Title: Development of a framework and assessment tool to investigate women's understanding of Down syndrome screening information presented by midwives

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Abstract

Aims: The research aimed to identify factors that could influence women's understanding of Down syndrome screening information presented by midwives.

Methods: Current literature was scrutinised. Components that could influence women's understanding were identified and a new framework was developed and refined. Measures were selected and developed to create a tool to assess the framework.

Findings: A new framework and assessment tool, Measuring Understanding of Screening Information and Communication (MUSIC), with developed to assess women's understanding of Down syndrome screening information, their cognitive status and the midwives' communicative style.

Conclusions: This new framework is the first of its kind, encompassing both women's cognitive status and midwife communication as an influence on women's understanding. Applying the framework and tool could inform midwifery practice by providing an insight into whether, to what extent and how, cognitive status influences understanding of Down syndrome screening information, the importance of tailoring information to each woman and highlighting areas of communication that are most effective.

1. Introduction

In England, Wales and Scotland all pregnant women are routinely offered antenatal screening for Down syndrome (DS) at their first meeting with their midwife, the "booking" appointment (UK NSC, 2007). Screening information should increase knowledge in order for women to make informed decisions (de Jong et al. 2014). However, some women undergo screening even though they have relatively little

knowledge of the test or the condition being screened (e.g. Dormandy et al. 2006; Skirton and Barr, 2010).

Advances in genetic/genomic technology are revolutionising antenatal screening and the UK National Screening Committee (UK NSC, 2016) has recommended introducing Non-invasive Prenatal Testing (NIPT) into the National Health Service (NHS) which is more accurate than current forms of screening. The way health professionals' present information is likely to influence screening uptake. Midwives should counsel women in the same way for NIPT as invasive testing as the tests carry similar diagnostic implications. If midwives can effectively communicate current DS screening information and support women's informed decision-making then it is anticipated that it will be easier to incorporate NIPT into practice. This paper proposes a framework to investigate what factors influence women's understanding of DS screening information. The two key factors in this are midwife communication and women's cognitive status.

Midwife communication

A number of researchers have attempted to describe components of language which could influence a listeners understanding. Adams et al. (2009) suggests health professionals should use plain language, limit "medical jargon", use diagrams to aid verbal explanation and checking clients have understood information.

Roter and colleagues (2009) found that individuals with low literacy learnt more in prenatal genetic counselling sessions which were more interactive, had fewer dense chunks of speech and shorter genetic counsellor speech within their speaking turn. Contrastingly, individuals with high literacy benefited from more complex language, dense chunks of speech and less interactivity. The differences required for optimum

learning in those with low and high literacy skills highlight the importance of tailoring information and this has been echoed by a number of researchers (Paradice, 2002; Ormond, 2013).

In order to tailor information it is important that women's current knowledge is established early in the appointment, otherwise time may be wasted either describing Down syndrome, when women already have full knowledge of the condition, or assuming knowledge and describing screening when women have no knowledge of what DS is (Bryant et al. 2010). The Nursing and Midwifery Council state that midwives should "check people's understanding" (NMC, 2018, p.9). However, midwives have expressed that due to workload they often do not ask open questions and encourage time consuming interactive conversation (Porter et al. 2007). Ongoing assessments of understanding throughout appointments are essential to facilitate informed decision-making (Dormandy et al. 2005).

Individuals with low literacy skills may be disadvantaged when presented with written or oral dialogue (Erby et al. 2008; Roter et al. 2009) and are less likely to understand medical information regarding risks and benefits (Tait et al. 2004). Information presented in diagram or picture form to support oral explanations may aid understanding, especially in those with low literacy (CHCS, 2013).

Oral information may be difficult to understand due to its subjective nature. Words can be either abstract or concrete. Concrete words allow the formation of images in our minds (Sadoski et al. 1997), for instance, it is easy to conjure an image of the concrete words; "chair" or "needle". It is much harder to produce an image in our mind of abstract words (Sadoski et al. 1997), such as "care" or "risk". Genetic risk information is often abstract which can complicate communication (Kim, 2009) and influence whether information is understood and remembered by the recipient

(Beukeboom et al. 2013). Roter et al. (2009) found that individuals with low literacy skills had superior learning when information was more concrete. Arguably, due to the subjective nature of abstract words, it would be preferable to communicate using only concrete words in to ensure understanding. However, this seems not to be the case, as Roter et al. (2009) demonstrated that individuals with higher literacy learnt better in prenatal genetic counselling sessions when more abstract information was presented. The role that abstract-concrete language plays in women's understanding has not previously been explored in relation to DS screening within the UK. Further research is necessary to help clarify whether concrete language aids understanding for all individuals, or whether tailoring language, as abstract or concrete, enhances understanding.

