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# Informed Choice in Maternity Care: An Evaluation of Evidence Based Leaflets



THE UNIVERSITY *of* York

REPORT 20



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**INFORMED CHOICE IN MATERNITY CARE:  
AN EVALUATION OF EVIDENCE BASED LEAFLETS**

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## Glossary of Terms

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<b>AFP</b>	Alpha-Feto Protein
<b>ANC/anc</b>	antenatal clinic
<b>ARM</b>	artificial rupture of membranes
<b>Bounty pack</b>	a pack of free samples and advertising materials routinely given to pregnant women at the booking visit
<b>breech presentation</b>	a baby positioned so that the presenting part is the buttocks (and genitalia) or one, or both, feet
<b>c/s</b>	caesarean section; also known as LSCS: lower segment caesarean section
<b>CDS</b>	central delivery suite; also known as LW: labour ward
<b>CRCT</b>	cluster randomised controlled trial
<b>CTG</b>	cardiotocograph; electronic monitoring of the baby's heart and mother's uterine activity
<b>CVS</b>	chorionic villus sampling
<b>doctors</b>	are hospital based doctors unless otherwise stated
<b>Domino delivery</b>	DOMiciliary IN and Out: delivery planned for hospital but the woman is assessed at home in early labour by the community midwife (who has provided antenatal care), is accompanied into hospital when labour is established and is transferred home soon after the baby is born.
<b>ECV</b>	external cephalic version: abdominal manipulation of the baby from a breech position to a head down position
<b>EFM</b>	electronic fetal monitor
<b>FH</b>	fetal heart
<b>GP</b>	general practitioner(s)
<b>HoM</b>	head of midwifery
<b>ICC</b>	intraclass correlation coefficient
<b>IUGR</b>	intra-uterine growth retardation
<b>MIDIRS</b>	Midwives Information and Resource Service
<b>mlc</b>	midwifery led care
<b>MSLC</b>	maternity services liaison committee
<b>multiparous</b>	a woman who has had one or more children
<b>NCT</b>	National Childbirth Trust

<b>NHS</b>	National Health Service
<b>obstetrician</b>	a doctor working in the speciality of obstetrics at, or above, the level of registrar
<b>OP positions</b>	occipito-posterior position of the baby which can increase the pain and length of labour
<b>parentcraft classes</b>	antenatal education classes
<b>primigravid</b>	a woman who is expecting her first baby
<b>primiparous</b>	a woman who has given birth to her first baby
<b>SCBU</b>	special care baby unit
<b>SHO</b>	senior house officer
<b>trimester</b>	a period of approximately three months (13 weeks)
<b>ultrasound practitioners</b>	medically and non-medically trained personnel who perform ultrasound scans on pregnant women
<b>VE</b>	vaginal examination
<b>woman/service user</b>	a childbearing woman who is receiving, or has recently received, maternity care

### BACKGROUND

The importance of informed choice for consumers has been recognised within the NHS and is emphasised in maternity care policy documents (Welsh Health Planning Forum 1991, Department of Health 1993). The Midwives Information and Resource Service (MIDIRS), together with the NHS Centre for Reviews and Dissemination, produced leaflets summarising research evidence for ten discrete topics on which decisions are made in pregnancy. The leaflets are produced in pairs: the woman's version summarises the research evidence; the health professional's version details evidence in greater depth and is fully referenced. The leaflets were intended to provide research-based information to inform choice in accordance with women's individual needs. The leaflets and associated staff training are usually purchased from MIDIRS by maternity units or individuals.

This research evaluated the use of the whole set of MIDIRS Informed Choice leaflets across maternity units to assess their effectiveness in promoting informed choice. The relationship between leaflet use and evidence based practice was not a primary focus of this research.

### METHODS

A mixed method approach was taken to address whether the leaflets were effective in promoting informed choice. The study was conducted in two phases. The first phase comprised an ethnographic study of three maternity units, which *had purchased and used* the leaflets for some time. This informed the development of the second phase in which a cluster randomised controlled trial (CRCT) was undertaken in conjunction with qualitative fieldwork. The qualitative research included observation of clinical practice, interviews with women and health professionals, and focus groups with women. The CRCT involved 13 maternity units, grouped into ten clusters; five were randomised to receive the intervention and five to act as controls. A postal questionnaire was sent to women who were 28 weeks pregnant and women at eight weeks post-delivery, both before the intervention and after the intervention had commenced. The overall response rate was 64% (6452/10070). The primary outcome was the change in the proportion of women agreeing with the statement that they had had 'enough information and discussion with midwives or doctors to make a choice together about all the things that happened during maternity care'. An economic study of costs and cost consequences was also undertaken.

### THE INTERVENTION

The intervention consisted of the full set of ten MIDIRS Informed Choice leaflets and training in their use. A sufficient number of leaflets for an eight-month intervention period were supplied to each of the intervention units. The supply of the woman's version of the leaflet was calculated as a percentage of the annual delivery rate for each unit. As midwives are primarily responsible for disseminating information, supplies of the professional's version were calculated on the basis of the total number of midwives employed in each intervention site.

### FINDINGS

#### Effectiveness of the leaflets

Between 92% and 99% of women who received each leaflet reported that it was helpful or very helpful. However, there was no evidence that the leaflets were effective in increasing the proportion of women who reported having exercised informed choice. The minimum important change of a 10 percentage point increase was not attained: +1% (95% CI: -13%, 15%) for women antenatally and -4% (95% CI: -13%, 5%) for women postnatally. The same conclusion emerged from the analysis of over 5,000 volunteered comments written in response to open-ended questions.

The qualitative research illustrated the complexity of the environment in which the intervention was applied and suggests reasons why the MIDIRS Informed Choice leaflets did not promote informed decision-making in this study.

## Why did the MIDIRS Informed Choice leaflets not promote informed decision-making?

- The lack of a coherent strategy for leaflet distribution or for the promotion of informed decision-making:

A number of practices hindered the distribution of leaflets and rendered them invisible to most women.

'Informed choice' was simply equated with having the leaflets. No strategy for achieving informed choice was evident on any of the study sites. Moreover, midwives, childbearing women and obstetricians articulated different and often incompatible understandings of the concept of informed choice.

- The cultural context:

Women wanted and needed more information than they were generally given by health professionals. In all the units researched, midwives articulated a strong commitment to giving information but opportunities were rarely maximised. This was particularly true for disadvantaged women. Information flow was observed and reported to be most effective when there was a relationship of trust between a childbearing woman and a midwife. However, organisational imperatives within the maternity care system often mitigated against such relationships. In the absence of trust, power differentials between participants in maternity care impeded information flow, restricted opportunities for decision-making and usually resulted in women's compliance with 'right' choices that mirrored normative patterns of care. These assumptions had significant implications for decision-making, either masking opportunities for choice or making it difficult for women to challenge practice norms.

Midwives were observed to work under considerable pressure, not least of which was the pressure of time. This limited opportunities for discussion and may help to explain why midwives were often observed to stereotype women, making assumptions about their information needs.

All professional groups expressed fear of litigation. This resulted in a tendency for health professionals to 'steer' women towards making decisions, which reinforced the status quo. Such decisions ensured informed compliance rather than informed choice.

## IMPLICATIONS

- Leaflets are tools for imparting information and although information is necessary to attain informed choice, it is not sufficient.
- The implications of this study are not that the MIDIRS Informed Choice leaflets are without effect. We cannot say from this study whether they *could* be effective at promoting evidence-informed choice as part of a coherent initiative rather than as the driver or focus of the initiative.
- The maternity services are characterised to an important degree by cultural inertia. Until this is addressed, introducing concepts of informed choice are likely to result merely in informed compliance. Currently, the MIDIRS Informed Choice leaflets are commonly used to reinforce the rhetoric of informed choice without challenging cultural inertia. Where evidence based information does not reinforce normative practices, this information may be denied by health professionals.
- There is potential for conflict where evidence based information, such as the MIDIRS Informed Choice leaflets, are prioritised over women's and professionals' experiential knowledge.
- The promotion of informed choice is not cost neutral. Resource use cannot be understood simply in terms of the costs of purchasing evidence based information such as the MIDIRS Informed Choice leaflets and associated training. Resource use will also be associated with cultural changes required to provide a context amenable to informed decision-making.

## RECOMMENDATIONS

### Department of Health

- The Clinical Governance aim of moving 'away from a culture of blame' (NHS Executive 1999) has particular resonance in the light of the findings of this research. Explicit strategies are needed to achieve such massive cultural change. This study highlights particular tensions in maternity care between the aims of evidence based care, choice, efficiency and equity. For instance, organisational imperative to maximise the efficient use of time result in articulate women claiming more staff time and disadvantaged women being excluded from decision-making. Such fundamental tensions need to be acknowledged and explored.
- Resource planning is required to prevent the Inverse Care Law (Tudor Hart 1971) becoming established within new national care initiatives.
- Improved access to information for women requires a strategic approach. There is a need to develop and define appropriate funding which might derive from public, private or consumer sources.
- The MIDIRS Informed Choice leaflets have been developed and are seen as helpful by women; therefore, decisions need to be made as to how they can best be funded, distributed and used.
- When a funding strategy is in place, information could be given in diverse and creative additional ways. Possibilities include:
  - \* Giving some leaflets with the Surestart Maternity Grant together with the telephone number of a maternity advocacy service.
  - \* Making leaflets available on the Internet.
  - \* Points of decision-making could be included in the chronology of pregnancy in the Pregnancy Book (Health Education Authority 1997).

### Professional Organisations

- There is a need for professional debate concerning the factors which prevent health professionals from listening to women and which encourage stereotyping as a professional defence mechanism.

### Education Providers

- There is a need for basic and continuing education for health professionals that emphasises skills development in particular areas including: listening and responding to cues, history taking, dealing with sensitive areas of information and appreciating the contribution of alternative perspectives.

### Service Providers

- The fostering of continuing trusting relationships between clients and professionals should be an aim in service planning.
- Equity should also be an explicit aim.
- There is a need to identify and develop strategies to enable women to access health professionals for information and discussion outside of scheduled appointments. This may be particularly important in early pregnancy.

### Health Care Professionals

- There is a need for individual practitioners to listen to women, to assess their knowledge levels and target information selectively.
- Health professionals need to be aware of the difficulties many women experience in asserting their need for information and dialogue. Health professionals should also assume the responsibility for creating openings to enable information flow.

### MIDIRS

- Consider a range of options for making evidence based information available to women and health professionals.

- Training in the use of evidence based information needs to be delivered as part of an integrated strategy for promoting informed choice. Each training session must be sensitive to local culture.

## **FURTHER RESEARCH**

As the MIDIRS Informed Choice leaflets are useful information tools that were generally liked and appreciated by women, it is important to consider how their utilisation might be improved. This research has highlighted the absence, within practice settings, of coherent strategies through which informed choice could be facilitated. Further research is therefore warranted to:

- understand the different meanings of informed choice articulated by participants within maternity care, the separate values attached to information and to choice, and the implications of these differences in practice.
- further delineate the concept of informed decision-making and the emphasis which may be placed upon different elements within different cultural contexts.
- assess the effectiveness of the leaflets when their use is embedded within a coherent strategy that is aimed at maximising informed decision-making in maternity care.

This study has highlighted other issues of significance to participants in maternity care. These also warrant further research.

- action research is required to explore the process of cultural change within maternity care. A particular focus upon power relationships is needed. It is important to reiterate that this study strongly suggests that the facilitation of informed choice is likely to be contingent upon changes in power relationships.
- there is a need to identify effective midwifery skills and the contexts that facilitate their use. In particular there is a need to elucidate the skills required by midwives to respond appropriately to cues and opportunities that may arise during interactions with women.
- the concept of trust warrants further explication. The factors that enable, or mitigate against the development of a trusting relationship between a childbearing woman and her carer/s need further exploration. This study has indicated that information flow is optimised within trusting relationships.

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# Chapter 1: Introduction

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## 1.1 BACKGROUND

As with other areas of health care, philosophies of maternity care have moved in recent years from requiring clients' consent to treatment to a more complex notion of informed choice. Evidence has existed for many years to show that childbearing women want more information and choices in their care (Cartwright 1979, Perkins 1991) and there are well established links between perceived control and improved emotional outcomes in this group (Green, Coupland and Kitzinger 1988). There are, however, dilemmas with increasing the power of clients relative to that of health professionals as the latter may then perceive their expert knowledge as being undermined (Kirkham 1996). Redefinition of the concept of expertise is possible but is unlikely to happen without radical changes in the philosophy and organisation of care (Guilliland and Pairman 1995). Whilst 'Patient Partnership' is an NHS Executive medium term priority (NHS Executive 1996), problems may be experienced where the organisation of care remains substantially unchanged and the midwife feels her work to be controlled by managerial and medical factors which are uninfluenced by client choice (Kirkham 1996). It was anticipated that the Informed Choice leaflets might move the maternity service towards a partnership approach in the delivery of care which was more equitable and for which a rational basis could be demonstrated.

## 1.2 THE INFORMED CHOICE LEAFLETS

In 1993, a government policy document for England (DoH 1993) charged providers of maternity care to work towards making the service more woman focused. It particularly emphasised the need for women to have information made easily available so that they could make informed choices about their care. This focus has been reinforced in subsequent policy documents underpinning other areas of health care (NHS Executive 1999, DoH 1998, NHS Executive 1995) although it has also been noted (Entwistle et al 1996b) that there is currently no definitive standard against which such information can be measured and that the benefits of involving patients in health care decision-making remain unproven.

In 1994, the Department of Health made funding available for MIDIRS (Midwives Information and Resource Service) and the NHS Centre for Reviews and Dissemination to collaboratively produce evidence based leaflets on ten discrete, pregnancy-related topics. This collaboration resulted in the production of series 1-5 of the Informed Choice leaflets, which were published in 1996; series 6-10 followed and were published in 1997. (See Appendix 1 for the full titles of the leaflets) The leaflets were updated towards the end of 1999 after the data collection for this research had been completed.

The initiative aimed to assist childbearing women to exercise informed choice by producing summaries of the research evidence on the safety and effectiveness of discrete areas of clinical practice. The leaflets were produced in pairs, with one leaflet aimed at the service user and the other, containing the references to published studies, intended for the service provider. The cost of each leaflet was 15p for the service user's version and 30p for the health professional's. It was the intention (as is stated on each of the consumer's leaflets) that if more detailed information was wanted, consumers could ask to see the professional's version.

### 1.2.1 The process of developing the leaflets

#### 1.2.1.1 Gathering expert opinions

An independent researcher was employed to conduct a series of focus groups with maternity service users and providers. Participants were recruited via pre-existing, informal networks and through a series of advertisements in local newspapers in different geographical areas of the UK. The sample was intentionally diverse and included women at different stages of pregnancy and those who were newly

delivered; women of different parity spanning the range of childbearing ages and women with different physical abilities and from different socio-economic backgrounds. In addition, health professionals involved in the delivery of antenatal care, such as midwives, obstetricians, ultrasound practitioners and anaesthetists, were also invited to participate in separate focus groups. Twenty such groups were thus convened and a total of 105 participants were invited to talk about choice in maternity care and about the information which would be needed to support informed choice. An additional two focus groups were held with midwives and two with doctors to explore the questions they were asked by pregnant women and what information they felt they needed themselves in order to support pregnant women making informed choices about their maternity care.

### **1.2.1.2 Analysing the data and writing the leaflets**

Once the topics had been agreed, authors with the appropriate knowledge and experience were then commissioned to synthesise and interpret the research evidence and to write the leaflets for the health professionals. Access to The Cochrane Database of Systematic Reviews ensured that the information contained in the leaflets was based on the best available research evidence. The leaflets were then subjected to a rigorous process of independent review. The intention was to make choices in contemporary maternity care explicit and to state clearly what is, and what is not known, about that care. For a full description of the development of the leaflets, see Oliver et al 1996a and Rosser et al 1996.

### **1.2.1.3 Accessibility for service users**

The leaflets for consumers were distilled from the material contained in the professional's leaflet and were then 'translated' by authors who were skilled in presenting information to the general public. In order to reduce inequality with respect to accessing the leaflets, the consumer leaflet was written for an audience with a minimum reading age of 11 years. Experts in the design and layout of printed materials were employed in the production process and specific regard was given to the guidelines produced by the RNIB (Royal National Institute for the Blind) for the visually impaired. It was intended (Rosser 1996) that the information contained in the leaflets would be available on audiotape and in Braille and that translation (both into text and audiotape) into the 11 languages most widely spoken by maternity users in the UK, would be undertaken. Unfortunately, estimated production costs have remained persistently beyond the financial capacity for MIDIRS to extend the product range.

### **1.2.1.4 Translation**

In accordance with the Welsh Language Act (1993), the women's version of the leaflets was translated into Welsh for the purpose of this study. The translation was funded by the Welsh Office.

## **1.2.2 The intended use of the leaflets**

### **1.2.2.1 Prescribing**

The MIDIRS trainer asked midwives to keep a written record of all leaflet transactions in the woman's notes. It was expected that health professionals would use the leaflets in a controlled and conscious way, in other words, that they would be individually prescribed in response to specified need. The leaflets were not designed to be left in racks in public places such as GP surgeries and antenatal clinics. It was intended that the timing and distribution of Informed Choice leaflets to service users would be such that service users could read the information before being invited to participate in decision-making. The leaflets were intended to complement, rather than substitute for, oral information and subsequent discussion with health professionals.

### **1.2.2.2 Using evidence in practice**

It was hoped that providing health professionals with more detailed information (as in the fully referenced version of the professional's leaflets) would enable them to counsel women in their care more effectively and also enable them to answer questions with greater clarity and conviction. In this way, the Informed



Choice leaflets were seen to have the potential for encouraging practitioners to give balanced, evidence informed advice and that this, in turn, would lead to a more rational basis for practice.

### **1.3 BACKGROUND TO THIS RESEARCH**

Although the leaflets had been in use throughout the UK since 1996, a large-scale evaluation had not previously been undertaken. In 1997, this study was commissioned to redress this deficit. The original call to tender outlined the broad aims of the evaluation as being:

- To examine the uptake and use of the leaflets and factors which might positively and negatively affect this;
- To assess the positive and negative impact of the leaflets on levels of knowledge, attitudes, beliefs, behaviour, satisfaction and fulfilment of women and health professionals;
- To assess the impact of the leaflets on relationships between patients and health professionals;
- To assess the impact of the leaflets on relevant health professionals.
- To provide insights into the area of patient partnerships.

A mixed methods study, in two phases, was planned to address these aims. The second phase was sited in Wales because it presented the largest area in the UK where the Informed Choice leaflets had not been purchased; it was therefore the logical area in which to construct such a trial. At this stage, collaboration with the University of Glamorgan was initiated and, as Wales had preceded England in examining the needs of contemporary childbearing women (Welsh Health Planning Forum 1991), it was anticipated that such a partnership would aid in furthering the development of the UK maternity services.

The timing of this study acknowledged a shift of emphasis and philosophy in the NHS agenda. In recent years, UK government directives have moved on from stressing the importance of patient informed consent to treatment, to rather more complex notions of incorporating evidence based care, informed choice and patient partnership (DoH 1993, WO 1996b, WO 1998, NHS Executive 1996). The imperative for NHS trusts to deliver a service in accordance with predetermined quality indicators, which include the aforementioned concepts, has since become a legal requirement (DoH 1999).

### **1.4 COMBINING QUANTITATIVE AND QUALITATIVE METHODS**

The primacy of experimental methods (randomised controlled trials) and the widely held belief that these models of scientific enquiry demonstrate a 'gold standard' in the evaluation of interventions in health care have been challenged in recent years (Barbour 1999, Holm and Smidt 1997, Scheff and Starrin 1997). In keeping with changing priorities in health services research (Murphy et al 1998), this study employed both qualitative and quantitative methods in all phases of the study design, data collection and analysis. The combination of methods facilitated the pragmatic approach adopted in this study and enabled the research team to explore issues arising throughout the research which were often of a multidimensional and multidisciplinary nature. The spectrum of methodologies employed was thus mutually supportive and assisted the research team in generating and testing hypotheses directly from observation of clinical practice.



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## Chapter 2: Overview of the Evaluation

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The evaluation of the Informed Choice leaflets was undertaken in two phases so that phase one could inform phase two. There were a number of aspects to phase two of the evaluation. An overview is given below.

### MAPPING EXERCISE

A **mapping exercise** (telephone survey) of Heads of Midwifery was carried out in one geographical area where the first set of leaflets had been purchased by the Health Authority. The majority of GP practices in the UK which had purchased the leaflets were also surveyed (Chapter 3).

### PHASE ONE

An **ethnographic study** was undertaken in three maternity hospitals in England and Wales where the Informed Choice leaflets had been purchased. Qualitative methods were used to inform the researchers about a range of issues underpinning informed choice and the use of the leaflets in practice. This phase informed the development of the postal questionnaire used in the cluster randomised controlled trial in phase two.

### PHASE TWO

A **cluster randomised controlled trial (CRCT)** was undertaken in 13 maternity hospitals. A postal questionnaire to maternity service users in the antenatal and postnatal period was used to assess the effectiveness of the leaflets in delivering informed choice (Chapter 7 and Appendix 2).

**Free-text analysis** was undertaken on the comments written by women on the questionnaire in the CRCT to identify issues around information and choice (Chapter 8).

An **economic study** was undertaken using data collected in the CRCT questionnaire. This addressed the cost and cost consequences of the leaflets (Chapter 9).

A **qualitative study** was undertaken in the 13 maternity hospitals in the CRCT. Observational studies and interviews with women and health professionals were carried out in order to identify factors affecting informed choice and decision-making, especially with respect to the informed choice leaflets (see Chapters 11-14 and Appendix 7). **Focus groups** were also undertaken with women who had recently used the maternity services (Chapter 15). In addition, some qualitative research was carried out in a number of **small maternity units**.

**Measures of knowledge** concerning the 10 leaflet topics were completed by women who completed the CRCT questionnaires, by midwives in the CRCT sites and by women known to have a breech presentation at term (Chapter 10).

## **Ethical Issues**

Ethics committee approval was sought, and given, for all sites participating in all phases of the research. These included: the three ethnographic sites, the smaller, rural hospitals and the thirteen hospitals participating in the CRCT. A charter for ethical research in maternity care guided ethical considerations in the research (AIMS/NCT 1997).

Women who were sent questionnaires were also sent a covering letter explaining the study; they could therefore decide at that point whether or not to participate in the study. The options available to women included completing and returning the questionnaire, throwing the questionnaire away or ticking a box on the covering letter and returning this to the research team thereby indicating that they wished to formally withdraw from the study. The covering letter stated clearly that choosing to participate or not would have no effect on women's care. At the end of the questionnaire women were asked for their consent for access to their maternity hospital notes for the economic assessment.

Respondents participating in the qualitative research were offered an information sheet explaining the study. The information sheet emphasised the confidential nature of the research enquiry, that respondents were free to leave at any stage of the research and that participation (or not) would not affect care. Once the information sheet had been read and questions had been answered, the researchers asked respondents for their permission to undertake observational work and interviews. Written consent was obtained for interviews carried out on sites where this was a condition of clearance by ethics committees.

# Chapter 3: The Mapping Exercise: Leaflet Use by the Maternity Services in the South West Region of England and by GPs

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The purpose of the mapping exercise was to explore the use of the MIDIRS Informed Choice leaflets in a health Region with a history of leaflet use that predated the research study.

## **3.1 METHODOLOGY**

In order to map activities with respect to the use of Informed Choice leaflets, a telephone survey of key informants (Heads of Midwifery [HoMs]) in the South West Region was undertaken. This location was chosen because the Regional Health Authority was known to have made an initial purchase of leaflets. Numbers one to five of the initial set of Informed Choice leaflets were bought by Region and distributed to all provider units between the spring and the summer of 1996. The mapping exercise was carried out in August 1998.

General Practitioners throughout the UK who had ordered the MIDIRS leaflets were also contacted.

### **3.1.1 Data collection method**

Telephone interviews are widely acknowledged in the research literature to be an efficient and reliable means of data collection (Lavrakas 1993, Groves 1989). Moreover, they are seen to be a valuable adjunct to other data collection methods within a multiple frame or mixed mode research design (Frey 1989, Marcus and Crane 1986).

Response rates to telephone interviews are highly sensitive to the mode of initial contact, the first 30-60 seconds of telephone contact time being critical in minimising non-response or poor compliance (Collins et al 1998, Oskenberg and Cannell 1988). In order to maximise response in this study, a letter was sent to all named individuals identified in the sampling frame. This provided information about the study and indicated that the researcher would attempt to make telephone contact within seven to ten days of receipt of the letter.

An interview schedule (Appendix 8) was devised and piloted. Some elements of the original schedule were subsequently amended and some were omitted from the final analysis as they did not elicit robust information. All interviews followed the same sequence.

### **3.1.2 Sample**

The sampling frame consisted of all heads of the names and addresses of all Heads of Midwifery in the South West Region. In addition, purchaser information was supplied by MIDIRS. Thus, a total sample population of 44 key informants was identified.

The introductory letter was sent to all 44 of the identified contacts (35 Heads of Midwifery and 9 GP practices). This was followed up by a telephone interview. All interviews were conducted by the same researcher in order to maximise consistency in data collection.

Data was subsequently obtained from 30 interviews (68% of potential sample): 28 of these interviews were tape recorded before transcription.

- Interview data were obtained from 24 of the 35 HoMs identified
  - ◊ 6 HoMs' accounts were subsumed by accounts given by more senior colleagues whose remit included the smaller maternity units, thus making the material from these HoMs redundant.
  - ◊ 5 HoMs chose not to participate.

- Interview data were obtained from 6 of the 9 GP practices identified as purchasers of leaflets.
  - ◊ It was not possible to make contact with 1 remote Highland practice, despite numerous attempts to do so.
  - ◊ One GP's secretary/receptionist refused participation on her employer's behalf
  - ◊ One GP chose not to participate

### 3.1.3 Analysis

Content analysis of the transcribed interview data was undertaken manually. Content analysis involves the classification of qualitative data, in this case textual responses, into categories chosen because of their theoretical importance. The technique provides a systematic means of measuring the frequency, order or intensity of occurrence of words, phrases or sentences (Burns and Grove 1993).

#### 3.1.3.1 Threats to reliability and validity

The major threat to reliability and validity of telephone interview data arose through a failure to elicit the appropriateness of the key informant identified. It may be that some Heads of Midwifery were not in post at the time that purchase decisions were made and the data about initial purchases may not be robust. Thus, a question<sup>1</sup> which sought to probe HoMs' understanding of the initial purchase of numbers 1 to 5 of the Informed Choice leaflets was omitted from the analysis because of the absence of contextual data.

## 3.2 RESULTS

### 3.2.1 Demographic Features

#### 3.2.1.1 Size of Units: (number of births per year) [n=24]

This varied very widely. The largest unit recorded over 5,000 births per year compared with the smallest with only 150-200 per year. In all, 13 units managed between 2,000 and 5,000+ births per year; a further eight provided services for fewer than 2,000 births per year. Some HoMs reported on both community and acute trusts. Three reports derived from community based trusts providing antenatal and postnatal care as well as some intrapartum care.

#### 3.2.1.2 General Practice: maternity care provision

This also varied with respondents reporting that they delivered care relating to between 150 and 400 births per year. Patterns of service delivery and involvement of GPs and midwives in care, also varied.

#### 3.2.1.3 Social characteristics of childbearing population

The overwhelming majority of respondents reported that they provided services to the whole range of socio-economic groups. Two HoMs and one GP suggested that their client group was 'middle to lower social class' and one HoM reported women in her area to be of 'pretty high social class'. Neither the HoMs nor the GPs reported large minority ethnic populations; eight respondents made it explicit that they did not have significant numbers of ethnic minority women. Social problems, including homelessness, unemployment and child protection issues were noted. Drug taking was perceived to be a problem by eight respondents, while six reported that they provided maternity care services for travelling communities.

### 3.2.2 Information about the purchase of the leaflets

#### 3.2.2.1 The funding of leaflets

There was considerable confusion evident within the interview data obtained from Heads of Midwifery with respect to the sources of leaflet funding. It was not always clear whether key informants had been in

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<sup>1</sup> 'How was the decision taken i.e. who prompted it and who was involved?'

post at the time of the initial purchase decision. Thus, some responses referred to the initial purchase, made by Region, and some to subsequent purchase decisions made within units.

The HoMs who had cited the Region as instigators of the decision to purchase the initial set of leaflets (numbers 1 to 5) all agreed that this was also the source of the funding. For subsequent purchases (either re-ordering from the first series, or an initial order from the second series of leaflets) a variety of other sources of funding were specified. These included 'midwifery income generation money', 'our own education funds' or the Trust's maternity budget. MSLC or health authority funds were also suggested as sources.

GP practices had to exploit a wide range of funding sources. Two practices purchased out of practice funds. One was a private purchase out of a GP's 'own pocket'. Two others received monies from local charitable trusts. The remaining GP practice suggested that they had funded the leaflets from 'petty

### **3.2.2.2 Subsequent purchase decisions: rationales for selective purchase decisions**

The cost of the leaflets and financial constraints experienced within units were constantly referred to. Seven of the HoMs offered this as the reason for not making subsequent purchases. Cost severely constrained efforts to purchase leaflets from the second set, or to replace the first set. Only one HoM reported that they had secured all the leaflets from 1 to 10. However, other reasons for not purchasing were suggested. Some lacked confidence in the information contained in the leaflets. Thus one HoM reported that they had chosen not to purchase the screening leaflet as their practice did not conform with the information it contained: they were planning to develop and introduce their own. One other unit noted that they already had their own in-house leaflets on a range of subjects (epidural, pain relief in labour, breech, caesarean section, and alcohol consumption). Another HoM, referring to the ultrasound scanning, epidural and breach leaflets, noted that they did not agree with all that was being said. One unit also reported hostility from obstetricians who had opposed the screening leaflet. Where an issue was not considered to be problematic, (such as consumption of alcohol) purchase of the leaflet was also seen as unnecessary. Finally, two HoMs suggested that the way in which they disseminated the leaflets made subsequent purchases unnecessary: one respondent replied that the leaflets had gone into the library and midwives could access them there. In the second unit, laminated copies of leaflets had been placed in the antenatal clinic: *'depending on whatever discussion we have and at any relevant point then we use them for discussion but we don't actually hand them out unless we need to*

Few positive reasons for selective purchases were offered. One unit bought only the infant feeding leaflet as they were working towards recognition under the Baby Friendly Initiative, but nine of the HoMs did not provide any rationale for their decisions.

By contrast, four of the six GP practices bought the complete set of Informed Choice leaflets. One had selected only the screening and infant feeding leaflets (though no rationale was given for this) and one made no response.

### **3.2.2.3 Continued use of leaflets by units / practices**

Ten of the HoMs and all of the GP practices noted that they were continuing to use the Informed Choice leaflets. Other responses alluded to selective use: 'on demand' (3), 'sparingly' (3) 'very selectively', and as a reference source (2). One respondent admitted to photocopying the leaflets. Three HoMs said that they no longer used them.

### **3.2.2.4 Reasons for discontinuing leaflet use**

As suggested earlier, reductions in leaflet use were primarily driven by financial constraints. The availability of other (cheaper) sources of information were also cited including information produced in-house. The availability of the Health Education Authority's *Pregnancy* book was noted and this was felt by two HoMs to be preferred by women. Difficulties in aligning leaflet contents with local practices (referred to earlier) were also an important influence on their use.

### **3.2.3 Distribution of the leaflets**

#### **3.2.3.1 Orientation**

Half of the HoMs and two of the GP practices recalled that MIDIRS had provided orientation before introduction of the leaflets. Most did not comment on how useful this had been though one positive response and one negative response ('no use at all') was received. In addition, two HoMs and one GP practice noted that they had used the MIDIRS resource pack to familiarise themselves with the intended use of the information leaflets. Two further HoMs spoke of in-house orientation, including the staging of an open day and the use of an instructional video. However, five HoMs and two GP practices said that there had been no orientation at all and three HoMs did not know what had happened.

#### **3.2.3.2 Distribution of the leaflets**

Responsibility for distributing the Informed Choice leaflets was most frequently reported, by HoMs, to lie with community midwives (8) and antenatal clinic staff (3). Patterns of use varied. Distribution of pregnancy related leaflets at booking was most often cited (7 HoMs and 2 GP practices) with the remainder being selectively targeted at women according to perceived need (5 HoMs and 1 GP). This was acknowledged by one HoM as 'a bit hit and miss'. In 6 units and two GP practices there was no routine distribution, all leaflets were given to women only when this was deemed to be relevant or at the discretion of the midwife (3 HoMs). In two units and one GP practice, leaflets were left out on racks for women to make their own selection.

Four HoMs and one GP did not describe the pattern of leaflet distribution. Three HoMs also noted that, at times, they distributed the professionals' version of a leaflet to women, with one noting that educated

#### **3.2.3.3 Staff reactions**

On the whole, responses were favourable, the majority of interviewees noting that their staff were positive about the leaflets, although this was frequently qualified in relation to specific leaflets to which staff took exception. One HoM noted that the ultrasonographers in her unit had initially opposed the scanning leaflet but they had subsequently 'made it their own'. Data regarding medical professionals' responses to the leaflets was rather patchy as it is reliant upon interviewees' familiarity with the opinions of obstetricians. Some HoMs were clear that they could not comment on this while a number of others mentioned problems that had occurred with medical staff in relation to specific leaflets. These included; ultrasound scanning (2), screening (1), breech birth (1), infant feeding (1) and monitoring in labour (1).

While the GP practices were also generally positive about the leaflets, one did note that the midwife attached to their practice had been told by her employing Trust that she had not got enough funded time to explain the leaflets to women!

### **3.2.4 Feedback**

#### **3.2.4.1 The use of monitoring systems or audit**

The use of Informed Choice leaflets was fairly new at the time of the mapping exercise and the vast majority of respondents had not then considered evaluating them. Two HoMs had carried out an audit and one sent a copy of their results to the research midwife. Two of the GP practices noted that they were in the process of auditing specific aspects of care delivery at the time that they were contacted.

#### **3.2.4.2 Changes in policy / outcomes as a result of using the Informed Choice leaflets**

The majority of respondents (16 HoMs and 2 GPs) indicated that there had been no policy changes, nor any notable changes in clinical outcomes, that they could attribute to using the Informed Choice leaflets. However, some practices were highlighted as having been influenced within specific locations. One HoM noted that they had rewritten their guidelines concerning care in labour while another two were attempting to reduce the amount of electronic fetal monitoring being carried out (one of these admitted that she was



'not sure this could be directly attributed to the leaflets'). Other units were considering introducing external cephalic version for breech presentations (1) and another had introduced anomaly scans. It was also suggested that the leaflets may have contributed to a rise in the epidural rate (1) and a rise in the Home birth rate (one GP and one HoM). An improved breastfeeding rate was noted in one unit, though the interviewee did not consider that this was related to the leaflets. 'Softer' outcomes were also cited, including the increased confidence felt by midwives in informing women of the choices available to them.

### **3.2.5 Future plans**

#### ***3.2.5.1 Intentions with respect to continuing use of the leaflets***

The general practices surveyed were very positive about their continuing use of the leaflets. Five out of the six practices said they would do so, with one non-response.

While the majority of HoMs were also hopeful of their continuing use, a number qualified this. Ten respondents answered this question in the affirmative. One other noted that they would continue with selective use of the leaflets and a second suggested that leaflet use would continue 'when she had the agreement of the consultants'. However, a further eight HoMs qualified their continuing support, noting that this could only continue use while they had the leaflets in stock or if they could find further sums of money.

Two HoMs replied that they would not continue using the leaflets, though gave no reason for this. One other mentioned lack of funds as the reason for withdrawing their support and another noted that they had subsequently introduced their own leaflets and had no further use for the MIDIRS information.

#### **3.2.6 Other comments about the leaflets**

Comments volunteered by interviewees were predominantly positive. The leaflets are seen as 'a good thing' or as one respondent from a GP practice put it, 'the best thing since sliced bread'.

The leaflets are generally considered to be informative, well produced, balanced and comprehensive in their content. Two respondents also noted that they are very easy to read. There was, however, some criticism of the level at which information is communicated. One GP and one HoM suggested that the information to women was, at times, too simplistic and the level could valuably be raised.

Respondents also made a number of suggestions for other potential changes to the leaflets. The principal concern was, not surprisingly, for the cost of the leaflets (six HoMs and two GP practices). There was a general feeling that this needed to be reduced. Suggestions ranged from allowing smaller orders to be placed (obviating the need for bulk buying) to changing their format. It was felt that price reduction could be achieved by reducing the size and the number of illustrations (2) or by putting the leaflet information on the Internet. Two HoMs suggested that the information would be useful in a booklet format, as women receive leaflets from many other sources (however, another HoM specifically mentioned that she would not welcome this).

Suggestions for extending the range of information were also made with one GP practice proposing Vitamin K and Waterbirths as useful topics; one HoM noted that she would value information concerning screening and diagnosis for Down's syndrome.

### **3.2.7 Discussion**

The leaflets are seen very positively as useful additions to the array of information sources currently available to professionals and childbearing women, though their cost (described by one HoM as 'extortionate') was a constant concern.

The leaflets are perceived as valuable instruments for updating professional's knowledge and for boosting midwives' confidence. They are also recognised to be valuable sources of information for women, though when the choices available to women in a particular care location do not accord with the information contained in the leaflet, they are liable to be withheld.

The commitment noted by a number of respondents to the provision of local, in-house information, is liable to impact upon the use of the MIDIRS leaflets, though this cannot be quantified through this study. The main driving forces behind this commitment are the reduced costs incurred and the ability to tailor information to reflect dominant patterns of care. The main challenge to the MIDIRS leaflets would seem to come not only from locally produced information, but also from the Health Education Authority's *Pregnancy* book. This is highly valued by midwives and childbearing women alike.

Although some tensions with obstetricians were noted, these tended to concern the content of specific leaflets and to arise when local practice was not in accord with leaflet information. Outside of these specific areas, however, there was a general feeling that obstetricians had little interest in their use and considered them to be of relevance only in encounters between midwives and childbearing woman. General practitioners, by contrast, reported themselves to be active users of the leaflets during their interactions with women.

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## Chapter 4: The Ethnographic Study

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### 4.1 INTRODUCTION

Prior to undertaking the randomised controlled trial (RCT) of the Informed Choice leaflets, a preliminary study was undertaken in three settings where the leaflets had been purchased locally and used for at least two years. The leaflets were only available in English on the ethnographic sites; they were translated into Welsh for the second phase of the study only.

Observational work and interviews allowed the researchers to access key respondents for their views on the leaflets; it also provided an opportunity to examine health professionals attitudes to important concepts such as evidence based information, informed choice, and decision-making in maternity care. This phase was also crucial in the design and development of the questionnaire tool used in the next phase of the study.

Two of the ethnographic sites were in England and one was in Wales. The sites were very different geographically, in the clientele they served, and in the organisation of maternity care.

In order to distinguish the three ethnographic sites, the notation 1.1, 1.2 and 1.3 is used to differentiate the quotations used throughout this section.

### 4.2 METHODS

This phase employed qualitative methods only. With the exception of focus groups which were not undertaken until phase two, the same qualitative methods were used during both phases of the study. For more detail on the qualitative methods, see Chapter 11.

#### 4.2.1 Ethnography

An ethnographic approach was taken to this phase of the study in order that the researchers might observe the use of the Informed Choice leaflets in a 'natural' setting. The phrase 'ethnographic approach' is used deliberately in order to convey that this was a partial, rather than complete, ethnography with the focus of data collection limited to aspects of pregnancy and childbearing and not the wider dimensions of respondents' lives.

The researchers, both of whom were midwives, each spent between ten and fourteen working days on each of the ethnographic sites. As the sites were previously unknown to the researchers, it was necessary to undertake a rapid assessment exercise about the way in which maternity care was accessed and delivered. The assessment exercise consisted of reading literature such as audits of various aspects of the maternity service, scanning patient information booklets and other in-house literature, noting the information displayed on notice boards, attending departmental and other meetings and, all the while, observing and listening to interactions amongst staff and between themselves and the childbearing women in their care. During this time the researchers also spent time chatting informally to both service providers and users wherever they congregated: in maternity waiting rooms, foyers and wards and in staff sitting rooms, offices and kitchens. Such intensive networking, with both NHS and non NHS service providers and users, enabled the researchers to identify a number of key respondents at an early stage of the fieldwork.

In its broadest sense, ethnography is a description of a people and the cultural basis of their peoplehood (Peacock 1986); 'doing' ethnography then, is a complex and time consuming enterprise which involves negotiating access, establishing rapport, selecting and interviewing respondents, mapping fields, keeping a diary, transcribing texts and so on (Geertz 1973). The ethnographer strives to observe and record events without censoring or filtering phenomena and to leave the field with 'thick' (contextual) descriptions.

It is taken for granted in qualitative research that the observations and fieldnotes made by the ethnographer are inevitably shaped by the 'personal biography of the gendered researcher who speaks from a particular class, racial, cultural and ethnic community perspective' (Denzin and Lincoln 1994).

#### **4.2.2 The researchers**

Two researchers, both of whom were midwives and one of whom lived and worked in Wales, took part in this phase of the study. Neither researcher had prior knowledge of, nor established networks within, the research sites. Neither researcher spoke Welsh although one had some understanding of the spoken language.

#### **4.2.3 Working arrangements**

In the initial stages of the study, two researchers worked collaboratively on the same site with each researcher observing different hospital and community based antenatal clinics. The researchers thus compiled their own individual observation and interview appointments but met on a daily basis to discuss their findings. The vast majority of observation sessions and interviews were conducted by individual researchers. For the joint purposes of induction and subsequent triangulation, a small number of observations and interviews were attended by two researchers.

#### **4.2.4 Interview prompts**

In order that the researchers observed a broadly similar approach to interviewing and that some background data common to all respondents was collected, a series of loosely formatted interview prompts were developed from the observation data and the literature. (See Appendix 6)

The order in which questions were asked of respondents did not necessarily follow that in which they appeared on the prompt and neither were respondents asked all of the questions. Respondents were not shown the interview prompts as they were intended only to be used as a guide by the researchers, rather than to serve as a rigid instrument for data collection.

The prompts were constantly revised in keeping with conventions of grounded theorising. As new concepts were generated, these were added to the respective prompt to replace those, which had reached the point of 'saturation'. The prompts were used until such time as the researchers felt confident and competent to devise questions in direct response to the themes emerging from the data.

#### **4.2.5 Confidentiality**

In order to protect the identity of respondents, the following abbreviations are used throughout the report: **M** for midwives; **W** for maternity service users (for whom the word 'woman' is used interchangeably throughout the report), **O** for obstetricians; **P** for women's husbands or partners; **I** for interviewer. The exception to this notation occurs in the analysis of the focus groups. (See Chapter 15)

#### **4.2.6 Advantages of the approach taken**

An ethnographic approach gave a comprehensive overview of the study sites at an early stage in the research process. This highlighted a number of important issues concerning the Informed Choice leaflets.

The 'outsider' status of both researchers enabled them to ask a number of 'naive' questions, which greatly assisted in the mapping of hierarchies and allegiances.

#### **4.2.7 Limitations of the approach taken**

As one of the maternity units was situated in an area where Welsh was widely spoken, it is acknowledged that Welsh speaking respondents may have been disadvantaged because the researchers were unable to understand, and therefore follow up issues raised in Welsh during the consultation. For this reason, the researchers may have failed in their efforts to ensure that saturation of analytical categories, in accordance with a grounded theory approach, was achieved. This was also true for the tiny number of service users observed who had no language in common with either health professionals or researchers.

Time constraints militated against the researchers establishing the trusted relationships with respondents considered integral to ethnography and because the focus was primarily on issues concerning childbearing, it is acknowledged that this rather narrow spectrum of experience may have 'undercut the very purpose of ethnography, namely contextual analysis' (Savage 1995). Some problems were experienced by the researchers in obtaining informed consent for the purposes of observational work. See Chapter 11 for more on this issue.

### 4.3 THE INFORMED CHOICE LEAFLETS IN PRACTICE

The leaflets were used exclusively by midwives on all three sites and they were used in a similar manner to that reported fully in the findings for phase two of this study. To summarise: leaflets were often disguised by being 'wrapped' with other pregnancy related information (including advertising materials) and inserted into Bounty packs; leaflets were often given to women without any discussion; the timing of leaflets did not always synchronise with women's requirements; once leaflets were given, there was generally no further reference to the leaflet topic(s); women were given leaflets in 'batches' and at fixed points in pregnancy rather than having them 'prescribed' according to need; midwives were selective in which leaflets they gave to women; women of lower social class tended to be given fewer leaflets.

Many women were given leaflets inappropriately. For instance, women in the third trimester were offered leaflets on ultrasound scans and screening for fetal abnormalities long after these decisions had been made (albeit sometimes by default). With respect to the leaflet on alcohol, many women who had clearly stated that they did not drink alcohol, or that they had stopped because of pregnancy, were nonetheless given this leaflet without the midwife ascertaining whether it was wanted. Midwives generally did not discuss the information contained in the leaflet, for example that a small amount of alcohol in pregnancy was probably all right, and neither did many midwives give women the option to refuse a leaflet.

Thus, women were given leaflets with a vague recommendation from the midwife *'to go away and read them'*. The following extract, taken from fieldnotes, illustrates a typical interaction between a community midwife and service user:

*M: There are some leaflets here about some of the things we've discussed, so if you have a read of them and then you can ask me if you have any questions...*

As she stands up, the community midwife hands the woman her notes, plus a bundle of information including three Informed Choice leaflets: alcohol, ultrasound and place of birth. This woman is 22 weeks pregnant and has already received three ultrasound scans (two 'mini', and one anomaly, scan) and does not drink alcohol. There has been no suggestion during the consultation that she might exercise any choice in where she has the baby nor in questioning the need for further 'mini' scans (which are routinely used by some obstetricians in this unit to listen to the fetal heart during abdominal palpation). antenatal clinic site 1.3

In some units, it was customary practice for the community midwives to discuss birth plans (at around 35-37 weeks) with the women in their caseloads. This was often the time when Informed Choice leaflets concerning labour, such as positions, support, epidural and monitoring, were given to women. The birthplan visit was also the occasion where a degree of variation in practice was observed in that a very small number of individual midwives were seen to open and discuss the leaflets contents with the woman concerned.

Parentcraft classes were also used as access points for women to receive leaflets as supplementary reading to topics, which had been discussed in the class. Typically, the leaflets were handed to the woman sitting closest to the midwife teaching the class with the instruction to take one and pass them on; in this way they were distributed amongst the women in the class. Women were not generally invited to read them at that point, but were typically requested to *'...read them at home...show them to your partners...come back with any questions...'* When the bundle was passed to them, the majority of women took a leaflet and either put it straight into their bags or flicked through it whilst the midwife continued talking. The researchers did not observe a consultation, or parentcraft class, when specific reference was made to leaflets previously given to women.

The way in which the Informed Choice leaflets were transferred to women seemed to play a crucial role in whether they were taken any further. Very few midwives were observed spending time discussing the content of the leaflets with women and even fewer were observed to be 'prescribing' the leaflets in response to a specific situation. It was customary practice across all three sites for a selection of the Informed Choice leaflets to be routinely inserted into the woman's notes or Bounty pack, together with a variable range of other routine information and advertising materials and this package was given to the woman at booking clinic. What happened after that point did not vary a great deal. Sometimes the leaflets remained bundled up with this other information for the duration of the pregnancy, following which the leaflets, in pristine condition, were sometimes retrieved for recycling. 'Wrapping' leaflets in this way required that women subsequently exercised considerable initiative and discrimination if they were to appreciate the significance of the leaflet contents.

Occasionally, midwives removed an individual leaflet from the pre-packed bundle during the course of the consultation. When midwives enquired about alcohol intake or infant feeding for example, the cover of the leaflet referred to might be shown to the pregnant woman. Mostly, however, the leaflets were simply referred to in passing. Maternity service users were not heard to have the differences between the Informed Choice leaflets, and any other sources of information explained to them, and this may have acted to render the leaflets even more invisible. These, and related issues, were also observed throughout the second phase of the study.

#### 4.3.1 Withholding leaflets

A number of health professionals volunteered that they did not use certain leaflets because they contradicted their personal philosophy, their customary clinical practice or because the leaflets conveyed 'a negative image'. The leaflets pertaining to epidural, home birth, ultrasound scans and breech presentation were all perceived in this way by some health professionals across all three sites. A number of midwives were observed withholding information from service users. When asked about this during a follow-up interview, a number of midwives admitted that they were 'more selective' with information which contradicted local policies and which might thus provoke confrontation with medical colleagues.

Doctors exercised considerable power over the information given to women and, therefore, over the options which were made available. For example, one consultant obstetrician would not allow the informed choice leaflet on breech presentation to be used because she disagreed with women being offered any choice in the mode of delivery. She was of the opinion that all women with a breech presentation should undergo an elective caesarean section. Another consultant obstetrician refused to allow women booked with him to have access to the informed choice leaflet on antenatal screening, because he considered the current tests to be insufficiently accurate. A community midwife did not offer women the informed choice leaflet on place of birth because of GP opposition.

Midwives largely colluded with doctors in withholding leaflets, although some voiced their disquiet during the course of an in-depth interview:

*I wasn't directly involved with her but I still feel awful about not having said anything. Watching her go through a (caesarean) section (for a breech presentation) and knowing that she'd had two perfectly normal vaginal births before. What upset me most was that she wasn't given any choice about it. She wasn't given any options. She was just told in the clinic to come in the next day for a section. I felt awful about not having said anything, knowing that if that woman had been a patient of Mr O, she'd have been offered ECV and if she'd wanted to, a try at a vaginal birth... midwife site 1.3*

The researchers observed a number of occasions when women were not informed that alternative options were available and nor were women routinely informed about the possible outcomes of certain choices. Withholding such information was problematic when, as in the case described in the above quotation, referral to a different consultant skilled in ECV and vaginal breech delivery might have avoided an operative delivery. The researchers frequently observed information being presented to women in such a way as to make it unlikely that they would disagree with the point of view advanced by the health professional, in this case that a c/s was necessary in the case of a breech presentation.

### 4.3.2 Perceptions of informed choice

The lack of strategy, or training, in the use of the leaflets to empower both service users and providers, was demonstrated in the very different views expressed on informed choice:

*Informed choice should only be offered when the service is well prepared and can meet the extra needs this will create. If we (health professionals) are not given information about what exactly is meant by informed choice, then we cannot be expected to provide it...informed choice is more than providing information. GP site 1.2*

*Well, for a start, there's a lot more to informed choice than spending a few hundred quid on some leaflets. It seems to me that informed choice is only available for the women who've already got libraries of books and more than enough information. They're the ones getting the informed choices. midwife site 1.1  
...(it's) a major problem...frankly I don't think they get much choice at all...they're told what's on offer and that's that really... and it's the same with the information we give them, I think a lot of it is not very impartial. It's what we think is the right thing to do...so we're advising them what we think is right rather than giving them impartial information and letting them choose... I think informed choice is an issue we've ducked out of really... GP site 1.1*

*What I understand by informed choice is that I'll have all the information I need to make decisions...that the information will come from a respected source...that I won't be pressured into doing something I really don't want to do... maternity service user site 1.3*

*Where the idea of informed choice falls down for me is where primips choose to have a home birth or where women want to have water births, or they don't want to be monitored...or don't want to have scans...I have great difficulty in understanding those decisions, but I also accept that they are probably making informed choices because in order to go against the tide, they need to be well informed... consultant obstetrician site 1.2*

*Informed choice is really about women using their initiative to find out what's not available, rather than what is... midwife site 1.2*

*Informed choice is about women asking for choice...it's about them asking for it...the women who ask for home birth or ECV for turning breech babies are well informed, but no-one's going to tell them about these things... No-one's going to tell them what their options are - they have to find out for themselves...then they can make the choices... midwife site 1.1*

In 'finding out for oneself' or 'asking for it', however, the onus of responsibility for ensuring that choices are made available is on the service user, not the service provider. It requires a command of English and a level of personal assurance which many service users currently may not possess; it also emphasises the imbalance of power in the relationship between both parties.

### 4.3.3 Informed choice, equity and consumerist values

The way in which informed choice was referred to by a number of health professionals strengthened the myth that pregnancy affords women choices which are not actually available within the context of a welfare system where, in reality, choice is very limited for disadvantaged women. The following quotations illustrate these points:

*Women who are undemanding of the service may lose out on being well informed and they're certainly far less likely to make decisions which are right for them. GP site 1.3*

*Informed choice is a nonsense for women who cannot access and use written information...they are likely to remain powerless and helpless because there are no resources being invested in them... Take these [informed choice] leaflets, they're useless for most of my women because they're only available in English... midwife site 1.2*

These views suggest that health professionals recognise that women on the receiving end of the maternity services are not equal and that effecting change will require investment on a number of levels. It is

extremely doubtful, however, whether informed choice can be presented as a viable option to either women or health professionals until the issue of inequality is acknowledged and strategies are put in place which make it easier for disadvantaged women to access the full range of maternity services.

Informed choice has become something of a fashionable concept in recent years and this is reflected not only in NHS directives but is also evident in the terminology of advertising and commerce. In a welfare state, healthcare is rationed and choices for health service users are set by government priorities, with some flexibility for manoeuvring at a local level. Given the variability in service provision, however, the information contained in the MIDIRS Informed Choice leaflets will continue to contradict local norms of practice and this will make it difficult for women who are disadvantaged and who are unassertive to achieve informed choice in their maternity care.

#### **4.3.4 Choice, inequality and stereotyping**

A number of community midwives considered the leaflets to be inappropriate for women in their caseloads. This was dealt with in varying ways but often resulted in women being stereotyped.

*I've had many women in this area refuse the Informed Choice leaflets because they look too complicated...I think they're a bit too posh for some of these girls around here...a lot of the girls I look after don't read...their reading matter is probably limited to the newspaper around the fish and chip package... midwife site 1.3*

*There are a lot of women in my caseload I wouldn't dream of giving the leaflets to...like I wouldn't give some of them certain information because I don't want them having certain choices...like not having a scan or having the baby at home for instance...it would be a complete waste of time giving them leaflets to read...anyway, they can't read, a lot of them and I don't want them feeling even worse about that than they do already... midwife site 1.2*

The following quotation is unusual in that it demonstrates a sensitive and creative approach to presenting information to women with different needs:

*There's a lot of women around here who may not want Informed Choice leaflets because they can't read... but one of the important aspects of informed choice is about finding out what people are good at so you know how to help them to get what they want...if they can't read for instance, then you draw or tell them stories about how other women did it, so they get the ideas in a different ways... midwife site 1.3*

A number of clinical midwives suggested that management decisions to purchase the leaflets were driven not so much by a commitment to informed choice, but by concerns about quality assurance indicators and risk management strategies. Thus, a range of other concerns militated against the leaflets being used to promote informed decision-making by service users. These issues also jeopardised the professional-client relationship and served to worsen the inequity of maternity care provision. The following quotation also suggests that economic concerns were sometimes an issue:

*I don't want to use the leaflets...they make me angry because they make the inequality issue a lot worse...especially with the way we've been told to use the leaflets... we've been given strict instructions about that...we were told that because of finance, we were only getting a limited supply and that we had to make them last us, so we're only to give them to those who would really benefit from them and who would look after them so that when they were given back, they would be in good condition... midwife site 1.1*

These quotations illustrate a number of dilemmas midwives face in clinical practice. In trying to do best by the women in their care, many midwives assumed decision-making responsibility on their behalf and this tended to result in some women being stereotyped. This seemed more likely to happen when women were materially disadvantaged. It is suggested that such responses may have encouraged midwives and other health professionals to accept, rather than challenge, sweeping judgements as accurate reflections ('women in this area can't, or don't read...') which are then held to be true for all women, in that geographical patch, for all time.



#### 4.3.5 The evidence imperative, informed choice and professional accountability

For some staff, only evidence from 'approved' sources, such as a RCT or systematic review, was admissible for the purpose of clinical decision-making. As the following quotation demonstrates, however, this created problems where the woman's decision was informed by other evidence, such as her successful past experiences of childbearing.

*I have had a recent incident which has made me think about informed choice from the professional's point of view. We've had a complaint against a fairly junior midwife.. she seems to have decided that evidence based practice is more important than the woman's choice...the husband was writing on her behalf....his wife (who was Asian) had wanted to lie flat on her back to give birth because this was what she had done before with the other births and it had worked fine so she wanted to do it again.... But it seems that the midwife did not want this and kept telling her that it was better for her, and better for the baby, if she was upright... The husband said he had to keep helping his wife to lie down, while the midwife kept trying to help her up again... I can see the midwife's dilemma but informed choice is not for midwives to be forcing on women... midwifery manager site 1.2*

Evidence based decisions, providing they emanated from sources considered legitimate by the health professional, were often seen as 'right', and many staff appeared to experience difficulty in dealing with alternative models of decision-making.

*It's disappointing when women are given the information and they don't make the choices you want them to or, when you try to give women information, they refuse it and say that they're not bothered or they're not interested... midwife site 1.3*

When women made decisions which were disapproved of, staff often appeared uneasy and some anticipated, or indeed, experienced, blame:

*Some women are never satisfied with the information or the explanations you give them...it doesn't matter how evidence based it is...but if they then make choices that are not based on good evidence, whose problem is it? midwife site 1.2*

*...they tend to blame me rather than themselves... consultant obstetrician site 1.2*

*...women... shouldn't put the blame on us when we try to tell them the other side of the story...like the Informed Choice leaflets...you tell them that it's all evidence based and that it can give them ammunition to argue a case for themselves but a lot of them just don't want to know... midwife site 1.1*

These contributions also attest to the real tensions many health professionals felt to exist between the concepts of evidence, informed choice and accountability.

#### 4.3.6 Time

Midwives from all sites spoke of the pressures on their time and gave this as a reason why information was not volunteered to women as a matter of course:

*Giving information to women takes so much more time and a far greater sense of commitment...I have to be selective with it...there isn't the time to do it well for all the women... midwife site 1.2*

*I only pass on the information that I have to now and I make dead sure it's all documented... To be honest, I only give them the stuff I'll get the rap for if I don't...I haven't the time for anything else... midwife site 1.2*

Some respondents expressed frustration that the current emphasis on informed choice and evidence based information in the NHS did not take account of the new pressures on health professionals. This was particularly with respect to the extra time required to convey complex information and to facilitate choice with consumers who were unused to participating actively in their care.

*I think sometimes we health professionals are in danger of becoming commodities. We'll be thought of in the same way as telephone hot-lines with endless amounts of time and patience and being available to everyone at any time...* consultant obstetrician site 1.2

The MIDIRS Informed Choice leaflets then, with their impressive and scientific credentials, could be said to serve an important function in conveying information in a concise and economical way. Time saving, an important consideration for maintaining organisational efficiency, thus becomes a legitimating function with regard to the exchange of information.

*When we first got the (Informed Choice) leaflets, I thought, well, that's great, you just give them the leaflet on, say, screening, which is so complicated to get across, and you know then that they've got the information and it saves you a lot of time because you don't have to think about it. Well that's what I thought, but it isn't like that, because you still have to explain what's written and with some of them there's actually a lot more written than you'd normally tell them. So no, I don't think they have helped really.* community midwife site 1.3

Clearly the leaflets were being used in a culture in which information is usually accepted as a statement of fact, rather than as a starting point for discussion. Indeed, as is illustrated in the following excerpt from fieldnotes, there were occasions on which a leaflet was given instead of a discussion.

A woman is attending the antenatal clinic. She is about 36 weeks pregnant with her first baby. She asks the midwife about pain in labour and expresses a preference for an epidural. The midwife does not attempt to discuss this with her but reaches to a shelf above her head and hands her an informed choice leaflet (on epidural in labour) saying:

*You can read about it in here...it's much better that you read about it first and then we can have a discussion about it...so write down any questions you have and then we'll discuss them next time... Now, have you remembered your urine sample...?* community midwife site 1.3

There was only a part-time epidural service available on this site but the midwife chose not to disclose this information; the informed choice leaflet was thus used to 'mask' the limitations in the local service. As well as constraints on time, professionals' fears (for example concerning the management of breech presentation) and economic constraints (in this case, that the service user might book at another unit) appeared to be major factors governing information disclosure.

Thus the leaflets could be, and were, used to block or pre-empt discussion. Such practices served to silence women and this effect was reinforced because midwives were unlikely, perhaps due to time constraints, to spontaneously refer back to subjects which had already been mentioned. Thus, if women were unclear about anything the midwife had said during a previous consultation, women themselves were required to initiate discussion. The perception women held of midwives as being busy people who were hard pressed for time, made this a difficult undertaking.

#### **4.3.7 The significance of leaflet use**

Whilst all of the units in this phase of the study had each financed the purchase of the Informed Choice leaflets, it appeared that only a tiny minority of health professionals involved in the delivery of maternity care had been involved in this decision-making process. The interview data suggested that midwives, the clinicians primarily involved in using the leaflets, had not been widely consulted on this issue but that senior managers had made decisions on their behalf. Such practices may have parallels with the way in which midwives appropriated decision-making on behalf of women. (See Chapter 10, entitled 'Informed choice and decision-making on CRCT sites') It also appeared that, whilst the units had received the standard MIDIRS training package in the use of the leaflets, the majority of midwives observed and interviewed could not recall having attended this event.

At the time the fieldwork was undertaken, none of the units had instituted any on-going training in the use of the leaflets and neither had any unit implemented systems for evaluating their use. This finding was reiterated in the mapping exercise. (See Chapter 3) It may thus have been one reason why participants in this phase of the study appeared unable to comment on the long-term strategies for leaflet use or to reflect on possible changes in outcome measures which might have been expected if the information

contained within the leaflets was applied to practice. The absence of long-term strategies did not appear to be particularly unusual in the maternity services; rather, the introduction of the Informed Choice leaflets was simply another change which a compliant workforce was practised at absorbing. Such an attitude of resignation may nonetheless be a contributing factor in the process whereby any innovation rapidly becomes 'routinised'. Thus, the MIDIRS Informed Choice leaflets were gradually assimilated into the existing model of care, rather than being seen as a vehicle to facilitate and promote choice for pregnant women. They certainly were not generally perceived as a vehicle for change.

It was perhaps understandable then, that the majority of the midwives who were observed issued the Informed Choice leaflets in the same manner as all other information was issued to pregnant women. The fact that midwives were not heard discussing the contents of the leaflets and were not themselves heard asking questions about the anticipated purpose, or function of the leaflets, suggests that the leaflets were not particularly valued. Observational work confirmed that the Informed Choice leaflets did not in any way challenge the power of the institution to direct the choices of service users, in part because midwives tended to maintain the status quo.

#### 4.4 SUMMARY OF THE MAIN POINTS

- ◆ A number of overlapping issues influenced leaflet dissemination and use during this phase of the study:
  - midwives 'wrapping' of leaflets, by placing them inside the covers of Bounty packs, served to render the leaflets invisible to service users.
  - midwives generally did not 'prescribe' the leaflets individually and according to need and this may have created problems for service users in appreciating that the leaflets were any different from any other information they were given by midwives, including advertising materials.
  - financial constraints resulted in midwives on one site attempting to conserve leaflet supplies through recycling. Thus, only women who were likely to return the leaflets in good condition were offered them.
  - materially disadvantaged women were more likely to be stereotyped and given fewer leaflets because midwives often made assumptions about their literacy levels and willingness to participate in their care.
  - the pressures on midwives' time often curtailed discussion about leaflet topics.
  - power differentials between midwives and doctors resulted in midwives withholding leaflets (and other information) with which their medical colleagues may have disagreed.
- ◆ The absence of strategic planning resulted in health professionals generally failing to recognise the potential impact of the leaflets on clinical outcomes:
  - the leaflets did not appear to be regarded as different from other pregnancy-related information and this made it difficult for midwives to use them as a vehicle for change.
  - some aspects of the (evidence based) information contained in a number of the leaflets was in conflict with local practices and this created difficulties for midwives presenting this information to women.
  - local variation in the choices available to women created difficulties around the issue of information disclosure because health professionals were anxious that women might transfer their care elsewhere.
  - lack of initial, and on-going, training in the use of the leaflets was identified as problematic. The quality of training sessions may also have been an issue.

- ◆ Different perceptions of relatively new and complex notions, such as informed choice, evidence based information and professional-client accountability, created tensions for health professionals:
  - some health professionals tended to privilege the evidence from RCT's and systematic reviews over other varieties of experience. This appeared particularly likely in the case of newly qualified practitioners.
  - fear of blame and of litigation tended to ensure all health professionals advanced the benefits of certain kinds of choices such as ultrasound scanning and c/s in the case of breech presentation.
- ◆ Decisions to purchase the leaflets were sometimes driven by management concerns about quality assurance indicators and risk management strategies rather than a commitment to facilitating informed choice with service users:
  - Midwives wishing to use the leaflets to actively promote informed choice experienced difficulty because of conflicts of interest between management requirements and evidence based practice.

## Chapter 5: Description of the Setting and Presentation of the Study to the CRCT Sites

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The setting for this phase of the study was thirteen maternity units in Wales. In this chapter, we describe the organisation of maternity care and the way in which the study, including the intervention, was presented to the units.

### **5.1 THE ORGANISATION OF MATERNITY CARE**

#### **5.1.1 The location of midwifery staff**

Midwives were generally either community or hospital based. The more experienced hospital based midwives were likely to hold permanent positions as 'core staff' in a designated clinical area, such as CDS or antenatal clinic. A small number of hospital based midwives worked permanent night duty.

#### **5.1.2 The location of care**

Antenatal care was provided in a range of settings including hospitals, GP surgeries and in women's homes. Although the overall orientation of care was hospital focused, considerable variation existed between sites as to what proportion of care was delivered in each setting. Reasons for the differences included management decisions, obstetrician preference and, in the case of domiciliary based care, it was usually a choice made by women themselves and individual midwives, and/or teams of midwives, operating at a local level. Many service users lived equidistant from two, or occasionally three, hospitals whilst a number of service users had the choice of only one hospital from which some lived at a considerable distance. Considerable numbers of service users relied on public transport to attend antenatal clinics.

The vast majority of service users were required to be seen by a doctor at a hospital based antenatal clinic on at least one occasion during pregnancy. Many were seen rather more often and this was regardless of identified risk factors. For the majority of women, the first hospital visit followed the initial booking by the midwife in a domiciliary or community based setting.

A small number of midwives undertook a chaperoning role in the antenatal clinic (regardless of the gender of the doctor) and a significant number of hospital based midwives were observed to undertake no clinical duties with the exception of testing women's urine and recording their blood pressure. In one such clinic, the examination couch in the midwife's room had long been in use as a table for displaying information (including a range of the informed choice leaflets).

The location for the booking visit varied greatly between sites, and indeed within sites, depending on the priorities of midwifery management and individual midwives or midwifery teams. On some sites nearly all women were booked in their own homes whilst on other sites, the tendency was for women to come to the hospital. There was similar variation with respect to whether midwives obtained blood samples in the woman's home (or GP surgery) or whether the woman was required to make a separate journey to the hospital based phlebotomist. It appeared that much of the variation was due to the philosophy (and perhaps skill) of individual midwives. Economics, geographical distance, women's preferences and a greater degree of anonymity, were suggested as additional reasons in favour of booking women in the hospital. The remainder of antenatal care by community midwives was undertaken in community based GP surgeries.

Following the first hospital visit (which, for the vast majority of women also included a dating scan) most women returned to the hospital at around 18-20 weeks gestation for the purpose of the anomaly scan. For many women, there was no formal contact with the community midwife between the initial booking visit (which in some units was as early as six to eight weeks) and following the anomaly scan.

## **5.2 MODELS OF MIDWIFERY CARE AND DESIGNATED PLACE OF DELIVERY**

Midwives on a number of sites exercised discretion with regard to the type of care women were offered. Thus, primiparous women were occasionally excluded from team and mlc schemes because it was anticipated that their (longer) labours would place an unacceptable strain on community midwives. The same rationale was advanced for not offering primiparous women the choice of a Domino delivery.

Women were also categorised according to perceived 'risk' factors. Women designated as 'high' risk were booked for delivery and/or antenatal care in a consultant unit whilst women designated 'low' risk might be given other options such as booking a Domino delivery or mlc where these schemes of care existed. A recent study (Campbell 1999) of one geographical region in England highlighted the wide variation in local definitions of the term 'low risk woman' and the poor focus on particular adverse outcomes; such arbitrary labelling of women by health professionals was similarly noted by the researchers undertaking this study.

### **5.2.1 Team midwives**

In all units, some form of 'team midwifery' was on offer. The size of teams varied and the on-call arrangements were such that many women interviewed volunteered that they had encountered midwives at all stages of their care whom they had not previously met.

### **5.2.2 Integrated midwives**

A number of 'integrated' midwifery posts, intended to increase continuity of care, had been developed in some units. Midwives in these posts usually worked one week in the community and one week in the hospital, occasionally changing their clinical grading (and therefore their salary) as they did so. In an ideal arrangement, the integrated midwives worked in pairs, within a team, and provided back-up for one another's caseload. These ideals often failed to materialise, however, because the broad skill base and situational flexibility of these midwives made them vulnerable to exploitation during times of staff shortages within the hospital.

### **5.2.3 Mlc and caseholding midwives**

On a small number of sites, some form of mlc and/or caseholding scheme was in operation. In theory, these forms of care were available to any woman meeting the strict entry criteria set by obstetricians; in practice, very few women were booked into these schemes.

On at least one site, women could not book for mlc unless they also agreed to a 'dating' scan and an assessment by an obstetrician. It is not possible to generalise further about these models of care because the definition of such care varied enormously.

### **5.2.4 Continuity of midwifery care**

The smaller maternity units participating in this study appeared to achieve considerably better rates of continuity of both care and carer than did the larger units. The exception were the tiny numbers of women booked with caseholding midwives working in the larger units. Considerable variation was noted with respect to definitions of the term 'continuity' as applied to midwifery care and carer.

### **5.2.5 Variations in models of care**

Anecdotal evidence, confirmed through observational work, indicated that considerable variation existed between different teams of midwives and, indeed, between individual midwives with respect to the options of care made available to service users. As outcome measures are not available on the basis of individual performance, however, further comment is not possible.

### **5.2.6 Women with special needs**

There appeared to be no systematic approach to the provision of care for pregnant women with special needs. That said, the researchers encountered a range of local innovations which included midwives who

had developed a range of visual aids to assist communication with non English speaking women; a community midwife who regularly provided antenatal care for pregnant drug users attending a drop-in centre and midwives who liaised with travelling families or pregnant teenagers.

### 5.3 MODE OF DELIVERY

**5.3.1 The c/s rate** for the year ending 1998 was approximately 20-25% for the larger units (over 2,000 deliveries p.a.) and, in most cases, appeared to be rising. Respondents from across the range of professional groups suggested that breech presentation, maternal request and fear of litigation were primarily responsible for the increase. No figures were available for planned versus emergency c/s and nor were the c/s's undertaken for breech presentation always available as a separate figure.

In response to complaints from service users on one site regarding poor post operative care following c/s, a specially designated ward, with better midwifery staffing, had recently been opened. One of the researchers noted that this feature of the service was used as a 'selling point' during an antenatal consultation in which a woman was exploring her options for delivery.

**5.3.2 The home birth rate** for the year ending 1998 varied between 1-3%. One community manager attributed the low numbers of women booking a home birth to the fact that there was now considerably less consumer pressure. This opinion was contradicted by women on most sites, however, who volunteered that they had never been given an option. A small number of women, who wanted to assess the experience of midwives facilitating home births, complained that statistics were not available for individual midwives.

Not all units could distinguish planned from unplanned home births, and neither were the number of babies born before arrival of the midwife available for all units. A number of women requesting home births, who were considered 'unsuitable' by midwives and/or doctors, received a visit from the supervisor of midwives (who in some cases was also the community manager). On the majority of sites, women requesting home births were required to be seen by an obstetrician. On at least two sites such women were required to undergo an ultrasound scan as a pre-requisite to booking a home birth.

Anecdotal comments indicated that the **Domino delivery rate** mirrored the pattern for home births. Further comment cannot be made as accurate figures were not available.

### 5.4 SOCIAL CLASS OF SERVICE USERS

Service users covered the full economic spectrum and included poor, inner city communities, those living on the impoverished housing estates of the Valleys of South Wales and women with considerable affluence and social status. The problems associated with severe, economic disadvantage such as high unemployment, homelessness, drug and alcohol abuse, crime and malnutrition affected considerable numbers of service users. A number of the maternity units also served small populations of travelling families, some of whom had been unsuccessful in their attempts to secure permanent, local sites.

### 5.5 ETHNICITY

The population served by all sites was almost entirely Caucasian. This was also the case for service providers, with the exception of the obstetric staff, a number of whom were of African or Asian origin. The maternity units in this phase of the study were not located in the areas where Welsh was the predominant language, although a number of interviews were undertaken in Welsh.

The researchers were informed that an in-house interpreter service was available on a number of sites for women who spoke neither English nor Welsh although this service was not seen to be accessed by service providers on any of the occasions where it was observed that there was no common language between service user and provider. On such occasions, the service providers presumed upon the relative accompanying the woman to translate for her.

## **5.6 SCREENING FOR SELECTED MATERNAL CONDITIONS**

Screening for HIV was by maternal request only and women wishing to undergo screening were usually directed to the local Genito Urinary Medicine clinic. The researchers did not hear any service user enquiring about screening for HIV although it is also acknowledged that their presence may have had an inhibiting affect on such enquiries.

At the time the fieldwork was undertaken, many units operated a policy of only offering Hepatitis B screening to selected women. This policy was under revision as the researchers were leaving the field because it became a statutory requirement, in April 1999, to offer screening to all women.

Screening for CMV (cytomegalovirus), toxoplasmosis or the haemoglobinopathies was not offered routinely on any site and the researchers did not often hear these tests being discussed with women during the course of fieldwork.

## **5.7 SCREENING FOR FETAL ABNORMALITIES (See also Appendix 4)**

### **5.7.1 Serum screening**

Some form of serum screening was available to most women and this was generally in the form of MsAFP screening for Neural Tube anomalies and for Down's syndrome. Some units were offering the 'Double' (i.e. two biochemical markers) test. The 'Triple' (i.e. three biochemical markers) test was generally only available by maternal request and in the private sector. No woman was heard to request screening for Down's syndrome and not Spina bifida (or vice versa) but this may have reflected the fact that information regarding the tests was presented to women as a combined package rather than as single options.

### **5.7.2 Diagnostic tests**

Amniocentesis was generally offered to all women over the age of 35, to women with a pre-disposing family history of the condition and to women whose serum screening result was higher than 1:250-300 for Down's risk (and approximate Spina bifida cut-off was 2.5mm of medium). Women requesting amniocentesis in the absence of pre-disposing factors were generally accommodated. CVS was not widely available on the NHS; a number of women interviewed had obtained this test in the private sector.

### **5.7.3 Screening by ultrasound**

The situation regarding ultrasound scanning for fetal abnormalities was more consistent across sites. The majority of units offered an anomaly scan at around 18 weeks gestation with an uptake of almost 100%. Some midwives and ultrasound practitioners, who worked on sites where routine anomaly scanning was not available, expressed concern that women were under the impression that the dating scan served the same purpose.

Nuchal translucency scanning was available on the NHS in a very small number of units; it was also available within the private sector.

Ultrasound scanning for the purpose of gender identification varied across sites with some ultrasound practitioners openly disclosing this information and others citing 'hospital policy' as the reason for withholding it. On sites where this service was available, women were generally asked to sign a disclaimer form.

### **5.7.4 Variation in screening**

Considerable variation in the availability of screening tests was evident between units and, indeed, within units. The preferences of individual consultants for 'their patients' reflected the screening services available to service users.



## 5.8 INTRODUCING THE STUDY TO THE SITES

Prior to the study commencing, members of the research team met with HoMs and senior midwifery managers to explain the research aims and objectives and the overall design of the project. Information regarding existing systems for collecting names and addresses for the questionnaire cohorts was also obtained as were the names of consultant obstetricians and heads of obstetric anaesthetic and ultrasound departments. The HoMs were also asked to provide lists of the community midwives antenatal clinics, details of consultant antenatal clinics and local GPs directly involved with delivering antenatal, and/or intrapartum, care.

The research team then arranged a mutually convenient time with HoMs to formally present the project to midwives and other health professionals involved in delivering antenatal care, including non NHS professionals such as antenatal educators and consumer representatives.

A formal letter of invitation confirming these details, together with information sheets about the research was sent to all HoMs and other key respondents including non NHS professionals known to be involved in the maternity services. The HoM was also asked to extend an invitation to other interested local parties with whom she was in contact. Thus, the HoM assumed responsibility for informing maternity service providers within their local unit about the research. In retrospect, it is acknowledged that this was an important role and may have resulted in some respondents being less than adequately informed about the project.

Attendance at the project presentations was extremely variable across all the sites. The sessions were attended by hospital and community based midwives and, on some sites, a variety of medical and other personnel. Representatives from consumer groups such as SANDS (Stillbirth and Neonatal Death Society) and the NCT (National Childbirth Trust) attended on one site, as did clerical staff assisting in collating the names and addresses for the questionnaire cohort on another site.

Many HoMs and senior midwifery managers confided in the researchers that a primary motivation for agreeing to participate in the study was the chance of being supplied with leaflets which they wanted but could not afford to purchase. Many of these midwives, who were working in units which were subsequently randomised to the control arm of the study, voiced their disappointment when the allocation was made known.

The project presentations were intended to inform as many health professionals and representatives of consumer groups as possible about the research and to provide an opportunity for questions to be asked and concerns to be aired. The researchers also used the occasion to emphasise the importance of confidentiality to the data collection and the desire to include a wide variety of local opinions. Respondents were reminded that participation in the research was entirely voluntary and that all data would be anonymised. The research team reminded the audience that anyone who chose to participate in the research would be free to withdraw at any time; that they would not be required to give a reason for doing so and that there would be no repercussions following such decisions.

### 5.8.1 Networking

On all sites, those attending the presentation sessions were invited to give their names, positions and contact phone numbers to the research midwives if they felt able to act as a conduit for the purpose of networking. Participants were reassured that their compliance at this level would not be read by the team as a willingness to participate in the actual research. Once the difficulties of planning from a distance, and of networking 'in the dark' were explained, many of those attending the presentations generously supplied these details. This information proved invaluable in facilitating immediate access to key respondents on all sites once the study was underway.

As the study was conducted at some distance from one of the collaborating universities and because the majority of the research team had no insider knowledge of the participating sites, they had no option but to rely on advice from the midwives and other health professionals working on those sites. This inevitably resulted in some aspects of practice being overlooked as some features of the service were simply invisible to health professionals who had been in post for many years. Whilst it is not suggested that such omissions were deliberate, they nonetheless were problematic with respect to the study. For

example, on some sites, women attended 'peripheral' (satellite) clinics for their antenatal care but the researchers were not initially made aware that these clinics existed. It was suggested that although both the main unit and the peripheral unit were geographically quite separate, they were not perceived as such with respect to the delivery of care. (See Chapter 11)

The issue of 'invisibility' cut across a number of aspects underpinning maternity care and gave rise to considerable tensions between individuals; in this instance it appeared to generate feelings of resentment and inferiority amongst those midwives working exclusively in the peripheral units.

## **5.9 THE INTERVENTION IN PRACTICE**

### **5.9.1 Arranging the training sessions on the intervention sites**

Once randomisation of the participating units had been agreed, arrangements were made for a representative from MIDIRS to undertake a one-off, routine training session with each of the intervention sites. Initially, five such sessions were scheduled at times mutually convenient to each of the intervention sites and to the MIDIRS trainer.

