for guidelines is that rather than simply presenting the alternatives, there is a need to anticipate the woman's concerns which might involve factors outside the remit of the guideline and impact on her autonomy.

(ii) Forward planning.

The woman suggests that her ability to engage in meaningful discussion with a complex decision is restricted by her understanding that the mode of delivery cannot be formally discussed until 33 weeks gestation. Entwistle and Watt (2006) refer to one of the benefits of professional carers giving close attention to the sequence of decision-making is the 'knock forward' effect, that is, patients' understanding and clarification of issues will help make patient involvement in subsequent consultations more likely.

My grounded theory of choosing when to choose suggests that greater attention should be paid in guidelines to the fact that throughout pregnancy, some decisions need to be revisited several times. This is particularly apparent with complex decisions and reflects the fact that women's autonomy is not a constant. 'Discussion points' in clinical guidelines tend to follow a logical process where specific information is provided at certain times. Although there are merits with this approach, there were instances women referred to when it failed to respond to their need for information which could have been a useful resource to prepare for more fruitful discussions at a later date, that is, reiterating the main finding that women

lack specific in-depth pregnancy and birth knowledge. The implications for guidelines is their need to reflect the need for information- giving ahead of recommended times and its effect on women's autonomy.

A further point is that women accepted in certain circumstances that their options were limited. If they were to express a wish, it was to gain a greater insight into the option itself, or in the case of a protracted labour, to terminate their labour, which relied heavily on their professional carers' communication skills and judgement in order to make a shared decision.

(iii) Fear.

My analysis suggested that choosing between several variables generated fear of the unknown. This finding resonates with Fisher *et al* (2006) who suggest that had women accepted an elective Caesarean section delivery, the decision would have been more clear- cut, despite the fact it was not what they wanted. Several studies report that women who deliver by Caesarean section typically have little or no control over most aspects of their delivery (Sargent and Stark: 1987; Fisher *et al*: 1997; Gray: 2005). If this is so, it raises the question of how much control they really wanted, given the fact that most Caesarean sections are performed to safeguard the foetus and recommended by healthcare professionals. My analysis suggested that women's autonomy is sometimes constrained by individual clinical circumstances, that is, being unable to make a final decision due to changes in the course of events in labour which may lead to an emergency Caesarean section. The findings from my empirical study indicate a similar line to Miller and Mangen (1983), Miller *et al* (1988) and Moffat *et al* (2007), whose work suggests that some women prefer not to have an active role in decision- making and derive no tangible benefit from it. My grounded theory suggests that healthcare professionals should explore with the individual woman to establish the level of decision- making that is appropriate for her- and this may be subject to change throughout the consultation. The implications of this leads us to consider the merits of making a final decision about the mode of delivery at any stage during pregnancy and that guidelines should reflect this.

I concluded that if a woman says she wants a healthcare professional to share decision-making with her when appropriate or even decide for her, it does not follow that she has no views of her own or does not care what happens. Rather, she is acting autonomously in selecting what she sees as the best route to a good pregnancy outcome. In a sense, she maintains control by deferring to her professional carers, indicating her wish for events to be appropriately managed as opposed to a situation of perceived chaos. Another possible explanation is that some women may still perceive that they have their autonomy, as although they have rejected the idea of being sole decision-maker, authority did not lie entirely with their professional carers.

Important decisions with limited options.

(i) Dependence on trusted healthcare professionals.

Catrin's account (**Extract 5.12**) suggested that undergoing an emergency Caesarean section was the only way of safeguarding her foetus. There are two points here. The woman exercised her autonomy and chose to place her trust in professional carers. This finding concurs with the work of Doherty and Doherty (2005), Levinson *et al* (2005) and Armstrong and Kenyon (2015). In addition, Caesarean section was seen as a route to what she autonomously wanted, that is a healthy baby.

What was important was that the woman was kept informed during labour as part of a process. My grounded theory suggests there were instances when women choose not to choose because they lack sufficient information. Healthcare professionals should strive to supplement timely and appropriately the knowledge deficit that becomes apparent in relation to the changing pattern of events in an emergency. My analysis suggested a knowledge deficit in these circumstances may exacerbate women's worries and impact on their autonomy. Furthermore, professionals need to acquire a better understanding of what makes a woman feel empowered and/or cared for. There were clear conceptual links between women's trust in their professional carers' ability to allay their fears and enhance their feelings of

security with the provision of a level of ongoing information most appropriate to their situation. The implications for guidelines is the need for greater emphasis on what women really want to know which may be more important still in an emergency.

Findings (iii). Screening for foetal abnormalities.

As I indicated in Chapter Three, Section One, Part Two and the Introduction to Chapter Six, I did not intend to focus explicitly on screening for foetal abnormalities, but women raised it themselves in response to my core question about decisions they had to make during pregnancy. In relation to the overall thesis, the offer of screening tests for all women is an example of where guidelines have introduced new and difficult choices for some women.

The offer of antenatal screening tests suggested diverse perspectives for different women. These findings heightened the challenge faced by professionals caring for different women. Guidelines clearly frame the option of tests as a choice, that is, women should be offered screening for Down's syndrome and ultrasound screening for structural abnormalities. The woman's right to accept or decline should be made clear (NICE: 2008).

Some women suggested that although they understood the tests were optional, they decided in the relational sense by considering not only their own wishes, but the implications for existing family members. This finding diverges from the much quoted work of Press and Browner (1997) exploring MSAFP testing in low-risk pregnant women which suggests women are frequently unaware that there is a decision to be made, or that testing is optional and they may either accept or decline.

(i) *The importance of reciprocal trust and familiarity in decision-making.*

Sarah's account (**Extract 6.1**) suggested that it was trust in a familiar community midwife and the care environment that enhanced her feelings of security and helped empower her. This was coupled with the midwife's respect for her decision, that is, the midwife trusts the woman to decide for

herself. In Chapter Two, Section Three I suggested that partnership in decision-making promoted in guidelines is ambiguous and may be unattainable. However, Bidmead and Cowley (2005) claim that partnership may be more achievable between women and their familiar professional carers in the community. The woman suggests she and her midwife established common ground based on reciprocal trust, but it was the woman who made the decision. My grounded theory suggested interactions between the woman and her midwife were instrumental in this respect. Reciprocal trust between the woman and a familiar midwife may not only enhance feelings of security, but may help promote partnership in decision-making. Current recommendations in guidelines do not distinguish between familiar and unfamiliar professional carers and do not specifically refer to locations of care. Both these factors could impact on women's autonomy.

