

University of Plymouth and University of Ulster

Antenatal screening: Informed choice and parental consent

Dr Heather Skirton and Dr Owen Barr

Funded by the Foundation for People with Learning Disabilities



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Abbreviations used in the report

CVS	Chorionic villus sampling
MSS	Maternal serum screening
NTS	Nuchal translucency scan
USS	Ultrasound scan

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1. Acknowledgements

This study was funded by the Foundation for People with Learning Disabilities, part of the Mental Health Foundation.

The authors wish to acknowledge the support of those midwives who helped us to recruit parents and staff for the study. We are particularly indebted to: Alex Davidson, Katy Evans, Mary Fosbrook, Carol Jewell and Jane McFarlane.

We are grateful to the members of the Advisory Group who guided us at key points in the study process. Our thanks also to Tina Wells and Julia Frost, who assisted with the data analysis, and Jean Smith, who performed many of the administrative tasks.

Finally, we acknowledge the time given to the study by all participants, both parents and health professionals.

2. Background to the study

The term screening applies to the application of a test or tests in a general population where most individuals will be considered at low risk (Skirton and Patch, 2002). Screening is used as a method of identifying those in the population whose risk might be high enough to warrant the offer of further diagnostic tests.

Antenatal screening of the fetus can be performed for a range of conditions, including chromosomal abnormalities (such as trisomy) and physical structural abnormalities (such as neural tube defect or congenital heart disease). Screening may be offered using either biochemical markers or ultrasound, or a combination of both. To focus on a specific example, in England, Scotland and Wales screening for Down syndrome is now being offered to all pregnant women as part of their antenatal care. The screening test result provides an indication of the level of risk for the fetus in a particular pregnancy, rather than a definite diagnosis and therefore false negative and false positive results are possible (Public Health Genetics Unit, 2005).

Parents whose fetus is assessed as having a significant chance of being affected with Down syndrome are offered invasive diagnostic testing (amniocentesis or chorionic villus sampling). Typically in the United Kingdom the threshold for offering invasive testing is a chance of Down syndrome equal to or greater than 1 in 250 (Public Health Genetics Unit, 2005).

The UK National Screening Committee (2003) is very clear about the information that should be provided to women considering antenatal screening. The essential information includes:

- Rationale for offering screening
- Information that the screening tests are optional
- Type(s) of screening tests offered
- False positive and false negative rates
- Diagnostic tests available if results indicate the fetus is at high risk
- Limitations of the screening tests
- The way in which the results will be conveyed to parents
- The options available if the fetus is diagnosed with a genetic condition, including discussion about termination of pregnancy.

However, key components of any discussion on optional antenatal screening, such as the parental approach to having a child with a disability, and attitudes towards termination of pregnancy, are not covered in the guidelines. Appropriate verbal and written information should be available for all parents, including for those who are not fluent in the language that is generally used in that healthcare setting and for those who find reading difficult. In practice, this may necessitate the use of trained interpreters and production of written materials in a range of languages. Specific materials for those who have difficulty reading and people who have sensory impairment or have learning difficulties should be included.

Screening for congenital abnormalities is no different from other optional health services, in that it should be offered in a way that is ethically acceptable and facilitates free choice. This project focused on the provision of information and support to parents that enhances informed choice. The project was underpinned by a review of published literature, websites and current research conducted by the researchers on behalf of the Foundation for People with Learning Disabilities (Barr and Skirton, 2007; Skirton and Barr, 2007).

Full ethical approval to conduct this study was obtained from the Somerset NHS Research Ethics Committee.

3. Aim and objectives of the study

The **aim** of the study was to identify the ways in which prospective parents can be supported to make informed decisions about antenatal screening for fetal abnormalities.

The **objectives** were:

1. To identify the types of information and decision-making support that prospective parents wish to have before making a decision about antenatal screening.
2. To identify appropriate and preferred ways of providing the required information and/or support to prospective parents making a decision about antenatal screening.
3. To identify the characteristics of good and poor practice in offering screening choices, as defined by both professionals and parents.
4. To make recommendations to the Foundation for People with Learning Disabilities on appropriate ways of providing material or information to support informed parental decision-making on antenatal screening.
5. To provide guidance on development of further educational materials for parents.
6. To identify unmet information needs of professionals offering antenatal screening.
7. To identify appropriate and preferred ways of providing the required information related to antenatal screening to professionals.
8. To provide guidelines on the content and type of delivery for training materials for professionals offering antenatal screening, to augment those that exist already.

4. Phase 1 - Focus groups: methods and findings

The aim of this project was to identify the ways in which prospective parents can be supported to make informed decisions about antenatal screening for fetal abnormalities. A first step in achieving this aim and the related objectives was to speak directly with pregnant women, their partners and professionals working within antenatal services. This information was gathered through the use of focus groups that were held with pregnant women and their partners and separate focus groups with staff from antenatal services. Data obtained from the focus groups were used to develop a questionnaire for the second phase of the project on the types of information required to inform choices on antenatal screening and preferred method of delivery.

Focus groups were used as they can have important advantages both in terms of creating dynamic communication between participants and gaining insights into views of a range of people. In particular, the dynamics generated within focus groups can potentially help participants to gain confidence and create safe, non-threatening and non-intimidating environments for discussion. Through providing an open environment for discussion, participants can have opportunities to share their views and thoughts as well as obtaining peer support and validation of views and experiences. Focus groups can provide an opportunity for people to participate in research from which they would otherwise be excluded due to limited literacy skills (Cambridge and McCarthy, 2001).

This chapter reports the findings arising from a total of eight focus groups, four of which were held with pregnant mothers and partners and four of which were held with health professionals who were directly involved in providing the offer of the choice of antenatal screening to pregnant women. The focus groups were held across five areas within England between January and May, 2007.

Location of focus groups

In arranging the focus groups, an attempt was made to recruit parents from a diverse range of geographical locations, socio-economic groups and ethnic background within England. The focus groups were to be held in a total of five locations in England, namely, Taunton, Bridgwater (SW England), Birmingham, London and Hull.

Four focus groups were held with pregnant women and their partners (if able to attend). One focus group was held in London, one in Hull (North Yorkshire) and two in Bridgwater (Somerset). The reason for holding two in Bridgwater was that after holding three other focus groups, we were keen to get the views of younger mothers and were given the opportunity to access parents through the Sure Start centre. An attempt was also made to recruit parents in Birmingham (West Midlands) but this was not successful. In addition, two parents who wished to attend the focus groups were interviewed individually. In Hull, one father was unable to attend the focus group at the allocated time,

and in Taunton two people were unable to attend the focus group at the last minute, leaving only one mother.

Identifying participants for the focus groups

i) Parent groups

The focus groups with parents included pregnant women and their partners. In both phases of the study, an attempt was made to recruit some parents prior to the offer of screening and some after the offer of screening to provide different perspectives on the screening process; this included seeking to include women who had, as well as those who had not, chosen to accept the offer of screening.

A local key contact midwife (in four out of five cases this was the local antenatal screening co-ordinator) agreed in each area to help to recruit parents for focus groups. Recruitment was undertaken through antenatal clinics and by community midwives. Information about the study was given to prospective parents either by health professionals involved in their care or via information on a website (Appendix 2).

The following inclusion and exclusion criteria were applied when recruiting pregnant women and their partners to focus groups:

Inclusion criteria

- Pregnant women 18 years and over
- Partners (of pregnant women) 18 years and over
- Individuals who were able to understand the study and give informed consent.
- Individuals who were sufficiently fluent in English to be able to contribute to a group discussion or respond to a questionnaire.

Exclusion criteria:

- Women who were experiencing a complicated pregnancy (and their partners)
- Individuals who were not able to give informed consent.

ii) Professional groups

Participants in these groups were drawn from health professionals (from four geographical locations) who were actively involved in offering antenatal screening to parents. These included screening midwives, midwives working in the community or antenatal clinics, ultrasonographer, obstetricians and general practitioners. Recruitment of a purposive sample was undertaken via both Primary Care Trusts and acute NHS Trusts. Information about the study (Appendix 3) was given to prospective participants by the local key contact, in each case this was the antenatal screening coordinator.

Attendance at focus groups

Focus groups with pregnant women and partners

A total of 22 prospective parents participated in the focus groups for pregnant women and their partners. This included 17 women and 6 male partners (Table 1) and a further two people (one pregnant woman and the partner of another woman) were interviewed separately. In total information was gathered from 24 participants. An overview of the biographical details of parents attending the focus groups is provided in Table 3.

Table 1: Profile of focus groups for pregnant women and their partners

Location	Total number of participants	Pregnant women	Partners
Focus groups			
Bridgwater, Somerset	10	5	5
Bridgwater, Somerset	2	2	0
Birmingham	0	0	0
Hull	5	5	0
London	5	4	1
Total	22	16	6
Interviews			
Taunton	1	1	0
Hull	1	0	1
Total	24	17	7

Focus groups with professionals

Across the focus groups for professionals, 22 participants who are directly involved in antenatal screening for fetal abnormality contributed (Table 2). This included five antenatal screening coordinators, one obstetrician and one antenatal ultrasonographer. An overview of the biographical details of professionals attending the focus groups is provided in Table 4.

Table 2: Profile of focus groups for professionals

Location	Total number of participants
Taunton	4
Birmingham	7
Hull	3
London	8
Total	22

Table 3: Demographic profile of parents attending focus groups

	Bridgwater	Hull	London	Individual Interviews
Gender				
Female	7	5	4	1
Male	5	0	1	1
Age				
<25years	6	3	0	
26-40 years	6	2	5	2
Over 40 years	0	0	0	
No of children already born				
0	12	4	1	1
1		1	2	1
2			2	
Occupation				
Student	1			
Manual or clerical	3	2		
Managerial	7		1	1
Professional	1	3	2	1
Other			2	
Highest educational achievement				
Secondary (e.g.GCSE)	3	1		
Vocational	5	2		1
A Level, BTEC of HND	1		1	
Diploma	0			
Degree	3	2	4	
Higher Degree				1
Ethnic background				
White British	11	5	5	2
White Other	1			

Table 4: Demographic profile of professionals attending focus groups

	Taunton	Birmingham	Hull	London
Gender				
Female	4	7	3	8
Male				
Age				
20-29 years	1	1	0	1
30-39 years	0	2	0	1
40-49 years	2	2	2	3
50-59 years	1	2	1	3
Years since qualification				
< 1 year	0	0	0	1
1-3 years	1	0	0	0
4-5 years	0	1	0	0
6-10 years	0	2	0	0
> 10 years	3	4	3	7
Occupation				
Antenatal midwife	1	2	1	1
Hospital and community midwife	1	1	1	3
Antenatal screening coordinator	1	2	1	1
Medical doctor	1	0	0	0
Other		2 (midwives in fetal medicine)	0	1 (Student midwife) 1 Sonographer
Ethnic background				
White British	3	6	3	5
White Irish				1
White Other	1			
Asian Pakistani		1		
Black African				1
Black Afro-Caribbean				1

The process within the focus groups

Focus groups were held in a comfortable room with no disruptions. All focus groups followed a similar pattern, which commenced with introductions of all the people present over refreshments. Following this, the previously provided explanation of the nature and rationale for the project being undertaken was revisited and consent for participation and to audio recording of the focus group was reconfirmed.