Cognitive status

The term cognitive status encompasses a whole set of mental processes such as attention, memory, intelligence, problem solving and reasoning. Cognitive status plays a role in how people process the world around them; therefore it is proposed that it may influence how women understand DS screening information. According to Piaget, cognitive development occurs in stages and the ability to reason abstractly emerges at the age of 12 (Piaget, 1972). Abstract reasoning forms the basis of logic (Tennant, 2005) and allows individuals to apply knowledge to novel situations (Campbell and Ritchie, 2002) and correctly solve problems by imagining alternative solutions (Stern and Prohaska, 1996). However, the speed of development can vary from one individual to another (Piaget, 1972), and it has been suggested that some adults may never truly gain abstract reasoning (Keating, 1979; Cole, 1990; Lehman and Nisbett, 1990).

Some individuals are more likely to ask questions and be more active in discussions than others. These individuals are said to possess high Need for Cognition (NfC). NfC is the extent that people engage in thinking to increase their knowledge (Cohen et al. 1955). Levels of NfC may be an indicator of understanding, for instance, women with high NfC have an "information seeker" disposition meaning they are more likely to ask questions requiring the midwife to provide more information. Thus, NfC could influence both women's understanding and midwife communication.

Cognitive status, in terms of abstract-concrete reasoning (Piaget, 1972) and NfC (Cacioppo and Petty, 1982), has not previously been investigated as an influence on how women understand DS screening information or the midwife's communicative style.

Satisfaction

Dissatisfaction with healthcare often results from a lack of communication (Roter et al. 2007; Deane-Gray, 2008). Good communication should result in women gaining an improved understanding of screening information and a greater satisfaction with the services received (Pope et al. 1998; Paradice, 2002).

In summary, there is a lack of literature on the influence of abstract language, women's cognitive status and resources on women's understanding of DS screening information. There is little evidence outlining how midwives check women's knowledge/understanding and whether they tailor information to suit each woman. All these factors have driven the creation of a new framework and tool to identify factors that may influence women's understanding of screening information.

2. Methods

Aims

The aim was to investigate what factors influence women's understanding of DS screening information. The study was split into two distinct phases:

1. Phase 1 involved developing a framework and measures to address the research questions. This is the focus of the current paper.

2. Phase 2 involved applying and testing the framework in practice. This will be discussed in subsequent papers.

Literature review

An extensive literature review was undertaken across multiple databases. The review identified different factors that could influence women's understanding of DS screening information. These components can be broken down into aspects of midwife communication and women's cognitive status. These are discussed further in subsequent sections and are incorporated into the new framework.

Developing the framework

Phase 1 of the research involved developing a new framework, Measuring Understanding of Screening Information and Communication (MUSIC), as a tool to assess women's understanding of DS screening information, their cognitive status and midwives' communication. The following aspects were considered during the development of the tool:

1. It should be applicable to booking appointments when screening discussions occur.

2. It should assess the interactive nature of communication between the midwife and woman.

3. It should break down communication into multiple components which could influence women's understanding.

4. It should assess the relevance of women's cognitive status.

5. It should assess the primary outcome: women's understanding.

6. It should assess the secondary outcome: women's satisfaction.

7. It should provide an objective measure to ensure inter-rater reliability and test-retest reliability.

MUSIC and midwife communication

Koenke (1987) outlined the following factors could influence understanding of written information:

> syntactic complexity, concept density, abstractness, organisation, coherence, sequence of ideas, page format, length of line print, length of paragraph, punctuation, illustrations, colour and reader interest (Koenke, 1987, pp.674).

Key components to ensure women's understanding have been set out for many years, these include checking knowledge, understanding, explaining medical terms, inviting questions and using diagrams (Ley, 1986). This research uses similar components to assess midwife's oral communication, outlined below.

Language complexity

Koenke's (1987) "syntactic complexity" is mirrored in the language complexity component of MUSIC. As highlighted by Ley (1986) the importance of explaining medical terms is vital since medical terminology may be unfamiliar. Words such as ''inheritance'' and ''susceptibility'' are unknown by the general population (Erby et al. 2008) and the term "genetics" itself has different meanings to different people (Burke et al. 2007).