(ii) Compelled to choose.

One woman's account indicated that she was not given information in a non-judgemental way, despite recommendations in guidelines, which set out non-directive counselling, suggesting the midwife's actions compromised her autonomy. The woman's account draws parallels with Marteau's work (1994) which suggests that the idea that a choice is being offered is not *bona fide* correct. (See **Jasmine's** account **Extract 6.5**).

The striking feature in **Jasmine's** account is the midwife's influence and possible subservience to her husband's wishes. The woman lacked the in-depth knowledge to challenge, which resulted in her making a decision against her will. The example is powerful in showing the divergence between what she and her husband wanted and the ways she links forceful to encouraging. My grounded theory suggests her autonomy was undermined because she was unable to choose when to choose. It is paradoxical that a member of the woman's caring team performed what could be seen as an uncaring act. The implications for healthcare professionals is that they should follow guidelines where they refer to being non-directive.

(iii) Restricting options.

Other women's accounts suggested that the offer of screening was irrelevant, much less the opportunity to deliberate upon and discuss the option with a professional. Recommendations in guidelines meant they could not elect *not* to be given the option of testing. On one level, they had little control over this aspect of their care as the offer of the option forced them to choose. On another level, they expressed their autonomy by justifying their reasons for declining.

Hannah's wish to decline testing (**Extracts 6.8** and **6.9**) was based on her decision to restrict her options in view of what she perceived as the unreliability of medical information about screening tests. Her account suggested that screening (as opposed to events in labour) was something over which she could exercise her autonomy. Her experiential knowledge became the means whereby the preventive objectives in antenatal screening tests were autonomously rejected. In this respect, she was able to express her autonomy to articulate her thoughts. This finding could be seen as unusual, given the theme of trust that runs strongly throughout the thesis.

Rebecca (Extract 6.10) referred to her religious beliefs as her basis for refusal. My analysis suggested this was her way of expressing her autonomy in a 'strong' relational sense. Although the guideline is sensitive to maternal choice, it has the contrary effect of placing a restriction on some women's wish *not* to choose and does not explore what women may *not* wish to know. My grounded theory suggested that this leads us to an understanding that there are instances when the woman's wish not to choose may be better protected by limiting the availability of such options. This is not to advocate deliberately keeping women uninformed. Rather, it means carefully exploring *at the outset* what is most important to each woman, that is, her autonomy may be expressed by being listened to. The implications for guidelines are that her needs would be better addressed by understanding her specific concerns about screening tests and why her circumstances restrict her options.

(iv) Eager to choose.

Other women suggested that the offer of a choice was a means of empowerment. **Lisa's** account (**Extracts 6.11** and **6.12**) showed an awareness of how a woman's past experience of a different type of care influenced her thinking.

In **Lisa's** current pregnancy, there had been a conscious effort to offer choice. Autonomy was expressed in two ways. First, in terms of access to the available options and second, the way in which authority was transferred to her, that is, the very act of being invited to choose. This is an example of the guideline and the woman's autonomy acting together. My grounded theory suggests this helped shape healthcare professionals' ways of supporting the woman to make her decision.

Other women's accounts suggested that the offer of screening was barely experienced as a choice. Rather, it was accepted as a stage to be completed in the process of having a healthy baby. Hence, what is clearly set out in guidelines as a choice became absorbed into the organisational context of antenatal care. This led me to reinterpret my primary analysis in line with grounded theory and I concluded that there are instances where trust in professional carers led to acceptance of the tests as a self-evident act. My grounded theory suggests that through the consultation process, professional carers need to make clearer the fundamentals of screening with women to help them gain a better *understanding* of the information they are given and to discover their views. My contribution is that recommendations in guidelines should place greater emphasis on asking women questions and learning from them as part of an ongoing process.

SECTION FOUR.

(i) **Strengths of study.**

A strength of this study was my adaptation of Constructivist Grounded Theory to data collection, transcription and analysis. It was the focus on the recommendations in guidelines in an interpretive sense and the

juxtaposition of these against women's quotes which contributed to the novel approach and helped deepen my analysis.

Another strength was that the study cut across the healthcare and bioethics literature. This enabled me to engage with both literatures to show how guidelines and autonomy act together.

A further strength of the empirical study was the minimal exclusion criteria. This enabled me to include in my sample a range of women in terms of their gestation, parity and pregnancy conditions. The women had varied socio-economic backgrounds, educational qualifications and professional status. In this respect, researchers have been encouraged to reflect upon factors such as gender and class identity and to 'abandon the illusion that researchers, their informants and the research setting do not influence each other reciprocally' (Ambert *et al*:1995:882).

Although in attendance as researcher as opposed to clinician, I have fairly substantial experience of talking to pregnant women. Previous experience helped my open-ended questioning of women at different gestations. Women showed readiness to talk at length about their experiences of pregnancy and childbirth. Their expressions of emotion and use of metaphors helped enrich the depth of meanings they attached to their experiences and brings into sharp focus *what matters most* to them. This finding reveals new insights which could previously have been overlooked or given only cursory attention.

(ii) Limitations of study.

There are several limitations that influence the interpretation of the study's findings.

One limitation was that the PPI involvement discussed in Chapter Three, Section One, Part One, although informative, was confined to one woman's comments about the PIS. Future work should invite more women to participate. This could be extended to include pilot work in developing and

writing the PIS, as opposed to reading and commenting on work in which the general purpose, scope and content had already been decided.

Another limitation of the study was that the Interview Schedule/ Topic guide was constructed by myself as researcher with some input from my academic supervisors and my on-site clinical supervisor. As I indicated in Chapter Three, Section One, Part Two, direct PPI in the development and subsequent refinement of the guide was confined to a single layperson. A small pilot study involving two or three women would be helpful in a future study. I have alluded to my inexperience of interviewing and retrospectively, I think the involvement of one person solely was an omission and it would be valuable in a future study to approach members of the local hospital PPI group and ask for their comments.

A further point is although I have fairly substantial previous experience of talking to pregnant women, as Ribbens (1989) says; an interview is more than a conversation. During the early interviews, I am aware that I did not develop the narrative as much as I could have done.