It was necessary to arrange one further training session on one site because the researchers were not made aware of the existence of a 'peripheral' antenatal clinic operating at some distance from the main unit where considerable numbers of women received their antenatal care. Such was the emphasis placed on the services provided by the main unit, none of the midwives working in the peripheral unit appeared to have been informed about the research; neither had any of the staff attended the project presentation nor the MIDIRS training session. The researchers thus considered this additional session essential to the introduction of the intervention.

### **5.9.2 Attendance at the training sessions**

Midwives were the main professional group in attendance at the training sessions on all sites but inevitably, on the majority of sites, only a small proportion of the total number of those employed were able to attend. See Table 5.1 for the proportion of midwives attending the training sessions on each of the intervention sites. Whilst individuals and representatives from other groups involved in antenatal care had attended presentations introducing the research, none were present at the MIDIRS training sessions.

**Table 5.1 Proportion of midwives attending the MIDIRS training sessions**

<b>Site</b>	<b>percentage of the total number of employed midwives</b>
2.1	8%
2.2	15%
2.3	33%
2.4	10%
2.5	14%
2.6	19%

### **5.9.3 Training aids**

Following the training session, MIDIRS also issued each of the intervention sites with a full set of the training acetates for use by those staff who were unable to attend the scheduled session. This special request was made to MIDIRS by the research team in order to create opportunities for further training by staff on the intervention sites.

### **5.9.4 'Prescribing' and disseminating the leaflets to women**

The training sessions stressed the need for the leaflets to be transferred to women and that this be documented in the woman's casenotes or co-op card; there was little emphasis on the 'conscious and controlled' use of leaflets and nor was the notion of 'prescribing' the leaflets according to individual need explicated. Midwives attending the sessions were encouraged to agree suitable times during the

antenatal period for dispensing the leaflets and the majority of sites agreed that the leaflets be divided into two 'batches'.

The leaflets which concerned the early antenatal period<sup>1</sup> were to be given at the booking visit with the remainder<sup>2</sup> being given at the 'hospital' visit (generally between 28 and 32 weeks gestation), or at the 'birthplan' visit (usually between 34-37 weeks gestation). The exception was the leaflet on breech presentation which was to be given to women in the antenatal clinic following confirmation of the breech by ultrasound. In the event, informed choice leaflets were also often given to women attending parentcraft classes. There was no noticeable difference in the manner in which community midwives dispensed the Informed Choice leaflets when they consulted with women in their own homes, compared with antenatal clinics.

### 5.9.5 Exceptions to the general arrangements for dissemination of leaflets

There were some exceptions to these general arrangements. On one site, three of the leaflets (*screening for fetal abnormalities, ultrasound scans and place of birth*) were posted to women with their hospital booking appointment and midwives on this site opted to give the second batch of leaflets to women following their anomaly scan (20 weeks gestation). Three leaflets (*screening for fetal abnormalities, ultrasound scans and epidural in labour*) were withheld on one site because health professionals were concerned lest women be made 'anxious' or 'confused' as these particular leaflets discussed interventions which were not locally available.

### 5.9.6 Concluding the training sessions

At the close of the training session, midwives were encouraged to take a range of the leaflets with them for their use; some community midwives also collected leaflets for absent colleagues. The MIDIRS trainer asked that a named midwife from each of the intervention units be nominated to liaise with MIDIRS in the event of problems arising in the use of the leaflets.

### 5.9.7 Midwives' previous knowledge of the Informed Choice leaflets

With the exception of newly qualified midwives and those undertaking further education, it appeared that very few midwives attending the training sessions had any previous knowledge of the informed choice leaflets and even fewer had read any of them. This is despite the fact that the leaflets have been in circulation since 1996, are regularly advertised in the midwifery press and are stocked by many midwifery libraries. It is also possible that midwives who were familiar with the leaflets did not feel that it was necessary to attend the training.

Midwives attending the training sessions were observed asking very few questions regarding the contents of the leaflets or their possible effects on practice. They were, however, most concerned to know where the leaflets would be stored, when they should be given to women, where the transaction was to be documented in the woman's notes and how to manage disapproving medical colleagues. Anticipatory anxiety, lack of curiosity, the need to have explicit directions, a readiness to follow orders, and a deference towards medical authority, were characteristic features of midwives' behaviour which were to be observed throughout the research period, on both intervention and control sites. Such patterns of behaviour may have worked against maximising the benefits of the leaflets for service users.

## 5.10 THE PRAGMATIC NATURE OF THE STUDY

In keeping with a pragmatic approach, the researchers made no attempt to change, nor deliberately influence, the way in which information was used or the way in which maternity care was delivered in any

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<sup>1</sup> **Ultrasound scans** - *should you have one?*

**Alcohol and pregnancy**

**Feeding your baby** - *breast or bottle?*

**Looking for Down's syndrome and Spina bifida** in pregnancy

<sup>2</sup> **Support in labour**

*Listening to your baby's heartbeat during labour*

**Positions in labour and delivery**

**Epidurals for pain relief in labour**

*Where will you have your baby* - **hospital or home?**

of the participating units. This approach was adopted for the ethnographic phase and continued throughout the study.

With respect to the Informed Choice leaflets, this meant that providing leaflets were given to service users, each intervention unit was free to interpret notions such as 'prescribing' or 'disseminating' leaflets in any way they wished. In the event, the units generally followed the advice of the MIDIRS trainer and dispensed the leaflets at two agreed points in pregnancy.

The pragmatic nature of the research also meant that the researchers made no attempt to institute stock-taking measures, nor keep any records of individual health professionals use of the informed choice leaflets. Thus, on the occasions when health professionals reported that they had run out of leaflets earlier than was anticipated by the research team, the units were simply issued with further supplies. It is acknowledged that in providing health professionals with a free supply of leaflets, which they were not required to account for, may have encouraged stockpiling.

It should be noted, however, that monitoring systems to account for leaflet use had not been put in place on any of the three ethnographic sites where purchase of the leaflets had been locally funded.

### **5.11 OTHER RESEARCH WHICH INVOLVED WRITTEN INFORMATION**

A detailed booklet on antenatal screening had been produced by one Health Authority and introduced into a number of the study sites just prior to the introduction of the Informed Choice leaflets. It was originally intended that community midwives would give this locally produced booklet to women at the booking visit. This practice was revised, however, following criticism from a number of midwives and obstetricians who were of the opinion that the information was too complex and lengthy.

It should be noted that a number of the units were participating in other national research studies and, whilst they did not necessarily pose any threat to the study, they nonetheless required time and attention from busy health professionals.

## Chapter 6: A Description of the Intervention

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The intervention consisted of:

1. The full set<sup>1</sup> of the MIDIRS Informed Choice leaflets. The five intervention units were supplied with one set of leaflets for every woman delivering in an eight month period; one set of professional's leaflets was also supplied for each midwife. For the purpose of this study, the woman's version of the leaflet was translated into Welsh.

2. The MIDIRS training session. A representative from MIDIRS visited each intervention unit and delivered a one-off, two hour training session in the use of the leaflets in clinical practice (see Chapter 12: The MIDIRS Informed Choice leaflets). Following the session, each intervention site was sent a set of the materials used in the training for use by staff who were unable to attend.

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<sup>1</sup> The 'full set' of leaflets consisted of ten leaflets on ten discrete topics of maternity care arranged as pairs of leaflets. One leaflet was designed to be used by the pregnant woman and the other, fully referenced leaflet, for the health professional. See Appendix 1 for the leaflet titles.



# Chapter 7: Cluster Randomised Controlled Trial of Informed Choice Leaflets

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## 7.1 INTRODUCTION

### 7.1.1 Aims

The leaflets under study aim to promote informed choice in maternity care. Informed choice, or evidence-informed patient choice, has been defined as a decision about health care interventions a person will or will not receive, where the person is given research-based information about the effectiveness of at least two alternative interventions and the person provides some input to the decision-making process (Entwistle et al 1998a). The leaflets aim to enhance the decision-making process rather than to promote the 'right decision'. Thus the primary aim of the cluster randomised controlled trial (CRCT) was to measure the effect of the leaflets on the decision-making process, rather than on the decisions made. In particular:

1. The primary aim of the CRCT was to assess the extent to which women exercised **informed choice**. This aim reflects the type of decision-making process which the leaflets intend to promote, as their title suggests.
2. A secondary aim was to measure the effect of the leaflets on **possible components of informed choice**, such as the extent to which women's information needs were met. This reflects evidence that people value information while not necessarily wanting to participate in decision-making (Charles et al 1997).
3. A secondary aim was to measure the **possible consequences of informed choice**, such as changes in the choices women make. This reflects evidence that changes in processes can affect outcomes, for example changes in decision-making processes have been shown to affect people's emotional health (Coulter et al 1999). A pilot evaluation of two of the leaflets identified views on the possible effects of the leaflets (Oliver et al 1996a). Although midwives thought the leaflet on ultrasound scans would inform women, help with discussions between midwives and women, and help women to get better care, ultrasonographers expressed concerns that the leaflet would raise women's anxiety and reduce the uptake of scans. It is important that any evaluation can provide evidence either to confirm or refute health professionals' hopes and fears for an intervention.
4. A secondary aim was to assess the effects of the leaflets on **different sub-groups of women**. There was evidence in the pilot study of two of the leaflets, that women in manual occupations found the leaflets more helpful than women in non-manual groups (Oliver et al 1996b).

### 7.1.2 A further aim

It was stated in the original protocol that the leaflets would be evaluated as a set. Had the intention been to evaluate the individual leaflets, a factorial design would have been necessary. As the questionnaires for use in the CRCT were developed, it became clear that it was difficult for women to consider informed choice without considering the individual decisions they made. The set of leaflets has been evaluated by asking about the topics on which the individual leaflets were based. Thus the study can assess the effects of the individual leaflets when used as part of the set of ten leaflets.

### 7.1.3 Objectives

1. To assess the effect of the leaflets on the proportion of women reporting that they exercised informed choice in their maternity care (the primary outcome).

2. To assess the effect of the leaflets on components of informed choice, in particular
  - (i) women's knowledge levels of topics covered by the leaflets
  - (ii) preferences formulated by women and the strength of those preferences
  - (iii) the proportion of women whose information needs were met
  - (iv) the proportion of women who were satisfied with the way choices were made
  - (v) the proportion of women whose needs for discussion with health professionals were met
3. To assess the effect of the leaflets on the consequences of informed choice, in particular
  - (i) women's sense of control over their pregnancy and delivery
  - (ii) women's depression and anxiety levels
  - (iii) satisfaction with care
  - (iv) use of health services
  - (v) information-induced anxiety
  - (vi) stillbirths and deaths in the first week of life.
4. To assess the effect of the leaflets on sub-groups of women, in particular sub-groups defined by
  - (i) age
  - (ii) parity
  - (iii) social class
  - (iv) educational status
  - (v) decision-making style

#### 7.1.4 Hypotheses

The leaflets will be deemed effective if they increase the proportion of women reporting that they exercised informed choice in their maternity care. They will be deemed partially effective if they improve women's knowledge of issues about which they have had to make choices, or help women to formulate strong preferences for particular options, or meet their information needs, or ensure they are offered choices, or allow them to have enough discussion with health professionals. Changes in any of these aspects of informed choice might have the beneficial effects of making women feel more in control of their care, improve women's emotional health, increase their satisfaction with their care, or the detrimental effect of inducing information-related anxiety. Finally, increases in informed choice may change demand for services in any direction which will have resource implications, which in turn may affect the occurrence of adverse events.

## 7.2 METHODS

### 7.2.1 Design

A pragmatic cluster randomised controlled before-and-after trial was undertaken, clustered at the maternity hospital level.

The trial was **pragmatic**, with the comparison of the set of leaflets with usual care. No attempt was made to direct the use of the leaflets beyond the usual training provided by MIDIRS. It was possible that usual care might include some women seeing the leaflets under study because individual midwives throughout the UK have purchased them. It was likely that usual care would include women seeing other leaflets usually available in hospitals.

A **cluster randomised controlled trial** was undertaken, with maternity hospitals as clusters. It was felt that there was a risk of contamination in a traditional randomised controlled trial (where randomisation occurs at the individual person level), with women in the intervention arm possibly sharing leaflets with women in the control arm. Additionally, it was felt that the leaflets might operate at a hospital level, possibly bringing about changes in hospital policy or changes in the way midwives facilitated informed choice. The cluster design is particularly widespread in the evaluation of non-therapeutic interventions such as educational programmes. Guidance on undertaking this methodology, which was available to the research team as work-in-progress, was followed throughout the trial (Ukoumunne et al 1999).

A **before-and-after** design was used because it was felt that the level of informed choice might be different in each maternity hospital and that it was important to measure change over time in the



intervention units compared with the control units after the intervention had been operating for a specified time period.

### **7.2.2 Randomisation**

Thirteen maternity hospitals in Wales, which had not already purchased the leaflets, were approached by members of the research team in the University of Glamorgan. All thirteen agreed to participate in the trial. Some hospitals shared medical or managerial staff with other hospitals in the study. Such hospitals were treated as one cluster.

There were ten clusters for randomisation. These were divided into five pairs principally on the basis of size; two units were further paired based on local knowledge of the deprivation level of their catchment populations. This pairing was undertaken to ensure that the numbers of women allocated to the intervention and control groups would be roughly equal and that the populations in these groups would be roughly comparable. The clusters were not matched using any variable known to be related to informed choice.

The ten clusters were anonymised and the statistician (SJW) randomised one member in each pair to the intervention group and the other member of the pair to the control group. This allocation was undertaken by the statistician whose only role was to analyse the data and was undertaken blind to the identities of the hospitals. The code was broken by the statistician and the CRCT co-ordinator (AOC). The CRCT co-ordinator informed MIDIRS about the identities of the intervention sites.

### **7.2.3 Measuring outcomes: the questionnaires**

The majority of study outcomes relied on measuring women's perceptions of decision-making processes and their reporting of outcomes; these were collected by postal questionnaire. Some of the leaflets related to decisions made in antenatal care and thus an antenatal questionnaire was developed to focus on these decisions only. Other leaflets related to intrapartum and early postpartum care and a postnatal questionnaire was developed to focus on these decisions only. See Appendix 2a for copies of the questionnaires used.

#### **7.2.3.1 The antenatal questionnaire**

An antenatal questionnaire was designed to cover four decisions which women may face during early pregnancy and which are covered by the Informed Choice leaflets:

- whether or not to have ultrasound scans;
- whether or not to have a screening test for Down's syndrome and spina bifida in the baby;
- whether to have the baby in hospital or home;
- whether or not to drink alcohol during pregnancy.

This questionnaire was sent to women at 28 weeks gestation because it was felt that women would have faced these decisions by this stage of their pregnancy.

#### **7.2.3.2 The postnatal questionnaire**

A postnatal questionnaire was designed to cover five decisions which women may face during labour, delivery and postnatally and which are covered by the Informed Choice leaflets:

- who to have with them during labour;
- which kind of monitoring to have in labour to listen to the baby's heartbeat;
- what positions to use during labour and delivery;
- whether or not to have an epidural;
- whether to breastfeed or bottle feed.

The questionnaire was sent to women eight weeks after the birth of their child. The Informed Choice leaflet about breech babies was not covered fully in the postnatal questionnaire because it was relevant to a small proportion of women only. A limited number of questions were asked about breech presentation.

### **7.2.3.3 The development and piloting of the questionnaires**

As far as possible, the questionnaires were developed based on instruments used in other studies. Questions about informed choice and the components of informed choice were developed based on the qualitative research in the ethnographic sites. The language women use and understand, and the difficulty of devising questions around informed choice which women felt were relevant to them was identified. For example, some women did not perceive that 'choice' was an issue around alcohol consumption, or that choice existed for having ultrasound scans. The tick-box options to questions were worded to reflect this difficulty. The questionnaire was then piloted face-to-face with women, resulting in further refinements. For example, some questions about informed choice and alcohol consumption were removed from the questionnaire because women found them frustrating. When a suitable questionnaire was developed, a postal pilot was undertaken with approximately 200 women in a local hospital. One mailing, without reminders, resulted in a response rate of 57% (47/82) to the antenatal questionnaire and 45% (43/96) to the postnatal questionnaire. Minor changes were made to the questionnaires based on this pilot.

### **7.2.3.4 The questions used in the questionnaires**

The primary outcome measure was the proportion of women answering 'yes' to the following question:

*Did you have enough information and discussion with midwives or doctors to make a choice together about all the things that happened during your care: yes, partly, no, there was no choice, did not apply.*

Other questions included the use of and helpfulness of Informed Choice leaflets, women's knowledge levels of topics covered by the leaflets, preferences, strength of preferences, whether they had enough information, satisfaction with the amount of information received, satisfaction with the way in which choices were made, whether they had as much discussion with health professionals as they wanted, control, the Edinburgh Postnatal Depression Scale, the short-form Spielberger's State Anxiety Inventory, satisfaction with care, and actions taken by women/use of health services. Details of the source of questions used in the questionnaires are in Appendix 2b.

### **7.2.3.5 Free text comments**

In addition to tick-box questions about satisfaction with services, women were asked to describe in their own words anything they were particularly satisfied with and anything they were particularly dissatisfied with during their care. The analysis of free-text comments made by women is reported in Chapter 8 of this report.

### **7.2.4 Measuring outcomes: routine data**

The intervention took place over the last eight months of 1998. Routinely available data were available for the year before the intervention and the year including the intervention to compare the occurrence of adverse events. The following data items from the All Wales Perinatal Survey and Confidential Enquiry into Stillbirths and Deaths in Infancy Annual Reports for 1997 and 1998 were compared:

Number and rate of stillbirths by intended place of birth

Number and rate of early and late neonatal deaths by intended place of birth

### **7.2.5 The samples**

A postal questionnaire was sent to four cohorts of women in each of the ten clusters of randomisation. Two cohorts were studied before the intervention commenced: an antenatal sample and a postnatal sample. Two cohorts were studied when the intervention had been in progress for eight months: an antenatal sample and a postnatal sample.

#### **7.2.5.1 Antenatal sample**

In each hospital, women estimated to have reached 28 weeks gestation during a six week period in March/April 1998 (BEFORE intervention) and an eight week period in February/March 1999 (AFTER intervention) were identified. The intention had been to identify a six week cohort after the intervention as well as before. However, because fewer than expected women had been identified in the BEFORE period,

this was extended to an eight week cohort in the AFTER period in order to maintain the power of the study. Women in the AFTER cohort were most likely to receive the leaflets in months six and seven of the intervention.

Identifying women was a difficult process because only three hospitals had adequate computer systems which could identify the samples. For the other nine hospitals, midwives and clerks in antenatal clinics in hospital and the community identified women at their booking appointment who would reach 28 weeks gestation during the study period. In one hospital in both periods, women were sent a letter by the hospital management, giving them the option not to have their names forwarded to the research team. In another hospital in both periods, staff asked women at their first scanning appointment for their permission to be sent a questionnaire.

Women were included if they received antenatal care in any setting from midwives attached to each hospital. The questionnaire was posted to women as they reached 28 weeks gestation.

#### **7.2.5.2 Postnatal sample**

In each hospital, women who delivered live babies during a six week period in January/February 1998 (BEFORE intervention) and during a six week period in December 1998/January 1999 (AFTER intervention) were identified. Women in the AFTER cohort were most likely to receive the leaflets in months seven and eight of the intervention.

In the BEFORE period, Child Health computer records were used as a sampling frame for ten hospitals; hospital and home delivery registers were used in two hospitals where Child Health did not allow access to their databases. In the AFTER period, Child Health computer records were used as a sampling frame for one hospital and hospital/home delivery records were used in the other eleven hospitals. This change was instigated because Child Health records are addressed to the parent of the child. In the BEFORE study higher response rates were received from hospitals where hospital records were used as a source of names and addresses. In one hospital in both periods, women were sent a letter by the hospital management, giving them the option not to have their names forwarded to the research team. Women delivering in hospital or at home were included. The questionnaire was posted to women at eight weeks post delivery.

#### **7.2.5.3 Exclusions**

Women who lived in areas outside the catchment area of the hospital and women living in areas where antenatal care was provided by midwives from other hospitals were excluded. Attempts were made to exclude women under 16 years old from the samples for ethical reasons. Women who had suffered a miscarriage and women whose baby had died or was known to have been very ill in the neonatal intensive care facilities were excluded.

#### **7.2.6 Posting the questionnaires**

Questionnaires were posted to women by second class mail with a reminder at three weeks and a second reminder three weeks later. The intention had been to send only one reminder to the antenatal sample because of the workload involved in checking that women in the sample had not miscarried over the postal period. However, the response rate was not acceptable after the first reminder and a short questionnaire covering four key questions was sent as a second reminder to boost the response rate.

#### **7.2.7 Analysis**

It is recommended that when the number of clusters per group is less than ten, a cluster level analysis should be undertaken. For analysis at the cluster level, individual level data are summarised at the cluster level. In this study, this resulted in ten summary data points for each outcome variable, five for intervention clusters and five for control clusters. The change between the BEFORE survey and the AFTER survey in the intervention sites versus change in the control sites was of interest. To illustrate, the proportion of women who reported that they exercised informed choice in each cluster was calculated for BEFORE the intervention. The proportion of women who reported that they exercised informed choice in each cluster was calculated for AFTER the intervention. The change which occurred in each cluster was calculated, resulting in ten data points. The mean of the changes in the intervention clusters were then compared with

the mean of the changes in the control clusters. The t-test was used to compare these means. Multi-level modelling (MLM) was undertaken, unadjusted and adjusted for covariates. See Appendix 2c for sample size calculation and details of the analysis.

## 7.3 RESULTS

### 7.3.1 Representativeness

All large hospitals in Wales, which could be included, agreed to participate in the study. The numbers of women identified for inclusion in the postnatal surveys were similar to the numbers expected; however, numbers were lower for the antenatal surveys, at 81% of expected numbers. By nature of the sampling method, women making contact with the service later than 24 weeks in pregnancy were not included. There was evidence of an over-representation of first-time mothers in the antenatal samples.

The overall response rate to the surveys was 64% (6452/10,070). The response rate was lower from women in manual social classes and minority ethnic groups. See Appendix 2d for details of the representativeness of the sample.

### 7.3.2 Baseline characteristics

Socio-demographic variables of women in the BEFORE surveys were compared for intervention and control sites at the cluster level (Table 7.1). There were no statistically significant differences between the intervention and the control arms.

**Table 7.1: Socio-demographic variables at baseline. Percentages unless otherwise stated.**

Socio-demographic variables	Antenatal		Postnatal	
	Intervention	Control	Intervention	Control
Mean age of woman in years (SD)	27.3 (1.07)	27.6 (0.66)	27.9 (0.40)	28.4 (1.02)
Mean age woman left full-time education (SD)	17.5 (0.29)	17.6 (0.47)	17.6 (0.28)	17.7 (0.56)
% manual - women	36%	33%	33%	34%
% manual - partner	57%	56%	60%	55%
% minority ethnic	2%	2%	3%	2%
% women in paid work	58%	58%	48%	49%
% first time mothers	46%	46%	44%	45%
Mean number of weeks pregnant on completion of q're (SD)	29.4 (0.60)	28.3 (2.02)	-	-
Mean age of baby on completion of q're (SD)	-	-	10.2 (0.37)	10.5 (0.59)

### 7.3.3 The leaflets: distribution, views, and influence

Before assessing the effectiveness of the leaflets, it may be useful to assess the *potential* of the leaflets to have an effect. In order for the leaflets to directly affect women, women must receive at least one of the leaflets, find the leaflets helpful, and leaflets as a medium must influence women's decision-making.

#### 7.3.3.1 Distribution

Approximately 40% of women reported that they had been given at least one of the Informed Choice leaflets before the intervention, in both intervention and control sites. This may not reflect actual use of Informed Choice leaflets because the qualitative research showed that women may not distinguish Informed Choice leaflets from other leaflets available in maternity care. That is, the Informed Choice leaflets were entering an environment where leaflets were already widely used.

Approximately 70% of women reported that they had been given at least one of the Informed Choice leaflets after the intervention, in the intervention sites. Because of the difficulty in distinguishing Informed Choice leaflets from other leaflets, we cannot calculate the increase in the proportion of women who received the intervention; however, we can say that there was an increase in use of Informed Choice leaflets in between approximately 30% and 70% of women. Some increases in leaflet use occurred in some control sites: three control sites introduced a screening leaflet during our study and one introduced an ultrasound scanning leaflet. See Appendix 2e for details.

Postnatally, younger women and primiparous women were more likely to report that they were given at least one of the leaflets: 84% of younger mothers compared with 71% of older mothers, and 84% of first time mothers compared with 68% of multiparous women.

### 7.3.3.2 Helpfulness of Informed Choice leaflets

The vast majority of women found the leaflets very helpful or helpful, varying between 92% and 99% for individual leaflets.

### 7.3.3.3 Influence of leaflets

Women reported many influences on what they wanted during their care, with more women influenced by health professionals, family or friends and their own experiences than by leaflets. That is, the Informed Choice leaflets were entering an environment where there were many influences on women. Antenatally 28% of women and postnatally 13% of women were influenced by leaflets prior to the intervention. There were no statistically significant changes in the proportions of women influenced by leaflets over time. See Appendix 2e for details.

### 7.3.4 Informed choice

Prior to the intervention, approximately half of women felt that they had exercised informed choice overall in their maternity care (Table 7.2). The minimum clinically important difference was considered to be a ten percentage point increase. There was no statistically significant change over time in intervention sites compared with control sites either antenatally or postnatally.

**Table 7.2: Percentage of women reporting that they had exercised informed choice overall**

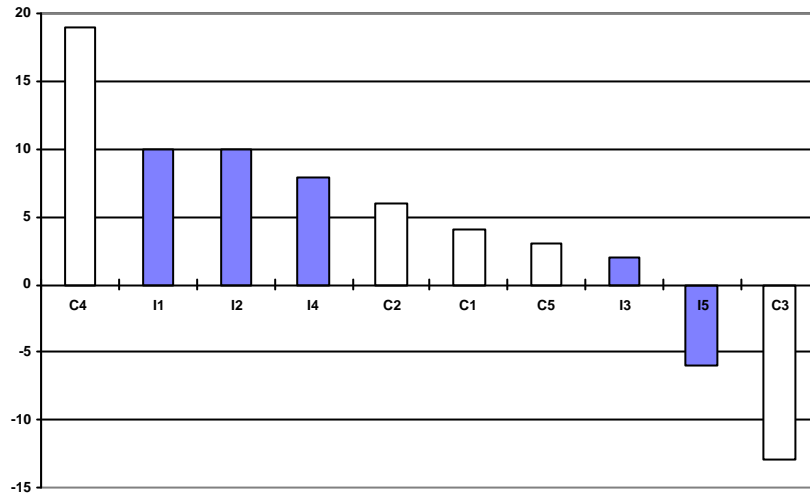
	Antenatal		Postnatal	
	Intervention	Control	Intervention	Control
	%	%	%	%
BEFORE	52	56	58	51
AFTER	57	60	59	57
CHANGE	5	4	1	6
DIFFERENCE (cluster level)	<b>1</b>		<b>-4</b>	
95% confidence interval	-13, 15		-13, 5	
T-test	p=0.9		p=0.3	
Wilcoxon	p=0.8		p=0.3	
Analysis of covariance	p=0.8		p=0.5	
DIFFERENCE (MLM unadjusted)	<b>2</b>		<b>-3</b>	
95% confidence interval	-11, 16		-12, 7	
	p=0.7		p=0.5	
	N=3089		N=3160	
DIFFERENCE (MLM adjusted)+	<b>3</b>		<b>-3</b>	
95% confidence interval	-11, 18		-13, 8	
	p=0.6		p=0.6	
	N=2599		N=2994	

+adjusted for woman's age, educational status, parity, decision-style preference

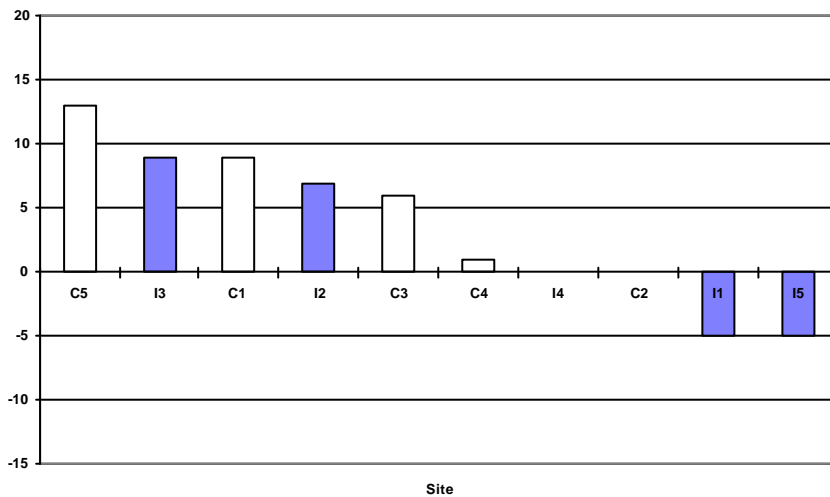
Given that this was the primary outcome of the study, further analysis was undertaken by site and individual leaflet. A ten percentage point increase, or higher, occurred in two intervention sites antenatally

(Figure 7.1) and no intervention sites postnatally (Figure 7.2). There were no statistically significant changes for individual leaflets (Figure 7.3).

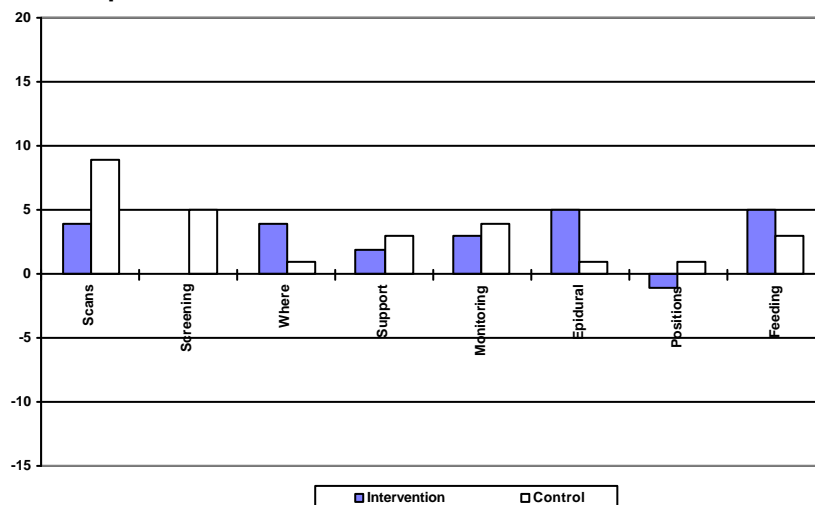
**Figure 7.1: Percentage point change in the proportion of ANTENATAL women exercising informed choice by site**



**Figure 7.2: Percentage point change in the proportion of POSTNATAL women exercising informed choice by site**



**Figure 7.3: Percentage point change in the proportion of women exercising informed choice by leaflet topic**



To determine whether the lack of change in the primary outcome was due to the wording of the question we used to measure informed choice, we analysed another question about women's involvement in decision-making overall. Women were asked to describe the role they preferred to take and the role they actually took in decision-making overall in their maternity care. Women who made choices, made them after seriously considering the midwives' and/or doctors opinion; those who shared responsibility for making choices were classified as 'active' in the decision-making process. Prior to the intervention, approximately three quarters of women said that they took an active role in decision-making overall (Table 7.3). There was no statistically significant change over time.

**Table 7.3: Percentage of women who reported taking an active role in decision-making**

	Antenatal		Postnatal		
	Intervention	Control	Intervention	Control	
	%	%	%	%	
BEFORE	80	81	74	69	
AFTER	85	85	73	72	
CHANGE	5	4	-1	3	
DIFFERENCE (cluster level)	<b>1</b>		<b>-4</b>		
95% confidence interval	-10, 12		-13, 5		
T-test	p=0.9		p=0.3		
Wilcoxon	p=0.8		p=0.3		
Analysis of covariance	p=0.9		p=0.9		

### 7.3.5 Components of informed choice

The components of informed choice studied were women's knowledge levels of topics covered by the leaflets, preferences, strength of preferences, whether they had enough information, satisfaction with the amount of information received, satisfaction with the way in which choices were made, and whether they had as much discussion with health professionals as they wanted. Some of these components were assessed for maternity care overall (Table 7.4). For postnatal women, there was an overall increase of 0.24 points on a ten point knowledge score. This was no longer statistically significant when adjusted for women's age, educational status, parity and decision-style preference. There were no other statistically significant changes in the components of informed choice overall.

**Table 7.4: Changes in the components of informed choice**

Component	Antenatal		Difference at cluster level	Postnatal		Difference at cluster level
	Change Intervention	Control		Change Intervention	Control	
Mean knowledge	0.24	-0.02	0.27	0.19	-0.05	0.24*
%Enough information	4	2	1	1	4	-3
%Satisfied with information	6	3	3	4	4	0
%Satisfied with making choices	4	3	2	-1	3	-5
%Enough discussion	6	2	4	0	5	-5

\* p<0.05 at cluster level

Change= change between BEFORE and AFTER surveys

Difference = difference between changes in intervention and control sites

Women's preferences and strength of preferences were assessed for each decision point covered by the leaflets. There were two statistically significant changes over time. There was an 11 percentage point reduction in the proportion of women wanting a screening test for Down's syndrome and spina bifida in the intervention sites compared with control sites when the leaflets were in use. This was statistically significant with the multi-level modelling, adjusted for parity, woman's age, educational status and decision-style preference. However, the change consisted of a reduction of seven percentage points in the intervention sites and an increase of five percentage points in women wanting tests in control sites. In addition, there was a statistically significant increase of eight percentage points in the percentage of women feeling very or quite strongly about their preferences for positions to adopt during labour and delivery in the intervention sites compared with the control sites. This was no longer statistically significant with a multi-level model adjusted for parity, woman's age, educational status and decision-style preference. Further details are in Appendix 2f.

### 7.3.6 Consequences of informed choice

The consequences of informed choice studied were control, emotional health, satisfaction with care, actions taken by women/use of health services, information-induced anxiety and stillbirth rate. Some of these consequences were assessed for maternity care overall (Table 7.5). There were no statistically significant changes over time.

**Table 7.5: Changes in the consequences of informed choice**

Consequences	Antenatal		Difference at cluster level	Postnatal		Difference at cluster level
	Change Intervention	Control		Change Intervention	Control	
%In control of what happened	1	0	1	-1	2	-4
%In control of staff	1	0	1	-3	0	-4
Mean depression score	-0.40	-0.58	0.18	-0.20	-0.17	-0.37
Mean anxiety score	0.32	-1.10	1.42	0.08	0.77	-0.69
%Satisfied with care	6	1	4	-2	3	-5

\*  $p < 0.05$  at cluster level

Change= change between BEFORE and AFTER surveys

Difference = difference between changes in intervention and control sites

Actions taken by women and their use of health services were assessed for each decision point covered by the leaflets. There were two statistically significant differences between intervention and control sites. First, there was a reduction in the proportion of women having screening tests for Down's syndrome and spina bifida in the baby. The reduction of 4% in intervention sites occurred alongside an increase of 6% in control sites. That is, the statistical significance of the change was dependent upon a reasonably large change in the opposite direction in the control sites. Multi-level modelling adjusted for covariates at the individual level gave a p-value of 0.06. The second significant difference was about where women planned to have their babies: there was a 2% reduction in the proportion planning to have hospital births in the intervention sites compared with no change in the control sites. This small difference was statistically significant because of the lack of variability between hospitals. It was not statistically significant in an adjusted multi-level analysis. Service usage is explored further in the economic study (Chapter 9).

There were no statistically significant changes in the proportion of women reporting that information they received made them more anxious or in the stillbirth rate. Further details are in Appendix 2g.



### **7.3.7 Changes in informed choice and knowledge for different sub-groups of women**

Changes in outcomes may have occurred in some sub-groups of women only. Changes in overall ability to exercise informed choice and overall knowledge were studied by age group, parity, woman's social occupation, educational status and decision-style preference using multi-level analysis. There were no statistically significant changes over time. Further details are in Appendix 2h.

### **7.3.8 Focus on each leaflet**

Outcomes were assessed for each leaflet and are summarised in Appendix 4. Approximately 100 statistical tests were undertaken on outcomes and thus we would expect five significant differences to occur by chance alone. Multi-level analysis was undertaken on outcomes which were statistically significant or close to significance with the cluster level analysis. Only two changes remained significant with an adjusted multi-level analysis. These were the change in preference for screening tests which has been discussed above, and the change in satisfaction with information about epidurals.

## **7.4 LIMITATIONS**

The lack of effect of the intervention was not due to limitations in the CRCT. Measuring a concept such as 'informed choice' is a complex undertaking, and the question used to assess informed choice may be open to criticism. However, a different question showed the same lack of effect. 'Ceiling effects' were not operating. That is, baseline values for our outcomes were sufficiently low to allow room for improvement. Contamination between sites did not account for the lack of effect because the size of changes in outcomes which occurred in the intervention sites were small before they were adjusted for changes which occurred in control sites.

There was some bias in the data collected, with under-representation from women from minority ethnic communities and manual occupations. The pilot study of two of the informed choice leaflets (Oliver et al 1996b) found that women from manual social classes might benefit more from the leaflets than women in other social classes, suggesting that the CRCT might have underestimated the true effect of the leaflets. However, there was little evidence in our sub-group analyses that the effect of the leaflets differed by social class and thus this bias was unlikely to have affected the conclusion of the CRCT. Smaller numbers of women were recruited to the study than originally planned and the number of clusters were reduced from twelve to ten. However, because the intraclass correlation coefficient was smaller than estimated, the power of the study remained high. There were some small differences between intervention and control sites and in the 'before the intervention' and 'after the intervention' surveys in terms of the types of women who responded. However, these differences were adjusted for in the multi-level modelling. The time of the year when women were surveyed differed. The effect of timing of the before and after surveys was unlikely to produce seasonal effects because, in the before survey, the antenatal cohort reached 28 weeks gestation in March/April and the postnatal cohort delivered their babies in January/February. In the after survey, the antenatal cohort reached 28 weeks gestation in February/March and the postnatal cohort delivered their babies in December/January. There was thus little overall difference between the cohorts studied.

## **7.5 SUMMARY POINTS**

- Approximately 70% of women in the intervention sites reported that they had been given at least one of the Informed Choice leaflets after the intervention commenced.
- The vast majority of women found the leaflets helpful.
- The leaflets operated alongside other influences on women's preferences, such as health professionals, family and friends, and leaflets other than Informed Choice leaflets.
- There was no evidence that the leaflets had an effect on informed choice.



# Chapter 8: Free Text Analysis of Comments Written on the Informed Choice Leaflet Questionnaires

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## 8.1 OUR TASK

On the questionnaire there were questions which invited women to write in their own words any comments which they had to make, particularly about anything which they had been particularly satisfied with or anything which they had been particularly dissatisfied with. The task which we were given was to analyse those hand-written comments (actually transcriptions into machine-readable form of them provided to us), and to see whether they indicated any levels or changes which were relevant to the hypotheses.

1. There would be a larger increase in the intervention sites than in the control sites in the proportion of comments mentioning *choice* and *information*, i.e. the topics would become of more interest to women in the intervention sites, however positive or negative their experiences. This would be interpreted as meaning that the intervention had raised consciousness of the issues with which the study was concerned.
2. There would be a larger increase in the intervention sites than in the control sites in the proportion of comments making *favourable* mentions in the choice and information categories, i.e. women in the intervention sites would report positive experiences about those categories. This would be interpreted as meaning that the intervention had produced results of which the women approved.

Of course, women wrote about many things. Apart from the themes of *Choice/Control* and *Information* (which we had to use because of the study design), two others figured largely in the comments. These were:

Personality and competence of staff  
Organisation of the service

We give examples later of what went into these two categories. They are necessary because we need to know the proportionate (not absolute) distribution of responses between categories. Suppose that women had increased their number of comments about, say, *Choice/Control* in the intervention sites. If they had also increased their number of comments about, say, *Service Organisation* to an even greater extent, to report the finding about *Choice/Control* on its own would have been misleading.

The dangers of undertaking any analysis of such free-text analysis are well known, although not always acknowledged. There is the danger of unchecked, and often uncheckable, personal bias creeping into the analysis, so that the reader (and even other members of the research team) has to take on trust what the researcher reports. One would wish in an ideal world (a) to make one's preconceptions open and accessible to others, and thus (b) to make the process repeatable.

Conventionally any coding of such free-text data is either done by hand, is carried out using a computer, but not using the automated programming facilities which a computer can offer. In both cases, one usually works to common conventions. Ideally, the coding should be done twice by different coders, preferably working blind, i.e. the second coder does not know how the first coder has allocated values to different fragments of text. This gives a check on reliability. It is, however, very time-consuming and therefore expensive. In many reports it is not mentioned, and therefore it remains unclear whether or not any reliability check has been undertaken.

### 8.1.1 A novel approach: automated coding

A more novel approach, which we have adopted with success in two previous studies, is to try to automate the process. Details are given in (2), but we include a brief summary here. It starts from the fact that free text data are today normally stored on a computer, and are thus available for a wide variety of searches, some of which can be automated.

One decides which words, phrases, or other fragments of text would be used by respondents if they were trying to express particular concepts. So, for example, if a respondent is talking about *Choice/Control*, they might use fragments such as chose, choose, choice, control, decide, decision, etc. A respondent who is talking about *Service Organisation* might use fragments such as appointment, waiting, late, unreliable, etc. One's computer program then searches in the database of text utterances, locates such fragments, and for each occurrence allocates the associated concept code automatically. In practice, it adds a record to a new table, and that record contains the statement, the term which has been matched, and the associated category code. This means that if a statement contains several themes, several records may be appended. This handles the usual problem of what to do when people make several points in one utterance. There is more to it than this, but that brief description provides the essence. Once the system has been set up, the whole process can be done automatically with no subsequent human intervention. This means that

- The fragments and their associated codes are readily available and are open for inspection
- If they are thought to be inadequate, they can easily be changed
- If a new concept emerges (a common feature of content analysis) one normally has to review all the previous codes. With automated method, one merely adds the new concept and its associated fragments and re-runs the program.

This matters when the data to be analysed contain many thousands of statements by respondents (as in the current case). Not only is conventional analysis very time-consuming, but the degree of concentration required means that many mistakes will be made – often even more than will occur with an automated approach.

### **8.1.2 Some decisions**

Moving to automation involved several decisions. Many of the statements were very general. In response to the question asking what the respondent was particularly satisfied with, an answer such as “Everything” should clearly be coded Positive, and would be useful if the study was mainly about patient satisfaction in general. However, it does not tell one anything about Who, Where, What, etc the respondent was particularly satisfied with. It tells one neither what the respondent is satisfied with, nor the context of that satisfaction. It clearly does not tell us much about the success of the leaflets in influencing attitudes to information and choice. The situation is similar, if one gets such a general response to the dissatisfaction question. It also applies if they reply with “Nothing”. Even when one of the dimensions is mentioned, it is difficult to extract any information of relevance to the study. If a respondent writes “The staff were all very good”, what does one make of that ? Such statements made up 37% of those made in the antenatal data, and 32% in the postnatal data. We therefore decided to count and report such cases, but not to include them in totals when calculating any effect of the leaflets on aspects of direct relevance to them.

Secondly, we had to reduce the number of categories to those needed for the current study, rather than the many dozen which we could have used if the approach of allowing categories to emerge from the entire data set to be adopted. We decided to amalgamate and report under 4 headings:

#### **8.1.2.1 Information**

This could be both positive and negative e.g. “they answered all my questions”, “I didn’t know what was going to happen”, “despite what I had read, they still wanted to do..”, “the doctor explained everything”.

#### **8.1.2.2 Choice/Control**

Again this could be both positive and negative e.g. “they wouldn’t even listen to the idea of a home birth”, “they respected my wishes”, “I felt in control the whole time”.

#### **8.1.2.3 Personality and competence of staff**

This is when members of staff are singled out for praise or criticism, but not on grounds covered elsewhere e.g. “she was very nice”, “she shouted at me and told me to push”, “she did not know about.....”

#### **8.1.2.4 Service provision and quality (Service Organisation)**

This covered matters such as staff availability or shortages (“they’re only a phone call away if I need them”), continuity (“I’ve seen 8 midwives so far”), timing (“you have to wait for 2 hours for a 2 minute consultation”, “they take 6 weeks to get the test results back to you”) *inter alia*.

The nature of the study forced us to use the concepts of *Choice/Control* and of *Information*. Some comment on the use of the other two categories is needed. The inclusion of the two major emergent categories of *Personality* and *Service Organisation* was vital. Without them, the results on *Information* and *Choice/Control* would have lacked context, and would have been grossly misleading. To have reported that our respondents wrote quite a lot about choice and control if we did not at the same time report that they wrote even more about the competence of their midwife or the problem they had in getting test results in a reasonable time period, would have misled the reader.

For each of these 4 categories we had to develop a list of search terms. The questions surrounding this process are covered in reference 2. In that study we found a concordance of 90% between the computerised automated coding and independent manual codings made by two independent and experienced nurse researchers.

#### **8.1.3 Debiasing**

All of the early work, both in developing the coding framework, in doing the reliability checking, and in correcting for the problems raised, were done without amalgamating the statement details with the details of whether they came from an intervention or a control site. Indeed, we completed all of the coding before we linked the site data into the tables of statements. Hence, it was impossible for us to be influenced by knowledge of which site particular statements came from. Thus, we hope that the coding is independent of the study design. If we coded a particular statement as being, say, a negative comment on information, we did not know whether it was made by a woman from an intervention site or from a control one. Such a process is one equivalent, in a qualitative study, of the blinding which is a major feature of quantitative studies.

Using this approach in the current study meant that we could not have influenced the results, even had we wanted to do so, and thus prevented a common source of bias.

## **8.2 RESULTS**

### **8.2.1 Response rates and their effect**

For the two antenatal groups combined, the percentage of questionnaire completers who had free-text comments recorded was 57. Given that this figure was based on a 100% which consisted only of those who chose to answer the questionnaire in the first place, the fact that the study started with a random sample does not mean that it achieved a random sample. To demonstrate such representativeness, it would be necessary at least to show that those who did not volunteer responses were similar in important respects to those who did so volunteer. For all we know the 43% who did not write anything may have been wildly enthusiastic about the leaflets, uncomprehending, or could not care less.

For the two postnatal groups combined the comparable figure was 77%. We can only speculate as to the reasons for this difference. Our suspicion is that labour and birth offer such a vivid experience, with occurrences (medical decisions, choice of delivery methods, monitoring, posture, pain relief, choice of feeding methods) which are different from everyday life, that there is simply more to talk and write about after such an experience. We stress that this is a suspicion, not a demonstrated fact. Nonetheless, the postnatal groups were much more likely than were the antenatal groups to write something, whatever that something was.

It is legitimate to count and to tabulate each of the categories of themes volunteered by the respondents because that shows what the respondents thought. However, given the high non-response rates it is not legitimate to generalise those findings to a wider population. Therefore, we present tabulations for the achieved sample, but do not test for significance, as the non-response was likely to be a greater source of error than any random effects which significance testing is intended to handle.

## 8.2.2 Topics which were salient to the respondents

The topics to which people paid attention, whether in a positive or negative way, gives an indication of the salience of those topics. If the leaflets had had an effect, one might expect intervention site respondents to talk more about *choice* and *information* in the post-test than in the pre-test period, compared to control site respondents. Had such a propensity been observed, it would have supported the first major hypothesis. (that in intervention sites, the salience of *choice* and *information* would increase, with no such increase in the control sites) Data on this issue are given in Appendix 9, tables 2-4, together with a brief explanation of how the tables should be read.

**Table 8.1: Salience of categories. The percentage of identifiable themes, broken down by main category and by intervention (I) or control (C) group**

Category	Group	Antenatal	Antenatal	Postnatal	Postnatal
		Pre-test	Post-test	Pre-test	Post-test
Choice/Control	I	10.6	10.4	16.4	15.6
	C	11.3	12.6	17.4	18.0
Information	I	37.2	33.9	28.9	31.3
	C	35.7	31.5	28.5	27.9
Personality & Competence	I	18.5	33.9	30.4	35.3
	C	20.8	29.3	31.6	34.6
Service Organisation	I	33.7	21.7	24.3	17.8
	C	32.2	26.6	22.6	19.5

In the pre-test period, antenatal respondents in both intervention and control groups wrote a lot about two major categories of themes: *Information* and *Service Organisation*. There was almost no difference between the intervention and control groups in the proportions of themes falling into these categories. Comments about the *personality and competence* of staff, came third, with *Choice/Control* a long way behind in fourth place.

For the postnatal group in the same period, the rank ordering was slightly different. Comments on *Personality* ranked first, very closely followed by *Information*. *Service Organisation* was relatively close behind and once again *Choice/Control* was a long way behind in fourth place.

For the main question of the study, the initial results for both the antenatal and postnatal groups indicate that the question of *Choice/Control* was not a major issue in the minds of the women. However, *Information* was, by a factor of two or three. **This suggests that any future conceptual framework should clearly distinguish the two.** Women appear to want to know the facts about their pregnancy even if most of them are not particularly concerned about who makes the final decision about possible clinical and other actions. Given the salience of *Personality & Competence* and *Service Organisation*, one might well do more to improve the perceived experience of women by implementing targeted staff training or selection policies, or by doing something about delays in appointments or the delivery of test results, than by concentrating attention and effort on the concepts of choice and control.

The differences on pre-test between the antenatal and postnatal groups were noticeable, if not dramatic. Although *Choice/Control* was the smallest category for both groups, it was some six percentage points higher in the postnatal group. For the *Personality* category, the postnatal group was some 12 percentage points higher. This was reflected in the fact that for the postnatal group, the *Service Organisation* element was some 10 percentage points lower, and *Information* some 7 points lower. It should be stressed that, whatever the pre- post test movements were, *Choice/Control* still remained the least frequently mentioned category.

An important comparison is that between the intervention and control groups. Of the eight possible comparisons between the intervention and control groups at pre-test, the *largest* difference between the

two groups was 2.3 percentage points. (*Personality* category, Antenatal group), which is dramatically lower than we obtained with experiments using manual coding (where we found differences of up to 40% due to coder variability). This remarkably consistent performance should give confidence both in the success with which the random sampling was done, and in the efficacy of the automatic coding which was undertaken. When you have a large group of undifferentiated women allocated at random to intervention or control status and their statements are coded automatically, it would have been unsurprising if the differences had been large. The fact that they turned out to be so small is very encouraging, and suggests that the automatic method adopted does capture a lived reality.

### 8.2.3 Changes over time in salience

The coding was undertaken at two points in time for each group. Indeed, a major purpose of the exercise was to see whether there was a change in the distribution of categories between the original and follow-up measures. If the leaflets had an effect, one would expect the proportion of responses in the intervention group to move from the *Personal* and *Service Organisation* categories towards the *Choice/Control* and *Information* ones, but with no such movement in the control group. The details are given in Appendix 9, table 4, which is reproduced here. Please note that these changes are expressed as percentage *points*, not as percentages.

**Table 8.2: Salience of different categories: Changes in percentage point distribution between pre- and post-test**

Category	Group	Antenatal	Postnatal
Choice/Control	I	-0.2	-0.7
	C	1.3	0.7
Info	I	-3.3	2.4
	C	-4.1	-0.6
Personality & Competence	I	15.4	4.9
	C	8.4	3.0
Service Organisation	I	-12.0	-6.6
	C	-5.6	-3.1

The picture in this case is not as clear-cut as in the simple analysis of the pre-test data. The movement is quite varied, from a decrease of 12.0 points (*Service Organisation* category, intervention group, antenatal) to an increase of 15.4 points (*Personality & Competence* category, intervention group, antenatal). All the other movements were small, being less than 10 percentage points in either direction.

As far as the study hypothesis is concerned, the intervention appears to have had little effect. The major movement was in the two categories which one would not have expected to be influenced by the intervention (*Personality & Competence* and *Service Organisation*) with a movement from the latter to the former. However, even this movement was relatively small, and, more importantly, it occurred in both the intervention and control groups.

As far as the two categories which one would have hoped to influence (*Choice/Control* and *Information*) the most striking feature was how little movement there was. The largest movement was a decrease of 4.1 points (*Information* category, Control group, antenatal). We had expected (if the hypothesis was correct) a substantial and consistent movement in the first four rows of the table above, with a large positive figure for the intervention groups. Three of the four relevant movements were actually negative, and the positive one was only 2.4 points. The fact that the movements were so small suggests strongly that the intervention had little or no effect on the sorts of choice and information issues which our respondents chose to raise.

### 8.2.4 Was the effect positive?

Of course, the purpose of the intervention was not merely to make women more aware of issues of choice and information. As we have seen, it did not appear so to do. However, it is quite conceivable that women were no more or less aware of the different issues, or at least continued to rank them in a similar order over time, but have a different attitude towards each of them. In that case, they might still be more interested in issues of service provision or the personal qualities of the staff who deliver such services, but nonetheless change their attitude or opinion on the other (to them minor) issues of choice and information.

We therefore attempted to assess the tone of every theme offered. There were a small number (under 1%) of the meaningful themes to which a tone could not be assigned. Those are not included in the data provided. For all the others we assigned a tone of Positive or Negative. The data, both raw and processed, are provided in tables 5 and 6 in Appendix 9. We here reproduce a summary table. The final column (N) is included to remind the reader that the actual number of comments on different categories varied markedly, with *Information* being the most commonly mentioned, and *Choice/Control* being by far the least commonly mentioned one.

**Table 8.3: Positive-negative judgements (All respondents combined)**

Category	Group	Pre %	Post %	Percentage	N
		+ve	+ve	Point Change	
Choice/Control	I	43.4	43.1	-0.3	829
	C	42.7	45.1	2.3	
Info	I	44.9	52.7	7.8	1900
	C	49.2	51.4	2.2	
Personality & Competence	I	73.4	76.8	3.4	1726
	C	76.8	76.9	0.1	
Service Organisation	I	34.0	42.3	8.4	1483
	C	33.0	44.3	11.3	
Overall		49.8	56.3	6.4	

The first thing to note is that the degree of positive judgement expressed varied dramatically from category to category. Comments on the personal qualities and competence of staff delivering services (and recall that this *excludes* the very large number of vague and general 'it was all wonderful' comments) were by a large margin the most positive recorded, with about three-quarters of those who commented on the qualities of their carers doing so positively. The *Service Organisation* elements received the least positive response, with *Choice/Control* and *Information* holding a middling position with about 45% positive judgements. In trying to come to an overall judgement, one has to bear in mind that each comment was analysed on two dimensions: salience and evaluative tone. Thus, at pre-test, *Information* mattered to the women, but fewer than half their comments about it were positive. By post-test, it still mattered, but the judgements had become rather more positive. *Choice/Control* did not matter so much to them, fewer than half of them gave it a positive evaluation at pre-test, and this evaluation did not change after the intervention.

Secondly, as in our previous analyses, whatever the movements may be between different points in time, at a given point in time the judgements are remarkably consistent. For any given category, the largest difference between the intervention and control groups was 4.3 percentage points at pre-test, and 2.0 at post-test. Once again, this gives one some confidence in the method adopted.

However, the important question is not how did the proportions of positive judgements vary at either pre-test or post-test, but how they varied *between* pre- and post-test. Overall, the proportion of positive



judgements increased by 6.4 percentage points, from 50% to 56%. This increase was not uniform between the categories. By far the largest change in the positive direction was in the *Service Organisation* category, with the intervention group increasing by 8.4 percentage points and the controls by 11.3 points. Given that the increase was larger for the controls, it is not possible to attribute this to the intervention. It should also be noted that the scope for a change in a positive direction was greatest for this *Service Organisation* category as it was by a fair margin the least positively rated at pre-test.

#### **8.2.4.1 Information specifically**

When we turn to perhaps the most important category for the purposes of the study (*Information*), the picture is more encouraging for the intervention. In this case, the intervention group increased by 7.8 percentage points. True, the controls also increased by 2.2 points, but it does appear that the use of the leaflets was associated with a slight tendency for the intervention group to make statements about *Information* elements which were more positive. One should not exaggerate this movement. Had the intervention been a dramatic success one might have expected that the proportion of positive judgements about *Information* elements to have risen from the original 44.9% to, say, 70% or above. In fact, they increased to 52.7%. The increase was modest, but it appears to have been real.

It should be noted that this increase was not uniform between the two samples (antenatal and postnatal). The effect seems to have been most marked for the antenatal sample, in which the intervention group gained 12.2 percentage points i.e. became noticeably more positive in their judgements after the use of the leaflets. In this gain they were mirrored, albeit at a rather lower level, by the controls, who made a 6.1 point gain. So, even though there was a positive movement overall, it was more marked for the intervention group.

In the postnatal group, there was a slight positive movement for the intervention group (2.2 points) and a slight negative movement for the controls (1.3 points). We interpret this as showing that for the postnatal respondents the use of the leaflets had little effect overall.

One thus has a rather mixed picture. There was a slight increase in positive statements about *Information* in the intervention group (but not about *Choice/Control*). However, the most substantial movements towards a more positive judgement came in the category *Service Organisation*, and even there the increase was greater for the control group respondents. To obtain such an increase was not a purpose of the study, and we cannot see how the provision of leaflets might have led to such a result.

#### **8.2.4.2 Choice/Control specifically**

It is thought that choice and information are related and one might have expected the judgements of these two categories to have been similar. This expectation was borne out for the controls, for whom the modest increase in the proportion of positive judgements was almost identical for both *Choice/Control* and *Information* (2.3 cf. 2.2). However, for the intervention group this was not the case. As noted above, for *Information*, the proportion of positive judgements increased by 7.8 points. However, for *Choice/Control*, they decreased very slightly (0.3 points). Thus, it appears that the use of the leaflets may have made judgements about *Information* more positive to a modest but useful degree, but had no similar effect on judgements about *Choice/Control*.

Thus, from our initial analysis of the free-text data, one has to conclude that the effect of the Informed Choice leaflets was

<b>For the “Informed” element</b>	<b>real, but small</b>
<b>For the “Choice/Control” element</b>	<b>nil</b>

This is fortunate, because the *Information* element is the one which is most frequently mentioned by the women. However, concentration upon this element should not obscure the fact that women were concerned about the personality and competence of their carers to almost the same degree as they were about information. Although the positive comments about personality matters did increase only slightly among the interventions (and not at all among the controls), this is less serious, since positive attitudes in that area were high in both the pre- and post-tests.

Similarly, the organisation and delivery of the service was a matter of considerable concern to the women. The positive judgements made on this issue were by a clear margin much lower at the pre-test stage than for the other categories, but increased markedly during the course of the study.

### 8.2.5 Quotations

It is normal in a qualitative analysis to include direct quotations to give the reader a feeling of reality and vividness. This is a reasonable thing to do, as long as the quotations provide a fair reflection of the totality of the views expressed by respondents. If they are merely selected according to the researcher's interests and preconceptions and do not reflect that totality, then the vividness of the quotations do a disservice, because they leave the reader with a feeling which is at variance with what was found.

To try to give a feeling of reality, we give below some quotations from respondents. Some of them contain only one theme, and would receive one code; others contain more than one theme, and would receive more than one code. The fact that we indicate only one code in the list below does not mean that only one code was allocated. Such cases are marked "inter alia".

To try to avoid the danger of vividness giving the reader a misleading impression of the totality of the results, we have included two positive and two negative quotations under each of the four major headings, even if that does not reflect the empirical frequency of responses. We would, however, stress that the true overall picture is given in the tables, not in the quotations. They are included for information and illustration only. Any spelling and grammatical errors are retained from the original data set provided (e.g. the word "them" in quotation 4 clearly means "than") to enhance the reflection of the reality which we encountered.

"They didn't explain the positions I could go in labour"	Information Negative
"I was not given a lot of information about my epidural whether what would happen if anything went wrong"	Information Negative
"Most points I had made on my birth plan were adhered to the care and advice from the midwives after delivery was excellent they were informative without being bossy"	Information Positive (inter alia)
"I feel I had more advice after care etc than I did with my first pregnancy e.g. should I consider an epidural this time as one of the babies may be breech – I was happy to go along with what the experts advised after discussion"	Information Positive (inter alia)
"Was not in control to make a definite choice. Was certain I wanted to breast feed"	Choice/Control Negative
"I wanted an epidural and was told I would have to wait 30 mins as the anaesthetist was busy so I declined methpid injection saying I would wait. I was flat on my back on a bed strapped to a monitor 45 minutes later my baby was born."	Choice/Control Negative
"I definitely knew my own mind especially breast feeding and not wanting epidural. (Or episiotomy unless absolutely necessary). I was able to leave hospital when I was ready and my community midwife came into hospital to deliver my baby"	Choice/Control Positive
"I am extremely satisfied with the way things went during labour due to past experience I was offered elective caesarean or induction. I choose induction and my wish was granted to try for a vaginal delivery and succeeded"	Choice/Control Positive
"I was given a pessary on a Thursday morning expecting another after 12 hours but due to a lack of staff and the fact that there were more women in labour than expected that night the 3 of us had to	Service Organisation Negative

wait until Fri a.m. for the next one.”

“Midwife forgot to book an appointment in the appointment book for a heel prick test, I waited in all morning and rang the hospital to be told that no appointment had been made for me in the main book”

Service Organisation Negative

“My community midwife was very helpful always came at the time she said she would and provided all the information I needed. Hospital staff were very thorough with all my checks.”

Service Organisation Positive (inter alia)

“The community midwife who visited me after I went home was excellent she reassured me about things and gave me all the right advice. She also kept to appointment times.”

Service Organisation Positive (inter alia)

“Attitude of midwives (not all) towards problems during breast feeding. A better support system should be in force for mothers who are having any problems for whatever reason with breast feeding.”

Personality Negative

“We couldn’t find our way into the hospital and delivery suit – (our baby was born less than hour after arriving) and emergency call button would have been helpful. The midwife delivering our baby was spending too much time just observing and writing notes”

Personality Negative (inter alia)

“My baby got very stuck once head was born and everything was very stressed for while even though there ended up a lot of people in the room my midwife kept talking to myself and my husband and reassuring us”

Personality Positive

“Midwives in hospital and in clinic were so nice and helpful and friendly one midwife in the hospital even stayed after her shift to help me deliver my baby.”

Personality Positive

We hope that the quotations above give a flavour of what the women actually wrote. A striking feature of the data set was that in general the negative comments tended to be longer and more detailed, whilst the positive ones were briefer and more general. Some of the stories, however we interpret them in terms of the study hypotheses, were heart-rending and at times shocking. However, these were very much in a minority, and to have included them in the list of illustrations above would have been to run the risk of a spurious vivid negativity which would have given a misleading impression of the totality of the womanise’ experience.

### 8.2.6 Are choice and control the most important topics to study?

Choice is a concept which is very fashionable among academics and politicians. It is acknowledged that choice is a meaningless concept unless the chooser has a substantial fund of accurate and relevant information. Thus, choice and information are often seen as naturally linked and are, as it were, two facets of the same coin. However, what the women wrote on their questionnaires suggested that the personal qualities and competence of their carers, especially of midwives, were more important to them than the more fashionable themes, and that a variety of aspects of service provision were both of concern and were judged to be inadequately provided.

## 8.3 SUMMARY POINTS

Of course, the problem of sampling remains. Those who wrote comments on the questionnaire were volunteers, and represented only just over half of the antenatal group and only three-quarters of the postnatal group. We know only a little about how well they represent the total population of pregnant

women and recent mothers. That, however, is another question. For those who did respond, it appears that:

1. Choice/Control was not a major expressed concern of many of them .
2. Information was an important concern, but less so than the personal characteristics and competence of the staff who cared for them, and than the organisation of the service provided combined.
3. Many of the expressed satisfactions were of a vague and general kind.
4. The intervention group did not change during the course of the study in their propensity to make positive comments about the Choice/Control elements in their attitude to the care received, nor did they do so more than the control group.
5. The intervention did increase the proportion of positive comments about information elements, and exceeded the change within the control group. However, the difference was modest.

The method which we adopted is still undergoing further testing and refinement. In a study in which it was the central mechanism one would have formally tested its reliability and validity. In practice, in the current study the remarkably small variations between groups at pre-test which it produced gives a measure of its reliability. The fact that the conclusions which it led us to draw were so close to those which came from the quantitative RCT gives a measure of its validity. Our confidence in the method has been reinforced, and we intend to develop it further.

Overall, from the data which we received, and the analysis which we undertook, we were forced to conclude that the leaflets which were used, delivered in the way that they were delivered during the study, had no effect on womanise' feelings of being in control, and little effect on their feeling that they had all the information that they required.

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## Chapter 9: The Economics of Leaflet Use in the CRCT

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### 9.1 GENERAL INTRODUCTION

The focus of this study was on the process of maternity care rather than on clinical outcomes. Although the key issues in the study were not economic, the provision of leaflets is clearly not costless and it was anticipated that their use might influence subsequent use of maternity care resources. Thus while a full economic appraisal was not attempted, resource use was monitored in order to indicate any effects which leaflet use might have on the immediate maternity budget.

### 9.2 COST OF LEAFLETS

We have not attempted to estimate the economic cost (value of resources) of producing the leaflets. MIDIRS charge 15p per leaflet (women) and 30p per leaflet (midwife).

### 9.3 TRAINING COSTS

Midwives in intervention hospitals were trained in the use of leaflets by MIDIRS staff. Six two-hour training sessions took place. The mean number of midwives attending each session was 14.5 (SD = 4.09, range = 10 –21).

Not all midwives in intervention hospitals received training. Although this may affect the explanatory aspects of the intervention it does represent pragmatism in the sense that in normal use it is unlikely that all midwives will be able to attend training sessions. The costs per trainee are thus more representative of reality than if training during the trial were more tightly controlled.

Cost of each session was made up of the trainers costs and the opportunity cost of trainee time. Trainer cost was based on charges by MIDIRS (£250 per session) which covered trainers' time plus travel costs. Trainee cost was based on two hours of midwife time valued at hourly gross employment cost of an E Grade midwife. Overhead charges for the training rooms have been ignored.

On this basis, the mean cost of each session was £566.23 (SD = £88.84, range = £467.40 - £706.54). Total training cost was £3397.38 (£566.23 x 6). This equates to £39.05 per midwife or £0.40 per woman in the intervention arm of the trial. As training is an investment, the per woman training costs will fall as increased numbers of women are seen by each trained midwife and will eventually fall to near zero.

### 9.4 DIFFERENTIAL USE OF RESOURCES

The principal economic question in this study was whether the intervention led to significant differences in resource use.

#### 9.4.1 Subjects and methods

Resource use data was obtained from questions in Section C of the antenatal and postnatal questionnaires sent at 28 weeks gestation and 8 weeks after delivery respectively. Descriptions of the questionnaires are given in Chapter 7 of this report and a copy of each questionnaire is provided in Appendix 2a.

This method of data collection relies on patient recall. It was chosen over scrutiny of case notes because of greater comprehensiveness (scrutiny of notes could only be done on a sample of participants),

supported by considerable evidence of good agreement on resource use between recall and medical record data (see below). A validity exercise assessing questionnaire data against a sample of case notes was undertaken and is reported in section 9.5 below.

### 9.4.2 Statistical analysis

An indication of heterogeneity between hospitals can be gleaned from Tables 1-7 in Appendix 10A which present before and after data on six resource use variables (number of scans, blood tests, amniocentesis tests, CVS tests, planned place of birth, heart monitoring and epidural) on a hospital by hospital basis.

The main analysis concerns the differences in before and after *changes* in mean resource use between women in control and intervention groups. Apart from number of ultrasound scans, all data are dichotomous variables referring to single events (yes/no e.g. amniocentesis) although a third option 'don't remember' was included for each question. Data on number of scans is continuous.

Initial analysis was performed on all data. In order to take account of within sample difference, a multi-level modelling exercise on adjusted values (adjusted for age, educational status, parity, and preference for participating in decision-making) was also performed.

### 9.4.3 Results

Before and after changes in resource use were broadly similar between women in intervention and control hospitals. Statistically significant between group differences were shown for only two variables; the proportion of women having blood tests for Down's syndrome and spina bifida ( $p < .05$ ) and the number of planned hospital births ( $p < .05$ ). In the first case the observed difference was due to a 4% reduction in blood testing in the intervention group being assessed against a 6% *increase* in blood testing in the control group during the intervention period which is discussed in the CRCT findings. As statistical significance was a result of this increase in testing on the control side, a degree of caution is needed when considering the resource implications of the intervention. Results are shown in Table 9.1 below.

**Table 9.1: Change in proportion of women reporting resource use**

Resource variable	% change (intervention)	% change (control)	Mean Difference	95% CI	Wilcoxon	t-test
Had a scan	0.00	0.00	0.00		0.22	ns
Mean no. of scans	-0.01	0.13	-0.14		0.31	ns
Had screening test	-0.04	0.06	-0.10	-0.20, 0.00	0.03	<0.05
Had amniocentesis	0.01	-0.01	0.02		0.15	ns
Had CVS	0.00	0.01	-0.01		0.42	ns
Planned hosp birth	-0.02	0.00	-0.02	-0.04, -0.01	0.02	<0.05
Had EF monitoring	-0.03	0.00	-0.03		0.84	ns
Had epidural	0.03	0.02	0.01		0.69	ns

#### 9.4.3.1 Results of multi-level modelling

A full explanation of the multi-level modelling exercise is given in Chapter 7 of this report. With regard to the significant differences in resource use reported above, the modelling exercise showed similar results when an adjustment was made for age, educational status, parity and preference for participating in decision-making. However, in the case of the two remaining variables, statistical significance disappeared when the adjustment was made (planned hospital birth  $p=0.2$ , blood test  $p=0.06$ ).

## 9.5 RESULTS

### 9.5.1 Antenatal data

Table 9.2 shows cross-tabulated data on screening for spina bifida or Down's syndrome. Both methods gave the same results and the Kappa statistics was therefore 1.0 (perfect agreement).

**Table 9.2: Screening for spina bifida or Down's syndrome by method**

	Hospital Notes		Total
	Yes	No	
Questionnaires	49	-	49
	-	5	5
Total	49	5	54

With respect to ultrasound, normal practice involves at least one scan. Unsurprisingly, therefore, perfect agreement was shown between methods to the question 'did you have a scan?' Of greater interest was agreement in the continuous data.

**Table 9.3** below describes the cross-tabulation of continuous data:

Questionnaires	Hospital Notes					Total
	2	3	4	5	7	
2	21	8	1	1		31
3	5	8	3			16
4	1	2	1			4
5			2			2
6					1	1
Total	27	18	7	1	1	54

Analyses of continuous variables frequently show cross-tabulations with a non-symmetric pattern spread. To overcome this, the data were transformed into the following classes.

**Table 9.4: Number of scans grouped in classes**

Questionnaire	Hospital Notes			Total
	2	3-4	>4	
2	21	9	1	31
3-4	6	14		20
>4			1	3
Total	27	25	2	54

Pairwise agreement = 0.67

Kappa statistics = 0.38

The choice of classes size is clearly important as enlarging the classes will increase the level of agreement (Landis and Koch 1977). According to the Landis and Koch scale, the above kappa statistics shows a 'fair' agreement between the two data collection methods. However, of greater interest is whether these discrepancies lead to any consistent under or over-estimation of resource use.

A more straightforward way of comparing resource use between methods is by comparing the mean estimation. Table 9.5 below shows no significant difference in means.

**Table 9.5: Number of scans according to the data source**

	Questionnaires		Hospital Notes		p value*
	Mean (SD)	95% CI	Mean (SD)	95% CI	
Number of scans	2.63 (0.91)	2.37 – 2.88	2.74 (0.97)	2.47 – 3.00	n.s.

\* = paired t-test  
 p = 0.335  
 95% CI = -0.3402, 0.1180

### 9.5.2 Postnatal data

Tables 9.6, 9.7 and 9.8 below report the results for three drugs used during labour.

**Table 9.6: Use of entonox**

Questionnaire	Hospital Notes		Total
	No	Yes	
No	10	6	16
Yes	13	43	56
Total	23	49	72

Pairwise agreement = 0.74  
 Kappa Statistic = 0.34  
 McNemar test: n.s.

**Table 9.7: Use of pethidine**

Questionnaire	Hospital Notes		Total
	No	Yes	
No	29	6	35
Yes	5	32	37
Total	34	38	72

Pairwise agreement = 0.85  
 Kappa Statistic = 0.69  
 McNemar t-test: n.s.



**Table 9.8: Use of epidural**

Questionnaire	Hospital Notes		Total
	No	Yes	
No	55	5	60
Yes	4	8	12
Total	59	13	72

Pairwise agreement = 0.88

Kappa Statistic = 0.57

McNemar Test: n.s.

All resource variables showed 'good' pairwise agreement. The McNemar test showed no differences between under-reporting and over-reporting and the Kappa statistics show 'good' agreement for use of pethidine and epidural and 'fair' agreement for use of entonox.

## 9.6 POSSIBLE BIASES

### 9.6.1 Recall bias

Recall bias occurs if one group's recall is consistently different from the other. Such recall bias would tend to produce over-estimates if recall by intervention group is superior, and under-estimates if recall by intervention group is inferior as compared with controls. In terms of the present study this would mean that the distribution of the leaflets might affect women's ability to remember the events which occurred.

In order to test this for recall bias, a comparison between the number of women who reported 'do not remember' in the questionnaires for some resource variables was made. The cross tabulation showed no statistical significance for any of the variables, which included the answer 'not sure'.

One notable omission with respect to scan recall was that so-called 'mini' scans were not recorded in women's case notes. These scans were used by some obstetricians during routine antenatal consultations to determine the position of the baby and to auscultate the heartbeat. Women also tended to accept such scans as routine clinical procedures. On the occasions that 'mini' scans were undertaken in the context of routine, antenatal care, under-reporting is likely to have occurred because they were taken for granted by all parties. As a routine intervention in maternity care, many scans were thus rendered invisible.

### 9.6.2 Response bias

Differences in response rates between groups can also introduce bias. This was not the case here. Baseline antenatal response rates were 66% intervention v. 64% control and after intervention were 67% intervention v. 64% control. Baseline postnatal response rates were 62% intervention v. 66% control and after intervention were 64% intervention v. 59% control.

## 9.7 CONCLUSION

The above results are consistent with those of previous studies and in some cases showed even better agreement, although this could be due to the present study involving a relatively short period of recall. Good performance on the questionnaire also reflects questionnaire protocol with most questions not requiring quantification. Where questions were felt to be potentially too technical, simple descriptions were added in brackets.

The intervention did not appear to have any effect on resource use. Trends towards lower use by the intervention group in terms of ultrasound scans, blood tests for spina bifida and Down's syndrome, fetal monitoring and planned hospital birth were detected, but when adjustments were made for age and other social factors, no statistically significant differences in any resource variables remained.

This can be contrasted with related studies, for example, Thornton et al (1995), which demonstrated that provision of additional information - in that case from individual or group sessions with a midwife rather than by leaflets - reduced the number of screening tests. This was especially so when the baseline rate for screening was high, as was the case in our study. Resource use, however, was not a primary outcome in the present study and the absence of significant differences in resource use might have been due to the study having been under-powered.

The overall conclusion is thus that postal questionnaires are a reliable way of gathering information on maternity services and their use for between group comparisons in this study are justified.

As stated above this study was primarily about the process of maternity care and not about clinical outcomes. However, it is important that the consequences of leaflet use are considered in the context of the costs of bringing them about. These would include the direct costs of the leaflets themselves and of training midwives in their use, plus any effects which they might have on subsequent resource use.

The economic investigation, however, suggests that use of leaflets does not significantly affect resource use. The cost to each maternity hospital is thus only the direct costs of their provision. For each midwife this is 30p for a leaflet plus £39 for training. Training, however, represents an investment which on a cost per woman basis will eventually fall to near zero as it is spread over more and more women over time.

## **9.8 SUMMARY POINTS**

- There was some evidence that the intervention resulted in a decrease in resource use in some of the key variables. However, when adjustments were made for age and other social factors in multi-level analyses, none of these trends showed statistical significance.
- The only attributable costs of the intervention are thus the direct cost of their purchase (15p per leaflet per woman, 30 per leaflet per midwife) and training (£39 per midwife equating to 40p per woman). This investment cost per woman, however, when spread over a sufficient number of women will fall to near zero.
- Use of leaflets does not significantly affect resource use. The one-off cost of training midwives in the use of the leaflets is low and when spread across a large number of women represents a low cost per woman. The only significant cost of the intervention is the cost of the leaflets themselves, which, although low on a per leaflet basis, can represent a significant cost to a hospital with a high number of deliveries.

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## Chapter 10: Measures of Knowledge

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This chapter presents the findings from knowledge questionnaires administered to a) midwives working on the CRCT sites and b) to a selected cohort of women with a breech presentation at term. The same questionnaires were used as were sent to service users who participated in the CRCT (see Appendix 3).

### 10.1 MIDWIVES

#### 10.1.1 Introduction

The researchers sought to measure midwives' knowledge on the ten topics of the MIDIRS Informed Choice leaflets. Previous research (Dyke 1998, Dyson et al 1996, Mulliner et al 1995, Smith et al 1994) has revealed that midwives lack knowledge in subject areas widely considered to be fundamental to the provision of midwifery care. In addition to measuring midwives' knowledge, the researchers wished to make comparisons between different groups of respondents, such as midwives and women (see Tables 10.1 and 10.2). Comparisons between midwives working on control and intervention sites was not possible because the relevant data were not consistently collected for both groups.

#### 10.1.2 Development of the knowledge questionnaires

A ten-item multiple choice questionnaire was devised from the women's version of each of the ten Informed Choice leaflets. The researchers decided to use only the simplified women's version of the leaflets for this purpose so that comparison of knowledge levels between midwives and service users would be possible. Thus, ten separate questionnaires, each containing ten multiple choice questions, were formulated and printed on different coloured paper. As mentioned in Chapter 7, two of the knowledge questionnaires were inserted into the CRCT postal questionnaire to service users. The researchers working in the CRCT units approached midwives directly and asked them to complete the questionnaires. Other health professionals were not invited to participate in this exercise.

##### 10.1.2.1 Piloting the questionnaires

The questionnaires were piloted with final year student midwives and with two different groups of midwives attending local study days. As described in Chapter 7, they were also piloted with service users and were sent to members of the project advisory group. Minor adjustments were made following feedback from these sources.

#### 10.1.3 Completion of the knowledge questionnaires

Qualified midwives, who were in clinical practice, were the only group of health professionals invited to participate in this exercise. The researchers approached midwives on all sites and, workloads permitting, asked them to complete as many knowledge questionnaires as they could, in the time they had available. In the event, the majority of midwives approached in this way completed the full set of 10 questionnaires (which totalled 100 separate, multiple choice, questions). Midwives from the research sites attending national study days were also invited to complete questionnaires and the majority generously gave of their limited time to complete at least some questionnaires during lunch and tea breaks.

All knowledge questionnaires were completed under examination conditions with the researchers acting as invigilators. The fastest time recorded for a midwife to complete the full set of (ten) knowledge questionnaires was 25 minutes and the slowest required more than an hour.

### 10.1.3.1 Midwives' responses whilst they completed the knowledge questionnaires

On the occasions when midwives completed the questions in a group situation, protests and complaints about the nature of the questions, and the state of the midwife's knowledge, often provided a running commentary for the first five or ten minutes. Many midwives expressed irritation when they encountered questions which suggested an alternative to the local policy. A number of midwives seemed to experience great difficulty in distinguishing between what they normally did in response to local policies, and what they might otherwise choose to do, given the opportunity to do so.

It is acknowledged that midwives working in specialised areas of clinical practice may have been disadvantaged by some of the knowledge questions; for example, many core staff who held permanent posts on CDS or in antenatal clinic complained that they knew little about *'the other end of pregnancy'*.