Dynamics

Depending on the dynamics of conversation, information may be easier or harder for women to understand and process. If midwives provide screening information in a dense chunk or "lesson type" format (Roter et al. 2009) there may be inadequate time for the woman to process all the information provided. More interactive speech allows equal contribution from the woman and midwife (Hunter, 2006; Deery and Fisher, 2010).

Knowledge / Understanding Check

Women's pre-existing knowledge and perception of genetics may affect their comprehension and recall of provided information (Michie and Marteau, 1996; Thompson et al. 2014). Questioning clients' knowledge can help guide the remainder of the appointment, providing the healthcare professional with insight into areas that are not fully understood and require further explanation (Weil, 2000). Questioning women's understanding throughout the appointment can clarify any misunderstandings and ensure the woman is making an informed decision. However, there are currently no guidelines to outline exactly how midwives should check women's understanding (Ahmed et al. 2013).

Resources

The resources component of MUSIC encompasses Koenke's idea of including "illustrations" and "colour" in written materials and Ley's (1986) use of diagrams to aid understanding. The extent that resources are used to aid midwives' verbal explanations is unknown.

Abstract Language

Lastly, the Abstract language component endorses Koenke's (1987) idea of "abstractness". The research may illustrate whether concrete language aids understanding for all individuals, or whether tailoring language, as abstract or concrete, enhances understanding.

Originally, additional components of "Non-Directive", "Length of appointment" and "Technical terminology" were considered for MUSIC. These were subsequently excluded for a number of reasons. Non-directive communication does not influence understanding but decision-making, which is not assessed in this research. Length of DS discussion, instead of length of appointment was measured since only the section of the appointment that covered DS screening information was analysed and not the whole appointment. Technical terminology makes language more complex, therefore assessment of technical terminology has been included in the "Language Complexity" component of MUSIC.

MUSIC and women's cognitive status

The exploration of cognitive status could highlight the role it plays, not only in women's understanding, but also in influencing the communication between the midwife and woman. NfC can influence women's understanding and midwife communication, since the "information seeker" disposition of those with high NfC means they might ask more questions and the midwife will provide more information. The best predictor of success on Piagetian tasks, and thus demonstration of abstract reasoning skills, is NfC (Stuart-Hamilton and McDonald, 2001; Parry and Stuart-Hamilton, 2010). Therefore, it is expected that women with higher abstract reasoning skills should have higher NfC.

Satisfaction

Ensuring a positive pregnancy experience goes beyond ensuring the physical health of the woman and her infant (Haines et al. 2013). It is important that women's satisfaction with antenatal care is established to gain their views regarding how and whether communication can be improved.

3. Findings

A new framework (Figure 1), Measuring Understanding of Screening Information and Communication (MUSIC), was developed to provide an insight into influences on women's understanding of DS screening information provided in antenatal appointments.
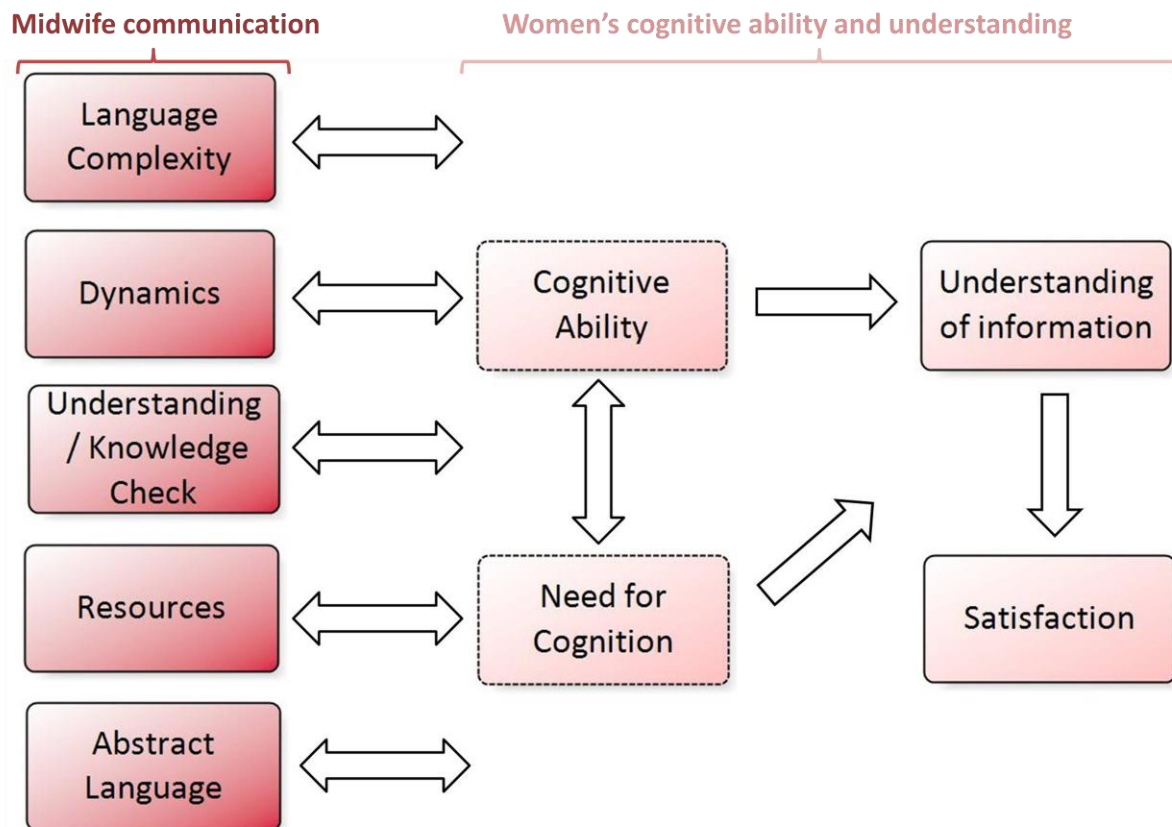
Figure 1. The MUSIC framework with communication, cognition and outcome measures. Cognitive measures are within dotted lines as these may be mediating factors, rather than direct influences, on understanding