The study was conducted in the Antenatal Clinic of an inner-city teaching hospital, that is, a single centre limited to one geographical location in the UK. Lock and Gibb's work (2003) suggests that the limitations of a piece of work can be seen as shortcomings, but limitations can also be used to describe the boundaries in which a study is carried out. For example, it may be that different geographical areas have more diverse populations where women's experiences vary from those in my study. The study was limited to those receiving predominantly hospital-based care attending as outpatients. The hospital is a regional referral unit and may have a particular focus on maternity care based on clinical guidelines. A different picture could have been gained at the study site by interviewing antenatal inpatients. Further perspectives could have been explored in antenatal clinics based in general practitioners' surgeries or in women's homes. Hence comparison data were unavailable.

The study was limited to those who could read, understand and communicate in English. However, the study makes no claim that it is representative of all women receiving predominantly hospital-based antenatal care, much less all women receiving hospital-based care in the UK. Another limit is that the study is confined to women's experiences of pregnancy and childbirth, hence pre-conceptual and postnatal care are excluded.

Interpretation of the study's findings is limited to women's ability to articulate their thoughts and give a clear account to the researcher (Woollett: 1996). The wider recommendations in guidelines are inclusive in this respect because they state that women with additional needs such as sensory impairments or learning disabilities and those who do not speak or read English should be given all relevant information (NICE: 2008).

A key point is that multigravid women's retrospective accounts were frequently referred to when recounting their experiences. The work of Johnson (1993) suggests these might have been further influenced by subsequent experiences or their thoughts at the time of the interview, that is, perceptions may change over time. This finding concurs with several of Charmaz' works (1991; 1995; 1999; 2002; 2009; 2010) on chronic illness and disability which showed that participants' perspectives can change quickly. For example, my findings suggested that women's experiences are influenced by relational matters. There may have been changes in their situation during the interim period which may impact on their accounts of their experiences. Furthermore, it is unknown to the researcher how accurately some women are able to recall their experiences.

Chapter Six of this thesis is dedicated to women's experiences of screening for foetal abnormalities. However, the interviews were conducted post-screening. Future work would need to take into account that women were interviewed at various different time points during pregnancy which may have influenced their accounts.

The methodological steps in the research process are presented in Chapter Three of this thesis. There was, however, the potential for error and bias in the methods used. 'Bias' has been interpreted as 'an influence that produces an error in the study results' (Polit and Beck: 2008: 177). Throughout the research study, I was aware that my assumptions and prejudices were inevitably carried into the interviews. As Hicks (2004) says, there is a risk that the human factor, that is, the very element that adds richness to the qualitative approach may detract from the objectivity of the recordings. I explained to the participants that I wished to understand their experiences of their care in their own words and that I might ask for more detail about what they meant from time to time. As Charmaz (2006; 2014) argues, it is important in grounded theory research for the researcher to be reflexive and acknowledge their own personal experience with study phenomenon. This is central to the process of data collection and interpretation because the researcher enters the participant's 'world'.

As I have set out in this thesis, the participant and researcher 'co-construct' meanings from the data. However, there was potential for researcher bias throughout the process of interviewing, data analysis and the development of categories and theory. Preconceived thoughts through a 'midwifery lens' were a potential bias. Taylor and Francis (2013) highlight the risk of researcher influence on the interview process. This may culminate from the researcher's preconceived ideas of what might be expected in a case, but is likely to be challenged by the woman's story (Cioffi and Markham: 1997). For example, if a healthcare professional had distinct memories of a twin pregnancy when the first twin was delivered vaginally and the second twin surgically, then their recollection of the case may be biased when analysing a woman's account which has similar features. On one level, the participant's viewpoint which accords with the researcher's expectations may be over-emphasised in the written report. On another level, anything the participant says which conflicts with the researcher's expectations may be insufficiently developed and consequently under-reported, that is, highlighting certain features of participants' insights and experiences whilst suppressing others. In this

respect, this might result in looking for evidence in the data to verify bias, but also looking for instances which might not stand up to scrutiny. Tjora (2006) suggests that researchers should use their professional knowledge to good effect so as to provide a '*significance filter*' about what to focus upon. In my study, it was the emphasis on women's autonomy and its relationship to guidelines that provided the significance filter. This framework is something that could inform future studies.

Although the study has drawn significant benefits from a rich and varied dataset, women's experiences cannot always be articulated in their responses to a researcher's questions. Hence some experiences remain untapped and women were only given the opportunity to be interviewed once. Charmaz (2014) says that when interviewers rely upon single interviews, they can miss opportunities to correct earlier errors and omissions, although these problems can be mitigated by ensuring that later interviews include questions that explicitly address theoretical issues.

A further pitfall associated with methodological error is the use of a single source of data, that is, interviews, the outcome of which may mean the researcher focuses solely on the participants' lived experiences, instead of on the context and social process (Benoliel:1996). As Charmaz (2006) says, in order to construct a thorough analysis and interpretation of data, there is a need to go beyond women's experiences to unearth the structure and context of their lives. In this respect, there was the need to be mindful about focusing on single quotes to the detriment of women's entire stories.

A further potential problem was the potential for lone researcher bias. Barbour (2001) points out the merits of an experienced researcher independent of the study reviewing the interview transcripts, data analysis and emerging themes. Retrospectively, I am aware that another researcher could have provided additional insights into the development of themes and theory and helped further deepen my analysis.

The study's findings might have differed- given another interviewer, a different or larger group of women in another country or even another

hospital. The study cannot say how women in different cultural and socioeconomic situations may experience their care. A further limitation is that some women are better than others in running relationships and communicating, that is, there may be inequalities dependent on women's interpersonal skills. More than one woman gave a short version of events without much detail, suggesting that they did not think about their experiences in the same way as women who talked in greater detail. It is unknown whether study participants' responses would have differed substantially from those who could not or declined to participate. They were the 'silent voices'.

The study is confined to maternity care which indicates that the usefulness and applicability of the study's findings may be limited to pregnancy and childbirth. Although the findings may have relevance to other pregnant women in similar circumstances, there is no claim that others will experience care based on recommendations in guidelines in the same way as the study participants. Excluded are situations when the offer of a choice may not have been available or when healthcare professionals sometimes steer women towards options not included in guidelines.