### 10.1.4 Scoring the knowledge questionnaires

The same scoring system was used for midwives and service users. Each knowledge questionnaire was scored by allocating a score of one for each fully correct answer; scores thus ranged from 0-10 for each of the knowledge questionnaires.

### 10.1.5 Results

1. Health professionals scored between 5 and 8 points out of 10 for the ten topics covered by the leaflets (Table 10.1).
2. Health professionals in intervention sites scored higher than those from control sites for ultrasound scans, screening for spina bifida and Down's syndrome, alcohol, support, feeding and breech (Table 10.1).
3. Health professionals scored higher than women for nine of the ten leaflets (Table 10.2). For the breech presentation leaflet, the number of women completing the knowledge questionnaire was small and therefore the power to detect a difference was low. In addition, midwives had the lowest score for this leaflet.

#### Caution

The data are clustered but this clustering has not been taken into account. The cluster information for the midwives' knowledge scores was not collected in full for all midwives completing questionnaires and therefore could not be used. Analysing clustered data without taking the clustering into account can result in statistically significant findings when there are no real differences. Thus, caution should be applied when interpreting these results. This concern is probably not relevant to the comparison between midwives and women because the differences between these groups are so large.

**Table 10.1 Comparison of midwives' knowledge scores in intervention and control sites**

Leaflet	All midwives		Intervention		Control	
	Mean (sd)	Number	Mean (sd)	Number	Mean (sd)	Number
Scans	6.4 (1.63)	273	6.6 (1.54)	154	5.9 (1.72)	83 ***
Downs <sup>1</sup>	5.7 (1.81)	230	6.0 (1.81)	128	5.2 (1.71)	65 **
Where	5.6 (1.81)	290	5.8 (1.78)	160	5.4 (1.76)	93
Alcohol	5.8 (1.67)	229	6.0 (1.62)	130	5.4 (1.80)	63 *
Positions	7.1 (1.45)	276	7.2 (1.43)	155	7.1 (1.60)	83
Epidurals	6.0 (1.93)	235	6.3 (1.91)	124	6.0 (2.05)	78
Support	6.2 (1.91)	262	6.4 (1.88)	145	5.7 (1.99)	80 *
Heartbeat	7.4 (1.46)	268	7.3 (1.59)	148	7.6 (1.38)	85
Feeding	5.4 (1.95)	262	5.8 (1.85)	143	4.9 (1.92)	83 ***
Breech	5.1 (1.57)	195	5.3 (1.61)	103	4.6 (1.46)	56 ***

\*p<0.05, \*\*p<0.01, \*\*\*p<0.005

<sup>1</sup>An abbreviated descriptor is used throughout the quantitative study. For example, this leaflet includes information on screening for spina bifida (See Appendix 1 for the full titles of the leaflets).

**Table 10.2 Comparison of midwives' and women's knowledge scores**

Leaflet	All midwives		All women	
	Mean (sd)	Number	Mean (sd)	Number
Scans	6.4 (1.63)	273	3.8 (1.85)	783 ***
Downs <sup>1</sup>	5.7 (1.81)	230	3.8 (1.78)	673 ***
Where	5.6 (1.81)	290	3.5 (2.05)	882 ***
Alcohol	5.8 (1.67)	229	4.5 (1.70)	771 ***
Positions	7.1 (1.45)	276	4.8 (1.95)	590 ***
Epidurals	6.0 (1.93)	235	2.8 (2.03)	623 ***
Support	6.2 (1.91)	262	3.6 (1.93)	598 ***
Heartbeat	7.4 (1.46)	268	2.3 (1.67)	618 ***
Feeding	5.4 (1.95)	262	3.9 (1.69)	623 ***
Breech	5.1 (1.57)	195	5.3 (1.61)	69

\*\*\*p<0.005

## 10.1.6 Limitations

### 10.1.6.1 The shortfall in the number of knowledge questionnaires completed

The researchers had originally hoped for a 90%+ return rate from the midwives' sample but this proved impossible to obtain. In the event, only approximately 20% of the total number of eligible midwives completed some of the questionnaires. A number of factors for this discrepancy were identified:

1. overestimating the numbers of midwives attending study days
2. identifying study days too late for a slot to be secured on the agenda to distribute the questionnaires
3. failure to make adequate arrangements with the organisers of study days to access midwives in attendance
4. despite rigorous piloting of the questionnaires, the researchers underestimated the length of time midwives required to complete a full set

It was not until the CRCT was well underway that the researchers appreciated the extent of the pressures on midwives' time. This sometimes meant that midwives had to choose between completing knowledge questionnaires or being interviewed. As the pressures of work left many midwives no option but to be interviewed in their own time, the researchers felt uncomfortable about suggesting that more time be given to complete knowledge questionnaires. An additional problem was that invigilating individual midwives to complete questionnaires was intensely time consuming.

With hindsight, it might have been possible to increase the total sample of midwives completing knowledge questions if individuals had been issued with two or three separate topics, instead of the full set of 10. This approach would, however, have resulted in fewer sets of knowledge questions being completed.

### 10.1.6.2 The scoring system

The scoring system adopted was such that partial knowledge was not credited as the multiple choice answer was marked as either 'right' or 'wrong'. Thus, for instance, where respondents had ticked three options out five as being correct but, in fact, only two of the five were correct, the answer was scored as 'wrong' and no marks were awarded.

It is further acknowledged that the validity of responses is affected by the way in which the measurement scale is constructed. Multiple choice questionnaires are known to be problematic in this area because apparent knowledge is vulnerable to manipulation both in the way questions are worded and the range of possible options made available to respondents. Smith et al (1994) have also suggested that questionnaires which measure knowledge are not necessarily predictive of respondents' attitudes and behaviour towards giving information and suggest that further research is necessary before such links can be made.

### **10.1.6.3 Location of clinical practice**

Midwives who did not rotate through a range of clinical areas and who were not familiar with the current literature on the subject, may have been at a considerable disadvantage in answering questions on some of the topics. Thus, for instance, 'core' midwives who only worked in antenatal clinic or CDS, experienced difficulty in answering questions outside of their area of clinical practice.

### **10.1.6.4 Questionnaire conditions**

The conditions under which many midwives were asked to complete questionnaires were often not ideal and the pressures of time referred to above remained problematic. Midwives attending study days were asked to complete the questionnaires during lunch breaks when they may have been tired and hungry and thus lacking in concentration, whilst midwives who were on duty at the time they were approached by the researchers, had to balance the demands of the workplace.

### **10.1.6.5 Variations in local practice**

Variations in local practices created difficulties for some midwives who were unsure as to whether they should mark the answer they knew to be correct, even though this was not local practice, or to score the answer which reflected local practice but which was incorrect.

## **10.1.7 Conclusion**

As mentioned earlier in this section, the study found that midwives scored higher than women on all topics with the exception of breech presentation where numbers were insufficient to allow statistical comment. (See Table 10.2) There was, however, considerable variation in the scoring for different leaflet topics. For a small number of topics (*heartbeat [monitoring in labour]* and *epidural*) there was a 3-4 point difference between the two groups; for the majority of topics (*scans, where to have your baby, positions and support in labour*) the difference was less than 3 points whilst for the remaining topics (*screening [Down's], alcohol and feeding*) the difference was less than 2 points. These results echo findings from other research in this field with respect to midwives' poor knowledge of the haemoglobinopathies (Dyson et al 1996) and on knowledge about antenatal screening for fetal abnormalities amongst midwives and obstetricians (Smith et al 1994).

Factual knowledge is doubtless essential if the midwife is to meet the demands of daily practice but it is difficult to assess what might be considered as 'good enough' knowledge with regards to clinical practice. Midwives work in a dynamic relationship with women, a number of whom can be expected to raise issues which occasionally require midwives to refer to a book or other source of information, including someone more knowledgeable than themselves. Completed questionnaires can, at best, only assess the static knowledge of the midwife and not her attitude towards facilitating choice nor her willingness to access other networks and sources of information on behalf of women in her care. Nonetheless, it must be remembered that the measures of knowledge were derived from the simplified version of the woman's version of the leaflet and not the more detailed, professional's version. It is perhaps not unreasonable to expect that midwives might have scored closer to 100% than the 50%-70% achieved. The results achieved by midwives completing the knowledge questionnaires might suggest a need for developing an on-going educational programme around the topics of the Informed Choice leaflets. It is unlikely, however, that such programmes will necessarily affect other issues which inhibit information exchange, such as time pressures and health professionals' attitudes.

Some midwives volunteered, during the course of interviews, that they felt increasingly challenged by the amount of information they were expected to dispense to women and, therefore, to be familiar with themselves. A small number of midwives also voiced anxiety when faced with technologically competent clients who accessed the world wide web and brought the results to midwives for critical comment. These issues require wider professional debate and will need to be considered against the continued expansion of the midwife's role and the increasing pressures on her time.

## **10.2 WOMEN WITH A BREECH PRESENTATION**

### **10.2.1 Introduction**

The knowledge questionnaire on breech presentation was not included in the antenatal and postnatal postal questionnaires to women in the CRCT. This decision was made on the grounds that breech presentation is a relatively uncommon event (3-4%; MIDIRS 1997) and thus the vast majority of women could not be expected to be well informed on the subject. For similar reasons, the antenatal and postnatal questionnaires included only a limited set of questions relating to breech presentation. A separate postal survey was therefore undertaken of women known to have had a breech presentation at term.

### **10.2.2 Recruitment**

#### ***10.2.2.1 Recruitment of women during the course of fieldwork***

Women on all the study sites who were known to have (or who had recently given birth to) a baby in the breech presentation were approached by the researchers and asked to complete a questionnaire. Where this was appropriate, such women were also asked if they would consent to an interview. The majority of women thus approached agreed to contribute to the study.

In addition, midwives were asked to refer women with a breech presentation to the research team for possible inclusion in the study. The majority of women approached in this way also agreed to participate. As a more systematic approach to recruitment was not possible and because this is a relatively uncommon event, the numbers of completed knowledge questionnaires on breech presentation towards the end of the intervention period were insufficient to permit statistical comment. As this was an important sub-group with respect to the Informed Choice leaflets, the research team decided to undertake a postal survey of a small group of postnatal service users known to have had a breech presentation.

#### ***10.2.2.2 Recruitment of women for the postal questionnaire***

Towards the end of the intervention period, Heads of Midwifery in all participating units were thus approached and asked if the labour ward birth register could be accessed for the purpose of identifying a postnatal sample of women known to have had a baby in the breech presentation at term. All but one unit, an intervention site concerned about issues of confidentiality, gave the researchers permission to access the information required. Five of the units preferred to undertake the search themselves and subsequently forwarded a list of women, who fulfilled the agreed criteria, to the research team. The units were asked to include only women with a singleton pregnancy and a confirmed breech presentation prior to the onset of labour. It was intended to exclude women who were pre-term (37 weeks), who commenced labour with an undiagnosed breech or whose baby was subsequently admitted to SCBU. Some difficulty was experienced in ascertaining whether the breech was confirmed at the onset of labour as this information was not always recorded in the labour ward register (as opposed to the woman's labour records which were not accessed). Written comments from a small number of respondents suggested that the sample included some women with an undiagnosed breech presentation.

#### ***10.2.2.3 The postal questionnaire***

The postal survey asked women about their perceptions of choice, information, whether they felt they were given sufficient time for discussion and whether they had received an Informed Choice leaflet on breech presentation. Also included in the survey was the multiple choice questionnaire on this topic (see Appendix 3). Women were also invited to contribute written comments on their experience of having had a breech baby and many did so, often in considerable detail. No reminders were sent.

### **10.2.3 Analysis**

Analysis was undertaken at the individual woman level rather than at cluster level because of the small numbers. Thus any differences found between intervention and control sites will need to be treated with caution.

### **10.2.4 Results** (see Table 10.3 below)

A total of 132 women were sent the questionnaire; 57 were returned and five were returned marked 'address unknown/no forwarding address'. The response rate was 45%. The 57 completed questionnaires were combined with the 12 completed by women during the course of the fieldwork, giving a total of 69. A further eight questionnaires, which were completed by women in the antenatal period, were not included because of the need for a coherent sample. Thus, only the results of questionnaires completed by women in the postnatal period were included in the analysis.

#### **10.2.4.1 Getting the leaflet**

Only 32% of women on intervention sites said they had been given an Informed Choice leaflet compared with 15% in control sites. By way of explanation, a small number of women who received antenatal care on intervention sites, but who were booked to deliver in control sites, may have received a leaflet. More likely, and this is reflected in both the CRCT and the qualitative findings, is that the Informed Choice leaflets made little impression on women and the majority made no distinction between these, and any other information, especially if this was conveyed in leaflet form.

#### **10.2.4.2 Knowledge**

Women scored a mean of 4.2 out of ten for the breech presentation knowledge questionnaire. This did not differ by intervention or control.

#### **10.2.4.3 Informed choice**

There was evidence that more women in the intervention sites felt that they exercised informed choice than in the control sites. However, numbers are small and there was no statistically significant difference.

There was evidence that more women in the intervention sites than the control sites had discussion and choice about breech presentation ( $0.05 < p < 0.1$ ).

#### **10.2.4.4 ECV**

17% of women indicated that an attempt was made to turn the baby. There was no difference between women in intervention and control sites.

#### **10.2.4.5 Written comments**

Women's written comments indicated that whilst many appeared satisfied with their care, a number were dissatisfied with the amount of information they received and because they had felt excluded from the decision making process. This was particularly true for those women who wanted a vaginal birth.

### **10.2.5 Limitations**

- No 'before the event' data was collected
- No analysis by cluster was undertaken
- The sample size was very small, therefore in-depth analysis is not possible and the power to detect differences is low

### **10.2.6 Conclusion**

There were no statistically significant differences between the intervention and control samples.



**Table 10.3: Results of the postal survey of women known to have had a baby in the breech position at term.**

	intervention	control	total
1. Did a midwife give you an <u>informed choice</u> leaflet called <i>Breech Baby; what are your choices</i> ? yes no	10 (32%) 21 (68%)	4 (15%) 23 (85%)	14 (24%) 44 (76%)
2. Did you have enough information and discussion with the midwives and doctors to make an informed choice about the way in which your baby was born? yes no	23 (74%) 8 (26%)	15 (56%) 12 (44%)	38 (66%) 20 (34%)
3. Did the doctor <u>discuss</u> the possibility of turning your baby to the head down position? yes no	19 (61%) 12 (39%)	10 (37%) 17 (63%)	29 (50%) 29 (50%)
4. Do you feel you actually made a choice about the way in which your baby was born? yes no	23 (82%) 5 (18%)	16 (59%) 11 (41%)	39 (71%) 16 (29%)
5. Did the doctor <u>attempt</u> to turn the baby to the head down position? yes no	6 (19%) 25 (81%)	4 (15%) 23 (85%)	10 (17%) 48 (83%)
6. Was this your first baby? yes no	16 (52%) 15 (48%)	18 (67%) 9 (33%)	34 (59%) 24 (41%)
7. Mean knowledge score (SD)	4.2 (1.92)	4.1 (2.00)	4.2



# Chapter 11: The Qualitative Research Methods

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## 11.1 INTRODUCTION

The qualitative research followed a grounded theory (Strauss and Corbin 1990) approach to the data collection and analysis in both phases of the study. This allowed respondents' perceptions of informed choice to be seen in context, whether as health care providers, or as receivers of that care. Data were collected from multiple sources including: non-participant observation<sup>1</sup>, 'natural' (informal) interviews and formal, semi-structured, in-depth interviews. During the CRCT phase of the study, a number of focus group interviews were also undertaken. Extensive fieldnotes, which were written up as soon as possible after the completion of each episode of fieldwork, were analysed alongside the data derived from interviews. Where extracts from fieldnotes appear in the report, they are enclosed within a box in order to differentiate them from direct quotations.

## 11.2 THE RESEARCHERS

A total of five female researchers were in the field during the intervention period. Some discontinuity in the research team was experienced during the early stages of the intervention period as one of the researchers decided to return to clinical practice and difficulties were experienced in recruiting a replacement at short notice. In the event, two midwives were recruited. Four of the researchers were midwives; three lived, and worked, in Wales; one was a Welsh speaker. One of the Welsh based researchers was widely known to many of the midwives participating in the study

The remaining researcher, who was in the field for a brief time and in one geographical area only, was a family physician visiting the UK on a Commonwealth scholarship. She had a long-standing interest in the issue of informed choice in maternity care.

## 11.3 INFORMATION SHEETS

Two separate information sheets about the research project were reformulated from those used during the ethnographic phase; that for the intervention sites mentioned the Informed Choice leaflets whilst that for the control sites did not (see Appendix 5). Contact details for the researchers were included. The project information sheets were offered to all respondents throughout the period of fieldwork and supplies were left with community midwives and midwives working in antenatal clinics.

## 11.4 RECRUITMENT OF PARTICIPANTS

Throughout all phases of the qualitative work, respondents were recruited in a variety of ways. The majority of respondents interviewed were maternity service users (163) and midwives (177); the voices of those who were closest to the wide range of normal childbearing experiences thus made the greatest contribution to the data collection. As the focus of the leaflets was on antenatal and intrapartum events, women were not asked to elaborate on their postnatal experiences, although many spontaneously volunteered such details during the course of the interview.

The researchers had hoped to interview 20% (250) of the total number of employed midwives (1250) working in the CRCT sites. In the event 14% of the sample were interviewed. See Appendix 7 for a summary of the qualitative fieldwork.

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<sup>1</sup> Bloor (1997) has made the point, which held true for this study, that most observational studies include materials that are not wholly, or purely, observational because social norms often require the observer to engage with the respondents, on some level and for varying periods of time, during the course of the observation session. Ignoring these constraints, in the pursuit of collecting 'pure' data, is unwise because of the possible offence this may cause to other parties who may react by withdrawing their co-operation.

#### **11.4.1 Sampling strategies**

The respondent sample was generated in a number of ways including: the 'snowball' effect (whereby an interviewee reported favourably on the experience to a friend, family member or colleague), by convenience, or was purposive in that the researchers actively solicited interviews from respondents. In addition, women's partners and significant 'others' including mothers, sisters and grandmothers also contributed their views, thus helping to achieve balance within a local sample and to ensure the inclusion of 'minority voices' across a broad range of issues.

The researchers were guided in assembling the respondent sample by the concept of theoretical sampling (Glaser and Strauss 1967). This is defined as 'the process of data collection for generating theory whereby the analyst jointly collects, codes and analyses his (sic) data and decides what to collect next' (Glaser and Strauss 1967:45). Thus, the respondent sample constantly evolved in line with emerging theory.

The researchers also engaged in what has been termed 'scrounging sampling' (Grogger et al 1999) by asking midwives to invite selected service users to participate in the research. These were women whom the midwives had described in ways which suggested to the researchers that they might be experiencing pregnancy 'differently'. Thus, a small sample of women with insight into particular situations, but whom the researchers would not otherwise have come into contact with, were recruited. Such women included those opting out of routine interventions such as screening and ultrasound scanning, those booking for home births (especially when this was against medical advice), as well as women who were homeless, who were registered disabled or who had recently given birth to babies with a disability not identified on routine screening.

In addition to these sampling strategies, a sample of community midwives, described by their managers as being excellent in facilitating informed choice, were observed and interviewed, as was a sample of women in their caseloads. This decision was taken following a discussion with the project advisory group in which concerns were aired that the opportunistic nature of the sampling approach could have resulted in only poor, or mediocre, midwifery practice being observed throughout the intervention period. It is acknowledged that the notion of 'excellence' may have been defined differently by women and by the colleagues of the midwives nominated by their managers.

The sampling techniques which were chosen resulted in the collection of a number of special cases and these helped to inform the researchers about specific issues. These special cases generated a number of questions about the concept of informed choice and how this was perceived by both service users and providers. Thus, the data collection was grounded in the experiences of those who were both delivering, and using, the maternity services.

#### **11.4.2 Accessing minority groups**

A brief article was written for 'The Traveller' (a quarterly national journal for travelling families) with an invitation for anyone interested in participating in the research to contact the researchers. This generated a modest response from travellers themselves and health visitors involved with the health and welfare of travelling families.

A city branch of the Lesbian and Gay switchboard were also contacted in the hope that lesbian women could be informed about the research and invited to participate. Unfortunately, this initiative failed to recruit respondents within the timespan of the intervention.

Attempts were made to contact organisations representing disabled people in order to access women using the maternity services but this work was not very fruitful, largely because of time constraints. Two registered disabled service users, referred by community midwives were, however, interviewed.

Six women from minority ethnic populations were recruited to the study, two of whom spoke no English. Female family members translated for the researcher interviewing these participants.

#### **11.4.3 Characteristics of respondents**

The majority of those observed and interviewed were midwives and maternity service users. The focus on midwives was deliberate as they are currently designated the lead professionals where normal pregnancy

and birth are concerned and, in intervention sites, they were almost exclusively responsible for ensuring the transfer of Informed Choice leaflets to service users.

The sample of **service users** included multiparous and primiparous women covering the social class spectrum and the age range for childbearing; they were at all gestational stages and the postnatal sample included women who had given birth within the previous six months. Of the total sample (163) of service users interviewed, 85 were antenatal and 78 were in the postnatal period. A good balance of service users was thus achieved.

The sample of **midwives** comprised managers and clinicians from all grades and with a variety of midwifery experience; they were all employed within the NHS. Midwives in full time, part-time and job sharing arrangements were included and the sample also included midwives who worked in schemes which delivered care in accordance with a variety of different models. Thus, some midwives worked in traditional community, or hospital based, posts and some worked as 'integrated' midwives whereby they worked between the hospital and community. A very small number of midwives held their own caseloads and a few worked in specialist roles such as bereavement counselling, ultrasound or genetic counselling.

A number of **doctors** also participated in the research. With respect to hospital doctors, the researchers concentrated on observing and interviewing consultant obstetricians, registrars and their locums. As SHOs are rarely invested with the authority to make important clinical decisions, they were not invited to contribute to the study. Other hospital-based medical staff, such as radiographers and anaesthetists, who might be expected to have an opinion about selected Informed Choice leaflets, were interviewed, as were a small number of GPs who were directly involved in delivering antenatal care.

In addition, the researchers sought opinions from other health professionals such as non medically trained ultrasound practitioners, non clinical managers, non NHS antenatal educators and representatives from consumer groups.

The gender of the participating midwives was exclusively female as were the majority of ultrasound practitioners. Amongst the medical staff, more men than women occupied senior positions.

The research team were fortunate to include the services of a Welsh speaking midwife during the CRCT phase of the study and thus a number of interviews were conducted in Welsh. A total of 17 service users were interviewed in Welsh.

The researchers were only partially successful in recruiting service users from non English speaking minority ethnic groups or women with special needs. These omissions resulted from language difficulties, time constraints and because the researchers did not have the established networks to readily access groups not accessible by ordinary means.

#### **11.4.4 Access to respondents**

The vast majority of participants granted the researchers access to observe antenatal consultations and to undertake interviews.

Only very occasionally were the researchers refused access and these refusals were almost entirely from obstetricians. Attempts to inform this group about the project, and to invite their participation, used disproportionate amounts of the researchers' time. Whilst the majority of obstetricians agreed to the researchers undertaking observational work, some refused to be interviewed. They did not necessarily refuse outright, but blocked access by not returning phone calls or messages or by telling the researchers that the clinic had finished for the morning or the afternoon, when it clearly had not. The excellent gate-keeping by their receptionists ensured that direct contact by telephone was almost impossible. Despite these problems, the researchers managed to conduct interviews with 17 obstetricians (at consultant, registrar and senior registrar level).

#### **11.5 CONSENT**

The researchers ensured that all respondents who were interviewed had read the information sheet pertaining to the study. Where low levels of literacy made this problematic, the researchers explained the

purpose of the study and the issue of consent orally. On the reverse side of the information sheet was a consent form which respondents were asked to sign before the interview commenced.

### **11.5.1 Problems obtaining informed consent**

The issue of obtaining informed consent in qualitative research has, for some time, presented researchers with a number of ethical dilemmas (Reynolds 1982). The very nature of the ethnographic enquiry defies the researcher's ability to define and predict, the research question(s) and the exact parameters of the research for the purpose of obtaining informed consent. There is an additional problem with respect to the placebo effect as 'ethnographers do not necessarily know what they are looking for (and) they do not necessarily want their subjects to know too much in case it changes their behaviour...' (Dingwall 1980).

Obtaining consent for observational work in antenatal clinics is acknowledged to be problematic by ethnographers (Bowler 1993) largely because the way in which the clinics are organised often precludes direct contact with women until they enter the consultation room. The researchers made every effort to obtain informed consent but this had to be balanced with the smooth running of the clinic and maintaining good relationships with clinicians.

## **11.6 CONFIDENTIALITY**

The research team did their best to uphold the confidentiality promised to participants. The confidentiality and anonymity accorded to individuals and units has been rigorously checked by the project's advisory group.

On a number of occasions, when sensitive and/or confidential material was raised for discussion, the researchers voluntarily left the consultation room; only rarely did the health professional request the researcher to leave.

The generic terms 'midwives' and 'obstetricians' are used throughout the report although they are qualified in some instances by the insertion of descriptors such as *community midwife*, *consultant obstetrician* or *midwifery manager*.

All quotations referring to Informed Choice leaflets are from intervention sites unless otherwise indicated. Where quotations are not attributed this is for reasons of confidentiality.

## **11.7 OBSERVATIONAL WORK AND INTERVIEWS** (See Appendix 7 for the completed schedule)

### **11.7.1 Observational work**

Non-participant observation was undertaken on all sites. This took place primarily within antenatal clinics and in the homes of service users on the occasions the researcher accompanied the community midwife, usually for the purpose of a 'booking' or 'birthplan' visit. Observation focused primarily on the interaction between the service user and provider during a scheduled appointment. Additional observational work was also undertaken during antenatal education classes, within the general waiting area of the antenatal clinic, in the antenatal and postnatal wards and in the general 'office area' of CDS. Observational work was not undertaken on women in labour.

Observation was overt in that the researchers wore identity badges with the designation 'research midwife'; they generally introduced themselves as researchers to service users; they did not wear uniforms and they made copious notes throughout the consultation.

The researchers made every attempt to make themselves inconspicuous during consultations by placing the seat they were offered in the most distant corner of the room and, wherever possible, by placing themselves out of eye contact with both service user and provider. The researchers did not participate in the consultation unless directly invited to do so. On the occasions this occurred, the researcher contributed the minimum required to avoid offence.

As little is known about the way in which information is solicited, presented or utilised within the context of maternity care, and as there is little research on what influences decision making behaviour, it was considered important to observe interactions between health professionals and women within a 'natural'

setting; i.e. in antenatal clinics or in women's homes. In addition to making notes of verbal exchanges, observational work enabled the researchers to create a taxonomy of non-verbal behaviours. This material was subsequently explored with respondents during interviews and was constantly refined in the light of their contributions. In this way the observational data served to triangulate data derived from other sources and thus enhanced the validity and reliability of the study.

#### **11.7.1.1 Limitations of observational work**

The scale of the research allowed little opportunity for the researchers to observe women attending the same health professional for consecutive visits. Thus, it was not possible to comment on the degree to which information disclosed in a previous encounter was brought to bear on the consultation being observed. The researchers usually, however, observed the same health professional throughout an entire clinic session and this enabled the general style of interaction and pattern of communication of individual health professionals to be documented in considerable detail.

#### **11.7.2 Interviews**

Interviews were of two kinds: informal and 'natural' whereby the researcher and respondent engaged in spontaneous conversation, and in-depth interviews lasting 30-60 minutes or more. Opportunities for informal interviews arose, for example, in the community midwife's car, between consultations when the health professional would discuss some aspect of the previous consultation(s) with the researcher and in the antenatal clinic waiting area whilst the researcher sat with women waiting to be called into the consultation room. Permission was sought, and granted, to take notes on these occasions as these informal interviews were generally not tape recorded. They sometimes involved two or three respondents and occasionally they occurred in semi-public areas such as the midwives' office, antenatal clinic waiting areas or the antenatal and postnatal wards.

A substantial number of the formal interviews followed on from observation sessions. These interviews allowed both researcher and respondent the opportunity to explore issues arising directly from the consultation. Many of these interviews were undertaken in the homes of midwives and service users. All formal interviews were conducted in privacy and the vast majority were tape recorded.

##### **11.7.2.1 Interview prompts**

The same, loosely formatted, interview prompts developed in the ethnographic phase were also used in the initial stages of the CRCT phase. (Chapter 7)

#### **11.7.3 Tape recording and note taking**

The vast majority of participants consented to the researchers taking notes during observation sessions and tape recording interviews. Very occasionally, respondents asked for the tape recorder to be turned off during the interview so that sensitive material could be mentioned 'off the record'. On some occasions the researcher switched off the tape recorder to allow a woman to recover her composure following tearful episodes as painful events were recounted. On these occasions, where the material was of relevance to the data collection, the researchers sought specific permission for some notes to be taken. On the rare occasion where this permission was not given, the researchers refrained from making any reference to the incident in fieldnotes.

##### **11.7.3.1 Transcription of tapes**

The majority of interviews were transcribed in full with a small number having only data which were relevant to the study transcribed. This decision was taken as a practical solution to clear the occasional backlog of tapes awaiting transcription.

### **11.8 AVOIDANCE OF RESEARCHER BIAS**

#### **11.8.1 In the sample**

Great care was taken to invite a representative sample of both maternity service users and health professionals to contribute to the data collection. This was largely achieved. Midwives and

ultrasonographers were the most easily accessed of the health professionals and, on the whole, the most co-operative. Indeed, many of the midwives went far beyond what the researchers had hoped for in facilitating the research and their efforts were greatly appreciated. Obstetric registrars were generally willing to participate but were not always available at appropriate times.

The researchers acknowledge that their unsuccessful attempts to recruit a full sample of obstetricians, women with special needs and those from minority ethnic groups meant that it was not always possible to explore emerging theories to the point of saturation. Whilst this may not have altered the final picture insofar as the data analysis was concerned, maximum variation in sampling was not achieved.

### **11.8.2 In the data collection and analysis**

Bias was more difficult to identify, and control for, amongst the individual qualitative researchers, the majority of whom were midwives. A number of factors were thought to contribute to difficulties in recognising, and interpreting, phenomena for subsequent analysis:

1. Only one of the researchers was continuous throughout the study.
2. Of the five qualitative researchers who contributed, at different times, to the data collection and analysis, three had little, or no, experience of grounded theory methodology. Initial mentoring of researchers as they entered the field was instituted. Providing an effective, longer term, mentoring system was not feasible, however, because of the considerable distances involved in carrying out the fieldwork on the research sites and because the individual researchers and the collaborating universities were situated at considerable distance from one another.
3. The majority of the researchers were based in Wales and whilst an emic perspective was useful in some instances, understandable feelings of loyalty made close scrutiny of those issues which were culturally defined as sensitive, more difficult. This problem has been recognised by Rachel Pritchard (1996) who discusses her experience of undertaking qualitative research on health service colleagues in the Welsh Valleys. It is acknowledged that the outsider position of the other researchers may equally have obscured important phenomena.
4. The diversity of midwifery experiences, and the backgrounds of the researchers, created tensions because each held rather different expectations regarding the interpretation of 'good' or 'acceptable' practice. This made it extremely difficult to arrive at a consensus for formulating a baseline against which midwifery and obstetric practice on the research sites could be compared. Thus, the multiple lenses through which practice was viewed by the individual researchers, created some problems for the data analysis but also ensured a thorough exploration of difficult issues.

That is not to suggest that these differences were insurmountable or that they obstructed the research process. To the contrary, the many debates that were generated created a dynamic environment which greatly assisted the exploration of a number of difficult analytical concepts. The researchers made considerable progress in adjusting their analytical positions relative to one another and this enabled a sharing of viewpoints and a deeper appreciation of the different ways of seeing the (same) world in which the research was taking place.

With respect to transcript analysis, the researchers regularly shared individual transcripts and work-in-progress within the group, and on occasions to outside experts, for the purpose of cross checking emerging themes and categories. This rigorous approach guarded against one or other researcher dominating the analytical process and thus helped to ensure reliability and validity throughout the research.

## **11.9 DATA CATEGORISATION AND ANALYSIS**

As mentioned previously, the style of the study appeared best suited to a grounded theory approach (Glaser and Strauss 1967, Strauss and Corbin 1990). Fieldnotes and transcripts were analysed throughout the process of fieldwork and the continual coding and re-coding of themes allowed for the emergence, and continual evolution, of analytical categories in synchrony with the actual research. Throughout the course of the fieldwork then, some categories collapsed or merged and others appeared. This process went on until such time as little



further 'movement' was possible and the research team felt confident that the majority of categories had reached the point of 'saturation'. The four analytical categories which emerged from this process were:

1. the MIDIRS Informed Choice leaflets in the context of clinical practice (See Chapter 12)
2. information as communicated and used (See Chapter 13)
3. informed choice and decision making (See Chapter 14)
4. the culture of maternity care (See Chapter 16)

Thus, theory was generated directly from the data and was subsequently modified, and/or elaborated on as fresh material was contrasted with it (Strauss and Corbin 1990, Vaughan 1992). This reiterates a number of issues inherent to grounded theorising: that theories were always traceable back to the data, that the researcher plays an important role in the process of analysis and translation, and finally, that the 'fluid' nature of grounded theory demands a constant reworking of any hypothesis.

Two of the researchers used the software package QSR NUD\*IST (Non-numerical Data Information Systems and Technology) to code and manage the complex data set more efficiently.

### **11.10 OBSERVATION OF THE MIDIRS TRAINING SESSIONS BY THE RESEARCH TEAM**

Two members of the research team observed five of the training sessions; the additional session arranged for staff working intervention site the peripheral unit was observed by a single researcher. Extensive fieldnotes were taken by the researchers throughout the training sessions and were compared afterwards for the purposes of triangulating data. The researchers notes and general impressions were largely identical.

The presence of the research midwives at the training sessions had the unfortunate consequence of linking them, in the eyes of some midwives on the intervention sites, with MIDIRS. This became apparent on the occasions midwives introduced the researchers to women attending for antenatal care by way of saying: '*This is the lady from MIDIRS...(she's) come to check up on the leaflets...*' This (erroneous) connection, between the organisation which produced the Informed Choice leaflets and the researchers undertaking the evaluation, may have resulted in a slight increase in displays of 'best behaviour' when these midwives were observed in practice. It is also suggested that a 'Hawthorne' effect may have resulted on control sites for similar reasons.

### **11.11 DISTRIBUTION OF THE INFORMED CHOICE LEAFLETS TO THE INTERVENTION SITES**

#### **11.11.1 Calculating leaflet supplies**

The research team arranged with MIDIRS to deliver leaflets directly to the intervention sites before the start date of the eight month intervention period. As it was anticipated that midwives would be primarily responsible for giving leaflets to pregnant women, supplies of the professional's version were calculated on the basis of the total number of employed midwives in each intervention site so that each midwife would have her own complete set. A number of additional sets were included for distribution at the discretion of the HoM. Supplies of the woman's version of the leaflets were calculated as a percentage of the annual delivery rate for each unit.

#### **11.11.2 Use of the professional's leaflet by women**

It was stressed that, in the event of a service user requesting the professional's version of a leaflet, units should hold sufficient supplies to replenish the midwives' stocks. In the event, the researchers were aware of only one instance where a woman was given the professional's version of a leaflet (on ultrasound). See appendix 4 for details. A limited supply of the professional's version of the leaflets was sent to senior midwifery managers on intervention sites for distribution to other health professionals involved in antenatal care, such as consultant obstetricians, radiographers and anaesthetists. From the interview data, it appeared that few of these health professionals had read either version of the leaflets and nor were many aware that the research was in progress in the unit in which they worked.

#### **11.11.3 Distribution problems**

The manner in which leaflets were distributed to midwives who did not attend the training session (and who were therefore unable to collect a supply for themselves) appeared rather haphazard. There was no

evidence of any unit instituting a mechanism which ensured that all community midwives received supplies of the leaflets and instructions for their use and this resulted in considerable confusion at the level of clinical practice. Considerable numbers of midwives, then, possessed neither version of the Informed Choice leaflets on the date agreed by senior midwifery managers for the start of the intervention period.

A small number of community midwifery team leaders on some sites, however, exercised considerable initiative and expended personal time and energy in transporting boxes of leaflets in their own cars to their community colleagues. They then distributed leaflets within their own teams with instructions for when the respective leaflets were to be given to women.

In addition to the distribution problems, the researchers encountered midwives who were under the impression that women already in the second and third trimester of pregnancy at the start of the intervention should not be given any leaflets. During the first few weeks of observational work, the researchers realised that even midwives who had attended the training sessions were unclear as to what arrangements had been agreed for dissemination of the leaflets and midwives attending the same training session had different interpretations of what was said regarding these arrangements.

#### **11.11.4 Midwives working in 'peripheral' units**

As mentioned earlier, midwives working in geographically isolated (referred to locally as 'peripheral' or 'satellite') clinics appeared much less likely to have received any information about the research; they were also less likely to have received any leaflets by the scheduled start date for the intervention. The focus on the main maternity unit thus had the effect of rendering invisible both the women who attended these peripheral clinics and the midwives who serviced them.

#### **11.11.5 Restocking the units with leaflets**

One unit was re-supplied with leaflets six weeks into the trial because they reported having used up the entire eight month supply. As the research team had no means of assessing the validity of the claim, they had no option but to comply with the request. One of the researchers was subsequently informed that '*hoarding*' and '*stockpiling*' was not uncommon amongst midwives working in this unit; it is quite possible that midwives on other intervention sites behaved in a similar manner.

Towards the end of the intervention all sites reported that they had run out of the majority of the woman's version of all leaflet topics. Further supplies were requested from MIDIRS but this batch was not translated into Welsh because MIDIRS were able to supply the English version ex-stock whereas the bilingual version required reprinting. As the research team were anxious that the intervention units should not be without leaflets during the intervention period, a decision was made to restock the units with the English version. The researchers subsequently discovered midwives who did not receive any of these additional supplies of leaflets and midwives on all intervention sites were observed using the bilingual version of the leaflets (when supplies of these were reported to have been exhausted). Midwives informed the researchers that they retrieved leaflets from postnatal casenotes for recycling and this could have explained the continued (re)appearance of the bilingual version. Another explanation is that midwives incorrectly perceived all supplies of the leaflets to be exhausted when, in fact, some midwives still had plenty.

### **11.12 MIDWIVES' USE OF INFORMED CHOICE LEAFLETS ON CONTROL SITES**

The researchers encountered the occasional midwife on a control site who had purchased her own set of leaflets and loaned them to women in her caseload. Some of these midwives were using the full set of 10 leaflets whilst others were using only the five leaflets published in the first series. The pragmatic nature of the research determined that no action was taken by the research team.

## Chapter 12: The MIDIRS Informed Choice Leaflets in the Context of Clinical Practice

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This chapter describes the general issues raised through the observational work and interviews with respondents on intervention sites who were using the Informed Choice leaflets. All quotations in this section are from intervention sites unless otherwise stated.

### 12.1 REACTIONS TO THE INFORMED CHOICE LEAFLETS

Midwives were the main professional group observed handling the Informed Choice leaflets on a regular basis and, throughout the intervention period, the researchers observed little difference in the way in which midwives disseminated routine pregnancy-related information and the Informed Choice leaflets.

Very occasionally, obstetricians were observed discussing the breech leaflet with women and some anaesthetists and ultrasound practitioners indicated that they were aware that leaflets, relevant to their particular speciality, were being used in the maternity unit. Few practitioners from either group had seen, or read, either version of the leaflets and, when asked, could not recall that women had spontaneously referred to the leaflets nor asked more questions on account of having received them.

A small number of service users and providers suggested that the Informed Choice leaflets had provided an opportunity to examine and critique existing information and to reflect upon other aspects of service provision. Many were also of the opinion that concepts such as informed choice and evidence based care were not widely understood within the present culture of the maternity services.

#### 12.1.1 Midwifery managers

As mentioned earlier in this report, midwifery managers on the intervention sites were delighted when randomised to the intervention arm of the trial and those on control sites were very disappointed with their allocation. A number of managers on all sites volunteered that they had wanted to purchase the leaflets but had been unable to do so because of cost. (See Appendix 8 for more on this issue.) The leaflets were widely perceived by managers as being '*a good thing*' and a number cited local initiatives such as risk management strategies and pressure to develop a range of in-house publications, as the primary reasons. Very few indicated that they had given thought to whether, or how, the leaflets might impact on the process of delivering maternity care, nor the outcomes of that care. The absence of strategic planning was also noted in the ethnographic phase of the research.

#### 12.1.2 Hospital and community midwives

The Informed Choice leaflets highlighted the (often unspoken) divisions between hospital and community based midwives, especially with regards to core staff working in CDS. A widely held belief was that the entire responsibility for every aspect of the leaflets belonged with community midwives because they had been given the task of dispensing the majority of the leaflets to pregnant women. This was despite the fact that at least four of the leaflets concerned choices which women would not be expected to make firm decisions about until the onset of labour.

The following excerpt, from fieldnotes made towards the end of the intervention period, is illustrative:

The core staff midwives on CDS were asked about the Informed Choice leaflets. They all looked rather blank... One volunteered that *'the community midwives had them...we didn't have them up here...I didn't realise they had anything to do with us up here on labour ward...we haven't been using them here...I haven't seen them up here...'* One of the senior midwives then left the room, only to return 10 minutes later with bundles of leaflets including the professional's versions of support, epidural and monitoring in labour. There was also a bundle of the woman's version of the leaflet on epidural. fieldnotes intervention site

Core staff working in antenatal clinics, although not generally involved in dispensing leaflets to women, were more likely to be familiar with the topics related to decision making in the early antenatal period than were core staff working on labour ward. This may have been because midwives in antenatal clinic valued the leaflets as an additional resource when discussing complex information with women. Another factor may have been that, unlike the labour ward environment, observation work was undertaken in all hospital antenatal clinics and midwives might have felt under pressure to be seen, and heard, making reference to the leaflets. It is also possible that some decision points, for example those relating to screening for fetal abnormalities, are privileged in such a way as to make it more likely that the service user will be offered information and a degree of choice, because failure to do so could result in litigation.

Community midwives appeared to have easier access to their own supplies of the Informed Choice leaflets than did their hospital based colleagues. This did not seem to confer any particular advantage in that observational work and interviews did not generally reveal community midwives to be any more knowledgeable about the contents of the leaflets. The following quotation, from a community midwife interviewed toward the close of the intervention period, is illustrative:

*I: What did you think of them (the Informed Choice leaflets)?*

*M: It is so long ago now, I cannot remember what I read. I cannot comment... I cannot remember... No, I just flicked through them. I didn't read them in depth... They are just like....there. That is a dreadful thing to say. community midwife*

Even at the close of the intervention period, large numbers of community midwives on all sites could not recall the full range of the leaflet titles and, when invited to voice their opinions about using them in practice, many offered responses such as: *'they were very good'* or *'I found them really helpful'*. It is perhaps unsurprising then, that midwives were not often observed promoting the benefits of the leaflets with women in their care. That said, the majority of clinical midwives contributing to this study did not appear to have been directly consulted about the pivotal role they would play in this research and only relatively small numbers had attended either the project presentation or the MIDIRS training session. It is therefore suggested that considerable numbers of midwives on all sites may have lacked the confidence to use the leaflets to promote informed choice. Furthermore, a small number of midwives admitted to feeling uncomfortable about conveying written information which they had not contributed to producing, particularly when this contained material with which they disagreed and/or which contradicted unit policies. It was not always clear, however, whether this was because the leaflets exposed these differences or the fact that women had access to information which had been produced by an independent organisation.

It is perhaps worth saying that the majority of all midwives implied that the Informed Choice leaflets were exclusively for use by service users, with any benefit to midwives being limited to providing a quick reference source for their own studies. The leaflets were certainly not widely perceived as a vehicle for changing practice. As the following quotation suggests, the leaflets were sometimes viewed as something of a novelty, or a luxury, rather than as an effective tool with which to facilitate informed choice:

*I could probably do my job without them...but using them means you can give a connoisseur service rather than economy. antenatal clinic midwife*

Indeed, very early on in this study one midwife also suggested that the very nature of written information created insoluble difficulties for both the service user and provider:

*Information in the form of a written leaflet which is 'evidence based' presumes there is a right (and wrong) way of doing things; it simply reinforces the medical model of dichotomy rather than really encouraging choice. community midwife*

Finally, some midwives were of the opinion that, whilst the leaflets might reduce the potential for conflicting advice, they raised questions about the credibility, and ranking, of research evidence:

*...it's easier for the women if you stick to one party line, so in that way they're good...they (Informed Choice leaflets) tend to stop the conflicting advice...when they read the leaflets you know they're all*

*reading the same thing. But you still get problems because even if it's research based it might not be the ultimate truth... Research can be wrong. community midwife*

A number of other health professionals were of the opinion that using the leaflets was difficult in situations where local practice or current thinking on the subject was substantially different to the information contained in the leaflets. This issue was raised with respect to leaflets on alcohol, screening for Down's syndrome and spina bifida and breech presentation. It prompted one obstetrician to suggest that policies need to be set at a national, rather than local, level.

### **12.1.3 Service users**

Women were asked for their impressions of the Informed Choice leaflets in a variety of settings: whilst they were waiting in antenatal clinics, as in-patients in either an antenatal or postnatal capacity and in the context of an in-depth interview or focus group. For the majority of women, questions about the leaflets initially effected a zero response or, indeed, a denial that they had actually received any leaflets and it was only after considerable coaxing that some comments were forthcoming. (See Chapter 15) Comments from service users suggested that the leaflets made little impact on decision making and this was particularly noted on the occasions when women had decided on a course of action before receiving a leaflet on the subject:

*They were OK...they were nothing 'Wow' or anything...they weren't anything new... They didn't change my mind... I already knew what I wanted to do...' service user (who wanted a scan and was intending to bottle feed as she had done with her last baby)*

For some women, however, receiving a leaflet was sufficient to powerfully influence decision making. This was true even on the occasions when midwives made no further reference to the contents of the leaflet as was the case for the following woman who had obtained an Informed Choice leaflet on epidural whilst attending parentcraft:

*...the fact that they were called Informed Choice...that's a very good title for them. They really push you to make an informed choice... The one about epidural really made me think. I didn't have one (epidural) this time...I know I might not have needed one because it was my second (baby) but I didn't want one either because of what it said in the leaflet about it. service user*

The quality of the Informed Choice leaflets was commented on by a small number of (middle class) women who were surprised and excited by such an initiative within the NHS:

*I: Did you appreciate they (Informed Choice leaflets) were all based on research...?*

*W: Oh yes, it's obvious... Yes I did appreciate that. You can see that a lot of effort has gone into producing these...a lot of people have been involved. That's what gave me so much confidence when I read them...it's very exciting to think leaflets of this quality will be available to people using the NHS. service user*

One such service user, an expert in information systems, suggested, however, that education would be necessary before evidence based information could influence consumer choice:

*The main downfall is always that people aren't briefed properly on how to handle this kind of information (the Informed Choice leaflets)... They're not briefed on how to use it...on how to refer to it...You might as well just not bother with it. It's just a complete waste of paper... service user*

Finally, a Welsh speaking woman was particularly pleased that the leaflets were available in her mother tongue:

*I found those leaflets invaluable. My friends also found them invaluable. One of my sister-in-laws who plans to have a baby next year...she read them here. She said 'Oh, these are great. Will you hang on to them for me?' ...I was very pleased that they were also printed in Welsh. service user*

### 12.1.4 Obstetricians

Of all health professionals providing antenatal care, obstetricians appeared the most variable in their response to the leaflets. A small number were fulsome in their praise for the informed choice initiative and were of the opinion that the leaflets *'are the best thing I've seen in terms of patient information...it's the way we should all be going in the health services... Everyone, including health professionals, needs access to information of that quality.'* The Informed Choice leaflets on breech presentation, screening, ultrasound scanning and epidural in labour received very positive comments from this group.

A small number of obstetricians were not so enthusiastic, however, and some refused the researchers access to observe them at work in antenatal clinics and would not be interviewed. (See Chapter 11) Time pressures, a disregard for research undertaken by midwives, and hostility to the Informed Choice leaflets, were suggested by midwives and managers as possible reasons for the opposition from this group.

More than any other group, obstetricians voiced concerns about 'bias' in the leaflets and the potential for harm to women if they were given information which *'pointed out the downside of everything'*. A number of obstetricians, however, appeared to view any information which described the disadvantages of obstetric interventions as 'biased'. Thus, the leaflet on epidural in labour was cited as being *'the worst of the lot... The advantages are listed in just one paragraph and the disadvantages are bullet points over two whole pages.'* Whilst it is true that the disadvantages do indeed cover approximately twice the amount of space as do the advantages in the women's version of this leaflet, the combination of both is actually less than one page.

It is perhaps worth stating that, as with midwives, a significant number of obstetricians did not appear to have read the Informed Choice leaflets and even towards the close of the intervention, some did not know that the unit in which they were working had been allocated to the intervention arm of the CRCT.

### 12.1.5 Ultrasound practitioners

The majority of obstetric ultrasound practitioners observed in practice and/or interviewed, were not familiar with the informed choice leaflet on ultrasound scanning and neither did they think that women were asking any more questions since this leaflet had been introduced. A number of ultrasound practitioners were of the opinion that women were generally poorly informed about the differences between dating and anomaly scans and they welcomed any initiative which might help to remedy this situation.

One ultrasound practitioner, employed on the site where a decision had been made to withhold the leaflet on ultrasound, nonetheless had read both the professional's and woman's versions of the leaflets and pronounced them as *'excellent'*. She offered the following reason for why women attending the unit in which she worked were denied access to this leaflet:

*It's not just because of the fact that anomaly scans weren't done...it's because they don't really want the women too well informed... I think there's a feeling here that it's just easier if they're not told too much about things.* ultrasound practitioner

Ultrasound practitioners occasionally volunteered that information contained in the leaflets was new to them:

*I was shocked to read that 1:200 pregnancies were terminated because of dubious scan results...I had no idea it was that many...* ultrasound practitioner

Interestingly, the recently updated (July 1999) woman's version of the leaflet on ultrasound makes no reference to the number of pregnancies terminated on doubtful or spurious grounds but simply states: *'However, 70-80% of severe or lethal abnormalities are picked up on scans.'*

### 12.1.6 Anaesthetists

Very few anaesthetists were interviewed (none were observed in practice because observation work was not undertaken on women in labour) but those who were, praised the informed choice leaflet on epidural for providing *'a balanced view'* and suggested that it *'was put together very well indeed'*.

The information contained in the leaflets sometimes prompted some health professionals to consider practice issues. In the following quotation, a consultant anaesthetist suggested a relationship between women who managed without epidural pain relief in labour and the midwife caring for them:

*It's not just a question of whether the women are stoic or not...the quality of the midwifery care is very important... Midwives' epidural rates in this unit vary a great deal and I'm sure it's the same everywhere... I think we need to know why that is... consultant anaesthetist*

The influence of the respective health professional on the information pregnant women received and on the interventions they were subjected to was referred to by a number of participants contributing to this study. Some respondents made direct reference to the leaflet topics when discussing this issue. (See Chapters 13 and 14)

## **12.2 GENERAL ISSUES RELATING TO THE USE OF THE LEAFLETS**

### **12.2.1 Barriers to 'prescribing' the Informed Choice leaflets**

Throughout the study midwives were rarely observed 'prescribing' Informed Choice leaflets to women on an individualised basis according to need. Neither did midwives appear to see themselves as responsible for whether women read, or understood, the information contained in the leaflets but tended to limit their professional accountability to ensuring that the transfer of leaflets was documented in the woman's notes. A number of explanations are offered for these observations:

1. In the case of the unit which withheld three of the Informed Choice leaflets, it is possible that the midwives would have been censured, or even disciplined had they offered these leaflets to women.
2. Many midwives volunteered that no extra time had been allocated them to ensure women's understanding of the information contained in the leaflets. Some midwives also volunteered that, short of asking women to undergo a test of some kind, they were unsure as to how they could assess women's knowledge and understanding of the leaflet topics.
3. Some midwives felt anxious lest they undermine women's decision making by insisting that they receive information about choices which they stated they did not want. Informed Choice leaflets on screening, alcohol, epidural and feeding were cited by a number of midwives discussing this issue.
4. On most intervention sites, the leaflets were not used by midwives as separate pieces of discrete information but were bundled into two sets of leaflets and given to women at two predetermined points in pregnancy. This may have created difficulties for midwives wishing to prescribe the leaflets on an individual basis.
5. The pressure on midwives to document the leaflets they issued to women may have made it easier for midwives to give women all the leaflets, rather than prescribe according to individual need and subsequently be reprimanded for having used the leaflets judiciously, but insufficiently.

A commonly observed scenario, whereby the leaflets were introduced to women, was by way of the midwife saying:

*Here's a leaflet on... (insert leaflet topic) Have a read of it... See what you think, it might give you some ideas... If you want to discuss anything, give us a ring...*

At the beginning and end of the intervention period, one of the researchers timed a random sample of midwives giving Informed Choice leaflets to women at routine antenatal consultations. Presuming that the leaflets were handled separately (i.e. not given as a bundle) and that there was little variation in the preamble which accompanied the transfer (see previous quotation), approximately 30-40 seconds were required to transfer each leaflet.

Only rarely did midwives seek to establish women's existing knowledge base or interest in a leaflet topic and many did not appear to anticipate that women would comment, or otherwise respond, when they were given leaflets. Neither did midwives tend to explore with women the basis for the decisions they had already made regarding some of the leaflet topics such as feeding, epidural and alcohol and thus midwives were often not in a position to judge whether or not women might benefit from the (additional) information contained in a leaflet. Rather than withhold a leaflet, however, midwives tended to suggest to women that '*...you might as well have it anyway....*'

Midwives did not generally appear to see the Informed Choice leaflets as any different from other information they offered women:

*We were doing it (conveying information to women) before anyway... We were giving them that information before we had the leaflets... community midwife*

A small number of midwives did, however, attempt to distinguish the Informed Choice leaflets from other information and were heard using terms such as 'research based' when they introduced the leaflets to women.

*...What's good about these leaflets is that they are all based on the latest research so they are telling you all the right things...*

Information which was based on 'research', however, was often linked with the notion of 'right' choices in terms of what was approved of within the local unit. (See Chapter 16)

A number of midwives expressed concerns that written information, in the form of leaflets, would be used as a substitute for, rather than as reinforcing, information conveyed orally. Some midwives were anxious lest managers and others in positions of influence might look on the leaflets as 'a short cut' to the consultation process, and that this would be detrimental to women receiving care. Such concerns tended to be aired in the context of discussions about perceived midwifery shortages and other pressures midwives were currently experiencing in their working lives. (See Chapters 13 and 16)

Whilst some midwives were heard advising women along the lines that the leaflets were 'a useful source of good quality information', no midwife was observed using the leaflets explicitly as a decision making tool to facilitate women in making informed choices about their care.

### **12.2.2 Framing information**

The point has been made some time ago (Marteau 1989) that if information concerning risk is framed negatively, service users are more likely to accept the intervention being offered. More recently, Bekker and colleagues (1999) have suggested that decisions may change when 'the same factual information is presented in slightly different ways'. Health professionals in this study were generally observed to frame information in such a way as to emphasise the benefits, rather than the limitations, of technology and service users tended to 'go with the flow' of the approach suggested. Thus, even when midwives on intervention sites had access to evidence based information in the form of the Informed Choice leaflets, only rarely did they point out to women the disadvantages associated with certain choices.

A small number of midwives indicated that they were well aware of the potential impact of the content of Informed Choice leaflets on local customs and practices relating to maternity care. These were the practitioners who also acknowledged that the care women received was more likely to be based on the personal preferences or entrenched habits of health professionals, than on good evidence or an understanding of current notions of 'best practice'. One such midwife summarised these tensions in suggesting that:

*...the Informed Choice leaflets actually put midwives between a rock and a very hard place... It's unreal to encourage women to go against local policies and guidelines when we all know that if she takes that line, she'll be given a really hard time, especially by the medical profession... I mean we've still got women in this area being threatened and struck off GP's lists just for saying they are considering a home birth, for godsakes...and they will have to live with the consequences of making a choice that goes against the local policy for a lot longer than I will... community midwife*

Understandably then, midwives tended to frame information in such a way as to 'protect' women in their care from the consequences of making choices which were well known to upset medical powerholders. Maintaining the status quo was important because midwives otherwise risked being marginalised and/or having their practice subjected to closer scrutiny. (See Chapter 16)

As is illustrated by the following quotation, from a woman expecting her third baby, some service users looked to the Informed Choice leaflets (as they did to other information) for reassurance and guidance. A few women appeared perplexed by information which was not framed in the usual format and which did not take a directive approach to decision making:



*I read them all (Informed Choice leaflets numbers 1-8 inclusive) but at the end of it there's no recommendations is there? I suppose they're helpful in the sense they give you all the options...they give you all the pros and cons but if they don't recommend you one way or the other then what's the point? You don't know where you stand then do you?* service user

This quotation also suggests that some women expected information to direct their decision making towards choices which had been previously sanctioned by a health professional. It seemed that women sometimes experienced difficulty in containing feelings of uncertainty and looked to health professionals and the information they dispensed for additional security. Many women who were expecting second and subsequent babies, commented to the effect that *'things had changed'* in the maternity services. Many of these comments were positive, suggesting that women currently perceived themselves as having more options in their maternity care. As the previous quotation reveals, however, very few women expected to be involved in decision making at the level suggested by the information contained within the Informed Choice leaflets.

### 12.2.3 'Wrapping' information

To save time, and to ensure the Informed Choice leaflets did actually reach women, some midwives inserted them into the Bounty pack, alongside the advertising materials. Midwives tended to remain silent about the links between advertising and sponsorship of the literature contained in the Bounty pack and thus their attempts to save time may have misled women and inadvertently promoted the choices recommended by such literature.

As an alternative to the Bounty pack, some midwives placed a selection of the Informed Choice leaflets inside the woman's maternity record; in either case, the researchers observed occasions when midwives omitted to tell women about the leaflets or made only a very brief reference to them. Anecdotal reports from some community midwives suggested that, on a number of occasions, Informed Choice leaflets in pristine condition were retrieved from casenotes at the close of the maternity episode and were subsequently reused. This was also confirmed by the researchers undertaking the economic appraisal, whose job required them to retrospectively examine the maternity records of a number of women on intervention sites. (See Chapter 9) It is also possible that women themselves placed the leaflets in their notes for safe keeping and subsequently forgot about them.

The researchers routinely asked women who were waiting in antenatal clinics, or who were being interviewed, whether they had been given leaflets. Women who gave a negative response to this question were then asked to look in their Bounty packs or casenotes. A significant number of women, some of whom were well advanced in pregnancy, were thus introduced to the leaflets. It thus required that women be both resourceful and enterprising if they were to recognise the potential of the evidence based information contained in the leaflets:

*If I hadn't actually stopped to read them (Informed Choice leaflets) I'd never have appreciated how important they were... The leaflets were just given to me... When I started reading them I thought 'Oh this is what I've been looking for...' I always had them with me when I went for my visits but nobody ever mentioned them, besides to say 'Have you got your leaflets?'. But nobody ever discussed them...* service user

Observational work confirmed that it was rare for midwives to follow up leaflets in a subsequent consultation and this limited opportunities for those women who would have liked an opportunity for further discussion. The following quotation reiterates the work of others in this field (Gwyn and Glyn 1999) that sharing information is not synonymous with sharing decisions and the latter is what some women wanted from health professionals:

*Where everything falls down is that once you've got those (Informed Choice) leaflets, the information stops... In my view the information just stopped at those leaflets. I had an excellent midwife but as soon as she gave me those leaflets she never talked about those things again...all she asked me was 'Did I get the leaflets...?' But I really wanted her to tell me about things...I didn't want to just read about it...* service user

## **12.2.4 The process of selection: which women; which leaflets?**

### **12.2.4.1 Childbearing history and professional networks**

Many midwives were selective in the leaflets they gave to women; this was volunteered by midwives themselves during interviews and was also observed by the researchers. Thus, women who had previously undergone a caesarean section were never offered an informed choice leaflet on place of birth; women who were friends or relatives of health professionals, or who were health professionals themselves, tended to receive more leaflets.

#### **12.2.4.2. Age and social class**

Women who were poor, and/or young, were sometimes discriminated against in that they tended to be given fewer leaflets:

*There are some ladies you don't want to be giving the leaflets to because you don't want them thinking they can have choices that aren't available.... There are some women who can't read for example... and the young girls don't tend to be that interested...* community midwife

The following quotations are from women in the caseload of the previously quoted midwife. They are both young, working class, women and their reflections highlight the stereotyping which inevitably results when health professionals attempt to predict the women most likely to read, and benefit, from information. The first young woman was 19 years old and she was interviewed shortly after the birth of her second baby:

*They're good...they were really good... P (husband) read them as well... The one about positions...no-one told me I could walk around last time... I didn't know you could stand up in labour...I thought it had to be lying on the bed... It were a real eye opener that one were...* service user

Interestingly, results from the CRCT found that women on intervention sites showed modest changes in terms of both an increase in knowledge and the proportion holding strong preferences on the subject of positions in labour. (See Chapter 7)

The next quotation is from a 17 year old, late in pregnancy with her first baby:

*I really liked them (the Informed Choice leaflets)...I read them all. I thought they made everything sound really straightforward and simple... They laid out all the information so it was really straightforward to read... I liked the way the pros and cons were laid out...I liked the fact that the leaflets were straight to the point; they didn't mess about with the facts.* service user

It is perhaps worth pointing out that in both cases, these women read the leaflets they were given without any additional prompting from their community midwife.

#### **12.2.4.3. Parity**

Leaflets also appeared to be given on the basis of parity with primiparous women more likely to be given (more) leaflets than multiparous women. This accords with the findings from the CRCT. (See Chapter 7) Many midwives were of the opinion that women *'who have already been through it all before know what they want...'* and this confirmed what the observational work had suggested: that midwives tended not to see pregnancy as a dynamic opportunity for updating women with respect to current thinking about childbearing issues. Furthermore, insofar as many of their multiparous clients were concerned, midwives appeared to see themselves as relatively powerless agents in the decision making process. This was particularly evident in communities where the cultural norm was for babies to be bottle fed. By comparison, primiparous women appeared more malleable and were thus more likely to be 'steered' in their decision making by midwives and other health professionals.

Women who had read the Informed Choice leaflets often commented very positively on being given explicit information about *'facts'*; about *'the pros as well as the cons'* of interventions. From the accounts of service users, it appeared that information of this kind was not generally available in the maternity services. For women expecting second and subsequent babies, some expressed surprise that this was the first time they had ever been offered information *'which was not biased towards doing what they (health professionals) wanted you to do'*.

### 12.2.5 Canvassing service users

As a crude measure of assessing which leaflets had been given to service users, the researchers canvassed women waiting in antenatal clinics and those who were in-patients, both on antenatal and postnatal wards in intervention sites. Sampling in this way revealed that women were more than twice as likely to have been given Informed Choice leaflets on ultrasound, feeding and screening than they were leaflets on other topics. Whilst some women had received Informed Choice leaflets on all the remaining topics in the series, very few appeared to have been offered the leaflet pertaining to place of birth. Some women, whose baby was not and had not previously been, in the breech position at the time the researcher made enquiries, were nonetheless in possession of an informed choice leaflet on the subject.

### 12.2.6 Timing and provision of the Informed Choice leaflets

A number of women reported that they had been given Informed Choice leaflets despite the fact that the decision point related to that leaflet had long passed. This was noted with respect to leaflets on screening and ultrasound scans. As the following quotation illustrates, women did not find this practice helpful with respect to making (informed) decisions about the interventions which they had often already accepted:

*I: Has your midwife given you any of these? (researcher displays a number of the Informed Choice leaflets)*

*W: Yes, she's given these to me, she gave them to me on Monday (at 27 weeks gestation)... She's given me the Downs syndrome and Spina bifida and she's given me the ultrasound scans... I think it would have been more relevant in the first three months of pregnancy...*

Midwives, for their part, generally dispensed leaflets in accordance with the decision taken during the MIDIRS training session. Although a number of community midwives did raise questions about the timing of leaflets, they mostly adhered to what had been agreed:

*I: The two leaflets - feeding and the place of birth - when would you give those two out?*

*M: At approximately 20 weeks... That was the time we were told to give them: at the booking and at 20 weeks...*

As mentioned earlier in this section, during the early phase of the intervention period, the researchers identified, and corrected, a misunderstanding held by some community midwives regarding the issue of the Informed Choice leaflets to women who were already pregnant. Some midwives interpreted the decision made during the MIDIRS training session very literally indeed and understood the intervention to be 'all or nothing', i.e. that pregnant women would only be given leaflets in two bundles at two separate points in pregnancy. By extension then, women who had entered the maternity system before the intervention commenced would not be given any leaflets as they would only ever have the opportunity to receive the first bundle. This particular misunderstanding was corrected because it was identified. It is acknowledged that other misconceptions may have been missed which may have affected the intervention.

### 12.2.7 Books v leaflets

Many women suggested that they valued, and consulted, pregnancy related books more than they did leaflets, which tended to be associated with junk mail. The following quotation, from a multiparous woman with learning disabilities, provides an interesting contradiction:

*It was OK having them (Informed Choice leaflets)... I wasn't grieved or anything when they gave me them... They were better...for me...the books are too long...you lose your patience with books...you keep putting it down and then you can't remember where your place was...the leaflets like...are more straightforward...they were better for me...*

The Pregnancy Book (HEA 1997) was universally commended, as were all books which followed a pictorial approach to the developmental stages of the growing baby. It seemed that women liked to be able to literally see 'where you're up to', with respect to anatomical and physiological development.

It is possible that if these books were rewritten in such a way as to emphasise that many stages of fetal development are also associated with technological interventions, it might result in a more holistic and natural framework for decision making.

Information in leaflet form which is free of charge is now widely available. Fieldwork during the CRCT revealed that the Informed Choice leaflets were regarded in much the same way as other pregnancy related literature: as potential advertising material which was not to be taken seriously and was to be disposed of at the earliest opportunity. Concepts such as evidence based information, shared decision making and informed choice did not appear to have entered the discourse of service users. It is perhaps understandable, then, that so many women appeared uninterested when given leaflets on pregnancy related topics, about which they would hitherto not have been expected to voice an opinion.

### **12.3 CONCLUSION**

The Informed Choice leaflets focused attention on a number of aspects of service delivery and highlighted deficiencies in health professionals' clinical skills. It is possible that educational initiatives could address some of these areas, such as improving communication skills to enable health professionals to assume a less dominant role in the decision making process. Breech presentation was identified as another area in which the clinical skills of obstetricians will need to be improved if women are to exercise choice in the mode of delivery.

Other areas of practice are rather more invisible and are therefore more difficult to address. Creating a no-blame culture wherein women feel able to decline interventions is one such example. Professional 'boundary' issues, including power differentials between different professional groups and between health professionals and service users, will also need to be addressed if more equitable relationships are to be instituted and sustained. Finally, many health professionals appear to lack the confidence and/or experience required to support women who make decisions which contradict local norms. In the case of midwives, this concerns traditional areas of practice such as the quality of support women require in order to succeed in giving birth at home; to labour without recourse to epidural anaesthesia and other pharmacological pain relieving agents; and to deliver the placenta without the use of oxytocic drugs.

### **12.4 SUMMARY OF THE MAIN POINTS:**

- ◆ The Informed Choice leaflets did not appear to be used by health professionals as decision aids in their encounters with pregnant women
  - the orientation of the training delivered by MIDIRS was largely concerned with the routine aspects of leaflet dissemination. The training did not address difficult issues such as using the leaflets with resistant populations of women nor in dealing with resistance from colleagues and/or management.
  - midwives are used to conveying information to pregnant women but have little experience of using information in order to facilitate informed decision making.
  - little is known about the process whereby service users make health-related decisions. Health professionals contributing to this study generally appeared to lack both the knowledge and the experience required to facilitate shared decision making (in partnership with pregnant women).
  - pregnant women were generally not invited to discuss the reasons for the decisions they made and only rarely did midwives attempt to assess women's prior knowledge on any of the leaflet topics. This made it difficult for midwives to judge the appropriateness of offering, or withholding, leaflets.
  - the leaflets were widely perceived as solely for use by service users and, as such, were not generally seen as a potential change agent by health professionals. It also appeared that many midwives did not receive a set of the professional's version of the leaflets for their own use.
- ◆ The priorities and the organisation of care and the relationships between professional groups did not always maximise opportunities for leaflet use.

- the distribution of the leaflets to midwives on the intervention sites appeared to be somewhat haphazard and, as relatively small numbers of midwives had attended training sessions, many were not well placed to use the leaflets to maximum effect with women in their care.
- a considerable number of women complained that they did not have sufficient contact with midwives, especially during the early phase of pregnancy, and this may have created difficulties for women who wanted to discuss the contents of leaflets prior to making decisions.
- women who had no prior relationship with the midwife who cared for them during labour seemed to experience greater difficulty in avoiding interventions such as continuous EFM and in assuming positions of their own choice.
- community midwives were widely perceived as being totally responsible for the leaflets despite the fact that considerable numbers did not regularly undertake intrapartum care and thus could not be expected to facilitate choice around leaflet topics pertaining to labour.
- the obstetric model of care informed the choices made available to women on all sites and these choices were sometimes in conflict with the information contained in the Informed Choice leaflets.



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## Chapter 13: Information as Communicated and Used

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This chapter explores general issues underpinning the exchange of pregnancy-related information between health professionals and service users.

### 13.1 FIRST ENCOUNTERS: SETTING THE SCENE FOR INFORMATION CONTROL AND EXCHANGE

For the majority of pregnant women, their first encounter with the maternity services was with a GP and most women simply went along with the early pregnancy options which were suggested. Two groups of women constituted important exceptions to this general observation:

1. Women who had previously encountered the maternity or reproductive services, for example, through miscarriage or assisted conception, gained insights into the way in which the service operated. These experiences appeared to foster a more assertive approach in such women and this was evident in the specific demands they made on the maternity services in a subsequent pregnancy, for example by requesting early ultrasound scans or referral to a consultant obstetrician. (See Chapter 15)
2. Some women expressed preferences which contradicted local norms, for example, requesting a home birth in the case of a woman pregnant for the first time or following a previous caesarean section. The latter decision was sometimes observed by the researchers to be made by women as a result of previous negative encounters with the maternity services, particularly regarding labour and delivery. Women who expressed such preferences tended to be well informed (by their own experience and by reading and networking with knowledgeable others) and, in both the consultation and interview settings, were usually able to offer reasoned explanations for their choices. Paradoxically, these women were sometimes heard to be described by health professionals to be "ignorant", "selfish" and/or "ill informed" in relation to the choices they made.

#### 13.1.1 Primiparous women and information needs

Many newly pregnant women expressed surprise that, at the point of first contact with a health professional, they were not given information concerning the full range of options available, nor about how to take care of their newly pregnant selves. Women appeared more likely to make such comments if the health professional concerned was a GP.

*It was wrong that I had to find it all out myself. You've got so much to read when you're pregnant, especially if it's your first pregnancy you don't know what's happening... You should be made aware of all your choices...in the magazines you read...it says you've got choices, where you have your baby and things, but you then have to go and find it out yourself. It's as though it's meant to be a secret: 'Don't tell women about their choices!' service user control site*

The tendency for primiparous women to engage more actively in information seeking around more diverse issues, and at all stages of pregnancy, was noted by the researchers undertaking observational work and interviews. **The CRCT and focus group** findings also reflected these observations. (See Chapters 7 and 15) This may also suggest that midwives responded to a perceived greater need amongst primiparous women and offered them more information, including the leaflets.

Many women felt that they had to actively seek out information but women pregnant for the first time were in a difficult position as very often they did not know what information they needed. The following quotation, from a woman expecting her first baby, is illustrative:

*...the professionals gave me quite a lot of information but somehow it didn't really help me to make my mind up... I think, on reflection, I couldn't really have gained that information before I had gone through*

*it. ... I remember the midwife saying to me 'If I were you I would have the (AFP) test. ...it was reassuring that the midwife would make her feelings known but my concern was that you don't have enough time to spend with people to find out what their values are and where they're coming from... I think it's probably very difficult to give people the information they need because you don't know what you need.* service user control site

### 13.1.2 Multiparous women and information needs

Prior experience, and having insight into the values of the health professional conveying information, thus appeared to be important factors influencing the decision making process. That said, many women expecting second and subsequent babies seemed to experience pregnancy with varying degrees of disillusionment. Midwives often assumed that they '*knew it all*' and tended not to offer multiparous women the detailed explanations of tests and procedures afforded to women pregnant for the first time; neither were the invitations to attend parentcraft classes given with the same degree of enthusiasm or frequency. This was despite the fact that some women had given birth many years previously, sometimes in a different health authority or country.

Occasionally, it appeared to the researchers that health professionals did not value the previous childbearing experience of their multiparous clients. Once the booking history was completed, few, if any, further references were made to earlier childbearing episodes. It was as if multiparous women were not only without childbearing experience, but also without personhood. The following quotations, from multiparous women, are illustrative:

*I've said several times to my husband and friends I work with that this time I've just been left to my own devices. I feel like, yes, it's my second baby but it's not my second best. To me it's still as exciting and apprehensive, maybe more so because I know what to expect this time round in terms of pain in labour.*

service user intervention site

*Nothing was spoken to me in depth this time. Obviously I'm healthy and I expected it to be like the other times. Anything I wanted to know I had to ask. Nothing was said to me. Also the parentcraft classes, I wasn't really encouraged...* service user intervention site

*When they asked if it was my first child, as soon as I said 'No' it was: 'been there, done that, got the T-shirt' sort of thing. That's what I felt.* service user control site

The exceptions to this general sense of neglect and lack of interest were the women who enjoyed a relationship of trust with their midwife and this seemed more likely to occur where a high degree of continuity featured throughout the childbearing episode. In many cases, the woman and midwife were known to one another from a previous childbearing episode.

Many women felt they had no option other than to rely on friends, family, the media and popular literature for information; in some cases this was because health professionals had failed to meet their information needs in early pregnancy. Thus, a number of multiparous women perceived the now widely implemented schedule of reduced antenatal visiting (Sikorski et al 1996) as 'less care':

*I don't know if it's because it's the second baby or whether the quality's changed, but the care's a lot less. I have to visit a lot less... it would be nice to have been seen a bit more often, like in the early months when everything is new and changing.* service user intervention site

Whilst fewer antenatal visits for healthy childbearing women may have economic advantages to the NHS and do not appear to have a detrimental affect on a range of social and health outcome measures, the impact of having less time in which to convey more complex (and evidence based) information and in which to facilitate informed choice with service users, is not known. Furthermore, the effect of reduced antenatal visiting on the midwife-client relationship, especially with regards to the evolution of trust between the two parties, has not been evaluated.

The reduced contact between midwives and pregnant women may also help to explain the differences in perception between the two groups with regards to accessing information, especially in the early phase of pregnancy. Many midwives expressed concern that they 'bombarded' women with information; that they had insufficient time to convey all that was needed and to ensure that women



understood the information they received. Many women, however, complained that they received insufficient information to make informed choices about their care, particularly during the first and second trimesters of pregnancy. This was especially the case for women who wanted information about alternative options to those routinely offered.

### 13.1.3 Building the professional-client relationship

A small number of midwives considered the first meeting with a pregnant woman to be of crucial importance because it largely determined what was possible in terms of subsequent information flow between both parties:

*That first meeting is where you lay the building blocks for the relationship... everything else is unimportant because if you don't get it right, you don't get another opportunity. Women won't listen if they didn't hear you the first time...if you didn't give them the opportunity to hear you the first time...*  
community midwife intervention site

A small number of women described their first meeting with a midwife in pregnancy as 'like coming home to an old friend'. These were the women who had been cared for by the same midwife in an earlier pregnancy and clearly, from the tone of this comment, had benefited from the relationship. The following quotation describes how a known, and respected, relationship with a midwife influenced this woman's information needs:

*...It's my fourth baby and the others were born at home too so I felt I knew most of it. I knew what I wanted. But I suppose, if I think about it, the reason why I didn't do any reading this time was because I had M (community midwife) again. I don't remember her saying anything that made me think...hang on a minute... like I had done before, with the others (midwives). I had to read up a lot with the others and get my husband involved because I never knew what they were going to spring on me next... So you had to be well informed. You had to be prepared. It's been so different these last 2 times...just having the one midwife you know...a midwife I could trust. Having someone who you know is on your side. You don't need the books and classes so much if you've got that.*  
service user intervention site

Such midwives were referred to as 'goldmines' by some women (see Chapter 16).

Not all women, however, viewed health professionals as reliable, consistent sources of information, especially where non standard practices were concerned:

*You can't rely on them (midwives) for information... No. Not at all. If I'd relied on them I'd have had no information about some options... like home birth and water birth and syntometrine are just three examples that were never discussed..*  
service user intervention site

*Basically you have to get it (information) from other places...The midwives and doctors... they tell you what they want you to know when they feel like you should know... They contradict themselves... They don't always tell you the truth about things...*  
service user control site

Health professionals' allegiances to their employing organisation and colleagues, together with a tendency to rely on the habits of custom and practice, often required that they 'steer' (Levy 1999, Elwyn et al 1999b) service users by emphasising particular aspects of information. Such practices often, however, mitigated against 'tell(ing) the truth', including revealing the uncertainty associated with clinical procedures and treatment options. Thus, it was unusual to hear a health professional conveying information about the possible risks of an intervention, even on the sites where they had access to the MIDIRS Informed Choice leaflets. The control exerted by health professionals over client access to information (Audit Commission 1993) and decision making (Dodds and Newburn 1995) has been noted and these issues, together with a number of additional barriers to informed decision making, were considered during the developmental phases of the Informed Choice leaflets (Entwistle et al 1998b).

### 13.2 TIMING OF INFORMATION AND THE AFFECT ON THE PROFESSIONAL-CLIENT RELATIONSHIP

The timing of information was important for a number of reasons, not least because many midwives were concerned about building and maintaining trusting relationships with the women in their care. This was particularly the case where information was of a sensitive nature. For example, some midwives volunteered that they would not always act on cues women made available during the booking visit, but would wait until the relationship was more established. The organisational priorities were such, however, that a number of the midwives observed volunteered that they had little regular contact with the women they had booked and so there was little opportunity to follow up these cues. During interactions between midwives and women, it appeared unusual for women to initiate conversation, including spontaneous referral back to information which had been disclosed by them at a previous consultation. It is acknowledged, however that the one-off nature of the observational sessions may have obscured such enquiries.

Thus, a number of women complained that the timing of information did not synchronise with their requirements. The following quotation, from a woman in the postnatal period, is illustrative:

*They don't give you a lot of information about what's going to happen when you go into labour... You don't really know a lot. All I was told was, when you go into labour, you pick up the phone. That was it. They didn't explain the pain relief to me or anything like that... It's just sheer guess work... No wonder women are so afraid of labour. Nobody bloody tells you anything!* service user intervention site

The next quotation is from a woman admitted to hospital late in her pregnancy for CTG monitoring because of reduced fetal movements:

*I wasn't getting no answers at all. Distressing it was...because we didn't really know if there was something wrong. It's as though they wanted to keep you in the dark because it was nothing to do with you.* service user intervention site

Poor women appeared particularly vulnerable to 'being kept in the dark', perhaps because some health professionals held a low opinion about their knowledge base, their capacity to understand information and their willingness to participate in their care. Observational work revealed that the ability to articulate a response, in language which was acceptable to the health professional, greatly influenced the amount of information made available to the service user; it also served to emphasise the inequity of service provision. The relationship between the social class of the service user and access to information from health professionals has been noted in a recent study of antenatal education in NHS and non NHS settings (Nolan 1999) and this confirmed well established research (Kirkham 1993) that knowledgeable women tended to be offered more information by health professionals than women who were less knowledgeable.