Developing and selecting measures to assess midwife communication

In addition to the development of MUSIC, this research has involved developing new measures and combining existing measures (table 1) to create a tool to assess the framework.

Table 1. Midwife communication components of MUSIC and associated measures. Scoring matrix for these measures is set out in Appendix 1

Communication Measures	
Language Complexity	**Number:** Word count and sentences
	Average: Sentences per paragraph, Words per sentences
	Readability: Passive Sentences, Flesch Reading Ease and Flesch-Kincaid Grade Level. Passive sentence measures how informative text is; the higher the score the more complex and formal the text. The higher the score on the Flesch Reading Ease the easier the text is to understand: | Score	Difficulty
0-40	Very difficult – Difficult
40-80	Average
80+	Easy – Very Easy | Flesch-Kincaid Grade Level should aim for a score of 4.0-5.0
	Technical terminology score: If any of the following eight words are used in the appointment it will be noted whether the midwife provides an explanation of these words or not: Screening, Amniocentesis, Amniotic, Diagnostic, Obstetrician, Millilitres, Obstetrician, Chromosome.
Dynamics	**Interactivity:** Number of speaking turns in a session per minute
	Pace: Average number of syllables per word x total transcript word count/session length (in seconds)
	Duration: Average duration in seconds spanning a block of uninterrupted speech
Check Knowledge / understanding	**Knowledge check**: Do midwives check women's current knowledge levels when they commence the appointment
	Understanding check: Do midwives check that women understand the information throughout the appointment. How do midwives check understanding, do they explicitly ask or use paraphrasing
Resources	Are additional resources used to aid explanations, e.g. pictograms
Abstract Language	**The Linguistic Category Model** (Semin and Fiedler, 1988): The higher the score the more abstract the text. Four word categories are distinguished to produce an "abstract score", computed as follows: | Word Type	Score
Descriptive Action Verbs (e.g. yell, hit, walk)	1
Interpretative Action Verbs and State Action Verbs (e.g. help)	2
State Verbs (e.g. to think, admire, hate, appreciate)	3
Adjectives (e.g. social, aggressive, honest, reliable)	4	

Developing and selecting measures to assess women's cognitive status, understanding and satisfaction

Two questionnaires were designed to assess:

1. Women's demographics, cognitive status and their understanding of DS screening information (Appendix 2)

2. Women's satisfaction with DS screening information provided by midwives (Appendix 3)

The measures used to assess these concepts are discussed. See Appendix 4 for a detailed scoring system for the questionnaires.

Cognitive status

For the purposes of this research, cognitive ability will be assessed on the abstract-concrete continuum. Abstract tests correlate highly with, and draw on more components of, intelligence than concrete tests, which correlate less with, and draw on fewer components of intelligence (Marshalek et al. 1983). The tests that have been selected vary by reasoning level (concrete vs. abstract), domain (verbal vs. non-verbal), and difficulty, allowing a comprehensive assessment of women's concrete-abstract reasoning.