It was clarified that information provided would be treated confidentially. Participants were also reminded that their involvement in the focus group was voluntary and they could choose how much they wished to say in response to the questions asked within the group and for how long they wished to stay.

After the information about the focus group had been clarified and people had agreed to participate, each participant was asked to complete a proforma sheet which gathered biographical details, in order that an overview of the people who attended the focus group could be reported (Table 3 and Table 4).

Following introductions from the researchers and the other group participants, the interview guide (Appendices 4 and 5) was used to structure the questions and prompts used within the focus groups. One of the researchers facilitated the group and the second kept field notes, at times contributing observations to prompt further discussion among participants. Across the eight focus groups the roles undertaken by the two researchers alternated.

After each question was asked, group members were encouraged to talk freely and express their views. The discussion among participants continued until it appeared that all group members felt they had given their views.

Each focus group concluded with a verbal summary of key points discussed to confirm these reflected the message conveyed by participants. Focus groups lasted between 45 minutes and 70 minutes.

Pregnant women and their partners were given a £10 voucher for a major department store in thanks for their participation in the focus group. An offer was made to pay travel expenses for parents and professionals who attended focus groups.

Data collection

Each of the focus groups was audio recorded on digital recording equipment. Field notes and observations were made by the second researcher present during each focus group. On completion of each group, both researchers discussed the group and added to the field notes that had been made during the group.

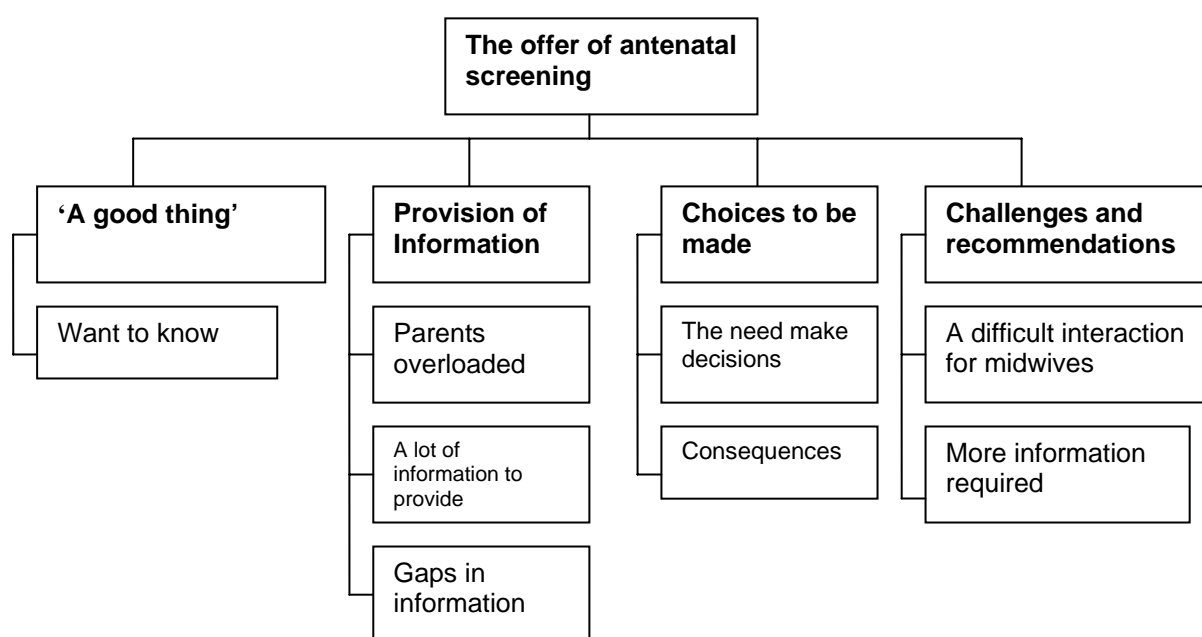
Data analysis

Verbatim transcriptions were made of the taped discussions and all these were read and analysed independently by Heather Skirton and Owen Barr, using a grounded theory approach. Tina Wells and Julia Frost also independently coded a number of the transcripts to verify the analysis. Following the independent analyses, Heather Skirton and Owen Barr met to discuss their analysis and agree the main themes identified. The findings of the focus groups provided a rich source of data that was used as a basis for the development of the questionnaires used in Phase 2. During the data analysis process, NVivo 7 was used to assist the process of data management.

Findings

The findings identified from the focus groups are presented under four main headings (Figure 1). The main themes reported have been identified across the data from both parents and professionals participating in the focus groups. Where key findings were only identified among either parents or professionals, these are reported as such within the sub themes.

Figure 1: Overview of themes identified within focus group discussions



'A good thing'

Parents within the focus groups were clear that the offer of antenatal screening for Down syndrome was available and they all reported being aware of this. Parents talked about how they had been provided with written information and also seemed to be clear that they had a choice to make as to whether they accepted screening or declined it.

Across the focus groups the offer of antenatal screening for Down syndrome was viewed as a 'good thing' by parents and professionals. Professionals agreed that the opportunity to receive information in order to make choices was positive and could reassure parents.

Parents also acknowledged the opportunity to receive information and gain some 'peace of mind'. Several parents highlighted how they would wish to know if they were at a higher risk of expecting a child with Down syndrome in order to prepare for further tests and the possible birth of the child with Down syndrome.

'I thought if it came back high risk then they said you would sort of prepare yourself a bit more for something else because if it comes back high risk you can have the amniocentesis.'

'We decided really as long as we were prepared for whatever was thrown at us to a certain extent, or prepared as well as we could be I think we both decided that we were happy to have this child whatever, cause it was just a joyous occasion really.'

However, not all midwives held a similar view to parents and, for at least one midwife, there was a direct connection between deciding whether to continue with a pregnancy and the decision to have a screening test. She appeared to see these as totally interconnected and did not identify the potential of a test to inform the preparation for the birth of a child with Down syndrome, stating:

'At the end of the day only they can make that decision as to whether they would terminate or not and therefore you have got to bring them back to say well could you see yourself with a Down's baby, could you see yourself having a termination and then take it from there and work backwards and do you want the test or not.'

Provision of information

Parents overloaded

Parents recognised the need to receive information during pregnancy and provided examples of the range of information they received and the number of professionals who provided them with information. Added to this, they talked about information they obtained for themselves from books, magazine and the internet, as well as information shared informally from family and friends.

Although accepting the need for information, many parents reported feeling completely overloaded with what they were given or told. They had difficulty deciding what to read and what to leave aside, possibly for a later time. As one parent put it:

'Well she (the midwife) gave us some leaflets in a folder which was actually that thick, just one of hundreds of things to read through.'

Another mother commented:

'I know that I didn't speak up more at the, cause you get so much information in that one, I mean you are only 12 weeks and you just get in your head well I am actually being pregnant and you get all this information put to you..., I should have really asked more questions I think'.

All parents appeared to have memory of receiving information about antenatal screening for Down syndrome, but their opportunities for discussing the information varied considerably. Some parents reported how the midwife had provided the information and the opportunity to discuss it. For example, one mother commented positively that:

'Obviously I was given the information to read through and we did discuss it and I found my midwife very helpful in having that opportunity to talk about I suppose, for me again it was my age and she had made it very clear on my notes I could go away and think about it... she also indicated telephone numbers I could ring if I wanted to discuss it further'.

However, many mothers who received the leaflet (which they did find helpful) reported that they had few opportunities for discussion unless they personally took the initiative.

'I don't think that they did with me I just got a leaflet and it was try reading and that was it.'

'it was just there's the leaflet to read and basically its been with me it was just get on with it yourself.'

'...if I had had more of a chance I would have been prepared to sit with somebody and discuss it more. I mean I only got to discuss it with me and my partner really, so just read through the leaflet.'

A lot of information to provide

Midwives recognised that there was a lot of information to be provided in a short space of time and felt that this affected the opportunities to discuss antenatal screening. As one midwife commented:

'I think one of the difficulties as well is when we are giving these women the information of all the screening tests including all of the bloods and the anomaly scan and the triple test we are doing the initial booking and they are given so much information at that point that you just wonder how much information they are actually taking on board because we are talking about car safety, we are talking about diet, about their health generally, asking them lots of questions then on top of that we are talking about all the screening tests, their bloods tests, everything, and I think at that point it is really difficult for them to take it on board. That's why I think that the level of understanding is quite poor in a lot of the screening tests from women'.

Midwives also appeared aware that pregnant women received a lot of information and might only read it when they think it is most relevant to them, for instance when attending for another appointment or when they are concerned. One midwife noted what she felt was a common response from parents when she asked if they had read the information provided after they had been recalled for another appointment:

'...sometimes they say 'well, I didn't read it until you rang me yesterday' but they had it and that is the important thing that when they needed it they had it and I think we can't expect everybody to read everything that we give them but it is of some comfort if they have it to hand when they feel that they need to access the information.'

Furthermore, even when pregnant women had been provided with information, there was a concern among midwives as to assumptions that were being made about background knowledge. There was some uncertainty expressed as to how much women really understood it and whether they agreed with any proposed screening because they were unsure about what to ask and therefore agreed to proceed without further discussions. One midwife summed this up when she stated:

'I think also when we are talking about screening we make huge assumptions that people understand what we are talking about, particularly with some of the conditions we talk about like Down's syndrome. What does Down's syndrome mean to some people? I mean a lot of them do know what it does but not everybody does and also like percentages, you know we reel off this risk and that risk... well there is a lot of information that is quite difficult to grasp and you know we are familiar with it but somebody who is faced with that information on a first occasion they are probably going to say yes, yes, but this is the millionth bit of information you are throwing at them and they are going to say yes aren't they?'

Faced with the need to convey information to pregnant women and their partners, and accepting there is a lot of information to be provided, some midwives reported adopting a strategy of *'getting the balance right'*, as one midwife noted:

'...it's making sure that they know enough but not frightening them or making them feel very negative about the pregnancy...that you have raised their awareness but not sort of frightened them or felt that you have put too much emphasis on the possibility of problems'.

Gaps in information: the nature of screening

Despite being aware of the offer of antenatal screening for Down syndrome being available and the majority of parents having received written information about this, there still appeared to be considerable confusion about the nature of the screening and the procedures that may be involved. The majority of parents viewed screening for Down syndrome as a blood test, but for others there was confusion with amniocentesis, as noted below when parents were discussing their understanding of screening for Down syndrome.

'An injection going straight through your stomach and into your sac...That would be the first thing that I would think of, an injection'.