On some occasions, the timing of information was inappropriate to the woman's gestational age. For example, it was not uncommon for community midwives to recommend folic acid (to prevent incomplete closure of the neural tube) to women already 8-10 weeks pregnant although, by this stage, neurological development is almost complete and, furthermore, it takes some weeks for serum folate levels to accumulate. Similarly, a number of women, in the third trimester, were given Informed Choice leaflets on ultrasound scanning and screening when these decision points had long passed. Some postnatal women contributing to focus groups in this study were also surprised to hear, during the course of the discussion, that concerns had been raised in the literature about the long term safety of ultrasound scans but that health professionals had not mentioned this issue. (See also Chapter 11)

It is perhaps worth saying that little is known about the effect of information which is poorly timed. It is possible that information, whilst poorly timed, nonetheless serves as useful 'health promoting' material for individual women anticipating future pregnancies. If this information is shared with friends and family members, childbearing women might thus serve as informal health promotion agents within the wider community. It is also possible, however, that information which is poorly timed does nothing other than raise women's anxiety levels.

The researchers noted a number of occasions when important clinical information was either not gathered from pregnant women by midwives at the booking visit, and/or was not passed on in an appropriate way to other colleagues within the maternity care team. Although this study did not

systematically explore the issue, a number of the problems described in a recent study on this subject (Hamilton and Maresh 1999) were observed. For example, ultrasound practitioners appeared to be given very little clinical information about the women presenting for ultrasound examination and, in the case of non-routine ultrasound, it was not always clear why the request for ultrasound had been made. The researchers observed ultrasound practitioners asking women themselves for this information and this sometimes created tension and anxiety for both parties. On some occasions, women were presenting for anomaly scans who were known to the researcher to have given birth to a baby with a major structural abnormality or to have had a previous termination of pregnancy for this reason. Such information was not always conveyed to the ultrasonographer by the practitioner making the ultrasound request. One ultrasound practitioner stated that lack of essential clinical information meant that she often had '*no option but to work in the dark and with a lot of guesswork*'. Failure to elicit, and pass on, relevant information resulted in some women not being offered appropriate screening tests; many more were denied the opportunity to make informed choices about their care. There are obvious medico-legal implications to be considered by the health professionals concerned. Further debate is also required about the kind of information different health professionals' require in order to best serve the needs of childbearing women and how that information might be transferred within the maternity care system without comprising confidentiality.

### 13.3 MIDWIVES CONVEYING INFORMATION: 'BOMBARDING' WOMEN

A recent postal survey of primiparous women in Wales (Churchill and Benbow 1998) concluded that whilst women were generally positive about the information they received during pregnancy, a significant number were dissatisfied with both the amount and diversity. These findings are echoed in both the qualitative and quantitative data collected during this study with many women experiencing a considerable gap between what they wanted, and what midwives and other health professionals thought they needed. This divergence of opinion supports a widely held viewpoint, that consumers generally want more information than they are offered by health professionals (Williamson 1992, Burn et al 1996).

Many midwives expressed concern that they gave women 'too much' information; that they 'bombed' women and that it was necessary to 'titrate' information:

*Sometimes I feel maybe too much (information) is given. I think you have to balance it out how it's given. Some women, especially in this area, can't take it all on board in one go. We have to, in a sense, weigh up the patient and find out what they want to know... I think you kind of have to titrate the information... You don't want to leave it too late but you don't want to bring it up too early so timing can sometimes be important. You have to start planting things...let them think about things...* midwife control site

Titration of information, however, usually resulted in midwives labelling women and making value judgements about them. One commonly observed consequence of such behaviour was that women were then stereotyped, especially if they made choices which did not conform with local norms. Autonomous thinking and expressions of difference in women appeared threatening to many health professionals and some responded to this by withdrawing their support.

Some midwives volunteered that they found it difficult to assess whether women understood information and they worried that further questioning, in order to satisfy the midwife's needs, might be perceived as undermining to the woman concerned. Unsurprisingly, in view of widespread fears about litigation, midwives often gave information regardless of the position women adopted:

*M: This leaflet (in-house publication, not an Informed Choice leaflet) is about Downs syndrome....*

*The woman interrupts: I wouldn't have that (screening test) anyway.*

*M: I'll explain it anyway...*

In a follow-up interview, the researcher invited the midwife to explain why she thought it necessary to give an explanation when the woman had clearly stated that she would not have the test. The midwife justified her actions by saying that she had to be certain that the woman understood the purpose of the tests and the only way she could satisfy herself was to explain the tests to her. Interestingly, the midwife did not appear to have considered asking the woman to explain what she understood to be the purpose of the tests. The issue of whether, and to what degree, health professionals were able to 'allow' women to refuse, or reject, information appeared to be problematic across all sites. Many health

professionals were concerned that, in the event of a poor outcome, women would complain that they had not been adequately informed and would subsequently seek compensation on these grounds.

A small number of service users, who made unconventional choices, praised the way in which midwives responded to their information needs. Women were quick to pick up on the occasions when health professionals were able to separate themselves from their own belief systems and convey information in a non-judgmental manner:

*I: What is it about the way M gave you information that you especially liked?*

*M is very non-judgmental. A lot of my opinions she won't agree with... She doesn't say anything though... She accepts it and it doesn't even register on her face. Another thing is she doesn't avoid it...like one of the other midwives just doesn't talk about the things she doesn't agree with...but with M, even though she might not agree with me, she'll still talk about it so that way I know she's really OK about what I want and she'll stick with me... service user intervention site*

The way in which information was conveyed, then, appeared to influence whether it could be 'heard', and therefore acted on. A determining factor in this process appeared to be the degree of 'coherence' between the service user and provider. High levels of coherence appeared to be particularly important when abstract notions such as 'risk' were discussed as this enabled health professionals to 'pitch' information at a level which women could understand and could subsequently apply to the decision making process. Achieving the right 'pitch' was difficult, however, because many of the midwives observed seldom attempted to establish the existing knowledge base of women in their care. It is acknowledged, however, that the 'one-off' nature of the observational sessions made this issue difficult to assess as the researchers had no way of knowing what information had been exchanged on a previous encounter.

#### 13.4 THE NEED FOR CERTAINTY

Considerable numbers of health professionals contributing to this study were heard conveying information to women with a surprising degree of certitude when admitting to a lack of evidence for many interventions and clinical decisions might have been more appropriate (Chalmers et al 1989). Such admissions might also have helped women to appreciate the uncertainty surrounding many childbearing events. Interviews and observational work also revealed that midwives rarely discussed the inherent uncertainty of the childbearing journey with women in their care. Indeed, this subject was often circumvented by the midwife offering a solution, however inappropriately, as is illustrated in the following excerpt from fieldnotes:

The community midwife is carrying out a birthplan visit with W who is 37 weeks pregnant with her sixth baby.

*M: Have you thought about what you'd like for pain relief? You can put down anything you like...whatever you want... Do you know what you want?*

*W, frowning, says: Will I be needing something then? I never had nothing before with any of the others. Do you think I'll be needing something with this one then?*

The midwife closes the conversation by giving W an Informed Choice leaflet on epidural in labour and admonishes her to 'have a read of this...have a think about it and we'll talk about it next time....' fieldnotes control site

These were the situations where 'having a leaflet' appeared to be something of a salve; as if midwives perceived written information as a container for some of the uncertainty faced by themselves and by the childbearing women in their care. This was particularly noted with the Informed Choice leaflets as this information offered an 'evidence based' choice and, for some midwives, this seemed to suggest a 'right' choice. (See also Chapter 16)

The observational work suggested that midwives often experienced difficulty in managing uncertainty on behalf of women in their care. Containing uncertainty, to the extent that contemporary midwives are

expected to, is a relatively recent shift in professional responsibility and one which midwives may be ill equipped to deal with. Many of this current generation of female health professionals have also been personally exposed to the uncertainties of decision making during their own childbearing careers, especially with regards to screening for fetal abnormalities. There was some evidence in this study that such experiences influenced (both positively and negatively) the ability of the health professional to be 'with women' in their own decision making. This was especially noted on the occasions where the decisions women made reflected a different set of values from those held by the health professionals.

### 13.5 LANGUAGE

The language used by health professionals to convey information to women about routine procedures often masked uncertainty and this precluded choice because there was often no inference that any other option was possible:

*When you go for your hospital appointment they'll do a little scan just to see how far on you are... They have the portable scanners in all the rooms so it's very quick. Then at 18 weeks you'll have your big scan...the detailed anomaly scan.* midwife intervention site

Health professionals, across all sites, used words such as 'mini', 'little' and 'quick' to minimise interventions, such as ultrasound scans. Similar language was also used when health professionals addressed service users and this appeared to infantilise them and trivialise their needs. Indeed, a significant number of service users reported that they had been made to feel 'childish', or that an encounter with a health professional made them feel as though they 'were back in school again'. Jocelyn Lawler (1991) has coined the term 'minifisms' to describe these 'verbal and behavioural techniques which assist in the management of potentially problematic situations by minimising the size, significance, or severity of an event... ..(these) are also methods of bringing a situation under control' (ibid:166).

#### 13.5.1 The language of 'risk'

The language used to convey information about perceived risk in maternity care appeared problematic for both health professionals and service users. Indeed, it has recently been suggested (Porter 1999) that the word itself constitutes 'a serious case of concept abuse'.

The following quotations, from two respondents on different sites, express the underlying tensions associated with the use of language with respect to breech delivery. In the first instance, the registrar was reputed to have considerable experience in ECV and vaginal breech birth and the multiparous service user has previously experienced two normal vaginal deliveries.

The registrar is discussing the mode of delivery for breech presentation and expresses concern that service users be made aware of what he termed 'the reality' associated with making choices which involve a degree of risk. Unusually, he contextualises the notion of risk within the norms of the institution and the clinical skills of the attending obstetrician. This is what he had to say:

*Giving them a choice is not enough, they need to know the reality behind it...about the head getting stuck, definitely. You can give them the scare stories but you don't even have to do that. You just have to mention a complication. Something like the baby might die and that changes the whole thing... Then obviously they tend to move towards caesarean section... External cephalic version...though people say that it is available, it's not widely done. Most of the hospitals just say that we try to do it but nobody really does it... It depends on how you tell them and if you are going to think of delivering them vaginally... But the thing is, it's not always the person who's counselling them who's on call when she comes in labour... The experience of the person is very important... I do tell them...that it depends on the person who is on labour ward when they come in and whether they are experienced in breech vaginal delivery or not. That is true not only for the vaginal delivery of the breech but for many other obstetric problems as well.* registrar intervention site

The service user conveys the undermining effect of obstetric language and the consequences for decision making when professional confidence and support are lacking:

*...she (consultant) basically told me that she didn't think there was much chance of the baby turning by itself... She was very negative about a normal delivery and the only outcome she could see was a caesarean which I was very upset about. It was her attitude more than anything and the way she described it... She pushed very much the negative side of a normal delivery. She said if the largest part of the baby wasn't out between 3 and 5 minutes I would have a brain-damaged child. I felt very worried about having a normal delivery after what she'd said to me. She implied that it wasn't really very safe. I was made to feel very much as though I was taking all that risk on myself... That's why I went for a caesarean... But I didn't see why the baby wouldn't fit through me because I'd had two normal deliveries before. Why didn't she concentrate on that instead of the baby getting stuck and being brain damaged?* service user control site

### 13.5.2 Risk and anxiety

Many health professionals appeared fearful lest they subsequently face accusations (and the threat of litigation) for having given women information without also conveying an appreciation of the attendant risk. But as there is no standard definition by which 'risk' is assessed, and because we know women are vulnerable to suggestions that they might be exposing their babies to risk, it is perhaps small wonder that this issue provoked considerable anxiety on both sides. This is further complicated by recent literature (Teixeira et al 1999) suggesting an association between maternal anxiety and fetal outcome. Given the earlier work of Statham and colleagues (1997) which revealed that anxiety about something being wrong with the baby is very common amongst pregnant women, introducing additional notions of clinical risk could have the unwanted effect of further increasing anxiety levels. That said, there was no evidence that written information raised anxiety levels in the participants who completed questionnaires for this study. (See Chapter 7)

A number of women indicated that 'worry' was a familiar state during pregnancy. Many were also told 'not to worry' by health professionals who rarely, however, attempted to discern whether there was anything women were specifically worried about. The following excerpt from fieldnotes describes a typical scenario.

W, 37 weeks pregnant and expecting her third baby, had been seen by her community midwife at a routine antenatal visit. During her consultation she attempted, on a number of occasions, to give the midwife information suggestive of early labour; the midwife consistently told her 'not to worry'.

*Afterwards it did occur to me that I should be worried...not there and then but when I got home.. Like I said, I was feeling so uncomfortable anyway that day and also I had a slight tracing of blood that morning. I did mention it to the midwife...I said 'I just wonder whether this is the start of something...?' Again she said 'Oh, there's nothing to worry about, if you have a show, you have a show...it's nothing to worry about...' But I was worried... I knew it was starting...*

W had an unplanned home birth later that day, attended by another midwife. intervention site

Observation work revealed that, when women offered information to midwives, it was often delivered in 'drips and drabs' throughout the consultation episode. This lack of a coherent sequence, with a recognisable opening and conclusion, may have made it difficult for midwives to grasp the significance of what was being recounted. Whatever the reasons, these 'missed cues' and 'lost opportunities' were regular features in the exchanges between the service users and providers observed and may have significant consequences for discussions concerning notions of 'risk'.

### 13.5.3 Posing questions

Women were often heard, in the consultation room, asking indirect questions or by responding with 'I don't know' to the questions put to them by midwives. Denying prior knowledge seemed to be an effective strategy, as it delayed decision making, whilst enabling women to continue gathering information. Midwives often seemed irritated or puzzled, however, when women responded in this way and did not appear to appreciate that women wanted information for a variety of reasons: for reassurance, for confirmation of existing knowledge; to confirm (or disconfirm) information acquired elsewhere and to assist them in decision making. Women also needed time to interpret information on behalf of important others such as partners, husbands and other family members. Furthermore, some of the information conveyed to women was complex; the booking visit alone required that women have

a basic understanding of anatomy, genetics, physiology, nutrition, biochemistry, the environmental sciences and the politics of the health service.

### 13.6 PRESSURES ON MIDWIVES' TIME

A number of midwives complained that the role of 'information broker' was yet another task for which they had assumed responsibility without any discussion and without any preparation. Furthermore, many community midwives were without a permanent consultation space and they also lacked secure storage for the increasing volumes of literature required in their daily work. Midwives across most sites suggested to the researchers that, as well as an increased workload, understaffing was commonplace. This perception may be open to debate as the vacancy rate in Wales is currently running at less than 2% of the total midwifery establishment (National Assembly of Wales 1998) but this may nonetheless have reinforced midwives' feelings of stress. Whatever the reasons, and it is probable that they are multifactorial, considerable numbers of midwives volunteered that, as they did not have time to ensure women understood the information conveyed, they simply '*covered their backs*' by documenting, in the woman's notes, that the information had been transferred:

*... (all the) issues take a lot of time to discuss and the booking is getting longer and longer. So I just skim through the main things and I say to them 'I've put some leaflets in this packet, I'd like you to read through them in your own time because you've had to ingest an awful lot of information today...'*  
community midwife control site

The midwife in the next quotation was one of a number who saw the Informed Choice leaflets as a pragmatic solution for shifting the responsibility for the organisational deficits to women in her care:

*Cost wise, I think, for a midwife to sit down with a woman and to discuss all the issues appertaining to pregnancy would take hours and at the end of the day we are governed by time, we haven't hours and hours to spend with each person. ... It's been good having the (Informed Choice) leaflets... it's a quick way out of it... You can give them a leaflet and tell them to have a read of it..* midwife intervention site

This point of view is not necessarily to suggest that it was the majority view as a number of other midwives suggested that the leaflets could not be used as aids to save time and that, if they were to be used as originally intended, more consultation time would be required.

Neither did service users necessarily perceive the leaflets as 'a quick way out' and some were dissatisfied when written information was prioritised over time for discussion. This was especially troubling for women facing difficult decisions.

The following quotation, from a primigravid woman with a breech presentation at term, who was given the relevant MIDIRS Informed Choice leaflet, is illustrative:

*I didn't feel happy throughout the pregnancy with the information I received... I constantly felt they (midwives) did not have any time for me. I was given plenty of leaflets but not enough discussion. I was never in the consulting room for any longer than five minutes at any of my ante natal appointments.*  
service user intervention site

Women participating in focus groups also commented in some detail that the pressures on midwives time inhibited them from soliciting support and information. (See Chapter 15) Many midwives appeared to see themselves simply as conduits for transferring information; only rarely did they perceive themselves as having any ownership, or responsibility, for the information they gave to women in their care. This may be one reason why so few appeared able to critique the literature they handled (including the Informed Choice leaflets) and it is also acknowledged that this may indicate an educational issue related to midwives' confidence in their critiquing skills. The absence of a critical midwifery voice may also have explained midwives' tendency to spend more time in the consultation on giving women 'negative injunctions' (Sherwin 1992) about diet, work, rest, exercise etc., rather than providing evidence-based information about specific childbearing scenarios which women were likely to encounter. This pattern of information provision was particularly observed in relation to injunctions regarding food, where midwives spent substantial amounts of consultation time giving women general dietary advice concerning foods which appeared to be unfamiliar or which many women indicated that they did not usually eat. This was particularly noted at the booking consultation when midwives

obtained a case history and formally 'booked' pregnant women into the maternity care system. Recent research (Hamilton and Maresh 1999) has highlighted the poor quality of the booking history and midwives' general failure to recognise, and convey to other colleagues, important information concerning women's past medical, obstetric and family history.

The way in which midwives prioritise and allocate their time is clearly an important issue. It is of some concern then, that midwives on the intervention sites in this study were observed spending relatively little time conveying evidence based information (in the form of the Informed Choice leaflets) and rather more time giving general 'lifestyle' advice, much of which has not been adequately evaluated (Enkin 1996). The fact that pregnant women are particularly vulnerable to health messages which appeal to the welfare of their unborn baby, (ibid) means that they may also prioritise health messages about lifestyle at the expense of literature which is evidence based.

### 13.7 ASKING QUESTIONS: I WAS NEVER SURE WHETHER I SHOULD...OR NOT

The observational work revealed that women did not ask many direct questions of health professionals. A number of reasons are suggested for this: it is possible that women lacked knowledge (or indeed a desire to know) about pregnancy related matters; the presence of the researcher may have had an inhibiting effect; women may have wanted to protect the midwife from embarrassment should they ask questions which the midwife was unable to answer. A further reason, which was commented on by a number of women during the course of a follow-up interview and during focus group discussions, was midwives general air of 'busyness', and their tendency to focus on the clinical task, rather than to sit, listen, and engage in discussion. Such behaviour patterns mirror the interventionist behaviours of obstetricians (Al-Mufti et al 1997). They also appeared to create a distance between midwives and women and signalled to women that listening to their concerns was less important than checking, measuring and documenting the results of these activities. (See Chapters 13 and 16)

Some hospital policies made it difficult for women to ask certain questions. Ultrasound scanning, for the purpose of gender identification, was a case in point and, like many service related issues, policies varied across the sites with some openly disclosing this information and others withholding. Fear of litigation '*for getting it wrong*', was the main reason cited by ultrasound practitioners for withholding although no practitioner questioned was aware of any successful legal challenge on this point. At the explicit request of pregnant women and/or their partners, some ultrasound practitioners were heard navigating the imposed censorship by making statements such as '*well he's exposing it all rather nicely today...*' or '*I think we can see a little something down there...*' or '*I can't see anything extra down there today...*'

Small numbers of women reported that, on the occasions they had overcome their reticence and approached midwives for information, their efforts had been well received:

*It's strange, but I found that there were often things that I felt I needed to know. I was never sure whether I should ask the midwife or not... Sometimes they are busy aren't they...? But if I did ask then they were brilliant. They would take time to explain to me, or if they didn't know, they'd find out by the next time or get back in touch. The information was there, but you had to ask for it, you couldn't expect it to come pouring out.*

service user intervention site

Asking questions of health professionals then, was generally uncharacteristic behaviour for service users and this may have been one reason why women who did so tended to be viewed with suspicion:

*I: So there's not very much discussion with the women?*

*M: No...none at all really. I think if any woman attempts to maybe discuss things then she's labelled difficult. You hear midwives saying things like 'be careful of her... she's not trustworthy...she's going to drop us into trouble...' midwife intervention site*

Being regarded as 'trouble' usually resulted in women being marginalised and not trusted. This made continued access to information very difficult unless women were so fortunate as to be in the caseload of a midwife who was not threatened by so called 'difficult' women. (See Chapters 12 and 16)



Raising questions appeared to be a difficult undertaking for many service users and one which required considerable planning, flexibility and courage. The exceptions to this were the occasions when women were able to establish trusting relationships with their midwives and this was usually only possible where there was continuity of carer. Such relationships generally enabled women to ask midwives more questions, in greater depth, and covering a greater diversity of topics; they were also more likely to initiate, rather than simply respond to, questions. Women also reported that they found it easier to approach their midwives between clinic appointments if they were worried.

### **13.8 TRUST: VOICES WHICH ARE HEARD...OR NOT**

On a number of occasions, women reported that they had tried to convey important information to midwives (and other health professionals), but that they had not been 'listened to'. (See Chapters 15 and 16) Some women reported this as being a feature of labour scenarios:

*I really wish she'd just listened to me. I really wish she'd believed me when I told her I was going to be quick... But whatever I told her just was irrelevant to her. She had it in her view what was going to happen...she felt that I was going to be a long time...I told her the baby was coming and she still didn't believe me...my husband screamed at her to get down (on the floor) and have a look... He could see her (baby's) head coming from where he was... service user intervention site*

The outcome for this woman was a healthy baby born in excellent condition. There may have been similar occasions however, when women's knowledge was disregarded by health professionals and a poor outcome has resulted. Furthermore, if midwives (and obstetricians) are unable to listen when women in labour attempt to convey crucial information about their own bodily processes, are they any more likely to attend to what women say at any other time?

That is not to say that some midwives do not also exercise great skill and clinical judgement when caring for women who, prior to the onset of labour, may have expressed a strong desire to avoid intervention, but when in strong labour will often make such requests.

Midwives also experienced not being heard when the clinical concerns they raised were disregarded by obstetricians:

*I was diagnosed with a breech baby by my midwife at 36 weeks (and) she sent me for a scan. The doctor was dismissive of the midwife's diagnosis and said the baby was head down. My midwife continually said he was breech in the following antenatal visits, but the doctor would not do a scan to confirm this, insisting he was head down. When I went into labour, at 7cm dilated I had an internal and was found to have a breech baby... service user control site*

*My midwife sent me twice to see the consultant because she thought my baby was too big to be born normally... He said she was talking rubbish and that it was a normal size... I was in labour for nearly 30 hours... I was pushing for ages and then they had to do a caesarean. He was over 11 pounds... service user control site*

It is possible then, that midwives' experiences of being silenced by more powerful others, may have desensitised them to hearing women in their care voicing concerns.

### **13.9 CONCLUSION**

The majority of health professionals observed did not use written information in such a way as to suggest that service users could do other than 'go with the flow' of local obstetric custom and practice. On the whole, service users conformed with what was expected of them and rarely used information to challenge individual health professionals or the maternity care system. These findings support existing research which has suggested that written materials alone do not appear to effect change in the behaviour of health professionals (Freemantle et al 1996). When women did not find the information or the reassurance they sought from health professionals, frustration and disappointment forced a small number to look elsewhere.

Over the past decade, a number of factors have altered the status quo with respect to the relationship between midwife and childbearing woman. University-based education has resulted in midwives entering the profession with a substantially different knowledge base and personal skills inventory; midwives are less accepting of their traditional (low) position in the institutional hierarchy; consumers have become powerful advocates in their own health care (Bastian 1998) and are less reliant on health professionals for information; 'advances' in reproductive technologies and a growing awareness of ethical and legal issues require that consumers are well informed and actively involved in decision making.

Health related information is no longer the exclusive province of health professionals, and whilst pregnant women are unlikely to eschew pregnancy related information from those providing maternity care, they are likely to become more critical. At the time this research was undertaken, the concepts of evidence based information and informed choice did not appear to have entered the consumer discourse and thus the majority of service users were not well placed to challenge the information they received from health professionals, nor indeed the decisions they made on their behalf. It is anticipated that promoting consumers' demands for evidence based medicine (Domenighetti et al 1998) will lead to a greater degree of 'healthy skepticism' (ibid) with respect to orthodox medicine and will eventually result in a public who are better informed. It is anticipated that these shifts in power will lessen the dependency on maternity service providers for information and could reduce the 'faith' service users currently place in these health professionals to act in their best interests.

### 13.10 SUMMARY OF THE MAIN POINTS

- ◆ The first encounter with the maternity services was influential in determining whether important information is gathered. This visit was also noted to influence the future control and further exchange of information.
  - most women followed the options presented to them by the first health professional they met.
  - a small number of women reported being dissatisfied with the information they received at their first meeting with a health professional.
  - women who had previous experience of the maternity services were more assertive in making early demands.
  - some pregnant women who had previous negative experiences of the maternity services made decisions which contradicted the norms of local practice.
  - a number of women without this experience also made early choices which contradicted the norms of local practice; they were more likely to be very well informed and to express strongly held preferences.
  - midwives sometimes failed to elicit important information about women's medical, obstetric and family history; many health professionals failed to communicate such information to relevant colleagues.
- ◆ Women received different amounts of information.
  - women pregnant for the first time appeared to be offered more information and greater detail about tests and procedures.
  - women whom health professionals perceived as more 'knowledgeable' appeared more likely to be offered (more) information and more detailed explanations. Women perceived as less knowledgeable tended to be stereotyped and, as a result, were offered less information.

- some health professionals assumed a relationship between women's knowledge and social class although no such relationship was apparent in the analysis of the postal questionnaire in this study.
  - women who enjoyed a relationship of trust with their midwife appeared to ask more questions and were more likely to initiate conversation.
  - trust was of greater benefit to women if it was established early in the relationship; trust maintenance depended on a high degree of continuity and coherence between midwife and woman.
- ◆ Health professionals' fears created conflicts between formulating an appropriate response to women's information needs and protecting themselves against subsequent litigation.
- a tendency was noted for health professionals to deliver information in a standardised, rather than individualised, manner.
  - health professional generally appeared unskilled in containing uncertainty on behalf of women and this appeared to make them more directive, rather than facilitative, in conveying information, especially when this concerned notions of 'risk'.
  - many health professionals wanted to 'do the right thing' for women in their care but were genuinely unsure how to achieve this.
- ◆ The language used by some health professionals created difficulties for service users.
- some women appeared to be made anxious by the language used by health professionals information about perceived risk was conveyed and this may have impinged on their decision making ability.
  - health professionals tended to use language which minimised routine interventions and this made it difficult for service users to both appreciate the degree of risk involved and to make informed decisions.
- ◆ The timing of information used by health professionals was sometimes inappropriate.
- the increased pressures on midwives time were thought to be a factor contributing to the inappropriate timing of information.
  - on occasions, information was given long after the decision making event.
  - information, whilst poorly timed in terms of gestation, might nonetheless serve as useful material for the wider purpose of 'health promotion'.
- ◆ A tendency was noted for midwives to spend more time during the antenatal consultation conveying information which was not evidence based and which has not been subjected to rigorous evaluation. This added to the pressures on midwives' time.
- ◆ The widely introduced schedule of reduced antenatal visits may have disadvantages for women and health professionals.
- many midwives reported having insufficient time in which to convey information to women and to assess whether women understood the information they received.
  - midwives generally experienced difficulty in selecting the information they offered to women. This may have explained why many perceived themselves as 'bombarding' women with information whilst women often complained that they received insufficient information to make informed choices about their care

- reduced contact between midwives and pregnant women, especially during the first and second trimesters, may have hindered the development of trusting relationships thought to facilitate informed decision making.

## Chapter 14: Informed Choice and Decision Making

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This chapter examines the complexity of informed decision making and identifies factors which appeared to contribute to, or hinder, this process.

### 14.1 CHANGING THE CULTURE

One respondent suggested that widespread acculturation to the relatively new concept of informed choice in the maternity services will take some time:

*As we get more experienced at presenting informed choice to pregnant women, the culture will change so that this becomes a normal, rather than an exceptional, part of care. We are at the beginning of a revolution with the concept of informed choice and at present there is a lot of pressure to 'get it right' and a lot of fear (of litigation) if you 'get it wrong'.* midwife intervention site

Recent work (Elwyn et al 1999b) suggests that health professionals have much to learn about the process of shared decision making and this study revealed that health professionals' feelings of guilt and blame tended to undermine the professional-client relationship. (See Chapters 4 and 16) It is also acknowledged that there is considerable variation in the cultural context in which decision making occurs and that some service users may not want to participate in decisions about their health care. This is not to suggest, however, that midwives and other health professionals were always accurate in recognising when service users did not want this responsibility. As the following quotation illustrates, there were occasions when normal patterns of information gathering, such as women asking the question: 'What would you do?', was interpreted as meaning that they were 'passing the buck' on decision making.

*I'm not sure women want to make a decision...There are a lot of women out there who say, 'What would you do?' Some women just don't want to make that decision. They don't want to take on board that responsibility. If something goes wrong at the end and they've made that decision, they want to be able to pass the buck to somebody else.* midwife intervention site

It is possible, however, that some women simply posed such questions in order to 'bide their time' whilst continuing to accumulate more information. Indeed, a recent literature review on clinical decision making (Sullivan and Pickering 1998) suggested that rather than indicating an abdication of responsibility, such behaviours reinforce the importance of giving clients enough time to make decisions.

A small number of service users spontaneously volunteered that their information and decision making needs had been accommodated within their own time-frame, rather than having to fit in with that imposed by an individual health professional or organisation. Such women were more likely to be receiving care from midwives working in the smaller maternity units where the cultural norms were rather different from the larger, centralised units. Women particularly seemed to appreciate the greater flexibility and responsiveness of these midwives:

*The midwives don't push you to make decisions. They let you change your mind and then change it back again. (woman laughs) ... When the midwife came to my house to book me she asked me if I wanted to have the baby at home. I was shocked. I'd never thought about it before. I said no because I thought it was too dangerous. But I've thought about it a lot more...my partner is all for it. The midwives have given me a lot to read... Last week I saw the midwife (at 38 weeks gestation) and we talked about it again. I said I still didn't know what to do so she told me I could wait and see how I feel when I go into labour. I can make up my mind then to stay at home or go to the hospital.* service user rural unit

Women booked at these smaller units appeared to enjoy close and supportive relationships with all of the midwives. Whilst each woman was usually assigned a 'named midwife' from whom she received

the majority of her antenatal care, this arrangement was often nominal in that women were observed approaching the midwife on duty with a similar degree of confidence and familiarity to that which had been observed during one to one consultations. The fact that women who were observed and interviewed appeared to enjoy a similar quality of care from all the midwives in the unit echoes the findings of Waldenstrom (1998) who suggests that continuity of care was more important to women than continuity of carer. The observational work and interview data collected from these smaller units supports recent research (Churchill and Benbow 2000) and suggests that there may be other factors (besides size) within the local culture of these units which enhances women's sense of participation in the decision making process.

## **14.2 THE INFLUENCE OF, AND THE INFLUENCES ON, THE HEALTH PROFESSIONAL**

### **14.2.1 Fear**

Fear (of litigation), rather than security with evidence based information, appeared to be a major factor influencing the way in which choices were presented to or withheld from service users:

*(I'm) saddened that obstetricians are forced to practice defensive obstetrics (because of) the fear of litigation. We let them (women) do what they want to do and then when things go wrong we get sued... We are now in a stage where we are afraid to go against the women's wishes... (But) you get very skilled at smelling a rat. We know now when trouble is approaching and that woman smells like trouble... obstetrician intervention site*

This particular obstetrician was observed striving to offer choice to service users, but nonetheless his words reflect an attitude of mistrust and fearfulness lest women he perceived as 'trouble' catch him unawares and unprotected. The qualitative research suggested that a number of health professionals maintained a similarly uneasy, if not adversarial, position with respect to women in their care and this made it difficult to foster alliances built on the principles of mutual respect and partnership. (See Chapter 16) This tendency was particularly noted amongst professionals occupying positions of considerable power (relative to the service user), such as obstetricians. The threat of litigious action, instigated by the service user at any point and without prior warning, appeared to generate considerable anxiety in health professionals; it also served to challenge power relations.

A number of health professionals responded to the climate of fear by inflating clinical risk when conveying information to service users. In the following quotation, an experienced midwife answers a question on the subject of breech presentation from a primigravid woman attending a parentcraft class:

*W: How would you know if you were having a breech?*

*M: Well, for a start, they're very, very rare, especially in first babies. So in that case, the doctors would do a caesarean and the reason is that you don't know if the baby's head can fit through the pelvis... The bottom usually comes through no bother but it's the head we get worried about and we don't want to be taking any chances there..' midwife control site*

The midwife does not attempt to answer the question, nor elicit whether the woman is actually carrying a breech baby, but proceeds immediately to outline what she perceives to be the risks associated with a vaginal delivery. She is incorrect, however, in stating that breech presentation is 'very, very rare, especially in first babies...' as the incidence is 3-4% at term (MIDIRS 1997) and is higher amongst primigravid women (Albrechtsen et al 1998, Rayl et al 1996). Of greater concern perhaps, is the message conveyed to approximately 20 women and their partners or labour supporters, that caesarean section is the only appropriate mode of delivery and that such decisions are the province of doctors, not women.

### **14.2.2 Lack of skill and confidence**

The increasing reliance of health professionals on technological and surgical intervention in so many areas of childbirth has led to a gradual decline in the confidence to undertake a range of clinical skills; in this case those required to perform ECV and/or facilitate a vaginal breech delivery. As the following quotation suggests, health professionals who lacked confidence and skill tended to become anxious and fearful and this potentially affected clinical outcomes:

*I actually enjoy a breech delivery. It's about the nearest I get to normal obstetrics (but) I think there is a generation of obstetricians that have lost their skills at delivering breeches. They are not confident (and) that lack of confidence is conveyed to the women... When a breech comes in (to CDS) people get in such a panic: 'get the drip up, get the epidural...get this, get that..!' They create an abnormal, nervous atmosphere. Then, when she's fully (dilated), everyone presses every button they can get their hands on... When I get there (to the labour room) they are running round like headless chickens... I have to say 'calm down...calm down...' What hope has the woman got of having a normal delivery...? obstetrician intervention site*

In this study, only small numbers of women with a breech presentation appeared to be offered the option of ECV by a skilled and confident practitioner and even on intervention sites, only about one third of women surveyed reported having been offered an informed choice leaflet on the subject. (See Chapter 10b)

The following quotations convey a sense of the limitations imposed by health professionals regarding choice in the mode of delivery for two women with breech presentations:

*I...had the choice of a tricky delivery or a relatively safe c-section. I could never forgive myself if something went wrong during a vaginal delivery when I could have had a section. service user intervention site*

*My midwife sent me to a consultant and they advised me to have a section the following week... service user control site*

Burr et al (1999) have recently commented on the wide variation in obstetricians skills in managing breech presentation at term and have suggested that the advice which is offered to women, and the delivery which is planned, is more likely to be based on the individual consultant's beliefs than on what constitutes best clinical practice.

There is also evidence that midwives' attitudes, and their lack of skills and confidence, similarly affect the information which is given to women and the choices subsequently made by them. Research into midwifery practice has looked at this issue with respect to pain relief and fetal monitoring in labour (McCrea et al 1998, Dover and Gauge 1995) and the uptake of screening for HIV (Jones et al 1998).

### **14.2.3 Evidence, uncertainty and the threat of litigation**

Despite the fact, then, that approximately half of the sites participating in this study had access to an evidence based information tool and, notwithstanding that evidence continues to mount in favour of alternatives to caesarean section for breech presentation (Coltart et al 1997, Cardini and Weixin 1998, Irion et al 1998), there did not appear to be a significant change in the mode of delivery. It has been suggested (De Ville 1998) that the threat of malpractice has accelerated the trend towards a more conservative and defensive, clinical practice, not the least because health professionals tend to use technology as a 'prophylaxis' against being sued.

Breech presentation appeared to generate attitudes of fear and blame in many obstetricians and some wanted the issue of accountability more clearly defined:

*I have a lot of experience with breeches...probably more than anyone in this unit so if it really matters to the woman then I will put myself on call for her. But then, I think well, why should I if she's going to turn round and sue me if something unpredictable happens...if it all goes wrong. I think if women want me to take these risks then they are going to have to accept the uncertainty involved. I'm very careful to assess the individual woman before I'll go on call. I want to know that they will really give it a go but that they'll also listen to when I'm concerned. I don't want them to be telling me what to do when I'm seriously concerned about something. I don't panic easily but I do need to feel they can put their trust in me... senior registrar intervention site*

Little is known about the factors which assist or deter childbearing women from placing their trust in a midwife they have not met prior to the onset labour and even less is known about the affect of trusting relationships and optimal clinical outcomes. This is especially the case where a degree of clinical risk has been identified.

#### 14.2.4 Trust and communication

On the whole, women did put considerable trust in doctors to act in their best interests (see Chapter 14) although many also put great store by the opinion of the midwife.

Midwives were noted to have an important role in mediating between hospital doctors and women. Indeed, they were often crucial to the process of 'translating' women's concerns and thus making it possible for them to be heard by doctors. This was necessary because existing power relations often prevented women's voices from being heard directly, especially if they were young and/or poor:

*I have always found the midwives very good. In fact, you can talk to them more so than a doctor if you have got a concern...and they sometimes relay it back to the doctor. They are very good.* service user control site

Rather than confront hospital doctors, however, many midwives avoided trouble and simply 'filled in' for them. Such behaviour served to maintain the unequal power relations amongst all parties, with the result that poor quality care was not open to examination. It also ensured that informed decision making was made very difficult for service users.

Interestingly, a number of obstetricians were of the opinion that midwives significantly influenced the choices women were offered:

*I think whether the patients are offered an informed choice really depends on the midwives doing their job properly. They're the ones who see the patients day in, day out. Some midwives do offer the patients choices and some don't. I see that especially when the ladies come in for screening (for fetal abnormalities)... I can see who has been well informed and who has not.* obstetrician intervention site

Some midwives concurred with this obstetrician's view and cited variations in midwives' clinical practices:

*You know who offers the choice and who doesn't... You've only got to look at the home confinements or the epidurals or the episiotomies to see that...* midwifery manager control site

Some obstetricians were also of the opinion that certain midwives 'negatively influenced' women:

After W leaves the room, Mr O confides that he thinks the midwives are sometimes negatively influencing women by telling them about the baby's position too early and that this makes them very frightened. He also suggested that midwives went 'on and on about OP positions' and that when they did birth plans with women, they placed too much emphasis on the use of epidurals in labour.  
excerpt from fieldnotes control site

*Midwives nowadays seem to think a baby (in the breech presentation) just can't come out the vagina... Around here they'll (midwives) generally recommend the ladies to have a caesarean section so when they come in to discuss it, it's a closed shop really... They've had the information and they've already made up their minds... I'm afraid to say that it's not always on the basis of the best information...* consultant obstetrician intervention site

It should be said, however, that it was not always clear from observational work or interviews with obstetricians that they routinely checked women's information sources about such matters. Health professionals in general did not seem to appreciate the multiple sources whereby women currently obtain information. Neither did many practitioners indicate that they recognised the powerful, and lasting, effect on women of the language (including non-verbal) they used when conveying information, particularly when this concerned perceptions of risk.



## 14.3 INFORMED CHOICE AND DECISION MAKING: FACILITATORS AND BARRIERS

### 14.3.1 Differences in philosophy and values

A number of service users were aware that considerable differences in philosophy and practice existed between midwives. A few women, who found themselves booked with midwives with whom they did not share a common view and for whom this was an important issue, reported that they had successfully managed to change their care to another team with whom they felt more comfortable. (See also Chapter 15) Interestingly, it was not necessarily the stereotype of the well informed, articulate, middle class woman who either wanted, or achieved, such change. To the contrary, such demands appeared just as likely to be made by working class women or by those who perceived they had been mistreated during previous encounters with the maternity services.

Some health professionals worked very hard to facilitate informed choice with women in their care but differences in philosophy between service user and provider, which sometimes mirrored differences in social class, often made this difficult to achieve. The passive and deferential attitude of many women further hindered those health professionals who were striving to challenge the status quo. It was thus difficult for these health professionals when women made decisions which did not accord with evidence based information. This is illustrated by the next quotation, where an obstetrician attempts to present an alternative viewpoint to a multigravid, working class woman with an uncomplicated obstetric history, who is requesting a caesarean section for a breech presentation at term. The woman, and her mother, have made it clear that they consider an elective section to be the only safe option.

*Well...women still die from caesarean sections... It's a big operation and not without it's risks and complications... What I want you to do, every morning, lunch-time and tea time, is get on the floor on all fours for 10 minutes, with your forearms on the floor and your bum in the air. Do that for 10 minutes three times a day. It might encourage that baby to turn round.*

*The woman just laughs; her mother looks disgusted.*

registrar counselling a multigravid woman with a breech presentation control site

Whilst it is acknowledged that recent research (Smith et al 1999) has raised doubts about the efficacy of the knee-chest position in breech presentation, this does not alter the fact that health professionals may face considerable resistance when introducing 'new' concepts into maternity care. Women's mothers exerted considerable influence on choice and decisions making (see Chapter 14) but nonetheless, the culture in which maternity care was delivered constantly reinforced the medical hegemony which privileged technological intervention over the 'natural' process. Obstetricians were widely perceived, especially by disadvantaged women, as '*the gods*'; ready, willing, and able to avert, and resolve, potential problems. Thus, on the rare occasions when obstetricians or midwives, went 'against the flow' in suggesting a non-technological approach to pregnancy related problems, they were met with disbelief or, as is illustrated here, with derision.

For considerable numbers of women, however, decisions were often contingent upon domestic arrangements:

W is 37 weeks pregnant with her second baby which is now in the breech position (but which has previously been an oblique breech presentation). She has had a previous normal delivery. W is accompanied by her partner. The Registrar in the antenatal clinic has started to explain her concerns about spontaneous rupture of membranes with an unstable lie. She has suggested an induction which the couple do not want.

*We (man speaking on behalf of his wife) were thinking last night...if W (wife) has an elective caesarean section. Things are really difficult for me to have time off. I've been to the union and there is no way I can have leave unless I take it off sick. We've got no family in the area so if (W) had a caesarean we could actually plan it.*

The registrar reluctantly agrees to an elective section. After the couple have left she tells the researcher that she finds it difficult sometimes; that she felt it really didn't matter what she said:

*They'll choose what they to choose in the end, you can't really call it informed choice, but it's the choice that suits them.* fieldnotes and interview data control site

A small number of women were heard requesting caesarean section on non-clinical grounds; whether such requests were accommodated seemed to depend on the views held by the obstetrician and on the social class and persuasiveness of the woman making the request. Economically deprived women were thus further disadvantaged and a number were observed exerting control by manipulating health professionals to intervene in a pregnancy on spurious grounds, for example, by reporting reduced fetal movements. (See Chapter 16)

That is not to gloss over the fact that poor women usually exercised little choice in decisions regarding their maternity care (Lazarus 1994). Lack of confidence and experience made their negotiations with health professionals extremely difficult. Nor is it to underestimate the ethical dilemmas faced by obstetricians wishing to respect the autonomy of the service user making requests for (unnecessary) surgical intervention, but who nonetheless are also entitled to exercise autonomy in refusing to act against their own views with respect to such surgery. The recent debate on the rising c/s rate (House of Lords 2000) has illuminated a number of issues pertaining to notions of consumer-led informed choice, not least because, in the case of c/s, the relative risks and benefits of this intervention have not been thoroughly evaluated. This particular debate also promises to stimulate wider discussion about the question of 'distributive justice', whereby scarce resources are fairly allocated to all users of the maternity services.

### **14.3.2 Negative attitudes amongst health professionals**

Many women, regardless of social class, were met with negative attitudes when health professionals disagreed with the choices they made. The following quotations, from practitioners on two different intervention sites, illustrate this issue with respect to women seeking a home birth:

*They (women who choose home delivery) are going to hear the negative things about home delivery when they walk in here (hospital antenatal clinic). It's scaremongery and all the horror stories. We've got one (consultant)...that frightens the life out of them... I actually warn them (women) about the consultant that will frighten them to death. She'll tell them all kinds of things, like we don't carry oxygen and that if she bleeds we don't have anything to stop it.* midwife intervention site

*Home deliveries are for pizzas and nothing else...women who choose to have home deliveries are very irresponsible... I know you can't stop them but I don't agree with them. If something does go wrong you haven't got a hope.* registrar intervention site

A study of GPs' attitudes towards women planning to give birth at home produced similar findings (Dodds and Newburn 1995). Choice and decision making, then, were heavily circumscribed by the norms of the dominant medical culture in which midwives did not usually see themselves as being powerful change agents:

*The choices tend to be limited in what's available to them (women)... If you've got an obstetrician who's very concerned about delivering a breech then his advice will reflect that. If a woman...wants a vaginal delivery, then I have to say the obstetricians put pressure on her. We can give the information but we can't control that side of it. You can't control another profession...* midwifery manager control site

Thus, even when women were knowledgeable and well informed and there was an evidence base which supported their decisions, they faced considerable pressures to make decisions which instead reflected local obstetric philosophy and practice.

## **14.4 ORGANISATIONAL BARRIERS TO INFORMED DECISION MAKING**

The majority of service providers did not appear to recognise that aspects relating to the organisation of antenatal care hampered women's ability to go against institutional 'tradition' to make informed choices about their care. This was particularly true for information concerning ultrasound, an intervention which has become so thoroughly routinised in maternity care that refusal is not seen as an option. Indeed, evidence from this study suggested that many women and health professionals would consider care to be substandard, or even unsafe, without the use of ultrasound in pregnancy.

The following two quotations, from a service user and a midwife, illustrate the 'reality gap' in the perception of choice from different positions:

*When I declined the dating scan, the receptionist said: 'Oh, I'll just go and see if you're allowed.'* (woman's emphasis) ... *that did annoy me, you're not allowed this, you're not allowed that... I didn't have a dating scan and I had a hassle over it right up to the end.* service user control site

*I don't think they (service users) understand they have a choice and can say no. I think they just go along with it because it's the accepted thing to do...* midwife control site

The local constraints on choice were such that the vast majority of women complied with suggested interventions and thus choice was often communicated as an ultimatum, with consent assumed rather than being explicitly sought. It was often only in the context of the research agenda, and sometimes long after the decision making event, that women became aware that other options existed.

A number of women attending focus groups on intervention sites were critical of the fact that midwives had not alerted them to the uncertainties surrounding information, for example that pertaining to ultrasound scanning. (See Chapter 15) That is not to suggest that women would necessarily have decided against a scan, just that they wished to make an informed choice and did not want to be protected, nor falsely reassured, by health professionals. It is worth noting that, on the occasions women did refer to information which questioned aspects of routine practices in maternity care, they almost always credited the media or, very occasionally, the internet, as the source. It was unusual for service users to volunteer that a health professional had provided explicit information about the disadvantages of routine interventions.

Some women were critical of the poor quality of the in-house literature they received. Samples of this literature, which were scrutinised by the researchers, revealed that most of it was undated, the photocopying was often of such poor quality as to make reading very difficult, errors in spelling and punctuation were common and evidence to support the claims made was generally lacking. The following quotation, from a service user, illustrates these points with respect to the administration of Vitamin K:

*Take the information they gave us about Vitamin K. First of all it was so badly photocopied it was almost unreadable. And the information was so biased. For instance they didn't say it had been linked with childhood cancers. They didn't mention that research at all, which is a bit stupid of them really, because it's so widely available. That's the thing that really got to me was being treated as if I didn't know anything. Like I was really stupid and had nothing to contribute...* service user intervention site

A small number of midwives on intervention sites suggested, however, that the MIDIRS Informed Choice leaflets had provided them with an important measure of quality against which to critique in-house information.

The organisation of the service made it difficult for spontaneous decision making because (service) planning often required that women be given information and asked to formulate a decision long in advance of an anticipated event. A number of women, especially primigravid women and those who had experienced a previous fetal loss or traumatic birth, volunteered that they were unable *'to think that far ahead...so you tend to just say anything that comes into your mind...'* Organisational pressures were such that the preferences expressed by women at the booking visit were often taken as firm decisions and only rarely did these decisions appear to be revisited later in pregnancy.

The choices women made then, largely reflected the policies of the local unit and the preferences of health professionals, particularly obstetricians. This observation reflects what has been described elsewhere: 'For many patients, what happens to them depends more on locally accepted practice than rigorous clinical evidence'; hence the phrase 'geography is destiny' (Farrell and Gilbert 1996;21).

## **14.5 HEALTH PROFESSIONALS AND THE CONCEPT OF INFORMED CHOICE**

Many health professionals contributing to this study genuinely believed that their interactions with women supported the concept of informed choice.

The following quotation, which concerns the delivery of the placenta, is worrying in that the midwife appears to think that she is offering women a choice between two different management approaches

where, in fact, she is following unit policy and merely offering women a choice between two oxytocic drugs:

*I: Do you usually discuss with women whether they would like an active, physiological, third stage?*

*M: Oh yes, I always give them a choice in third stage: syntometrine or syntocinon?*

Observational work suggested that health professionals generally lacked awareness and understanding of the complexity underpinning the concept of evidence-informed patient choice, although it should be said that many offered 'text book' definitions when invited to comment on this issue during follow-up interviews. Practitioners appeared to believe that simply by using the phrase 'informed choice' in their consultations with service users, they ensured that choice was conferred.

Literature on this subject however, suggests that evidence-informed patient choice requires an individual to be given explicit (research-based) information about the effectiveness of interventions (Entwistle et al 1998a and 1996a) which includes information about possible risks (Department of Health 1991). It also requires that the health professional involves the individual, to the degree that is wanted, in discussion and decision-making, recognises the importance of education to enable some patients to make use of information (Hope 1996) and appreciates the context and social influences in which informed decision making occurs (Bekker et al 1999). Considerable data were collected during this study which suggested that, whilst these are laudable aims, the concept, the process, and the outcomes of evidence-informed patient choice were poorly understood by the majority of those involved in both delivering, and receiving, maternity care.

The following quotation illustrates this from the perspective of a service user:

*Informed choice...I don't know really...it's not something I've thought about...I suppose it means having some information about whatever it is you decide to do...but there aren't many things that you have much choice about when you have a baby really are there?...I mean...you know...you go for your check-ups and then you have the baby...*

## **14.6 CONCLUSION**

The choices available to women attending for maternity care on the CRCT sites appeared to be moulded by institutional pressures, by the attitudes of the health professionals working therein and by the relationships women had with care providers, particularly with midwives. Across all sites, service users were observed to exercise little control or decision-making power in their encounters with providers of maternity services and few examples of alternative models of decision making (Stapleton 1997) were observed. This attitude of compliance towards the medical model, on the part of service providers and users, was a common feature of maternity care observed across all sites. Finally, there was little indication that choice or decision making on any intervention site was influenced by the evidence provided in the MIDIRS leaflets.

The findings from both the ethnographic and CRCT phases of this study suggest that health professionals generally held a rather simplistic understanding of the factors underpinning informed decision making. Many midwives on intervention sites also appeared to believe that, in offering service users an evidence based information tool, informed choice and decision making would inevitably result. The qualitative research has identified a number of intractable barriers which may need to be addressed if the efforts to transform the NHS to a service which is consumer sensitive, are to succeed. These include dismantling the paternalistic attitudes and hierarchical nature of the NHS; attending to health professionals' fears concerning litigation; reconciling the demands of an affluent society with high expectations for accessing expensive medical technologies in health care, with NHS priorities and current financial constraints.

## **14.7 SUMMARY OF THE MAIN POINTS:**

- ◆ A number of factors which promoted informed choice and decision making were identified:
  - the skill and confidence of the health professional affected the decisions made by service users. Data suggests that this also influences clinical outcome measures. There was some

evidence to suggest that women appreciated it when health professionals were honest with them, when they lacked skill and/or confidence.

- good quality information which is accurate, up to date and which is sensitively communicated, assisted informed choice and decision making. The MIDIRS Informed Choice leaflets provided some midwives with a quality control instrument against which to critique 'in-house' publications.
  - good communication skills and the ability of the health professional to tolerate a wide variety of different patterns of information seeking behaviours from service users allowed service users to make decisions in their own time. Women attending the smaller maternity units and those who enjoyed close and supportive relationships with their midwife were more likely to report this as being a feature of their care.
- ◆ A number of barriers to informed decision making were identified:
- informed decision making was a relatively new concept for both service users and providers and many respondents appeared to be uncertain of their role in this initiative. In particular, health professionals need assistance in supporting service users to achieve the degree of ownership in decision making with which they are comfortable.
  - fear of litigation created pressures on health professionals to 'get it right' in terms of the information they conveyed to women and the subsequent decisions they made. Many health professionals reported feeling responsible for the decisions made by service users and this turned to anxiety when the health professional feared that the decision could result in a poor outcome.
  - the paternalistic attitudes and hierarchical nature of the NHS worked against service users and providers, creating relationships based on mutual respect and trust.
  - the position of disadvantaged women could be worsened by initiatives which privilege written information and which require sophisticated language and reasoning skills.
  - diminishing clinical skills and professional confidence amongst health professionals reduced the range of options available for service users. This was particularly noted with respect to ECV and vaginal breech delivery and it is possible that the MIDIRS Informed Choice leaflet may have highlighted this deficit.
  - both primiparous and multiparous women stated that they had insufficient contact with midwives during the antenatal period and this was thought to adversely affect information flow and decision making. This issue was particularly noticeable in the early antenatal period when women faced complex decisions about screening for fetal abnormalities.
  - the emphasis on technological intervention and regular surveillance throughout the maternity care episode created difficulties when women made decisions which rejected this model of care. Such an emphasis also made it difficult for health professionals to appreciate that safe, alternative options existed.



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## Chapter 15: Focus Groups with Childbearing Women

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### 15.1 BACKGROUND

Towards the end of the data collection period of the study, additional research data was generated through focus group discussions. Gibbs (1997) suggests that there may be a role for focus groups to play at any stage in a study. While they may be used as a 'stand-alone' method, focus groups can, as Morgan (1998) argues, also be used to complement other methods and thus contribute to triangulation and validity checking. In this study, focus group data was generated in order to support or to challenge data collected through other methods, and in order to help sensitise the overall process of analysis.

### 15.2 METHODOLOGY

Focus groups are used to gather research data through the bringing together of individuals, by researchers, in order to discuss and reflect upon the issue that is the subject of the research within a group situation. The key characteristic that distinguishes the focus group from other qualitative data collection methods is its ability to generate data that is produced through interaction between participants (Morgan 1997, Greenbaum 1998, Barbour and Kitzinger 1999). What makes focus group data distinctive is, therefore, the impact of the group dynamic – enabling insights into the 'moving picture' as well as the 'snapshots' (Catterall and Maclaran 1997). It is through group interactions that participants' perspectives and experiences are highlighted. Interactions help to illustrate the values that people hold, and help to tease out their implicit and explicit beliefs about a situation. They also provide opportunities for individuals to reflect upon their own experiences and to reconsider the interpretations that they place upon them (Kitzinger 1994, 1995, 1996). Focus groups thus enable participants not only to tell their own stories but to reconsider and refine these through interaction with other participants.

#### 15.2.1 Benefits and limitations of focus groups

Focus groups enable researchers to find out why an issue is salient, as well as what is salient about it (Morgan 1988). They are therefore useful for exploring the gap between what people say and what they do (Lankshear 1993). Moreover, they have the advantage of being 'data rich, flexible, stimulating to the respondent, recall aiding, and cumulative and elaborative, over and above individual responses' (Frey and Fontana 1993).

A number of positive and less positive attributes of this method have been noted in the literature (Kitzinger 1996, Gibbs 1997, Morgan 1997, 1998, Greenbaum 1998, Barbour and Kitzinger 1999). Purported benefits of focus groups include their ability to facilitate discussion around sensitive topics. They are also argued to have the potential to empower participants who may be able to put their own experiences into a broader perspective: to 'shift from personal, self blaming psychological explanations to the exploration of structural solutions' (Kitzinger 1996 p.38). Focus group discussions may also generate more critical comments than other data collection methods and, in some circumstances, this may be considered a positive attribute: 'A method that facilitates the expression of criticism and the exploration of different types of solutions is invaluable if the aim of research is to improve services' (Kitzinger 1996 p.39).

However, a number of less positive attributes of focus groups also need to be recognised. The group dynamic may not be supportive of all participants, indeed, it may serve to silence individual voices of dissent. Focus groups may be inhibiting for an individual whose experiences lie outside the group norms.

Inevitable consequences of focus group participation include the inability to ensure confidentiality and anonymity to individuals, as all comment is shared within the group. Outside of the group, however, participants require the same consideration of confidentiality and anonymity as any other research

subjects. Thus, in the presentation of data from this research study, the identity of focus group participants has been protected by anonymising each group, by the allocation of pseudonyms to individuals and by preventing disclosure of other forms of individually identifiable information. A further, inevitable consequence of the focus group method concerns the researcher's limited ability to control the data that is collected: 'By its nature, focus group research is open ended and cannot be entirely predetermined' (Gibbs 1997 p.3).

Finally, the extent to which focus groups enable generalisation of findings to a whole population is limited. Data is collected from relatively small numbers of participants and it is unlikely that these will be representative. Nevertheless, focus group analyses may make an important contribution to research triangulation, as has already been noted.

### 15.3 DATA COLLECTION

There is some debate within the literature about the optimum size of focus groups. Suggestions range from 4 to 12 persons (MacIntosh 1993, Greenbaum 1998, Barbour and Kitzinger 1999). There is also some debate about the constitution of focus groups. As Gibbs (1993) points out, it is not always easy to identify the most appropriate participants for a focus group. In general, the advice often given is that interaction may be facilitated where there is sufficient homogeneity among participants for people to feel comfortable in the presence of others, while also ensuring sufficient heterogeneity to draw out diverse experiences and opinions (Gibbs 1997, Morgan 1998, Greenbaum 1998, Barbour and Kitzinger 1999).

Once the characteristics of focus group participants have been defined, recruitment commonly uses theoretical sampling in order to invite participation from as broad a range of the total study population as possible (Kitzinger 1996). In this study, two principle techniques were used to recruit to the focus groups. These were the use of key informants (community midwives) and the use of existing social networks. Focus groups were convened towards the end of the intervention period (Dec. 98 - Spring 99). The timing of this phase of data collection was partly defined by the logistics of a multi-method approach. However, the most important determinant was the timing of the intervention within the CRCT. It was felt that focus groups should not be convened until the intervention had become established. This would maximise the possibility of recruiting women postnatally, who *could* have been exposed to the intervention throughout their pregnancy.

Group discussions were held in two control sites. However, when participants spontaneously raised issues relevant to the content of the Informed Choice leaflets, the decision was taken to concentrate the remaining data collection in intervention sites. Six further focus groups were subsequently organised.

In order to maximise the potential of the focus group method, theoretical sampling informed the recruitment process. Thus, the intention was to recruit women who had in common, recent experience of motherhood. Women up to three months postnatally were invited to participate, though some women with babies more than three months old did attend. In order to draw out diverse experiences and opinions, attempts were made to ensure heterogeneity by accessing as wide a cross section of women as possible. Though Gibbs (1997) suggests that incentives will usually need to be offered for participants to take part in focus groups, no incentives were available to participants in this study. Thus, theoretical sampling was supplemented by pragmatic recruitment of postnatal women, who were willing and able to participate.

A range of strategies were used in order to recruit women to the groups. Two of the groups were set up by researchers. For one this involved accessing an existing social network (a postnatal group) while for the other, researchers drew upon a list of women's names that was supplied by key informants (midwives). For the remaining four groups, participants were selected and invited to attend by community midwives in each location.

Three of the groups were convened in local centres that were not associated with health care (a Church centre and leisure centres). The remaining three focus groups were held in local health centres which were convenient for, and familiar to, women and were available for use by the research team. Women were asked to devote a total of two hours of their time and babies generally stayed with their mothers throughout.



Group discussions were attended by three midwife-researchers. Two were usually present for each group with one researcher facilitating while the other acted as note-taker (though this was not always possible). Discussions were recorded on audio tape and transcribed verbatim.

### 15.3.1 Potential sources of bias

The recruitment by community midwives and use of venues which are associated with the health care provision could have biased the sample. The presence of the community midwife during one focus group could also have inhibited discussion. However, pressures of time in a large study and the need to maintain good relationships for on-going fieldwork, precluded other options.

## 15.4 METHOD OF ANALYSIS

Analysis of focus group data is, as Kitzinger (1996) points out, basically the same as for any qualitative data. Thus, analysis followed the conventions of grounded theorising already explicated. However, the distinctive interactions that take place in the generation of focus group data need to be reflected in data analysis. Analysis therefore needs to consider both the interactions between participants and the transcript content, the Snapshots (themes) and the Moving pictures (Catterall and Maclaran 1997). As Catterall and Maclaran (1997) point out, computer aided qualitative analysis programmes offer little to the researcher as tools for exploring interactions within focus groups. Focus group data for this study was thus analysed 'by hand'. Data from seven groups were initially analysed independently by members of the research team. A final, overall analysis of the entire data set was then undertaken by one member of the research team with continuing feedback from, and reference to, the other researchers to promote credibility and trustworthiness of the analytical process.

## 15.5 NUMBER AND CHARACTERISTICS OF WOMEN PARTICIPATING IN FOCUS GROUPS

	Site	Number of primiparous women	Number of multiparous women	Total number of women participating
1	Control	7	2	9
2	Control	2	3	5
3	Intervention	4	3	7
4	Intervention	6	5	11
5	Intervention	3	4	7
6	Intervention	11	0	11
7	Intervention	8	1	9
8	Intervention	9	2	11
		<b>50</b>	<b>20</b>	<b>70</b>

### 15.5.1 Type of birth experienced by participating women

The majority of women had vaginal births that took place within a hospital. Other types of births experienced by women in the focus groups were:

Type of birth / pattern of care	Multiparous women	Primiparous women	Total
Domino Bookings	2	2	4
Home Births	2	4	6
Births by Caesarean Section	3 <sup>1</sup>	7 <sup>2</sup>	10
			<b>20</b>

<sup>1</sup> One multiparous woman had a planned caesarean section (previous section): two had emergency caesareans, one for failure to progress (large baby) one for fetal distress.

<sup>2</sup> One primiparous woman had a planned caesarean section (breech baby): three had emergency caesareans, one for failure to progress, two for fetal distress. The reasons for three caesarean births are not known.

## 15.6 FINDINGS

Observational and interview data collected throughout this research study indicate that women tend to be silent in their formal interactions with maternity care services. However, the focus groups were convened in order to provide women with the opportunity to have their voices heard. Through the medium of the focus group, space was provided for women to develop their own narratives in relation to their birth experiences.

### 15.6.1 Moving pictures: interactions within focus groups

Interactions within focus groups are not only a crucial source of data in their own right, but they create what Catterall and Maclaran (1997) call the 'moving pictures', the context within which the 'snapshots' or analytical themes emerge. Analysis of these interactions is therefore presented first in the findings section in order to lend insights into 'what was happening in the group as well as why it might have been happening' (Catterall and Maclaran 1997 p.3).

(Pseudonyms have been applied throughout, in order to ensure participants' anonymity.)

#### 15.6.1.1 Forms of participation

Discussion within focus groups can be characterised as fluid and dynamic. Generally, women who had birth experiences that differed significantly from the remainder of the group tended to contribute less frequently to discussions. Thus, in focus group 1, Patsie who felt '*really, really pleased with the care*' and who described herself as being '*horribly normal all the way through*' made few contributions within a group that was frequently critical of the maternity care they had received. Women are highly sensitive to the experiences of others in the group and unwilling to set themselves up as having achieved a 'better' experience than others. In order to deny any personal responsibility for a positive outcome (and presumably the personal responsibility of others for a less positive outcome) women often attributed a good experience to 'Luck'. Women were lucky not to experience any complications during pregnancy, lucky to be able to make decisions concerning their experiences during labour, lucky to establish breastfeeding and lucky to live in an area where the '*midwives are great*'. (Focus groups 1, 5, 6, 7 and 8.)

Women do not wish to rub salt in the wounds of others in the group by heralding their own success stories. This may underlie the tendency for multiparous women to be strangely quiet in focus groups dominated by primiparous women. This tendency was observed on a number of occasions (in particular, focus groups 1, 7 and 8).

Birth stories incur moral or value judgements. Women whose experiences were at odds with the most highly valued outcomes also tended not to raise their voices and not to draw attention to their own experiences. Thus, where a 'normal' vaginal delivery is seen as proof of a woman's own ability to birth her baby, the 'normal' outcome to labour, women whose births had been aided by a caesarean section rarely drew attention to their mode of delivery. In focus group 4, for example, two women whose babies had been born by caesarean section made infrequent contributions to the discussion when it concerned issues related directly to the birth experience. This was not always the case, however. Women who were unhappy with their operative birth were likely to voice this. In these instances other group members proved to be important conduits through which individuals could tell their stories and confirm their dissatisfaction with their maternity care management. Focus group 2 was unusual in that three of the five participants had caesarean section births (two emergencies and one planned). In this group, one member played a very dominant role in the discussion, frequently drawing into the conversation the one other woman who had had an emergency caesarean section.

The general observation that women whose experiences were outside the group norms felt less willing or able to contribute, was not without important exceptions. Clearly personalities also play a part in determining the extent to which women feel able and willing to express opinions within a group and air their individual experiences. In focus groups 4 and 5, one participant from each group, who had birthed at home, made significant, frequent and prolonged contributions to discussions. It is also notable that in group 5, a second, multiparous woman who had birthed at home made many fewer contributions than the primiparous woman who had birthed at home.

### 15.6.1.2 Individuals' narratives

Throughout the data it is notable that individual women's reflections upon their maternity care experiences tend to be neither uniformly positive, nor uniformly negative. In focus group 2, Megan's narrative over time is illustrative. (Megan is a primiparous woman whose baby was born by emergency caesarean section for 'failure to progress'.)

*I opted for one of these Domino births and I've got to be honest, the midwife was wonderful. She came out to the house and she was absolutely brilliant. I couldn't sing her praises enough. She was so good. She came to the house, when I went to the bath she was behind me, rubbing my back. She was a dream.*

Subsequently, she was transferred to hospital and had an epidural:

*So anyway, the epidural went in, fine. There was no pain there, I was up on the bed it was wonderful, 10 hours, 15 hours, 20 hours, 25 hours (others start laughing) my midwife had long gone home. I was now on to the hospital midwives. My husband was exhausted, I was as happy as Larry and there was a stream of midwives coming and going they'd come on shifts and off shifts and I'd just keep talking, chatting away. Then after about 32 hours my husband said 'For God's sake what the hell is going on? This is ridiculous now, how far is she now?'*

Her partner's intervention, in Megan's account, initiated medical attention that rapidly led to an emergency caesarean section.

*There was no 'Do you mind having a caesarean', no talk about what was going to happen. I couldn't stop my jaws from shaking. I was so frightened.*

Later

*Anyway I had the caesarean everything went fine there wasn't a problem.*

Later

*This domino thing, that was wonderful, I've got to be honest it was wonderful.*

When elements of Megan's story are considered as discrete strands, they are liable to be interpreted as wholly positive or wholly negative. The challenge that focus group methodology presents to the researcher is therefore to understand the narrative as a whole, and not to impose upon a woman's story a coherence that does not do justice to the complexity of her experience. Thus, global statements of satisfaction need to be interpreted with some care as they may gloss over significant concerns or elements of dissatisfaction associated with specific interactions or stages of the maternity care process. Similarly, specific concerns may disguise aspects of care upon which women reflected positively and with real satisfaction. In addition, individual's positive experiences of maternity care may not always have emerged strongly, or may have been downplayed by women in groups within which the majority of participants had contrary experiences.

### 15.6.1.3 Focus group interactions: participants as sources of information

Within groups, women frequently sounded out views or explicitly sought information from other members, particularly from women with birth experiences different from their own.

Facilitator: *Did you all have your babies at (named hospital)?*

Nefyn: *I had mine in the house.*

Megan: *There's brave you were.*

Facilitator: *How did you get to that situation then?*

Nefyn: *My second one was born at home, she was an accident I didn't make it to the hospital, so I thought this time now I'll do it properly, get it sorted from the beginning.*

Cerys: *What's it like?*

Nefyn: *Brilliant, fabulous. It's just so relaxed. You're hanging about your own house just sitting about. You're just sitting there and you think right, I'm going to give birth, gave birth, had breakfast and went back to bed. It was lovely.*

Hafren: *I can't believe it. Just like that? I mean did you have the baby on the bed? On the floor?*

Nefyn: *It was my choice. I could have it wherever. I was going to have it downstairs because the kids were in bed, but the contractions started about half past three, we were watching telly but then I went upstairs because one of the kids woke, the other was still asleep. But I just fancied going back to bed, it was more comfortable. So I had him in bed. There were no complications or anything. The cord was wrapped round his neck but that wasn't a problem. I had gas and air.*

Hafren: *You had the gas and air in the house? (focus group 2)*

Other examples of information exchanges within focus groups concerned ultrasound scanning, spontaneous rupture of the membranes, a woman's right to choose which consultant she booked with for maternity care, and issues concerning antenatal care.

#### **15.6.1.4 Focus group interactions: participants as sources of reference**

Women also used the focus group to check out their definition of the situation with other participants. Great care was taken when articulating conflicting opinions or information but, where a woman was felt to be asserting a definition erroneously, this was noted and efforts to correct the error were made. Tanya, a primiparous woman who had had a planned home birth, was recounting a conversation her husband had had with another man, about stillbirths:

Tesni: *My husband and I said 'A stillborn baby is a baby that has actually been dead for 48 to 72 hours before the birth. That is a possibility'. He said 'That is the definition of what you're asking me, if the baby's stillborn.' He said 'Whether my wife is at hospital or at home, that baby will be born dead anyway'. This man turned round and said 'You're sick'. My husband said 'No, I've read up about it.' He is ignorant about things that happen.*

Facilitator: *Tilly, were you wanting to make a response there?*

Tilly: *I've got a very good friend who had a stillborn baby and it actually died during the labour.*

Saran: *Yes, there was a baby born stillborn when I was there.*

Facilitator: *Died during labour?*

Tesni: *Well I don't know if I've been misinformed but my understanding of the definition of stillborn was, according to my midwife, was the baby had been dead for some time.*

Jane: *Not necessarily.*

Tilly: *It could happen at home or at hospital, it's just a tragedy that happens. (focus group 4)*

#### **Anger**

Women not only 'checked out' information and interpretations, they also used exchanges with other group members to validate their own disquiet or anger. Jane, a primiparous woman who had given birth in hospital, described her experience of trying to give birth on a labour ward bed:

*Your bum falls between the cracks and you think Oh! you've got a dodgy bed here ... and then they say, Oh you can't push, and they write in my notes 'lack of maternal effort', five times. When you think about it you think, what a witch! (general laughter). How do you expect me to feel after twelve hours lying on this bed, chained up? (focus group 1).*

Anger fueled a number of interactions, particularly in the two focus groups held in the control sites. In focus group 2, women were discussing their efforts to breastfeed in the postnatal ward. Megan (whose narrative was drawn upon earlier) had been given a teat by a midwife to put onto her breast :

Megan: *Can you imagine, it wasn't even a nipple shield, it was a teat off a bottle. I just thought this is not funny and I was not impressed at all. That made me even worse. I know I'm in hysterics over it now.*

Hafren: *Did you make a complaint?*

Megan: *I said 'I'm going to see her, I'm going to see her face to face and I'm going to demand that this child has got to have a bottle'. How the hell can you feed a baby through that?*

Cerys: *Did you put that on your form when you went?*

Megan: *Yes, I did, because I was very angry about it. In the end then I finished up having to bottle feed, I was made to feel so bad because I was bottle feeding her.*

The 'advice' given by the midwife on this occasion was clearly inappropriate. However, there are other dimensions to this narrative. The construction of stories by women helps to give coherence and meaning to their experiences (Kirkham 1997). Where a woman perceives that she has failed to achieve something of great cultural value, such as breastfeeding, she must make sense of this 'failure' and rationalise it, in terms of her own sense of self. Interactions within the focus group are illustrative of the processes through which Megan constructs her infant feeding story, and negotiates it with others (Linde 1993).

Emotional exchanges were not confined to the groups convened in the control sites. There were also examples of anger in the intervention sites. In focus group 8, women's discussion of their experiences of labour fueled the following emotional exchange:

Ann: *I didn't like the Doctor's attitude at all. I found then, well I'd been in labour for 32 hours, I'd been pushing for 2 hours. The doctor came into the room and said 'I don't call that a push!' I could have hit him (Gasps from the others). I could have done without that, he could have said 'You've done really well but we're going to have to give you a helping hand'.*

Lydia: *When you've been pushing for so long, you just can't do it. The midwives are trying to encourage you 'The baby's nearly there, it's coming', but if I was doing that well the baby would have been born by now.*

Ann: *You think you're pushing and it's certainly the best you can do.*

Meryl: *There was actually a point when they did actually ignore what I was saying.*

In a number of focus groups, the dynamics of the interactions between participants were such that women felt able to voice anger as they reflected on aspects of their maternity care. Other women who have recently birthed constitute informed commentators on each participant's story. Anger that is validated by other group members becomes enhanced within the individual's birth story. However, interpersonal support was not only prompted by anger, but could be advanced to comfort women who had reflected negatively on their own experiences during group interactions. Joanne had tried breastfeeding, but had quickly changed to artificial feeding.

Joanne: *I feel really disappointed now seeing you (another group participant) (breast) feeding here, I'd love to do it.*

Delwen: *But you did have a go didn't you, if you hadn't tried and then felt guilty that's different, but you had a go. (focus group 7)*

### **15.6.2 Themes: snapshots within focus groups**

The following themes emerge from analysis of data generated in the process of interactions described above.

### **15.6.2.1 The flow of information**

#### **Information needs: timing**

Access to information about the childbearing process was seen to be of fundamental importance to women. The possibility that information could induce anxiety was raised by only two, primiparous women (focus group 2 and 8). However, it was clear that this was associated with the timing of information. Information accessed after the event could raise hitherto unrecognized questions about potential risk. Megan, a participant in a control site, for example, explained that receipt of the research questionnaire had raised safety issues for her in relation to ultrasound scanning. Hafren (focus group 2) described how she had received information 'quite late':

*When I was reading through that I thought 'Oh my God, I wished I would have known this before'. My neighbor had 6 cats, and I have never worn gloves to do the gardening, and things about the Folic Acid and cat's poo. Then I suddenly panicked. I was worried. I would have appreciated having that much earlier.*

There was an overwhelming sense within the data of the importance that women attached to relevant and timely information. In part this was as a defence against the unknown; being prepared 'just in case'.

*I think the unknown is frightening isn't it? But at least if you have an idea of what would happen in the eventuality then you can have that preparation in your mind, don't you? There's things we don't want to happen but sometimes, for the baby's benefit, then that will occur, and if that was to happen you wouldn't want yourself to be frightened. .... so if you've read and you have the benefit, I think it's going to help. (focus group 6)*

Women express a fundamental need for information throughout the childbearing process. Articulation of this need suggests that they require information in order to equip themselves to negotiate through the maternity care system, and to enable them to understand and make decisions in relation to their maternity care experiences.

#### **Areas of information need**

Women made reference to very many information needs, in relation to a wide range of maternity issues and experiences. Information needs ranged from the general to the context specific. Not surprisingly, primiparous women articulated substantially more information needs than multiparous women: some issues were mentioned by both primiparous and multiparous women.

Information needs articulated by primiparous women:

- Antenatal screening
- Duration of pregnancy (post-term)
- Onset of labour
- Induction (prostin)
- Length of labour
- After-pains
- Sutures
- Infant feeding: breast feeding and artificial feeding
- Life changes (tiredness, blood loss, depression, social networks)

Information needs articulated by multiparous women:

- Infant feeding: breast feeding
- Specific experiences (manual removal of the placenta)
- Life changes (tiredness, effects of a new baby on social networks)

Three areas of information need dominated women's discussions. Two of these (antenatal screening and infant feeding) relate directly to the subject matter of the Informed Choice leaflets. The third area of concern related to the onset of labour. Thus, it is notable that the CRCT element of this research study examined the impact of leaflets that impacted on a minority of the topic areas identified by women.

## **Antenatal screening**

Issues concerning antenatal screening were particularly evident in focus groups convened in control sites. Some women felt that information given with respect to antenatal screening had been very positive.

*At first I said to my husband 'Well, Dear God, I've only just found out I'm pregnant and she's telling me to think about this'. But in hindsight, I thought she was quite right because we talked about it in depth, and we had time to sort out our thoughts. I did ask the midwife a lot, I had a lot of questions for her and then obviously I talked about it a lot with my husband. (focus group 1)*

A positive experience was thus tied as much to the timing of information as to the quantity and quality of information received. Women suggested that information given in relation to antenatal serum screening tended to be routinised and geared towards encouraging them to have the tests carried out. More detailed information and advice that would enable women to understand the implications of a positive screen was not routinely provided, but was available if women sought it out. Women who screened positive for Downs syndrome were able to access appropriate information from midwives. However, they tended to experience a period of intense anxiety after the test result, before they could talk things over with a knowledgeable professional.

*The only thing through the pregnancy was, I became at high risk for Down's. I wished I'd known more information before actually I was told .... I was told over the telephone by the hospital which devastated me really, it's not something that you really go into an awful lot before it happens. I just wished I'd have had more information.*

This woman went on to comment further:

*When I actually went to see the hospital midwife about the options, she went completely through everything because I was so upset really, and she put my mind at rest then and there really and that was fabulous and I felt that maybe if I'd have either had more information to start off with, or if I'd had a more appropriate way of telling me and been asked to go in and discuss the results, it would have been better.  
(focus group 1)*

## **The onset of labour**

Primiparous women described great uncertainty around the onset of labour. The concerns expressed in control group discussions were closely mirrored in the intervention sites. Many women felt that they had insufficient understanding of the process of labour and insufficient information to interpret what was happening to them.

*I was amazed really that my waters had gone with the amount of water that came. I didn't understand what was going on at that stage. I was more prepared for the next, more intense stage of labour than I was for the early stages. (focus group 6)*

Women experienced great difficulty in comparing their embodied experiences with the objective descriptions of labour available from books and other written materials. One woman describes how she had taken out all her books and found contradictory descriptions that were very confusing.

*They said every 5 minutes and I timed it and I was doing 2 minutes, 2 minutes, 7 minutes, 8 minutes. I wanted somebody, a voice to say to me 'Yes, you're in labour'. I wanted somebody at the beginning of it to come to the house and say 'Yes, go now'. If there was somebody you could, phone who could go round. Just somebody to say 'Go in now'. (focus group 6)*

Contact with community midwives in early labour, either over the telephone or through a home visit, was therefore spoken about very positively. The minority of women who described this option were greatly appreciative of it as they felt more able to interact appropriately with the maternity care services and therefore less likely to either 'leave it too late' or to go into hospital 'too early'.

### **Infant feeding choices**

The need for information, advice and support around infant feeding choices was raised in all the focus groups. Factual information was sought by women in relation to both breast feeding and artificial feeding. Women described interactions with health professionals in which information had been exchanged which they considered, either at the time or subsequently, to be incorrect or unhelpful. Indeed, midwives would themselves seem to have been lacking in factual knowledge at times. Thus, Betsan, a primiparous woman in focus group 1, recounts her experience of breast feeding in the postnatal ward.