Cognitive ability (Verbal Abstract Reasoning Measure)

Gorham's proverbs (1956) have been used widely within psychology to classify individuals who do not possess abstract thought. Proverbs measure verbal reasoning and can assess where individuals lie on the abstract-concrete continuum (Campbell and Ritchie, 2002). Participants will be provided with multiple-choice response proverbs. This ensures better standardisation of the measure as each answer is scored as Abstract (2), Somewhat Abstract (1) or Concrete (0). Open

questions could elicit many responses which would take longer to code and cause difficulty in defining the answer on the abstract-concrete continuum. This study does not rely on proverbs alone as an assessment of abstract ability; Raven's Standard Progressive Matrices (RSPM) is also used to measure non-verbal reasoning ability.

Cognitive ability (Non-Verbal Abstract Reasoning Measure)

The original RSPM consists of sixty items with five sets containing twelve items each. Each set represents a different conceptual theme and increases in difficulty, therefore, each set requires a different thought process (Jones, 2010). Each item within RSPM requires the identification of relationships between patterns and reasoning to make comparisons between them (Coaley, 2009). Due to time constraints and attrition concerns, a shorter nine item version will be employed which has the same predictive power, reliability and validity as the sixty item matrices (Bilker et al. 2012).The nine items (A11, B12, C4, C12, D7, D12, E1, E5, E7) sample each conceptual theme of the full matrices.

Alternate tests of cognitive ability were considered. The Mill Hill vocabulary scale (Raven, 1962), and the National Adult Reading Test (Nelson, 1982) were disregarded as they do not measure abstract reasoning ability and instead measure verbal intelligence, and neither of these scales would capture women's ability to solve novel problems, such as those presented by the midwife. The Alice Heim (Heim, 1975) and the Wecshler Adult Intelligence Scale (WAIS-IV) (Wechsler et al. 2008) were also considered however, time was a concern due to the length of these tests. Furthermore, WAIS-IV assesses intelligence as a whole, however the current research aims to capture only abstract-concrete reasoning, therefore, the majority of the scale would be disregarded. Whilst WAIS-IV includes proverbs as an

assessment of verbal reasoning abilities and uses pictures to assess non-verbal reasoning abilities, the current study selected shorter tests.

Need for Cognition

The Need for Cognition (NfC) scale was developed by Cacioppo et al. (1984) who tested the scale on different populations and reported a reliability coefficient of a=0.90 (Cacioppo et al. 1996). The test includes 18 statements where individuals score on a likert scale the extent that they enjoy thinking about particular tasks and exerting cognitive effort.

Down syndrome understanding

A six item multiple-choice understanding questionnaire was developed to assess understanding of DS information covered in the booking appointment. Questions were created from similar studies which included questionnaires to assess understanding of screening information and from information in the "Screening for Down's syndrome in pregnancy, Antenatal Screening Wales" leaflet (2013).

Satisfaction measures

Care must be taken with the interpretation of satisfaction questionnaires since participants often do not want to criticise their healthcare provider (Fitzpatrick, 1993) and thus generally provide high satisfaction ratings (Dowswell et al. 2010; Andersson et al. 2013). However, when service users are asked more specific questions about aspects of their healthcare care they tend to be more critical (Sofaer and Firminger, 2005). Thus, specific questions regarding certain aspects of information provided by the midwife are included. The satisfaction questionnaire will be sent to women a week after their appointment and thus prior to receiving any screening results which could influence their satisfaction with provided information.

Demographics

A demographics section will capture women's age, ethnicity, English language ability and parity. Features of the appointment which could affect communication will also be captured, such as the presence of another during the appointment, or the appointment setting; home or clinic.

Piloting

The questionnaire was piloted with a convenience sample of colleagues and lay individuals (n=45). Based on the results of the pilot it was anticipated that the questionnaire to assess women's cognitive status and DS understanding would take approximately 20 minutes to complete, and the satisfaction questionnaire would take approximately 5 minutes. Time was an important consideration when designing the questionnaires to try and create as short a questionnaire as possible without loss of functionality.

4. Discussion

Previous research has established that not all women are fully informed regarding DS screening (e.g. Dormandy et al. 2006; Beulen et al. 2016). Due to the introduction of NIPT into the NHS (DoH, 2016) there will be additional pre-screening information for women to understand within booking appointments. It is imperative that DS screening information is currently understood before a test with greater implications is fully introduced.