'Yes, like the Down's Syndrome test. The first thing I would think, you know, is a huge needle going straight through your stomach. Yes, I decided that I didn't want the injection into the amniotic fluid and I thought that when I actually took my bloods that I was going to actually have that done but it was just discussed when I had my next appointment with the midwife'.

The focus of the parents' thoughts about antenatal screening was quite narrow and was directed towards the screening for Down syndrome. It was also noted that many pregnant women did not view the mid trimester scan as a screening test.

In contrast, midwives viewed screening in pregnancy from a wider perspective and included within this *'screening tests that we offer to women in pregnancies so from infectious diseases to blood grouping and rhesus antibodies through to Down's Syndrome and fetal anomaly scans'*. Many midwives did acknowledge that at times antenatal screening is used as *'shorthand'* for the offer of antenatal screening for Down syndrome.

Gaps in information: the mid trimester scan

Midwives also appear to recognise that:

'...the parents' perception, they don't see it [mid trimester scan] in the same way as we see as an opportunity to look for they want to see whether the baby is laying correctly. It is a chance to have a scan and see the baby and information about those two things doesn't always marry up'.

The confusion among parents was also highlighted by a midwife who commented that:

'People who will willingly say no to blood tests because that isn't what they want will hardly ever refuse a scan because they don't see it as a screening test'.

A few parents had thoughts about the scan as providing an indication of how the baby was progressing:

'I thought that the 20 week scan for me, not that I went thinking screening but for me it was another way of not confirming but yes everything seems to be OK'.

However, the focus for parents was not on screening, but rather on the scan as performing a social function:

'I am going to have a picture of my baby at end of this and put in my purse and show everyone. I didn't think I wonder if they find this, or find that, I didn't worry about it at all'.

'I had geared myself up so much to ask them if it was a boy or a girl on the 20 week one anyway and I was really excited to find out whether it was a boy or a girl.'

For one mother it was only during the scan that she realised a problem might be found:

'I really realised that they actually weren't really looking so that they could give me a nice day it was actually because they were measuring all the bits and pieces.'

Gaps in information: lives of people with Down syndrome

Within the focus groups pregnant women and professionals were asked to share their understandings of the lives of people with Down syndrome. It became clear that, apart from people who had family relatives with Down syndrome or one parent who had worked with people with Down syndrome, people's understanding was based on people with Down syndrome they had met socially or had heard of from other people.

The views expressed by pregnant women and their partners were a combination of respect, empathy, uncertainty, pity and in some instances stereotypical views of people with Down syndrome.

Respect and understanding of individuals are evident in comments such as:

'They were quite good at my primary school with that lad... They treated him differently and all that, but because everyone still got on with him, and we still went round with him. I don't obviously know, but I don't think he felt left out... I think if you have that support you are all right.'

'I had a friend down the road who had Down's Syndrome ...I mean he was lovely he is such a kind and caring chap and I just think they have an awful lot of love to give, Down Syndrome children, they just seem very carefree. I don't think it is as such a disability, maybe in some people's eyes it is.'

'I know of someone, I think he is about 35 or something, and he is ever so nice and he has a better social life than me sometimes, he goes to computer classes and all sorts.'

Some views of parents were more directed towards stereotypes, uncertainty and pity, including comments such as:

'I think you get Down syndrome groups, adults going off for the day to the beach and stuff. You couldn't actually physically go off and get....but you could go to town and do stuff on your own if you had Down's, but I think if you are put in a group or somewhere where you feel comfortable, and you are in a group with other people with medical conditions, the same as you....'

'I would feel quite upset actually, if I see a lad or a girl on her own walking around town, who had Down's I would feel quite sad for them, so I would think

oh, they are on their own. But there again you get specialist schools and stuff where you can send your babies things like that, which I think is really, really good, because they are going to need a lot more attention than normal school'.

It was clear that midwives had a clearer understanding of the nature of Down syndrome as a medical condition:

'...you know all the midwives know Down syndrome. They know the features; they know the life expectancy is now about 70 odd now. They are aware that the majority might have cardiac defects'.

However, the views expressed by other midwives also reflected sadness, pity and stereotypical impressions:

'It is sad, really, really sad. It is shocking. I don't have anything against Down syndrome babies, nothing at all, but I feel if somebody had a baby that was Down syndrome I would feel very, very sad for them...we know that, it is still a hard life isn't it? We know that the normality, if you like, has been taken away from them. Their expectations have been taken away from them'.

'I knew a family who had a Down Syndrome boy. He is still alive, he is in his thirties now, but they had horrendous trouble when he was little. They found it very difficult to cope with life actually'.

Some midwives recognised a need to learn more about the lives of people with Down syndrome in a structured way, for example through professional training, from parents or directly from people with Down syndrome. However, this view was not shared universally, as captured in the view of one midwife who stated:

'...[knowledge of wider lifestyle issues] fall outside our remit, because we finish with them at 28 days.'

Choices to be made

Need to make decisions

Parents and midwives all seemed well aware that the offer of screening could lead to the need for more decisions to be made. Indeed one pregnant woman recognised this when she stated:

'I suppose it is a bit like a risk assessment to see whether you need it to go through to the next step... That's what I view it as, whether you are going to be at high risk of something or low risk of something, and whether you needed then to see whether you wanted to go through for further tests.'

The need to consider practical aspects, such as how one would manage as a parent or the impact of existing children was put forward by another mother as their reason for deciding to undergo screening:

'... it would be nice to bring every child into the world, but at the end of the day the way that I was thinking is you have to be a bit practical about it and OK it would have to be pretty bad to not have the baby but what went through my mind was that you might have to contemplate or be prepared to make that choice at some time if the test came back really bad would you be prepared to go through with it so it's a compromise really.'

Another mother commented that, although they were not at risk of anything in particular they *'just wanted to sort of be, just to have that bit of confidence to have the screening, to feel I wasn't such a high risk as I thought I would be'*. Undertaking the test as a means to seeking peace of mind was explicitly stated by one mother, although they did appear to recognise the possibility of the need for further decisions and tests as noted in their comment:

'...my own feeling was have the test done if it comes back high risk we will look and see what to do if it comes back low risk fine it's peace of mind and we can get on with the next 6 months'.

Similar views were expressed by another mother when she stated:

'I wanted as much information as possible really so I would be in control of what was going to happen. What could be done?'

It was noted that pregnant women did not make decisions totally on their own and in each of the parents' focus groups there was discussion on how women had discussed issues with midwives and other friends and family members. They were also clear that in their situations the decision they would make about further tests and the future of any pregnancy would be a joint decision with their partner.

As two women put it:

'I feel very strongly that it is not just my baby, he helped put it there, do you know what I mean?'

'...we decided really as long as we were prepared for whatever was thrown at us to a certain extent, or prepared as well as we could be I think we both decided that we were happy to have this child whatever'.

Consequences

Parents and midwives appeared to recognise that screening will provide information that may lead to the need to make further decisions about additional tests or procedures. There was some discussion in the focus groups about the potential decision that ultimately a pregnancy may not continue, either because of the decision by parents to terminate the pregnancy or as a complication of amniocentesis.

Parents and midwives appeared to separate these out from decisions about screening. As one mother recounted:

'My midwife didn't like make that great a deal out of it to be honest she just sort of said do you want it and if it comes back low risk that's good and if it comes back high risk you can cross that bridge if and when you come to it and that was it really.'

Other mothers appeared to have given some consideration to the future decisions that may need to be made, but held the view that these would only be made after further information was available. They did recognise that some of this information may not be possible to provide. One mother recounted the comments of her midwife as having reasoned that:

'...at the end of the day it is your decision what you have done but she said obviously if you do have the Down's test then it all depends at the end of the day whether you would be happy.'

Another mother recognised the uncertainty of any decision made as to the future potential of a child with Down syndrome:

'I think the other thing as well is if there was a test that said yes you are going to have a Down's Syndrome and on a scale of 1 to 10 this is how bad it is going to be then that would affect your decision if you know that 10 is the worst it is possibly going to be then you can say that if my baby is going to be born and have a quality of life that is next to nothing...'

Some midwives who participated in focus groups also expressed concerns about situations when a baby with Down syndrome is born unexpectedly. There appeared to be an expectation that, given the screening that was in place, it should be possible to identify babies with Down syndrome before birth. The reaction of midwives on the birth of a child with Down syndrome, as noted earlier, has been reported as one of sadness. However, there is also a concern for some midwives about the possibility of litigation. One midwife recounted her initial thoughts following the birth of a baby with Down syndrome unexpectedly by stating:

'Just this morning, there was a baby born unexpected Down's syndrome and the first thing I thought was, do I know her? Is she one of my patients, did she have a nuchal scan? All these sort of things...without even seeing her, that is just being aware that this has happened, and I am thinking, and in my mind thinking, did we offer her everything. Did she have every opportunity to choose to go, but obviously she didn't, in the sense that it was undiagnosed and whatever, and before you even get to dealing with the emotional side of the whole thing, I couldn't agree more. I think we might think that having a baby that has Down's syndrome is acceptable for other people, but I don't necessarily think it is acceptable to us.'

In the above quotation it appears clear that the initial concerns of the midwife on hearing of the unexpected birth of a child with Down syndrome was the possibility of an error on their behalf or the service, rather than the welfare of the mother or baby. It also appears that the assumption was made that, if

screening had been accepted, the condition would have been identified, which does not take account of false negative results.

Challenges and recommendations

A difficult interaction for midwives

The process of offering an antenatal screening test for Down syndrome to pregnant women was difficult for midwives on two levels: practically in terms of communicating the information, and at an ethical level.

Across the focus groups, midwives talked about how there was a heavy reliance on the written information. However, this presented challenges when communicating to a level that ensured understanding, when there was uncertainty around a woman's ability to understand the written information. Most commonly, difficulties arose when the woman to whom the offer was being made did not speak or understand English very well because it was not her first language. In such circumstances midwives would have sought to provide written information in the woman's language; however, this written information was not always to hand.

'We have, you can get hold of information, but the information we routinely give out is not directly translated in other language than English. So some kits, like the Down's syndrome programme have produced quite good translations in a wide variety of languages, we don't have them sitting around...'

'But sometimes they don't read the language they speak and that is another issue for our client group as well, we have to be aware of that even if we have that information we would need a verbal interpreter.'

It was also noted that written information was often not available in the language required. Although other language versions were planned, midwives felt they were not available soon enough or, because of the number of languages spoken, not available at all.

'They decided to roll it out in English and then translations to follow but when that has happened in other cases the translations haven't followed. They get the money to roll it out in the first place and then that gets dropped by the wayside...'

'I think sometimes it can be even harder because sometimes the women do not understand the information being given, especially where English is not their first language. The problem is the fact that we do not have full access to all the information leaflets in the different languages, and I find that very very annoying...'

The lack of written information then led in some instances to a reliance on someone to interpret what midwives were saying. At times this was done face to face with an interpreter present. However, that was not always possible and it was necessary to use phone based interpreter services, such as Language

Line. Even when such services were satisfactory, use of telephone interpreters added a limiting dimension to the person to person interaction between the midwife and mother. At times it was difficult when some of the words did not easily translate into the women's language and a further explanation had to be given:

'There are some languages that I mean, information does not translate – there are things you can't translate in other languages. It is not that you can't, because it has not been done – it is as simple as that.'