An exploratory study cannot lead to definitive recommendations, but further quantitative research might complement, confirm or refute the generalisability of my novel findings.

(iii) Recommendations for future practice.

My analysis has suggested that information-giving and exchange right through to the point of decision-making between women and professional carers is frequently not straightforward. Although it is not suggested that there should be major alterations to the structure of maternity care guidelines, it is reasonable to aim for modest improvements. Whilst it is not recommended that women's perspectives should unilaterally determine a framework for maternity care guidelines, nonetheless evidence from my analysis of the empirical data and my grounded theory of choosing when to choose can make an important contribution.

Guidelines aim to strike a balance between providing options based on the best available evidence and women's wishes. I suggest that the offer of a choice has become so embedded in practice that its true effects on individual women may be difficult to discern by healthcare professionals. Hence, a framework is needed that better defines women's interests and moves a step forward to providing *what the woman wants from her maternity care (not necessarily a wide choice of alternatives)*. This needs to be challenged. As my grounded theory suggests, it may be, for example, that the opportunity to share decision-making or a no choice situation is the preferred option for some women and to deviate would compromise their autonomy. Kirkham's work (1997) draws attention to the gap between the 'professional story' and the 'woman's story', highlighting a danger of reductionism and missing the essence of the matter. This point could be incorporated into guidelines to make it more explicit and reflect its value.

It would be difficult to dispute that, despite attempts to make guidelines more woman-centred; they are concerned primarily with clinical aspects (which is the bedrock of good maternity care). However, the study's findings have identified that one of the most likely mechanisms to enhance maternal autonomy is effective interaction between women and healthcare professionals. This has important implications for educating healthcare professionals. As I have set out in the three propositions arising from my grounded theory in Section Two of this Chapter, measures such as setting an agenda, the importance of context and the need to develop an awareness of when it is appropriate to be directive or nondirective can help engage women in the decision-making process, if that is their wish, or to redirect the dialogue if appropriate. Knowledge such as this could be used to tailor care to individual women's needs and to understand how women and healthcare professionals can optimally work together to promote women's autonomy.

My finding that guidelines are not clear and specific regarding the meaning of 'partnership' suggests the need for further development, support and possibly training for clinical staff.

Recommendations.

(a) Contribution to knowledge.

My recommendation is the introduction of a small scale scheme in the form of a client record and combined guideline which requires something qualitatively different to the current format in guidelines. The study has established that most women have great trust in their professional carers and under current maternity care arrangements; it is frequently the midwife who is the first point of contact in pregnancy. My analysis suggested that professional carers need to be mindful that there are pitfalls associated with standard interpretations of informed choice. Negotiation in a timely sense combined with information-giving and exchange should be stressed. Within the guideline, there should be a zone delineated for understanding and subsequently developing the woman's care. For example, (with respect to multigravidae) it should *make more visible* her previous pregnancy *experiences* and *expectations* in her current pregnancy in order to better shape the next steps in her care. In a sense, this is not new. For example, Edwards' study (2005) found that women had problems convincing professional carers about the legitimacy of their own knowledge. One instance related to the woman's knowledge of when she conceived. Bergstrom and her colleagues (1997) found that healthcare professionals assumed they knew better than the woman when her baby was about to be born.

When giving information and offering choices, healthcare professionals need to become more sensitive and responsive to signals (predominantly verbal and sometimes nonverbal) which suggest women's limited knowledge relating to pregnancy and birth and the importance women attach to certain topics. These may enhance or restrict the options available to women and impact on their autonomy in ways healthcare professionals had not anticipated. My analysis suggested this is an overlooked area of women's maternity care. My grounded theory suggests healthcare professionals *need to better capture* women's previous experiences and current expectations, being mindful that *these may differ to a greater or*

lesser extent from the account presented in the woman's case notes or MHHR.

In this respect, a clearer understanding of the issues that confront women should be our guiding principle. Perhaps it is time to place less emphasis on the offer of a choice and focus on women's experiences and *the type of* interactions that help make communication and care more effective. This approach may help women to be more specific and to marry their concerns with the information they receive, rather than striving for all out control. Time spent talking to the woman about what is most relevant to her is not time wasted. The pregnant woman/healthcare professional relationship extends over several months and there exists (at least theoretically) some opportunity to pre-empt potential tensions and build more robust relationships.

An important point is that some decisions are likely to involve a series of actions that current guidance does not capture. Furthermore, the fact that women's expectations may need to be revisited and subsequently revised merits closer attention than current guidelines afford. The organisational context of maternity care often makes continuity of professional carer difficult. This has implications for partnerships promoted in guidelines. My analysis of findings suggest that an alternative approach is shared decision-making which is inferred in guidelines. In this respect, what is important is that each consultation should be treated as an ongoing part of the woman's care and emphasis placed on interaction as part of the process. Relational trust places both parties in a favourable position to facilitate these objectives.

There is a tendency in guideline recommendations to give information to women in a logical order. This may sometimes be entirely appropriate. However, several women's accounts suggested that they would welcome the opportunity to raise certain issues and consider their options prior to the designated times recommended in guidelines. This is reasonable, given that pregnancy is a process with a beginning and an end. Guidelines currently recommend when healthcare professionals should raise matters.

An example of this is writing a birth plan at 34 weeks gestation in the Antenatal care guideline (NICE: 2008). However, this recommendation does not factor in different women's wishes to expedite, defer or delay writing their birth plan and fails to acknowledge the importance it might have at different time points in pregnancy-something my analysis suggested women value.

My recommendations make no claim that the healthcare professional can be certain that she/he has adequacy of rapport and has overcome prejudices and misunderstandings that might exist between the woman and her professional carer. Neither would it be realistic to prepare women for every eventuality. Taking this line of reasoning to an extreme would lead us to conclude that anything the woman says should be incorporated into her care. I suggest this represents a bridge too far in transferring too much responsibility alongside apparent authority, but nonetheless should alert us to what matters most to individual women.

(b) Reframing of guideline recommendations.

The centrality of concepts identified in women's accounts help contribute to an understanding of the kind of interventions in guidelines that could benefit women.

EXAMPLE ONE.

Clinical Guideline 70. Induction of labour (NICE: 2008).