This paper has introduced phase 1 of a study which involved developing a novel framework and tool to assess factors which could influence women's understanding of DS screening information. Whilst some factors have previously been considered such as language complexity and dynamics (e.g. Roter et al. 2009), MUSIC is the

first of its kind to encompass a combination of factors which could influence women's understanding. All or some components of the framework may influence women's understanding of DS screening information.

In Phase 2 the research team will apply the MUSIC tool to assess women's understanding of DS screening information, their cognitive status and midwives' communicative style. The study that will follow will encompass a mixed methods design with two distinct components, transcript analysis of recorded consultations and quantitative questionnaires.

This research is the first to simultaneously evaluate multiple aspects of midwife communication and women's cognitive status as an influence on their understanding of DS screening information. By revealing the day-to-day consultations between midwives and women an insight into the way DS screening is communicated and consequently understood can be obtained. The framework may clarify the importance of tailoring information to women's cognitive status by gaining an insight into how it influences women's understanding and midwife communication.

5. Conclusion

During phase 1 a framework, MUSIC, has been developed which incorporates a combination of factors which could influence women's understanding of screening information. Once the tool has been tested the results will advance current knowledge in this field both in terms of aspects of midwife communication that are effective in facilitating informed choice as well as outlining the role that cognitive status plays in women's understanding of screening information. It is anticipated that findings will be assembled to inform a "best practice" model for midwifery. The scope

of the framework means that any recommendations proposed may have relevance to information provision beyond midwife communication of DS screening.

Acknowledgements

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Key phrases:

- A new framework, was developed to assess understanding of screening information.

- The framework encompasses midwife communication and women's cognitive status.

- Findings could inform a "best practice" model for midwifery practice.

- The tool developed may be applicable beyond Down syndrome screening information.

Appendix 1. Scoring Midwife Communication

MUSIC component	Score	
Language complexity	Average: Sentence per Para (The higher the number of sentences=the more difficult information is to understand)	(Word →Review→Spelling & Grammar)
	Average: Word per sentence (The higher the number of words=the more difficult information is to understand)	(Word →Review→Spelling & Grammar)
	Average: Characters per word (The higher the number of characters=the more difficult information is to understand)	(Word →Review→Spelling & Grammar)
	Passive Sentences (The higher the number of passive sentences=the more difficult information is to understand since it is more complex and formal)	(Word →Review→Spelling & Grammar)
	Flesch Reading Ease (The higher the score=the easier information is to understand) *(score reversed)*	(Word →Review→Spelling & Grammar)
	Flesch Kincaid Grade Level (The higher the score=the more difficult information is to understand)	(Word →Review→Spelling & Grammar)
	Technical Terminology: - Screening - Diagnostic - Chromosome - Amniocentesis - Abnormalities - Amniotic - Obstetrician - Millilitres	Word from list brought up in conversation and not explained = score 1 point for each time the word is mentioned and not explained. If word that has been used previously is later used and explained it does not discount the previous score it had for not being explained.
Overall	**High score = High language complexity, harder to understand**	
Dynamics	Interactivity (The higher the interactivity=the easier information is to understand as it is more interactive)	Number of speaking turns in session per minute Interactivity= no. speaker turns / total

	(score reversed)	session length (secs) x 60
	Pace (The faster the pace= the more difficult information is to understand)	Average number of syllables per word x total word count/total session length (in seconds)
	Duration (The higher the duration = the more difficult information is to understand)	Average duration in seconds spanning a block of uninterrupted speech
Overall	**High score = High dynamics, harder to understand**	
Knowledge/Understanding Check	Knowledge Check	Check knowledge = score 1 point for each time knowledge checked If do not check knowledge = score 0 points
	Understanding Check	Check understanding = score 1 point for each time understanding checked If do not check understanding = score 0 points
Overall	**Low score = Did not check knowledge / understanding** *(scores reversed)*	
Resources	Are resources used to aid explanations, e.g. pictograms, graphs, pictures	Resources used = score 1 point for each time a resource is used Resources not used = score 0 points
Overall	**Low score = Did not use resources to aid understanding** *(scores reversed)*	
Abstract language	Linguistic Category Model	Word Type / Score table below
Overall	**High score = More abstract terms used, harder to understand**	

Word Type	Score
Descriptive Action Verbs	1
Interpretative Action Verbs & State Action Verbs	2
State Verbs	3
Adjectives	4

Appendix 2. Questionnaire 1: Cognitive ability and Down syndrome understanding

Title of Project: Presentation and women's understanding of information provided at antenatal booking appointments

This questionnaire should take you about 20 minutes to complete. If you do not understand any of the instructions included in the questionnaire please ask the researcher for help. **Please note** this is not a test, there is no correct answer, it is more like a puzzle to assess how you think.