'But even with interpreters, they will say I don't know how to relay that particular information because that is not in the language, but you see the thing is, that you often find, that they can't interpret.'

Given the nature of the choice being offered, midwives appear to prefer to use interpreting services rather family members, relatives or friends, although this was not without some concerns:

'But even if you use an interpreter they are going to put their slant on it, you don't know do you what an interpreter is saying.'

These concerns increased when family members acted as interpreters and some midwives worried about how the offer of the choice may be presented to some women by relatives who may not want to worry a pregnant women or who hold strong views:

'I think sometimes too when you get a relative coming, they don't always translate it correctly. Occasionally they would tell their friend or relative what they think they would like to hear, rather than being absolutely objective about it.'

'...that language barrier that was one thing that is quite difficult if you have got a lady that is a non English speaking lady, which bearing in mind... if you are using the father as the interpreter try not to take into the religious beliefs cause a lot of people who have religious beliefs about non termination do actually have screening tests explained to them, if you said a whole long spiel about a screening test and the father interprets it as one sentence you know he hasn't said what you have said and we talk about the screening test and they say no she doesn't want it, that is particularly difficult.'

Challenges also arose when women whose first language was English could not read at a sufficient level to understand the information provided, due to difficulties in literacy. However, as two midwives noted, such difficulties are often well concealed and may be missed:

'...from what I know about it, people that aren't that good at reading or have difficulty in reading English are very good at deceiving people into believing that they can because its still got a taboo around it and so they may accept it and say thank you.'

'That is something that is very difficult, as I am having to deal with that problem in that I have a client who is nearly 34 weeks, and it is only now that we have discovered that she can't read or write, because she hid it very well. Um... until you actually meet them in person, you won't know. Even then they may not necessarily tell you that they actually....'

'I have been in a situation where we've had.....I gave a lady a set of notes as she has come unbooked and the doctors won't see you without your notes. If you can complete the front section for us and there was just something, you just knew there was something. Then eventually she said she did not have her pen with her today, and asked if one of us would complete it for her, which was no problem. But when we took her into the room, she told me...'

Throughout the focus groups with midwives it was clear that presenting the offer of antenatal screening for Down syndrome (and the questions that may follow on from the results) was difficult for some midwives. Many midwives reported practical difficulties in conveying the information; however, another dimension was the difficult situations and conflicting emotions midwives experienced, for instance:

'...sometimes you end up having to recall people about something that they probably haven't ever had discussed with them when you were offering them the test and that might be you know that the triple test has flagged up that there is an increased risk of (another condition). You can't ignore it because they need to be told about it but it's quite difficult to call people back and say actually you know this is something completely different to what we spoke to you about but you are at increased risk of this thing and this puts you in quite a difficult position'.

Another midwife outlined her thoughts when she was faced with:

'...a woman who has for example perhaps had three attempts at an IVF pregnancy and got pregnant on the 3rd attempt and then wants Down's Syndrome screening I sometimes find that quite challenging. It's not the fact that she wants screening but it's the fact of what it might lead on to and what she has been through but obviously you can't let any of that influence any of your discussions with her but I do find that kind of thing quite challenging sometimes'.

Some other midwives felt uneasy with the presence of the offer of antenatal screening for Down syndrome as a service and one midwife expressed the conflict by stating:

'...[screening] is from the very beginning something that I have felt very uneasy about. It is the whole concept of Down's Syndrome screening in the first place. You can argue it both ways, can't you? You can argue, yes, you should give women the choices, but you can also argue that it is eugenics... and we shouldn't be offering people the opportunity to kill these babies off in the first place'.

More information required

Three key gaps were identified in relation to the offer of antenatal screening for Down syndrome. These were: confusion over the nature of 'screening' as distinct from diagnostic tests; the purpose of the mid trimester scan, and information about the lives of people with Down syndrome.

When considering the availability of information on the lives of people with Down syndrome, both as children and adults, it was found that the pregnant women, their partners and professionals attending the focus groups all appeared to agree that more information would be particularly useful. It was felt this information should be balanced, showing the positives and also the difficulties that may be encountered and possible solutions. One parent summed this up as:

'To hear from a parent's point of view would be very, very helpful. This is our daily routine. This is what we do, this is what don't do, this is how we cope when you know, when he is not so willing to compromise with us. I think that would be very, very helpful.'

It was felt important by professionals that information provided included:

'...the human aspect to some of the information we give- I think it is all very clinical the information we have and something a bit more...'

Both parents and professionals felt that information should be provided in a range of formats, but with the emphasis on electronic formats that could be more easily updated. The formats mentioned included DVDs, web based material and possibly information on memory pens that could be taken away and uploaded on personal computers by parents or professionals. For parents, DVDs were seen as particularly useful at getting information across, as one parent commented:

'Like all the best sort of baby information that we have had, the ones that we have really, that I took in the most, is DVD stuff and you watch it and actually take it in but we have been given so much literature you know. I don't mind reading, I read quite a lot anyway but it's just literally having time to take it all in.'

The opportunity to work through material at one's own pace was seen as in contrast to the current approach of large sections of information provided at different times, as one parent put it:

'It's like everything comes in bursts when you first find out it's all in burst, bang done and then 12 or 20 weeks whatever, bang another load of stuff, and then you come to now another load of stuff and then there is the birth. There is like long periods of doing absolutely nothing in between... It would be nicer, I mean I enjoy it if it is drip fed to me, so like the only way I can compare it is if you subscribe to an internet newsletter, once a week you get something through that says you are now 30 weeks pregnant this is what happens and everything.'

One possibility supported by the majority of parents and professionals was the use of a DVD with relevant information that could be run on a small TV within the antenatal clinic as an introduction to other resources that may be available.

It was recognised that a considerable amount of written material already existed. Although there may be some merit in updating this when it is being reviewed, to reflect a broader picture of the lives of people with Down syndrome, it was not considered a priority to rewrite all this material. Rather it was felt it would be useful to provide an up to date list of the material already available and how to access this. However, another suggestion was to include more information on screening and people with Down syndrome together with other conditions in magazines about pregnancy and also books. It was acknowledged some people may skip over this information and there was a need for it to be balanced, and *'not too scary'*, but it was felt it could be a useful avenue to make information available to parents.

In discussing with professionals their needs for information, the content areas were the same as for parents. However, professionals felt that in addition to web based material there was a need to review how the information was provided. It was noted that a teaching package on antenatal screening for Down syndrome already existed but:

'...because of you know shortness of staff and things most places haven't been able to introduce that but it's a full day's training about Down's syndrome'.

It was acknowledged that midwives who had the opportunity of attending training with the National Screening Committee teaching package found it very beneficial, but there continued to be difficulties in both finding teachers and having the resources to release staff to attend study days. While it is accepted time is still necessary to avail oneself of web based material, it did provide more flexibility in when it could be accessed and was not a lost resource if people were not able to attend at a given time.

5. Phase 2 – Surveys: methods and findings

Phase 2 – Questionnaires

Two distinct questionnaires (one directed at parents, one at professionals) were developed from the analysis of the focus group data. Questions related to the following topics: knowledge of antenatal screening tests; conditions potentially detected using screening tests; those involved in decision making; information or support used in decision making; unmet needs for information or support; knowledge of the lives of those with Down syndrome; preferred method of delivery of any additional information sought. The questions were reviewed and amended by members of the Advisory Group. The final questionnaires can be found in Appendices 6 (parent questionnaire) and 7 (professional questionnaire).

Parents and professionals were recruited via NHS antenatal clinics and maternity services in inner London, Taunton (Somerset), Bridgwater (Somerset), Hull (North Yorkshire) and Birmingham (West Midlands) by the local key contact midwife. Pregnant women and their partners were informed about the study in antenatal clinics, using posters and information sheets.

Participants were also recruited through advertisements on appropriate websites and via organisations (Appendix 8) for prospective parents and professionals. Two newspaper advertisements in the Metro (in Newcastle and in Birmingham) were used to attract a range of participants. An effort was made to recruit people of non-white British ethnic background through managers and key workers in a number of community centres and cultural organisations (Appendix 8). It was made known that a translator could be funded for those who were not fluent in English. An information sheet very similar to those used for Phase 1 was given to potential participants. Potential participants were able to go directly to the questionnaire and complete it and the consent form online, or they were sent a paper copy of the questionnaire and consent form, with a reply paid envelope. The questionnaire data were entered onto a database (SPSS) and analysed using descriptive statistics and cross-tabs.

A total of 111 questionnaires was received from parents, while 78 were received from professionals involved in offering screening. The results will be presented separately.

Parents

Description of those who responded

Fifty-three people returned a postal questionnaire, while 58 completed the questionnaire online.

Of those who responded, 90.1% (100) were pregnant women and 9.9% (11) were partners of pregnant women. All respondents were aged between 20 and 48 years. The demographic characteristics (education, ethnic group and employment status) of parents who participated are presented in Table 5.

Information on screening

Recall of screening tests offered

In terms of tests offered, 39.6% (44) of parents were offered a nuchal translucency scan, 14.4% (16) a combined test, 41.4% (46) a triple or quadruple test and 93.7% (104) a detailed ultrasound scan. In this study, 13.5% (15) remembered being offered an antenatal screening test but could not remember the nature of the test.

Discussion of the test with a health professional

When asked if screening tests had been discussed with them by a health professional, 87.4% (97) said it had been discussed, 3.6% (4) said it had not and 9% (10) could not remember if it was discussed or not.

The gestation at which screening was first discussed with a health professional varied enormously, with 4 weeks gestation being the earliest and 20 weeks the latest. Discussion occurred at 4-10 weeks for 40.5% (45), at 11-13 weeks for 35.1% (39), at 14-16 weeks for 7.2% (8) and between 17 and 20 weeks for 3.6% (4).

For the majority of respondents, screening was discussed by the midwife (Table 6). However, 2.7% (3) could not remember who discussed screening with them.