'Women having or being offered Induction of labour should have the opportunity to make informed decisions about their care and treatment in partnership with their healthcare professionals' (NICE: 2008).

My analysis suggested that healthcare professionals do not really understand the physiological and psychological issues that this option conveys to women. Women were told what would happen, but not what care they might receive. This point may not be attributable to guidelines, but analysis suggested that information relating to choices that could be seen as difficult warrant greater understanding of women's concerns.

The revised guideline might read:-

'Explicitly encourage the woman being offered Induction of labour to reflect on her options and, drawing on her previous experiences (if appropriate), current pregnancy risk status and her own wishes, invite her to ask questions'.

'Actively explore with the woman the effects of the choice on the woman's circumstances'.

What women worry about and why should become an integral part of their care. My grounded theory suggests these issues should become a formal part of the care process in guidelines, but appropriate measures should be taken into account to weight this recommendation against the wishes of those who have no expectations and those who express their autonomy by declining to talk.

EXAMPLE TWO.

Clinical Guideline 62. Antenatal care. Routine care for the healthy pregnant woman (NICE: 2008).

Screening for foetal abnormalities.

The guideline recommendations state:-

Booking appointment (ideally by 10 weeks).

- Offer screening for Down's syndrome (NICE: 2008).

For women who choose to have screening, arrange as appropriate:-

- Down's syndrome screening using either:
 - 'combined test' between 11 weeks 0 days and 13 weeks 6 days.
 - serum screening test (triple or quadruple test) between 15 weeks 0 days and 20 weeks 0 days.
- Ultrasound screening for structural anomalies, normally between 18 weeks 0 days and 20 weeks 6 days (NICE: 2008).

My analysis suggested there is currently more emphasis on offering tests than enabling women to choose. What is unaccounted for in the guideline is that some women may not want information about tests. Other women, in view of their clinical situation, relational responsibilities and experiences, may require additional information and support to make an informed decision. Healthcare professionals should also recognise the limits of their own working knowledge about the conditions being screened for.

Testing falls under the umbrella of antenatal care which is designed to promote foetal welfare. Once under this rubric, it is difficult for some women to think about testing and abortion together. This is challenging for women and healthcare professionals.

The offer of screening tests is frequently taken as a message for general approval. The test is not presented as something to be avoided; hence women are inclined to accept it.

Additional recommendations to the current guideline might read:-

Booking appointment (ideally by 10 weeks).

- Explore with the woman what is important to her and her family relating to antenatal screening tests for foetal abnormalities.
- Ask how she feels about testing, that is, gauge how testing might affect the individual woman. Gain an understanding of how her circumstances might enhance or restrict the available options and impact on her autonomy.
- In the case of a multigravida, refer back to her case notes. In order to understand more fully her perspectives, relate to her account of previous experiences to usefully expand upon that documented in her case notes.
- Use simple language and appropriately pace the information.
- Gauge the most appropriate detail for the individual woman.
- Cover one point at a time.
- Check the woman's understanding of the information

- Offer the woman the opportunity to revisit and discuss her options at a subsequent time. An example might include making the woman aware of the availability of 'drop-in' sessions at her local health centre.

EXAMPLE THREE.

Clinical Guideline 62. Antenatal care. Routine care for the healthy pregnant woman (NICE: 2008).

The 34 weeks gestation antenatal appointment.

The guideline recommendations state:-

Give specific information on:-

- Preparation for labour and birth including the birth plan, recognising active labour and coping with pain (NICE: 2008:19).

In this context, exercising her autonomy might mean the woman develops a personal action plan.

The revised guideline might read:-

- Negotiate with the woman a designated time for her to request information. If the woman expresses a view, *aim to discover its basis*, for example, information, family experiences. *Actively explore* with her how options presented in guidelines may be enhanced or limited not solely by clinical factors, but by both familial and social factors.
- Understand what makes the woman feel empowered. Enquire which features of her care are most important to her.
- Respond to the woman's wished to obtain information and revisit/expedite/defer decisions in ways timely with her own agenda at subsequent antenatal appointments, whenever appropriate.
- Recognise that several healthcare professionals may have input into the woman's care.

It may also be useful to set out in guidelines dedicated counselling sessions, concurrently being mindful of the fact that time is a constraint in clinical practice.

These points should be presented in a user-friendly format with appropriate academic and healthcare professional input to help ensure factual accuracy of information, general appropriateness to the reader and overall usability.

(iv) Recommendations for future research.

My analysis and interpretation of the study's findings identified specific areas in which further maternity care research would be valuable. However, some authors have argued that qualitative findings can be useful for other patient groups, but further research on those groups is needed (Polit and Beck: 2011; Snowden *et al*: 2011). For example, the finding that patients want timely information that takes account of their own experiences and is tailored to their own situation could be generalised to other patient groups and subsequently inform further empirical research.

More research is needed if healthcare professionals are to look beyond current structures of maternity care. For example, my thesis concluded women's experiences were influenced by insufficient knowledge about pregnancy and birth and the concept of time was important to women. It would be useful to conduct further research to explore the varying degrees of usefulness of knowledge at different time points in pregnancy. Further research is needed to capture *when* healthcare professionals can interact with women to good effect, including an exploration of how time points set out in clinical guidelines may restrict the options available to some women. This information could help identify aspects of the service women would like improved.

Further research is needed to explore the *types* of decisions women find more difficult as findings suggested women tend to rely more upon professional input for some decisions.

Chapter Six of my study is dedicated to women's experiences of screening for foetal abnormalities, but this is confined to one aspect of screening. It would be valuable to explore women's experiences of other aspects of antenatal screening. An example is screening for gestational diabetes and the experiences and support needs of women affected.

Findings suggested that women's experiential knowledge influenced their expectations. There may well be certain aspects of pregnancy and birth that need more detailed reflection than others and more research is needed to explore what these are, the ways in which these relate to women's expectations and wishes and the impact on their autonomy in the current pregnancy.

Findings suggested that women lacked sufficient pregnancy and birth knowledge. In this respect it would be valuable to capture women's experiences of care following an intervention in which they received more complete information tailored to their needs and ways in which it enabled them. A controlled comparative study would be useful in this respect. Further consideration could include an exploration of the factors that best facilitate this objective and ways in which this aspect of care could be further improved.