*I've actually been to see a breast feeding counsellor, I just found the attitude among the midwives was, 'Well, everybody gets sore and cracked nipples', it kept coming back to the way the baby was going on and it turns out that she thinks it's a lollipop and she just licks (laughter) and she won't open her mouth. But we persevered with it.*

Some women did have access to appropriate and readily available support from midwives. When women receive factual knowledge and support, enabling them to develop experiential knowledge of breast feeding, then they report a positive and satisfying experience. Alwen, a primiparous woman recollects:

*'I didn't have any problems with it at all. I'd read up on it a lot as well and I had a lot of help from the community midwives. Even in hospital I found they were quite helpful, suggesting different tips and things like that. How to get into position. I thought they were quite good at hospital, yes.'* (focus group 6)

However, it was much more common for women to give voice to unmet need with respect to breast feeding support. Women's inability to access adequate support was a dominant concern in discussions of infant feeding. Women's narratives illustrate the difficulties that they experienced in developing embodied knowledge through the process of breast feeding their own child. Collwen had been left alone in the delivery room after the birth of her first baby. During this time she had '*stuck him on*' the breast.

*That was it. I was just left to it. They thought because I had done that I knew what I was doing and he was fine, but he wasn't. He was like 24 hours permanently hungry and not getting anything.* (focus group 4)

In their discourses, women in the focus groups demonstrate a need for knowledge in diverse areas that is both theoretical and experiential or embodied. Thus, while information needs in relation to antenatal screening and the onset of labour were referred to predominantly in the context of factual or theoretical knowledge, women's need for knowledge in relation to breast feeding was articulated predominately in terms of experiential knowledge. However, in practice, these needs are intricately interlinked. The context within which information is exchanged, the relationship a woman has with health care professionals and the timing of the exchange, all impact directly upon her experience of effective information flow.

#### **15.6.2.2 Information seeking**

##### **Whose responsibility?**

It is clear that some women entered pregnancy with the expectation that they would be provided with all necessary information by knowledgeable professionals. Primiparous women had often not anticipated the need to actively seek out information and some reflected negatively on the responsibility that they felt had been laid upon them. Moreover, women suggest that exercising this responsibility can be problematic, at least initially, in a first pregnancy as they do not know what their information needs are, and they therefore experience considerable difficulties in developing appropriate knowledge.

*Having not gone through a pregnancy before, I didn't know what questions to ask. I was being led by what they told me. I didn't really know what I was doing, just used to turn up for my appointments and luckily everything was all right. I didn't know what I should be asking.* (focus group 5)



*I think it's difficult because you don't know what options are available and you don't know what questions to ask, but then your midwife doesn't know what concerns you've got, so its sort of both of you working in the dark. (focus group 5)*

Particularly in the early months of pregnancy, women can feel disorientated, 'floating' or 'adrift'. This confusing situation may be exacerbated by patterns of maternity care provision that provide infrequent contact with professionals.

*I think I first saw the midwife, I was eight or nine weeks and then she made an appointment to see you again at 23 weeks, I know you've got an appointment in the hospital at 16 weeks, but then at the 23 weeks appointment she told me about the classes, then things got better. But up to then, from 8 to 23 weeks I didn't know what to do. (Anita, a primiparous woman in focus group 7)*

However, even when contact is made with doctors and midwives, sufficient information to meet women's needs is not always forthcoming.

*I felt I had to do a lot of finding out myself, and I had to refer myself to another surgery. I felt that, you know, it was my responsibility really. I felt a bit out on a limb at first, I felt 'Oh no, what am I going to do?' I didn't feel that .. I felt that I needed more information than the doctor could offer. (Brenda, primiparous woman, focus group 1)*

Women quickly learn that they must actively seek out information for themselves and they may take on this responsibility with alacrity. Given that primiparous women articulated a more diverse range of information needs, it is not surprising that information seeking was frequently illustrated in their contributions to group discussions.

*I read everything, every parent magazine, what to expect when you're expecting. I talked to all my girlfriends and I was getting conflicting advice of course but at least I was able to take the information and digest it and say 'OK, well this is what I'm going to choose to do for my pregnancy and my baby'. (focus group 6)*

Thus, women recognise early in their pregnancy, that the responsibility for finding out lies on their own shoulders. They do not feel able to rely on midwives or doctors to provide relevant and timely information.

*You just have to get it all from books really and magazines. You don't really get told much at all. (focus group 2)*

*I think if I hadn't found out things from friends who've had babies before, everything would have been a damn sight harder (Yes of agreement). I couldn't have got by relying on midwives and the doctors at all. (focus group 8)*

### **Sources of information**

In the seeking of information, women access a range of sources. Reference was made to information derived from health professionals, predominantly midwives and doctors. However, less frequent mention was also made to other health professionals including ultrasonographers and health visitors. Information giving by health professionals takes place predominantly within the context of formal clinic encounters, such as antenatal check ups. Some women also noted the ability to contact (usually community based) midwives if and when required. Parentcraft sessions were also frequently mentioned though women's experiences of these varied widely. There were reports of highly effective parentcraft provision with midwives sharing information in imaginative and accessible ways. Parentcraft is appraised positively when women feel they have been given information that is useful and which increases their knowledge. Learning from others in the group is considered as important as learning from professionals. A 'good' session is one that is interactive in nature and reactive to the needs of participants. Mwynen speaks very positively of the midwife who facilitated the parentcraft sessions that she attended. She also illustrates the benefits of continuity, being able to revisit issues with the same midwife.

*She would discuss everything in full if you wanted to discuss it (others agree). So she briefly went over something, if no one was really interested in it she didn't bother going any further. I found she went into*

*quite a bit of depth about things. And if you went to relaxation class and you wanted to discuss something you would. And if you went the following week, and you still hadn't understood something, she would keep going over it until you felt comfortable with it. She was always there if you wanted any more information about something. If you wanted to know more, she would go and find it. Like she would look at magazines and things. She'd like, go to Tesco's and look at magazines and then recommend 'Right, go and get that magazine, It's got everything in it about whatever'. She was always there to give you that information. (Others agree). (focus group 7)*

Women also appreciate parentcraft sessions as social occasions that can stimulate the development of a supportive network through pregnancy and beyond.

However, this positive response to parentcraft is by no means universal. Sessions provided by some individuals were denounced as 'boring' and 'hopeless' and were considered to be too didactic, inflexible and inappropriately focused (focus groups 2 and 7).

Other women are also perceived as valuable sources of childbearing information. Women access procedural knowledge from those with recent experience of the maternity care services. However, other women were most frequently referred to as valuable sources of experiential knowledge, particularly in relation to breast feeding. As Myfi, a primiparous woman in focus group 6 suggests, *'it worked for her, I'll give it a go'*.

Group participants also made occasional reference to visual media (videos and the television) as sources of information. However, the medium accessed most frequently by women during pregnancy was written text, either in the form of books, magazines or leaflets. Emma's diary received a consistently negative response from women, being perceived as *'crap'* (focus groups 1 and 8) and *'awful; total waste of time'* (focus group 2). This publication is felt by women to be patronising and demeaning.

*Is it written for children? I couldn't read it, I read the first two pages and I couldn't read no more, I thought this must be for children. This must be for 12 year old girls or something. (focus group 2)*

By contrast, the Health Education Authority's publication the Pregnancy Book, was spontaneously alluded to by women as a useful source throughout pregnancy (Health Education Authority 1997). Information is considered to be well presented, being both comprehensive and easy to read and digest (focus groups 1, 2 and 7). It *'explains everything so well'* (focus group 7). Other commercially available books were also valued as sources of information (such as the Mothercare book and publications by Miriam Stoppard) though the price of some of these was seen by some to be prohibitive.

### **Informed Choice leaflets**

Informed Choice leaflets were rarely referred to spontaneously within groups during discussions of sources of information. In the two control sites, two women made unprompted reference to leaflets; one to a leaflet on breech birth and one to a leaflet concerned with antenatal screening<sup>3</sup>. In neither case did the women comment on the usefulness of these sources, merely noting that they had been given out. In focus group discussions held in the intervention sites, facilitators sought to draw out respondents' views of the Informed Choice leaflets. However this proved to be extremely difficult. One strategy used was to ask participants to talk about sources of information. In focus group 3, this elicited no mention of the Informed Choice leaflets at all. In focus group 4, leaflets were mentioned briefly after a prompt for women to consider gaps in the information that they had received. However, some concern was expressed about the extent to which they transferred responsibility for knowing from professionals to women.

*Because there's so much information in the leaflets that you get these days they expect you to know and to have read it and know what's what. (focus group 4)*

Generally, individual women could identify only a small number of leaflets. Some women had not been given leaflets but had seen them, while others were not aware of ever having seen the leaflets. The variability in patterns of leaflet use, described in other sections of this report, was confirmed by women

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<sup>3</sup> These may have been informed choice leaflets or information produced 'in house'.

in the focus groups. When prompted, women could identify the content of some though not all of the MIDIRS leaflets. For example, in focus group 4, women offered the following list of subjects; alcohol, smoking in pregnancy, breast feeding, positions in labour, ultrasound scanning, Downs' syndrome, diseases contracted from animals. Clearly there is overlap in their recall with leaflets from other sources. In addition, in recollecting the subject of the leaflets, they provide a strong indication of the dominant message that they have taken from them. Thus we can assume that 'diseases contracted from animals' may well have derived from a leaflet concerning toxoplasmosis. Moreover, it was clear that women who had received selected leaflets from the Informed Choice set, had found this confusing and struggled to understand the logic of selection:

Lisa: .... *the other thing with the missing numbers, I did think well what was number whatever, I thought what aren't they telling me?*

Rhianwen: *That was exactly what I thought.*

Lisa: *You think what information have they left out?*

Rhianwen: *Why aren't they telling me everything? What information are they holding from me?* (focus group 5)

Group facilitators also raised the subject matter of some of the MIDIRS leaflets for discussion. Sometimes this included a visual prompt using specific leaflets. Even this direct reference did not always evoke discussion of the MIDIRS leaflets and where they were mentioned this was commonly only in passing, with the conversation quickly moving to other sources or issues. The following extract, from a discussion in focus group 7, is typical:

Facilitator: *Are any of these leaflets familiar?* (Showing scans, screening, place of birth, alcohol)

LOTS OF YES'S

Tanwen: *I had those in parentcraft. I was about twenty eight weeks then. I had all my information about the test through the Boots magazine. The 'Mother and Baby' one in quite informative. In the early weeks I didn't know about these classes and I bought that book when I was first pregnant. It goes from week one to week forty. It's got a lot of information in there. I found going to the clinic, well, you're just there for the test and they don't really go into explaining what you're having done.*

The women in focus group 6 were, however, prompted to discuss the relative value of different textual sources:

Nerys: *Leaflets are topical especially at the classes, if you've covered an area and get handed a leaflet, and you listen and go home and read it again perhaps, and it just reiterates what's been said, just topically. Books I think, you tend to look back on when you've got a question.*

Myfi: *They've got different things in them haven't they? The leaflets are only going to tell you about that and it doesn't lead onto the next thing whereas with the book you can look back at different things as well.*

Nerys: *I think either/or is good. They're both information pieces and you do have questions.*

Myfi: *They were quite handy at the parentcraft again, because you talk a lot about different things in the parentcraft every week and then you get the leaflets and you forget. 'What did she say about that'. You've got the leaflet then that you've taken home from that night and you can have a look at it when you get home and think 'Oh, yes that's what she said'. You do tend to forget a lot of things I think.*

Though it proved difficult to stimulate discussion of the Informed Choice leaflets as a discrete source of information, this does not mean that women do not value them. Rather, they are perceived as one of a multitude of potential sources. Although they were described as 'very good' and 'balanced' (focus groups 4 and 5) women did not generally make a qualitative distinction between this textual source of information and others. Though many women voiced a preference for the *Pregnancy Book* (Health Education Authority 1997) there would appear to be no 'gold standard'. Furthermore, there is no evidence in women's narratives that discourses around research-based information, or evidence based

care, have influenced this population of childbearing women. In addition, there would appear to be some confusion between scientific knowledge and experiential knowledge:

Facilitator: *OK, one of the things it says on the leaflets is that they are based on research, is that important to you?*

Dwysan: *Yes, because it's what other people have been through. Until you go through something yourself you don't realise, people can tell you, but then it's totally different when you go through it.* (focus group 7)

What is clear, is that women seek to access multiple sources of information. Women are eclectic in their information gathering: *'the more you get the better. You're not left scrapping about for information'* (focus group 5). Thus, information seeking for the majority of women is a proactive pursuit, requiring access to multiple sources that the individual considers, and weighs up, in the light of her own experiences and needs.

### **15.6.2.3 Norms of practice**

Women experience strong normative pressures to conform to existing patterns of care, though this is not necessarily experienced as problematic. However, interactions within focus groups clearly demonstrate that practice norms can make women's information needs invisible, and disguise the potential for women to make choices and influence their maternity care. A recurring example of unrecognised information need concerned the use of ultrasound scanning during pregnancy.

Megan: *At the antenatal I just mentioned it, I said I'd had this survey through from Sheffield University as well and I'd seen the questionnaire about scans and I thought, hang on! What are they asking that for? 'Were you given the option for having a scan?' And I thought, every pregnant woman is immediately given a scan because it's just the norm. I filled it in and gave my views on it and then when I asked about it in the health centre, it was 'Don't be silly, it's not proven' and 'Don't worry, everything will be fine'. But I just felt I would have liked it to have been pointed out and just said there could be dangers but they are very, very remote. I would have been satisfied then, whereas now I'll always wonder should I have been told. But there again, perhaps I'm just a worrier. I'll worry about everything!*

Facilitator: *Can anybody else relate to that, or recall your scans?*

Hafren: *None, no information at all.* [Shaking of heads]

Megan: *Just go and have your scan.*

Nefyn: *Yeah. Just go for a scan, that's it. I had load of scans with my first because he was so small and they wanted him scanned every couple of months. If there is a risk, then you should be told because I had so many. I didn't realise that there were any risks.* (focus group 2)

Though this discussion took place within one of the control sites, similar experiences were also recounted by women in intervention sites. Jude remarks that *'It didn't occur to me to think whether they were necessary or not because everybody had one as a matter of course'* (focus group 6). Thus norms of practice strongly influence women's expectations and experiences of maternity care. There is a well documented demand for scans from women and focus group participants reflected this. Women appreciate the reassurance that scans may give when they are able to visualise a live and apparently healthy child. However, this demand may not always be informed.

Moreover, the data strongly suggest that the use of ultrasound scans in early pregnancy is perceived by women to have protective qualities: a panacea against miscarriage. Women with previous miscarriages spoke of the reassurance that an early scan gave (focus groups 1, 3 and 5).

*After having a miscarriage you are promised so much, like next time they'll be looking after you, looking out for you.* (focus group 1)

*I felt I had better care because I'd had a miscarriage last time. .... This time you ask for an early scan and had one 8 weeks, 12 weeks, 16 weeks. It was brilliant this time.* (focus group 5)

This is a worrying indication that warrants further exploration that is beyond the scope of this study.

Practice norms that mean that 'everybody has one or more' scans (focus group 6) do not, however, overshadow all women's information needs. Interestingly, when women's experiences of scanning were discussed, the issues that were raised often lay outside of the content of the Informed Choice leaflet. In particular, women feel unable to ask for adequate explanation and they therefore lack the information that they require to interpret the findings that are presented to them. This is associated with the perception that radiography departments are overly pressured and the feeling that (especially where scan results are 'within normal parameters') women are quickly moved on.

*I would have liked maybe a little bit more explaining (Yes. Agreement from the others) by the radiographers. Explaining rather than they are just writing it down, and somebody else is sometimes there, writing it down, to point out what they are seeing and what it means. Like, that's a bit longer or bigger than usual or whatever. I just felt that if we were asking questions well we were in the way a bit. They want to get you out, that's your scan done, it looks OK. I would have felt happier, especially for my partner, because it's his first baby. He was asking me then when we came out 'Is that the right size? Is that the right length? Is that the normal length?' You know, trying to make sense of the graph they gave you. Perhaps they should try and explain a little bit more. (focus group 2)*

#### **15.6.2.4 Power hierarchies**

Norms of practice are, of course, sustained by underlying power relationships within the maternity care setting. Women quickly become orientated to the dominant power hierarchies, as was evidenced in narratives produced in both control and intervention-site focus groups. As Petra, a multiparous woman in focus group 1 remarks, 'they're all in awe of the consultants' (focus group 1). She went on later to explain:

*You get the distinct impression that you wish your midwife was given more power, than they are ... it comes to a certain question which they have to refer to a doctor and you think, but they know! They're in there .... But they still have to defer, they should be empowered to do this.*

Thus doctors are seen to have ultimate control over women's maternity care experiences. Claire, a multiparous woman in focus group 5 discusses the influence of the midwife:

*In the later stage they don't seem to have as much say in your care really. It's down to the consultant whether he chooses, or whether he recommends to you if the baby should be born.*

Not surprisingly, therefore, there was evidence that women were aware that midwives were also constrained by dominant norms of appropriate care. For an individual to confront these norms and support women in actions that go against preferred 'ways of doing', is highly problematic. Midwives are often perceived to be constrained by their position within the professional hierarchy and by the responsibility that they feel to adhere to contemporary dogma. As individuals, midwives may challenge authoritative knowledge (Jordan, 1997) but this is often not done openly. On occasions, women recalled midwives using subterfuge to support them in choices that challenged the dominant norms. This support is therefore both hidden from wider scrutiny and individualised.

*The midwife couldn't say to me, bottle feed your baby. Because it was a breast feeding hospital she said 'Don't say who I am. Don't say I've said this, but if you get in a state, bottle feed her'. But she wasn't allowed to say that to me. (focus group 4)*

#### **Professionals' influence on the flow of information**

Women experience maternity care hierarchies very directly and clearly recognise the influence that both doctors and midwives exert upon the flow of information and the provision of support within care settings. There are many examples cited by women of the pressure (whether overt or covert) to follow conventional patterns of care. As one woman in a control site comments: 'You tend to do as you're told' (focus group 2). Mona, a multiparous woman in focus group 5 concurs: with her first child she describes herself as 'not having a clue. You just go along with whatever they are saying'. Thus it is difficult for women to bring alternative childbirth perspectives into encounters with health professionals, and even more difficult to sustain these in the face of professional opposition.

*You start to doubt yourself if you think differently to the midwife or whoever is advising you, and if you don't agree, you think, 'Oh! I must be wrong', or at least, I did. (focus group 1)*

Women describe feeling 'belittled' and 'talked down to' when they question norms or challenge practice. They are told that they are being 'silly' or their questions are 'poo-pood' (focus group 2 and 4). Staff can curtail discussion of a subject by refusing to acknowledge the legitimacy of information needs (for example, in relation to bottle feeding) (focus groups 2 and 4). Professionals are perceived to get 'cranky' (focus group 4) when women seek information that does not actively promote accepted ways of doing. Occasionally, they directly threaten the care available. A request for a home birth from a woman in focus group 5, for example, provoked her general practitioner to threaten to withdraw care. A threat that was not, subsequently, carried out.

*I do think you can be bullied into things, particularly if you're not strong-minded about what you want. It's quite easy for them to bully you, they say things like 'The baby will die' or whatever if you don't do so and so. Or 'You'll be in danger'. It's very easy for them because you don't really understand the medical stuff. (focus group 5)*

### **Soliciting support**

A dominant theme in women's narratives was the extent to which they experienced difficulties in asking professionals for support. Some women had very positive experiences describing what they perceived to be very good quality care. Key elements of good care were the ability to get information and help when needed and women's perceptions that staff 'made time for them' (focus groups 7 and 8). When this happened, women were highly appreciative, describing midwives as 'brilliant' and 'very, very supportive' (focus group 6). This positive relationship was often contingent, however, upon staff providing openings for women. Some midwives, and occasionally doctors, were seen to have deliberately striven to provide opportunities for women to ask questions or solicit help. In these instances, women reported positive and effective flow of information and support. Cerys, a primiparous woman in focus group 2, describes what made one midwife 'really good'.

*She kept on coming back to me to make sure I was all right. She sat on my bed and explained, and listened, and reassured me whereas he (a doctor) just gave me a row and went.*

However, where health care professionals are unable or unwilling to provide openings to women to help bridge the power divides, women experience real difficulties in getting the support they need. In these circumstances, women's principal concerns are not so much for factual or theoretical information, to which they often seek access from other sources, but for support that would enable them to develop procedural knowledge, acquire particular skills or develop other forms of experiential knowledge (especially around breast feeding). Women thus strive to develop strategies that do not challenge or confront professionals. Erin, a primiparous woman in focus group 8, suggests that approaches that are seen as opportunistic, rather than premeditated, are received less problematically by midwives and are therefore more likely to invoke the required response (help).

*You wait until somebody walks past. You felt awkward sometimes having to ask.*

Her strategy had been successful. Ellen acknowledges that the midwives were very good: *'I had to ask for help but as soon as I did ask they were very willing to help'* .

Lack of continuity of staff can make help seeking even more problematic for women.

*They are just fleeting in and out, you never know who you're going to see, from one minute to the next. I felt I never knew who they were. Nobody ever introduced themselves, so I never knew who to ask for, or anything. Sometimes somebody would say 'Has this been done?' And you'd feel stupid saying 'I'm not sure, but this lady did this and that lady did that'. It's not very nice. Little things really get to you. (focus group 8)*

Women's reticence in actively seeking help and support when it is needed, can mean that they wait until they perceive their problem or difficulty to be severe. Megan recalls her attempts at breast feeding in the postnatal ward:

*It was the middle of the night and she was screaming her head off, I was getting more and more upset. The more upset I was getting, the worse she was getting. Anyway this (pause) woman ... horrendous midwife .... I said, 'Please, can you help me? I'm in a pickle now, she's starving'. She (the midwife) did*

*try and whatever, the first time. But after the first time she refused to come back and kept sending an auxiliary in. Fair play to this auxiliary, I didn't think it was her job.* (focus group 2)

Moreover, women can find it difficult to assert their need for the scarce resource of professional support over the needs of others. When professionals are not proactive in encouraging women to seek help, they may ration their own needs in relation to the perceived needs of others.

*You can feel so guilty though, there were two women that had had caesareans when I was in and another one had to come back in because her baby wasn't feeding very well. So you know there are women there whose needs are greater, so you feel really guilty pushing the button.* (focus group 8)

Difficulties in accessing professional support can mean that women draw upon others for help. In hospital wards, women may overcome their reticence in calling upon midwives, by helping each other. Thus more experienced women may offer assistance to women with less experience. Anita, a primiparous woman in focus group 7, recalls one mother in her postnatal ward:

*She didn't have a clue how to change a nappy. It was as though she was just left there, and myself and the other girl in the room had to show her and help her. She wouldn't call anybody. She didn't like to call for help.*

### **Pressure of work and its influence upon the flow of information**

Women are very sensitive to the pressures that midwives work under and are aware of the profound affects this pressure may have on information flow and access to support. Focus group data clearly illustrate the extent to which pressure of work within the maternity care system detrimentally influences women's childbearing experiences. We have already noted the difficulties that women articulate in asking for explanation of ultrasound scan results in busy radiography departments. Such difficulties are also experienced in other contexts. Ward midwives, and sometimes community midwives, are perceived to be 'very busy' (focus groups 5 and 8). Women are unwilling to trouble busy midwives. 'I didn't want to bother them. I didn't know what to do, but I didn't want to bother them' (focus group 7). This can be very distressing when women are left feeling unsupported.

*If it's busy it's, like, they've no time for you. I know it's like a factory, but at the end of the day if you're first time, like we all are, you haven't a clue and I felt I just wanted to cry, and I wasn't getting the help I wanted.* (focus group 6)

Pressure of work may even lead to a situation in which women experience physical discomfort. Dwysan, a primiparous woman in focus group 7, describes a session when she was attached to a cardiocograph to enable electronic monitoring of her baby's heartbeat to take place:

*It was the fact that they'd say only another 5 minutes and, like, 45 minutes later you were still on it and desperate to go to the loo. And you think I've got to get up. But you hang on until she comes back. Another 5 minutes perhaps. You don't want to be a nuisance but that would go to quarter of an hour, and that's how you went on.*

When midwives fail to acknowledge to women the constraints that they experience through pressure of work they may promise support that they are subsequently unable to provide.

*During the day the midwives were so busy they just didn't have enough time. You know, when she (baby) didn't latch on in the first 5 minutes, they'd say 'Don't worry I'll come back', but they didn't.* (focus group 8)

Women are much more forgiving of the effects that pressure of work has upon them, if midwives acknowledge the potentially detrimental influence on care and allow women an active role in mediating this. Myfi, a primiparous woman speaking in focus group 6, explains:

*They did say that in the beginning, didn't they, that if you think they've forgotten you, you need to call them and say, 'Look, this had been on for half an hour and 40 minutes is about the limit'. They've got so many other things on their minds.*

However, women are also adamant that the barriers to communication and the constraints upon interactions that they experience, cannot always be explained by pressure of work. The discussion that

took place in focus group 2 is illustrative. Lluan begins by commenting on the distribution of antibiotics in the postnatal ward:

Lluan: .... *I didn't like to keep buzzing, and they'd bring them (antibiotics) and say 'don't take them now, until whatever, and then take those in some hours.*

Cerys: *It's not up to you to remember is it?*

Lluan: *No, no and they weren't busy. I mean it was very, very quiet there.*

The facilitator prompts for further explanation:

Cerys: *I don't think they were interested. It was as if (pause), I mean in any job you can be at work and you can be having a laugh with your mates at work. It just seemed, well I just thought, if you're a midwife, it should be more than a job, and they should be (pause), you know, they should be more caring. But they just seemed as though they were just in work.*

Hafren: *It's just a job to them.*

Cerys: *Yes, as if they were on the shop floor in Debenhams or something.*

Megan: *Yes, just having a chat and a laugh.*

(Yes: General agreement)

Lluan: *They all just sit around the desk don't they (Yes) and then you feel really stupid when you go up to ask them something.... Don't want to bother you, but ...' and they look up.*

Hafren: *But I've got a clot about this size.*

(Gestures with hands. Others – Yes! Yes! And laugh.)

In this interaction, focus group participants illustrate the influence that the culture of midwifery, explicated later in this report, has upon their maternity care experiences. Particular facets of this culture are made explicit in women's discussions. Thus, two issues were raised by women, which they considered further impeded communication and the seeking of information and support. Both concern the isolation of women within the maternity care system. Firstly, women feel isolated when they perceive that their partners are being excluded from care processes. They feel vulnerable and alone in what may be an unknown and confusing environment. A second concern frequently voiced by women was for the barrier to communication posed by single rooms in postnatal wards. If finding openings to approach midwives is problematic, this is made much more difficult by the physical isolation of single rooms. Women also noted the difficulty of learning from other women when in single rooms. Isolation and atomisation both assume particular significance in cultural contexts in which midwives are overly pressured and in which they are unable or unwilling to invite questions and provide opportunities for women to solicit help and support.

#### **15.6.2.5 The decision making process**

Women's narratives, developed in the process of interactions within focus groups, do not allow for exploration of the decision making process in any coherent or systematic fashion. That is, we can gain only limited insights into the decisions that individuals made and how, why and in which circumstances these were informed decisions. Focus group data cannot, retrospectively, illuminate the complex and highly individualised cognitive processes through which each woman makes sense of the information that she receives. Similarly, such data can lend only limited insights into the ways in which these processes inform her decisions or how her actions or inactions are related to these decisions. Even so, the data does offer some valuable insights into the decision making process.

The ways in which women articulate their maternity care experiences indicate that decision making can fruitfully be considered as a process, rather than a one point in time occurrence. Decisions and / or actions can be called into question after the event. We have already seen examples of this in relation to the safety of scans and potential exposure to infectious agents. Throughout pregnancy and birth,



however, women articulate the importance of being able to revisit issues, to read a leaflet or a book over and over again, to be able to refer to material each time a question arises for them (focus group 6). Tanwen, a primiparous woman in focus group 7 explains:

*I just found myself just reading and reading the same bits over and over again. You read a certain stage, and then the next one just in case.*

### **Facilitating the decision making process**

Women also need to be able to revisit, rework and clarify their own position in relation to aspects of the childbearing process with the professionals who are providing care for them. However, it is clear from women's narratives that distinctions are made between types of contacts. Dwysan, for example, suggests that antenatal appointments which focused upon the collection of biomedical data, did not fulfil all of her needs. Monitoring blood pressure can overshadow a woman's need for interaction with, and continuing information seeking and reinforcement from, her carer.

*Well the last few weeks I had high blood pressure, then they'd come to the house. It was always different midwives. The one poor midwife who came, well my blood pressure was always high when she took it, I used to tell her 'don't want to see you here again' (laughter). I was only joking with her like. But I still don't think you're seen enough. (focus group 7)*

Although 'checked' regularly, Dwysan does not appear to have found the contact with professionals sufficient. Here, her words suggest a qualitative distinction is being made. Other women imply that regular and continuing interaction with fewer midwives may facilitate the development of particular, and satisfying, interpersonal relationships and foster 'trust' between a woman and her midwife. The concept of trust, enunciated earlier in this report, was highlighted in a discussion that took place in focus group 6.

*They become your friends don't they? It's not just about the pregnancy. They start to know what your husband, what you did, what you worked as and it's the trust thing. Going back to that word again, they become part of your life and you do put in your trust towards that person.*

The women in focus group 4 provide further illustration of the importance of trust between a childbearing woman and her health professional.

Facilitator: *What makes you trust your midwife? What is it about? Is it what she says? Is it just believing what she says?*

Jane: *It's her attitude towards you.*

Tesni: *I think the paternalistic attitude of a lot of midwives can be a bit off-putting. You know, if you go back to my mum and granddad's era, people were very respectful of doctors and medical people. Today, people are far more educated and they have a lot more access to information via the Internet, libraries. People tend to read up a lot and they don't like to be patronised. That's how we did feel in the beginning. My husband witnessed it as well.*

Within a trusting relationship, information gathering may be optimised: *'the more information you are given, the more you ask. So as (the midwife) was telling me things I was asking more'* (focus group 5). Though some decisions have to be made rapidly when action is required within a limited time period, generally women's decision making is considered, ongoing and processual. Trust, and the active creation of opportunities by professionals (particularly midwives) for women to ask questions, evaluate their own experiences, and consider the choices available to them, would seem to facilitate the decision making process. Of course, a woman's interpretation of available information, the decisions she makes on the basis of this and the actions or inactions that follow are informed by a variety of broader social relationships. Heledd, who participated in focus group 7, points out the need to interpret information for herself as well as her husband.

*We get information from lots of different sources, the leaflets were good, the book, the classes, there seemed to be quite a few things on the telly and I was always watching those. All these different sources, and friends, it all helps you manage your partner, which we haven't really touched on. I don't*

really mean manage, but it helps you explain to him what's going on and why. When he asked me a question, I could actually answer him.

### **Information and decision making**

Women are very clear that adequate information is an essential prerequisite to decision making and to their ability to influence what is happening to them. This was illustrated in data from both control and intervention sites. There is evidence that some women did indeed feel very well informed, and able to make their own decisions and to exert a degree of control that they were satisfied with, over aspects of their childbearing experience.

*I think I was quite well informed when I went into labour, I knew what I wanted to do and what choices I had, it was excellent.*

And:

*I was so well informed, the midwives in the team made sure that I knew. I knew what all my options were, I went in with a really open mind. Although I'd made this birthplan of roughly what I wanted to do, I went in ready for anything. At first I didn't want an epidural, but when they explained about them and I learnt about them I was prepared to have one if I needed one. It was really good. Good to know that you had so many choices. (focus group 7. Tanwen, a primiparous woman.)*

However, some women had less positive experiences. Data demonstrate that women do not necessarily welcome professionals' efforts to filter information or to shelter them from aspects that are seen as potentially worrying: '*I would rather be prepared for the worst, rather than someone else decide that 'she better not find out how awful it can be, we better not tell her how bad it can be, it might put her off.'*' (focus group 8). Women are adamant that they want 'both sides of the story'. In this vein, the continual reinforcement of breastfeeding as the preferred method of infant feeding was not always appreciated. Tesni, a primiparous woman in focus group 4 comments:

*How can you make an informed choice if they don't give you the advantages and disadvantages of both sides?*

For issues concerned with the development of specific skills and experiential knowledge, factual or theoretical knowledge acquired from health professionals and a range of media, may not be sufficient. In these instances, adequate information to inform the decision making process needs to derive from other 'knowledgeable doers'; from women with embodied knowledge of the childbearing process.

Mwynen: *We had a couple of girls come in (to parentcraft sessions) and they were breast feeding. I saw one of them yesterday and she said she'd has mastitis, it was nice to hear her views because she'd actually had it. She'd overcome that and still breastfeeding, so we were hearing some worse case scenarios and she was still breastfeeding.*

Facilitator: *Straight from the horse's mouth.*

Mwynen: *That makes a difference definitely. (focus group 7)*

### **Decision making and the exercise of informed choice**

Although many women's experiences were structured by normative practices which were taken for granted within the maternity care systems that they encountered, there were significant examples of assertiveness recounted by women in focus groups. These were occasions when women made decisions and exercised choices that went against the usual pattern of maternity care provision within that setting. Many examples of assertiveness are illustrated in the data, pertaining to all phases of the childbearing process. These include: requests for screening tests; avoidance of antenatal screening; avoidance of dating scan; choice of place of birth; choice of consultant; avoidance of cardiocograph tracing in labour; decisions concerning analgesia; decisions concerning discharge from hospital (in early labour and postnatally); decisions concerning positions in labour.

Not surprisingly, when women's decisions and choices did not challenge practice norms, they were more likely to be translated into action. Thus, when Wena, a multiparous woman in focus group 5

judged herself (by virtue of her age) to be at increased risk of carrying a baby with Downs syndrome, she requested 'an early scan and an anomaly scan'. This request was acceded to. However, when Betsan, a primiparous woman in group 1, chose not to have a dating scan, this decision was far more problematic:

*I (...) didn't have a dating scan, but I had hassle over that right up to the end. I felt quite assertive about it. I knew what I wanted out of it. I think that's probably why we went to (chosen hospital) we got the feeling that they might be slightly better, you know if everything is OK. (focus group 1)*

When a woman's decision challenges professional control, decision may not be translated into action. Ceri, a primiparous woman in group 6, was adamant that she did not wish to have continuous fetal monitoring by cardiotocograph during labour. Nevertheless, her desire to have the monitor removed was frustrated by the attending midwife, and it would seem that, despite her strength of feeling, Kim did not feel able to remove the monitor herself. Doing so would, in all probability be judged to be highly confrontational.

Facilitator: (Discussing the MIDIRS leaflets) *It says in here if you're healthy and have had a trouble free pregnancy like Kim's, standard textbook pregnancy, you can listen to baby's heartbeat in labour with just a hand held monitor or pinnard's stethoscope. Did you know that kind of information?*

Alwen: *Not 'till after.*

Ceri: *I knew that. That's why I kept insisting for her to take it off and she kept insisting 'No, no, just another ten more minutes'. So she wanted to get a longer trace that she could show to the consultant and when the consultant finally saw it, I was already pushing. It was like ... may as well keep the monitor on now.*

#### **15.6.2.6 The importance of 'experience' to decision making and control**

Although, of course, assertiveness in decision making and action is not restricted to 'experienced' women, it is clear from the data that the concept of experience is central to understanding the process through which information, decision and action are linked. Focus group 5 is discussing decision making in labour when Janet, a multiparous woman, makes the following comments:

*I think the major gap is they don't tell you why. I think you're very insecure, especially in your first pregnancy, you're very vulnerable and insecure because you don't really know a great deal about what's happening to you and sometimes people want to do things to you and they don't tell you why. I feel if they told you why you still might not like it but you might find it more acceptable. At least you'd know what they were doing it for. Sometimes they seem too busy resolving a situation and trying to find things out for themselves to explain why they're doing something to you. It leaves you feeling very, very frightened. I think I've got an advantage over everybody else here because this is my fifth baby and I really felt in control this time. I knew this, I knew that, I knew what their jargon was. If they said we just want to do this, that and the other, I did know why they were doing it. The first baby I didn't have a clue and I did have a horrendous labour with her, shocking my first baby. It was a nightmare. I never want to go through that again.....*

*But because I knew why different things were being done, it was 'We're going to do this now Janet. We're going to do that now Janet'. I knew why. If I didn't have known why nobody was there to volunteer why they were doing it.*

#### **Different forms of knowledge**

For Janet, experience is closely associated with parity. She emphasises the importance of procedural knowledge: knowing how the system works, being familiar with maternity care practices. A woman who brings with her previous experience of the maternity care services is seen to be less likely to passively or unquestioningly accept the dominant norms (focus group 2).

*With my first, I was monitored the whole time. I didn't realise that you could move round. Nobody explained that to me, but the second time around I knew that you didn't have to do it. I think the second*

*time round I knew you had an option. You're stronger. You're a stronger person. You know what to expect.* (focus group 5)

Procedural knowledge may also be reinforced by embodied knowledge: I've done it once, there's a good chance I can do it again. For some women at least, motherhood is in itself seen as empowering. Moreover, the 'guilt' that is commonly experienced during a first pregnancy 'Am I doing this right, am I doing that right?' may weigh less heavily for the second (focus group 2). Women may therefore feel more able to assert their own definition of the situation and make decisions which challenge accepted ways of doing, within a particular care setting. Focus group 4 is discussing the use of cardiocotographs:

*I think it's a question of confidence because I mean if you know that that's ridiculous and someone comes, even if they just come and be cross with you because you've buzzed, you say 'Excuse me, I've been on this ever such a long time, can't someone take me off?' But at first you haven't got the confidence to say that. You feel 'Well, they've put me on, I've got to stay on this monitor'. After three quarters of an hour I'd have said 'Look, this is ridiculous, three quarters of an hour, can I disconnect please?'*

However, assertiveness need not be confrontational. 'Experience', the accumulation of procedural and embodied knowledge, may manifest as skilfulness in developing non-confrontational strategies that nevertheless, enable women to realise their choices.

Claire: *I never offered to sit on the bed the second time.*

Facilitator: *You never offered?* (laughter)

Claire: *That's right, I mean the first time round she said 'Sit on the bed'. Monitor was on, and that was it. I was there the whole time, I didn't move. This time I never went anywhere near the bed until the very last minute.*

(Laughter) (focus group 5)

'Experience' can also be grounded in other contacts with reproductive health services. Primiparous women who have miscarried a previous pregnancy may also bring with them knowledge and expectations that directly affect the decision making process. The data here is not robust. This was not an issue that the research team sought to explore. Rather, the issue of previous fetal loss arose spontaneously in a number of focus group discussions (groups 1, 4, 5 and 6). Though this would warrant further exploration elsewhere, there are indications that previous miscarriage and other forms of contact with reproductive health services (such as assisted conceptions) may also constitute relevant 'experience'. As both Lisa and Alys illustrate, these experiences may also prompt women to become more active participants in the decision making process. Lisa requested an early scan after a previous miscarriage and recalls her care subsequent to this:

*I went to a different hospital last time. It was the after care at the other hospital that made me change this time. I knew it was more low key, and I knew things wouldn't be forced down my neck... It was more sort of you could make more choices, although some of the choices are limited.* (focus group 5)

Alys, whose baby had been conceived following In Vitro Fertilisation treatment, illustrates the extent to which service familiarity enabled her to exert control over the care she received.

*In the hospital I had my blood test at sixteen weeks and then they phoned me up to say that my risk for Downs was high, and that they were going to arrange for me to have a detailed scan in (names hospital). But because I'd had the IVF treatment, I knew the nurses in the IVF clinic, and the antenatal was only round the corner, I got on the phone to them at three o'clock Monday afternoon. The person I needed to talk to had gone home. So I left a message with another person and by half past eight on the Tuesday morning, she'd rung me back and said be here by eleven o'clock for a scan. So I just shot straight to (the hospital) for a scan and had it done. But then, when I went back to work, I phoned (other hospital) and they hadn't bothered to do anything about it. Now to me it was, it has to be done straight away.* (focus group 7)

## 15.7 DISCUSSION

Data derived from focus group discussions provide clear evidence of the importance that women attribute to the acquisition of adequate and timely information. Not surprisingly, primiparous women describe a broader range of information needs than multiparous women. However, in general all childbearing women are eclectic information gatherers who devote considerable energy to developing theoretical, procedural and experiential knowledge of the childbearing process. This is an ongoing pursuit which requires continual revisiting of information and reworking of each woman's understanding with others, particularly family members and the health professionals who provide their care. However, the way in which information and support is made available by maternity care professionals may not always acknowledge the processual nature of decision making. Thus, in situations when Informed Choice leaflets are merely handed over by midwives in health care encounters, and women passively receive information from a midwife whom they are unlikely to meet again, it is unsurprising to find that these do not assume great significance to women as sources of information. Leaflets are valued as one of a range of potential sources. But acquisition of information is only one element of the decision making process. Lack of continuity of staff, work pressures and cultural contexts which distance professionals from childbearing women are all factors that impinge upon, and constrain, the decision making process, impeding women's ability to make informed choices and to translate these into preferred actions or inactions.

## 15.8 SUMMARY OF MAIN POINTS

- ◆ Minority voices tended to be relatively silent within focus groups.
- ◆ Women's individual narratives tend to be neither uniformly positive nor uniformly negative.
- ◆ Individuals frequently sought to check out and negotiate their definition of a situation with other participants.
- ◆ Access to information is of fundamental importance to women.
- ◆ Women articulate a very wide range of information needs, from the general to the context specific.
  - primiparous women articulate substantially more information needs than multiparous women.
  - three areas of information need predominated in women's narratives. These were antenatal screening, infant feeding and the onset of labour.
  - the Informed Choice leaflets trialed in the CRCT of this research study impacted on only a minority of areas of information need identified in focus group data.
- ◆ Primiparous women may enter pregnancy with the expectation that all necessary information will be provided for them by health care professionals.
  - particularly in the early months of pregnancy, women can feel disorientated and adrift and this feeling may be exacerbated by patterns of maternity care that provide infrequent contact with professionals.
- ◆ Women quickly learn that they must seek out information for themselves and they often take on this responsibility with alacrity.
- ◆ Women access a range of information sources and are eclectic information gatherers.
- ◆ The medium accessed most frequently by women was the written text. The Health Education Authority's *Pregnancy Book* was spontaneously alluded to by women as a useful source throughout pregnancy.
- ◆ Informed Choice leaflets were rarely referred to spontaneously within groups.
  - women who had received selected leaflets from the set found this confusing and were liable to assume that information had been withheld from them.
  - women do appear to value the MIDIRS leaflets as one of a multitude of potential sources

- there is no evidence in women's narratives that discourses around research-based information, or evidence-based care, had influenced the population of childbearing women who participated in focus groups.
- ◆ Women experience strong normative pressures to conform to existing patterns of care. This is not necessarily experienced as problematic.
  - practice norms can render invisible women's information needs; this was clearly articulated in relation to ultrasound scanning.
- ◆ It is difficult for women to bring alternative childbearing perspectives into encounters with health professionals and even more difficult to sustain these in the face of professional opposition.
  - staff may reinforce practice norms and impede the flow of information by refusing to acknowledge the legitimacy of information needs.
- ◆ A dominant theme in women's narratives is the extent to which they experience difficulties in asking professionals for support.
  - a positive experience of support is contingent upon professionals providing openings for women to solicit help
- ◆ Women recognise the pressures of work midwives work under and are aware of the profound effects this pressure may have on information flow and access to support.
  - women are adamant that the barriers to communication and the constraints upon interactions that they experience, cannot always be explained by pressure of work.
- ◆ Decision making is experienced by women as a process rather than a one point in time occurrence.
- ◆ The concept of 'experience' is central to understanding the process through which information, decision and action are linked.

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## Chapter 16: The Culture of Maternity Care

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### 16.1 THE CULTURE OF MIDWIFERY IN THE NHS

In a previous study (Stapleton, Duerden and Kirkham 1998), we looked at the culture of midwifery in England. This culture developed within gendered institutions (Davies 1995), where the midwife's position was very low in the hierarchy. Aspirations to professional status ensured that a midwife's allegiance was primarily to her profession and employing institution rather than her clients (Heagarty 1996, Kirkham 1996). Midwives behaved as an oppressed group (Freire 1972, Roberts 1983), internalising the values of medicine and management and practising horizontal violence (Fanon 1963, Leap 1997) towards colleagues seen as deviant.

The culture which emerged was one of service and sacrifice where midwives lacked the rights as women which they were required to offer to their clients, particularly around choice. There was a lack of mutual support and of positive role models of support with considerable pressure to conform. Guilt and self-blame<sup>1</sup> were common as was learned helplessness and muting. This created many dilemmas and barriers to change especially in relationships. Change was either resisted, brought about by stealth or, less frequently, strategically planned (Kirkham 1999).

This culture of midwifery was observed throughout the present study and served to inhibit change. The cultural context and the tensions created by the many pressures upon midwives are ever present in our data. To save constant repetition in the text, these factors must be borne in mind by the reader throughout. The focus of this study is, however, wider. We seek to examine maternity services rather than just midwifery.

### 16.2 OBSTETRIC AUTHORITY AND ITS IMPLICATIONS

#### 16.2.1 Doctors as decision-makers

In the sites studied, which included the majority of the maternity units in Wales, doctors were held in high regard and their words carried authority.

*At the end of the day the patient looks up to the doctor as somebody who knows what they're doing...who knows best...who knows what's right for them...doctors have the overview of the situation that the patient doesn't have.* registrar intervention site

Consultant obstetricians' words carried great and ultimate authority:

*...it's a consultant-led service. You may disagree with what your consultant says but if you're working for that consultant that's what you've got to tell the patient... Whether you like it or not that's what you do, whether you totally disagree, you've got to do it.* registrar intervention site

Service users held doctors in high regard and expected them to make decisions:

*It was a case of the doctor telling me and he's got to be right... He's obviously a doctor and he's qualified and done all his exams and I just thought 'OK then, whatever he's telling me must be right...'* service user intervention site

*Even when you disagree with what they're saying, you tend not to say anything... There's no point in arguing with them. Whatever you think, they'll do what they think is best...* service user intervention site

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<sup>1</sup> Furlong and Young (1996) suggest that women seem more practised at self blame whilst men tend more readily to blame others

Some midwives were of the opinion that service users from the valleys of South Wales tended to hold doctors in particular awe:

*...Then you've got the valley girls and I'd say that probably their measure of a good doctor is the one who does things, and the more he does the better he is. So they're quite happy then with seeing the doctors...they tend to look up to them...what they say goes...* midwife intervention site

A number of midwives described how the awe in which doctors were held made it unlikely that service users would give critical feedback on the service. Indeed, the cultural expectations were so strong that, on the few occasions when obstetricians were observed to offer women real choice in the management of their care, rather than pressing a right choice, the women concerned did not respond. Accustomed to a position of powerlessness, those service users who were not happy to 'go with the flow', tended to either manipulate the situation or to blame in retrospect.

### **16.2.2 Language and power**

Few of the doctors observed were Welsh and very few spoke Welsh. For bilingual Welsh women (Pugh 1996) the status of 'major' and 'minor' languages reinforced medical dominance and created a parallel with medical/professional and lay languages and their assumed power differences (Read and Garcia 1989, Kirkham 1998). Welsh speaking women have been found to feel 'less confident and the sense of feeling inadequate and even powerless was not uncommon' during antenatal consultations conducted in English (Thomas 1999). Our bilingual researcher (previous research *ibid*) noted how accent too was important. Local midwives were heard to accommodate their accent towards that of their clients as a means of enhancing rapport. An English accent, however, would be perceived, by a woman with a Welsh accent, as adding to the dominance of a doctor's relationship with her. An English accent may be seen as superior, intelligent and articulate whilst their Welsh accent may be considered inferior, less intelligent and lacking fluency (Baker 1996, Davies 1994). The following quotation is illustrative:

*I felt the locum just wanted to dismiss me... he wasn't listening to what I had to say. He was kind of 'Oh, don't be so silly, you're over-anxious.' He didn't actually say those words but that was sort of his attitude. I think he thought I was a thick Welsh woman who didn't know anything.* service user control site

Many of the doctors observed were African or Asian and, whilst their English was usually both fluent and technical, it was often heavily accented in unfamiliar ways which added further complexity to consultations for women.

Our efforts to understand Welsh culture, as manifest in antenatal consultations, produced a limited range of literature (John 1991, Aaron et al 1994, White and Williams 1998). However traditions of hospitality and respect for visitors, as well as 'a culture that has a desire to give praise' (Bale 1999), are likely to emphasise the power imbalance with non-Welsh doctors.

Compared with other parts of the UK, Wales is home to a very small non-white, ethnic minority population, with one source quoting less than 2% (Rees 1999). Thus, very few women from minority ethnic groups were observed accessing the maternity services. That said, there appeared to be little provision for such women, many of whom shared no common language with their primary care giver, to access interpreter or advocacy services easily.

### **16.2.3 Manipulation<sup>2</sup> and blame**

Accepting that doctors make the decisions, some clients sought to achieve their aims in a manner widely documented for nurses and midwives (Stein 1967, Stein, Watts and Howell 1990, Kitzinger, Green and Coupland 1990), by making the doctor think it was his idea. For a few women this extended to conveying a false clinical picture:

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<sup>2</sup> The word manipulation is used here with reluctance because of its negative connotations. We have been unable to find another word which primarily means 'to handle with some skill, to control or influence cleverly or skilfully' but will extend to 'to falsify for one's own advantage' (Collins Dictionary 1987). The word 'engineer' does not seem to work grammatically and words with military origins such as strategy or manoeuvre imply a power which the women do not have. We are very aware that such actions were seen by the women as the only way to achieve their aims and wish to avoid the value judgement which is linguistically in-built.



G5P4 Term. 26 years old. Waiting to see a consultant obstetrician. *W: Had enough now...want to be induced... don't want to be in over Easter (2 weeks time).*  
*I: So what do you hope to get out of today's appointment?*  
*W: Talk the Doctor round to inducing me... (Grins) Tell him it's not moving as much now.*

Since they accepted the obstetrician's authority, many women blamed him in retrospect:

*I were bored and fed up so when the doctor offered me a date to come in I were really pleased..... but I'd not do it again. I'd never go through that again. It were so intense... I regret it really... (if the doctor had not booked the induction) I'd still have been bored and fed up, but I'd have listened to him... you do, don't you, because they're the experts...you know...doctor knows best sort of thing...so if he'd said that I'd be better off waiting for it to come naturally, I'd have had to wait...I'd have had no choice would I? service user control site*

Such responses were common, especially from poor women who lacked control and choice in the rest of their lives. Nevertheless, this response was inevitably difficult for doctors, as is illustrated in the following quotation from a consultant obstetrician:

*One thing I have noticed is that I do get a bit angry when I've put a lot of time into explaining difficult and sensitive issues to women but when women don't understand or misinterpret what I've said, then they tend to blame me rather than themselves...*

Blame and manipulation by service users served to reinforce obstetricians' need for control of the service. This could lead to problems for other professions and for clients.

*In my previous job, if I found a problem, I would pass on the information to the patient. It was difficult but I think it was better that they got it from me at the time rather than have to wait to make an appointment to see the consultant. Here, I'm not allowed to pass on information to the patient if I see a problem. That's for the consultant (obstetrician). It's a bone of contention at the moment.*  
ultrasonographer intervention site

This climate of blame and obstetricians' need for control provided fertile ground for stereotyping of women who did not agree to the 'right' options. Many women appeared to be stereotyped on the basis of circumstances (age, dwelling, parity, marital status or social class) over which they had little, or no, control.

*There's no amount of information that will enable them to see that they must.....some of them lead problem lives but they're not the types to take the information in... consultant obstetrician control site*

*I personally do not have much difficulty in communicating with the ladies. It's probably easier with enlightened people who are on the same wavelength and can appreciate the importance of your concern. The most distressful thing is to have a client that you do your best to communicate information to and because of her own what I will call stubbornness, will like to take a risk, for example the grand multip I discussed with you earlier or a girl who is smoking heavily and has evidence of intra-uterine growth retardation or a girl who has breech presentation who insists she must be delivered in her caravan...Such clients I think are really just being stubborn. They don't really want any information... consultant obstetrician intervention site*

This stereotyping always demonstrated the unreasonableness of women and their lack of attention to the reasoned arguments of the obstetrician (or other professional - see below). Other factors influencing women's decision-making were not considered and certainly not allowed as evidence. On the rare occasions when authority failed, 'fear tactics' were used to inflate risk and thus dissuade women from making choices with which the health professional disapproved.

*He's (obstetrician) a real Jekyll and Hyde that one...he was fine as long as he thought I was going to the hospital but as soon as I said I wanted to have the baby at home it was all about haemorrhage and the risks to the baby...if anything went wrong it would be my own fault; it would be on my head...it was horrible...I came home and cried... service user intervention site*

Thus, obstetricians' response to women who did not do as they wished was exactly the same as that of the women when the obstetrician did not do as they wished: manipulation or blame. The power of the obstetricians was greater but the parallel processes are clear in the actions of all involved. Sadly neither manipulation or blame could improve the overall situation.

#### **16.2.4 Rhetoric and resistance**

Fear of litigation also cast a dark shadow for obstetricians and other health professionals, many of whom volunteered that they worked *'with a lot of fear around'*. Very few were able to identify specific triggers for their fears, however, except for that of litigation. The following respondent was of the opinion that it was fear of litigation, rather than the striving for standards of excellence, which was currently the primary motivation for change in the maternity services:

*I've been working since '91 and I can honestly say that the nature of people around is changing. There's now more and more stress on evidence based medicine. You've got to be able to justify yourself.. But it's not just because of the evidence based medicine... You do things out of fear and litigation comes into it. So if you've done something you've got to be able to justify it. You can't just be strong-headed about it and say 'that's what I always did and that's what I'll always do...'. I think that is hurting people more than the evidence based...*

senior registrar control site

The climate of fear and blame led to emphasis on doing things right in terms of current Department of Health documents. 'Informed choice' and 'evidence based practice' were, therefore, frequently mentioned. In clinical practice, however, this rhetoric tended to be interpreted very narrowly. Appropriate local practice was derived from the authoritative knowledge of the consultant. Sometimes, the climate of blame and fear led consultants to stick rigidly to their tried and tested experience rather than taking the risk of acquiring new skills or changing their practice in line with evidence. Thus 'right' practice became that which was tried and tested and with which obstetricians felt skilled and secure, such as elective caesarean sections for breeches. Informed choice meant making the locally defined 'right' choice.

*For example they will always guide a woman towards elective section for breech even if she wants to try for a vaginal delivery..... they're so geared towards an elective section... Even when the woman comes in with an undiagnosed breech in labour, fully dilated, ready to push,...they'll do an emergency section at that point rather than let her deliver vaginally... So what's the point of giving (women) a leaflet...what's the point of giving them information about choices they haven't got?*

midwife intervention site

Sometimes 'right' choices were described as 'dictated by economics' such as when limited screening options were offered.

#### **16.2.5 Vicious circles**

Thus, the culture of the maternity service held a number of vicious circles of acceptance of obstetric authority and mutual manipulation to maintain the status quo in a context of blame and fear. Such a culture was inevitably oppressive for all involved and the awareness of threat and the potential for blame often provoked rigid responses and lack of flexibility in relations with clients and between professionals. In any situation there was a 'right' choice or course of action whether this was derived from research evidence, local circumstances or the individual experiences and skills of those in authority. In the vast majority of cases women and/or their carers made the 'right' choices. Problems or 'trouble' arose when another choice was made.

The Informed Choice leaflets were, therefore, introduced into a somewhat rigid, and potentially brittle, social situation. The concept of informed choice, however, carries great potential to resolve many of the problems observed: real informed choice and partnership in decision-making would lessen the burden of responsibility and blame presently experienced so widely. However, the benefits of informed choice could only be felt after a fundamental change in power relationships and this was just what the existing culture resisted.

The extent of obstetric authority had immediate implications for the Informed Choice leaflets. On one site, after access had been agreed, the Informed Choice leaflets on ultrasound scanning, screening for

Down's syndrome and Spina bifida, and epidural, were withheld because the obstetricians did not want service users to be alerted to what could be perceived as inadequacies in local provision. Before this decision had been made however, a midwife on this site had correctly predicted that *'the screening and ultrasound leaflets will cause an absolute riot here because of the incomplete service that's offered. Once the obstetricians get wind of what's in these leaflets ... that'll be the end of the leaflets!'* (See Chapter 3)

### 16.3 INEQUALITY IN SERVICE PROVISION

Inequality of service provision appeared to be widespread although some aspects of inequity were more visible than others. Health professionals identified a number of causative factors, some of which were outside of their direct control. For example, staff in one unit reported that the local Health Authority had refused to finance as "full" an ante-natal screening service for detecting foetal abnormalities as was available elsewhere; in another unit staff complained about the lack of a full anaesthetic cover for labour ward; midwives in a number of units stated that they were unable to offer all women a home birth or DOMINO service because of staffing shortages.

Staff did not, however, appear to be aware that sometimes their own behaviours, attitudes and lack of clinical skills also contributed to inequality in service provision. For example, the researchers observed that midwives and obstetricians rarely ignored the questions of middle class women; to the contrary they tended to be much more receptive in their non-verbal bodily gestures, to give more detailed explanations and to take more time in making sure that such women understood the information they were given. This accommodating style of communication was accentuated if such women were accompanied by their male partners and the attending practitioner was a consultant obstetrician.

Substantial numbers of women, particularly those who were poor and/or young, or whom health professionals judged to be unwilling participants in care, were often observed being treated rather differently from middle class women. This was despite the fact that such women usually lacked any control over the variables on which they were judged. Although relative silence on the part of childbearing women was a feature of many ante-natal consultations, women who were socio-economically disadvantaged rarely initiated conversation. The general demeanour of some staff suggested that women who could not articulate their experience in language familiar to the health professional were discounted and rendered invisible. This may be one reason why many staff made erroneous assumptions about their needs and preferences.

Finally, childbearing women who were described as "trouble" by health professionals also tended to be marginalised and some volunteered that they were required to be very assertive in order to obtain information and exercise choice. Health professionals tended, however, to (mis)interpret assertion as aggression and this provoked an array of negative defence mechanisms.

### 16.4 MIDWIVES IN THE MIDDLE: BALANCE AND VULNERABILITY

Midwives' experience held many parallels with that of service users and obstetricians. Midwives practised according to local norms and saw doctors and clients acting in conformity with those norms or taking the options of manipulation or blame.

Some also described themselves as *'handmaidens'* with varying degrees of irony or frustration:

*You drop into the waiting-on mode before you've even realised you've done it...it's automatic to think they're (consultants) top and you're bottom...* midwife intervention site.

Other contextual factors are explored in a recent RCM report on 'Industrial Relations in Wales':

Bullying and harassment of midwives is a serious concern within Wales. Despite a campaign in 1998, we return to this topic regularly in stewards' training. The incidence and severity of the bullying and the difference in treatment received by midwives compared to other members of staff have all been considered. Violence by obstetricians against midwives has occurred on more than one occasion, to the concern of both Trust management and the RCM. The Trusts

agree that bullying cannot be tolerated, but difficulties have been experienced in applying the policies to all staff, irrespective of position. (Tinsley 2000)

#### 16.4.1 Seeking a balance

The rigid observance of hierarchical norms hindered communication and midwives not infrequently found themselves 'caught in the crossfire' when they attempted to support women making decisions which went against unit policies and/or consultant preferences. One midwife described this position as '*a bit of a piggy in the middle...you're caught between trying to advocate for the women but you're also having to mediate for the consultant..*' Midwives appeared to expend considerable amounts of energy in trying to '*keep both sides happy*' and many struggled to maintain an equilibrium (Levy 1997), especially in situations where what women wanted, was very different from what was considered appropriate, in terms of the local, medical agenda. The majority of midwives appeared to '*go with the flow*' of obstetric opinion because '*it made life easier*'. This had a divisive effect on relationships which could be reflected in horizontal violence towards those who did not conform:

*There is a lot of good will amongst the midwives here...many of the midwives try and facilitate women and their choices but there are still a lot of midwives who are quite happy to follow obstetric procedure because in many ways it's easier for them...because it doesn't make a fuss...so they tend to go with the flow...it's not so confrontational... So yes, they'll go along with what the obstetricians ask because it makes their life easier... You end up with an awful lot of aggression and back-biting between the midwives...between the ones who go with the consultants and the ones who go with the women...*  
community midwife intervention site

Most midwives sought to avoid 'trouble' and therefore identified strongly with medical powerholders.

*...you always come back to 'this is what we normally do' and the women will just comply with it. If you look at Vitamin K, you've got to give the information and sometimes we slant it in a way that they would comply with us. We're very powerful and very able to do that. Not always, but when it suits us. When it doesn't, we manipulate the situation...we give them informed choice as long as they make the choice we want so we still hold the power. I think obstetricians have had a lot of power and I think midwives are taking on that power...*  
midwife control site

Midwives certainly ensured that the vast majority of women made what were seen locally as the 'right' choices. However, considerable numbers of midwives volunteered that it was only by resorting to tactics of 'doing good by stealth' (Stapleton et al 1998) that they were able to balance differing agendas and support women in making choices which were right for them. In addition to the obstetric team, and the women in their care, midwives are also professionally accountable to other agencies such as the UKCC and their employing hospital trust, all of which greatly increased the potential for conflicting loyalties.

Some midwives complained that the intense, and ever increasing, pressures upon their time added to the stress of their working lives. For many community midwives, this stress was added to because they often worked in inadequate premises where they could not always even guarantee they would have access to a vacant consulting room.

#### 16.4.2 Going against the flow

Some excellent care was observed around the facilitation of informed choice but this was the work of individuals rather than the strategy in any unit and often these individuals endeavoured to keep a low profile. One characteristic of midwives who were prepared to challenge the medical hegemony was that although they were powerful agents for change within their local communities, they appeared to occupy a fragile position with respect to the institutional hierarchy. A further distinguishing feature of these midwives was that they were very often union representatives or members of groups working to improve the maternity services. Thus, their largely invisible, but highly political, work also benefited midwives as much as it did users of the maternity services.

It is widely accepted that being 'with woman' largely defines the role, and purpose, of the midwife. What the midwifery profession has yet to acknowledge are the conflicts midwives must resolve if they are to be 'with women' in providing them with evidence based information which is in direct conflict with

obstetric policies. In declaring that 'Information is an evident political good. It has the power to help consumers protect their interests...(it) is contentious', Williamson (1992;80) makes a case for midwives taking a political stance. Political activism is not, however, commonly associated with the midwifery profession and may be counter-productive because of the risk of alienation and social exclusion. The small number of midwives who did attempt to challenge the medical hegemony by openly confronting obstetric policies, confided that they lived in constant fear of reprisal, from both midwifery and obstetric colleagues. Such actions were also potentially self defeating because they risked effecting an increased scrutiny over the midwife's practice:

*I think you get looked at a lot more...I know that I've personally had things brought back to my attention a lot more than I've noticed with other midwives...certain people see my name and will therefore look more closely at what's happened and what's been written and what's been done... midwife intervention site*

As is implied in the following quotation, making one's politics public and working towards changing the local culture was stressful and not without potential repercussions for personal health and well-being:

*You feel a bit out on a limb...it's very stressful...but with any revolution, there are always the sacrificial lambs...that's how I see myself...but better me than the women... I think midwives like me are a bit like those SAS hit-men...we should only be exposed on the front-line for short bursts and then we should be brought back to recuperate! You can't be on the front line all the time...But there isn't any choice...you have to keep going for the women... community midwife intervention site*

Midwifery managers also varied and their allegiance to a midwifery model of care could not be presumed:

*You do get support from some (midwifery managers) but you have to be careful...there is one (midwifery manager) in particular who will always go on the medical side...she'll always take the side of the medics over the midwives. So you just choose who you go to for support if you've got a woman who wants something they (consultants) disagree with... midwife intervention site*

Midwives who did prioritise women's expressed needs also had a tendency to undervalue themselves and demean their own efforts. They frequently lacked support and were often kept at a distance by their peers who considered them to be 'a bit radical'; or as 'offering women too much'. There was a strong sense of censorship in these comments; possibly because such modelling of practice threatened to expose and undermine the position of colleagues who preferred 'a quieter life'. But these were the midwives who were striving to facilitate informed choice for women in their care and, given the conservative nature of the maternity culture, this required that they constantly challenge the status quo. They did this at considerable personal cost.

*I'm shattered. I've been called out every night this week...last night I was out all night for a home birth. I'm here doing the clinic today because there's no-one else to cover. I'm praying that one of my home birth women won't phone tonight... It's moments like this when I think my colleagues are right not to touch Dominos or home births because they do put a lot of extra stress on you... We get no support... community midwife intervention site*

#### **16.4.3 Horizontal violence**

Some midwives described colleagues policing their practice to ensure conformity with local practice. This, together with much of the behaviour described above, fits the analysis of midwives as an oppressed group. The tensions of the many pressures upon them as released in 'horizontal violence' (Fanon 1963:4) conflict within the oppressed group especially towards those seen as slightly deviant; which, in turn, reinforces the status quo. In midwifery:

... scapegoating, back-stabbing and negative criticism. (t)he failure to respect privacy or keep confidences, non-verbal innuendo, undermining, lack of openness, unwillingness to help out, and lack of support have all been described as horizontal violence.  
(Leap 1997:689)

In the following quotation, a community midwife is reflecting on the inappropriate use of continuous electronic fetal heart monitoring in labour for low-risk women. She is of the opinion that introducing evidence based practice, such as intermittent monitoring in labour for low-risk women, is difficult to achieve because of the power and control exercised by midwifery colleagues holding permanent positions on central delivery suite:

*...it's also peer pressure from our own (midwifery) managers sometimes...(and) colleagues on labour wards...'G' grades on the labour ward who only work on the labour ward...who aren't out and about... We don't trust each other enough - we're too quick to criticise instead of supporting each other a little bit more... Some of the G grades here are getting to be like the doctors: 'Why haven't you done an ARM (artificial rupture of membranes)...?; Why isn't she monitored...?; Why haven't you done a VE (vaginal examination)...?' (They're) often on your back... community midwife intervention site*

This respondent illustrates one of the many dilemmas midwives face in their attempts to foster trusting relationships when the imposed model of care was not one which all midwives held in equal regard, was rarely evidence based, and, perhaps most importantly, was not woman focused. Examples of horizontal violence also illustrate the cultural reality of resistance to change. Describing, and accounting for, 'discrepant views' (Kleinman et al 1978) of health and illness, traditionally the preserve of anthropology, may thus be a useful prelude to implementing and managing change within the clinical environment.

## **16.5 SILENT WOMEN**

In the antenatal consultations observed, service users were largely silent. This silence was remarked upon by each of the midwife researchers collecting data but was clearly seen as normal in all the research settings and taken to indicate both compliance and a lack of need for information. The silence was greatest during consultations with doctors, where often women did not speak at all but simply gestured compliance. Consultations with midwives had a different atmosphere. Many midwives skilfully used the palpation of the fetus as an opening to conversation which led some women to raise issues of concern. Nevertheless, women said relatively little in most of their consultations with midwives.

### **16.5.1 Checked but not always heard**

These silent women, however, voiced clear and perceptive views when interviewed by the researchers. Their expectations of doctors and midwives were different, with doctors expected to undertake physical 'checks' in silence. They felt that discussion should, however, be possible with midwives. Whilst many felt this was achieved, a number of women of all social classes, spoke of midwives placing undue emphasis on tasks rather than the listening and facilitation required for support and informed choice.

*I: You mentioned earlier that the midwives did a lot of 'checking'...?*

*W: Yes that was it. Not how I was myself emotionally...or any of my feelings I had from losing my second child. Again, that was very much always on my mind. But they never asked me about that... It was just have you remembered your urine sample...let's have a feel of the baby...things like that to do with my body; not about how I was feeling... service user intervention site*

*I don't think midwives know how to handle that stuff...they can't handle when you get upset so you don't tend to show them...you tend to keep that for you friends and partner...the midwives are good for checking the baby and making sure all your tests get done... service user intervention site*

Thus the physical tasks of monitoring the pregnancy, as well as local imperatives on monitoring choices, could act as an obstacle to establishing and meeting women's needs. Women were also aware that midwives were often very busy and pressed for time and this inhibited their ability to listen, to pick up cues and to give information.

### 16.5.2 Learning in silence

Antenatal consultations were frequently interrupted and often lacked privacy. Whilst the majority of women tolerated interruptions in 'silence', a small number of women spontaneously voiced their discontent during an interview:

*I don't know why they (midwives) bother closing the door sometimes... Sometimes you feel like, why have I bothered, for all they seem to care when you do go down there (GP surgery)...* service user control site

On some occasions consultations were interrupted by telephone calls from women seeking advice from midwives. Such calls were often favourably commented upon by women as they realised *'that it really is OK to contact her (the midwife) if you run into trouble'*. The way in which midwives responded to such phone calls was also of significance to women: *'That way (taking phone calls during the consultation) you really get to know how all the different midwives work...you get to know which one you hope is on call if you ever have to ring them up and which one you hope isn't...'* Eavesdropping phone calls of this nature thus provided opportunities for women, in silence and without troubling midwives, to gain insight into the style of individual midwives and about the limitations of local maternity service provision.

### 16.5.3 Local culture

The following excerpt, from fieldnotes of a conversation between a researcher and a midwife from one of the South Wales valleys, showed the deference to the medical profession shared by local midwives and mothers.

She (midwife) said that it was impossible to get women to be critical of their care; that this was a small and intimate community where news travelled fast and it was also a community where 'stirrers' were not well tolerated. Even the fact that she (midwife) was 'one of them' with the additional status of a health professional did not give her any special privileges. She volunteered that *'it was very dangerous to go too far against the grain because then you risk losing your professional status so it's totally counterproductive really...'*  
fieldnotes control site

As earlier research in the valleys has established (Home Ante-natal Care in the Valleys 1994), the influence of mothers and grandmothers on pregnant, working class women was strong. Whilst in some senses, the Welsh 'Mam' 'is a figure of the past' (Beddoe 1991 p207), these second and third generation bottle feeding mothers carried tremendous authority with regard to their daughters' choice of infant feeding method:

*No, I don't think I'll be breast feeding, my mum's dead against it...I live at home so it would be difficult to go against her...she fed us all with the bottle, so I think that's what I'll do to...my sister has just finished using all the stuff (equipment for bottle-feeding) for her baby so I can have it all after it's born...*  
service user intervention site

In balancing the many other pressures upon themselves and their clients, midwives were reluctant to challenge these grandmothers' authority, despite the weight of evidence for breast feeding. Even so, many women complained to the researchers that midwives 'pushed' breast feeding. With the weight of medical authority with regard to antenatal and labour care and the weight of grandmother's authority with regard to feeding and baby care, the scope for midwives to offer, or for many women to make, their own informed choices was limited.

### 16.5.4 Avoiding troubling staff

The vast majority of service users expected to conform with the care offered by doctors and midwives and were anxious to avoid 'troubling' or 'bothering' staff. In this they correctly assessed the views of many staff.

*I think if any woman attempts to maybe discuss things then she's labelled difficult. You hear midwives saying things like 'be careful of her... she's not trustworthy...she's going to drop us into trouble...'*  
midwife intervention site

Many service users saw the midwives caring for them as 'stressed out' or 'too frazzled' and this deterred them from accessing midwifery advice outside of their scheduled appointments. Even when they were extremely worried or upset about things, they rarely contacted a midwife because they 'didn't want to trouble her'. The following quotation, from a woman at term with her second baby, is illustrative:

*Well I just didn't want to bother them with trivial things. I didn't really ring the midwife this time round until I knew (I was in labour). P (partner) knew my waters had broken but I said 'wait until it's more established'. I didn't particularly want to bother anybody. Because it happened at one in the morning, I didn't want to disturb anyone. I think that's probably just in my nature not to bother anybody with anything. It probably wasn't trivial because eventually after 25 minutes my waters had quite gone I felt I wanted to push. P was ready and gathering bits and pieces and said 'just ring them and explain the situation'. So I did. I only just made it.*  
service user control site

### **16.5.5 Change without challenge**

Women used a number of ploys to alter the power balance in consultations but the options open to them largely depended upon their social class. Some manipulative techniques, used largely by poor women, have been discussed above. For professional women, a partner could sometimes act as an advocate.

*You'd be amazed at the difference in the way I'm treated when I take him (husband) with me...not that anyone speaks directly to me of course...he's (husband) an (profession) so the consultant just speaks to him and I'm made out to be some pathetic little wife... It's disgustingly sexist but quite frankly, I've given up...as long as we get some respect and we get our questions answered, I don't care anymore... The consultant talks to him (husband) where he wouldn't ever talk to me... And I don't mean just answer your questions with a monosyllable but really talk...you know, discussion going back and forth...he's never done that with me but he does with my husband... it's the respect thing isn't it - he respects my husband's status and position but he doesn't respect mine...*  
service user control site

Like the midwives 'doing good by stealth', the tactics used by women could achieve their individual objectives without disturbing the 'sentimental order' (Glaser and Strauss 1968) of the service but they did not create pressure towards wider change and informed choice.

### **16.5.6 Insight into barriers to change**

#### **16.5.6.1 Midwives seeing women**

Some midwives attempted to get around their powerlessness by withdrawing themselves and 'priming' service users, in the hope that they would then take on the role of change agent. As the following quotation illustrates however, not all midwives agreed that this was an appropriate or effective role for pregnant women to occupy:

*I don't think it's fair to expect the women to initiate the change because I think when they're pregnant they're in a vulnerable position... When they're in labour they're in an exceptionally vulnerable position and they will conform to whatever person is looking after them really...they will go along with that so it's the carers - the midwives and the doctors who need to make the change in their practice.*  
midwife intervention site

In the absence of formal consultation with service users and explicit permission being given by individuals, it is also ethically questionable whether it is appropriate to involve service users in this way.

#### **16.5.6.2 Women seeing midwives**

Many women praised their midwives and showed considerable insight into their situation.



*I was very impressed. I thought the midwives were excellent. I think they were incredibly hard worked. Some people got annoyed that maybe they weren't getting their pain killers when they should have done - on the dot of when it was due. But I just thought they were so busy there. They never seemed to get off for a break and they often had to stay on because the next shift were short. They were really stressed out some of them. One of the junior ones sat on my bed and cried with me one day... We cried together...*

service user intervention site

Women's awareness of the pressures upon midwives generated sympathy but was likely to make women even less likely to raise issues which might 'trouble' the midwives.

Some service users spoke of the midwives' position which prevented them from acting as advocates for women.

*I get the impression it's the system that's the problem. I got the impression that if they (midwives) did cause a row or queried anything they would have been knocked back. So it was a case of they didn't do it. So the onus is put back on the patient to make that challenge if they wanted to because they were more likely to get away with it than the midwife... The midwives would do if they knew they'd be listened to. I think it's a shame that the midwives haven't got enough say and they're not listened to...they're going to have a better understanding of you, your personality and your needs and I think it's a real shame that the system's not letting those people speak for you. At the end of the day you want somebody that you feel comfortable with. You're going through quite a major event in your life and you want that person to give you the support and back-up. So it is a shame that they're not listened to more.*

service user intervention site

A number of service users recognised midwives as an oppressed group who appeared to have very limited opportunities for acting as autonomous and empowered professional women:

*It comes across that midwives are very oppressed. You see it in the way midwives get chucked out of their room in the antenatal clinic by the doctor if he needs it... One day I was there and we had to be in three different rooms before she found one we didn't get chucked out of by a doctor. They are ruled by the doctors...that's the impression I got.*

service user intervention site

*It just seems like they always have to toe the line. They went along with what the consultant said . All the time they went along with that. They never seemed to challenge anything, especially what the doctors said. They just went along with it all.*

service user control site

The midwives contributing to this study spent considerable amounts of time in trying to reconcile the needs of very different interest groups. That they mostly achieved this is perhaps a testimony to their skill and ingenuity. It also, however, speaks of a culture in which midwives are almost as powerless as the women for whom they provide care. Service users who hold these views of midwives cannot see them as role models or change agents within the maternity services.

Service users were also aware where there were tensions between professions.

*The doctors and midwives have got to sort things out...they have to have better relations with each other. It really affects the care you get... It's been terrible... It's been like in a family where the parents are constantly at each other's throats and putting the other one down in front of the kids... The kids don't know who to trust...who to believe...they don't know which one they can go to...it's been just like that... It's so confusing...*

service user control site

### **16.5.7 Trust, confidence and perceived safety**

Considerable numbers of service users spoke about their relationships with health professionals in ways which suggested they linked trust with safety, for both themselves and their unborn babies. When women were having to make decisions when they were emotionally distressed and under considerable time pressure, they especially needed to be able to trust the health professional from whom information was sought. The status of health professionals was such that they generally expected and were accorded trust. As the following quotation illustrates, however, women sometimes realised that their implicit trust was ill founded:

*W: They told me I needed to be induced because I was 12 days overdue...they started on about it before he was even due! They told me I was risking the placenta coming away and then the baby would die... At first I believed them. I was all booked up for the induction. Then I phoned up a friend and then I started reading and I began to realise it wasn't all like they'd said. So I cancelled the induction... I think you do need other information as well...you do need to get that rounded view because midwives and doctors are all like us, they all have a certain view... So what you do is you go round and collect all the views and then you make your mind up... You feel much safer that way...*

*I: So there's a relationship between feeling safe and having this rounded view?*

*W: Yes definitely. You do feel safer that way...you've got to find people you can trust to talk to... I wasn't very lucky with that...I didn't feel I could trust the midwife...* service user control site

This respondent makes a clear case for the necessity of consulting with sources external to the maternity services if 'a rounded view' is to be obtained. This was also the opinion of many other service users, especially those whose confidence and trust the service had betrayed on a previous occasion. A number of service users reported that they experienced particular difficulties when they asked for further information but, instead, were offered the health professional's personal opinion and/or the hospital policy. Further attempts simply led to the health professional becoming more defensive and less willing to engage in any conversation, a pattern of behaviour which was also noted by the researchers undertaking observation work. Apart from clearly defined points of decision making, with their 'right' choices, professionals expected women to trust them and seeking information on which to base such trust was perceived as threatening.

*We were given the feeling that there's certain kinds of information that we're not supposed to be asking about...like we're not entitled to it. They seemed to think we didn't need to know and their response was that it doesn't matter whether the birth happens in hospital or at home because all the midwives are confident... My response to that was 'well that's fine but we're the ones who need to feel confident.'* service user intervention site

Women needed to trust their caregivers if they were to have confidence that their decisions would be respected and achieved. Midwives who demonstrated their solidarity with women making decisions which went against local norms were universally praised and held in high esteem. This appeared to be the case regardless of outcome. Thus, for example, primiparous women booking for home births who subsequently required transfer in labour, appeared just as satisfied with their experience as women who achieved a home birth. The following quotation is from one such woman:

*I realised I'd hit a gold mine when she said that they'd guarantee one of them would be there during the labour and they'd stay with me even if I needed to go to hospital... None of the others (midwives) would commit themselves to that. It made such a difference... (Interview interrupted as woman begins to cry) ... It was such a relief not to have to read everything in sight just so you've got some protection...they (community midwives) were the best protection I ever could have and I'd never have got that through reading!* service user control site

This woman felt she needed 'protection' to achieve the labour and birth of her choice, which was a much wider issue than achieving a booking for a home birth. Making a choice which was not the locally defined 'right' choice, she sought an advocate and protector to prevent her from having to defend her choice constantly with well read arguments. Informed choice here implies ongoing protection, not just a moment of choice. Only on rare occasions, however, did service users indicate that they had encountered 'goldmines' when they sought midwifery care. For the women who were so fortunate, the experience often provided an opportunity to integrate previous negative experiences of the maternity services and to move on from a position of hurt and blame. The midwives who were able to facilitate women in this way appeared more likely to hold expectations of childbearing as an empowering, rather than a disabling, event.