Table 5. Demographic characteristics of parent survey participants

Characteristic	Groups	% (number)
Education (highest level achieved)	Secondary school (GCSE)	14.4% (16)
	Apprenticeship	1.8% (2)
	A level, BTEC, HND or equivalent	10.8% (12)
	Diploma	14.4% (16)
	Degree	51.4% (57)
	Other	6.3%(7)
	Current working status (outside home)	Full-time
Part-time		18.0% (20)
Maternity leave		15.3% (17)
Not working outside home at present		13.5% (15)
Ethnic group		White English
	White other British	6.3% (7)
	White Irish	2.7% (3)
	White any other	7.2% (8)
	Mixed any other	3.6% (4)
	Asian Pakistani	1.8% (2)
	Asian Bangladeshi	1.8% (2)
	Black or Black British African	0.9% (1)
Geographical area (recorded from paper questionnaires only)	South East England	11
	South West England	16
	West Midlands	16
	North East England	0
	Other	10

Table 6. Health professional who discussed screening (parents had option to name more than one health professional)

Health professional	% (number)
Midwife	78.4 % (87)
General practitioner	13.5 % (15)
Obstetrician	13.5 % (15)
Health visitor	0
Other health professional – not named - ultrasonographer	6.3 % (7) 1.8% (2)
Cannot remember	2.7% (n=3)

Table 7. Type of screening accepted

Type of test	NHS	Private
Nuchal translucency scan	25.2 (28)	9.0% (10)
Combined test	8.1% (9)	0
Triple or quadruple test	22.5% (25)	0.9% (1)
Detailed ultrasound scan	85.7 (95)	3.6% (4)
Accepted but not sure which test	6.3% (7)	
No screening accepted	2.7% (3)	

Parents were questioned about the conditions that could be detected by screening tests. Only 77.5% (86) thought Down syndrome could be detected, although that is the condition for which antenatal screening is offered. Spina bifida and heart defects were thought to be detectable by 79.3% (88) and 70% (78) of parents respectively. Fragile X was believed detectable by 9% (10) of those parents who responded, cystic fibrosis by 20.7% (23) and 2.7% (3) believed autism would be detected. However, 25% (28) thought that all kinds of abnormalities would be picked up by the screening tests. Other conditions cited by the 15.3% (n=17) of respondents who thought other abnormalities could be detected were physical abnormalities, abnormal organs, chromosomal anomalies and mosaicism.

Information about screening

In response to a question about sources of information on screening (other than health professionals), 57.7% (64) replied that they had not used other sources of information. Others cited a variety of sources of information (Table 8).

Table 8. Other sources of information about screening

Source	% (number)
Partner	5.4 % (6)
Friend	18.9% (21)
Relative (not partner)	9.9% (11)
Other expectant parents	5.4% (6)
Other sources (included booklets, friend who is a doctor, internet).	9.9% (11)

Decision making

When asked who **was** involved in making the decision about screening, 79.3% (88) of respondents said both parents were involved, 14.4% (16) said it was only the mother and 6.3% (7) replied that only the woman's husband or partner was involved. However, only 31.5% (35) said they discussed the decision with their partner a lot, while 19.8% (22) said they had discussed it a little. Therefore almost a third of parents who reported it was a joint decision had not discussed it with their partner.

The final decision was made by both partners in 75.7% (84) of cases, while twelve participants (10.8%), all pregnant women, said that their partners had left it to them to make the decision. Of the 11.7% (13) who said they made the decision alone, one was a partner of a pregnant woman. Two participants felt that they had not made the decision; in one case they were advised to have screening by a health professional and in another the couple were given the information too late in the pregnancy to make a decision.

When asked who **should** make the decision, the results were very different. The number who thought that both parents should make the decision dropped to 42.3% (47), while 41.4% (46) thought it should be left to the pregnant woman, and 8.1% (9) thought that both parents and other relatives should make the decision together. The number who felt that the woman's husband or partner should make the decision alone remained the same at 6.3%.

While 64.9% (72) of parents felt they had all the information they needed to make their screening decision, 20.7% (23) felt they did not have enough information and 12.6% (14) were not sure if they had enough.

When asked what was helpful in making the decision, the following responses were received (Table 9).

Table 9. Level of helpfulness of sources of information

Type of help	Possible responses	% (number)
Information from health professionals	Very helpful Slightly helpful Not helpful Didn't use	52.3%(58) 38.7% (43) 6.3% (7) 2.7% (3)
Advice from health professionals	Very helpful Slightly helpful Not helpful Didn't use	45.9% (51) 27.0% (30) 10.8% (12) 15.3% (17)
Information from books and leaflets	Very helpful Slightly helpful Not helpful Didn't use	37.8% (42) 40.5% (45) 5.4% (6) 15.3% (17)
Information from friends and relatives	Very helpful Slightly helpful Not helpful Didn't use	10.8% (12) 41.4% (46) 9.0% (10) 36.9% (41)
Information from other parents	Very helpful Slightly helpful Not helpful Didn't use	10.8% (12) 30.6% (34) 9.9% (11) 45.9% (51)
Experience of knowing people with the condition being screened for	Very helpful Slightly helpful Not helpful Didn't use	20.7% (23) 17.1% (19) 3.6% (4) 57.7% (64)
Information from the internet	Very helpful Slightly helpful Not helpful Didn't use	22.5% (25) 33.3% (37) 3.6% (4) 40.5% (45)
Information from parent support groups	Very helpful Slightly helpful Not helpful Didn't use	6.3% (7) 10.8% (12) 2.7% (3) 78.4% (87)

When asked specifically about the most useful type of help, a large range of responses was given, but the most common were named as discussion with the midwife or other health professional (14), support by partner or husband (8), and reading booklets and books (6).

Those who felt they did not have enough information to make their decisions wanted more information about the following topics:

Table 10. Topics on which information was wanted

The tests available	9.0% (10)
The abnormalities screened for	9.0% (10)
How likely the test was to detect abnormality	13.5% (15)
How the test was done	5.4% (6)
What the results mean	10.8% (12)
What options are available after the test	9.9% (11)
The life of an affected person	11.7% (13)

When participants were asked if they had enough support to make a decision, 64.9% (72) felt they had enough support, whereas 17.15% (19) would have liked more support and 15.3% (17) were unsure. Partners were named most frequently as the most useful source of support (9), with midwives (7) second in rank.

Participants said that they would have liked more personal discussion with health professionals and information offered to them at an earlier stage in the pregnancy.

Table 11. Personal contact with individuals with Down syndrome

Never known child with Down syndrome	20.7% (23)
Never known adult with Down syndrome	17.1% (19)
Knew child with Down syndrome in past	19.8% (22)
Knew adult with Down syndrome in past	15.3% (17)
Know child with Down syndrome now	5.4% (6)
Know adult with Down syndrome now	3.6% (4)

The majority of respondents (50.5%, 56) had never had personal contact with a person with Down syndrome and only a small minority had current contact with a person affected with Down syndrome. However, only 19.8% (22) thought that knowing about the lives of those with Down syndrome was irrelevant, with 35.1% (39) thinking they would like to know more and 44.1% (49) believing they already knew enough about the lives of those affected with the condition.

While 64.9% (72) felt that knowing more about the lives of people with Down syndrome would not have affected their decision to have screening, 13.5% (15) thought it would have been helpful to them and 9.9% (11) felt they knew a lot about Down syndrome already. Although a small minority, there were those (2.7%, 3) who felt that knowing more about the lives of those with Down syndrome would have made their decision harder.

In terms of accessing information about the lives of those with Down syndrome, the responses were as indicated in Table 12 below. Parents were invited to tick as many as they felt they would use.

Table 12. Sources that would be used for additional information on screening

Source of information	% (number)
Additional information provided in person by midwife or doctor	44.1% (49)
Internet site recommended by a health professional	24.3% (27)
Information from the parent of a child	18.9% (21)
Video provided by a midwife or doctor	3.6% (4)
DVD provided by a midwife or doctor	11.7% (13)
Book or leaflet provided by a midwife or doctor	26.1% (29)
DVD or video in antenatal waiting area	7.2% (8)
Other form of information (group discussion session)	1.8% (2)

Over a third (37.8%, 42) of those who participated thought that the method they were **most likely** to use to obtain information about the lives of those with Down syndrome was via a book or leaflet given by a health professional. Another one-third (34.2%, 38) would prefer to use an internet site recommended by a health professional, while 19.8% (22) would use a DVD provided by a health professional. Only 4.5% (5) preferred to watch a DVD or video in an antenatal clinic. There were no differences in preference between those who replied by post and those who completed the questionnaire using the internet.

Professionals

Seventy-eight professionals who offer antenatal screening responded by completing a questionnaire, 75 replied online and three returned a questionnaire by post.

Description of those who responded

Of 78 participants, only one was male. All were midwives, and 87.2% (68) also had a nursing qualification.

Table 13. Demographic characteristics of professional survey participants

Characteristic	Groups	% (number)
Professional role	Hospital and/or community midwife	50.0% (39)
	Antenatal screening co-ordinator or screening specialist	38.4% (30)
	Independent midwife	7.6% (6)
	Midwife in birth unit	2.5% (2)
	Student midwife	1.2% (1)
	Ethnic group	White English
	White other British	7.7% (6)
	White any other	6.4% (5)
	Black or Black British African	1.3% (1)
Age	20-29	2.6% (2)
	30-39	39.7% (31)
	40-49	32.1% (25)
	50-59	21.8% (17)
	60 years and over	2.6% (2)
		Missing data
Area of practice	Central area of city	20.5% (16)
	Suburbs in a city	12.8% (10)
	Large town	14.1% (11)
	Rural area	51.3% (40)
		Missing data

Information on screening

Table 14. Type of screening offered to women in own practice

Type of test	
Nuchal translucency scan	41.0% (32)
Combined test	19.25 (15)
First trimester serum screening	26.9% (21)
Second trimester serum screening	53.8% (42)
Detailed ultrasound scan	62.8% (49)
Not involved directly in offering screening	3.8% (3)

Of the midwives surveyed, 92.3% (72) said they felt well enough prepared to offer screening in the work setting, while 5.1% (4) said they did not and 2.6% (2) were unsure. Those who did not feel prepared said that they need to read more (1), needed an informal update (1) and needed to do a mandatory update that had been cancelled due to lack of staff (1).

Respondents reported that they felt the following conditions could be detected by current screening offered (Table 15)

Table 15. Conditions detected by screening

Condition	Number of professionals who believed the condition could be detected by screening	Detected by:
Spina bifida	64.1% (50)	By serum screening (8) By USS (9) By combination of serum screening and scan (18) By USS and amniocentesis (1) No response from 14 of those who thought it could be detected.
Autism	0	
Heart defect	53.8% (42)	Ultrasound scan (27): most commented that detection was not 100%. No response from 15 of those who thought it could be detected.
Cystic fibrosis	16.7% (13)	Echogenic bowel on USS (6) USS (2) Carrier test for parents (1) DNA test (1) Blood spot (2) No response from one of those who thought it could be detected.

Condition	Number of professionals who believed the condition could be detected by screening	Detected by:
Down syndrome	64.1% (50)	Amniocentesis (4) NTS, serum screening or combination of both (29) No response from 17 of those who thought it could be detected
Galactosaemia	1.3% (1)	Blood spot (1)
Fragile X	9.0% (7)	Amniocentesis or CVS (3) Anomaly scan (1) Exclude female fetus on scan (1) No response from 2 of those who thought it could be detected.

Table 16 indicates on a scale of 0-10 (where 0 is low and 10 is high), how much the midwives thought they knew about the lives of those with Down syndrome.