My study was confined to a single teaching hospital. There is a need for further research with more diverse populations. For example, we need to understand how women receiving predominantly community -based maternity care experience care based on recommendations in guidelines. This could first, increase understanding about low-risk women's expectations and experiences and second, increase understanding about whether partnerships or shared decision- making are most appropriate in the community. This would help understand how the influence of the institution might influence women's perceptions, similarities and differences and how these might provide information which could help inform direction for planning care for this group.

My study was limited to women who could read, understand and communicate in English. Research with non- English speaking women from different ethnic groups could reveal further variations of the ways women experience their care.

Analysis of findings revealed complexities which merit further exploration. Future research could include focus groups and participant observation. Observation could provide further insight into the interaction process between women and healthcare professionals in order to deepen understanding of this key issue. An observational study of interactions between women and healthcare professionals working with recommendations in guidelines would add a further dimension. This could help determine the type of interactions that are most helpful in enhancing maternal autonomy.

My study explored women's experiences of their care. Having identified concepts that are important to women, it would be valuable to explore the complexities and diversity of healthcare professionals' experiences to provide new insights and increase understanding.

Healthcare professionals face enormous pressures in providing maternity care. Research exploring how best to support healthcare professionals working with maternity clinical guidelines care would be helpful.

FINAL CONCLUSION.

Maternity care clinical practice guidelines are sensitive to patient autonomy and choice, but this does not necessarily work in the interests of all pregnant women. There is no neat resolution. Some degree of interdependence may be a necessary precondition for women to exercise their autonomy. In certain situations, there may be tensions between women's autonomy and interdependence, although there are cases where the two can co-exist and the woman can retain her autonomy.

Although the offer of a choice was well received by some women in certain instances, it may be that current guidelines rely to some extent on the consumerist assumption that pregnant women are autonomous agents, who act rationally on the basis of the choice they are offered. This assumption fails to account for the complexities women might face in interpreting the options available to them. As we have seen in this thesis, some women elect to reconfigure their autonomy in ways that are not predicted by the liberal model of autonomy or the consumerist model of informed choice.

My study concludes that guideline recommendations should be negotiated more closely alongside women's previous experiences and current expectations. This is challenging for healthcare professionals caring for different women. Professionals need to be more than guides. It is through a process of shared decision-making that the woman's autonomy can often be enhanced. This could involve the professional using different approaches during the consultation. These might range from an open informative approach to a more directive approach depending on the woman's clinical condition, her wishes and the flow of the dialogue with her professional carer. The proposed new recommendations bring their own challenges and cannot include all the finer details about women's maternity care. Nonetheless, in line with the ambition of Grounded Theory to produce useful research, they aim to make modest improvements.

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APPENDIX (i)

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Participant Information Sheet.

Study Title:- Evidence-based guidelines – Pregnant women's perceptions.

You are being invited to take part in a research study. Before you decide, it is important that you understand why the research is being done and what it would involve for you. Take time to read this information sheet and discuss it with family, friends and members of your clinical care team if you so wish. I will go through the information sheet with you. Please feel free to ask if anything is unclear or if you require further information.

Purpose of the Study

In maternity care today, we have a growing body of research which has an influence on decisions which affect the care and treatment given to you and your unborn baby/ babies. This is often referred to as 'evidence', that is, which treatments work well and which treatments do not work so well. We know that it would be an impossible task for healthcare professionals providing your maternity care to read all the research evidence, hence they turn to evidence-based clinical practice guidelines which are a useful way of referring to the known evidence in the form of a guideline.

We already know that many women want their maternity care to be based on evidence wherever possible and we are also aware that there are those who are interested in the direct relevance of the evidence in their particular case.

What is not currently known are the experiences of women themselves relating to the use of evidence-based clinical practice guidelines in their maternity care. This study aims to address the gap that exists. On a spectrum, it may be that guidelines have had a major impact, or little or even no impact on your maternity care. I

would like to ask you some questions but wish to emphasise that whatever your views, I am very interested in listening to them.

You experience at first hand the pregnancy journey and are well placed to talk in an informed way about the topic.

Why have I been invited?

You have been invited because you are between 20-36 weeks pregnant,

You attend the Antenatal clinic at Liverpool Women's NHS Foundation Trust and you face a pregnancy- related decision.

Do I have to take part?

It is up to you to decide whether to take part. The Researcher, Alison Ledward will describe the study to you and go through the information sheet. This should take approximately half an hour. If you agree to take part, she will ask you to sign a consent form. You are free to withdraw at any time without giving a reason. This will have no effect on the standard of care you receive.

What will happen to me if I decide to take part?

If you decide to take part, you will have an interview with the researcher which, with your permission will be audio-recorded. The interview will last approximately one hour and it will take place in a private room in the Antenatal clinic at Liverpool Women's NHS Foundation Trust. In order to

minimise inconvenience to you, the interview will be scheduled to correspond with your Antenatal appointment. It may sometimes be

necessary to contact you on one further occasion to provide final confirmation of details of what you have told me in the interview. There will be no follow-up interviews.

What will I have to do?

Having read carefully through this information sheet, if you decide you would like to participate, you will be asked to sign a consent form and you will be given the sheet to keep.

What are the possible advantages and inconveniences of taking part?

We cannot promise any direct benefit to you personally, although you may derive some sense of satisfaction in the knowledge that your contribution to the study may help other pregnant ladies in the future.

A slight inconvenience to you is that your clinic appointment will be extended by approximately one hour.

Furthermore, there is a risk in some cases that the interview may bring to the surface something you may find upsetting. We will try as far as possible to avoid this kind of situation, but should it occur, the interview will be stopped and we will seek advice from your clinical care team. There are also professional counselling services available which are externally based, should your clinical team identify the need

Expenses and payments

The study will not incur any additional expenses to you. You will not be paid for taking part in the study. The researcher will not be paid for including you in the study.

Will my taking part in the study remain confidential?

Yes. We will follow ethical and legal guidelines and all information will be handled in confidence. All information that is collected from you during the interview will be kept strictly confidential and any information about you which leaves the hospital will have your name and address removed so that you cannot be recognised. However, during the interview, should you disclose information that suggests individuals may be at risk or illegal activities, I will have a duty of care to escalate according to Liverpool Women's NHS Foundation Trust guidelines. If you join the study, some parts of your medical notes and/or data may be looked at by responsible individuals from the study team, the Sponsor, the Research Ethics Committee, the NHS Trust or from regulatory authorities where it is relevant to you participating in the research. In addition, some of your personal data will be retained by authorised persons involved in organizing the research at the University of Leicester. All will share a duty of confidentiality to you as a research participant.