Clearly the health professional's 'clinical construction of reality' (Taussig 1980) is of great importance here. For most midwives their clinical construction of reality was created from a medical model and their considerable efforts to 'balance' (Levy 1997) the many pressures upon them. Recently 'evidence', inseparable from the (medical) language of randomised clinical trials and systematic reviews, is entering the professional discourse of midwives. It is a named and trusted reality, owned by experts to whose definition of 'right' choice it adds further scientific authority. It is worth noting that the concept of

'evidence' did not appear to have entered the consumer discourse for the vast majority of service users contributing to this research. Trust, beyond the trust accorded to their profession, was earned by individual professionals by their behaviour, particularly if they trusted and respected the client. The authority behind 'right' choices, and the many pressures upon them, made it very difficult for midwives to trust women. Most women simply respected the professionals' expertise and made the 'right' choices. A much greater degree of informed choice was achieved by those women who felt that they were trusted with the information they sought and that their decisions were respected. Trust was then a two way process.

Whilst trust was greatly valued and achieved much when present, the culture of the maternity services certainly did not foster it.

## **16.6 CONCLUSION**

The culture of the maternity services was essentially a defensive culture in which all the actors, variously, felt themselves to be oppressed. Some were more oppressed than others. Considerable guilt was also experienced which further inhibited change. Trust was rarely evident and manipulation was widely practised. All these factors served to protect the status quo with its 'right' choices in each setting.

It was into this culture that the MIDIRS Informed Choice leaflets were introduced.



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### 17.1 INTRODUCTION

The use of multiple research methods was a positive feature of this research.

*(it)* encourages the researcher to approach their research questions from different angles, and to explore their intellectual puzzles in a rounded and multifaceted way. This does enhance validity, in the sense that it suggests that social phenomena are a little more than one-dimensional, and that your study has managed to grasp more than one of those dimensions (Mason 1998;149).

The multiple methods used in this study, enabled exploration of a range of complex issues and identification of key elements for theoretical analysis. Thus, while the CRCT showed that the MIDIRS Informed Choice leaflets were not effective in promoting informed choice, analyses of the qualitative data illustrated the complexity of the environment in which the intervention was applied and reasons for the lack of effect.

### 17.2 WHY DID THE MIDIRS INFORMED CHOICE LEAFLETS NOT PROMOTE INFORMED DECISION MAKING?

A number of factors that help to explain why the MIDIRS Informed Choice leaflets were not effective in promoting informed choice. These fall into three areas:

- **The intervention and its implementation**
- **The lack of a coherent strategy for the promotion of informed decision making**
- **The cultural context**

#### 17.2.1 The intervention and its implementation

It is worth considering whether the lack of effect observed in this study could be due to the quality of the intervention or the quality of its implementation. It is unlikely that the lack of effectiveness was associated with the quality of the intervention since the leaflets were well researched, both in terms of content and presentation, and are of high quality according to criteria for assessing evidence-based information for clients (Rosser et al 1996).

The implementation of the intervention may be open to criticism: there was only one training session for staff in each hospital and a considerable minority of women did not recall receiving the leaflets in the intervention sites. However, it must be emphasised that the trial to evaluate the leaflets was pragmatic. In practice, hospital management purchase the leaflets and the training session (currently costed at £150 per session) as separate items. At the request of the research team, MIDIRS sent all of the intervention sites a copy of the training materials and they were encouraged to undertake further, cascade training for the purpose of this study.

##### 17.2.1.1 Training sessions

The MIDIRS Informed Choice leaflets were originally conceived of as part of an ‘informed choice initiative’ which ‘encourages practitioners to include informed choice as an integral component of maternity care’ (Rosser et al 1996).

The leaflets were originally designed to be used on a ‘prescription’ basis: that is, the midwife would offer leaflets to individual women when, and if, it seemed appropriate. They were also intended to be used as a tool for discussion, emphasising that the contents are based upon the latest research and are not simply advertising or opinion (Stewart 2000).

All of the MIDIRS training sessions that took place in intervention sites during this study were observed. While training emphasised that women should be given the leaflets at agreed points in pregnancy and the importance of documenting these transactions, it did not examine techniques for using the leaflets to facilitate informed choice. Nor did training examine ways in which midwives could best respond to women's individual needs and prescribe the leaflets appropriately. Midwives reacted to the practical orientation of the training session with queries about documentation and storage of leaflets rather than raising questions about facilitating client choice or presenting evidence based information to women whose views contradicted current evidence. It may be that the interface between the MIDIRS training sessions and the maternity services' culture has gradually changed the nature of that training to reflect the current emphasis on that which can be routinised and measured. In recent correspondence with MIDIRS, it is recognised that 'there have been some problems in training (NHS) staff in the use of the leaflets' (Stewart 2000).

It is also noteworthy that training sessions were attended, almost exclusively, by midwives. This reflected widespread perceptions that the leaflets were primarily applicable to midwifery practice. While it is true that the majority of leaflet topics concerned information which midwives might be expected to discuss with childbearing women, whether or not informed choice was possible was the province of those with considerably more decision making and organisational power than clinical midwives.

It is possible that results may have been different had there been more training sessions in each hospital and had they attracted greater numbers of staff concerned with the delivery of ante-natal care. Extra training sessions may have given more staff a better understanding of the purpose of the leaflets and how to use them. However, it is unlikely that more training sessions alone would have changed confidence levels to the degree that enabled staff to offer more of the options suggested in the leaflets, nor would extra sessions have affected the lack of time for discussion between health professionals and women.

#### **17.2.1.2 Women receiving or remembering the Informed Choice leaflets**

Approximately 70% of women reported receiving at least one of the Informed Choice leaflets during the intervention. We would not have expected all women to have received the full set of ten leaflets as they were intended to be used prescriptively, according to individual need. However, there were also problems with the distribution of the leaflets which may have accounted for women reporting that they had not received the intervention. Women may have received the leaflets but did not realise this because the leaflets were often concealed, for example, when 'wrapped' with information contained in the Bounty pack or inserted inside the cover of the client-held notes. Indeed several pristine sets of leaflets were found in maternity records when these were examined postnatally, by the researchers undertaking the economic study. Additionally, some women were not given leaflets because their midwives had not received leaflets. At times some midwives did not give the leaflets to, or actually withheld leaflets from, individual women.

The research team had not anticipated that the supply of Informed Choice leaflets would run out prematurely, especially as they had been expected to be used prescriptively. On all sites, however, midwives reported having exhausted their stock of leaflets towards the end of the intervention period and more were therefore supplied. On some sites, leaflets were left on tables or in racks, in waiting rooms and corridors for women to help themselves. It is possible that the results of this study might have been different had more women received the intervention. However, the pattern of leaflet use in the CRCT mirrored that seen in the three ethnographic sites and thus reflects practice outside of the trial.

#### **17.2.2 The lack of a coherent strategy for the promotion of informed decision making.**

##### **17.2.2.1 What is 'Informed Choice'?**

When clinicians and, very occasionally, women referred to 'informed choice', the words had very different meanings for different people. When used by professionals, these words could often be equated with informed compliance. There were midwives who worked hard to facilitate informed choice especially with women for whom this was also important, however, the situation of these midwives and women was difficult within their settings. Generally, professionals assumed a 'right' choice with respect to each issue of clinical practice addressed by the leaflets. Assumptions about 'right' choices were observed in the qualitative study and were also evident in the data from interviews

with midwives in senior management. The leaflets were seen as containing information that enabled women to make the 'right' choice an informed choice. In such circumstances it is not really surprising that no change in service use occurred.

### **17.2.2.2 Lack of a coherent strategy**

There appears to be a widespread assumption in midwifery that leaflets entitled 'Informed Choice' will effect informed choice: it appeared then, that 'informed choice' was simply equated with having the leaflets. Though informed choice is currently seen as important within the NHS and is emphasised in maternity care policy documents (Welsh Health Planning Forum 1991, Department of Health 1993), the process by which it can actually be achieved has not been thoroughly examined. In units where the leaflets had been purchased, managers were somewhat vague as to why they were perceived as desirable items. In the CRCT, senior midwives were pleased when they learned that their unit had been randomised to receive the leaflets and disappointed when randomised to the control group because they saw the leaflets as helpful in conveying options to women.

Although one HoM, interviewed as part of the Mapping exercise, was able to supply evidence of audit, this was the exception. There was no other evidence of efforts to assess or audit leaflet use. Furthermore, none of the managers interviewed in the various parts of this study had considered that client choice could have implications in terms of uptake of services or resource use in the areas to which the leaflets were addressed. On no site researched could there be said to be management commitment to the realities of facilitating informed choice or its possible implications and nor did we find evidence on any site of a strategy for achieving informed choice.

In the questionnaires used in this study we have created a tool to evaluate informed choice and a range of other issues around leaflet use. It was originally planned to develop simple tools to monitor and assess the use and appropriateness of leaflet use. However, in the absence of a coherent strategy, or even a clear conception of appropriate use, this did not prove possible. Indeed, as we have already noted, we have reason to surmise that MIDIRS' own perception of appropriate use, as conveyed through their training, has changed somewhat in response to the culture within which leaflets are used.

### **17.2.3 The cultural context**

Analyses of qualitative data, derived from multiple data collection methods, highlight a number of facets of the culture and of the environment into which the intervention was introduced, which were important for facilitating or impeding the promotion of informed decision making. These can be summarised as:

- **Women's information needs**
- **Evidence Informed Choice**
- **Power relationships and information flow**

#### **17.2.3.1 Women's information needs**

Women contributing to this study wanted, and needed, more information than they were generally offered by midwives or other health professionals. Though many women, especially those pregnant for the first time, looked initially to health professionals to meet their information needs, they quickly assumed responsibility for accessing information themselves. Primiparous women in particular were noted as being avid and eclectic gatherers of information who accessed a wide range of sources, of which the MIDIRS Informed Choice leaflets were but one.

In all the units researched, midwives articulated a strong commitment to giving women information. However, in interactions between midwives and women, 'missed cues' and 'lost opportunities' were regular features of the exchanges that took place. This may, in part, be due to the lack of coherence in women's stories, for information was often offered by women, to midwives, in 'drips and drabs' throughout the consultation episode. Whatever the reason, the effect was that midwives often gave information without ascertaining a woman's existing level of knowledge or her need for information.

Much of the information that was given by midwives was conveyed orally and took the form of warnings. For instance, considerable time was devoted to giving 'negative injunctions' (Sherwin 1992)

on diet. Clearly individuals have choices as to what food they purchase and consume. Yet midwives rarely attempted to elicit from women details about their dietary habits and thus food related information was not given in the context of choice, but as lists of foods which should not be eaten in pregnancy. Given that this is the form in which midwives generally receive such information (WO 1996, DHSS 1990) and that midwives have a long history of being required to pass on such advice to women, this behaviour is not surprising. In practice, therefore, though midwives were committed to the principle of information-giving, the process through which this took place was problematic for both parties.

For their part, midwives experienced considerable anxiety about the amount of information they were required to convey. They frequently expressed a concern, not shared by their clients, that they were 'bombarding' them with information. Furthermore, midwives were generally of the opinion that the amount of time currently allocated to the antenatal consultation was not sufficient to enable them to undertake both the role of information broker and clinician. This situation was further complicated by a concern, expressed by many health professionals, over possible litigation. The duty of care to inform has now been recognised as part of the law of negligence (Dimond 2000). Not surprisingly, many health professionals appeared fearful lest they subsequently face accusations (and the threat of litigation) for having given women information without also conveying an appreciation of the attendant risks. But as there is no standard definition by which 'risk' is assessed, and because we know women are vulnerable to suggestions that they might be exposing their babies to risk, it is perhaps small wonder that this issue gave rise to considerable concerns on both sides. This may be exacerbated by the suggestion in recent literature (Teixeira et al 1999) of an association between maternal anxiety and fetal outcome. Given the earlier work of Statham et al (1997) which revealed that anxiety about something being wrong with the baby is very common amongst pregnant women, introducing additional notions of clinical risk could have the unwanted effect of further increasing anxiety levels.

Tensions such as these, around information-giving, may help to explain both the tendency for midwives to deliver information in standardised verbal packages, rather than in an individualised manner, and the emphasis placed upon documenting the information given.

### **17.2.3.2 Evidence informed choice**

Discourses around evidence based information and/or care did not feature spontaneously in women's narratives. As evidence based information, such as that contained within the MIDIRS Informed Choice leaflets, was rarely presented to women as being different from any other information (including advertising materials), it required women to be highly discriminating in order to make informed decisions about their care. A recent study (Gready and Newburn 1999) suggests, however, that where the evidence base of the leaflets is emphasised to women, changes in expectations and experiences of labour may result. On many sites, some of the information presented in the MIDIRS leaflets was at variance with local, clinical practice and this resulted in women being 'steered' to make the 'right' decision in accordance with existing, normative patterns of care. While many health professionals appeared to be familiar with the terminology of 'informed choice' and 'evidence based care', the data collected through a range of methods in this study suggest that these concepts were poorly understood. There was little evidence to suggest that clinical practices had changed on sites where health professionals had access to the MIDIRS Informed Choice leaflets and there was no evidence of a change in outcome measures.

Whilst some decisions have to be made at a particular stage in pregnancy, different understandings of the timing of decision making were evident. The orientation of the service was such that women tended to be presented with a series of choices to be made and documented at agreed points in pregnancy. This pre-existing pattern of service delivery may have explained the ease with which decisions were made to issue the leaflets at predetermined, fixed, points in pregnancy. A number of women, however, spoke of decision making as a process occurring over a varying period of time. Some women needed to 'bide their time', to gather information and talk to a variety of people before coming to a decision. Women attending the smaller maternity units and those who enjoyed close and supportive relationships with their midwife were more likely to report this process as being a feature of their care. Women who made decisions that went against local practice often faced repeated challenges in later consultations. A small number of midwives, however, were seen to make great efforts to protect such women and the choices that they had made.



The decisions on which the leaflets focused were, with the exception of that on drinking alcohol, decisions which staff saw within a clinical context. As we have suggested, there was usually a clinically 'right' choice, or at least a choice that was seen as the norm by staff. Women did, however, make some decisions that could not be justified as 'right' in terms of the weight of evidence but which were, nonetheless, generally accepted by midwives. Women who lived in areas where the local culture supported bottle feeding were one such group and a number of midwives admitted that they felt defeated in trying to convey information about the health gains associated with breast feeding. Indeed, the researchers occasionally observed such women correctly reciting the disadvantages of bottle feeding to midwives even though they had decided to adopt this method of infant feeding. Overall, the women and midwives observed chose to 'go with the flow' of clinical opinion in matters claimed as clinical and with local opinion on matters such as infant feeding. The words 'go with the flow' were frequently used in interviews. Both women and midwives reacted to their relative powerlessness within the maternity care setting by accepting and reinforcing the status quo. Midwives' considerable efforts to give information were, therefore, mostly directed towards ensuring informed compliance rather than informed choice. From this viewpoint midwives' efforts to render the MIDIRS leaflets invisible could be seen as preventing any disruption to this process.

Some women chose not to 'go with the flow' and made other decisions. Some midwives went to great lengths to support such women and to facilitate women's active decision making. Both groups were a small minority. It is clear, however, that access to information and decision making were fundamentally influenced by the nature of the relationship between the childbearing woman and health professionals. A number of factors were seen to influence both this relationship and the ability of women to exercise informed decision-making in maternity care.

#### **17.2.3.3 Power relationships and information flow**

Our findings echo those of a parallel study of birth choices:

Health professionals have greater status and power than the women who seek care. In order for them to feel comfortable and on equal footing, professionals must make a deliberate effort to understand women's needs and provide for them. (Gready et al 1995)

In most of the consultations observed in our study, status differences were maintained and women interviewed did not experience, nor did many expect to achieve, such an 'equal footing' in decision making.

#### **17.2.3.4 Inequities**

Informed choice, based on a consumerist logic underpinned by notions of 'rights' and 'entitlements', has become something of a fashionable concept in recent years. Consumerism does not, however, necessarily recognise, nor take account of, the power invested with the health service provider and thus the menu of 'choice' inevitably reflects another set of priorities. Furthermore, choices are limited to what the service can supply, rather than what might be requested by any individual or group of consumers. There is a sense in which the MIDIRS Informed Choice leaflets could be seen as commodifying choice. The same could be said of any information which encourages clients to increase their expectations of a service with limited resources. In the maternity service, this inevitably means that women who are more demanding of the service are more likely to have their needs attended to, perhaps at the expense of others, especially those who are less articulate. In this study, materially disadvantaged women were observed as being more likely to be stereotyped and given fewer leaflets, because midwives appeared to make assumptions about their literacy levels, desire for knowledge and willingness to participate in their care. The postal questionnaire did not, however, find the often assumed relationship between women's social class and their knowledge.

The growing insistence on evidence based information in the NHS promises to be an interesting challenge to a service which is also striving to improve health by reducing 'persistent unacceptable inequalities' (Department of Health 1998). There is a danger, however, that an emphasis on written materials as decision aids in maternity care could reinforce, rather than reduce, the long established link between poverty, poor health and low standards of educational achievement. The internet has the potential to create a 'profound levelling affect' on relationships which have historically been 'marked by an imbalance of power' (McLellan 1998), and was experienced thus by a few women interviewed. However, this resource is generally available only to more educated women. Women with privileged

access to information do not necessarily require less consultation time with health professionals. Observation work in this study revealed the opposite to be true; the more information service users collected on their own initiative, the more time was needed for discussion with midwives who, in turn, felt obliged to make time available. The limited amount of total midwifery time available for ante-natal consultations was thus used by those most able to access information independently, a finding which reiterates the inverse care law proposed by a GP in Wales almost 30 years ago (Tudor Hart 1971).

### **17.3 CONSTRAINTS ON THE WOMAN/MIDWIFE RELATIONSHIP**

#### **17.3.1 Midwives under pressure**

Throughout this study it was clear that midwives experienced many pressures upon them. They nevertheless, gave generously of their time to this research. The researchers are very aware of how research that is originally agreed to by managers, imposes considerable extra work upon clinical midwives. For the researchers, these time pressures were exemplified in decisions about whether to interview, or administer knowledge questionnaires to busy midwives who had already given considerable time to the study.

For the midwives themselves, such choices and juggling of priorities were constant features of their working lives. Not least of the pressures upon them was the pressure of time. Time was a real issue for midwives in giving information to women. Women also perceived this pressure and spoke of midwives and doctors as 'busy' people. Initiating conversations with health professionals therefore required a considerable degree of assertiveness from women. Aware of this 'busyness', most women could not, and did not, exhibit such assertiveness. The responsibility for creating openings was particularly difficult for women who needed to access health professionals for information and/or discussion outside of scheduled appointment times. Women who enjoyed a relationship of trust with their midwife appeared likely to take a more equal part in consultations and were observed asking more detailed questions and were more likely to initiate conversation. Women felt such trust to be of greater benefit where it was established early in the relationship. Trust maintenance depended upon a high degree of continuity and coherence between midwife and woman. The need for coherence is reflected in the concern expressed in the questionnaire free text responses about the 'personality and competence' of carers. Situations where there was continuity of care were likely to promote women's decision making by creating the continuing relationship where trust could develop. These same conditions were likely to enhance midwives' feelings of professional autonomy.

Balancing the needs and demands of obstetricians, managers and midwifery colleagues placed considerable pressure upon clinical midwives. Their own position within the maternity services meant that, while midwives expended considerable effort to achieve balance, many had little power to manoeuvre when trying to accommodate the many calls upon them. This led some to feel unable to support women, especially those who made informed choices that had the potential to alienate power holders. This reflects the findings of Kaplan et al (1996) who reported that patients were more likely to rate physicians as having 'participatory styles' where the doctors reported high levels of satisfaction with their level of professional autonomy.

#### **17.3.2 Skills and knowledge**

Facilitating informed choice requires a number of skills such as ascertaining the information needed, communicating appropriate information, supporting the exploration of options and nurturing the appropriate conditions for informed decision-making. Leaflets are tools for imparting information, but although information is necessary to attain informed choice, skills as well as tools are needed. Women greatly appreciated staff with good communication skills and the ability to tolerate and respond to women's differing information seeking behaviours.

The observation work undertaken in this study suggests that midwives lacked the sophisticated negotiation skills required when introducing sensitive topics to populations with long standing resistance. Such lack of skill has been identified in other studies and highlighted by midwives themselves (Pope et al 1996). The majority of midwives interviewed had no formal counselling skills and neither had they received training in presenting or discussing, complex information. This may be a reason why a number of midwives were observed to block conversation when uncomfortable feelings

surfaced during discussions with clients and leaflets were, on occasion, used to convey information which the midwife found difficult to give orally.

However, it must be remembered that skills in communication are built upon knowledge which may not be available to midwives. Conversation patterns around decision making were observed in this study which have not been analysed in the midwifery literature. For instance the phrase 'I don't know' was used frequently by women during consultations in such a way as to suggest that they sought to defer decision making whilst continuing to seek out other aspects, and additional sources, of knowledge. Yet we could find no literature describing or exploring such patterns of speech. It is scarcely surprising, therefore, that midwives' response to 'I don't know' was usually to take the phrase at face value and deliver a standard package of information on the subject in question without first attempting to assess the woman's existing knowledge and need for such information. Considerable time was thus spent giving standard packages of information to women, some of whom were very knowledgeable on these subjects, and this left little time for midwives to address women's specific, individual, information needs.

Lack of skill may also explain why a considerable number of women reported that midwives carried out clinical checks but did not listen to them. Listening, whilst essential in facilitating informed choice, requires time as well as skill. The midwives interviewed and observed felt very pressed for time and their clients were aware of this. Whilst this has been the case in midwifery for many years (Kirkham 1983), current changes in the NHS have legitimated and routinised working at speed and under pressure, even in sensitive areas of client decision making. For instance, recent proposals around antenatal screening for HIV are costed upon an average of three minutes pre-test 'counselling' from a midwife (Ades et al 1999). In such a climate midwives are unlikely to learn or dare to practise much skill in listening or counselling. Such a climate also influences the priorities of clinicians and adds to the pressures to prioritise what is perceived as necessary and available for audit, as was reported by many midwives in this study.

It is also possible that the MIDIRS leaflets were used by midwives to cover up for their lack of knowledge, especially in areas such as screening for fetal abnormalities which have undergone substantial change in the last decade. Two studies (Sadler 1997, Smith et al 1994) have revealed poor levels of knowledge about serum screening for fetal abnormalities amongst midwives. Midwives in this present study achieved consistently higher knowledge scores than their clients and midwives on intervention sites recorded higher levels of knowledge on the majority of leaflet topics, including ultrasound and antenatal screening. Nevertheless, midwives' knowledge was incomplete on a measure derived from leaflets aimed at women and therefore greatly simplified from those written for professionals. It is possible that lack of both knowledge and confidence inhibited midwives in giving appropriate information for decision making.

### **17.3.3 Organisational factors**

A number of features of the culture in which women accessed their maternity care hindered their attempts to secure information and make informed decisions about their care. Maternity care services in all of the settings observed were characterised by a considerable degree of cultural inertia. Many health professionals adopted a defensive, and sometimes adversarial, attitude on the occasions women questioned them about aspects of routine practice or made decisions with which they did not agree. Feelings of guilt and blame were widespread and were occasionally employed as mechanisms to manipulate situations to the advantage of one or other party. The paternalistic and hierarchical nature of the NHS meant that information which did not conform with medical opinion tended to be withheld from services users; it also reinforced the low status of midwives who were widely perceived by pregnant women as oppressed and powerless. Doctors, by contrast were invested with considerable authority and this made it difficult for pregnant women and/or midwives to challenge their opinions.

The fact that interventions, such as ultrasound scans, have become normative elements of maternity care, makes the notion of 'informed choice' particularly problematic. Their routine use has rendered such interventions invisible, but essential. Indeed, choosing not to have an intervention, such as an ultrasound scan, or an amniocentesis in the case of a 'high risk' serum screening result, was widely perceived as irresponsible. The emphasis on technological intervention and the constant surveillance of women throughout the episode of maternity care created difficulties for those women and health professionals whose decisions challenged the obstetric model of care.

## 17.4 CONCERNS ABOUT COSTS

Concerns about costs were very evident in interviews with HoMs during the Mapping Exercise. Managers expressed doubts about their ability to allocate funding to the purchasing of leaflets, from budgets that were already tightly stretched. Similarly, some of the general practices that had funded purchases of the MIDIRS Informed Choice leaflets had been required to look outside of their usual funding sources. Costs were therefore perceived to exert a real constraint upon the utilisation of leaflets. However, in this study, the leaflets were distributed free to all intervention units and costs cannot, therefore, explain the lack of effect seen.

## 17.5 GENERALISABILITY AND LIMITATIONS

The CRCT was undertaken in Wales. The qualitative research for the CRCT produced similar results to the qualitative research in the three ethnographic sites which had purchased the leaflets, and two of these three sites were in England. There were no differences in the way the leaflets were used and in barriers to informed choice between the English and Welsh maternity units. The hospitals in the intervention sites were given the leaflets whereas in practice, hospitals purchase them. The three ethnographic sites in the qualitative research purchased the leaflets and were found to use them in the same ways as the sites in the CRCT. The study can thus be considered to be generalisable to situations within the UK where leaflets are purchased. The study is not generalisable to situations in which the leaflets are used as part of a broader strategy to promote informed choice nor to situations in which the leaflets are used in other ways, for example, where they are used to promote evidence based practice. In addition, it is not possible to generalise to situations in which other media are employed. The research literature does, however, have evidence of similar results for other media. A simple leaflet, a video and an expanded leaflet all performed in the same way (Michie et al 1997). Written birth plans have been shown to have no effect on involvement in decision-making (Brown and Lumley 1998). Indeed, the conclusions from the study on birth plans read similarly to our own:

It is clear from the existing literature on birth plans that context and setting play a critical role. The degree to which hospital staff are involved in developing and implementing birth plans devised by women themselves or adapted from other settings, are likely to have powerful effects. How birth plans affect practice, and how well they achieve the purpose of promoting communication between women and care-givers cannot be separated from existing hospital policies and cultures, the extent of support for evidence-based practice, degree of continuity of care, and commitment to involving women and their partners in decision-making (Brown and Lumley 1998).

Even though there are limitations within the study (which are discussed in each of the results sections of this report) we do not consider that these have compromised the research findings in any significant way.

## 17.6 INTERPRETATION OF THE STUDY FINDINGS IN THE LIGHT OF OTHER RESEARCH

Since our study commenced, other researchers have identified the complexities of informed or shared decision-making (Elwyn et al 1999a, Entwistle et al 1998a, Sullivan and Pickering 1998). Entwistle makes the point that evidence-informed patient choice 'is not a simple concept that can easily be implemented, particularly in national/public health care systems' (Entwistle et al 1998a). Work by Glyn Elwyn and colleagues with GPs, has led to a call, not for more decision aids, but for more time to be made available within consultations, improved ways of communicating risk to patients and the acquisition of new communication skills (Elwyn et al 1999a). Our qualitative work suggests that this is also the case in maternity care.

Decision aids have been defined as interventions designed to help people make specific and deliberate choices among options by providing information on the options and outcomes relevant to a patient's health (O'Connor et al 1999). The MIDIRS Informed Choice leaflets fit this definition but they were only rarely observed to be used in this way. The use of decision aids is likely to be particularly problematic where decisions are invisible to staff. Such 'invisibility' is likely to influence decision making in relation to ultrasound scans (in all settings) and where there is a clear 'right' choice, such as the preference for

elective caesarean section for breech presentation (in some settings). In these circumstances, non-compliance with the 'right' choice is seen as dangerous.

A recent systematic review of decision aids concluded that they improved knowledge, reduced decisional conflict, improved patients' perceptions of feeling informed, and increased the proportion of people assuming a more active role in decision making (O'Connor et al 1999). The largest and most consistent benefit was better knowledge of the options and outcomes. Decision aids did not affect satisfaction with the decision-making process nor did it affect satisfaction with the decision, nor patients' anxiety. Decision aids had variable effects on decisions made. Many of the findings of our study agree with those of the systematic review: there was an improvement in knowledge, but no effect on satisfaction with the decision-making process or patient anxiety and there was some evidence that the leaflets had some effect on the decisions women made. The most important difference between the systematic review and our study was that in our study there was no change in the proportion of women assuming a more active role in decision making. Furthermore, qualitative data from our study reinforces this finding as women's active involvement in decision making was rarely observed.

Individual studies in the systematic review (O'Connor et al 1999) were based on approximately 100 intervention individuals with the implicit assumption that all received the intervention. Our pragmatic study involved thousands of women potentially receiving the intervention and a maximum of 70% recalling having received it. Perhaps if the decision aids included in the systematic review were used on a widespread basis there would have been a dilution of some of the effects and a loss of others. This issue of scale may also explain some of the difference between the findings of the pilot study to evaluate two of the leaflets (Oliver et al 1996) and our larger scale study. The pragmatic nature of our study as well as its scale may also account for the difference between our findings and the reported effect attained from planned use of the MIDIRS leaflets with small groups of women in two other, unpublished, studies (Newburn 2000, Murrow 2000).

The MIDIRS leaflets may have been designed as decision aids but the qualitative research has shown that generally, at best, they were used as sources of information. A recent systematic review of informed decision-making found that:

...information and education are relatively ineffective ways of facilitating informed decision-making, compared with the context and social influences. Studies reporting manipulation of information, and provision of feedback, were the most likely to report an effect. (Bekker et al 1999)

This is illustrated by a study that compared a general educational pamphlet with a tailored decision aid. This found that the decision aid prepared women better for decision making than the general pamphlet, although knowledge levels were similar with the two interventions (O'Connor et al 1998). Some studies have shown that leaflets can improve knowledge (Little et al 1998) and other outcomes such as anxiety levels (Marteau et al 1996). However, there is little or no evidence that information alone can deliver informed choice or change the behaviour of health professionals (Freemantle et al 1997).

Another medium might have been more successful. Yet a comparison of a video with a simple leaflet and an expanded leaflet showed that they performed the same (Michie et al 1997) and an in-house leaflet in one of our control sites appeared to perform at least as well as the Informed Choice leaflet on the same subject. Thus the medium may not be the important issue. The manner in which any video or leaflet is used is likely to be more important than the medium itself.

## 17.7 IMPLICATIONS

- Leaflets are tools for imparting information and although information is necessary to attain informed choice, it is not sufficient.
- The implications of this study are not that the MIDIRS Informed Choice leaflets are without effect. We cannot say from this study whether they *could* be effective at promoting evidence informed choice as part of a coherent initiative rather than as the driver or focus of the initiative.
- The maternity services are characterised to an important degree by cultural inertia. Until this is addressed, introducing concepts of informed choice are likely to result merely in informed compliance. Currently, the MIDIRS Informed Choice leaflets are commonly used to reinforce the

rhetoric of informed choice without challenging cultural inertia. Where evidence based information does not reinforce normative practices, this information may be denied by health professionals.

- There is potential for conflict where evidence based information, such as the MIDIRS Informed Choice leaflets, are prioritised over women's and professionals' experiential knowledge.
- The promotion of informed choice is not cost neutral. Resource use cannot be understood simply in terms of the costs of purchasing evidence based information such as the MIDIRS Informed Choice leaflets and associated training. Resource use will also be associated with cultural changes required to provide a context amenable to informed decision making.

## **17.8 RECOMMENDATIONS**

### **17.8.1 Department of Health**

- The Clinical Governance aim of moving 'away from a culture of blame' (NHS Executive 1999) has particular resonance in the light of the findings of this research. Explicit strategies are needed to achieve such massive cultural change. This study highlights particular tensions in maternity care between the aims of evidence based care, choice, efficiency and equity. For instance, organisational imperative to maximise the efficient use of time result in articulate women claiming more staff time and disadvantaged women being excluded from decision making. Such fundamental tensions need to be acknowledged and explored.
- Resource planning is required to prevent the Inverse Care Law (Tudor Hart 1971) becoming established within new national care initiatives.
- Improved access to information for women requires a strategic approach. There is a need to develop and define appropriate funding which might derive from public, private or consumer sources.
- The MIDIRS Informed Choice leaflets have been developed and are seen as helpful by women; therefore, decisions need to be made as to how they can best be funded, distributed and used.
- When a funding strategy is in place, information can also be given in creative ways. Possibilities include:
  - \* Giving some leaflets with the Surestart Maternity Grant together with the telephone number of a maternity advocacy service.
  - \* Making leaflets available on the Internet.
  - \* Points of decision making could be included in the chronology of pregnancy in the Pregnancy Book (Health Education Authority 1997)

### **17.8.2 Professional Organisations**

- There is a need for professional debate concerning the factors which prevent health professionals from listening to women and which encourage stereotyping as a professional defence mechanism.

### **17.8.3 Education Providers**

- There is a need for basic and continuing education for health professionals that emphasises skills development in particular areas including: listening and responding to cues, history taking, dealing with sensitive areas of information and appreciating the contribution of alternative perspectives.

### **17.8.4 Service Providers**

- The fostering of continuing trusting relationships between clients and professionals should be an aim in service planning.
- Equity should also be an explicit aim.

- There is a need to identify and develop strategies to enable women to access health professionals for information and discussion outside of scheduled appointments. This may be particularly important in early pregnancy.

#### **17.8.5 Health Care Professionals**

- There is a need for individual practitioners to listen to women, to assess their knowledge levels and target information selectively.
- Health professionals need to be aware of the difficulties many women experience in asserting their need for information and dialogue. Health professionals need to assume the responsibility for creating openings to enable information flow.

#### **17.8.6 MIDIRS**

- Consider a range of options for making evidence based information available to women and health professionals.
- Training in the use of evidence based information needs to be delivered as part of an integrated strategy for promoting informed choice. Each training session must be sensitive to local culture.

### **17.9 FURTHER RESEARCH**

As the MIDIRS Informed Choice leaflets are useful information tools that were generally liked and appreciated by women, it is important to consider how their utilisation might be improved. This research has highlighted the absence, within practice settings, of coherent strategies through which informed choice could be facilitated. Further research is therefore warranted to:

- understand the different meanings of informed choice articulated by participants within maternity care, the separate values attached to information and to choice, and the implications of these differences in practice.
- further delineate the concept of informed decision making and the emphasis which may be placed upon different elements within different cultural contexts.
- assess the effectiveness of the leaflets when their use is embedded within a coherent strategy that is aimed at maximising informed decision making in maternity care.

This study has highlighted other issues of significance to participants in maternity care. These also warrant further research.

- action research is required to explore the process of cultural change within maternity care. A particular focus upon power relationships is needed. It is important to reiterate that this study strongly suggests that the facilitation of informed choice is likely to be contingent upon changes in power relationships.
- there is a need to identify effective midwifery skills and the contexts that facilitate their use. In particular there is a need to elucidate the skills required by midwives to respond appropriately to cues and opportunities that may arise during interactions with women.
- The concept of trust warrants further explication. The factors that enable, or mitigate against the development of a trusting relationship between a childbearing woman and her carer/s need further exploration. This study has indicated that information flow is optimised within trusting relationships.





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## Appendix 1: Titles of the MIDIRS Informed Choice Leaflets

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	WOMEN'S VERSION	PROFESSIONALS' VERSION
1	<b>Support in labour</b>	<b>Support in labour</b>
2	<i>Listening to your baby's heartbeat during labour</i>	<b>Fetal heart rate monitoring in labour</b>
3	<b>Ultrasound scans - should you have one?</b>	<b>Ultrasound screening in the first half of pregnancy: is it useful for everyone?</b>
4	<b>Alcohol and pregnancy</b>	<b>Alcohol and pregnancy</b>
5	<b>Positions in labour and delivery</b>	<b>Positions in labour and delivery</b>
6	<b>Epidurals for pain relief in labour</b>	<b>Epidural pain relief during labour</b>
7	<b>Feeding your baby - breast or bottle?</b>	<b>Breastfeeding or bottle feeding; Helping women to choose</b>
8	<i>Looking for <b>Down's syndrome</b> and <b>spina bifida</b> in pregnancy</i>	<b>Antenatal screening for congenital abnormalities: helping women to choose</b>
9	<b>Breech baby: What are your choices?</b>	<b>Breech presentation - options for care</b>
10	<b>Where will you have your baby - hospital or home?</b>	<b>Place of birth</b>

**The first series** of leaflets, published in July 1996, included leaflets 1-5; **the second series**, published in January 1997, included leaflets 6-10.



## **Appendix 2: Cluster Randomised Controlled Trial**

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## **Appendix 2a: Cluster Randomised Controlled Trial - Questionnaires**







**Confidential**

# **A SURVEY OF INFORMATION AND CHOICE IN MATERNITY CARE**

*In this booklet we ask about:*

- A - Dates and your baby**
- B - How you feel about being in control**
- C - What has happened to you so far**
- D - What you wanted**
- E - Information**
- F - Making choices**
- G - Some questions about pregnancy**
- H - Leaflets**
- I - How satisfied you are with your care**
- J - Your health**
- K - You and your household**

## A - Dates and your baby

A.1 When is your baby due?

Please fill in date expected

Day			Month			Year	1	9	9	8
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(Example for month: fill in '06' if June, '07' if July etc)

A.2 How many weeks pregnant are you today?

If you are not sure, please give an estimate.

Please fill in number of weeks pregnant

A.3 Is this baby your

- 1st
- 2nd
- 3rd
- 4th or more
- Please tick one*

## B - How you feel about being in control

B.1 Do you **feel** you have control and can make choices about things that happen **generally in your life?**

- yes
- partly  *Please tick one*
- no

B.2 How **important** is it for you to feel in control and make choices about things that happen **generally in your life?**

- very important
- quite important
- not very important
- Please tick one*

**B.3 How important is it for you to feel in control and make choices about things that happen in your antenatal care?**

- very important
- quite important
- not very important
- Please tick one*

## C - What has happened to you so far

***Please answer all the following questions about this pregnancy only***

**C.1 Have you had an ultrasound scan, which showed the baby on a screen?**

- Yes, had an ultrasound scan
- No
- Please tick one*

**IF YES** - How many times have you been for an ultrasound scan during this pregnancy? *If you are not sure please give an estimate. Include all ultrasound scans.*

Fill in number of scans

**C.2 Have you had any blood tests to find out the risk of your baby having either spina bifida or Down's syndrome?**

- Yes
- No
- Don't know / not sure
- Please tick one*

**C.3 Have you had any of the following tests to check for problems with the baby?**

- |   | Yes                      | No                       | Don't know /<br>not sure |   |
|---|--------------------------|--------------------------|--------------------------|---|
| amniocentesis, where fluid is removed from round the baby | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <i>Please tick one box on each line</i> |
| CVS - Chorionic Villus Sampling in early pregnancy        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |   |

**C.4 Where have you planned to have your baby?**

- at hospital
- at home  *Please tick one*
- other e.g. GP unit  *If other, please say where \_\_\_\_\_*

**C.5 (a) How often do you drink alcohol now you are pregnant?**

- never
- occasionally  *Please tick one*
- a few times a week
- every day

**(b) Has this changed since you found out that you were pregnant?**

- yes, I drink more alcohol now
- yes, I drink less alcohol now  *Please tick one*
- no, I drink the same amount of alcohol now
- I did not drink alcohol before I was pregnant

**(c) If you want to say anything about the amount of alcohol you drink, please write it below**


---

## D - What you wanted to happen this pregnancy

**D.1 Which of the following did you want to do?**
*Please tick one box on each line*

	Yes	No	No preference
<u>have</u> an ultrasound scan	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<u>have</u> a blood test to look for Down's syndrome and spina bifida in the baby	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
plan to have your baby <u>at home</u>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<u>drink</u> alcohol during pregnancy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**D.2 How strongly did you feel about what you wanted or did not want?**
*Please tick one box on each line*

	very strongly	quite strongly	not very strongly	not strongly at all	does not apply
having ultrasound scans	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
having blood tests to look for Down's syndrome and spina bifida in the baby	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
planning to have your baby in hospital or home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
drinking alcohol when pregnant	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**D.3 What influenced your thoughts about what you wanted?***Please tick all that apply*

doctors, nurses or midwives	<input type="checkbox"/>	
family or friends	<input type="checkbox"/>	
books or magazines	<input type="checkbox"/>	
leaflets given by doctors, nurses or midwives	<input type="checkbox"/>	
TV programmes	<input type="checkbox"/>	
past experience	<input type="checkbox"/>	
antenatal classes	<input type="checkbox"/>	
other	<input type="checkbox"/>	please say what _____

**E - Information***Please try to tick a box on every line in every question***E.1 How important was it for you to have information about....** *Please tick one box on each line*

	very important	quite important	not very important	not important at all
whether to have ultrasound scans	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
whether to have blood tests to look for Down's syndrome and spina bifida in the baby	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
whether to have your baby in hospital or home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
whether to drink alcohol when pregnant	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<u>all the things</u> that happened during your care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**E.2 What do you feel about the amount of information you have had from midwives or doctors about....** *Please tick one box on each line*

	I have had <b>too much</b> information	I have had <b>enough</b> information	I <b>needed</b> <b>more</b> information	I have had <b>no</b> information	I <b>did not</b> <b>need any</b> information
whether to have ultrasound scans	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
whether to have blood tests to look for Down's syndrome and spina bifida in the baby	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
whether to have your baby in hospital or home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
whether to drink alcohol when pregnant	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<u>all the things</u> that happened during your care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**E.3 Did the midwives or doctors give you information at the right time for you, about....**

*Please tick one box on each line*

	given too early	given at the right time	given too late	does not apply / given no information
whether to have ultrasound scans	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
whether to have blood tests to look for Down's syndrome and spina bifida in the baby	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
whether to have your baby in hospital or home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
whether to drink alcohol when pregnant	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<u>all the things</u> that happened during your care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**E.4 How satisfied are you with the information you have had from midwives or doctors about....**

*Please tick one box on each line*

	very satisfied	satisfied	found it acceptable	dissatisfied	very dissatisfied	does not apply
whether to have ultrasound scans	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
whether to have blood tests to look for Down's syndrome and spina bifida in the baby	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
whether to have your baby in hospital or home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
whether to drink alcohol when pregnant	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<u>all the things</u> that happened during your care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**E.5 How has the information you have received from midwives or doctors made you feel about the following....**

*Please tick one box on each line*

	more anxious	no effect	less anxious	does not apply
having ultrasound scans	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
having blood tests to look for Down's syndrome and spina bifida in the baby	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
having your baby in hospital or home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
drinking alcohol when pregnant	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<u>all the things</u> that have happened during your care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## F - Making Choices

**Please try to tick a box on every line in every question**

**F.1 Were you able to discuss what you wanted, as much as you wanted, when talking to midwives or doctors about the following.....**

*Please tick one box on each line*

	Yes	Partly	No
whether to have ultrasound scans	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
whether to have blood tests to look for Down's syndrome and spina bifida in the baby	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
where to have your baby	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<u>all the things</u> that happened during your care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**F.2 Did a midwife or doctor offer you a choice about.....**

*Please tick one box on each line*

	Yes, I was offered a choice	No, I was not offered a choice	There is no choice
whether to have ultrasound scans	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
whether to have blood tests to look for Down's syndrome and spina bifida in the baby	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
whether to have your baby in hospital or home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Please carry on answering the questions even if you did not feel you were offered choices**

**F.3 When choices are made about your antenatal care, which role do you prefer to take?**

*Please tick one box only*

I prefer to make the final choice	<input type="checkbox"/>
I prefer to make the final choice after seriously considering the midwife's and doctor's opinions	<input type="checkbox"/>
I prefer that my midwife and doctor and I share responsibility for making choices	<input type="checkbox"/>
I prefer that my midwife and doctor make the final choice but seriously consider my opinion	<input type="checkbox"/>
I prefer to leave all choices to my midwife and doctor	<input type="checkbox"/>

**F.4 When choices were made about your antenatal care, how would you best describe what actually happened?**

Please tick one box only

I made the choices	<input type="checkbox"/>
I made the choices after seriously considering the midwives' and/or doctors' opinions	<input type="checkbox"/>
a midwife and/or doctor made the choices and I shared responsibility for making the choices	<input type="checkbox"/>
a midwife and/or doctor made the final choices but seriously considered my opinion	<input type="checkbox"/>
I left the choices to the midwives and/or doctors	<input type="checkbox"/>
midwives and doctors made the choices without considering my opinion	<input type="checkbox"/>

**F.5 Have you had enough information and discussion with midwives or doctors to make a choice together about .....**

Please tick one box on each line

	yes	partly	no	there is no choice	does not apply
whether to have ultrasound scans	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
whether to have blood tests to look for Down's syndrome and spina bifida in the baby	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
where to have your baby	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<u>all the things</u> that happened during your care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**F.6 How satisfied are you with the way choices have been made about....**

Please tick one box on each line

	very satisfied	satisfied	found it acceptable	dissatisfied	very dissatisfied	does not apply
having ultrasound scans	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
having blood test to look for Down's syndrome and spina bifida in the baby	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
where to have your baby	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<u>all the things</u> that happened during your care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**F.7 Have you felt in control of what has happened during your care to date?**

Please tick one box on each line

	yes always	yes, most of the time	only some of the time	no, hardly at all
In control of the things that have happened	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In control of the things doctors and midwives have done to you	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



## G- Some questions about pregnancy

Please fill in the questions on the two sheets of coloured paper. Please answer them as best you can. It is not a test, so do not worry if you feel that you do not know the answers. When you have finished, please carry on with Section H below.

## H- Leaflets

H.1 Has a midwife or doctor given you the following leaflets. Only tick YES if you are sure you have been given Informed Choice Leaflets.

Please tick one box on each line

	Not sure	No	Yes
✓ Informed choice Ultrasound scans - should you have one?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
✓ Informed choice Looking for Down's syndrome and spina bifida in pregnancy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
✓ Informed choice Where will you have your baby - hospital or home?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
✓ Informed choice Alcohol and Pregnancy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you ticked YES to any part of H.1, please go to question H.2, otherwise go to Section I.

H.2 If you were given any of the leaflets listed above, how helpful did you find them?

Please tick one box on each line

✓ Informed choice leaflet .....	very helpful	helpful	not very helpful	not helpful at all	does not apply
Ultrasound scans - should you have one?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Looking for Down's syndrome and spina bifida in pregnancy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Where will you have your baby - hospital or home?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Alcohol and pregnancy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## I - How satisfied you are with your care

**I.1 How satisfied are you with the care you have received from the health services during antenatal care?**

	very satisfied	satisfied	found it acceptable	dissatisfied	very dissatisfied	does not apply
having the ultrasound scans	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
having the blood test looking for Down's syndrome and spina bifida in the baby	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
discussions with midwives and doctors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
choices made	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
overall	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**I.2 (a) Please describe any things about your care during pregnancy which you are particularly satisfied with**

**(b) Please describe any things about your care during pregnancy which you are particularly dissatisfied with**

## J - Your health

*We would like to know how you are feeling. Please tick the answers which are closest to how you have felt in the past 7 days, not just how you feel today.*

**J.1 I have been able to laugh and see the funny side of things:** *Please tick one*

- as much as I always could
- not quite so much now
- definitely not so much now
- not at all

**J.2 I have looked forward with enjoyment to things:** *Please tick one*

- as much as I ever did
- rather less than I used to
- definitely less than I used to
- hardly at all

**J.3 I have blamed myself unnecessarily when things went wrong:** *Please tick one*

- yes, most of the time
- yes, some of the time
- not very often
- no, never

**J.4 I have felt worried and anxious for no very good reason:** *Please tick one*

- no, not at all
- hardly ever
- yes, sometimes
- yes, most of the time

**J.5 I have felt scared or panicky for no very good reason:** *Please tick one*

- yes, quite a lot
- yes, sometimes
- no, not much
- no, not at all

**J.6 Things have been getting on top of me:** *Please tick one*

- yes, most of the time I haven't been able to cope at all
- yes, sometimes I haven't been coping as well as usual
- no, most of the time I have coped quite well
- no, I have been coping as well as usual

**J.7 I have been so unhappy that I have had difficulty sleeping:**

*Please tick one*

- yes, most of the time
- yes, sometimes
- not very often
- no, not at all

**J.8 I have felt sad or miserable:**

*Please tick one*

- yes, most of the time
- yes, quite often
- not very often
- no, not at all

**J.9 I have been so unhappy that I have been crying:**

*Please tick one*

- yes, most of the time
- yes, quite often
- only occasionally
- no, never

**J.10 The thought of harming myself has occurred to me:**

*Please tick one*

- yes, quite often
- sometimes
- hardly ever
- never

**J.11 A number of statements which people have used to describe themselves are given below. Read each statement and then tick the most appropriate box to the right of the statement to indicate how you feel right now, at this moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.**

*Please tick one box on each line*

	not at all	somewhat	moderately	very much
I feel calm	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am tense	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel upset	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am relaxed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel content	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am worried	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*Please make sure that you have answered all the questions*

**J.12 Have you been feeling at all depressed?**

*Please tick one*

- no, not at all
- only mildly depressed
- yes, quite depressed
- yes, very depressed

## K - You and your household

*Could you fill in these questions about yourself.  
They will show us the kinds of people who have taken part in the survey.*

**K.1 How old are you?**

**years old**

**K.2 Do you and your household own or rent the house or flat where you live?**

own (or are buying)

*Please tick one*

rent (or live rent free)

**K.3 How old were you when you left full-time education?**

**years**

**K.4 Which ethnic group do you consider yourself to belong to?**

*Please tick one*

White

Pakistani

Black-Caribbean

Bangladeshi

Black- African

Indian

Chinese

Any other ethnic group

**K.5 (a) Do you do any paid work as an employee or as a self-employed person?**

yes, full-time

yes, part-time

*Please tick one*

no, not at the moment

no, I have never been in paid work

**(b) What is the name of your job - OR if you are not in paid work at the moment, what was your last job?**

occupation \_\_\_\_\_

industry \_\_\_\_\_

**K.6 (a) Do you live with a partner?**

Yes

No

(b) If Yes, do they do any paid work as an employee or as a self-employed person?

yes, full-time

*Please tick one*

yes, part-time

no, not at the moment

no, they have never been in paid work

What is the name of their job - OR if they are not in paid work at the moment, what was their last job?

occupation \_\_\_\_\_

industry \_\_\_\_\_

### Consent Form for access to hospital notes

We would like to look at your hospital notes related to your pregnancy *to obtain information about any procedures or special tests that you had during pregnancy, labour and delivery.*

The information will be treated in strict confidence. It will not be used in any way in which you can be identified.

*Please tick below:*

I agree to my medical notes related to this pregnancy being reviewed by our researchers

I do not agree to my medical notes related to this pregnancy being reviewed by our researchers

**Thank you for taking the time to complete this questionnaire.**

**Please return the questionnaire in the envelope provided.**

**NO STAMP IS NEEDED.**





# A SURVEY OF INFORMATION AND CHOICE IN MATERNITY CARE

*In this booklet we ask about:*

- A - Dates and your baby**
- B - How you feel about being in control**
- C - Your experiences**
- D - What you wanted**
- E - Information**
- F - Making choices**
- G - Some questions about pregnancy**
- H - Leaflets**
- I - How satisfied you are with your care**
- J - Your health**
- K - You and your household**

## A - Dates and your baby

**A.1 When was your baby born?**

Please fill in date baby born

Day	Month	Year
<input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>

*(Example for month: fill in '01' if January, '02' if February etc)*

**A.2 How many weeks old is your baby now?**

Please fill in number of weeks old

**A.3 How much did your baby weigh at birth?**

lbs	oz	<b>OR</b>	kilos
<input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>		<input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>

**A.4 How many weeks pregnant were you when your baby was born?**

Please fill in number of weeks pregnant

**A.5 Was this baby your**

- 1st
- 2nd
- 3rd
- 4th or more

*Please tick one*

**A.6 Where was your baby born?**

- in hospital
- at home
- other e.g. GP Unit  *If other, please say* \_\_\_\_\_

*Please tick one*

*If other, please say*

**A.7 What is the name of the Hospital or Unit where your baby was born?**

Name of Hospital or Unit \_\_\_\_\_

**A.8 Was this the Hospital or Unit where you were originally booked to have the baby?**

- Yes**, born in the same Hospital or Unit as originally booked
- No**, different place

**IF NO** - When did you change from the original booking?

- Before you were 32 weeks pregnant
- When you were 32 weeks pregnant or later



## B - How you feel about being in control

B.1 Do you **feel** you have control and can make choices about things that happen **generally in your life?**

yes

partly  *Please tick one*

no

B.2 How **important** is it for you to feel in control and make choices about things that happen **generally in your life?**

very important

quite important  *Please tick one*

not very important

B.3 How **important** was it for you to feel in control and make choices about things that happened **during labour, delivery and a few weeks after?**

very important

quite important  *Please tick one*

not very important

## C - Your experiences

### C.1 Who was present in the room with you for most of the time during labour?

- your partner
- a friend/relative
- a midwife  *Please tick all that apply*
- your antenatal class teacher
- a doctor
- other  *If other, please say \_\_\_\_\_*

### C.2 During your labour, how was the baby's heartbeat monitored (checked)?

- a hand held monitor was used now and then
- staff listened with a stethoscope (ear trumpet) now and again
- a monitor was used now and again, with a belt around my abdomen  *Please tick all that apply*
- a monitor was used constantly with a belt around my abdomen
- a monitor was used constantly with a clip attached to the baby's head
- none of these

### C.3 During labour, did you have anything, or do anything to help relieve the pain?

- Please tick all that apply*
- yes, used natural methods such as breathing exercises, massage, moving round
- yes, gas and air (Entonox)
- yes, injection of pethidine or similar drugs
- yes, epidural injection in my back
- yes, TENS machine (with pads on my back)
- yes, water e.g. birthing pool or deep bath
- no, none of these
- don't know/can't remember if had anything

### C.4 What position were you in for the birth of the baby? *Please tick one*

- lying on the bed
- sitting or propped up on the bed
- standing, squatting or kneeling
- in stirrups, lying on the bed with my legs supported
- in a birthing pool
- other  *If other, please say \_\_\_\_\_*

**C.5 (a) Before you went into hospital to have the baby, what kind of delivery were you expecting?**

normal vaginal delivery

Caesarean

*Please tick one*

or that you might need a Caesarean delivery

**(b) What kind of delivery did you have?**

normal vaginal delivery

ventouse (vacuum extractor)

*Please tick one*

forceps delivery

vaginal breech delivery

planned caesarean section

emergency caesarean section (once labour had started)

don't know / not sure

**(c) If you had a caesarean section, did you have**

an epidural/spinal block

*Please tick one*

a general anaesthetic

**C.6 Have you breastfed your baby at all?**

yes, breastfed (or fed with expressed milk)

*Please tick one*

no, fed with bottle milk only

**C.7 Currently, how do you feed your baby?**

breast milk only (including expressed milk)

both breast milk and bottle (formula) milk

*Please tick one*

bottle (formula) milk only

**C.8 Did you have a breech baby (where the baby stays head up) after 34 weeks of your pregnancy?**

yes

*go to question C.9*

no

*go to Section D*

don't know / not sure

*go to Section D*

**C.9 Was an attempt made to turn the baby?**

no, because it turned round on its own

no, an attempt was not made

yes, a doctor attempted to turn the baby

**C.10 What happened on the last occasion when an attempt was made to turn the baby?**

- the baby refused to turn
- the baby turned but then turned back  *Please tick one*
- the baby turned and stayed turned

**C.11 Did you have any choice about the type of delivery you would have with your breech baby?**

- no choice
- yes, I chose to have a caesarean section  *Please tick one*
- yes, I chose to have a normal vaginal delivery

**C.12 What type of delivery did you actually have?**

- normal vaginal delivery  *Please tick one*
- Caesarean section

## D - What you wanted

**D.1 Which of the following did you want to do?**

*Please tick one box on each line*

	Yes	No	No preference
<u>have</u> someone to support you through labour, as well as the midwife	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<u>have</u> Electronic Fetal Monitoring (a belt is put round your waist)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<u>have</u> an epidural	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
lie <u>in bed</u> throughout labour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<u>breastfeed</u> your baby	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**D.2 How strongly did you feel about what you wanted or did not want?**

*Please tick one box on each line*

	very strongly	quite strongly	not very strongly	not strongly at all	did not apply
who to have with you during labour, as well as the midwife	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
the type of monitoring to listen to the baby's heartbeat during labour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
the type of pain relief	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
which positions to get into during labour and delivery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
the way you would feed your baby	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

D.3 What **influenced** your thoughts about what you wanted?Please tick **all that apply**

doctors, nurses or midwives	<input type="checkbox"/>
antenatal classes	<input type="checkbox"/>
family or friends	<input type="checkbox"/>
books or magazines	<input type="checkbox"/>
leaflets given by doctors, nurses or midwives	<input type="checkbox"/>
TV programmes	<input type="checkbox"/>
past experience	<input type="checkbox"/>
other	<input type="checkbox"/>

please say \_\_\_\_\_

**E - Information****Please try to tick a box on every line in every question**E.1 How **important** was it for you to have **information** about....Please tick **one box on each line**

	very important	quite important	not very important	not important at all
who to have with you during labour, as well as a midwife	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
the kind of monitoring to have in labour to listen to your baby's heart beat	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
whether or not to have an epidural	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
what positions to get into during labour and delivery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
whether to breast feed or bottle feed your baby	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<u>all the things</u> that happened during your care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

E.2 What do you feel about the **amount** of information you had from midwives or doctors  
about....Please tick **one box on each line**

	I had too much information	I had enough information	I needed more information	I had no information	I did not need any information
who to have with you during labour, as well as a midwife	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
the kind of monitoring to have in labour to listen to your baby's heart beat	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
whether or not to have an epidural	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
what positions to get into during labour and delivery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
whether to breast feed or bottle feed your baby	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<u>all the things</u> that happened during your care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**E.3 Did the midwives or doctors give you information at the right time for you, about....**

*Please tick one box on each line*

	given too early	given at the right time	given too late	did not apply/ given no information
who to have with you during labour, as well as a midwife	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
the kind of monitoring to have in labour to listen to your baby's heart beat	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
whether or not to have an epidural	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
what positions to get into during labour and delivery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
whether to breast feed or bottle feed your baby	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**E.4 How satisfied were you with the information you had from midwives or doctors about....**

*Please tick one box on each line*

	very satisfied	satisfied	found it acceptable	dissatisfied	very dissatisfied	did not apply
who to have with you during labour, as well as a midwife	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
the kind of monitoring to have in labour to listen to your baby's heart beat	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
whether or not to have an epidural	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
what positions to get into during labour and delivery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
whether to breast feed or bottle feed your baby	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<u>all the things</u> that happened during your care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**E.5 How has the information you received from midwives or doctors made you feel about....**

*Please tick one box on each line*

	more anxious	no effect	less anxious	did not apply
who to have with you during labour, as well as a midwife	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
the kind of monitoring to have in labour to listen to your baby's heart beat	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
whether or not to have an epidural	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
what positions to get into during labour and delivery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
whether to breast feed or bottle feed your baby	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<u>all the things</u> that happened during your care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## F - Making Choices

**F.1 Were you able to discuss what you wanted, as much as you wanted, when talking to midwives or doctors about the following....**

*Please tick one box on each line*

	Yes	Partly	No
who to have with you during labour, as well as a midwife	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
the kind of monitoring to have in labour to listen to your baby's heart beat	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
whether or not to have an epidural	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
what positions to get into during labour and delivery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
whether to breast feed or bottle feed your baby	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<u>all the things</u> that happened during your care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**F.2 Did a midwife or doctor offer you a choice about....**

*Please tick one box on each line*

	Yes, I was offered a choice	No, I was not offered a choice	There was no choice
who to have with you during labour, as well as a midwife	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
the kind of monitoring to have in labour to listen to your baby's heart beat	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
whether or not to have an epidural	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
what positions to get into during labour and delivery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
whether to breast feed or bottle feed your baby	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Please carry on answering the questions even if you did not feel you were offered choices**

**F.3 When choices were made about your care, which role did you prefer to take?**

*Please tick one box only*

I prefer to make the final choice	<input type="checkbox"/>
I prefer to make the final choice after seriously considering the midwife's and doctor's opinions	<input type="checkbox"/>
I prefer that my midwife and doctor and I share responsibility for making choices	<input type="checkbox"/>
I prefer that my midwife and doctor make the final choice but seriously consider my opinion	<input type="checkbox"/>
I prefer to leave all choices to my midwife and doctor	<input type="checkbox"/>

**F.4 When choices were made about your care, how would you best describe what actually happened?**

Please tick **one** box only

I made the choices

I made the choices after seriously considering the midwives' and/or doctors' opinions

a midwife and/or doctor made the choices and I shared responsibility for making the choices

a midwife and/or doctor made the final choices but seriously considered my opinion

I left the choices to the midwives and/or doctors

midwives and doctors made the choices without considering my opinion

**F.5 Did you have enough information and discussion with midwives or doctors to make a choice together about the following.....**

Please tick **one** box on each line

	Yes	Partly	No	There was no choice	Did not apply
who to have with you during labour, as well as a midwife	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
the kind of monitoring to have in labour to listen to your baby's heart beat	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
whether or not to have an epidural	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
what positions to get into during labour and delivery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
whether to breast feed or bottle feed your baby	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<u>all the things</u> that happened during your care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**F.6 How satisfied were you with the way choices were made about....**

Please tick **one** box on each line

	very satisfied	satisfied	found it acceptable	dissatisfied	very dissatisfied	did not apply
who to have with you during labour, as well as a midwife	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
the kind of monitoring to have in labour to listen to your baby's heart beat	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
whether or not to have an epidural	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
what positions to get into during labour and delivery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
whether to breast feed or bottle feed your baby	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<u>all the things</u> that happened during your care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**F.7 Did you feel in control of what happened during your care?**

Please tick **one** box on each line

	yes always	yes, most of the time	only some of the time	no, hardly at all
In control of the things that happened	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In control of the things doctors and midwives did to you	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



## G- Some questions about pregnancy

Please fill in the questions on the two sheets of coloured paper. Please answer them as best you can. It is not a test, so do not worry if you feel that you do not know the answers. When you have finished, please carry on with Section H below.

## H- Leaflets

H.1 Did a midwife or doctor give you the following leaflets. Only tick YES if you are sure you were given Informed Choice Leaflets.

Please tick one box on each line

	Not sure	No	Yes
✓ Informed Choice Support in labour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
✓ Informed Choice Listening to your baby's heartbeat during labour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
✓ Informed Choice Epidurals for pain relief in labour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
✓ Informed Choice Positions in labour and delivery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
✓ Informed Choice Feeding your baby - breast or bottle?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
✓ Informed Choice Breech baby. What are your choices?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you ticked Yes to any part of H.1, please go to question H.2, otherwise go to Section I.

H.2 If you were given any of the leaflets listed above, how helpful did you find them?

✓ Informed choice leaflet .....

Please tick one box on each line

	very helpful	helpful	not very helpful	not helpful at all	does not apply
✓ Informed Choice Support in labour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
✓ Informed Choice Listening to your baby's heartbeat during labour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
✓ Informed Choice Epidurals for pain relief in labour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
✓ Informed Choice Positions in labour and delivery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
✓ Informed Choice Feeding your baby - breast or bottle?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
✓ Informed Choice Breech baby. What are your choices?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## I - How satisfied you are with your care

**I.1 How satisfied were you with the care you received from the health services during labour, delivery and a few weeks after?**

	very satisfied	satisfied	found it acceptable	dissatisfied	very dissatisfied	did not apply
who you had with you in labour, as well as a midwife	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
the type of monitoring of the baby's heartbeat	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
pain relief	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
the positions you were in during labour and delivery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
support you had for feeding the baby	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
discussions with doctors and midwives	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
choices made	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
overall	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**I.2 (a) Please describe any things about your care during labour, delivery and a few weeks after which you are particularly satisfied with**

**(b) Please describe any things about your care during labour, delivery and a few weeks after which you are particularly dissatisfied with**

## J- Your health

*We would like to know how you are feeling. Please tick the answers which are closest to how you have felt in the past 7 days, not just how you feel today.*

**J.1 I have been able to laugh and see the funny side of things:**

*Please tick one*

- as much as I always could
- not quite so much now
- definitely not so much now
- not at all

**J.2 I have looked forward with enjoyment to things:**

*Please tick one*

- as much as I ever did
- rather less than I used to
- definitely less than I used to
- hardly at all

**J.3 I have blamed myself unnecessarily when things went wrong:**

*Please tick one*

- yes, most of the time
- yes, some of the time
- not very often
- no, never

**J.4 I have felt worried and anxious for no very good reason:**

*Please tick one*

- no, not at all
- hardly ever
- yes, sometimes
- yes, most of the time

**J.5 I have felt scared or panicky for no very good reason:**

*Please tick one*

- yes, quite a lot
- yes, sometimes
- no, not much
- no, not at all

**J.6 Things have been getting on top of me:**

*Please tick one*

- yes, most of the time I haven't been able to cope at all
- yes, sometimes I haven't been coping as well as usual
- no, most of the time I have coped quite well
- no, I have been coping as well as usual

**J.7 I have been so unhappy that I have had difficulty sleeping:**

*Please tick one*

- yes, most of the time
- yes, sometimes
- not very often
- no, not at all

**J.8 I have felt sad or miserable:**

*Please tick one*

- yes, most of the time
- yes, quite often
- not very often
- no, not at all

**J.9 I have been so unhappy that I have been crying:**

*Please tick one*

- yes, most of the time
- yes, quite often
- only occasionally
- no, never

**J.10 The thought of harming myself has occurred to me:**

*Please tick one*

- yes, quite often
- sometimes
- hardly ever
- never

**J.11 A number of statements which people have used to describe themselves are given below. Read each statement and then tick the most appropriate box to the right of the statement to indicate how you feel right now, at this moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.**

*Please tick one box on each line*

	not at all	somewhat	moderately	very much
I feel calm	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am tense	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel upset	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am relaxed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel content	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am worried	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*Please make sure that you have answered all the questions*

**J.12 Have you been feeling at all depressed?**

*Please tick one*

- no, not at all
- only mildly depressed
- yes, quite depressed
- yes, very depressed

## K - You and your household

**Could you fill in these questions about yourself.  
They will show us the kinds of people who have taken part in the survey.**

**K.1 How old are you?**  **years old**

**K.2 Do you and your household own or rent the house or flat where you live?**

- own (or are buying)  *Please tick one*
- rent (or live rent free)

**K.3 How old were you when you left full-time education?**  **years**

**K.4 Which ethnic group do you consider yourself to belong to?**

*Please tick one*

- |  |   |
|--|---|
| <input type="checkbox"/> White           | <input type="checkbox"/> Pakistani              |
| <input type="checkbox"/> Black-Caribbean | <input type="checkbox"/> Bangladeshi            |
| <input type="checkbox"/> Black- African  | <input type="checkbox"/> Indian                 |
| <input type="checkbox"/> Chinese         | <input type="checkbox"/> Any other ethnic group |

**K.5 (a) Do you do any paid work as an employee or as a self-employed person?**

- yes, full-time
- yes, part-time  *Please tick one*
- no, not at the moment
- no, I have never had paid work

**(b) What is the name of your job - OR if you are not in paid work at the moment, what was your last job?**

occupation \_\_\_\_\_

industry \_\_\_\_\_

K.6 Do you live with a partner? yes

no

**IF YES, do they do any paid work as an employee or as a self-employed person?**

yes, full-time

yes, part-time

*Please tick one*

no, not at the moment

no, they have never had paid work

**What is the name of their job - OR if they are not in paid work at the moment, what was their last job?**

occupation \_\_\_\_\_

industry \_\_\_\_\_

### Consent Form for access to hospital notes

We would like to look at your hospital notes related to your pregnancy to obtain information about any procedures or special tests that you had during pregnancy, labour and delivery.

The information will be treated in strict confidence. It will not be used in any way in which you can be identified.

*Please tick below:*

I agree to my medical notes related to this pregnancy being reviewed by our researchers

I do not agree to my medical notes related to this pregnancy being reviewed by our researchers

**Thank you for taking the time to complete this questionnaire.**

**Please return the questionnaire in the envelope provided.**

**NO STAMP IS NEEDED.**



## Appendix 2b: Cluster Randomised Controlled Trial - Source of Questions Used in the Questionnaire

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### 1. Leaflets

Women were asked if a midwife or doctor had given them any of the Informed Choice leaflets. In addition, women were asked how helpful the leaflets had been, a question which was based on a question used in the pilot study of two of the leaflets (Oliver 1996). These questions can be seen in Section H of the questionnaires used in this study.

### 2. Knowledge

Members of the research team (MK, HS) developed a ten-item multiple choice knowledge questionnaire for each of the ten leaflets. The questions were derived from information provided in the women's leaflets rather than the professionals' leaflets. Nine of these questionnaires were inserted into the main questionnaires in pairs. Knowledge questionnaires on scanning, screening, where to have your baby and drinking alcohol in pregnancy were paired and inserted in the antenatal questionnaire. Knowledge questionnaires on support, monitoring, positions, epidurals and feeding were paired and inserted in the postnatal questionnaire. Thus each woman completed two knowledge questionnaires. A separate survey was undertaken to determine women's knowledge levels of breech presentation. See Appendix 2a for copies of the questionnaires used.

Knowledge questionnaires were scored by allocating a score of one for each fully correct answer, with scores ranging from 0 to 10 for each knowledge questionnaire.

### 3. Preferences

Women were asked whether they had a preferred option for each of the issues covered by the leaflets, what those preferences were, their strength of feeling about their preferences and the influences on those preferences. These questions can be seen in Section D of the questionnaires used in this study.

### 4. Informed choice and its components

The questions about informed choice are in sections E and F of the questionnaires. Question F.5 is the key question and is based on the definition of evidence-informed patient choice: a decision about health care interventions a person will or will not receive, where the person is given research-based information about the effectiveness of at least two alternative interventions and the person provides some input to the decision-making process. Since this definition was unlikely to be understood by lay people, it was broken down into its component parts and then rebuilt into a question about Informed Choice. First, women were asked about the amount of information they had about each of the decisions to be made, and overall in maternity care (question E.2). This was based on an Audit Commission question (Audit Commission 1996) and adapted based on the qualitative research and piloting in the ethnographic sites. Evidence-based information was not specified because this was a professional term. Second, women were asked whether they had had enough discussion with health professionals about each of the decisions, and overall in maternity care (question F.1). Third, women were asked about whether they were offered a choice about each of the decisions (question F.2). Finally, women were asked

*Did you have enough information and discussion with midwives or doctors to make a choice together about all the things that happened during your care: yes, partly, no, there was no choice, did not apply.*

This was asked for each decision, and overall in maternity care. Women were also asked about their satisfaction with the way choices had been made for each decision, and overall in maternity care (F.6).

### 5. Control

Two questions were included to cover the issue of the amount of control women felt they had about their care (question F.7). These were based on a question which Green used in her seminal work

Great Expectations in which she asked 'In general did you feel in control of what staff were doing to you during labour?' (Green 1988). This was adapted to ask about two issues: control of things that happened and control of actions undertaken by staff.

## **6. Emotional health**

### ***Depression***

The Edinburgh Postnatal Depression Scale (EPDS) was developed as a screening tool for postnatal depression (Cox 1987) and has been used as a research tool for measuring depression antenatally as well as postnatally (Murray 1990). It has been suggested that it is more appropriate to use the EPDS as a measure of 'low emotional well-being' rather than as a direct measure of depression (Green 1998). Since a set of leaflets are unlikely to relieve depressive illnesses and are more likely to be able to impact upon emotional well-being, the EPDS was suitable for use in this study. It can be seen in Section J of the questionnaires used in this study.

The EPDS consists of 10 items, each of which can be scored from 0 to 3. Scores are totalled and range from 0 to 30 where higher scores indicate more negative feelings. The score can be dichotomised because 'women who score above a threshold of 12/13 are most likely to be suffering from a depressive illness of varying severity' (Cox 1987). However, there is criticism that valuable data are lost by dichotomising and therefore the mean score is reported (Green 1998).

### ***Anxiety***

The Spielberger State-Trait Anxiety Inventory (STAI) is a widely used measure of anxiety (Spielberger 1983). It is 40 items long, 20 of which measure state anxiety (which fluctuates depending upon context) and 20 of which measure trait anxiety (a relatively stable personality characteristic). State anxiety was of interest in this study since the hypothesis was that the leaflets might change women's current feelings about their experiences. The length of the state scale was prohibitive and thus a six-item short-form state scale of STAI was used (Marteau 1992). This was developed with data from 200 pregnant women waiting for a routine outpatient appointment and shown to have internal reliability and validity both for pregnant women receiving routine care and pregnant women with abnormal results on a screening test. Prorated means were shown to be identical to the means for the full 20-item state questionnaire. These questions can be seen in Section J of the questionnaires used in this study.

The short-form state scale of STAI consists of six items, each of which can be scored from 1 to 4. Scores are totalled and range from 6 to 24 where higher scores indicate more negative feelings. Prorated scores have been calculated to range from 20 to 80 and prorated means are reported here to allow comparability with other studies.

## **7. Satisfaction with care**

Women were asked about their satisfaction with their care overall and with different aspects of their care, including the decisions relevant to this study, the choices made and discussions with staff. This section was based on the OPCS maternity questionnaire (Mason 1989). These questions can be seen in Section I of the questionnaires used in this study.

## **8. Actions taken by women and their use of health services**

Women were asked about the actions they took and the services they used which were relevant to the study. Questions were based on the OPCS survey and the Audit Commission survey. These questions can be seen in Section C of the questionnaires used in this study.

## **9. Information-induced anxiety**

Women were asked specifically about the effect of information on their anxiety levels (question E.5).



## **10. Sub-groups of women**

### ***Social and demographic variables***

Women were asked their age, their age when they left full-time education, the ethnic group they considered they belonged to, whether they owned or rented their accommodation, their employment status, their occupation (coded using the Standard Occupational Classification and classified into non-manual and manual), their partner's employment status and occupation, whether the baby was their first, second etc. These questions are based on the OPCS survey and questions used in the Census (Census 1991). These questions can be seen in Section K of the questionnaires used in this study.

### ***Type of decision-maker***

People have different information seeking styles. The extent to which women want to participate in decision-making may affect their perceptions and experiences of decision-making. Women were asked which role they preferred to take when making choices about their care, with the options ranging from making the choice themselves through to leaving all decisions to health professionals. This question was based on Degner's Control Preferences Scale and was followed by a similar question asking about what actually happened (Degner 1997). These are questions F.3 and F.4 in the questionnaires used in this study.



## **Appendix 2c: Cluster Randomised Controlled Trial - The Analysis**

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### **1. The power of the proposed study**

Standard sample size formulae are not appropriate for a cluster design because individuals within clusters may be more similar than those in different clusters. Formulae for calculating sample size in cluster trials adjust standard formulae by a design effect. The design effect depends on the average size of the clusters and the intraclass correlation coefficient (ICC), where the ICC is the proportion of the total variation that is between the clusters. The original sample size calculation for this study was based on 12 clusters because some of the relationships between the hospitals were unknown when the calculation was made. With the assumptions that the true effect would be the same in all clusters, that the total number of deliveries per week in the intervention clusters and the control clusters would be the same and that the ICC was 0.007, and with an average cluster size of 200 women, it was calculated that a total sample size of 2260 women would give an 80% chance of detecting an improvement from 50% to 60% in the proportion of women perceiving that they made informed choices in intervention clusters compared with no change in control clusters at a two-tailed significance level of 5%. Allowing for loss due to exclusions and a 75% response rate to the questionnaire, 3120 women were needed in each cohort, that is six weeks of women booked for antenatal care for the antenatal questionnaire and six weeks of women delivering babies for the postnatal questionnaire.

### **2. Unmatched analysis**

The clusters were paired to ensure balance in the two trial arms. This pairing was based mainly on the size of the cluster and partly on local knowledge of the social deprivation indices of the populations served by them. Matching can lead to considerable gain in statistical precision. However, pair-matched designs have been shown to have severe limitations (Klar 1997). In fact, when the number of pairs is small, matching can decrease the power of the design unless the matching variable is highly correlated with the outcome variable (Diehr 1995). If there are fewer than ten pairs, an unmatched design has the most power (Diehr 1995). When matching is preferred to ensure balanced trial arms, it is recommended that an unmatched analysis is undertaken to increase power (Diehr 1995). In this trial it was important to balance the two arms because of the small number of clusters. Since it is unlikely that the size of the hospital would be highly correlated with a change in the proportion of women reporting they had exercised informed choice, this matched design has been followed by an unmatched analysis.

### **3. Statistical analysis**

There are three basic approaches to the analysis of cluster randomised trials (Ukoumunne 1999):

1. Cluster level analysis with the cluster means or proportions used as observations.
2. Univariate analysis of individual level data with standard errors adjusted for the design effect.
3. Regression analysis of individual level data using methods for clustered data.

Methods 1 and 3 were applied to this data. All analysis was undertaken on an intention-to-treat basis.

#### **3.1 Cluster level analysis with the cluster means or proportions used as observations**

It is recommended that when the number of clusters per group is less than ten, a cluster level analysis should be undertaken. For analysis at the cluster level, individual level data are summarised at the cluster level. In this study, this resulted in ten summary data points for each outcome variable, five for intervention clusters and five for control clusters. The change between the BEFORE survey and the AFTER survey in the intervention sites versus change in the control sites was of interest. To illustrate, the proportion of women who reported that they exercised informed choice in each cluster was calculated for BEFORE the intervention. The proportion of women who reported that they exercised informed choice in each cluster was calculated for AFTER the intervention. The change which occurred in each cluster was calculated, resulting in ten data points. The mean of the changes in the intervention clusters were then compared with the mean of the changes in the control clusters. There is some debate about how to proceed to analyse these cluster level data. Options include the Wilcoxon's rank-sum test, the t-test, the weighted t-test, the permutation test or a re-randomisation

technique, or analysis of covariance. The Wilcoxon rank-sum test is a non-parametric test which does not require the assumption of normality. The two-sample t-test is robust to departures from normality, is suitable for use on ten data points, and is slightly more powerful than the Wilcoxon's rank-sum test, and thus may be more suitable. A possible problem is that it assumes that all ten data points are based on equal sized clusters and therefore have equal weighting. Since the clusters in the study vary in size, a weighted t-test, weighted to reflect the cluster size, takes this extra information into account (Kerry 1997). However, this approach assumes that the cluster size and the effect size are independent, that is that there is the same effect in large hospitals and small hospitals, which may not be the case. We do not know whether the effectiveness of the set of leaflets is dependent on the size of a maternity hospital or not. Given the uncertainty about this, the t-test rather than the weighted t-test has been undertaken. In addition, the results of the Wilcoxon test are reported.

The cluster level analyses have been based on the change between two time periods. For individual level clinical trials the preferred method is analysis of covariance where baseline measurements are taken into account by using them as a covariate in a linear model for comparison of the means after the intervention (Frison 1992). Given that this is the preferred method for individual level analysis, we have also undertaken analysis of covariance at the cluster level.

### 3.2 Regression analysis at the individual woman level, with allowance for the clustering of women's responses within the maternity unit

The design of this study is a 'pretest-posttest control group design' as illustrated in Figure C.1 (Murray 1998). It is a nested cross-sectional design because maternity hospitals were randomly assigned to either a control or intervention group and the views of women within these groups were measured to assess the impact of the intervention. In this nested cross-sectional trial each maternity unit was measured twice (pretest (BEFORE) and posttest (AFTER)), but each woman was measured only once. That is, different women were measured during each time period.