Table 16. Knowledge of the lives of those with Down syndrome

Score	Number of respondents
0-3 (low)	34.6% (27)
4-6	19.2% (15)
7-10 (high)	46.1% (36)

Table 17. Personal contact with individuals with Down syndrome

Never known child with Down syndrome	15.4% (12)
Never known adult with Down syndrome	12.8% (10)
Knew child with Down syndrome in past	33.3% (26)
Knew adult with Down syndrome in past	28.2% (22)
Know child with Down syndrome now	30.8% (24)
Know adult with Down syndrome now	20.5% (16)

While 29.5% (23) of the midwives surveyed felt they knew enough about the lives of those with Down syndrome to help parents make a decision about screening, almost as many (26.9%, 21) wanted to know more. Only 9.0% (7) thought knowledge of the lives of those with Down syndrome was irrelevant to their role.

Supporting decision making

Midwives were asked about their approach to parents when offering screening. Only one said he or she explained the screening to the mother only, as she was the one carrying the fetus. Over a third (34.6%, 27) explained to both parents if they happened to be present, but a further 25.6%

(20) tried hard to explain the screening to the baby's father as well as the mother and 6.4% (5) responded that they liked to involve the father if possible.

When offering screening, 57.7% (45) said that they felt equally comfortable whether the mother accepted the offered screening or not; only one midwife felt more comfortable if the mother accepted and three if she declined. However, a number of participants (24) failed to reply to this question. Almost two-thirds said that they did not feel more vulnerable to litigation if the mother declined screening. However, two reported feeling vulnerable and one said she was worried parents did not understand the implications of having a child with Down syndrome when they declined screening.

The vast majority had no concerns about inequity of services in their area.

Table 18. Sources of information about screening – midwives' views

Source of information	% (number)
Additional information provided in person by midwife or doctor	67.9% (53)
Information from the parent of an affected child	21.8% (17)
Video provided by a midwife or doctor	19.2% (15)
DVD provided by a midwife or doctor	37.2% (29)
Book or leaflet provided by a midwife or doctor	56.4% (44)
DVD or video in antenatal waiting area	23.1% (18)
Other form of information	
• Recommended websites	6.4% (5)
• Support group	1.2% (1)

Almost a third (29.5%, 23) of those who participated thought that the method parents were **most likely** to use to obtain additional information about screening was a book or leaflet given by a health professional. A total of 15.4% (12) thought parents would prefer to use an internet site recommended by a health professional, while 14.1% (11) thought they would prefer to watch a DVD provided by a health professional. Only 2.6% (2) thought parents would prefer to watch a DVD or video in an antenatal clinic.

6. Summary and discussion of the main findings

Parents appear to appreciate the offer of screening, with uniform approval from respondents in both phases that choice was 'a good thing'. However, many parents expressed the view that they did not have enough time to consider their decisions and there were some instances where screening was not discussed with them until the second trimester. The provision of information about so many aspects of pregnancy, birth and even postnatal care at the first booking consultation with the midwife was seen by both parents and midwives to be counter-productive to achieving informed decision making about screening tests.

Parents and professionals agreed that in some cases parents use screening to gain reassurance about the health of the fetus, rather than seriously considering that it may indicate they have an increased chance of having a baby with Down syndrome. Professionals seek to make a genuine 'offer' of screening, but the apparent separation of screening and other decisions that may arise if a high risk result is obtained may leave parents vulnerable if screening results indicate a higher risk. While some midwives talked about encouraging parents to think about the screening decision in terms of their values and beliefs, many simply said they did not have enough time to spend on the issue of screening.

There is recognition amongst parents and some, but not all, professionals that screening could be used to prepare for the birth of a child with Down syndrome and this is a valuable role for it. Some parents wish to use screening to help them prepare for the birth of a baby with Down syndrome. While agreeing it could be used by some parents to prepare, reports from parents about the way screening had been discussed with them indicated that some midwives felt that screening was inappropriate if a parent was not willing to have a termination.

While the printed material provided about screening is appreciated by parents, this is not generally supported by adequate personal discussion with the health professional offering screening. The majority of our participants could write and read English, but there are serious concerns about those parents who cannot read well or who do not have material in their languages. Given these results and the information included in a report by the BBC on the increasing number of immigrant mothers using NHS services (BBC, 2008), there is a need for more material that is not reliant on written text alone.

While pregnant women and their partners felt that the decision about screening should be made by both parents, in the majority of cases midwives reported that they only involved fathers in the discussion if they 'happened to be present'.

Both parents and professionals overestimated the ability of the screening tests to detect a range of abnormalities. This causes difficult issues for both parents and professionals when a child is born affected with Down syndrome and this is not expected. Indeed, through the study we found examples of the

birth of an affected child being viewed as a failure of the system and a 'critical incident'. More thought may be needed on the way critical incident reporting could reflect on midwives' attitudes to babies with Down syndrome.

Professionals in the focus groups appeared to be overly confident in the ability of the current arrangements to detect all instances of a baby with Down syndrome, but there were contradictory findings from the survey data. In addition, some professionals believed antenatal screening could detect conditions such as cystic fibrosis and fragile X.

Midwives were concerned that parents were not well-prepared for the possibility that abnormalities may be detected via an ultrasound scan, believing it was viewed more as a social experience than a screening test. However, some parents had come to a realisation as they were waiting for the scan that problems might be detected. There appear to be insufficient information materials that focus on the use of scans to detect abnormalities in the fetus. There was little evidence that parents were being asked to consent to scans in the same way as they were asked to consent to other screening tests. Findings from the 2007 Healthcare Commission Review of Maternity Services (Healthcare Commission, 2007) showed that 27% of UK mothers had not felt that they had not had any choice about having a 20 week detailed ultrasound scan, while 8% had not had the reason for the scan explained to them.

The majority of parents and professionals recognised that knowledge of the lives of people affected with Down syndrome is relevant to the decision about screening. However, there were concerns expressed by many parents and some professionals about the way in which having a child with Down syndrome is presented in a medical context and is often a negative rather than a balanced view. Health professionals were wary of recommending material on Down syndrome from parent support groups as they felt this was overly positive.

A number of parents and professionals supported the provision of information that provides a balanced account of the lives of people with Down syndrome and moves beyond the clinical condition and childhood images. Both groups stressed the need for information that was recommended by health professionals. The two methods of providing information thought to be most useful by both parents and professionals were via books and leaflets or via a website recommended by a professional.

Strengths and weaknesses of the study

We aimed to achieve a maximum variation sample of parents, and the range of ages, educational background, occupation and parity of parents in the focus groups was broad. This was a strength of the study and ensured that the survey questionnaire was based on findings of focus groups with a range of participants.

One of the main challenges was recruitment in Phase 2. A range of strategies was used, but achieving the numbers presented was a struggle. Despite personal contact between the authors and those running community centres and relevant websites, the number of responses from parents of black and ethnic minority groups was poor. This needs to be addressed in further work.

While the range of professionals was satisfactory in terms of age and years of experience, it is relevant that surveys were only completed by professionals working as midwives. While this is the main group involved in antenatal care, it would have been helpful to have the views of general practitioners, obstetricians and ultrasonographers. Letters to the Royal College of General Practitioners, Royal College of Obstetricians and Gynaecologists and the Society of Radiographers did not elicit replies.

7. Recommendations

1. At the initial consultation between midwife and prospective parents, a high priority should be given to discussion of issues specific to the antenatal period, with discussion of labour, birth and the postnatal period left to a later time when it is more relevant.
2. Information about antenatal screening should be produced in a format that is easily understandable, regardless of ability to read: for example, in a book or DVD that relies upon visual images to communicate the key points. This could be presented in the form of a decision tool. Care should be taken with terminology, for example the use of the words risk and chance.
3. Information about the detailed ultrasound scan should be provided to prepare parents for the possibility of a problem being detected. This should be used as the basis for seeking informed consent.
4. Information about the lives of people with Down syndrome should be available to parents and professionals, with an emphasis on the social (rather than the purely medical) aspects of life. This material should provide a balanced view of the range of potential issues faced by both the affected person and his or her family. This material should be available in booklet form and via a website.

8. Dissemination of the study findings

The results of this project have been or will be disseminated via:

- Interim reports and a final report to the Foundation for People with Learning Disabilities.
- Publication of the results in peer-reviewed professional journals (2 papers in progress).
- A briefing paper for the Foundation for People with Learning Disabilities.
- Reports in lay language in the newsletter and website of the Foundation for People with Learning Disabilities.
- Presentations to appropriate professional groups, including at the following conferences:

Barr, O. and Skirton, H. (2008) Royal College of Nursing International Research Conference, April 2008

Skirton, H., Barr, O., Wells, T. and Frost, J. (2008) European Society of Human Genetics Conference, May 2008

Skirton, H., Barr, O. and Doris, F. (2008) International Congress of Midwives, June 2008.

9. Glossary of terms

Affected individual: A person who has the signs and symptoms of the genetic condition.

Amniocentesis: Withdrawal of amniotic fluid from the amniotic sac, usually for the purpose of testing the fetal chromosomes.

Carrier: A person who is generally not affected with the condition, but carries one mutated copy of a gene.

Chorionic villus biopsy: Removal of cells from the chorionic villi (developing placental tissue).

Chromosome: The physical structures into which the DNA is packaged within the nucleus of cells. The usual number of chromosomes in humans is 46.

Down syndrome: a condition that occurs when an individual has three copies of chromosome 21 rather than the usual two copies.

Genetic counsellor: A person whose main professional role is to offer information and support to clients who are concerned about a condition which may have a genetic basis.

Genetic screening: This term usually refers to population screening for a genetic variation or mutation.

Neural tube defect: An abnormality of the spinal column or cranium (spina bifida or anencephaly).

Nuchal translucency scan: a method of screening that involves measurement of the nuchal fold (at the back of the neck) in the fetus. A measurement that is larger than normal may indicate that the fetus has Down syndrome or other congenital abnormality.

Spina bifida: A form of neural tube defect in which there is an interruption to the spinal column, with possible herniation of the spinal cord and meninges (myelomeningocele).

Syndrome: A number of physical features or abnormalities that fit a recognised pattern.

Trisomy: Having three copies of a particular chromosome.

Ultrasound scanning: Investigation of physical structures using ultrasound device (sound waves).

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Appendix 1. Project Team and Advisory Group

Principal investigator

Heather Skirton PhD, RGN, Registered Genetic Counsellor, Certified Midwife
Deputy Head (for Research) of School of Nursing and Community Studies
Faculty of Health and Social Work
University of Plymouth
Taunton TA1 5YD
United Kingdom
Telephone 44 (0)1823 366911
Fax 44 (0)1823 366901
Email heather.skirton@plymouth.ac.uk

Co-investigator

Owen Barr PhD, RNMH, CNMH cert, RGN,
Head of School
School of Nursing
University of Ulster
Magee Campus
Londonderry BT48 7JL

Telephone 44 (0) 28 7137 5141
Fax 44 (0) 28 7137 5493
Email O.Barr@ulster.ac.uk

Advisory Group

- Ms Alison Giraud-Saunders, Co-Director of the Foundation for People with Learning Disabilities
- Mrs Mary Fosbrook, Regional antenatal screening co-ordinator and community midwife, Mayday NHS Trust, London.
- Ms Marie Benton, Down's Syndrome Association (for first part of the project)
- Ms Susannah Seyman, Down's Syndrome Association (replaced Ms Marie Benton)
- Ms Faye Doris, Head of Midwifery, University of Plymouth
- Dr Melanie Robson, Consultant Obstetrician, Taunton and Somerset NHS Foundation Trust.
- Professor Jane Sandall, Professor of Midwifery and Women's Health, King's College, London.