What will happen if I do not want to carry on with the study?

If you wish to withdraw from the study, you may do so at any time without giving a reason and it will have no impact on your clinical care. If you withdraw, we will ask you if we may use the data already collected.

Will the findings be anonymous?

Yes. Your interview will be assigned a code number so that you cannot be recognised. This will apply equally to any direct quotations of what you say.

Who will have access to the findings

The researcher and her two academic supervisors at the University of Leicester.

What will happen to the findings?

They will be stored securely on University computers which are encrypted and password protected. They will be analysed by the researcher and will eventually form part of a written report which will form part fulfilment of an educational qualification for the researcher.

They may also be presented in healthcare journals and conference presentations.

You may request a summary copy if you wish.

What happens when the study stops?

The data will be destroyed confidentially by the researcher after 5 years duration.

What if there is a problem?

If you have a concern about any aspect of the study, the researcher will do her best to answer your questions. However, if you feel that your concern has not been satisfactorily resolved and you wish to complain formally, you can do so using the NHS Complaints Procedure at Liverpool Women's NHS Foundation Trust by contacting the Patient Quality Team on Telephone Number:- 0151 702 4416.

In the unlikely event that something goes wrong and you are harmed during the research and this is due to someone's negligence, then you may have grounds for legal action for compensation from the NHS, but you may have to pay your legal costs. The normal NHS complaints mechanisms will still be available to you.

Who is organizing the research?

The University of Leicester is sponsoring the research.

Who has reviewed the study?

All research in the NHS is inspected by an independent group of people called a Research Ethics Committee to protect your interests.

This study has been reviewed and given a favourable opinion by Liverpool Central Research Ethics Committee.

Further information and contact details:-

General information about research contact PALS(Patient Advice and Liaison Service) .Telephone Number:- 0800 0320202.

To obtain further information about this study, please contact the researcher, Alison Ledward via her email address at the University of Leicester:- al281@le.ac.uk or you may wish to speak to her on her work mobile telephone number :- 07806726760. Alison will return your call.

If you would like to take part in this research study:-

Please register your interest by sending an email to the Researcher, Alison Ledward via her email address at the University of Leicester:-

al281@le.ac.uk

Following receipt of your email, I will make the necessary arrangements to meet

with you at your next Antenatal clinic appointment at Liverpool Women's NHS.
Foundation Trust.

**Alternatively, if you prefer, you can contact Alison Ledward on her work mobile
telephone:- 07806726760. Alison will return your call.**

Finally, thank you for taking the time to read through and consider the
information related to the research study presented to you on this sheet.

APPENDIX (iii)

Interview Schedule/ Topic Guide.

Evidence-Based Guidelines. Pregnant Women's Perceptions.

Sequence.

Welcome the participant. Introduce one-self, remind participant of the purpose of the interview, re-affirm assurances of confidentiality and anonymity, confirm permission to audio-record the interview. Explain to participant there are no right or wrong answers and what is important is that she expresses her views. Emphasise that if there are questions she prefers not to answer, then it is fine to avoid them.

Warm-up questions: - A few general, easy questions to map out and generally set the tone and pace for the interview.

Main body of interview: - To follow a logical sequence. Semi-structured questions will be utilised in order to explore the participant's experiences and to ensure that missed topics are returned to – unless deemed inappropriate.

Cool off questions: - A few straightforward questions to tie up issues.

Closure: - Thank the participant for her valuable contribution. Goodbye.

Rationale.

The rationale behind the interviews is an in-depth exploration of women's experiences of their care based on recommendations in clinical guidelines. The issue of fundamental importance is the woman's position vis-a-vis the guideline. Clinical practice guidelines are widely applicable; hence there is the potential to include women with a range of pregnancy conditions. My target group are those who face a pregnancy-related decision of some kind.

Topic guide.

Main question.

Have you had to make or will you have to make any decisions about your maternity care?

There were three main target questions of interest.

1. Can you give me an example?
2. What was your experience like?
3. What were the main reasons for your decision?

If there were issues of particular interest, it may be appropriate to say to the participant 'Could you please tell me more about.....'

Some women may share their experiences without prompting, but it may be appropriate to ask others probing questions.

Follow- up questions that may be asked if not addressed by the woman.

- Why did you choose this particular event?
- Who was involved?
- How much did you know about the options available to you?
- What were the sources of information you had?
- Was there any communication between yourself and the professional caring team?
- Do you think communication is important?
- On reflection, did you feel empowered to make your own decisions about your maternity care?
- Has your experience made you think about what you might do differently in a future pregnancy?

Let us suppose, for example, that a woman, Para 1 faces a decision between VBAC or an elective Caesarean section delivery.

Questions that might help a participant express her perspective:-

Researcher: - I understand you had a Caesarean section delivery last time but there is a possibility of a natural birth this time.

- Why did you have a Caesarean section last time?
- Tell me about the events that led up to it as you recall them.
- How did you feel about it at the time?

Prompt:-

- Was it in your and/or your baby's best interests?
- Did you fully understand the reasons behind it?
- Were you happy with the explanation?

- Overall, did you feel that you were sufficiently involved in the decision?
- On balance, were you happy with the decision or were you disappointed/ shocked/angry?
- Have your feelings changed now - or do you feel much the same?
- Has a final decision relating to your mode of delivery been made yet this time?
- If yes - were you involved in the decision-making process?
- If no - do you wish to be involved?
- How much involvement would you like to have?

(a) All women were asked about their experiences of screening for foetal abnormalities.

The opening questions were:-

- Were you offered antenatal screening tests?
- Was it made clear the tests were optional?

Follow –up questions, (if not addressed by the woman):-

- What were your feelings about the tests?
- Did they affect your relationships with others?
- Did they affect your future plans?
- Is there anything you wish had been different about the care you received?
- Is there anything you would like to add?

(b) Women were asked about lifestyle choices during pregnancy.