**Figure C.1: Layout of the Pretest-Posttest Control Group Design**

	Time Interval	
Condition	Pretest (BEFORE)	Posttest (AFTER)
Intervention		
Control		

The following multi-level model was fitted to the data for an unadjusted analysis. All random effects are in bold type, while fixed effects are defined in normal type:

$$Y_{ijkl} = m + G_l + T_j + TG_{jl} + \mathbf{U}_{kl} + \mathbf{TU}_{jkl} + \mathbf{e}_{ijkl}$$

$$i = 1, \dots, n.$$

$$l = 1 \text{ or } 2.$$

$$j = 1 \text{ or } 2$$

$$k = 1, \dots, 10.$$

$Y_{ijkl}$  is the outcome or dependent variable e.g. knowledge score  
 $G$  is the group (control or intervention)  
 $T$  is the time period (pretest or posttest)  
 $U$  is the maternity unit

Here the observed value for the  $i^{\text{th}}$  women nested within the  $k^{\text{th}}$  maternity unit and  $l^{\text{th}}$  group and observed at the  $j^{\text{th}}$  time was expressed as a function of the grand mean ( $m$ ), the effect of the  $l^{\text{th}}$  group ( $G_l$ ), the effect of the  $j^{\text{th}}$  time ( $T_j$ ), the joint effect of the  $l^{\text{th}}$  group and the  $j^{\text{th}}$  time ( $TG_{jl}$ ).

In this trial, group, time, and their interaction were fixed effects. In order to account for the positive intraclass correlation expected in the data,  $\mathbf{U}_{kl}$  and  $\mathbf{TU}_{jkl}$  were included in the analysis as random effects. The three random effects allowed for correlation among women within a hospital ( $\mathbf{U}_{kl}$ ), for correlation among women within a time x hospital survey ( $\mathbf{TU}_{jkl}$ ), and for random variation among the women ( $\mathbf{e}_{ijkl}$ ). The random effects are assumed to be independent and distributed as  $\mathbf{U}_{kl} \sim N(0, S_u^2)$ ,

$TU_{ijkl} \sim N(0, s_{tu}^2)$ . and  $e_{ijkl} \sim N(0, s_e^2)$ . The hypothesis test of interest was the test for the Time x Group (TG<sub>ij</sub>) interaction.

A further model was fitted, adjusting for covariates. Because different women are seen at each time in a nested cross-sectional design, the covariates must be measured separately before and after the intervention. As a result, this regression adjustment is not the same as an adjustment for baseline values that might be used in a cohort design. Regression adjustment was made for the following covariates and factors: age of woman, age woman left full-time education, parity (nulliparous and multiparous), decision making style of woman. The model for the adjusted analysis differs from the model for the unadjusted analysis only by the addition of the covariates.

$$Y_{ijkl} = m + G_i + T_j + TG_{ij} + B_1age + B_2age\_ltd + B_3parity + B_4d\_style + U_{kl} + TU_{ijkl} + e_{ijkl}$$

$$\begin{aligned} i &= 1, \dots, n. \\ l &= 1 \text{ or } 2. \\ j &= 1 \text{ or } 2 \\ k &= 1, \dots, 10. \end{aligned}$$

$Y_{ijkl}$  is the outcome or dependent variable e.g. knowledge score

Age (age in years)

Age\_ltd (age left full-time education)

Parity (0 =nulliparous; 1 = multiparous)

D\_style (decision making style 0=prefer clinician to make decisions; 1=shared; 2=prefer to make decisions for self).

#### 4. Statistical packages

MLwiN software was used to analyse the primary outcome and the output was compared with that of the SAS PROC MIXED procedure using Restricted Maximum Likelihood (REML) to estimate the fixed and random effects in the model (reference SAS Institute). The results were similar. Since SAS was easier to use, SAS has been used for the analysis and Murray's suggested procedures followed for use with this design (Murray 1998).

#### 5. Intraclass Correlation Coefficient

It is good practice to display the intraclass correlation coefficient (ICC) as an aid for other researchers wishing to use the ICCs for future studies (Ukoumunne 1999). The ICCs for the baseline antenatal and postnatal cohorts were estimated, along with 95% confidence intervals, in STATA using Kish's  $\rho$  (roh) (Kish 1965) with the LONEWAY procedure (StataCorp 1997). See Table C.2.

**Table C.2: Intraclass correlation coefficients for outcomes, based on data from before the intervention**

Cohort	Outcome	N	SS between clusters	SS within clusters	ICC	(95% CI)
Antenatal	Informed choice	1352	4.6	331.3	0.0079	(0.0000, 0.0225)
	Knowledge	1233	49.7	2619.9	0.0130	(0.0000, 0.0330)
Postnatal	Informed choice	1674	4.0	411.0	0.0049	(0.0000, 0.0151)
	Knowledge	1720	67.3	4570.1	0.0105	(0.0000, 0.0259)

The ICCs for the pretest-posttest control group design are different to that of the simpler single time point or posttest-only control group design. The ICCs for a single time point reflect the correlation among members within a group or cluster. For the pretest-posttest control group design with two or more time points the ICC of interest reflects the correlation among members within a 'time x group' survey. These were estimated in SAS from the MIXED procedure using Murray's methodology (Murray 1998). Unfortunately no easy methods of confidence interval estimation were available. Murray emphasises that there is no such thing as a universal ICC that is applicable across all endpoints,

designs and analyses. The ICC of interest depends on the endpoint, the design, and the analysis under consideration.

Estimated ICCs for the pretest-posttest control group design analysis for the two main outcomes are shown in Table C.3. Generally they are smaller than the ICC of 0.007 used in the power calculation.

**Table C.3 Estimated ICCs for the main outcomes for the pretest-posttest control group design analysis**

Cohort	Outcome	Estimated ICC
Antenatal	Informed choice	0.01
	Knowledge	0.002
Postnatal	Informed choice	0.002
	Knowledge	0.002

## Appendix 2d: Cluster Randomised Controlled Trial - Representativeness of the Sample

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### 1. Hospitals

Twelve of the 15 large hospitals in Wales were included in the study, where large was defined as having over 1000 deliveries per year. Three hospitals could not be included because they were already using the leaflets. A small hospital, which shared managerial staff with one of the large hospitals, was also included.

### 2. Samples and sample bias

The number of deliveries per year in the selected hospitals were used to calculate the expected numbers of women in the antenatal and postnatal samples for each hospital. These numbers were taken from the All Wales Perinatal Survey (Cartlidge 1999). We used 1997 for our BEFORE survey and 1998 for our AFTER survey.

#### 2.1 Postnatal sample

The numbers of women provided by Child Health or the hospital/home registers for the postnatal samples were 93% (5756/6211) of those expected in a six week period (Table D.1). Given that the number of deliveries in a maternity hospital can fluctuate on a weekly basis, this indicates that the postnatal samples were reasonably complete. The inclusion criteria of live births and women from the catchment area of the hospital reduced the numbers of women included in the study. Eligibility varied between hospitals mainly because of the geographical location of the hospitals, with some hospitals sharing the care of women in specific locations with other hospitals.

The numbers of women AFTER the intervention were lower than BEFORE the intervention: 2584 versus 2762. The birth rate in Wales reduced between 1997 and 1998 but this did not account fully for the reduced numbers, with 84% of women eligible for the 1998 compared with 88% in 1997. Different techniques were used to obtain the names and addresses in the two time periods and we must address whether this may have accounted for the difference. In the BEFORE period, Child Health provided names for the majority of the hospitals and in the AFTER period hospital/home registers provided names for the majority of the hospitals. However, Child Health records were used for one hospital in both time periods and a similar reduction in numbers of women in the AFTER period was found for this hospital.

In the hospital where women could remove their names from the list of names sent to researchers, very few women withdrew their names. Therefore this hospital had a sample as complete as other hospitals in the study.

**Table D.1: Numbers of women expected and obtained in the POSTNATAL SAMPLES for each cluster**

Site	Expected numbers in 6 week period		Actual numbers		Eligible numbers		Eligible as % of expected	
	1997	1998	BEFORE	AFTER	BEFORE	AFTER	BEFORE	AFTER
I1	294	299	271	273	268	271	91%	91%
I2	574	548	578	530	552	514	96%	94%
I3	319	319	328	309	318	277	100%	87%
I4	249	245	217	185	196	179	79%	73%
I5	203	188	198	187	176	187	87%	99%
C1	248	263	229	210	229	201	92%	76%
C2	555	534	536	401	432	391	78%	73%
C3	324	322	308	306	271	266	84%	83%
C4	173	173	170	146	147	136	85%	79%
C5	194	185	199	175	173	162	89%	88%
I	1639	1599	1592	1484	1510	1428	92%	89%
C	1494	1477	1442	1238	1252	1156	84%	78%
All	3133	3078	3034	2722	2762	2584	88%	84%

I= intervention site

C=control site

## 2.2 Antenatal sample

The numbers of eligible women in the postnatal sample were used to determine expected numbers in the antenatal sample. Fewer women were identified than expected: 81% (5247/6444) of those expected in the survey time periods (Table D.2). To be included in this sample, women had to be in contact with the maternity service by 24 weeks pregnant. Women making contact with the service later in pregnancy were excluded by nature of the sampling process.

One cluster, I3 in the intervention arm, had particularly lower than expected numbers. This hospital asked women to give their permission for their name to be included in the study. This small sample is unfortunate but is less of a problem because of the before-and-after aspect of the study design. A real problem occurs if the numbers obtained are different BEFORE and AFTER the intervention. The techniques used to collect the antenatal sample in each time period were similar. Nevertheless, the control cluster C5 had a considerably lower identification rate AFTER the intervention. Reasons for this are unknown. The same Antenatal Clinic Clerk identified the samples in both time periods. When the situation was brought to her attention she attempted to identify more women but could not do so.



**Table D.2: Numbers of women expected and obtained in the ANTENATAL SAMPLES in each cluster**

Site	Expected numbers		Actual numbers		Eligible numbers		Eligible as % of expected	
	BEFORE	AFTER	BEFORE	AFTER	BEFORE	AFTER	BEFORE	AFTER
I1	268	357	178	247	175	243	65%	68%
I2	552	736	478	597	455	555	82%	75%
I3	318	424	176	253	175	251	55%	59%
I4	196	261	175	288	173	221	88%	85%
I5	176	235	138	187	127	160	72%	68%
C1	229	305	187	262	177	242	77%	79%
C2	432	576	367	433	360	427	83%	74%
C3	271	361	266	373	257	359	95%	99%
C4	147	196	145	177	144	166	98%	85%
C5	173	231	168	152	167	147	97%	64%
I	1510	2013	1145	1572	1105	1430	73%	71%
C	1252	1669	1133	1397	1105	1341	88%	80%
All	2762	3682	2278	2969	2210	2771	80%	75%

I= intervention site

C=control site

### 3. Response rates

The overall response rate to the surveys was 64% (6452/10,070). The response rate to the antenatal questionnaire was 65% before the intervention and 66% after the intervention (Table D.3). Rates were similar for the intervention arm and the control arm. The response rate to the postnatal questionnaire was 64% before and 62% after the intervention. The response rate to the postnatal questionnaire for the control arm after the intervention was low for all the control sites; the response rate in the control arm was statistically significantly different in the two time periods: 66% before v 59% after ( $p < 0.005$ ).

It is likely that the relatively high response rate to the antenatal survey in intervention site I3, 70% before and 77% after the intervention, was due to women being asked to give permission for their names to be included in the study.

The numbers of completed questionnaires used in the analysis are shown in brackets in Table D.3. There were 1386 and 1778 completed questionnaires in the before and after antenatal surveys respectively; there were 1741 and 1547 completed questionnaires in the before and after postnatal survey respectively.

**Table D.3 RESPONSE RATES to antenatal and postnatal questionnaires, with number of completed questionnaires in brackets**

Site	ANTENATAL		POSTNATAL	
	BEFORE	AFTER	BEFORE	AFTER
I1	60% (105)	68% (162)	67% (173)	68% (176)
I2	67% (296)	63% (340)	60% (325)	61% (308)
I3	70% (120)	77% (191)	59% (187)	64% (174)
I4	69% (111)	65% (143)	63% (123)	58% (101)
I5	63% ( 75)	64% ( 99)	65% (114)	68% (127)
C1	65% (110)	68% (161)	76% (171)	59% (114)
C2	67% (229)	65% (271)	62% (266)	59% (220)
C3	67% (167)	62% (219)	64% (169)	58% (163)
C4	59% ( 80)	64% ( 98)	65% (144)	56% ( 74)
C5	57% ( 93)	62% ( 94)	70% ( 93)	56% ( 90)
Intervention	66% (707)	67% (935)	62% (922)	64% (886)
Control	64% (679)	64% (843)	66% (819)	59% (661)
All	65% (1386)	66% (1778)	64% (1741)	62% (1547)

The Return To Sender rate and the Refusal to Participate rate were acceptably small at each stage of the study (Table D.4).

**Table D.4: Return to Sender and Refusal to Participate rates**

	ANTENATAL		POSTNATAL	
	BEFORE	AFTER	BEFORE	AFTER
Return to Sender	3.7%	2.3%	1.4%	2.8%
Refusal	2.1%	1.5%	2.2%	2.6%

A response rate of 75% had been expected, a realistic expectation given that a recent postal survey to users of maternity services obtained a response rate of 72% (Dowswell 1997) and that our pilot antenatal and postnatal surveys had obtained response rates of 57% and 45% respectively on one mailing only. It is important to understand why our response rate was lower than expected and understand the biases which may be present in the data. However, it is also important to appreciate that the response rate was by no means out of the ordinary, with examples of lower response rates for maternity surveys available in the literature, for example 62.5% (Brown 1998).

#### 4. Reasons for lower than expected response rates

Meta-analyses of the factors which affect response rates to postal questionnaires have been used, together with a study specific to maternity surveys, to look at possible reasons for lower than expected response (Cartwright 1986, Fox 1988, Heberlein 1978).

##### **Population**

An influential factor on response is the population surveyed. The same survey administered in different geographical areas can produce response rates varying from 66% to 87% (Cartwright 1986). These differences are related to the proportion of people in the population from minority ethnic communities and manual social classes. There were certainly different response rates for each of the hospitals in our study, with rates varying between 56% and 77%. However, since the overall response rate was lower than expected, the population of Wales would need to have higher proportions of minority ethnic communities and manual social classes than Britain as a whole to account for this. The 1991 Census shows that the population of Wales has a lower proportion of people from minority ethnic communities than Britain (98.5% white versus 94.5% white) and a higher proportion of unemployed men (10.4% versus 9.8%). It is difficult to say what the overall effect of population differences are on the response rate, given that the two factors act in opposite directions. However, it is reasonable to say that even if the social class make-up of Wales accounts for some of the lower response, it cannot possibly account for all of it.

## ***Saliency***

The relevance or interest of the subject of a questionnaire has a large impact on the response rate to it. A questionnaire about maternity care to pregnant women and recent mothers would be highly salient. However, the focus of the questionnaires in this study was on different aspects of information and choice in maternity care rather than maternity care itself. If women are not given choices and do not understand that different choices are available, they may not see the relevance of the questionnaire to them. In addition, our agenda as researchers was to explore some of the subtleties of information and choice on topics important to us, rather than the women. A total of 218 women telephoned or wrote to the research team to explain why they would not complete the questionnaire (Table D.5). Sixteen women said that the questions were irrelevant, half because they had had an elective caesarean and thus had no choice about position, support or heart monitoring. Although these are very small numbers compared with the sample size, they might nonetheless reflect the views of other women who did not respond.

**Table D.5: Reasons given for not completing either the antenatal or the postnatal questionnaire**

Reason	Number
Do not want to	93
No time / too busy	40
Saw survey as breach in confidentiality	20
Questions irrelevant	16
Questionnaire confusing/long/repetitive	9
Personal reasons	7
Have moved or will move soon	7
Difficulty reading or writing English or Welsh	6
Blank -no reason given	5
Baby ill	4
Health professional	3
Do not complete questionnaires	3
Other	5
Total	218

## ***Length and complexity of questionnaire***

The questionnaires in this study were long, with a fourteen page A4 antenatal questionnaire and a sixteen page A4 postnatal questionnaire, each with two knowledge questionnaires inserted which added a further eight pages. Forty women refused to participate because they said that they did not have the time, sometimes detailing the difficulty of looking after a number of children and having to work outside the home (Table D.5). A further 9 women felt that the questionnaire was long, repetitive or confusing. Cartwright studied the effect of the length of the questionnaire and the type of questions asked on response rates (Cartwright 1986). She found that the length of the questionnaire did not affect the response rate using lengths of 8, 16 or 24 pages on A5 paper. However, a review of factors affecting response rate found that the length of questionnaire affected response rate once saliency was controlled for. It is likely that the combination of long length with a possible lack of saliency contributed to the lower than expected response rate.

Cartwright showed that women were more likely to respond to questionnaires containing factual only, rather than factual and attitudinal questions. She showed a 4 percentage point reduction in response if attitudinal questions were used. The questionnaires in this study had a large number of attitudinal questions rather than factual questions. This is highly likely to have affected the response rate of the study.

## ***Survey methodology***

The methodology of this study included many of the techniques reported to gain higher response rates: two reminders, reply paid envelope enclosed, university sponsorship, and coloured paper for the questionnaires. Some techniques were not used: prenotification, stamped return envelope, first class outgoing mail. However, the balance was very much in favour of techniques shown to increase response rates.

## **5. Response bias**

People from minority ethnic communities and manual social classes are less likely to respond to postal questionnaires than to face-to-face interviews (Cartwright 1986). Two small studies of non-respondents were undertaken here to understand the bias in response to this survey. The studies were limited by the information easily available to us.

### ***Antenatal sample***

For two hospitals in the AFTER period, mother's occupation, partner's occupation, number of previous live births and mother's age were available for the whole sample. The woman's name was used to identify ethnic group. Data from the first six weeks of the sample were coded. Women who had responded were compared with women who had not responded or who had refused to complete the questionnaire, with Return to Senders excluded from the analysis. Thus a comparison of respondents and non-respondents was undertaken on 312 women, 68% of whom had responded. The response rate was statistically significantly higher for women in non-manual social classes compared with women in manual classes (chi-squared=5.33, df=1,  $p<0.02$ ), although this association was no longer statistically significant when other social groups such as housewives and unemployed were included (Table D.6). A similar, but non-statistically significant difference, was apparent with the women's partners' social class. There was also some evidence that older women were more likely to respond, with the mean age of respondents being 29.4 years compared with 28.1 years for non-respondents ( $t=1.86$ ,  $0.05<p<0.1$ ). There was no statistically significant relationship between parity and response rate. There were too few women from minority ethnic groups to allow comparison.

### ***Postnatal sample***

For one hospital in the AFTER period, mother's occupation, partner's occupation, number of previous live births, mother's age, ethnicity of mother, type of delivery and type of pain relief were available for the whole sample. Data from the first three weeks of the sample were coded. Women who had responded were compared with women who had not responded or who had refused the questionnaire, with Return to Senders excluded from the analysis. Thus a comparison of respondents and non-respondents was undertaken on 198 women, of whom 66% had responded. There was evidence that women from manual social classes and minority ethnic groups were less likely to respond although this was not statistically significant. Surprisingly, given the comments made by a few women who refused to complete the questionnaire, women undergoing caesarean section had an average response rate.

### ***Combining both samples***

Looking at the social class of the woman and her partner, parity, age and ethnicity for both samples together shows that there is under-representation from women in manual social classes (chi-squared=10.8, df=3,  $p<0.05$ ) and evidence of under-representation from women in minority ethnic groups (chi-squared=2.8, df=1,  $0.05<p<0.1$ ).

### ***Further comparison with All Wales data***

Data on parity were obtained for the whole of Wales in 1995 (Andrews 1996). The proportion of primiparous women in Wales in 1995 was 41%. In our antenatal BEFORE survey 47% of women were primiparous and in our postnatal BEFORE survey 44% of women were first-time mothers. Although there may be some difficulty in making comparisons because of differences in definitions of parity, there is evidence of an over-representation of first-time mothers in our antenatal data.

Data on caesarean deliveries were obtained for the hospitals in this study for 1997 and 1998 (Cartlidge 1999). The caesarean rate in this two year period was 20% and the elective caesarean rate was 8.0%. In our postnatal surveys, 21% and 7.7% of women had caesareans and elective caesareans respectively. There does not appear to be any bias in our data by delivery type.

**Table D.6 Response rates in different groups of women, based on the sub-sample described in part 5 of this appendix. The total numbers of women which these response rates are based on are shown in brackets.**

Factor	Antenatal	Postnatal	Both
Woman's social class			
non-manual	74% (129)	77% (70)	75% (199)
manual	56% ( 55)	62% (34)	58% ( 89)
unemployed	53% ( 15)	62% (21)	58% ( 36)
housewife	67% ( 66)	58% (60)	62% (126)
Partner's social class			
non-manual	77% ( 96)	75% (51)	76% (147)
manual	67% (136)	65% (98)	66% (234)
unemployed	56% ( 18)	68% (22)	63% ( 40)
Previous live births			
none	71% (132)	72% ( 76)	71% (208)
one or more	65% (172)	63% (119)	64% (291)
Mother's age			
16-24	61% ( 66)	64% ( 55)	62% (121)
25-34	68% (197)	69% (117)	68% (314)
35+	78% ( 41)	62% ( 21)	73% ( 62)
Ethnic group			
white	68% (303)	68% (175)	68% (478)
other	40% ( 5)	55% ( 20)	52% ( 25)
Type of delivery			
vaginal	-	67% (137)	-
assisted	-	60% ( 20)	-
caesarean	-	68% ( 38)	-
Type of pain relief			
epidural/spinal	-	67% ( 63)	-
no epidural	-	67% (132)	-

## 6. Requests for Welsh questionnaires

Nineteen women requested a Welsh questionnaire; 14 returned completed Welsh questionnaires and one returned a completed English questionnaire. Free-text comments were translated into English and included with all other free-text comments for analysis.



## Appendix 2e: Cluster Randomised Controlled Trial - The Leaflets: Distribution, Views and Influence

### 1. Level of leaflet use prior to the intervention

The CRCT was pragmatic and thus no attempt was made to change the reality that women may receive a range of leaflets during maternity care, including Informed Choice leaflets which individual midwives may purchase themselves. In both the BEFORE and the AFTER surveys, women were asked if they had been given each of the ten Informed Choice leaflets. BEFORE the intervention, a considerable minority of women reported that they had been given Informed Choice leaflets. Approximately 40% of women reported that they had been given at least one Informed Choice leaflet, varying between approximately 10% for the breech presentation leaflet and 40% for the feeding leaflet (Table E.1). This is unlikely to be explained by individual midwives purchasing the leaflets. The qualitative research revealed that women see many leaflets during their care and that they have difficulty distinguishing between Informed Choice leaflets and other leaflets. Although we attempted in the questionnaire to emphasise that we were interested in Informed Choice leaflets only, we were aware from the pilot of the questionnaire that it was difficult to devise a question which women would complete accurately. The important point is that the Informed Choice leaflets were entering an environment where other leaflets were available.

**Table E.1: Percentage of women reporting that they had been given Informed Choice leaflets**

Leaflet	BEFORE		AFTER		CHANGE		DIFFERENCE (cluster level)	
	I	C	I	C	I	C		
	%	%	%	%	%	%		
Alcohol	23	29	51	29	28	0	28	***
Scans	21	23	52	33	31	10	21	*
Screening	29	43	60	52	31	9	22	*
Where to have baby	15	17	38	19	23	2	21	***
Antenatal survey:								
at least one leaflet	34	47	63	53	29	5	24	**
all four leaflets	6	7	23	10	17	3	14	*
Support	14	12	43	16	29	4	26	***
Heart monitoring	11	9	35	12	24	3	21	***
Epidural	23	20	55	25	32	5	27	***
Positions	17	15	42	16	25	1	24	***
Feeding	42	42	72	45	30	3	26	***
Breech baby	10	8	19	8	9	0	8	**
Postnatal survey:								
at least one leaflet	45	44	75	47	30	3	28	***
all five leaflets <sup>b</sup>	5	5	22	6	17	0	16	***

<sup>b</sup>breech not included      \*p<0.05, \*\*p<0.005, \*\*\*p<0.001

### 2. Change in leaflet use over time

Changes occurred in the proportions of women in the intervention sites who reported that they had been given Informed Choice leaflets once the intervention was in place (Table E.1). Approximately 70% of women reported that had been given at least one of the leaflets. Statistically significant changes occurred in intervention sites, over and above any changes which occurred in control sites. For example, there was a 28 percentage point increase in the proportion of women reporting that they had been given the alcohol leaflet in intervention sites compared with no change in control sites. For most of the leaflets, the proportion of women reporting that they had been given the leaflets increased by approximately 30 percentage points in the intervention sites compared with small increases in the control sites. Because of the difficulty in distinguishing Informed Choice leaflets from other leaflets, we cannot calculate the exact increase in the proportion of women who received the intervention; however, we can say that there was an increase in use of Informed Choice leaflets in between approximately 30% and 70% of women.

For the antenatal leaflets, two intervention sites had larger changes in leaflet use than the others: I4 and I5 (Table E.2). For the postnatal leaflets, one intervention site had a larger change than the others: I2.

**Table E.2: Percentage point change in the proportion of women reporting that they had been given at least one Informed Choice leaflet by site**

Site	Antenatal %	Postnatal %
I1	25	25
I2	21	37
I3	24	30
I4	38	32
I5	38	28
C1	-8	1
C2	9	3
C3	18	12
C4	13	-7
C5	-5	4

The changes in leaflet use for control sites were small, with the exceptions of ultrasound scans and screening tests in specific sites. In one control site, there was a 36 percentage point increase in the proportion of women reporting they had been given the Informed Choice leaflet for ultrasound scans. This site introduced two in-house scanning leaflets during the study: one was used for women undergoing routine scans and the other was used for women undergoing anomaly scans. This latter leaflet covered spina bifida and Down’s syndrome. In three control sites there were increases in women reporting that they were given the Informed Choice screening test leaflet. One control hospital had purchased the Informed Choice screening leaflet after our baseline survey and reported use increased by 17 percentage points. Another introduced a different leaflet and there was a 27 percentage point increase in women reporting that they had received the Informed Choice leaflet on screening. Another introduced an anomaly scan leaflet as explained above and there was a 15 percentage point increase in women reporting that they had been given an Informed Choice leaflet on screening.

Should we simply ignore the introduction of in-house leaflets during the study period? After all, changes will occur in intervention and control sites which may have enormous effects on informed choice, such as a change in management or staff. We are trying to measure change attributable to the leaflets over and above any changes which may be occurring anyway within the hospitals - hence the analysis of change in intervention sites compared with change in control sites. However, the important issue is that both the intervention and control sites should be as likely as each other to see these changes over the study period. It seems likely that having Informed Choice leaflets available will reduce the probability of the production of in-house leaflets and thus it is important to know about changes in the use of leaflets. Contamination is present for ultrasound scans and screening tests. Since decisions about these topics contribute to women’s overall views of antenatal care, there will be contamination there too. Further analysis has been undertaken for ultrasound scans, by excluding the one control site which introduced their own leaflet on scans.

**3. Who received the leaflets?**

An individual level analysis was undertaken on women in the intervention sites who reported receiving the Informed Choice leaflets after the intervention had commenced. Women who reported that they were given any of the Informed Choice leaflets were compared with those who reported that they were not or that they were unsure (Table E.3). Postnatally, younger women and first time mothers were more likely to report that they had been given any of the Informed Choice leaflets covered in the postnatal questionnaire: 84% of younger mothers reported receiving at least one of the leaflets compared with 71% of older mothers, and 84% of first time mothers compared with 68% of multiparous women.



**Table E.3: Percentage of women in different sub-groups who reported receiving at least one Informed Choice leaflet, intervention sites only after the intervention. Percentages with denominators in brackets.**

Sub-group		Antenatal	Postnatal
Age	<=23 years	72% (185)	84% (206)***
	24-28	76% (234)	76% (250)
	29-32	73% (226)	69% (236)
	33+	69% (183)	71% (194)
Parity	Primiparous	75% (350)	84% (413)***
	Multiparous	71% (599)	68% (471)
Educational status	<18 years	74% (458)	75% (541)
	18-19	75% (214)	74% (198)
	20+	66% (133)	74% (125)
Woman's social class	Non-manual	73% (484)	76% (497)
	Manual	70% (212)	73% (237)
Decision-style preference	Self	71% (570)	74% (478)
	Shared	73% (176)	76% (221)
	Clinician	83% ( 58)	81% (152)

\*\*\* p<0.001

#### 4. Helpfulness of leaflets

An individual level analysis was undertaken on women in the intervention sites who said they had received the Informed Choice leaflets after the intervention had commenced. The vast majority of women found the leaflets very helpful or helpful, varying between 92% and 99% for individual leaflets. (Table E.4).

**Table E.4: Percentage of women finding the leaflets helpful in the intervention sites AFTER the intervention**

Leaflet	Very helpful	Helpful	Not helpful	N=100%
Alcohol	34%	62%	3%	388
Scans	42%	56%	3%	421
Screening	46%	50%	4%	486
Where to have baby	35%	58%	8%	292
Support	33%	61%	6%	365
Heart monitoring	38%	56%	6%	286
Epidural	35%	58%	7%	443
Positions	37%	56%	7%	336
Feeding	42%	53%	5%	584
Breech baby	48%	51%	1%	149

## 5. Potential of leaflets to influence women's preferences

We asked women what influenced their thoughts of what they wanted during their care. Women reported a number of sources of influence, with more women influenced by health professionals, family or friends and their own experiences than by leaflets (Table E.5). That is, the Informed Choice leaflets were entering an environment where there were many influences on women. Antenatally 28% of women and postnatally 13% of women were influenced by leaflets prior to the intervention. There were no statistically significant changes in the proportions of women influenced by leaflets over time. Over the period of the study, there was one statistically significant change in influence on women's preferences. The influence of health professionals on postnatal women in intervention sites increased by ten percentage points more than control sites. There was evidence that leaflets and television programmes may have exerted influence on more women antenatally in intervention sites after the intervention. A possible explanation is that one of the hospitals in our study was the focus of a television programme on maternity care broadcast during the study period.

**Table E.5: Percentage of women influenced by different sources**

Influence	BEFORE		AFTER		CHANGE		DIFFERENC E (cluster level)
	I %	C %	I %	C %	I %	C %	
<b>ANTENATAL</b>							
Health professionals	57	61	57	65	0	4	-4
Family or friends	50	49	48	51	-2	2	0
Past experience	48	47	50	44	3	-3	1
Books or magazines	42	38	38	38	-4	0	-4
Leaflets given by midwives etc.	25	31	32	33	7	2	5 +
TV programmes	8	12	15	13	6	1	6 +
Antenatal classes	9	8	8	7	-1	-1	0
<b>POSTNATAL</b>							
Health professionals	46	48	54	46	8	-2	10 *
Family or friends	38	39	40	42	2	3	-1
Past experience	51	49	45	45	-6	-4	-2
Books or magazines	30	34	45	50	-1	2	-3
Leaflets given by midwives etc.	13	13	20	18	7	5	3
TV programmes	4	4	6	9	2	5	-3
Antenatal classes	18	19	22	23	4	4	0

+ 0.05 < p < 0.1, \* p < 0.05

## Appendix 2f: Cluster Randomised Controlled Trial – Components of Informed Choice

### 1. Knowledge

Each woman completed two knowledge questionnaires. An overall knowledge score was calculated for each woman by adding together scores for the two knowledge questionnaires completed and dividing their total by two. Prior to the intervention, women scored approximately 4 points out of ten antenatally and 3 points out of ten postnatally (Table F.1). For antenatal women there was an overall increase of 0.27 points in the knowledge score for the intervention sites compared with control sites; this was not statistically significant. For postnatal women there was an overall increase of 0.24 points which was no longer statistically significant when adjusted for women's age, educational status, parity and decision-style preferences.

**Table F.1: Overall knowledge score**

	Antenatal		Postnatal	
	Intervention mean	Control mean	Intervention mean	Control mean
BEFORE	3.8	3.8	3.3	3.3
AFTER	4.0	3.7	3.5	3.3
CHANGE	0.24	-0.02	0.19	-0.05
<b>DIFFERENCE (cluster level)</b>	<b>0.27</b>		<b>0.24</b>	
95% confidence interval	-0.11, 0.64		0.03, 0.45	
T-test	p=0.14		p=0.03	
Wilcoxon	p=0.12		p=0.05	
Analysis of covariance	p=0.05		p=0.03	
<b>DIFFERENCE (MLM unadjusted)</b>	<b>0.25</b>		<b>0.26</b>	
95% confidence interval	-0.7, 0.58		0.09, 0.47	
	p=0.11		p=0.02	
	N=2792		N=3255	
<b>DIFFERENCE (MLM adjusted)+</b>	<b>0.19</b>		<b>0.20</b>	
95% confidence interval	-0.12, 0.50		0.05, 0.44	
	p=0.19		p=0.10	
	N=2617		N=3054	

+adjusted for woman's age, educational status, parity, decision-style preference

Given that there was a statistically significant increase in overall knowledge at the cluster level, analyses were undertaken at the individual leaflet level. For the individual leaflet topics there was evidence of an increase in knowledge in intervention sites for alcohol, ultrasound scans, epidurals, positions and feeding (Table F.2). There was a statistically significant increase over and above any change in control sites for the topics of positions and feeding.

**Table F.2: Change in knowledge scores for individual leaflet topics**

Leaflet topic	Change in intervention	Change in control	Cluster difference (95% CI)	MLM unadjusted difference	MLM adjusted difference+
Alcohol	0.60	0.03	0.57 (-0.10,1.24) p=0.08	0.48 p=0.05	0.36 p=0.08
Scans	0.34	-0.07	0.41 (-0.17,0.99) p=0.14	0.31 p=0.16	0.19 p=0.4
Screening	0.16	0.13	0.03 (-0.37,0.44) p=0.9	0.07 p=0.7	0.09 p=0.7
Where to have baby	-0.03	-0.16	0.12 (-0.43, 0.68) p=0.6	0.15 p=0.5	0.08 p=0.8
Support	0.01	-0.14	0.16 (-0.46,0.77) p=0.6	0.16 p=0.6	0.17 p=0.5
Heart monitoring	0.04	0.16	-0.12 (-0.53,0.29) p=0.5	-0.16 p=0.4	-0.21 p=0.3
Epidural	0.42	0.17	0.25 (-0.11,0.60) p=0.15	0.29 p=0.2	0.23 p=0.10
Positions	0.24	-0.19	0.43 (0.05,0.80) p<0.05	0.41 p<0.05	0.33 p=0.11
Feeding	0.28	-0.11	0.39 (0.06,0.72) p<0.05	0.37 p<0.005	0.41 p=0.05

+adjusted for woman's age, educational status, parity, decision-style preference

## 2. Preferences

It was not possible to ask women about their preferences overall in maternity care. Women were asked about their preferences for each of the decision points covered by the leaflets. Prior to the intervention, the majority of women wanted to have an ultrasound scan, have screening tests for Down's syndrome and spina bifida, and have someone to support them during labour (Table F.3). A minority wanted to drink alcohol in pregnancy and have a home birth.

There was one statistically significant change over time, in that fewer women wanted a screening test for Down's syndrome and spina bifida in the intervention sites compared with control sites when the leaflets were in use. This was statistically significant with the multi-level modelling, adjusted for parity, woman's age, educational status and decision-style preference. However, it is worth noting that the change consisted of a reduction of 7 percentage points in the intervention sites and an increase of 5 percentage points in women wanting tests in control sites. The reduction occurred in four of the five intervention sites and the increase in the three control sites which had introduced screening leaflets during the study. The shift appeared to be from women wanting the tests to women not wanting the tests, rather than changing the opinions of women who had no preference (Table F.4). There was some evidence of a shift in preferences for home births, heart monitoring and breastfeeding.

Women were asked about the strength of their preferences for each decision point (Table F.5). The majority of women felt very or quite strongly about their preferences for ultrasound scans, where to have their baby, support in labour, pain relief and feeding method. There was a statistically significant increase of 8 percentage points in the percentage of women feeling very or quite strongly about their preferences for positions to adopt during labour and delivery in the intervention sites compared with the control sites. This was no longer statistically significant with a multi-level model adjusted for parity, woman's age, educational status and decision-style preference.

**Table F.3: Percentage of women with preferences for different decision points**

Preference	BEFORE		AFTER		CHANGE		DIFFERENCE (95%CI)	
	I	C	I	C	I	C		
	%	%	%	%	%	%		
Drink alcohol	10	8	12	11	2	3	-1	( -8, 6)
Have a scan	99	99	99	100	0	1	-0	( -2, 2)
Have screening	83	75	76	80	-7	5	-11	(-22, -0)*
Have home birth	5	5	7	4	2	-1	3	( -0, 6)+
Have support	95	97	96	97	1	0	1	( -3, 4)
Have Electronic Fetal Monitoring	41	39	35	41	-6	2	-8	(-17, 1)+
Have an epidural	22	22	24	22	2	0	3	(-7, 12)
Lie in bed in labour	23	24	24	23	1	-1	2	(-3, 8)
Breastfeed	58	62	64	60	6	-2	8	(-1, 17)+

+ 0.05<p<0.1, \* p<0.05

**Table F.4: Preference for having a screening test for Down's syndrome and spina bifida in the baby (individual level analysis)**

Preference	Intervention		Control	
	BEFORE	AFTER	BEFORE	AFTER
Yes	84%	76%	70%	77%
No	12%	18%	25%	19%
No preference	4%	6%	5%	5%
N=total	610	815	605	737

**Table F.5: Percentage of women feeling very or quite strongly about preferences**

Topic	BEFORE		AFTER		CHANGE		DIFFERENCE (95%CI)	
	I	C	I	C	I	C		
	%	%	%	%	%	%		
Alcohol	40	37	39	38	-1	1	-2	(-11, 7)
Scans	98	97	100	98	2	1	0	( -3, 4)
Screening	45	45	43	47	-2	2	-4	(-15, 8)
Where to have baby	77	76	77	74	0	-2	2	( -8, 12)
Support	95	96	96	96	1	0	1	( -2, 3)
Heart monitoring	56	52	53	55	-3	3	-6	(-15, 3)
Epidural	77	78	82	75	5	-3	7	( -2, 17)
Positions	49	53	56	52	7	-1	8	( 4, 12)***
Feeding	93	93	93	91	0	-2	2	(-1, 5)

\*\*\*p<0.001

### 3. Information

Prior to the intervention, approximately two thirds of women reported having enough information overall in their maternity care (Table F.6). There was no statistically significant change in the proportion of women whose information needs were met. It might be that the leaflets met *some* information needs but not *all* the information needs of women. This can be explored by studying satisfaction levels with information (Table F.7). There was no evidence that the leaflets changed satisfaction levels with information overall.

**Table F.6: Percentage of women with enough information overall**

	Antenatal		Postnatal	
	Intervention	Control	Intervention	Control
BEFORE	65	71	72	68
AFTER	69	73	73	72
CHANGE	4	2	1	4
DIFFERENCE (cluster level)	<b>1</b>		<b>-3</b>	
95% confidence interval	-8, 11		-11, 6	
T-test	p=0.8		p=0.5	
Wilcoxon	p=0.8		p=0.9	
Analysis of covariance	p=0.7		p=0.8	

**Table F.7 Percentage of women very satisfied or satisfied with information overall**

	Antenatal		Postnatal	
	Intervention	Control	Intervention	Control
BEFORE	64	71	71	68
AFTER	70	74	75	72
CHANGE	6	3	4	4
DIFFERENCE (cluster level)	<b>3</b>		<b>0</b>	
95% confidence interval	-4, 11		-10, 10	
T-test	p=0.3		p=1.0	
Wilcoxon	p=0.5		p=0.5	
Analysis of covariance	p=0.5		p=0.4	

#### 4. Making choices

Prior to the intervention, approximately three quarters of women were very satisfied or satisfied with the way choices were made overall in maternity care (Table F.8). There was no statistically significant change in women's satisfaction levels with the way choices had been made.

**Table F.8: Percentage of women very satisfied or satisfied with the way choices had been made overall**

	Antenatal		Postnatal	
	Intervention	Control	Intervention	Control
	%	%	%	%
BEFORE	70	75	79	76
AFTER	74	78	78	79
CHANGE	4	3	-1	3
DIFFERENCE (cluster level)		<b>2</b>		<b>-5</b>
95% confidence interval		-8, 12		-18, 8
T-test		p=0.7		p=0.4
Wilcoxon		p=0.6		p=0.5
Analysis of covariance		p=0.6		p=0.7

#### 5. Discussion with health professionals

Prior to the intervention, approximately two thirds of women felt that they were able to discuss what they wanted, as much as they wanted, when talking to midwives or doctors (Table F.9). There was no statistically significant change in this proportion over time.

**Table F.9: Percentage of women who felt able to discuss issues with health professionals**

	Antenatal		Postnatal	
	Intervention	Control	Intervention	Control
	%	%	%	%
BEFORE	58	61	66	62
AFTER	64	63	66	67
CHANGE	6	2	0	5
DIFFERENCE (cluster level)		<b>4</b>		<b>-5</b>
95% confidence interval		-7, 15		-16, 6
T-test		p=0.4		p=0.3
Wilcoxon		p=0.5		p=0.3
Analysis of covariance		p=0.7		p=0.7





## Appendix 2g: Cluster Randomised Controlled Trial – Consequences of Informed Choice

### 1. Control

Prior to the intervention, approximately three quarters of women said that they felt in control of what happened to them or what staff did to them most or all of the time (Tables G.1 and G.2). There were no statistically significant changes over time.

**Table G.1: Percentage of women feeling in control of what happened to them most or all of the time**

	Antenatal		Postnatal	
	Intervention %	Control %	Intervention %	Control %
BEFORE	85	88	78	74
AFTER	87	88	77	77
CHANGE	1	0	-1	2
DIFFERENCE (cluster level)		<b>1</b>		<b>-4</b>
95% confidence interval		-6, 8		-16, 9
T-test		p=0.8		p=0.5
Wilcoxon		p=0.8		p=0.6
Analysis of covariance		p=0.6		p=0.9

**Table G.2: Percentage of women feeling in control of what staff did to them most or all of the time**

	Antenatal		Postnatal	
	Intervention %	Control %	Intervention %	Control %
BEFORE	83	88	74	70
AFTER	84	88	71	70
CHANGE	1	0	-3	0
DIFFERENCE (cluster level)		<b>1</b>		<b>-4</b>
95% confidence interval		-8, 11		-15, 8
T-test		p=0.8		p=0.5
Wilcoxon		p=0.6		p=0.8
Analysis of covariance		p=0.1		p=0.8

### 2. Emotional health

A decrease in the Edinburgh Postnatal Depression Score (EPDS) indicates an improvement in emotional health. No statistically significant changes occurred in either the antenatal or postnatal women (Table G.3). One item on the EPDS has been shown to be invalid when the EPDS is completed antenatally because women interpret the question about self-harm being about accidental self-harm (Green 1998). It has been suggested that a nine-item score is calculated without this question. This makes no difference to the result. A decrease in the short-form Spielberger's State Anxiety Inventory (STAI) indicates an improvement in emotional health. No statistically significant changes occurred in either the antenatal or postnatal women (Table G.4).

**Table G.3: Mean Edinburgh Postnatal Depression Score**

	Antenatal		Postnatal	
	Intervention	Control	Intervention	Control
BEFORE	10.01	9.93	8.10	7.97
AFTER	9.61	9.35	7.90	8.14
CHANGE	-0.40	-0.58	-0.20	0.17
DIFFERENCE (cluster level)	<b>0.18</b>		<b>-0.37</b>	
95% confidence interval	-0.93, 1.29		-1.27, 0.52	
T-test	p=0.7		p=0.4	
Wilcoxon	p=0.9		p=0.8	
Analysis of covariance	p=0.4		p=0.4	

**Table G.4: Prorated Spielberger State Anxiety Score**

	Antenatal		Postnatal	
	Intervention	Control	Intervention	Control
BEFORE	37.34	38.23	34.03	34.88
AFTER	37.66	37.13	34.11	35.65
CHANGE	0.32	-1.10	0.08	0.77
DIFFERENCE (cluster level)	<b>1.42</b>		<b>-0.69</b>	
95% confidence interval	-1.17, 4.00		-2.91, 1.53	
T-test	p=0.2		p=0.5	
Wilcoxon	p=0.3		p=0.5	
Analysis of covariance	p=0.3		p=0.5	

### 3. Satisfaction with care

Prior to the intervention, over three quarters of women were very satisfied or satisfied with their maternity care overall (Table G.5). There was no statistically significant change in the level of satisfaction with care over time.

**Table G.5: Percentage of women very satisfied or satisfied with their care overall**

	Antenatal		Postnatal	
	Intervention	Control	Intervention	Control
	%	%	%	%
BEFORE	73	81	83	79
AFTER	79	82	81	82
CHANGE	6	1	-2	3
DIFFERENCE (cluster level)	<b>4</b>		<b>-5</b>	
95% confidence interval	-6, 15		-14, 4	
T-test	p=0.4		p=0.2	
Wilcoxon	p=0.3		p=0.1	
Analysis of covariance	p=0.6		p=0.6	

### 4. Actions taken by women/use of health services

There were two statistically significant differences between intervention and control sites in terms of changes in the services used and actions undertaken by women (Table G.6). First, there was a reduction in the proportion of women having screening tests for Down's syndrome and spina bifida in the baby. The reduction of 4% in intervention sites occurred alongside an increase of 6% in control sites. That is, the statistical significance of the change was dependent upon a reasonably large change in the opposite direction in the control sites. Multi-level modelling adjusted for covariates at the individual level gave a similar result, with a p-value of 0.06. The second significant difference was about where women planned to have their babies: there was a 2% reduction in the proportion planning to have hospital births in the intervention sites compared with no change in the control sites. This small

difference was statistically significant because of the lack of variability between hospitals. It was not statistically significant in an adjusted multi-level analysis.

In addition, there was some evidence of a reduction in the proportion of women drinking less alcohol; again this was dependent on a change in the opposite direction in control sites and was not statistically significant in an adjusted multi-level analysis. There was also evidence of a tiny change in the numbers of women having ultrasound scans, not statistically significant in an adjusted multi-level analysis.

Service usage is explored further in the economic study (Chapter 6).

**Table G.6: Percentage of women taking actions/using services before the intervention and the change occurring after the intervention**

Action	BEFORE		AFTER		CHANGE		DIFFERENCE (95%CI)	
	I	C	I	C	I	C		
	%	%	%	%	%	%		
Reduced alcohol intake	80	74	78	80	-2	6	8	(-16, 1)+
Had a scan	100	100	100	100	-0.1	0.3	-0.4	( -1.0, 0.1)+
Had screening test	84	76	80	82	-4	6	-10	(-20, -1)*
Planned hospital birth	99	97	97	97	-2	0	-2	( -4, -1)*
Support by partner/friend	94	94	94	93	0	-1	2	( -2, 5)
Used Electronic Fetal Monitoring	49	48	46	48	-3	0	-3	(-11, 4)
Had epidural	23	20	26	22	3	2	1	( -6, 9)
Labour lying on bed	47	51	51	52	4	1	3	( -4, 10)
Breastfed baby at all	56	58	59	55	3	-3	6	( -5, 16)

+ 0.05<p<0.1, \* p<0.05

## 5. Adverse events

### 5.1 Information-induced anxiety

Concern has been expressed that Informed Choice leaflets might raise the anxiety levels of women. Women were asked if the information they received from midwives or doctors made them feel more anxious, less anxious or had no effect. Prior to the intervention, approximately 10% of women felt more anxious. There was no statistically significant change in the proportion of women feeling more anxious regarding information (Table G.7).

**Table G.7 Percentage of women who felt more anxious because of information given by health professionals**

	Antenatal		Postnatal	
	Intervention	Control	Intervention	Control
BEFORE	10	13	11	11
AFTER	12	12	9	9
CHANGE	2	-1	-2	-2
DIFFERENCE ( cluster level)	<b>3</b>		<b>0</b>	
95% confidence interval	-3, 8		-5, 5	
T-test	p=0.3		p=1.0	
Wilcoxon	p=0.3		p=0.9	
Analysis of covariance	p=0.4		p=1.0	

### 5.2 Mortality

Stillbirth, early and late neonatal death rates were taken from the All Wales Perinatal Survey (Cartlidge 1999). Our study was not powered to detect changes in these outcomes. They are displayed here for information (Table G.8).

**Table G.8: Mortality by intended place of birth. Numbers (percentage).**

	Stillbirths		Early neonatal deaths (first 6 days of life)		Late neonatal deaths (aged 7-27 days)		Total registrable births	
	1997	1998	1997	1998	1997	1998	1997	1998
I1	13	13	6	11	2	0	2547	2591
I2	31	13	9	7	4	4	4977	4747
I3	10	19	6	9	3	3	2766	2765
I4	10	14	5	4	0	2	2158	2120
I5	12	10	4	4	5	0	1763	1630
C1	8	12	9	4	3	4	2148	2277
C2	24	19	18	14	7	5	4806	4627
C3	15	11	12	8	6	5	2809	2790
C4	6	9	3	3	1	2	1502	1503
C5	5	9	6	3	0	1	1682	1606
Intervention	76 (0.5)	69 (0.5)	30 (0.2)	35 (0.3)	14 (0.1)	9 (0.1)	14211	13853
Control	58 (0.4)	60 (0.5)	48 (0.4)	32 (0.2)	17 (0.1)	17 (0.1)	12947	12803
All	134 (0.5)	129 (0.5)	78 (0.3)	67 (0.3)	31 (0.1)	26 (0.1)	27158	26656

## Appendix 2h: Cluster Randomised Controlled Trial – Different Sub-Groups of Women

### 1. Age group

The data were divided into approximate quartiles. There was no evidence that different changes occurred in different age groups for either knowledge scores or informed choice (Tables H.1a and H.1b).

**Table H.1a: Change in overall KNOWLEDGE SCORES by age group (denominators in brackets)**

Age group	Antenatal				Postnatal			
	Intervention		Control		Intervention		Control	
<=23 years	0.04	(331)	-0.28	(309)	0.22	(394)	-0.02	(323)
24-28 years	0.23	(419)	0.00	(409)	0.28	(536)	-0.05	(391)
29-32 years	0.42	(397)	0.18	(363)	0.18	(459)	0.08	(378)
33+ years	0.39	(282)	0.00	(268)	0.18	(377)	0.06	(354)
DIFFERENCE (MLM unadjusted)	p=0.8				p=0.9			
DIFFERENCE (MLM adjusted)	p=0.8				p=0.8			

+adjusted for woman's educational status, parity, decision-style preference

**Table H.1b: Change in proportion of women exercising INFORMED CHOICE by age group (denominators in brackets)**

	Antenatal				Postnatal			
	Intervention		Control		Intervention		control	
<=23 years	9	(323)	7	(300)	4		7	
24-28 years	4	(411)	5	(405)	2		3	
29-32 years	-1	(394)	-3	(359)	2		0	
33+	18	(280)	2	(259)	3		10	
DIFFERENCE (MLM unadjusted)	p=0.3				p=1.0			
DIFFERENCE (MLM adjusted)	p=0.3				p=0.3			

+adjusted for woman's age, educational status, parity, decision-style preference

### 2. Parity

There was some evidence that knowledge increased more in primiparous women than multiparous women antenatally, with primiparous women in intervention sites increasing their knowledge by 0.37 points compared with 0.15 for multiparous women (Table H.2a). There was no evidence that changes in informed choice differed by parity (Table H.2b).

**Table H.2a: Change in overall KNOWLEDGE SCORES by parity (denominators in brackets)**

	Antenatal				Postnatal			
	Intervention		Control		Intervention		Control	
Primiparous	0.37	(626)	-0.10	(636)	0.31	(797)	0.00	(698)
Multiparous	0.15	(803)	0.08	(710)	0.14	(982)	-0.04	(764)
DIFFERENCE (MLM unadjusted)	p=0.12				p=0.5			
DIFFERENCE (MLM adjusted)+	p=0.08				p=0.5			

+adjusted for woman's age, educational status, decision-style preference

**Table H.2b: Change in proportion of women exercising INFORMED CHOICE by parity (denominators in brackets)**

	Antenatal		Postnatal	
	Intervention	Control	Intervention	Control
Primiparous	9 (615)	0 (629)	1 (770)	5 (673)
Multiparous	5 (800)	4 (689)	5 (958)	5 (744)
DIFFERENCE (MLM unadjusted)		p=0.3		p=0.6
DIFFERENCE (MLM adjusted)+		p=0.3		p=0.6

+adjusted for woman's age, educational status, decision-style preference

### 3. Social class

There was no evidence that different changes occurred in different social classes for either knowledge scores or informed choice (Tables H.3a and H.3b).

**Table H.3a: Change in overall KNOWLEDGE SCORES by woman's social class (denominators in brackets)**

	Antenatal		Postnatal	
	Intervention	Control	Intervention	Control
Manual	0.23 (387)	0.01 (331)	0.24 (476)	-0.19 (391)
Non-manual	0.20 (818)	-0.01 (793)	0.14 (999)	0.11 (811)
DIFFERENCE (MLM unadjusted)		p=0.9		p=0.13
DIFFERENCE (MLM adjusted)+		p=0.9		p=0.11

+adjusted for woman's age, parity, educational status, decision-style preference

**Table H.3b: Change in proportion of women exercising INFORMED CHOICE by woman's social class (denominators in brackets)**

	Antenatal		Postnatal	
	Intervention	Control	Intervention	Control
Manual	5 (378)	1 (324)	8 (462)	6 (387)
Non-manual	7 (811)	1 (783)	0 (984)	3 (790)
DIFFERENCE (MLM unadjusted)		p=0.9		p=1.0
DIFFERENCE (MLM adjusted)+		p=0.9		p=1.0

+adjusted for woman's age, parity, educational status, decision-style preference

### 4. Educational status

There was no evidence that different changes occurred by educational status for either knowledge scores or informed choice (Tables H.4a and H.4b).

**Table H.4a: Change in overall KNOWLEDGE SCORE by age left full-time education (denominators in brackets)**

	Antenatal		Postnatal	
	Intervention	Control	Intervention	Control
< 18 years	0.14 (825)	-0.01 (781)	0.34 (1105)	0.06 (846)
>= 18 years	0.29 (563)	-0.01 (527)	-0.02 (648)	-0.06 (591)
DIFFERENCE (MLM unadjusted)	p=0.9		p=0.5	
DIFFERENCE (MLM adjusted)+	p=0.8		p=0.4	

+adjusted for woman's age, parity, decision-style preference

**Table H.4b: Change in proportion of women exercising INFORMED CHOICE by age left full-time education (denominators in brackets)**

	Antenatal		Postnatal	
	Intervention	Control	Intervention	Control
<18 years	6 (812)	7 (768)	4 (1072)	3 (821)
>= 18	8 (555)	-3 (516)	2 (630)	7 (575)
DIFFERENCE (MLM unadjusted)	p=0.3		p=1.0	
DIFFERENCE (MLM adjusted)+	p=0.2		p=1.0	

+adjusted for woman's age, parity, decision-style preference

### 5. Decision-style preference

There was no evidence that different changes occurred in women with different decision-style preferences for either knowledge scores or informed choice (Tables H.5a and H.5b).

**Table H.5a: Change in overall KNOWLEDGE SCORE by decision-style preference (denominators in brackets)**

	Antenatal		Postnatal	
	Intervention	Control	Intervention	Control
Self	0.29 (957)	0.03 (880)	0.27 (970)	0.02 (823)
Shared	0.21 (320)	-0.15 (311)	0.15 (453)	-0.02 (336)
Clinician decides	-0.20 (124)	0.17 (132)	0.17 (290)	-0.07 (255)
DIFFERENCE (MLM unadjusted)	p=1.0		p=0.9	
DIFFERENCE (MLM adjusted)+	p=1.0		p=1.0	

+adjusted for woman's age, educational status, parity

**Table H.5b: Change in proportion of women exercising INFORMED CHOICE by decision-style preference (denominators in brackets)**

	Antenatal		Postnatal	
	Intervention	Control	Intervention	Control
Self	6 (958)	0 (875)	2 (955)	2 (803)
Shared	11 (314)	9 (308)	4 (442)	4 (331)
Clinician decides	10 (121)	5 (128)	1 (287)	13 (250)
DIFFERENCE (MLM unadjusted)	p=0.9		p=0.5	
DIFFERENCE (MLM adjusted)+	p=0.9		p=0.6	

+adjusted for woman's age, educational status, parity





## **Appendix 3: Sample Knowledge Questionnaire**



***Where will you have your baby - hospital or home?***

These questions were drawn from an overview of the available research. They may not necessarily reflect what happens in your area.

Tick as many boxes as you think are correct. Please answer all questions.

---

**1 For a healthy woman who is pregnant for the first time and has had a normal pregnancy, where is the safest place for the baby to be born?**

- at home
  - in hospital
  - hospital or home; wherever she feels safest and most comfortable
  - wherever the midwives and doctors feel is the safest place
  - wherever the woman's partner and family feel is the safest place
  - I don't know
- 

**2 Doctors and midwives are able to predict very accurately during pregnancy which healthy women will have complicated labours and need hospital care.**

- no, this is not true
- yes, this is definitely true
- very often this is possible
- only very occasionally is this possible
- I don't know

### 3 It is safer for the baby if the place of birth

- is decided on as early as possible in pregnancy
- is not changed once the decision has been made
- is decided on at the time when the pregnant woman feels ready  
to make this decision
- is decided on by the midwives and doctors looking after the  
pregnant woman
- none of the above
- I don't know
- 

### 4 During pregnancy, how many women who have booked for a home birth, will develop complications and be advised to switch to a hospital birth?

- about 5% of women (i.e. about 5 in every hundred)
- 15% of women (i.e. about 15 in every hundred)
- 25% of women (i.e. about a quarter)
- 50% of women (i.e. about half)
- 75% of women (i.e. about three quarters)
- I don't know
- 

### 5 During labour at home, some women will need to be transferred to hospital because of complications which are

- usually very serious and need immediate emergency treatment
- not usually serious, but may need treatment such as a drip or  
pain relief
- serious and usually mean that the woman should not have been  
at home
- not serious - most women are transferred to hospital because  
of false alarms
- I don't know

**6 In your opinion, which of the following statements best describes a labour which takes place at home?**

- a woman feeling in control, comfortable and as relaxed as possible
- a woman having her baby continuously monitored
- a woman who is more likely to have an episiotomy (a cut into the opening of the vagina)
- all of the above
- none of the above
- I don't know
- 

**7 During labour at home, some women will need to be transferred to hospital because of complications. For women who have already had a baby, how many are likely to be affected?**

- 10 -15% (i.e. a small number of these women)
- 20 -30% (i.e. about a quarter of these women)
- 40 - 50% (i.e. about half of these women)
- 60 - 70% (i.e. nearly three quarters of these women)
- 80 - 90% (i.e. nearly all of these women)
- I don't know
-

**8 If labour takes place in hospital, which of the following statements is likely to be true?**

- a wider choice of pain relief is likely to be available to the labouring woman
- the woman can decide for herself what, and when, to eat and drink
- there is a lower chance of the woman having an episiotomy (a cut into the opening of the vagina)
- the woman will have quietness, privacy and familiar surroundings
- all of the above
- none of the above
- I don't know
- 

**9 During labour at home, some women will need to be transferred to hospital because of complications. For women having first babies, how many are likely to be affected?**

- approximately 10% (i.e. not many of these women)
- approximately 30% (i.e. about a third of these women)
- approximately 50% (i.e. about half of these women)
- approximately 75% (i.e. about three quarters of these women)
- approximately 90% (i.e. nearly all of these women)
- I don't know
- 

**10 Research suggests that women who have had both a home, and a hospital birth, say that they much preferred the home birth.**

- true
- false
- I don't know

## Appendix 4: An Overview of the Ten Individual MIDIRS Informed Choice Leaflets

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### INTRODUCTION

This section draws on observational and interview data to provide a brief commentary on how each of the Informed Choice leaflets was used in clinical practice. A table of the findings from the CRCT is also included for each leaflet topic. It is perhaps worth reminding the reader that, as observation work was not undertaken during labour, no comment can be made on the direct application of the relevant Informed Choice leaflets, by either service users or health professionals, during this time. The researchers thus asked midwives, during the course of in-depth interviews, to discuss their normal practice when caring for labouring women and service users were prompted to recall specific aspects of labour (such as the use of EFM and the position they assumed) which might not otherwise have held any significance.

The quotations and excerpts from fieldnotes are all from intervention sites unless otherwise stated.

### LEAFLET NUMBER 1: Support in labour

This leaflet appeared to be widely misinterpreted by midwives and, indeed, was often summarily dismissed by both midwives and service users. It appeared that 'support' in labour was not only taken for granted, but was quite literally interpreted to mean the presence of another person (usually the male partner), regardless of their ability to provide the quality of support associated with good labour outcomes. Midwives frequently introduced this leaflet to women by asking her if '*you've thought about who you want with you in labour...?*' Women generally replied that a husband or other male partner, sister or mother would accompany them; many were then advised that no more than two people would be allowed into the labour ward at any one time. No midwife was heard discussing with women (or their chosen birth supporter) the known benefits of one-to-one, continuous support in labour.

Midwives appeared to attach little importance to meeting women's labour supporter(s) and no midwife was heard giving women information about the association of good quality support with improved labour outcomes. Some women volunteered during interviews that they had spent varying periods of time during labour without the presence of a midwife. A number reported that they had been '*very frightened*' by the midwife's absence with some commenting that their male partners had been '*worried*' or '*upset*' at being '*left in charge... He didn't know what he was 'sposed to be doing...*' Research cited in the professional's version of this leaflet suggests that it is unlikely that birth supporters can be effective advocates for women, nor provide the quality of support required to effect good outcomes, when they themselves are fearful and anxious (Berry 1988, Westreich et al 1991). It is possible that midwives may have left women unattended in order to enhance their sense of intimacy and/or privacy but as such decisions did not appear to have been discussed, these good intentions were not perceived as such by the women concerned.

Of the women who laboured and/or gave birth in their own homes, the majority of those interviewed appeared to be rather more satisfied with the level of support they received from the attending midwives. These women also reported that their partners, and other chosen labour supporters, had been more involved in discussions with midwives during the antenatal period. This pattern was also observed by the researchers on the occasions they accompanied midwives carrying out home visits to women booked for domiciliary care.

As anticipated from the qualitative fieldwork, there was no evidence of any changes in the study outcomes in intervention sites compared with control sites for this leaflet. (See Table 1) Changes in the

proportion of women having enough information or being satisfied with information in intervention sites were matched by similar changes in control sites.

**Table 1 leaflet title: Support in labour**

Effect	BEFORE		AFTER		CHANGE		DIFFERENCE (cluster level)
	I	C	I	C	I	C	
Given the leaflet	14%	12%	43%	16%	29%	4%	26% ***
<b>Informed choice</b>	<b>61%</b>	<b>57%</b>	<b>63%</b>	<b>60%</b>	<b>2%</b>	<b>3%</b>	<b>-1%</b>
Knowledge score	3.7	3.5	3.7	3.4	0.01	-0.14	0.16
Preference for support	95%	97%	96%	97%	1%	0%	1%
Very or quite strong preference	95%	96%	96%	96%	1%	0%	1%
Enough information	61%	62%	70%	69%	9%	7%	1%
Very sat or satisfied with information	68%	64%	72%	69%	4%	5%	-1%
Offered choices	69%	66%	69%	69%	0%	3%	-4%
Very sat/satisfied with way choices made	80%	80%	81%	83%	1%	3%	-2%
Enough discussion	77%	74%	78%	79%	1%	5%	-4%
Very sat or satisfied with support	91%	87%	92%	92%	1%	3%	-2%
Partner/friend present at labour	94%	94%	94%	93%	0%	-1%	2%
Information-induced anxiety	5%	6%	4%	6%	-1%	0%	-1%

\*\*\*p<0.005

LEAFLET NUMBER 2: Listening to your baby's heartbeat during labour

The following excerpt from fieldnotes describes a typical scenario in which a community midwife presents this particular leaflet to a woman in her care:

W is 22 years old and is 33 weeks pregnant with her third baby

The midwife concludes the consultation by turning to W and saying: I've got some leaflets for you today... M picks up an informed choice leaflet on monitoring in labour, holds the leaflet in her hand, and says:

*Do you know anything about how they'll monitor the baby when you're in labour...?*

W shakes her head to indicate No.

M gives her the leaflet saying:

*The leaflet will tell you all about it. There's what we call intermittent monitoring, which you can have if everything's all right, or if there are problems then it's better for you and baby to have continuous monitoring... This leaflet will tell you all the pros and cons...*

It appeared to be standard practice for midwives on all study sites to carry out a 'twenty minute admission trace' on women admitted to labour ward. A number of women interviewed postnatally reported that midwives often forgot to return and remove the monitor at the end of the twenty minute period. Women participating in focus group discussions also reported this experience. (See Chapter 15) Only very rarely did women volunteer that they removed the monitor themselves although a small number did say that they had told the midwife they needed to go to the toilet and in this way the CTG was discontinued.

Many midwives, on both control and intervention sites, appeared to be aware of the evidence in support of intermittent monitoring for healthy women with uncomplicated pregnancies, although this



awareness rarely seemed to be translated into clinical practice. As the following passage illustrates, continuous monitoring in labour appeared to be the norm, even on the occasions healthy women had enjoyed an uneventful pregnancy and chose to remain upright and mobile in labour:

*I: So even though you were on the floor, on your hands and knees, the monitor stayed on?*

*W: Yes. Until the very end, where I think they took it off because it was difficult for her (the midwife) to get under (the bed) and actually deliver the baby. She kept kneeling on the cords and they kept coming out of the machine...*

*I (later on during the interview): Were you given any of these (informed choice) leaflets? (researcher shows respondent the series of Informed Choice leaflets)*

*W: Yes... the midwife gave me that one (heartbeat) at parentcraft... Yes, I definitely had that one...*

*I: Was monitoring (the baby) in labour ever discussed with you?*

*W: No...not really... They gave me that leaflet and told me to read it but they never said anything about what would happen in labour. They said they had to do a little trace when I first came in and then I think they just forgot to take it off... But I'm laid back about monitoring anyway so probably that was led by me. I didn't really mind...*

This final passage in this excerpt illustrates the reluctance of service users to imply any criticism of the health professional and this was particularly true for women still in the antenatal period. It also hints at the changes which will required before evidence based information can be implemented into clinical practice.

The habits and the weight of custom and practice surrounding monitoring in labour suggested that it would be difficult for midwives to implement the information contained in this leaflet and for women to make an informed choice on the subject. This was supported by the CRCT findings. (See Table 2) There was, however, evidence of a reduced preference for electronic fetal monitoring. As with the support leaflet, changes in the proportion of women having enough information or being satisfied with information in intervention sites were matched by similar changes in control sites.

**Table 2 leaflet title: Listening to your baby's heartbeat during labour**

Effect	BEFORE		AFTER		CHANGE		DIFFERENCE (cluster level)	
	I	C	I	C	I	C		
Given the leaflet	11%	8%	35%	11%	24%	3%	21%	***
<b>Informed choice</b>	<b>33%</b>	<b>30%</b>	<b>36%</b>	<b>34%</b>	<b>3%</b>	<b>4%</b>	<b>0%</b>	
Knowledge score	2.2	2.1	2.2	2.3	0.04	0.16	-0.12	
Preference for EFM	41%	39%	35%	41%	-6%	2%	-8%	+
Very or quite strong preference	56%	52%	53%	55%	-3%	3%	-6%	
Enough information	61%	61%	68%	66%	7%	5%	3%	
Very sat or satisfied with information	61%	59%	67%	64%	6%	5%	1%	
Offered choices	21%	21%	25%	27%	4%	6%	-2%	
Very sat/satisfied with way choices made	67%	67%	67%	69%	0%	2%	-3%	
Enough discussion	53%	51%	57%	53%	4%	2%	1%	
Very sat or satisfied with monitoring	80%	79%	78%	80%	-2%	1%	-3%	
Use of EFM	49%	48%	45%	48%	-3%	0%	-3%	
Information-induced anxiety	10%	11%	9%	12%	-1%	1%	-3%	

+ 0.05 < p < 0.1, \*\*\*p < 0.005

### LEAFLET NUMBER 3: Ultrasound scans - should you have one?

In keeping with the norms of obstetric care antenatal practised throughout the UK, ultrasound scanning was regarded as a routine procedure in the CRCT sites. The majority of women were scanned on at least two occasions: at the hospital booking visit when the 'dating' scan was performed and at 18-20 weeks when the 'anomaly' scan was carried out. The dating scan was also heard referred to by health professionals as the 'viability' scan whilst the anomaly scan was heard variously described by the same group as the 'big', 'deep', 'marker' or 'expert' scan. (See Chapter 13)

Hospitals participating in the research operated on an 'opt out' basis with respect to routine ultrasound scans. Women were automatically booked for a scan before their explicit consent was obtained and this arrangement made it difficult for women to do other than 'go with the flow' of decision making. (See Chapter 15) As the following excerpt from fieldnotes illustrates, it also made it difficult for the information contained in the informed choice leaflet to be used effectively:

M asks W if she knows whether or not she wants to have a scan. W looks a little puzzled and reminds M that she has already said that her scan appointment would arrive in the post.

*M: Yes, but you do know you have a choice now...you can choose not to have one...it's up to you...*

*W: Oh, I think I will...I had them with X (other child)... Why...? Is it not a good idea?*

*M: Oh no... All the ladies have them so you'd be doing what everyone does... Here's a (informed choice) leaflet that tells you more about it..*

A small number of midwives were heard attempting to 'sow seeds of doubt' about the benefits of routine ultrasound when they gave women an informed choice leaflet on the subject. Some midwives appeared to use this leaflet in such a way as to 'buffer' the discomfort they experienced when giving information which could be construed as having negative implications, especially at a time when women were likely to be emotionally fragile. A few midwives suggested that this leaflet was particularly useful because it presented ultrasound scanning as a method of screening for fetal abnormalities:

*...what I like is that it's (informed choice leaflet on ultrasound) pointing a lot of things out that the mothers don't realise that we do scans for... women think that they're having a scan just for their dates...they don't think about that they're looking for defects as well...I also like the fact that it also says that it doesn't pick up everything. So this one wins with me, it's probably my favourite out of all of them. I like that one. midwife*

This quotation also illustrates the utilitarian function of the leaflets for midwives; the leaflets on ultrasound scanning and screening for fetal abnormalities seemed to have particular value because both presented information which midwives found difficult to convey.

On many sites, scanning machines were either in the consultation rooms or in an adjacent room and were often used by obstetricians at routine antenatal appointments to determine the presenting part and to listen to the fetal heart of the baby. Women were not generally invited to discuss the pros and cons of whether a scan was necessary and explicit consent to this intervention was rarely sought:

#### W G2P1 30/40 Accompanied by toddler

The obstetrician undertakes the palpation in complete silence. His body is positioned so that he does not make eye contact with W throughout the procedure. Immediately he completes the palpation he makes his way back to the desk, sits down, turns his head and announces to the auxiliary:

*I think it's a bit on the small side... I think we need a scan...*

Without further discussion, the obstetrician bends over to make an entry in W's notes; the auxiliary ushers W out of the room and down the corridor to the scan room. The obstetrician follows shortly afterwards. Fieldnotes intervention site

The observation and interview data confirmed that women tended to accept such scans as routine clinical procedures, perhaps because they appeared to be taken for granted by health professionals. When used as a routine intervention in maternity care, ultrasound scans were thus rendered invisible.

The researchers also observed ultrasound being used as a means of screening for fetal abnormalities when women had not explicitly consented to this intervention. This was most likely to occur in conjunction with the routine 'dating' scan at 10-12 weeks when the foetus was visualised and women were given *'the all clear'* but there were occasions when more explicit screening was undertaken, for example measuring the nuchal fold. The point has been made that not only has ultrasound for such screening been introduced into obstetric practice with little formal evaluation, but the shift from clinical to screening activity is subtle and thus may easily pass unnoticed (Wald et al 1998).

The following quotation, from a woman waiting in the antenatal clinic, is unusual in that she had made a conscious decision not to read an informed choice leaflet on this subject:

*I decided not to read that (ultrasound) leaflet because I'm scared stiff about scans...they never turn out good do they...? At least not for me they don't...'*

W had suffered three previous miscarriages and on each occasion it was an early scan which had informed her of her loss. Fieldnotes intervention site

Women tended not to read Informed Choice leaflets (or other pregnancy-related information) if they had already made a decision about the particular subject. As the following quotation illustrates, women frequently assumed that information was only for women who were still undecided:

*I: What did you think about that leaflet?*

*W: I didn't read it to be honest...I didn't see much point 'cause I already had the appointment for the scan... I thought they (the Informed Choice leaflets) were only for when you didn't know what you wanted...'*

The pressures of the organisation, including the need to anticipate and predict service demands, made it difficult for women to change their minds once decisions had been made. Thus, decision making tended to be a series of fixed, one-off, events rather than a spontaneous process which was able to be (re)negotiated as new information, such as the Informed Choice leaflets, became available.

The researchers' were only aware of one instance of a service user being given the professional's version of an Informed Choice leaflet and this concerned the leaflet on ultrasound scans. It appeared that the leaflet had not been requested by the service user, but had been given to her by an antenatal clinic midwife who had run out of the woman's version of this leaflet. The woman told the researcher that the leaflet had been given to her in response to questions she had asked about the necessity for a routine dating scan. This particular woman volunteered that not only had she and her husband (who was educated to higher degree level) failed to understand much of the contents of this leaflet but that it made them feel:

*...really, really upset.. This is my third pregnancy... I've been scanned with all of them... The detail in that leaflet makes me wish I'd never had one scan... It's not like it's new information either...they've known some of it for a long time...some of the references are from before I had my first baby... service user*

This leaflet did not appear to have much impact on the choices women made about ultrasound scans and this lack of effect was supported by the CRCT findings. (See table 3) The proportion of women who reported that they had been given the ultrasound leaflet in the intervention sites increased by 21 percentage points more than control sites. The increase in leaflet use in control sites was due to one site introducing a leaflet about scanning during the study period. Large changes occurred in this site. Further analyses were undertaken with this site removed. Although the results obtained were more in line with our proposed hypotheses, there were no statistically significant changes. However, there was evidence of small changes such as an increase in satisfaction with information and an increase in information-induced anxiety. Almost 100% of women in each site had ultrasound scans. The statistical test for service use is close to significance because of the lack of variability in the data.

**Table 3 leaflet title: Ultrasound scans - should you have one?**

(Difference without the control site which introduced an ultrasound scan leaflet is reported in brackets)

Effect	BEFORE		AFTER		CHANGE		DIFFERENCE (cluster level )
	I	C	I	C	I	C	
Given the leaflet	21%	23%	53%	33%	32%	10%	21% *
<b>Informed choice</b>	<b>54%</b>	<b>55%</b>	<b>58%</b>	<b>64%</b>	<b>4%</b>	<b>9%</b>	<b>-4% ( 0%)</b>
Knowledge score	3.6	3.6	4.0	3.5	0.34	-0.07	0.41 (0.24)
Preference for having ultrasound scan	99%	100%	99%	100%	0%	1%	0% (-1%)
Very or quite strong preference	97%	97%	99%	98%	2%	1%	0% ( 2%)+
Enough information	72%	76%	80%	80%	8%	4%	3% ( 7%)
Very sat or satisfied with information	73%	78%	80%	83%	7%	5%	2% ( 5%)+
Offered choices	33%	34%	42%	58%	9%	14%	-5% ( 3%)
Very sat/satisfied with way choices made	79%	81%	82%	85%	3%	4%	-1% ( 3%)
Enough discussion	65%	68%	70%	71%	5%	3%	2% ( 4%)
Very sat or satisfied with having scans	90%	89%	88%	91%	-2%	2%	-5% (-3%)
Had a scan	100%	100%	100%	100%	-0.1%	0.3%	-0.4%+ (-0.5%)+
Information-induced anxiety	11%	14%	13%	14%	2%	0%	1% ( 4%)+

+ 0.05 < p < 0.1

#### LEAFLET NUMBER 4: Alcohol and pregnancy

This topic was the only leaflet in the series under the direct control of the service user and which concerned personal behaviour located within the private sphere of women's lives. During the booking visit, when midwives collected details about a woman's history, they tended not to probe for information about patterns of alcohol consumption before conception. When asked, at the booking visit, about current alcohol intake, many women volunteered that they had stopped drinking as soon as they thought they might be pregnant; a small number replied that they never consumed alcohol. Some women replied that they were 'social' drinkers whereby tiny numbers of midwives enquired further and attempted to record this information in terms of units of alcohol consumed per week. Regardless of the information women offered midwives about their alcohol consumption, many were given this leaflet without further discussion.

The following quotation is a typical response from a service user who was asked about this issue in a follow-up interview. The woman had been observed attempting to tell the midwife that she did not want an informed choice leaflet because she had ceased her 'social' intake of alcohol once she realised she was pregnant.

*I didn't bother with that one (informed choice leaflet on alcohol) 'cause I thought that was only if you drank...to find out what to do about it... It's stupid to give it... I told her I didn't drink so what's the point...? service user*

Midwives observed the same pattern of information gathering in this area of women's childbearing knowledge as they did in other areas. With respect to this particular informed choice leaflet, very few midwives were observed establishing what women already knew about the association between alcohol and pregnancy and neither did they explore the basis on which women made decisions to stop drinking alcohol. It could be said then, that they were not in a good position to judge the usefulness (or not) of this leaflet to the women in their care. This was also the case for a number of other Informed Choice leaflets such as infant feeding and the use of epidural in labour . It reiterates what has been said earlier in this report, that many midwives reported feeling uncertain about whether, and to what extent, they should question the decisions women made for fear of undermining them or appearing judgemental. (See Chapter 13)

Whilst the vast majority of service users accepted this leaflet without comment, that is not to suggest they were necessarily neutral about being given it. Indeed, a small number of women were irritated or offended; one woman asked the researcher conducting the interview to take the leaflet away because it offended her religious principles. Some women also inferred, from being given a leaflet on alcohol, that the midwife was concerned about their (excess) alcohol consumption. Others were of the opinion that this leaflet contradicted what they had read elsewhere or what they intuitively thought about consuming alcohol whilst pregnant:

*I thought she (midwife) was just too polite to ask me directly... I think she thought if I read this leaflet I'd get the message... Which is a joke really because it says there that you can drink when I've always thought that you shouldn't... I mean nobody really knows whether it matters or not do they...?*  
service user

Substantial numbers of women were, however, reassured by this leaflet. One such woman commented:

*It was helpful to know I could have some alcohol and not feel guilty...* service user

It was often this aspect of the leaflet which midwives drew to the attention of women. A small number of midwives were concerned that this leaflet gave women *'the wrong message'* and this may have made it more difficult for women who were addicted to alcohol to voice their concerns. As is illustrated in the following discussion between two midwives, some were of the opinion that this leaflet gave credence to the notion of a 'safe' level of alcohol consumption during pregnancy when it was felt that there was currently insufficient evidence to support this suggestion:

*M<sup>1</sup>: The alcohol leaflet is a tricky one... We know that alcohol consumption is never accurately revealed so how can we be sure about safety...*

*M<sup>2</sup>: ...we don't know enough about early fetal development to be able to talk about 'safe' levels of drinking. The alcohol leaflet puts midwives and women in a real dilemma. Who's to say that in five years time that the research won't be highlighting damaging effects from even small amounts of alcohol in pregnancy...?*

Despite the fact then, that this leaflet contained information which was counter-intuitive for some midwives, they continued dispensing it to women without comment, perhaps because information which was underpinned by 'scientific' research was invested with greater authority:

*Some of my colleagues didn't really like this leaflet either because we've always said that no alcohol is policy and yet this actually gives them permission... But fair enough, if it's recent research and that's what we should be saying, well, fair enough. But we should stick to one policy, really, shouldn't we... We shouldn't be telling them one thing and then giving them a leaflet which says something else...*  
midwife

It is interesting that it was this leaflet which often drew midwives attention to the 'theory-practice' gap, when it was probable that every leaflet contained some information which contradicted local practice and policy.