Appendix 2. Parents' Focus Group Information Sheet

Research Study Information Sheet Informed choice and antenatal screening study

My name is Heather Skirton. I am a researcher from the University of Plymouth, and I have a background as a nurse and midwife. This information sheet is about a research study I am doing at present.

What is the study about? The study is being done to find out more about the information needed by people who are offered a screening test during pregnancy to see if the baby has an abnormality. We are interested in the views of women and their partners. The results of the study will be used to help us plan how to give the best types of information for people making decisions about screening during pregnancy.

Does this study concern me? If you are 18 years or over and you are currently pregnant or your partner is pregnant, we would value your help with this study.

What will happen if I decide to help? You can phone, write, email or text me to let me know you are willing to help. I will contact you to invite you to a focus group at a meeting room in your local area with some other prospective parents. At the focus group, you will be asked to sign a consent form as a record that you are willing to be involved. The discussion group will take about 1 -1/2 hours. The discussion will be recorded on audio-tape but when it is typed out you will not be able to be identified and your comments will not be able to be connected with your name. I would be very happy to answer any further questions you might have about the study before you decide about being involved. We will be happy to reimburse you for the costs of travelling to the meeting. If any difficult issues arise for you as a result of our discussion in the focus group and you would like to talk with someone about them, we will be able to put you in contact with an appropriate person.

Can I change my mind about being involved? Even if you tell me you would like to help, you can change your mind about being in the study without giving a reason. Your health care will not be affected in any way, whether or not you decide to be involved.

How do I get involved?

If you are willing to help or want to ask a question, please contact me by:

Telephone: (daytime) 01823 366911 **OR** 01823 366902

OR Email: heather.skirton@plymouth.ac.uk **OR** text me on 07968 635909

OR Mail: Heather Skirton, FHSW, University of Plymouth, Wellington Road, Taunton TA1 5YD.

Finallythank you for reading this information sheet. Heather Skirton

Appendix 3. Professionals' Focus Group Information Sheet

Research Study Information Sheet Informed choice and antenatal screening study

My name is Heather Skirton. I am a researcher from the University of Plymouth, and I have a background as a nurse and midwife. This information sheet is about a research study I am doing at present.

What is the study about? The study is being done to find out more about the information needed by people who are offered a screening test during pregnancy for Down syndrome and other congenital abnormalities. We are interested in the views of professionals who are involved in offering antenatal screening. The results of the study will be used to help us plan how to give the best types of information for people making decisions about screening during pregnancy and for health professionals involved in that screening.

Does this study concern me? If you are a health professional who is involved in offering or performing antenatal screening for Down syndrome, we would value your help with this study.

What will happen if I decide to help? You can phone, write, email or text me to let me know you are willing to help. I will contact you to invite you to a focus group in a meeting room in your local area with other health professionals (travel expenses will be reimbursed). At the focus group, you will be asked to sign a consent form as a record that you are willing to be involved. The discussion group will take about 1 -1/2 hours. The discussion will be recorded on audio-tape but when it is transcribed you will not be able to be identified and your comments will not be able to be connected with your name. I would be very happy to answer any further questions you might have about the study before you decide about being involved. In the unlikely event of unsafe practice being highlighted during a focus group, it may be necessary to discuss this with the supervisor of midwives. This will not be done without discussion with you.

Can I change my mind about being involved? Even if you tell me you would like to help, you can change your mind about being involved without giving a reason.

How do I get involved?

If you are willing to help or want to ask a question, please contact me by:

Telephone: (daytime) 01823 366911 **OR** 01823 366902

OR Email: heather.skirton@plymouth.ac.uk)

OR Mail: Heather Skirton, FHSW, University of Plymouth, Wellington Road, Taunton TA1 5YD **OR** text me on 07968 635909.

Finally, thank you for reading this sheet. **Heather Skirton**

Appendix 4. Focus Group Schedule – parents' group

This study is about screening in pregnancy and how parents make decisions about that screening.

Can we start by asking what you understand by the word screening?

If we focus now on screening that might be related to the health of the baby, what do you understand by that?

Which conditions do you think the screening might pick up?

Has your midwife or doctor spoken to you about this type of screening? Can you tell us about that?

Thinking about making the decision about screening, what has been helpful to you? What about anything that has not been helpful?

Have you any suggestions about how parents could be supported in making the decision about screening?

Can you say something about the sorts of discussions you have had with your partner about screening?

Just going back to the conditions that screening is offered for, can you say what you know about the lives of people with those conditions?

Prompt – child, adult, Down syndrome, neural tube defect, cardiac abnormality.

How do you think knowing more about the lives of people with those conditions would affect you when you made your decision about screening?

(if want more information) What way would you like that information to be given to you?

*Prompt – leaflets, in person, CD/DVD, website, video.
Home, in clinic.*

Is there anything you wish to add?

Appendix 5. Focus Group Schedule – professionals' group

This study is about screening in pregnancy and how parents make decisions about that screening.

Can we start by asking what you understand by the word screening?

If we focus now on screening that might be related to the health of the baby, what do you understand by that?

Which conditions do you think the screening might pick up?

In your own practice, how do you discuss this issue with parents?

Prompt – professional and personal challenges, ? equipped, ? support, ? information?

How do you see your role in supporting parents to make the decision about antenatal screening?

Just going back to the conditions that screening is offered for, can you say something about your impression and knowledge of the daily lives of people with those conditions?

Prompt – child, adult, Down syndrome, neural tube defect, cardiac abnormality.

What types of information about the condition or lives of people with the conditions would you find helpful in your practice?

(if want more information) What way would you like information to be given to you?

Prompt – leaflets, in person, CD/DVD, website, video.

Home, in clinic.

Training delivery – pre-registration, post –registration, CPD

What information do you think parents might find helpful?

Prompt - gaps

What way would do you think would be most effective for parents?

Prompt – leaflets, in person, CD/DVD, website, video.

Home, in clinic.

Is there anything you wish to add?

Appendix 6. Parents' questionnaire

Antenatal screening and parental choice

Parent Questionnaire

This questionnaire is about screening during pregnancy. We are asking *you* only about screening that is RELATED to the HEALTH of the BABY.

Before starting the questionnaire, please tell us about yourself. Tick the box beside the correct answer. Are you:

A woman expecting a baby	<input type="checkbox"/>
A person whose wife or partner is expecting a baby	<input type="checkbox"/>

These questions are about what has happened to you during **THIS** pregnancy (your own pregnancy or your wife's or partner's pregnancy).

1. What type of screening tests have you been offered during this pregnancy? Place a tick in the box beside all the answers that apply to you.

Nuchal translucency screening	<input type="checkbox"/>
Triple or quadruple test	<input type="checkbox"/>
Combined test	<input type="checkbox"/>
Detailed ultrasound scan at about 20 weeks of pregnancy	<input type="checkbox"/>
Offered screening, but not sure which test	<input type="checkbox"/>
Do not remember being offered screening test	<input type="checkbox"/>

2. Were the screening tests discussed with you by a health professional?

Yes	
No	
Don't remember it being discussed	

3. If you answered yes to Question 2, at what point in the pregnancy were screening tests (to assess the health of the baby) **FIRST** discussed with you by a health professional?

First discussed atweeks of pregnancy

4. Which health professionals discussed the offer of the screening test with you? Tick all those that apply.

Midwife	
GP	
Obstetrician	
Health Visitor	
Other health professional (please state)	
I remember it was mentioned but can't remember who spoke to me about it	

5. Did you accept any screening tests that were concerned with the health of the baby? Please tick those that apply. If you had them under the NHS tick in the column headed NHS, if you paid privately, tick in the column headed Privately

Type of screening	NHS	Privately
Nuchal translucency screening		
Triple or quadruple test		
Combined test		
Detailed ultrasound scan at about 20 weeks of pregnancy		
Other (please state)		
Accepted screening, but not sure which test		
Did not have any screening tests		

6. Which conditions do you think the screening test might pick up in the baby? Tick all those that you think would be detected by the screening tests you were offered

Spina bifida	
Autism	
Heart defect	
Cystic fibrosis	
Down syndrome	
Fragile X	
All kinds of abnormalities	
Other (please state)	

7. Have you **received information** from anyone (apart from a health professional) about screening in pregnancy?

No, no-one else	
My partner/wife/husband	
A friend	
A relative (eg sister, brother, mother)	
Other parents expecting a baby	
Others (please state)	

8. In your own case, who was involved in making the decision about whether to have antenatal screening? (Tick one answer)

Only the pregnant mother	
Only the pregnant mother's husband or partner	
Both parents	
Parent(s) and other relatives	

9. In general, who do you **THINK** should be involved in making the decision about whether to have antenatal screening? (Tick one answer)

Only the pregnant mother	
Only the pregnant mother's husband or partner	
Both parents if possible	
Parent(s) and other relatives	

10. Have you discussed whether or not to have screening with your wife/husband/ partner? (Tick one answer)

Yes, we discussed it a lot	
Yes, we discussed it briefly	
No, we didn't discuss it at all	
I do not have a current partner	

11. Who made the FINAL decision about whether to have antenatal screening?

My partner and I decided together	
My partner left it to me to make the decision	
I left it to my partner to decide	
I made the decision myself	
Other (please state)	

12. Thinking about making the decision about whether or not to have screening, what has been helpful to you? Place a tick in the correct column box to show the level of helpfulness for each item

For example, if you felt that information from professionals was slightly helpful. Mark like this

	<i>Very helpful</i>	<i>Slightly helpful</i>	<i>Not helpful</i>	<i>Didn't use</i>
<i>Information from professionals</i>		✓		

	Very helpful	Slightly helpful	Not helpful	Didn't use
Information from professionals				
Advice from professionals				
Information from books and magazines				
Information from friends or relatives				
Information from other parents				
Experience of knowing people with the condition that was screened for				
Information from the internet				
Information from parent support groups				
Other				

13. Did you feel you had **enough information** to make your decision about screening? Tick the box beside the correct answer

Yes, I had all the information I needed	
No, I would have liked more information	
Not sure	

If yes, what was the most useful?

If no, what information would you have liked to have? Tick all those that apply

What screening tests are available	
What abnormalities would be screened for	
How likely the test was to detect a health problem in the baby	
How the test would be done	
What the results would mean	
What options there would be after the screening test	
Information about the life of a person with that health problem	
Other (please describe)	

13. Did you feel you had **enough support** to make your decision about screening? Tick the box beside the correct answer

Yes, I had all the support I needed	
No, I would have liked more support	
Not sure	

If yes, what was most useful?