Contents:

1) Familiar sayings
2) Shapes puzzle
3) What am I like?
4) What I know about Down Syndrome
5) About me

Familiar Sayings

A proverb is a short, well-known saying, stating a general truth or piece of advice. Please read the following five proverbs. From the four options provided for each proverb, draw a circle round the statement (a, b, c or d) that you think each saying means. If you make a mistake or want to change your answer, put a cross, or "X", through your incorrect answer, and then circle your new answer.

1) Don't cry over spilled milk.
   a. It won't do any good to cry.
   b. Don't be concerned about mistakes of the past.
   c. Stop crying and clean it up.
   d. It is better to laugh than to cry.

   e. Are you familiar with the above proverb?   Yes   No

2) Rome wasn't built in a day.
   a. It takes some things longer to happen than others.
   b. It took a number of years.
   c. Great things come about slowly.
   d. You can't do certain things in a day.

   e. Are you familiar with the above proverb?   Yes   No

3) A drowning man will clutch a straw.
   a. When a person is drowning, he'll grab the person nearest to him.
   b. No one will ever actually give up on anything.
   c. A desperate person will try anything.
   d. Don't ever let go.

   e. Are you familiar with the above proverb?   Yes   No

4) The sun shines upon all alike.

    a. It's the same sun everywhere.

    b. All are created equal.

    c. The sun shines on everybody.

    d. People that do the same things are alike.

    e. Are you familiar with the above proverb?   Yes   No

5) A rolling stone gathers no moss.

    a. Be consistent.

    b. The moss gets brushed off.

    c. If you don't settle down, you won't accomplish much.

    d. A person who thinks no evil does no evil.

    e. Are you familiar with the above proverb?   Yes   No

Shapes Puzzle

The practice item below is a pattern with a piece missing. Look at the pattern; think about what piece is needed to complete the pattern correctly.

Practice item:
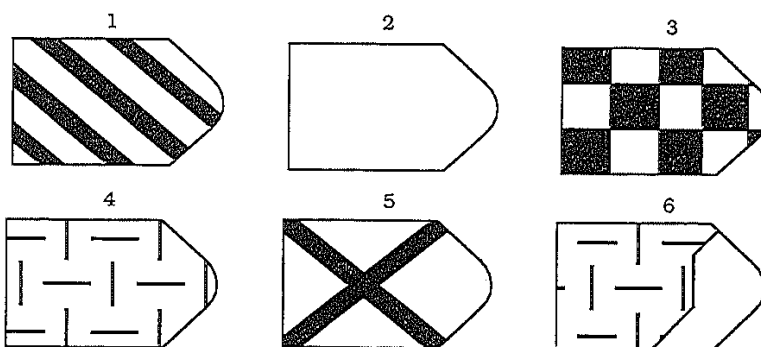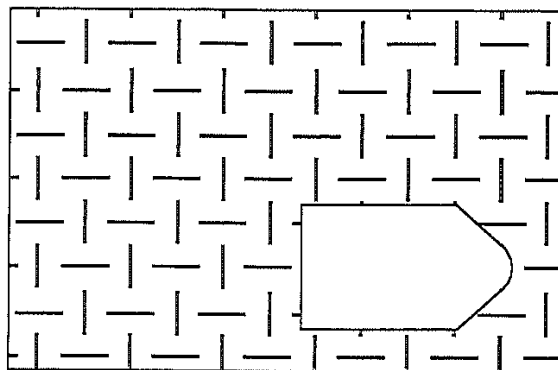
Number 4 is the correct answer because it is the only piece that correctly completes the pattern going across the row and down the column.

Please look at the following nine patterns and circle the number you think is correct. If you make a mistake, put a cross (X) through your incorrect answer and then circle your new answer. Please do each puzzle in order but if you get stuck, move on and come back to the item later. Check your answers carefully.