Some changes were evident in the CRCT findings with respect to this leaflet. (See Table 4) The proportion of women who reported that they had been given the alcohol leaflet in the intervention sites increased by 28 percentage points more than control sites. More women were satisfied with information about alcohol: an eight percentage point increase over and above any change in control sites. There was evidence of an increase in knowledge and a lower proportion of women reducing their alcohol intake. This latter change is in the direction expected because the leaflets inform women that moderate alcohol intake is not harmful in pregnancy. We did not include questions about choice and informed choice for this leaflet.

**Table 4 leaflet title: Alcohol and pregnancy**

Effect	BEFORE		AFTER		CHANGE		DIFFERENCE (cluster level)	
	I	C	I	C	I	C		
Given the leaflet	23%	29%	51%	29%	28%	0%	28%	***
Knowledge score	4.1	4.1	4.7	4.1	0.60	0.03	0.57	+
Preference for drinking alcohol	10%	8%	12%	11%	2%	3%	-1%	
Very or quite strong preference	40%	37%	39%	38%	-1%	1%	-2%	
Enough information	55%	57%	61%	60%	6%	3%	3%	
Very sat or satisfied with information	52%	57%	60%	57%	8%	0%	8%	*
Reduced alcohol intake	80%	74%	78%	80%	-2%	6%	-8%	+
Information-induced anxiety	7%	8%	7%	7%	0%	-1%	1%	

+ 0.05 < p < 0.1, \* p < 0.05, \*\* p < 0.01, \*\*\* p < 0.005

#### LEAFLET NUMBER 5: Positions in labour and delivery

Many midwives reported that the maternity unit in which they worked 'allowed' women to choose whatever position they wanted for labour and birth. From the accounts of service users, however, it appeared that the majority were in bed and attached to a electronic fetal monitor, when they gave birth. There was some evidence then, of a discrepancy between what midwives knew to be evidence based practice with regards to both positions and monitoring in labour and what they actually practised with labouring women in their care.

Community midwives who maintained their intrapartum skills appeared to be more comfortable with women adopting a variety of upright positions throughout labour than were their colleagues employed as core staff on CDS. This was particularly the case when women laboured, and/or birthed, in their own homes although it should be pointed out that the low home birth rate across the intervention sites meant that this was true for only a tiny number of women.

Multiparous women appeared less concerned about the benefits of maintaining an upright position in labour than they were about being '*stuck on the bed and them (midwives) forgetting about me still being on the monitor...*' Women were informed by their previous experiences of labour and birth and it was often this 'subjective knowledge' (Belenky et al 1997) rather than an informed choice leaflet or, indeed the advice of health professional, which empowered many to act differently in a subsequent labour. (See Chapters 13 and 15) Thus, women often learned for themselves, and by themselves, what was possible in childbirth:

*...with my first...from beginning to end...I was monitored the whole time. I didn't realise that you could move round. Nobody explained that to me. But the second time round I knew that you didn't have to do it (remain on the bed and on a CTG monitor). I think the second time round I knew you had an option... You're stronger... You're a stronger person. You know what to expect... service user*

A number of midwives were concerned that the information in this leaflet would require them to adopt positions which were simply uncomfortable or which might aggravate pre-existing back problems. Some suggested that lack of training made it difficult for them to offer adequate support when women in labour adopted different positions and concern was expressed lest women spontaneously adopt positions which midwives considered '*unsafe*' or even '*dangerous*'. A number of midwives were also worried that 'upright' positions might compromise the accuracy of vaginal examinations. Whilst these may be valid concerns, healthy women experiencing normal labour must be facilitated to labour and give birth in ways which do not compromise, or indeed, contradict the (safe) choices they have made. It is also problematic if midwives offer women evidence based information which supports the adoption of upright positions in labour, only to then impose restrictions on those very positions. The following passage, contributed by a woman interviewed shortly after the birth of her second baby, powerfully articulates some of these issues:

...the pain was so intense in my back that I just quietly got off the bed and got on the floor and crouched down...the midwife just couldn't believe it...she was in a state of complete shock...she just did not expect that. She said 'Don't you want to get back on the bed...how am I going to examine you on the floor...it's all upside down from that position...' I said 'No I'm comfortable in this position, the pain is all in my back'. I didn't talk to her after a while...that was it. Her main objective seemed to be to get me off that floor back onto that bed. That was my most uncomfortable position. I'd had a baby before and I was confident enough to say no. So then she had to crawl right the way round me and put towels on the floor... She complained that it was uncomfortable for her...that she couldn't see properly...she told me she couldn't see my perineum properly... If it had been my first baby I would have been terrified...I would have thought that everything was totally against my control...  
service user

In the following quotation, a primiparous service user who had not previously met the midwife caring for her in labour, suggests that Informed Choice leaflets are not helpful unless midwife reads the information and is prepared to facilitate the options suggested:

*Well, she (the community midwife) clearly hadn't read the informed choice leaflet on positions in birth... She wanted me to get back on that bed no matter what and yet I knew that I was in a really good position. Midwives should know what's in the leaflets if they give them to you and they should expect you to read them and then want to do some of what it says in them.* service user

A number of women expressed frustration with being given information about choices which, in reality, were not available. The previous quotation suggests that the midwife has failed to appreciate the information contained in this leaflet about the beneficial affects of women remaining upright and mobile during labour. Moreover, it seems that she is unwilling to change her practice with respect to her client's intuitive knowledge on this subject. Continuity of carer, and of care, appeared to be a major factor in determining the choices available to women in labour. If, as was true in this case, the same midwife who conveyed the information did not also provide intrapartum care, many women were unable to translate the information they received into preferred actions.

Some changes were apparent in the CRCT findings with respect to this leaflet. Knowledge scores increased by 0.24 of a point in intervention sites compared with a reduction of 0.19 points in control sites for the positions in labour leaflet. (See Table 5) There was an increase of 8 percentage points in the proportion of women holding strong or very strong preferences about positions.

**Table 5 leaflet title: Positions in labour and delivery**

Effect	BEFORE		AFTER		CHANGE		DIFFERENCE (cluster level)	
	I	C	I	C	I	C		
Given the leaflet	17%	15%	42%	16%	25%	1%	24%	***
<b>Informed choice</b>	<b>46%</b>	<b>42%</b>	<b>45%</b>	<b>43%</b>	<b>-1%</b>	<b>1%</b>	<b>-2%</b>	
Knowledge score	4.6	4.7	4.8	4.9	0.24	-0.19	0.43	*
Preference for lying in bed during labour	23%	24%	24%	23%	1%	-1%	2%	
Very or quite strong preference	49%	53%	56%	52%	7%	-1%	8%	**
Enough information	55%	54%	62%	55%	7%	1%	6%	
Very sat or satisfied with information	55%	53%	60%	54%	5%	1%	4%	
Offered choices	57%	58%	55%	55%	-2%	-3%	2%	
Very sat/satisfied with way choices made	63%	62%	64%	60%	1%	2%	2%	
Enough discussion	57%	57%	57%	57%	0%	0%	0%	
Very sat or satisfied with positions	70%	68%	69%	70%	-1%	2%	-3%	
Lie in bed for birth	47%	51%	51%	52%	4%	1%	3%	
Information-induced anxiety	6%	8%	6%	6%	0%	-2%	1%	

\* p<0.05, \*\*p<0.01, \*\*\*p<0.005

## LEAFLET NUMBER 6: Epidurals for pain relief in labour

A number of health professionals, particularly obstetricians and anaesthetists, levelled accusations of bias against this leaflet. Some cited the 'long list of disadvantages' and the use of words such as 'paralysed' in the leaflet text as evidence of the 'negative slant of that leaflet'. These issues did not appear to concern service users however. Of those who had read the leaflet, the majority seemed to value the information it contained, often for the very reasons that health professionals did not. For instance, many women commented on the fact that health professionals had not mentioned the problems, or side effects, associated with the use of epidurals in labour. The following quotations, from women expecting their first and third babies respectively, are illustrative:

*I thought that leaflet was good... It told you about the side effects in black and white... It didn't hide it like they (doctors and midwives) do... service user*

*I liked the fact that all the pros and cons were listed... All the books I read... You get the feeling that having an epidural is the done thing so it was good to read that there are problems... The books gloss over all that and they don't really point that out at the (parentcraft) classes... I think the leaflet was really good for that... service user*

Interestingly, some midwives used this leaflet to advertise the menu of pain relieving agents available in the local maternity unit and to counteract what they perceived as 'old wives tales' with respect to the disadvantages of epidurals:

*I think it's (informed choice leaflet on epidural) made women much more aware of what they can have for pain relief. It made them understand the epidural, as far as they're concerned, it's the injection in the back, or they're definitely not going to have it because it paralysed somebody ten/twenty years ago. midwife*

*I think the epidural one is really good. Often the women say 'I don't want an epidural' because they are scared of them. It's their ignorance about them, not their knowledge of them that is talking. So I think that leaflet is particularly good. (It) gives them the facts about epidural so that they know before they go into labour. They are better armed than when they are on their hands and knees at 5 to 6 centimetres screaming for an epidural. midwife*

A number of service users maintained that, however well informed they were about the reasons for wanting to avoid an epidural in labour, it would make little difference if the health professional was of the opinion that an epidural was necessary. The following quotations, both from multiparous women, offer two common clinical perspectives on this issue. In the first instance, the woman was undergoing an induction of labour whilst the second woman was expecting twins:

*You can read all the leaflets you like but at the end of the day if they think you need an epidural then they'll find a way of persuading you to have it. That's my view. I read that leaflet and I decided not to have one this time... I even wrote it in my birth plan but then they said I needed a drip and that it would be too painful without the epidural. service user*

*So I was still thinking should I, shouldn't I, have, an epidural. This leaflet was guiding me whether I should or shouldn't... In the end I had no choice anyway. When I went to deliver my babies, I had no choice. They were deciding how I was going to deliver my babies and they told me I needed an epidural... I didn't know whether I did or not... service user*

Service users who read this leaflet sometimes discovered for the first time that, whilst the prevailing culture strongly supported the use of epidural in labour, childbirth might also be possible without it. Many of these women appeared to welcome the fact that the leaflet clearly stated the disadvantages of epidurals and felt that such information was critical in helping them to make informed choices:

*I convinced myself right the way through the pregnancy that I would probably have an epidural because I needed one last time because of my blood pressure. But then I started thinking maybe I won't because my blood pressure hasn't been high... Then when I read that leaflet... I decided to try without one this time and I managed without it... I didn't know that they sometimes didn't work and that they made it more common that you couldn't deliver the baby yourself... I ended up having a ventouse*



*with him (first baby) and now I wonder if that was because I had the epidural. I didn't know that before reading that leaflet.* service user

A small number of women volunteered during interviews that the Informed Choice leaflets provided new information and this often resulted in previous experiences of childbirth being seen differently; it also meant that women sometimes came to different conclusions about those same experiences.

Some women, who were heard clearly stating that they did not want an epidural in labour, were nonetheless observed being given this leaflet without the midwife attempting to explore the reasons behind their decisions. When invited to discuss this issue in the context of an in-depth interview, a number of midwives said that they did not know whether to insist on conveying the information regardless, and thus risk undermining the woman's confidence in her own decision making ability, or to take a woman's decision at face value and withhold further information. Many midwives worried that if they did not give women information, and document that they had done so, they would be in a vulnerable position should women subsequently complain that they had not been fully informed about the issue. This point was raised by midwives with respect to other Informed Choice leaflets and a range of other pregnancy-related information.

A primigravid woman, who was 36 weeks pregnant at the time, was also interviewed and invited to comment on this issue:

*I: I remember you telling the midwife that you didn't want an epidural...then almost immediately she gave you a leaflet...?*

*W: Yes, she did. She said it was about pain relief. I didn't realise at first that it was about epidurals. That annoyed me, the fact that she gave it to me when I'd told her I didn't want to have an epidural... She didn't ask me why I didn't want it...all she did was write in my notes 'Does not want an epidural' and then she gave me the leaflet and told me to read it... I didn't read it immediately because I thought it was all about epidurals. I thought it was promoting epidurals... Then I read it and I realised that it was giving you all the information, the good and the bad. Why didn't she just tell me that? That's one thing I'd say was bad was that you can't tell from the cover whether it's pushing something or not... service user*

Besides explicating this respondent's preference for a more shared approach to decision making, this quotation also reflects the power of advertising on consumers who live in a time of rapid and voluminous information exchange and who increasingly expect to know, 'from the front cover', whether the contents warrant reading. It also suggests that if the significance of the evidence based information contained within the leaflets is left for the service user to discover, it may not be recognised at all. (See Chapter 13)

Although there were barriers to women using this leaflet to make informed choices, women nonetheless valued the information. There was evidence of an increase in satisfaction with information about epidurals: an 8 percentage point increase over and above any change in control sites. (See Table 6) There was also evidence of an increase in the proportion of women who felt they had had enough discussion about epidurals.

**Table 6 leaflet title: Epidurals for pain relief in labour**

Effect	BEFORE		AFTER		CHANGE		DIFFERENCE (cluster level)	
	I	C	I	C	I	C		
Given the leaflet	23%	20%	55%	25%	32%	5%	27%	***
<b>Informed choice</b>	<b>46%</b>	<b>44%</b>	<b>51%</b>	<b>45%</b>	<b>5%</b>	<b>1%</b>	<b>4%</b>	
Knowledge score	2.5	2.4	2.9	2.6	0.42	0.17	0.25	
Preference for epidural	22%	22%	24%	22%	2%	0%	3%	
Very or quite strong preference	77%	78%	82%	75%	5%	-3%	7%	
Enough information	57%	54%	66%	56%	9%	2%	7%	
Very sat or satisfied with information	52%	49%	61%	50%	9%	1%	8%	+
Offered choices	60%	57%	64%	63%	4%	6%	-2%	
Very sat/satisfied with way choices made	57%	51%	62%	53%	5%	2%	3%	
Enough discussion	60%	60%	65%	59%	5%	-1%	6%	+
Very sat or satisfied with pain relief	78%	76%	76%	78%	-2%	2%	-3%	
Had epidural	23%	20%	26%	22%	3%	2%	1%	
Information-induced anxiety	12%	11%	13%	12%	1%	1%	0%	

+ 0.05 < p < 0.1, \*\*\*p < 0.005

#### LEAFLET NUMBER 7: Feeding your baby - breast or bottle?

This leaflet appeared to be discounted equally by midwives and service users. Interestingly, it was often heard referred to by midwives as *'that leaflet on breast feeding'*. A small number of midwives felt that the title of this leaflet was ambiguous and confusing in the message it gave women. Some felt that whilst it promoted choice, it also undermined efforts to promote and increase breast feeding rates. Some midwives also suggested that the subject of breastfeeding had been 'over-exposed' in recent years and that health messages had become diluted in the process.

Breast feeding was a subject which appeared to provoke considerable discomfort for both midwives and childbearing women. Many women reported that they had been made to feel guilty for stating an intention to bottle feed whilst midwives often reported feeling under considerable pressure to give all women information about the benefits of breastfeeding, regardless of a woman's intended method of feeding her baby. This pressure appeared particularly acute if the maternity unit in which the midwife worked had applied for 'Baby Friendly' status (UNICEF/UK 1998). On one such site, community midwives contravened the breastfeeding policy and invited a local representative from an infant formula company to attend a parentcraft class to present information about infant feeding methods. Midwives elsewhere were observed offering advice and written information to bottle feeding women which did not reflect the breast feeding policy operating within the unit. Many midwives volunteered that they experienced great difficulty in challenging women's decisions to bottle feed for fear that this would be construed as intrusive or as undermining *'a woman's right to choose what's right for her.'*

As mentioned earlier in this chapter (see leaflet number 3) service users who expressed clear preferences, for example to bottle feed, appeared disinclined to read further information on the subject of infant feeding:

*I didn't bother with that leaflet (informed choice leaflet on feeding) because I know what I want to do... I thought that one was only where you hadn't made up your mind already... service user*

Some midwives were of a similar view:

M asks W (10 weeks pregnant with her second baby) if she has had time to think about how she'll feed the baby.

W replies that she breastfed last time and that she hopes to do the same again.

M smiles and says: *Oh, that's good...you'll not be needing this (informed choice) leaflet then... This one won't tell you much that you don't already know but I'll leave it here for you to flick through anyway...you never know there might be something in it for you..* Fieldnotes

For some women, particularly those who had suffered previous fetal loss, the vulnerability and tentative nature of early pregnancy precluded information and decision making in some areas. The following quotation is from a woman who had suffered three previous miscarriages, had no children and was currently 20 weeks pregnant:

*I've not read the leaflet on feeding yet because it's not relevant yet...I've not thought about it...that's for when the pregnancy really is settled...I don't want to tempt fate... service user*

Midwives generally expected women to have thought about how they were intending to feed their baby at the time of the booking visit (usually at 10-12 weeks of pregnancy). Whatever preference women stated was documented in the maternity record and remained largely unchallenged for the remainder of the pregnancy. Women who had previously bottlefed usually indicated that they intended to do the same again; only on rare occasions were they heard to spontaneously volunteer a desire to attempt breastfeeding in the current pregnancy. Some women rationalised this in terms of it being 'unfair' on the previous baby who had been bottlefed. The following excerpt, from fieldnotes taken during the booking of a woman 12 weeks pregnant with her second baby, illustrates how the midwife fails to act on the cue a woman offers to (re)consider breastfeeding:

M asks W whether she had considered breast feeding. Without waiting for her to reply she lists a number of the benefits. She then pauses and asks W if she also knows 'any of the benefits...?'

W responds with an advantage not previously recited by M, who does not comment, but proceeds to give W a few more advantages of breastfeeding.

W then tells M that just after she had given birth to X (her son) a midwife asked 'me if I was going to breast or bottle... I just chose the bottle... I don't know why...'

W goes on to repeat that she didn't really know why she chose the bottle as she had been intending 'to give breast feeding a go... It was very selfish of me... I should have really have tried...'

M does not engage with this, but just says that there are lots of benefits to breast feeding which the leaflet will explain. She hands the informed choice leaflet to W. Fieldnotes

Unlike other leaflets in the series, midwives were often heard 'testing' women on their knowledge of the advantages of breastfeeding. As indicated in the previous excerpt, many women were well able to cite a wide range of the advantages of breastfeeding and the disadvantages of bottle feeding; they appeared well informed on the subject regardless of their intended method of feeding.

Mothers and grandmothers of pregnant women strongly influenced infant feeding decisions. (See Chapter 16) Midwives working in areas where women had bottle fed for two generations or more appeared to be resigned to this practice continuing and did not generally see themselves as agents of potential change in reversing this trend. Observation work confirmed that women who had only been exposed to bottle feeding practices showed little interest in the subject of breast feeding. Indeed, a number of these women reacted with visible signs of disgust when midwives suggested that they might consider breastfeeding. On the occasions the women's mother was present, she often reacted in a similar manner.

Some changes, perhaps more than were expected from the qualitative fieldwork, were evident in the CRCT findings. (See Table 7) Knowledge scores increased by 0.28 of a point in intervention sites compared with a reduction of 0.11 points in control sites for the feeding leaflet. There was an increase

of 4 percentage points in the proportion of women reporting being offered a choice about feeding, although this was dependent on a reduction in choice in control sites rather than an increase in choice in intervention sites. There was evidence of an increase in preferences for breastfeeding.

**Table 7 leaflet title: *Feeding your baby - breast or bottle?***

Effect	BEFORE		AFTER		CHANGE		DIFFERENCE (cluster level)	
	I	C	I	C	I	C		
Given the leaflet	42%	42%	72%	45%	30%	3%	26%	***
<b>Informed choice</b>	<b>72%</b>	<b>70%</b>	<b>78%</b>	<b>73%</b>	<b>5%</b>	<b>3%</b>	<b>2%</b>	
Knowledge score	3.6	3.8	3.9	3.7	0.28	-0.11	0.39	*
Preference for breastfeeding	58%	62%	64%	60%	6%	-2%	8%	+
Very or quite strong preference	93%	93%	93%	91%	0%	-2%	2%	
Enough information	64%	65%	71%	73%	7%	8%	-1%	
Very sat or satisfied with information	69%	68%	76%	73%	7%	5%	3%	
Offered choices	87%	89%	88%	86%	1%	-3%	4%	*
Very sat/satisfied with way choices made	83%	81%	85%	81%	2%	0%	2%	
Enough discussion	78%	77%	80%	79%	2%	2%	0%	
Very sat or satisfied with support for feeding	73%	74%	73%	77%	0%	3%	-3%	
Breastfed baby at all	56%	58%	59%	55%	3%	-3%	1%	
Information-induced anxiety	9%	8%	9%	9%	0%	1%	-1%	

+ 0.05 < p < 0.1, \* p < 0.05, \*\* p < 0.01, \*\*\* p < 0.005

#### LEAFLET NUMBER 8: *Looking for Down's syndrome and spina bifida in pregnancy*

A number of units had produced their own literature on the subject of screening for fetal abnormalities and this created problems for some midwives who were anxious not to 'overload' women by also offering an informed choice leaflet. Coincidentally, at the time the Informed Choice leaflets were introduced to the intervention sites, one health authority was in the process of evaluating a comprehensive booklet they had produced on screening for fetal abnormalities. Whilst a number of health professionals voiced their concerns about aspects of this booklet to the research team, to the extent that some refused to give it to women in their care, the booklet nonetheless competed with the informed choice leaflet. (See also Appendix 2e)

Midwives were concerned that information given to women should meet local specifications and thus many preferred to give literature produced in-house rather than offering an informed choice leaflet. This was particularly the case where the information contained in the MIDIRS informed choice leaflet contradicted that produced locally. The most commonly cited instance was the cut-off figure used to separate 'high-risk' from 'low-risk' serum screening results:

*The thing was...the information in the MIDIRS leaflets was sort of nation-wide, whereas you obviously get differences in small, local areas. So ours (locally produced leaflet on screening) was probably the leaflet we used...(it) was more specific to our area, and our special needs and problems, whereas the others (Informed Choice leaflets) were more generalised.* midwife

Many midwives were observed giving women in-house literature, where this was available, rather than the Informed Choice leaflets because the latter did not always reflect local practice. This was despite the fact that much of the in-house literature scrutinised by the researchers was not based on evidence and some of it was very poorly reproduced. (See Chapter 13) In the case of serum screening, some maternity units operated different cut-off points for women who were 'screen positive' (high risk) and those who were 'screen negative' (low risk) and this occasionally caused confusion, especially when women received their antenatal care from midwives employed by a different trust in which they were booked to deliver. The use of this particular Informed Choice leaflet therefore highlighted local and regional differences in the screening services for fetal abnormalities which have been commented on

elsewhere (Berer 1999). Such variations have also been raised as a point of concern (Wald et al 1998), not the least because they emphasise the inequity in the maternity services.

Some midwives were of the opinion that their knowledge about screening, and their ability to discuss related issues, had improved. Indeed, midwives working in intervention sites scored higher on this knowledge questionnaire than did midwives on control sites. (See Chapter 10) Midwives working on intervention sites did not, however, necessarily attribute the shift in knowledge or awareness to having access to an informed choice leaflet, but as a result of a more generalised awareness:

*I think there's more awareness (about screening) now anyway... I think there's been a drive for everyone to know what they are saying and doing over the last year. I think we are better now at discussing screening, but not because of the leaflets.* midwife

That said, considerable numbers of midwives volunteered that they did not feel confident in discussing this subject with women. Some also disliked having to impart information which had the potential to arouse considerable anxiety, whether in themselves and/or in women and their partners. It is thus possible that some practitioners used the Informed Choice leaflets to shield them from uncomfortable feelings which might otherwise have been aroused in the course of face to face discussions. (See Chapter 13)

As mentioned earlier in this report, it is also possible that the leaflets were used by some midwives to cover up for their lack of knowledge, especially in areas such as screening for fetal abnormalities which have undergone substantial change in the last decade. Two studies (Sadler 1997, Smith et al 1994) have revealed poor levels of knowledge about serum screening for fetal abnormalities amongst midwives, with somewhat better scores amongst obstetricians .

Many of the midwives interviewed volunteered that they had no formal counselling skills and neither had they received training in presenting, and discussing, the increasingly complex information they were required to convey to women in their care. This reiterated the findings of an earlier study of midwives educational needs in which counselling/communications skills were identified as priority areas (Pope et al 1996). Lack of experience and/or personal discomfort may explain the researchers observations for midwives to avoid discussion, or move the conversation on, when uncomfortable feelings surfaced during consultations with women. It is possible that appropriate training might enable midwives to accommodate uncomfortable feelings and thus enable women to explore their options more fully.

As with many other aspects of antenatal care, women tended to follow decision making patterns of previous childbearing experiences. Midwives, however, often failed to point out to women the aspects of care which had changed in the interim period and thus they did not assist women in reconsidering decisions. The following excerpt from fieldnotes is from a booking consultation between a community midwife and a woman expecting her second baby after a five year gap in which anomaly scanning and the Double test had been introduced:

<p><i>M: What did you do last time?</i> W says nothing but frowns and looks a bit puzzled. <i>M: Did you have any tests to see if the baby was all right...whether it had anything like Down's syndrome or spina bifida?</i> <i>W: Oh, I think had all the tests last time... I had everything... I'll do the same thing this time...</i> M gives her an informed choice leaflet saying: <i>'Well, have a read of this anyway. There might be something in it to help you decide either way...'</i></p> <p>W places the unopened leaflet on top of the pile of leaflets the midwife has given her.      Fieldnotes</p>
--

Observation work revealed that midwives were rarely heard to advise women against serum screening. This was despite a significant number of midwives expressing the opinion during an in-depth interview that what was offered locally was *'inadequate'* or *'out of date'* and that they had chosen screening options for themselves which were only available in the private sector. Only on rare occasions, however, were midwives heard to spontaneously volunteer such information women in their care. More commonly, childbearing women self-referred to the private sector or asked midwives detailed

questions about local screening services in response to news items, an article or book they had read or as a result of talking to colleagues and pregnant friends in other parts of the UK.

It was difficult to assess the effectiveness of this leaflet because of contamination in some control sites which received an in-house leaflet. The two significant changes are linked. (See Table 8) Women's preference for the screening tests decreased and women were less likely to actually have the tests. However, these changes involved a decrease in use in the intervention sites and an increase in use in the control sites.

Intervention and control sites started with different baselines and moved towards a middle point. That is, intervention sites which started with high usage, reduced their usage and control sites which started with low usage increased their usage. This may have been the work of their respective leaflets or merely a tendency to regress towards the mean. This result should be treated with caution.

**Table 8 leaflet title: *Looking for Down's syndrome and spina bifida in pregnancy***

Effect	BEFORE		AFTER		CHANGE		DIFFERENCE at cluster level	
	I	C	I	C	I	C		
Given the leaflet	29%	43%	60%	52%	31%	9%	22%	*
<b>Informed choice</b>	<b>70%</b>	<b>77%</b>	<b>70%</b>	<b>82%</b>	<b>0%</b>	<b>5%</b>	<b>-5%</b>	
Knowledge score	3.6	3.8	3.8	3.9	0.16	0.13	0.03	
Preference for having screening tests	83%	75%	76%	80%	-7%	5%	-11%	*
Very or quite strong preference	85%	81%	83%	83%	-2%	2%	-4%	
Enough information	76%	81%	79%	85%	3%	4%	0%	
Very sat or satisfied with information	73%	79%	76%	83%	3%	4%	-1%	
Offered choices	79%	84%	80%	91%	1%	7%	-6%	
Very sat/satisfied with way choices made	82%	85%	81%	88%	-1%	3%	-4%	
Enough discussion	73%	80%	76%	81%	3%	1%	2%	
Very sat or satisfied with screening tests	87%	87%	86%	89%	-1%	2%	-4%	
Had screening tests	84%	76%	80%	82%	-4%	6%	-10%	*
Information-induced anxiety	22%	29%	23%	28%	1%	-1%	2%	

\*p< 0.05

#### LEAFLET NUMBER 9: Breech presentation - options for care

The majority of intervention sites decided to issue this leaflet to women in the antenatal clinic following confirmation of the breech by ultrasound at about 37 weeks of pregnancy. Thus, it could be said that this leaflet was treated differently in that it was the only one which could be said to have been 'prescribed' in direct response to clinical findings. That is not to suggest all 'eligible' women necessarily received the leaflet; nor does it imply that the options suggested in the leaflet, such as ECV and vaginal breech birth, were always locally available. One woman, who had been given this leaflet, but who was subsequently informed that the obstetrician with whom she was booked did not offer these options suggested, had this to say:

*It was tantalising... It was good to have information that didn't try to sway you either way. That didn't scare you. It confirmed my suspicion that other things (besides a caesarean section) were possible but what's the use of getting information if they don't allow you the choice? What's the point of them telling you about all the risks you're taking, like my pelvis being inadequate so the head won't come through, and then telling me it's my choice? You don't have a choice if the doctor can't do the delivery... I wished they'd not given me the leaflet... service user*

Regardless of the mode of delivery, most women who read this leaflet commented positively on the contents. It appeared that there was little information about breech presentation in women's magazines and what was available tended to be written in an emotive, or scaremongering, style, presenting

caesarean section as the only option. Although this leaflet was generally only given to women following confirmation of a breech by ultrasound, a number of women, whose babies had been in the breech position at some point in the third trimester, indicated that they would have welcomed such information, regardless of whether the baby subsequently turned. One such multiparous woman, whose baby turned spontaneously to a head down position at 39 weeks gestation, had this to say:

*I didn't ever get that (informed choice) leaflet. I'd have liked it. It would have eased my mind. They don't tell you anything...it was just a 'wait and see' kind of situation. I didn't know what they were planning to do if he hadn't turned at the last minute. They don't tell you things like that. They should do though, so you can be prepared...* service user

Some midwives expressed concern lest giving such information to women who were subsequently found not to have a breech presentation might not so much '*prepare them as frighten them*'. Thus, some midwives were observed withholding this leaflet as a way of 'protecting' women until such time as the breech was confirmed by ultrasound.

The use of this leaflet made explicit the lack of skill and confidence amongst consultant obstetricians. Recent research (Burr et al 1999) suggests that these, and other issues, such as the obstetrician's individual beliefs and clinical experience, are more likely than research to determine clinical management of the breech at term. With respect to this study, obstetricians who had maintained their skills in performing ECV and facilitating vaginal delivery were primarily from Africa and the Indian subcontinent and mainly practised at (senior) registrar level. However, the majority of registrars did not generally practice autonomously but were expected to perform according to the clinical norms imposed by a consultant obstetrician. (See Chapter 16) Thus, if the consultant's preference was for an elective caesarean section, these practitioners were often prevented from offering women an alternative option.

Whilst the majority of health professionals volunteered that women whose babies were in the breech position did have a choice with respect to mode of delivery, the vast majority of babies were nonetheless delivered by elective caesarean section. This was especially the case for women expecting first babies and those who had undergone a previous caesarean section, for whatever reason. Indeed, it was not uncommon for a caesarean section to be performed when multiparous women, with uncomplicated birthing histories, arrived on labour ward in established labour with an undiagnosed breech presentation.

A number of midwives, especially those trained fifteen to twenty years ago, were surprised by the contents of this leaflet as they had thought that ECV *had gone out of fashion*'. Many newly qualified midwives had never witnessed ECV being performed under controlled conditions and nor had they witnessed a planned vaginal breech birth. Some midwives, on both control and intervention sites, were heard advising women '*not to try*' for a vaginal breech delivery on grounds of '*safety*'. Health professionals occasionally confided that reading the professionals' version of an Informed Choice leaflet had been personally educative:

*That professional's leaflet on breech was a real education. I hadn't realised 'til I read it that I was still operating on the old model. I'd been taught that ECV was a really dangerous, out-dated practice...that it caused abruptions...that it really wasn't safe. Where I trained, no-one did it and women who presented with a breech were just routinely sectioned. No-one knew there was any alternative. I wonder how the consultants feel about this leaflet. There can't be many of them around who have the foggiest idea about ECV and now they're going to have midwives and women looking at them expecting them to be able to do it...* midwife

Despite the literature now available on alternative strategies for turning breech babies such as moxabustion, acupuncture, yoga and other positions known to promote 'optimum fetal positioning' (Sutton and Scott, undated), midwives were rarely heard to give women such advice or refer them to a knowledgeable person or an appropriate book. It must be said, however, that this was also true for a number of other problems regularly encountered by pregnant women where it might have been anticipated that midwives would direct women in their care to alternative sources of knowledge. Neither did midwives advise women to seek the advice of another consultant if the one with whom she was booked did not offer ECV or vaginal breech birth.

In the following quotation a working class, multiparous, woman with a breech presentation but an otherwise uncomplicated history, eschews an informed choice leaflet on the subject because her caesarean section had already been booked for the following week:

*...it (the Informed Choice leaflet) was just given me. They told me to read it an all...to ask 'em any questions I had about it... They gave me the date to come in (for the elective caesarean section)... I didn't see the point of asking them questions... I haven't read the pamphlet (informed choice leaflet) to be honest. They told me I was having the caesarean next week so I didn't see it were worth it really... service user*

This leaflet appeared to reinforce existing divisions between hospital and community based midwives, possibly because it was generally dispensed by hospital based staff. Whilst community midwives were often the first to confirm women's suspicions that the baby was indeed in the breech position, very few took advantage of this opportunity to prepare women for the subsequent appointment with the consultant by discussing with them the possible options available. Thus, for example, even on the occasions women expressly stated they did not want a caesarean section and were booked with a consultant known to offer no alternative, midwives rarely advised women to request referral to another obstetrician who did have such expertise.

A limited amount of information was collected about breech presentation from women completing the postnatal postal surveys and this was analysed at the individual, rather than the cluster, level because of the small numbers involved (See Table 9). Only 266 women indicated that they had had a breech presentation and 103 of these babies appeared to have turned spontaneously to a head down position.

There was no evidence that there was an increase in attempts to turn the baby, or choice about delivery type or actual delivery type between intervention and control sites.

See Chapter 10b for a description of the postal survey of women known to have had a breech presentation at term

**Table 9** Percentage of women with breech presentation (denominator in brackets)

	BEFORE intervention	AFTER intervention	BEFORE Control	AFTER Control
Doctor attempted to turn the baby	15% (75)	9% (72)	8% (60)	10% (51)
Had no choice about type of delivery	39% (59)	30% (54)	46% (46)	33% (33)
Had normal vaginal delivery	41% (63)	38% (60)	39% (49)	27% (37)

#### LEAFLET NUMBER 10: Where will you have your baby - hospital or home?

Many women volunteered during interview (and this was confirmed by observational work) that they did not have a 'proper discussion' about where to have their baby. The 'choice' midwives presented to women with respect to the place of birth, was generally between one or more local hospitals and on some sites, between slightly different models of midwifery care. On sites where this was an option, sometimes women were offered a choice between male and female consultants. The majority of midwives then, either issued this leaflet as something of an afterthought, or not at all and it was often withheld unless women themselves expressed an interest in home birth. Interestingly, a number of midwives referred to this leaflet as *'the one on home birth'*. The CRCT findings revealed a 2% decrease in women planning to have hospital births after the intervention period but it cannot be assumed that this is on account of the Informed Choice leaflets.

Midwives were rarely heard to present home birth as a safe, and viable, option for healthy women. Rather, it usually required women to initiate such discussions and, depending on midwife's experience of home birth, they were met with varying degrees of enthusiasm. Women who had experienced a previous traumatic hospital delivery appeared more likely to request a home birth subsequently as did some primigravid women for whom it afforded greater coherence with their personal philosophies and



lifestyles. Women in this latter group tended to be well informed on the subject of home birth; they were also more likely to be regarded as 'difficult' or 'demanding' by midwives.

A number of midwives worked in circumstances where the views of medical colleagues (GP's and obstetricians) prohibited them presenting home birth as an option; this was especially true for women expecting their first babies. Indeed, a small number of service users who were interviewed following a home birth reported that they had been removed from the list of a GP for doing so. This issue was also raised by women attending focus groups. (See Chapter 15) A small number of community midwives were nonetheless observed giving women this particular leaflet in situations when doing so would have been considered as flouting medical authority.

As the following excerpt from fieldnotes illustrates, on the occasions midwives did offer this leaflet to women, the accompanying commentary often indicated their underlying feelings on the subject:

M takes the informed choice leaflet on place of birth from her bag and shows it to W saying:

*Most women don't consider home as an option any more...which is a shame...*

M does not open the leaflet but gives it to W without further comment.

The point has been made both in this and elsewhere (Proctor 1998) that, in the absence of discussion, information did not appear to enable women to make informed decisions about their care:

*I: Was the option of having this baby at home discussed?*

*W: No...it did cross my mind. I thought I wouldn't mind considering a home birth but it wasn't mentioned. It was either the choice of (hospital X or hospital Y)...*

*I: And were you given this leaflet? (Interviewer shows W the informed choice leaflet on place of birth)*

*W: Oh yes, I had that one but she never discussed it with me...I though she would ask me at the next visit if I'd read it but she never did so I just dropped it really. It wasn't that important...I'm quite happy with (X hospital). I don't know why she bothered giving it me. I did wonder that...*

The researchers observed midwives on all sites applying a wide range of criteria to women with respect to booking the place of birth and/or the type of midwifery care. Some criteria were on the basis of medical/obstetric history, some on account of consultant preference whilst yet other criteria reflected organisational priorities. Thus, on site women were rendered ineligible for mlc or home birth if they did not consent to both an ultrasound scan and an initial consultation with an obstetrician and on other sites perceived shortages of community midwives restricted primiparous women booking home or Domino deliveries. Women on all sites who volunteered a variable range of medical or obstetric 'risk factors' were not offered anything other than a hospital booking. The variation in criteria for booking women for place of birth and the poor focus on particular adverse criteria has led one researcher to comment that 'given the diversity of the criteria used and the absence of any clear evidence of their effectiveness...far from increasing choice for women, the application of these criteria amounts to a constraint on women's choice' (Campbell 1999;554).

The proportion of women who reported that they had been given the place of birth leaflet in the intervention sites increased by 21 percentage points more than control sites. There was a two percentage point decrease in women planning to have hospital births in intervention sites compared with control sites and evidence of an increase in preferences for home births, the proportion of women offered choices and information-induced anxiety.

**Table 10 Leaflet title: *Where will you have your baby - hospital or home?***

Effect	BEFORE		AFTER		CHANGE		DIFFERENCE (cluster level)	
	I	C	I	C	I	C		
Given the leaflet	15%	17%	38%	19%	23%	2%	21%	***
<b>Informed choice</b>	<b>47%</b>	<b>45%</b>	<b>51%</b>	<b>46%</b>	<b>4%</b>	<b>1%</b>	<b>3%</b>	
Knowledge score	3.7	3.6	3.6	3.4	-0.03	-0.16	0.12	
Preference for home birth	5%	5%	7%	4%	2%	-1%	3%	+
Very or quite strong preference	77%	76%	77%	74%	0%	-2%	2%	
Enough information	52%	54%	59%	56%	7%	2%	5%	
Very sat or satisfied with information	54%	58%	61%	58%	7%	0%	7%	
Offered choices	46%	41%	56%	43%	10%	2%	8%	+
Very sat /satisfied with way choices made	63%	65%	67%	64%	4%	-1%	5%	
Enough discussion	54%	57%	61%	58%	7%	1%	6%	
Very sat or satisfied with place of birth	-----		-----		-----		-----	
Planned hospital birth	99%	97%	97%	97%	-2%	0%	-2%	*
Information-induced anxiety	7%	10%	8%	-7%	1%	-3%	4%	+

+ 0.05 < p < 0.1

## CONCLUSION

Use of the Informed Choice leaflets on the intervention sites raised some important issues with respect to the provision of choice and informed decision making for maternity service users. The different leaflets faced different barriers but they all produced very similar results in that none could be said to have been used in such a way as to promote informed choice for childbearing women. A number of health professionals experienced difficulty in presenting information perceived as technical and/or difficult to convey with clarity, whilst others were uncomfortable about raising issues with clients which could provoke anxiety. In both cases, it is possible that the Informed Choice leaflets were perceived as something of a salve by midwives in that they shifted the burden of responsibility (for reading the information and making a choice) to the service user.

Many health professionals were concerned that the information contained in the leaflets contradicted local practice or current thinking on the subject. This was problematic for health professionals such as midwives whose low position in the hierarchy meant that they exercised little decision making power. An obstetrician who raised this issue in relation to the leaflet on breech presentation was of the opinion that policies need to be set a national, rather than a local level, in order that health professionals might all '*sing from the same hymn sheet*' especially insofar as they presented options for mode of delivery.

It appeared that some service users approached the leaflets in the same way as they would other literature of this kind, including advertising and other freely available, and disposable, materials. There appeared to be an expectation amongst a number of service users that '*the front cover*' would indicate whether or not the contents were likely to be of interest. Many service users were not used to participating in decision making about their care and were unlikely to spontaneously open a leaflet and recognise that the contents might be of any value to them. Those who did often faced resistance from health professionals, many of whom were unable to accommodate the direction for clinical practice suggested by the information contained in the leaflets.

## **Appendix 5: Information Sheets and Consent Forms**

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## Control sites



# An Evaluation of Information and Choice in Maternity Care



Professor Mavis Kirkham  
The University of Sheffield

Professor Donna Mead  
The University of Glamorgan

Funded by the NHS Centre for Reviews and Dissemination and the Wales Office of Research and Development

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## Can you help us to learn about information and choice in maternity care?

The findings from this study will be used to inform maternity services in the future. The two research midwives, visiting maternity units in Wales, would like to:

- Interview women who receive maternity care and professionals who provide it
  - Sit in on antenatal consultations and attend parentcraft classes
  - Distribute questionnaires to midwives about various subjects relating to pregnancy and birth
- In your unit we are also interested in the range of information you currently provide for pregnant women.

## Confidential

If you decide to take part in the research, anything you say will be completely confidential. No-one will be able to trace any part of the findings back to an individual person or maternity unit.

## Tape recording

We hope you will allow tape recordings to be made of interviews and consultations. This will ensure that we have an accurate record. Tapes are stored securely and their contents treated as completely confidential.

## You do not have to take part

If you decide not to take part in the research, you do not have to give a reason.

If you are receiving maternity care:  
Your care will be just the same whether you take part or not.

If you are providing maternity care:  
Your conditions of work will not be affected by your decision to take part or not.

## More information

Further information in Welsh or English is available on request from Research Midwives:

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The University of Sheffield and The University of Glamorgan



# An Evaluation of Information and Choice in Maternity Care

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## CONSENT FORM

*Please cross out as necessary*

- Have you read the information sheet? Yes / No
- Have you had an opportunity to ask questions and discuss this study? Yes / No
- Have you received satisfactory answers to all your questions? Yes / No
- Have you received enough information about the study? Yes / No

To whom have you spoken?  
.....

Do you understand that you are free to withdraw from the study at any time, without having to give a reason, and that this will in no way affect your conditions of work? Yes / No

Do you agree to take part in this study? Yes / No

Signed ..... Date

(Name in block letters)  
.....

Signed (Witness) ..... Date

Signed (Researcher) ..... Date

## Intervention sites



# An Evaluation of Information and Choice in Maternity Care



Professor Mavis Kirkham  
The University of Sheffield

Professor Donna Mead  
The University of Glamorgan

Funded by the NHS Centre for Reviews and Dissemination and the Wales Office of Research and Development

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## Can you help us to learn about information and choice in maternity care?

The findings from this study will be used to inform maternity services in the future.

Your maternity unit will receive a supply of the MIDIRS Informed Choice leaflets to use in whatever way is considered most appropriate locally.

The two research midwives, visiting maternity units in Wales, would like to:

- Interview women who receive maternity care and professionals who provide it
- Sit in on consultations at antenatal clinics and attend parentcraft classes
- Distribute questionnaires to midwives about various subjects relating to pregnancy and birth

## Confidential

If you decide to take part in the research, anything you say will be completely confidential. No-one will be able to trace any part of the findings back to an individual person or maternity unit.

## Tape recording

We hope you will allow tape recordings to be made of interviews and consultations. This will ensure that we have an accurate record. Tapes are stored securely and their contents treated as completely confidential.

## You do not have to take part

If you decide not to take part in the research, you do not have to give a reason.

If you are receiving maternity care:  
Your care will be just the same whether you take part or not.

If you are providing maternity care:  
Your conditions of work will not be affected by your decision to take part or not.

## More information

Further information in Welsh or English is available on request from Research Midwives:

Helen Stapleton                      Mobile: 0966 502 152  
Valerie King                            Tel: 0114 222 9707  
School of Nursing and Midwifery, University of Sheffield, Winter Street, Sheffield S3 7ND.

Gwenan Thomas                      Mobile: 0468 483626  
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School of Nursing and Midwifery, University of Glamorgan, Pontypridd, Mid Glamorgan. CF37 1DL.



The University of Sheffield and The University of Glamorgan



# An Evaluation of Information and Choice in Maternity Care

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## CONSENT FORM

*Please cross out as necessary*

- Have you read the information sheet? Yes / No
- Have you had an opportunity to ask questions and discuss this study? Yes / No
- Have you received satisfactory answers to all your questions? Yes / No
- Have you received enough information about the study? Yes / No

To whom have you spoken?  
.....

Do you understand that you are free to withdraw from the study at any time, without having to give a reason, and that this will in no way affect your conditions of work? Yes / No

Do you agree to take part in this study? Yes / No

Signed ..... Date

(Name in block letters)  
.....

Signed (Witness) ..... Date

Signed (Researcher) ..... Date





## Appendix 6: Interview Prompts

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H Stapleton  
WICH Research Group, School of Nursing and Midwifery, University of Sheffield

### Managers

Position; Title; Responsibilities; Areas of special interest?

Involvement in the decision to purchase leaflets?

Contract specification? Funding? Audit/Evaluation of leaflet use?

What do you think of them?

Any problems you associate with using the leaflets?

Responses from the different groups of health professionals?

Have you noticed any changes in outcome measures?

Consulted about/made aware of the study? Feelings about being randomised?

Input and visibility of consumer groups into maternity care.

Organisation of maternity care in the unit? Midwives autonomy?

How well informed do they think women are about pregnancy related issues?

Sources of their information?

How do you feel about consumers making decisions and participating in their care?

Any problems/difficulties which you might anticipate with women being better informed?

Any thoughts about longer term outcomes?

Any thoughts about the limitations to consumer choice and decision making?

What does the phrase *Informed Choice* mean to you? Do you see it working here?

Are you constrained in implementing informed choice? (budgetary, competition/rivalry from different professional groups, prestige of particular discipline,...)

How would you describe relationships between the different professional groups?

Do you have any particular views on the care pregnant women receive?

Do you think women should be given information? Why?

Can you identify any barriers to communication and the flow of information?

Is there any provision for women with special needs? Are there many women who do not speak English? Interpreter service and use?

Are there risk management policies in place in the unit?

Who has input into formulating policies and guidelines?

How do you see the relationship between risk management and informed choice?

Would you describe the guidelines and policies as being evidence based?

How much of an issue is litigation? And complaints about the service?

Is there any particular management philosophy operating in the trust/maternity unit?

How they felt about being interviewed.

## **Obstetricians (including consultants, registrars and GP's)**

Position; Title; Responsibilities; Areas of special interest?  
*depending on position, may want to refer to manager's prompt*

Any involvement in the decision to purchase leaflets?  
Consulted about/made aware of the study?

Something about their views on the organisation of care locally; recent changes?  
Relationships amongst health professionals in the unit?

Visibility/perception of consumer groups?  
Provision for women with different needs?...

How well informed do they think women are about pregnancy related issues?  
Sources of that information? Do you think women should be given information? *Reasons*

How do you rate your ability to present information?  
Facilities and policy for screening for fetal abnormally? Policy on divulging sensitive information? *Who is "allowed"/responsible?*

### Leaflets:

Have you seen them? Do/would you use them? Comments?  
Have you seen midwives using them? Have you heard women referring to them?

How do you feel about women making decisions and participating in their care?  
Are there particular women with whom you find this process more or less difficult?  
Do women ever make decisions which you find difficult to accommodate/disagree with?  
Have you ever looked after women who made decisions and then change their minds?

What does the phrase *Informed Choice* mean to you? Do you see it working here?

When you give women information, do you need to agree with/approve of/believe in it?  
Are you selective? Women about whom you have reservations re: making info. available?  
Do you find it easier/more difficult to give information to some women rather than others? Different needs/Barriers to communication?

Any problems/difficulties which you attribute directly to women being more informed?  
Does it make your job any easier/more difficult

Is there information which you find difficult, complicated or unpleasant to get across?  
Is there information you want to give women which contradicts unit policy?  
Do you feel a sense of responsibility for the choices women make?

Do you think having information helps women to make choices about their care?  
Is there a down-side to this - i.e. are there any negative/side effects?

Have your own personal experiences had any affect on the way you think about issues related to pregnancy/birth? Has this affected the way in which you give information?  
Would you describe yourself as having (strong) feelings about any particular aspects of pregnancy/childbirth?

Have you ever been asked to act as an expert witness?

How they felt about being interviewed.

## Midwives

Position; Title; Responsibilities; Areas of special interest?

Views on the organisation of care locally e.g.: criteria for consultant referral; accessing blood tests and scans, hand-held notes; birth-plans etc. (recent changes and reactions to same)

What they think about routine pregnancy related information women are given.

How do you rate your ability to present information?

Do you think women should be given information? Why?

How well informed do you consider pregnant women to be about pregnancy related issues? Sources?

Local options: screening for fetal abnormality; home birth etc. Variability?

Their opinions on the quality and variety of written information women receive (*esp. re ic leaflets*).

Visibility/perception of consumer groups.

Women with different needs...

How would you describe relationships between the different professional groups?

### leaflets:

How and when leaflets received/distributed? Comments of process?

Attended training session...comments?

Have your views/perceptions of the leaflets changed?

Scenarios when most likely to use leaflets with women?

Selective use; are there women for whom you think the leaflets (in)appropriate?

Do you find it easier/more difficult to give information to some women rather than others?

When you give women information, do you need to agree with/approve of/believe in it?

Encountered any problems/difficulties which you attribute directly to using the leaflets?

Has using the leaflets made your job any easier/more difficult? (*time, questions, heightened sense of responsibility, awareness of own gaps in knowledge, conflicts with hospital policy...*)

What does the phrase *Informed Choice* mean to you? Do you see it working here?

How do you feel about women making decisions and participating in their care?

Are there particular women with whom you find this process more or less difficult?

Do women ever make decisions which you find difficult to accommodate/disagree with?

Have you ever looked after women who made decisions and then change their minds?

Can you identify any barriers to communication and the flow of information?

Is there information which you find difficult, complicated or unpleasant to get across?

Is there information you want to give women which contradicts unit policy?

Do you feel responsible for the choices women make?

Do you think having information helps women to make choices about their care?

Is there a down-side to this - are there any negative/side effects?

Have your own personal experiences had any affect on the way you think about issues related to pregnancy/birth? Has this affected the way in which you give information?

Would you describe yourself as having (strong) feelings/views about any particular aspects of pregnancy/childbirth? Do they influence the way in which you convey information?

How they felt about being interviewed.

## Ultrasonographers, Radiographers and Anaesthetists

Position; Title; Responsibilities; Areas of special interest?

How do you rate your ability to present information?

Is there information which you find difficult, complicated or unpleasant to get across?

Is there information you would like to give women but which contradicts unit policy?

Do you feel any responsibility for the choices/decisions women make?

How well informed do you consider pregnant women to be about pregnancy related issues?

Sources of their information?

How would you describe relationships between the different professional groups working here?

*informed choice leaflets:* Have you seen the informed choice leaflets? Which ones?

What do you think of them? (conceptually, layout, contents etc.)

Have you seen midwives using them? Have you heard women referring to them?

*Depending on practitioner, refer specifically to leaflet on ultrasound or epidural.*

*ultrasound practitioners:* do you involve yourself in any 'health education' with women whilst they are being scanned? (e.g. IUGR in women who smoke, drink, or use other drugs)

Would you advise women who may have been inappropriately scanned? (e.g. women presenting for anomaly scans, who are found to be much earlier on in pregnancy but who have already been screened for Down's and spina bifida)

How would you rate the ultrasound facilities in this unit?

What is your opinion about the use of "mini scans"; using ultrasound to routinely determine the position of the a baby and/or to detect the FH?

Are you allowed to tell women yourself if you detect something wrong with the baby?

*anaesthetists:* What do you think of the epidural service in this unit?

Have you ever found yourself performing what you consider to be unnecessary epidurals?

*general:*

What are the pressures you face in your work? Do threats of litigation concern you?

Have your own personal experiences had any affect on the way you think about issues related to pregnancy/birth? Has this affected the way in which you give information?

Would you describe yourself as having feelings about any particular aspect of childbirth?

Do these feelings/views make any difference to the way in which you deliver information?

What does the phrase *Informed Choice* mean to you? Do you see it working here?

How do you feel about women making decisions and participating in their care?

Are there particular women with whom you find this process more or less difficult?

Do women ever make decisions which you find difficult to accommodate/disagree with?

Have you ever looked after women who made decisions and then change their minds?

How do you cope?

Do you think having information helps women to make choices about their care?

Are there any negative/side effects? Does it make your job easier/more difficult?

Encountered any problems/difficulties which you attribute directly to women being more informed?

Do you think women should be given information about the options available? *Reasons*

When you give women information, do you need to agree with/approve of/believe in it?

Are you selective with the information you give? *Reasons*

Can you identify any barriers to communication and the flow of information?

How they felt about being interviewed.

## Service Users

*adapt to ante-natal, post-natal phase*

Childbearing herstory and use of the maternity services (current, prior, local and elsewhere).

Health of children, partner etc.

Influence of previous childbearing experience(s) on choice and decision making?

Influence of partner, family, friends etc.?

Would you describe yourself as having (strong) feelings/views about childbirth?

Social factors (education, ethnicity, employment, housing, different needs...)

How well informed do you consider yourself to be about pregnancy related issues? *Sources of information?*

What do you think about the way health professionals present information?

Do you think women should be given information? *Reasons*

Their opinions on the quality and variety of written information they have received from health professionals? (*esp. re informed choice leaflets*).

Information preferences: verbal v written; leaflets v books etc.

How good are health professionals at explaining things to you? Have you ever left the clinic not understanding what has been said?

How easy/difficult is it to raise the issues you want to talk about? Have you ever been afraid to talk about things because of the reactions of health professionals?

Has this affected the choices you made/ not made?

How have health professionals treated you during your pregnancy (& afterwards)?

Knowledge/views on the organisation of care locally.

Do you think all pregnant women should be given choices in their care? *Limitations?*

Do they see themselves as able to make choices? *Inhibiting factors?*

Local options: screening for fetal abnormality; ultrasound scans, home birth etc.

What choices have they made this pregnancy? *Any differences with other pregnancies?*

How would you describe relationships between the different health professionals you have come into contact with?

Your relationship with the midwife (team etc.) and /or other health professionals involved in your care?

General attitudes of health professionals?

Attending ante-natal education classes?

Does the phrase *Informed Choice* mean anything to you?

If someone says that information may, or may not, be based on good evidence... does that mean anything to you? *What counts as evidence to you?*

How they felt about being interviewed.



## Appendix 7: Summary of Fieldwork Undertaken During the CRCT

H Stapleton  
WICH Research Group, School of Nursing and Midwifery, University of Sheffield

### 1. Intervention sites

respondents	episodes of observation	informal/ in-depth interviews <sup>1</sup>	follow-up in-depth interviews <sup>2</sup>
midwives	356	97	58
obstetricians	87	10	8
ultrasonographers	23	4	0
anaesthetists	<i>n/a</i>	2	<i>n/a</i>
service users *	466 <sup>3</sup>	86	46
<i>primip/multip</i> <sup>4</sup>		41 <i>p</i> ; 45 <i>m</i>	
<i>breech</i> <sup>5</sup>		11	
<i>c/s</i> <sup>5</sup>		14	
<i>home birth</i> <sup>5</sup>		11	
<b>TOTAL</b>	<b>466</b>	<b>199</b> incl. 12 Welsh <sup>6</sup>	<b>112</b>
parentcraft classes <sup>7</sup>	8		
other <sup>8</sup>	1	1	

### 2. Control sites

respondents	episodes of observation	informal/ in-depth interviews	follow-up in-depth interviews
midwives	297	80	44
obstetricians	80	17	13
ultrasonographers	42	6	2
anaesthetists			
service users *	387	77	38
<i>primip/multip</i>		40 <i>p</i> ; 37 <i>m</i>	
<i>breech</i>		7	
<i>c/s</i>		12	
<i>home birth</i>		3	
<b>TOTAL</b>	<b>387</b>	<b>180</b> incl. 5 Welsh	<b>97</b>
parentcraft classes	4		
other		3	

\* includes a small number of women whose babies were in SCBU

<sup>1</sup> Does not include focus groups but does include informal and small group interviews.

<sup>2</sup> Refers to interviews which followed on from an observation session.

<sup>3</sup> Is the sum total of the service users observed in consultation with the different health professionals.

<sup>4</sup> In the adjacent column, "*p*" refers to primiparous women; "*m*" to multiparous women.

<sup>5</sup> The sub-sets for breech, *c/s* and home birth are approximate and include women who, whatever the plan at the time of the ante-natal observation/ interview, might have had a different outcome.

<sup>6</sup> The interview was conducted in Welsh.

<sup>7</sup> This figure refers to the number of classes observed and not the number of participants. The majority of midwives facilitating classes were subsequently interviewed.

<sup>8</sup> Includes a very small number of non-NHS ante-natal education classes and MSLC meetings.

### 3. The Small, Rural Units

respondents	episodes of observation	informal/ in-depth interviews	follow-up in-depth interviews
midwives	27	7	6
obstetricians/GP's	8	3	2
ultrasonographers	0	0	
anaesthetists	<i>n/a</i>		
service users	35	11	8
<i>primip/multip</i>		<i>6p;5m</i>	
<i>breech</i>		1	
<i>c/s</i>		0	
<i>home birth</i>		1	
<b>TOTAL</b>	<b>70</b>	<b>21</b>	<b>16</b>
parentcraft classes	3		
other	1		



## **Appendix 8: Interview Schedule for Mapping Exercise**

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*H Stapleton<sup>1</sup> and S Kirkman<sup>2</sup>*

*<sup>1</sup>WICH Research Group, School of Nursing and Midwifery, University of Sheffield*

*<sup>2</sup>School of Nursing and Midwifery, University of Glamorgan*

### **1. Demographic features**

- a) Size of unit - number of deliveries
- b) Socio-economic characteristics of childbearing population

### **2. Information about the purchase of leaflets**

- a) How was the purchase funded, by whom?
- b) Subsequent purchase decisions by provider units: if the whole set not bought what rationale was used for selection?
- c) Are you still using the leaflets?
- d) If not, why not?

### **3. Distribution of the leaflets**

- a) How were they introduced? (Any orientation/instruction in use?)
- b) How were they accessed/distributed? (Who uses them, with whom, how the exchange takes place?)
- c) Reactions/attitudes of staff?

### **4. Feedback**

- a) Any monitoring/audit system in place (copy please)?
- b) Any changes in policy and/or any changes in outcomes as a result of using the leaflets?

### **5. Future plans**

- a) Will you continue to use the leaflets?

### **6. Is there anything else you would like to say about the leaflets?**



## **Appendix 9: Free Text Comments in the CRCT Questionnaires**

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*D Mead and L Moseley  
School of Nursing and Midwifery, University of Glamorgan*

**Table 1: Pattern of responding**

	<b>Antenatal Pre-test</b>	<b>Antenatal Post-test</b>	<b>Postnatal Pre-test</b>	<b>Postnatal Post-test</b>
Sample	1243	1778	1741	1547
Respondents	740	990	1329	1219
Statements	1658	1498	2349	1962
Themes	1833	1501	2889	1970
% writing comments	59.5	55.7	76.3	78.8
Statements per respondent	2.2	1.5	1.8	1.6

e.g for the Antenatal Pretest, there were 1243 respondents in the SPSS SAV file provided, which represented the number of people who completed questionnaires. Of these, 740 appeared in the CSV file of transcribed comments. Between them they made 1658 identifiable statements. These statements contained 1833 themes, since there were often more than one theme per statement.

**Table 2: Raw data on themes**

This table gives the number of identifiable themes, broken down by main category and by intervention (I) or control (C ) group. For example, in the antenatal pre-test data from the experimental group, there were 84 themes identified as to do with the category Choice.

<b>Category</b>	<b>Group</b>	<b>Antenatal Pre-test</b>	<b>Antenatal Post-test</b>	<b>Postnatal Pre-test</b>	<b>Postnatal Post-test</b>
Choice	I	84	88	136	110
	C	90	66	156	99
Info	I	296	287	240	220
	C	283	165	256	153
Personal	I	147	287	252	248
	C	165	153	284	190
Service	I	268	184	202	125
	C	255	139	203	107
Totals	I	795	846	830	703
	C	793	523	899	549

**Table 3: Percentages on themes**

This table gives the percentage of identifiable themes, broken down by main category and by intervention (I) or control (C) group. For example, in the antenatal pre-test data from the intervention group, 10.6% of the themes were identified as to do with the category Choice.

Category	Group	Antenatal Pre-test	Antenatal Post-test	Postnatal Pre-test	Postnatal Post-test
Choice	I	10.6	10.4	16.4	15.6
	C	11.3	12.6	17.4	18.0
Info	I	37.2	33.9	28.9	31.3
	C	35.7	31.5	28.5	27.9
Personal	I	18.5	33.9	30.4	35.3
	C	20.8	29.3	31.6	34.6
Service	I	33.7	21.7	24.3	17.8
	C	32.2	26.6	22.6	19.5

**Table 4: Changes between pre- and post-test**

The numbers in this table represent the percentage point change (not the percentage change) between pre- and post-test for the antenatal and postnatal respondents. Thus, the -0.2 cell shows that for the antenatal respondents the proportion of themes identified as to do with Choice fell very slightly between pre- and post-test i.e. it went down from 10.6% to 10.4%, showing effectively no difference between the two time periods

Category	Group	Antenatal	Postnatal
Choice	I	-0.2	-0.7
	C	1.3	0.7
Info	I	-3.3	2.4
	C	-4.1	-0.6
Personal	I	15.4	4.9
	C	8.4	3.0
Service	I	-12.0	-6.6
	C	-5.6	-3.1

**Table 5: Positive-Negative judgements:Raw data**

The data in these two tables consist of raw numbers of themes in each group (intervention and control) allocated to each category

**A:Antenatal samples**

Category	Group	Pre +ve	Pre -ve	Post +ve	Post -ve
Choice	I	26	57	34	53
	C	31	58	25	41
Info	I	116	177	148	138
	C	123	156	138	137
Personal	I	93	52	122	43
	C	118	42	111	41
Service	I	92	176	80	104
	C	88	165	64	75
Total		687	883	722	632

**B: Postnatal samples**

Category	Group	Pre +ve	Pre -ve	Post +ve	Post -ve
Choice	I	66	63	50	58
	C	72	80	48	48
Info	I	119	111	117	100
	C	137	112	80	69
Personal	I	196	53	195	53
	C	216	59	152	38
Service	I	66	131	50	73
	C	61	138	45	62
Total		933	747	737	501

**Table 6: Positive-negative judgements. Processed data**

These two tables give the percentage positive judgments in each cell, together with the percentage point change (not the percentage change) for each category-group combination

**A: Antenatal samples**

Category	Group	Pre % +ve	Post % +ve	Percentage Point Change
Choice	I	31.3	39.1	7.8
	C	34.8	37.9	3.0
Info	I	39.6	51.7	12.2
	C	44.1	50.2	6.1
Personal	I	64.1	73.9	9.8
	C	73.8	73.0	-0.7
Service	I	34.3	43.5	9.1
	C	34.8	46.0	11.3
Overall		43.8	53.3	9.6

**B: Postnatal samples**

Category	Group	Pre % +ve	Post % +ve	Percentage Point Change
Choice	I	51.2	46.3	-4.9
	C	47.4	50.0	2.6
Info	I	51.7	53.9	2.2
	C	55.0	53.7	-1.3
Personal	I	78.7	78.6	-0.1
	C	78.5	80.0	1.5
Service	I	33.5	40.7	7.1
	C	30.7	42.1	11.4
Overall		55.5	59.5	4.0

**C: Both samples combined i.e. all respondents who wrote codable comments**

<b>Category</b>	<b>Group</b>	<b>Pre % +ve</b>	<b>Post % +ve</b>	<b>Percentage Point Change</b>	<b>N</b>
Choice	I	43.4	43.1	-0.3	829
	C	42.7	45.1	2.3	
Info	I	44.9	52.7	7.8	1900
	C	49.2	51.4	2.2	
Personal	I	73.4	76.8	3.4	1726
	C	76.8	76.9	0.1	
Service	I	34.0	42.3	8.4	1483
	C	33.0	44.3	11.3	
Overall		49.8	56.3	6.4	





## **Appendix 10: The Economics of Leaflet Use in the CRCT**

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*M Longo and D Cohen  
Business School, University of Glamorgan*



## Appendix 10a: The Economics of Leaflet Use in the CRCT Hospital by Hospital Before and After Comparisons of Resource Use

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**Table 1: Number of Scans**

Maternity Units ( n = before/after)	Baseline		After Intervention	
	Mean (SD)	Median (Min – Max)	Mean (SD)	Median (Min – Max)
Int 1 (n = 43/72)	2.11 (1.25)	2.00 (1.00 – 8.00)	1.93 (1.00)	2.00 (1.00 – 5.00)
Int 2 (n = 101/116)	2.58 (1.25)	2.00 (1.00 – 10.00)	2.63 (1.20)	2.00 (1.00 – 9.00)
Int 3 (n = 46/69)	2.33 (0.69)	2.00 (1.00 – 5.00)	2.50 (0.96)	2.00 (1.00 – 8.00)
Int 4 (n = 38/48)	2.51 (0.93)	2.00 (1.00 – 8.00)	2.67 (1.54)	2.00 (1.00 – 16.00)
Int 5 (n = 25/35)	2.70 (1.58)	2.00 (1.00 – 9.00)	2.45 (0.84)	2.00 (1.00 – 5.00)
Con 1 (n = 47/64)	2.15 (1.19)	2.00 (1.00 – 8.00)	2.26 (1.26)	2.00 (1.00 – 7.00)
Con 2 (n = 75/82)	2.71 (1.31)	2.00 (1.00 – 8.00)	2.86 (1.46)	2.00 (1.00 – 10.00)
Con 3 (n = 54/71)	2.84 (1.80)	2.00 (1.00 – 15.00)	2.74 (1.41)	2.00 (1.00 – 10.00)
Con 4 (n = 31/30)	2.46 (1.22)	2.00 (1.00 – 8.00)	2.79 (1.17)	2.00 (1.00 – 8.00)
Con 5 (n = 41/37)	2.17 (0.57)	2.00 (1.00 – 4.00)	2.35 (0.82)	2.00 (1.00 – 6.00)
Total (n = 501/624)	2.51 (1.28)	2.00 (1.00 – 15.00)	2.55 (1.26)	2.00 (1.00 – 16.00)

**Table 2: Blood test for either spina bifida or Down's syndrome**

Maternity Units (n = before/after)	Had any blood test					
	Baseline			After Intervention		
	Yes (%)	No (%)	Not Sure (%)	Yes (%)	No (%)	Not Sure (%)
Int 1 (n = 90/136 )	77 (85.6)	10 (11.1)	3 (3.3)	118 (86.8)	12 (8.8)	6 (4.4)
Int 2 ( n = 260/304)	227 (87.3)	26 (10.0)	7 (2.7)	249 (81.9)	51 (16.8)	4 (1.3)
Int 3 ( n = 107/170)	67 (62.6)	38 (35.5)	2 (1.9)	107 (62.9)	61 (35.9)	2 (1.2)
Int 4 ( n = 95/128)	84 (88.4)	11 (11.6)	--	105 (82.0)	22 (17.2)	1 (0.8)
Int 5 ( n = 67/86)	63 (94.0)	3 (4.5)	1 (1.5)	74 (86.0)	9 (10.5)	3 (3.5)
Con 1 ( n = 102/146)	93 (91.2)	9 (8.8)	--	128 (87.7)	14 (9.6)	4 (2.7)
Con 2 ( n = 203/232)	103 (50.7)	92 (45.3)	8 (3.9)	153 (65.9)	77 (33.2)	2 (0.9)
Con 3 ( n = 152/194 )	101 (66.4)	49 (32.2)	2 (1.3)	157 (80.9)	36 (18.6)	1 (0.5)
Con 4 ( n = 75/84 )	68 (90.7)	6 (8.0)	1 (1.3)	80 (95.2)	3 (3.6)	1 (1.2)
Con 5 ( n = 89/86 )	72 (80.9)	17 (19.1)	--	71 (82.6)	14 (16.3)	1 (1.2)
Total (n = 621/742)	437 (70.4)	173 (27.9)	11 (1.8)	589 (79.4)	144 (19.4)	9 (1.2)

**Table 3: Amniocentesis test**

Maternity Units (n = before/after)	Had the amniocentesis test					
	Baseline			After Intervention		
	Yes (%)	No (%)	Not Sure (%)	Yes (%)	No (%)	Not Sure (%)
Int 1 (n = 90/137)	2 (2.2)	85 (94.4)	3 (3.3)	3 (2.2)	130 (94.9)	4 (2.9)
Int 2 (n = 258/304)	14 (5.4)	240 (93.0)	4 (1.6)	22 (7.2)	280 (92.1)	2 (0.7)
Int 3 (n = 104/169)	3 (2.8)	102 (96.2)	1 (0.9)	11 (6.5)	157 (92.9)	1 (0.6)
Int 4 (n = 94/127)	2 (2.1)	89 (94.7)	3 (3.2)	5 (3.9)	118 (92.9)	4 (3.1)
Int 5 (n = 67/86)	2 (3.0)	63 (94.0)	2 (3.0)	1 (1.2)	82 (95.3)	3 (3.5)
Con 1 (n = 71/143)	5 (5.0)	91 (90.1)	5 (5.0)	9 (6.3)	134 (93.7)	--
Con 2 (n = 202/228)	13 (6.4)	184 (91.1)	5 (2.5)	4 (1.8)	220 (96.5)	4 (1.8)
Con 3 (n = 147/194)	15 (10.2)	131 (89.1)	1 (0.7)	16 (8.2)	176 (90.7)	2 (1.0)
Con 4 (n = 74/84)	5 (6.8)	69 (93.2)	--	7 (8.3)	77 (91.7)	--
Con 5 (n = 86/86)	7 (8.1)	78 (90.7)	1 (1.2)	6 (7.0)	79 (91.9)	1 (1.2)
Total (n = 610/735)	45 (7.4)	553 (90.7)	12 (2.0)	42 (5.7)	686 (93.3)	7 (1.0)

**Table 4: CVS test**

Maternity Units (n = before/after)	Had any CVS* test					
	Baseline			After Intervention		
	Yes (%)	No (%)	Not Sure (%)	Yes (%)	No (%)	Not Sure (%)
Int 1 (n = 88/138 )	3 (3.4)	62 (70.5)	23 (26.1)	3 (2.2)	106 (76.8)	29 (21.0)
Int 2 ( n = 252/284)	5 (2.0)	185 (73.4)	62 (24.6)	4 (1.4)	228 (80.3)	52 (18.3)
Int 3 ( n = 102/162)	3 (2.9)	78 (76.5)	21 (20.6)	5 (3.1)	112 (69.1)	45 (27.8)
Int 4 ( n = 93/125)	3 (3.2)	61 (65.6)	29 (31.2)	5 (4.0)	94 (75.2)	26 (20.8)
Int 5 ( n = 66/85)	1 (1.5)	47 (71.2)	18 (27.3)	3 (3.5)	70 (82.4)	12 (14.1)
Con 1 ( n = 95/140)	2 (2.1)	63 (66.3)	30 (31.6)	7 (5.0)	103 (73.6)	30 (21.4)
Con 2 ( n = 194/229)	4 (2.1)	160 (82.5)	30 (15.5)	12 (5.2)	181 (79.0)	36 (15.7)
Con 3 ( n = 145/185)	4 (2.8)	103 (71.0)	38 (26.2)	6 (3.2)	130 (70.3)	49 (26.5)
Con 4 ( n = 71/79)	2 (2.8)	54 (76.1)	15 (21.1)	1 (1.3)	56 (70.9)	22 (27.8)
Con 5 ( n = 85/83)	2 (2.4)	63 (74.1)	20 (23.5)	3 (3.6)	67 (80.7)	13 (15.7)
Total (n = 590/716)	14 (2.4)	443 (75.1)	133 (22.5)	29 (4.1)	537 (75.0)	150 (20.9)

**Table 5: Planned place of birth**

Maternity Unit	Planned Place of Birth							
	Baseline				After Intervention			
	Hospital (%)	Home (%)	GPUnt (%)	NotSure (%)	Hospital (%)	Home (%)	GPUnt (%)	NotSure (%)
Int 1 (n = 90/138)	89 (98.9)	1 (1.1)	--	--	134 (97.1)	3 (2.2)	--	1 (0.7)
Int 2 (n = 260/304)	253 (97.3)	6 (2.3)	--	1 (0.4)	294 (96.7)	8 (2.6)	--	2 (0.7)
Int 3 (n = 107/171)	106 (99.1)	1 (0.9)	--	--	166 (97.1)	5 (2.9)	--	--
Int 4 (n = 95/128)	93 (97.9)	1 (1.1)	--	1 (1.1)	123 (96.1)	5 (3.9)	--	--
Int 5 (n = 67/85)	67 (100.0)	--	--	--	82 (96.5)	2 (2.4)	--	1 (1.2)
Con 1 (n = 100/146)	97 (97.0)	3 (3.0)	--	--	143 (97.9)	2 (1.4)	1 (1.7)	--
Con 2 (n = 203/233)	199 (98.0)	4 (2.0)	--	--	227 (97.4)	5 (2.1)	1 (0.4)	--
Con 3 (n = 152/194)	151 (99.3)	1 (0.7)	--	--	192 (99.0)	2 (1.0)	--	--
Con 4 (n = 76/84)	70 (92.1)	2 (2.6)	4 (5.3)	--	77 (91.7)	1 (1.2)	6 (7.1)	--
Con 5 (n = 89/86)	87 (97.8)	2 (2.2)	--	--	86 (100.0)	--	--	--
Total (n = 620/743)	604 (97.4)	12 (1.9)	4 (5.3)	--	725 (97.6)	10 (1.3)	8 (1.1)	--

**Table 6: Heart monitoring**

Maternity Units (n = before/after)	EFM			
	Baseline		After Intervention	
	Yes (%)	No (%)	Yes (%)	No (%)
Int 1 (n =173/176 )	100 (57.8)	73 (42.2)	108 (61.4)	68 (38.6)
Int 2 ( n =325/308)	160 (49.2)	165 (50.8)	122 (39.6)	186 (60.4)
Int 3 ( n =187/174)	78 (41.7)	109 (58.3)	54 (31.0)	120 (69.0)
Int 4 ( n =123/101)	52 (42.3)	71 (57.7)	40 (39.6)	61 (60.4)
Int 5 ( n =114/127)	61 (53.5)	53 (46.5)	73 (57.5)	54 (42.5)
Con 1 ( n =171/114)	79 (46.2)	92 (53.8)	56 (49.1)	58 (50.9)
Con 2 ( n =266/220)	122 (45.9)	144 (54.1)	103 (46.8)	117 (53.2)
Con 3 ( n =169/163)	86 (50.9)	83 (49.1)	86 (52.8)	77 (47.2)
Con 4 ( n =93/74)	51 (54.8)	42 (45.2)	38 (51.4)	36 (48.6)
Con 5 ( n =120/90)	49 (40.8)	71 (59.2)	36 (40.0)	54 (60.0)
Total (n =1741/1547 )	838 (48.1)	903 (51.9)	716 (46.3)	831 (53.7)



**Table 7: Epidural**

Maternity Units (n = before/after)	Epidural			
	Baseline		After Intervention	
	Yes (%)	No (%)	Yes (%)	No (%)
Int 1 (n = 173/219)	43 (24.9)	130 (75.1)	61 (34.7)	115 (65.3)
Int 2 (n = 325/308)	75 (23.1)	250 (76.9)	57 (18.5)	251 (81.5)
Int 3 (n = 187/174)	53 (28.3)	134 (71.7)	49 (28.2)	125 (71.8)
Int 4 (n = 123/101)	15 (12.2)	108 (87.8)	18 (17.8)	83 (82.2)
Int 5 (n = 114/127)	30 (26.3)	84 (73.7)	38 (29.9)	89 (70.1)
Con 1 (n = 171/114)	27 (15.8)	144 (84.2)	23 (20.2)	91 (79.8)
Con 2 (n = 266/220)	68 (25.6)	198 (74.4)	51 (23.2)	169 (76.8)
Con 3 (n = 169/163)	58 (34.3)	111 (65.7)	69 (42.3)	94 (57.7)
Con 4 (n = 93/74)	12 (12.9)	81 (87.1)	9 (12.2)	65 (87.8)
Con 5 (n = 120/90)	12 (10.0)	108 (90.0)	8 (8.9)	82 (91.1)
Total (n = 1741/1547)	393 (22.6)	1348 (77.4)	383 (24.8)	1164 (75.2)



## **Appendix 10b: The Economics of Leaflet Use in the CRCT Validity Exercise on Agreement Between Hospital Notes and Patient Questionnaires**

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### **INTRODUCTION**

The two most common ways of collecting resource use data alongside clinical trials are scrutiny of medical records and patient recall. There are problems associated with both methods.

Use of medical records is complicated by problems of access, issues of confidentiality, interpretation and sometimes incomplete information. Patient recall via questionnaires or interviews generally yields lower response rates and respondents may be unwilling to disclose sensitive information (Martin 1987). The collection of data alongside controlled trials thus involves trade offs between comprehensiveness and manageability in terms of data handling and the cost of data collection (Coyle et al 1994). Previous studies (e.g. Tilley et al 1985, Oakley et al 1990, Bryant et al 1989, Hewson and Bennett 1987, Martin 1987, Githens et al 1993) all provide evidence that self-reporting is a valid method of assessing resource use during pregnancy, delivery and early infancy.

In the present study a validity check was undertaken to compare a sub-sample of questionnaires' data with medical records. Discrepancies between the two data collection methods will occur when mothers report an event or procedure which was not reported in the hospital notes or, conversely, when information extracted from the records was not mentioned by the mother. When inconsistencies were found, it was not assumed that the hospital notes were necessarily correct.

### **Subjects and methods**

The validity exercise was run in 2 of the 13 participating sites – one intervention and one control site. From study women registered with these hospitals, a random sample of 126 returned questionnaires was selected for the exercise; 54 for antenatal and 72 for postnatal data.

Data were abstracted on two possible episodes of antenatal care (ultrasound and blood test for spina bifida or Down's syndrome) and three possible episodes of intra-partum care (use of entonox, pethidine and epidural). All data from hospital notes were abstracted by a senior research midwife. Data from the patient questionnaires were abstracted separately by the economist researcher on the trial.

### **Questionnaires**

Most questions relating to resource use involved tick box responses and all referred to items which could be retrieved from hospital patient notes. The final response rates were antenatal before (65%) and after (66%), postnatal before (64%) and after (62%) (see Chapter 7 for more details on the response rate).

In absence of a gold standard method, agreement between the two sources of data was assessed by pairwise agreements and kappa statistics. The former measures the percentage of the matches over the sample. The Kappa statistics are calculated from observed and expected frequencies and take into account the distribution explained by chance (Bland 1995). Both are normally used for categorical/continuous data by cross-tabulation of the observations. Also, statistically significant differences between data sources on the one continuous variable (number of scans) was calculated using paired t-tests. Dichotomous variables were compared using the McNemar test. Analysis was performed using SPSS.