- Do you smoke? If 'Yes':-
- Are there any factors which might prompt you to reduce or discontinue smoking?
- What is your understanding of the risks of smoking in pregnancy?
- Have you sought advice from your midwife or doctor about smoking in pregnancy?

(c) Women were asked about their plans for the birth.

- Have you been informed about what options will be available to you?
- What do you know about these different options?
- Which option do you prefer?
- Why do you prefer that option?

- What type of information would be useful in helping you reach a decision?
- How would you like to be given information? (Prompt- by a healthcare professional/ leaflets/ books/ the internet or a combination of these).
- How far do you feel able to choose?
- Who or what influenced your decision?
- Have you talked to your midwife/ doctor about your previous experiences? (Multigravidae).

Some possible questions to be included:-

- Were you made aware of the evidence (knowledge) on which the decision about your care was based?
- As a result of the verbal/written information given to you, were you better able to understand the reasoning behind the decision?
- Does the evidence matter to you?

- How did you see your role in the decision-making process?
- Were you involved as an active participant – or were you not involved - or somewhere in between the two?
- Did your position raise anything of particular significance for you? If so, to what extent (if at all) has it affected you and your maternity care?

APPENDIX (IV).

Analysis Strategies.

I will outline my analysis strategies:-

In accordance with grounded theory, coding was conducted after each interview and previous interviews were revised and re-coded in the light of the current interview and emerging codes. Initially, I had 95 codes. Some codes addressed general themes such as the importance of foetal welfare. Other codes addressed specific issues, for example, problems with the offer of a choice of alternatives. Others were participants' views, for example, problems they saw with making decisions independently. Others were based on my interpretation of the data, for example, where there was a clear role for maternal autonomy in decision-making.

As set out in Chapter Three, my analysis was conducted in three stages.

To summarise these points:-

1. During the early stages of my analysis, I used my coding system to gain an oversight of the general themes in the dataset. I made notes in the margins of words and short phrases which summed up what was being said in the text, that is, it accounted for almost all the interview data. This is open coding and was part of the process by which I made some inroads into categorising my data.

In accordance with my adaptation of Constructivist Grounded Theory (Charmaz: 2006) some of my codes were also generated from relevant extracts in clinical guidelines.

List of Codes.

- **A**
Acceptance.
Alternatives – choice of.
Ambiguities.
Assert.
Autonomy - exercise of. Autonomy - restrictions on. Autonomy - ways of expressing.
Authority.

- **B**

Beliefs.

Boundaries.

- **C**

Cared for - need to feel.

Choice – informed .Choice- lack of. Choice - offer of. Choice - too much.

Choosing- having to. Choosing - invited to. Choosing - needing to.

Choosing - wanting to.

Complexities.

Comply.

Compromise.

Concerns.

Confer.

Confirm.

Consequences.

Constraints.

Control.

- **D**

Decisions- how made.

Decisions- important, minor, major, non- routine, routine, shared.

Decline- importance of option.

Dependence.

Dilemma.

Doubts.

- **E**

Expectations.

Experiences - women's.

- **F**

Familiarity – with care, with environment.

Foetal welfare- importance of - to women, to professional carers.

Flow of events - pregnancy, labour and childbirth.

Formality.

Frustration.

- **G**

Gatekeepers.

Guides.

- **H**

Healthcare professionals - anchor. Healthcare professionals - experts.

Healthcare professionals - guide. Healthcare professionals -

knowledgeable. Healthcare professionals - safety net. Healthcare

professionals - women's need to defer to.

- **I**

Individualised.

Independence.

Influence.

Information.

Interactions.

Interdependence.

- **K**

Knowledge - acceptance of. Knowledge- appropriate. Knowledge - experiential. Knowledge-lack of. Knowledge- scientific.

- **L**

Loyalties - partner, family.

- **O**

Obligations - foetus.

Offer – of a choice.

Options - making sense of. Options - offer of a range of. Options - restrictions on.

- **P**

Participation.

Partnerships – in healthcare decision-making.

Perspectives.

Predictions.

Preferences.

Preparation.

Priorities.

- **R**

Reasoning.

Reassurance.

Reflections.

Relationships – maternal - with foetus, with family and friends, with professional carers.

Reliance upon.

Resistance.

Responsibility.

Risk – women’s fear of.

- **S**

Sacrifice - maternal.

Safeguarding - foetus

Security.

Support.

- **T**

Testing out.

Timescales - changing. Timescales - forward planning. Timescales - women’s agendas.

Trust - importance of women's need to trust professional carers.
Trust - importance of professional's carers' need to trust women.

- U

Uncertainties.

Unknown – women's fear of.

- V

Values - women's.

Vulnerabilities - women's.

2. The next step included careful re-reading of the data to ensure that the main categories covered the initial codes. Many of the 95 categories were superfluous; hence I focused on reducing, refining and subsequently combining the categories I would use in my rigorous analysis to write the report.

I coded the data for specific issues. For example, I had a collection of codes which picked out different aspects of women's interactions with professional carers.

EXAMPLE: - Main thematic category

Importance of interactions with trusted healthcare professionals.

An example of an initial coding framework.

Interview transcripts.

Initial coding framework.

Extract 4.15

It is clearer from some knowing person, GP or midwife - need to confer with them.

Interdependence.

Sharing.

Extract 4.16

My opinion is face-to-face with the midwife, because in my experience, it's good.

Interactions.

Participation.

Extract 5.14

... You have to put your trust in professional people. Professional authority.

For me, the trust comes from feeling this person's giving me the information I need to make a decision. Professional knowledge.

3. The next step is to reduce the number of categories by funnelling some of the ones that are similar into broader categories. For example, all three Extracts above refer to healthcare professionals and suggest women's need to involve them in their deliberations.

- Healthcare professionals are knowledgeable.
- Women do not want to decide alone.
- Women have positive experiences of their interactions with their professional carers.

Relationships between the codes were identified to form the main thematic category.



Main thematic category: - **Importance of interactions with trusted healthcare professionals.**

Summary of the process to generate my grounded theory.

The theory rests on my two main thematic categories, namely the knowledge asymmetry between women and their professional carers and the importance of interactions with trusted healthcare professionals.

My grounded theory of 'Choosing when to choose' was generated by:-

- (i) Rigorous data analysis.
- (ii) Interpretation of the empirical study data.
- (iii) Synthesis of the study's findings in response to my research question.

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