If no, what additional support would you have liked?

14. Have you any other suggestions about how parents could be supported in making the decision about screening?

15. Just going back to the types of conditions that screening is offered for, how much do you know overall about the lives of people with those conditions? (Make a mark on the line in the place that best fits you own knowledge)

Example, if you know very little, mark like this

I know very little_ X_____ I know a lot

I know little _____ I know very a lot

16. Do you know or have you **known anyone personally** with, for example, Down syndrome? Tick those that apply

I have never personally known <i>a child</i> with Down syndrome	
I have never personally known <i>an adult</i> with Down syndrome	
I have known <i>a child</i> with Down syndrome in the past	
I have known <i>an adult</i> with Down syndrome in the past	
I know <i>a child</i> with Down syndrome at present	
I know <i>an adult</i> with Down syndrome at present	

17. Which of the following statements best describes your attitude with regard to making the decision about screening? Tick one answer

I would like to know more about the life of a child or adult with Down syndrome	
I know enough about the life of a child or adult with Down syndrome	
I do not think knowing about the life of someone with the condition is relevant	

18. How do you think knowing more about the lives of people with those conditions could affect you when making a decision about screening?

I do not think it would make any difference at all	
It would have been helpful to me	
It would have made making the decision harder	
I knew a lot about it already	
Not applicable to me	

19. In your opinion, how should any additional information about screening be given to parents? Tick **all** that you believe YOU would use

In person from your midwife or doctor	
At an Internet site recommended by a professional	
From a parent who has a child with the condition	
In a video given to you by your midwife or doctor	
In a DVD given to you by your doctor or midwife	
In a book or leaflet given to you by your doctor or midwife	
By watching a DVD or video in the antenatal clinic waiting area	
Other (please state)	

Thank you very much for your help. We appreciate the time you have taken to complete the questionnaire. Finally, it helps us to know a little more about you when we look at our results, so that we know if we have opinions from a range of different people in the population. The last set of questions is about you.

If you prefer not to answer any of the final set of questions, please feel free to leave the answer to that question blank.

22. Your gender:

Female	
Male	

23. Your age: Years

24. About your work, are you:

Working full time	
Working part-time	
On maternity leave	
Not in work at present	

25. Your usual job:

26. The formal education you have undertaken. Tick all that you have completed

Primary school	
Secondary school (GCSE)	
Apprenticeship	
A-levels (or BTEC or HND)	
Diploma	
Degree	
Other (describe)	

27. Your postcode at home

--	--	--	--	--	--	--	--

28. What is your ethnic group (the options are based on groups defined by the Office for National Statistics). Tick only one box

White

- English
- Other British
- Irish
- Any other white background, write in _____

Mixed

- White and Black Caribbean
- White and Black African
- White and Asian
- Any other mixed, write in _____

Asian or Asian British

- Indian
- Pakistani
- Bangladeshi
- Chinese
- Any other Asian background, write in _____

Black or Black British

- Caribbean
- African
- Any other Black background, write in _____

Other ethnic group

- Arab
- Gypsy / Romany / Irish Traveller
- Any other, write in _____

Appendix 7. Professionals' questionnaire

Antenatal screening and parental consent

Professional Questionnaire

This questionnaire is about screening during pregnancy. We are asking you about screening that is related to the HEALTH of the baby.

First we would like to ask you about yourself. Please place a tick in the box beside the correct answer

1. Are you:

A midwife working in both community and hospital settings	
A midwife mainly working in a hospital setting	
A midwife mainly working in the community	
An obstetrician or obstetric registrar	
A GP	
An ultrasonographer	
Other (please state)	

If you are a midwife, do you also have a nursing qualification?

Yes	
No	

2. Your age:

20-29 years	
30-39 years	
40-49 years	
50-59 years	

60 years or over	
------------------	--

3. Your gender:

Male	
Female	

4. Years in practice where you have been involved in discussing antenatal screening with parents: years months

5. Where you work:

Central area of a city	
Suburbs in a city	
Large town	
Rural area	

6. What is your ethnic group (the options are based on groups defined by the Office for National Statistics). Tick only one box.

White

- English
- Other British
- Irish
- Any other white background, write in _____

Mixed

- White and Black Caribbean
- White and Black African
- White and Asian
- Any other mixed, write in _____

Asian or Asian British

- Indian
- Pakistani
- Bangladeshi
- Chinese
- Any other Asian background, write in _____

Black or Black British

- Caribbean
- African
- Any other Black background, write in _____

Other ethnic group

- Arab
- Gypsy / Romany / Irish Traveller
- Any other, write in _____

7. Your postcode at home

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These questions are about antenatal screening tests that relate to the health of the fetus.

8. What type of screening tests do you offer women in your care during pregnancy? Tick all that apply

Nuchal translucency screening	
First trimester maternal serum screening	
Second trimester maternal serum screening	
Combined screening	
Fetal anomaly ultrasound scan at about 20 weeks gestation	
Other (please state)	
Not involved in offering screening	

9. Do you feel well enough prepared to offer the antenatal screening tests available to parents in your work setting?

Yes	
No	
Not sure	

If you answered no, what further preparation do you feel you need?

10. Which conditions do you think the antenatal screening test might pick up in the fetus? Tick all those that you think would be detected by the screening tests you offer and provide the name of the screening test

Condition	Detected by screening?	Screening test used in your work setting to detect this condition
Spina bifida		
Autism		
Heart defect		
Cystic fibrosis		
Down syndrome		
Galactossaemia		
Fragile X syndrome		
Other (please state)		

11. Thinking about the conditions that antenatal screening is offered for, how much do you feel you know about the lives of people with a condition such as Down syndrome? Make a mark on the line in the appropriate place

Example, if you know very little, mark like this

I know very little_ X_____ I know a lot

I know little _____ I know very a lot

12. Do you know or have you known anyone personally with, for example, Down syndrome? Tick those that apply

I have never personally known <i>a child</i> with Down syndrome	
I have never personally known <i>an adult</i> with Down syndrome	
I have known <i>a child</i> with Down syndrome in the past	
I have known <i>an adult</i> with Down syndrome in the past	
I know <i>a child</i> with Down syndrome at present	
I know <i>an adult</i> with Down syndrome at present	

13. Which of the following statements best describes your attitude with regard to supporting parents to make a decision about screening? (Tick the answer that applies)

I would like to know more about the life of a child or adult with Down syndrome	
I know enough about the life of a child or adult with Down syndrome	
I do not think knowing about the life of someone with the condition is relevant to my work	

14. When you offer screening, which of the following best describes your own approach?

I explain the screening tests to the mother, as she is the one carrying the baby and should make the decision	
I explain the screening tests to both parents if they happen to be present	
I try hard to have the opportunity to explain the screening tests to both parents	
I would like to involve the father whenever possible but pressure of time prevents this	
I find fathers/partners are not usually interested	
I do not offer screening	
Other	

15. Which of the following best applies to you when offering antenatal screening?

I feel equally comfortable whether the mother accepts or declines screening	
I am more comfortable if the mother accepts screening	
I am more comfortable if the mother declines screening	
Depends on the circumstances	
I do not offer screening	

16. Have you **ever** felt worried that you might be more vulnerable to litigation because a mother declined screening?

Yes	
No	
Not applicable	

If yes, can you say more about the situation?

17. Have you **ever** felt concerned because you are unable to offer specific tests to women under the NHS provision in your area?

Yes

No

Not applicable

If yes, can you say more about the situation?

18. In your opinion, how should any additional information about screening be given to parents? Tick **all** that you believe parents might use

In person from the midwife or doctor	
At an Internet site recommended by a professional	
From a parent who has a child with the condition	
In a video given by the midwife or doctor	
In a DVD given by the midwife or doctor	
In a book or leaflet given by the midwife or doctor	
By watching a DVD or video in the antenatal clinic waiting area	
Other (please state)	

19. Which method of receiving additional information do you think parents would be **most likely** to use? Tick only ONE

At an Internet site recommended by a professional	
In a video given by the midwife or doctor	
In a DVD given by the midwife or doctor	
In a book or leaflet given by the midwife or doctor	
By watching a DVD or video in the antenatal clinic waiting area	
Other (please state)	

20. Do you have any other comments to help us with the study?

THANK YOU FOR YOUR HELP WITH THIS STUDY.

Appendix 8. Recruitment – websites and organisations contacted

Table of organisations contacted to recruit parents and professionals

Organisation	Response
To recruit parents	
Africa Advocacy Foundation	No response
Centre for Armenian Information and Advice	No response
Jeevan Project (Asian Women's Mental Health)	Agreed to circulate PIS, sent by email.
Kiran Asian Women's Aid	No response.
Bosnia Herzegovina Advice Centre	No response
The Chinese National Healthy Living Centre	Circulated PIS to other Chinese centres and women's groups.
Chinese Community Centre	Do not have pregnant clients.
Eritrean Community in the UK	Paper forms sent to Mr Russom, he agreed to give to Eritrean women.
Iranian Community Centre	Agreed to give out PIS, paper versions sent to him.
Iraqi Community Centre	Agreed to give out PIS, paper versions sent to him.
Kurdish Cultural Centre	Agreed to give out PIS, paper versions sent to him.
Al-Hasaniya Moroccan Women's Centre	Agreed to help clients with questionnaires, sent 8 PIS and questionnaires.
Pakistani Women's Welfare Association	Agreed to give out PIS and help with questionnaire if needed. Paper copies of PIS sent.
Interconnections	Advertisement put into e-bulletin
Health for asylum seekers and refugees	No response
Black Health Initiatives	Placed ads in their centre in Leeds
Metro newspaper – Newcastle and Birmingham	Paid for ads
Mumsnet	Allowed ad on website bulletin board
Gingerbread Lone Parent Families	No response
Dads UK	Placed advertisement on website bulletin board
Contact a Family	No response
Disabled Parents Network	Placed ad on relevant webpage.
Full time mothers	Posted ad on their website
Twin and Multiple Birth Association	Phoned me back, placed article about the study in their newsletter
Parentline plus	Replied that website mostly for parents of teens.
Stonewall Gay and Lesbian parents	No response
Sure Start	Placed link to study website
Ask a Mum website	Allowed me to post ad on bulletin board

Think Baby website	No response
National Childbirth Trust	National centre did not wish to publicise. Some individual NCT teachers gave information to parents they knew.
BBC Asian Network Radio, Manchester	Interview with researcher on air
<i>To recruit professionals</i>	
Royal College of Midwives	Advertisement posted onto RCM website
Royal College of Obstetricians and Gynaecologists	No response
Royal College of General Practitioners	No response
Society of Radiographers.	No response
Ms Faye Doris	Circulated information to wide professional networks of midwives across UK
Professor Marlene Sinclair	Circulated information to wide professional networks of midwives across UK
Independent midwives	Sent information by email to all members.