1)

2)

34
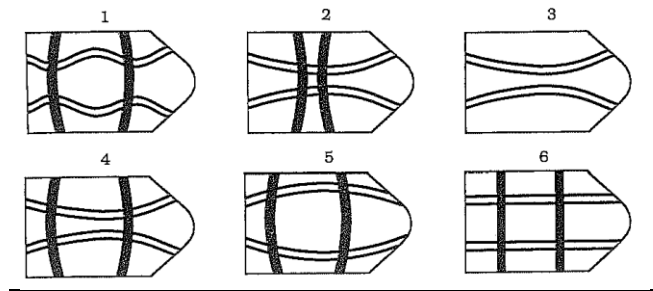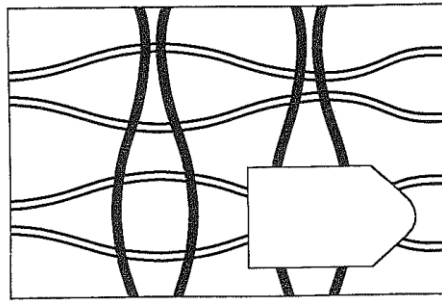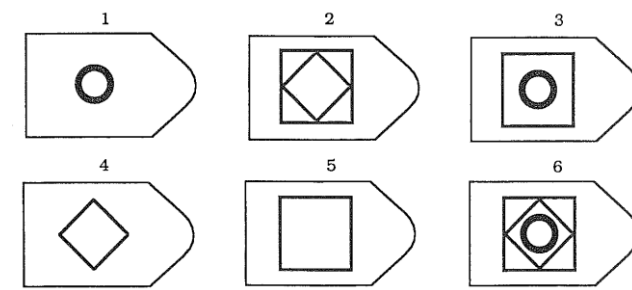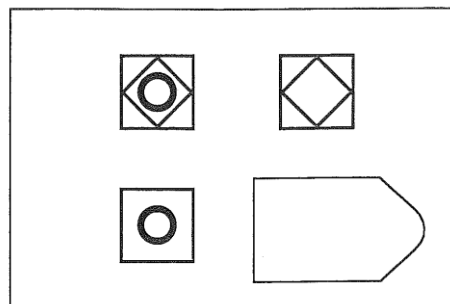
3)
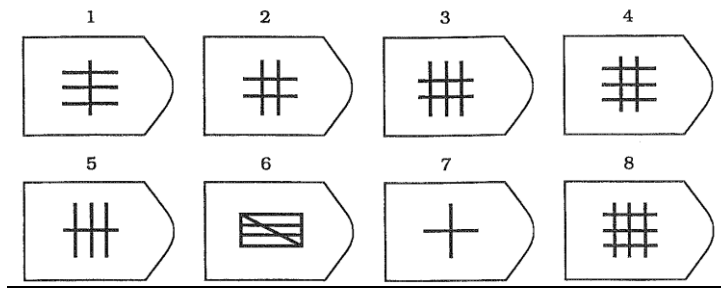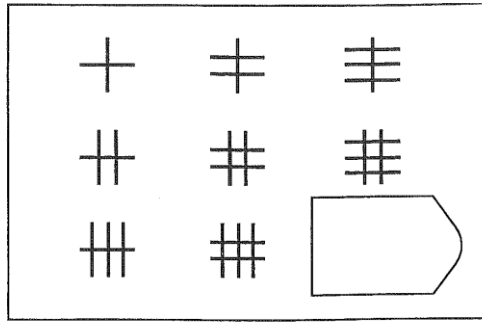
4)
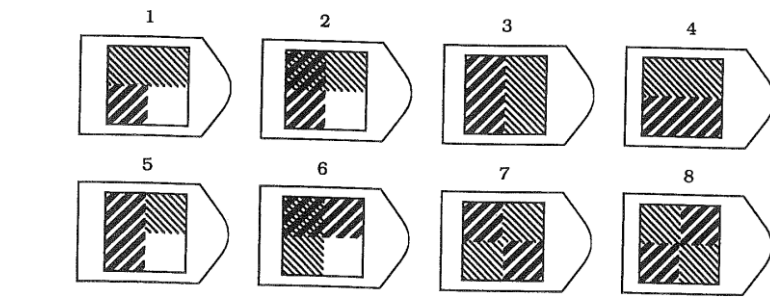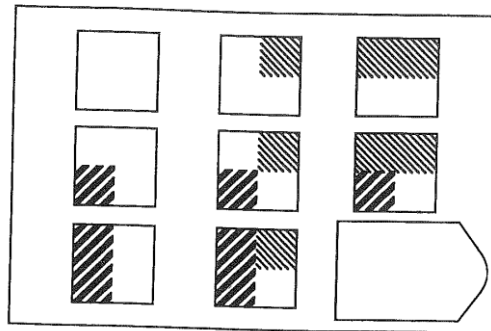
5)
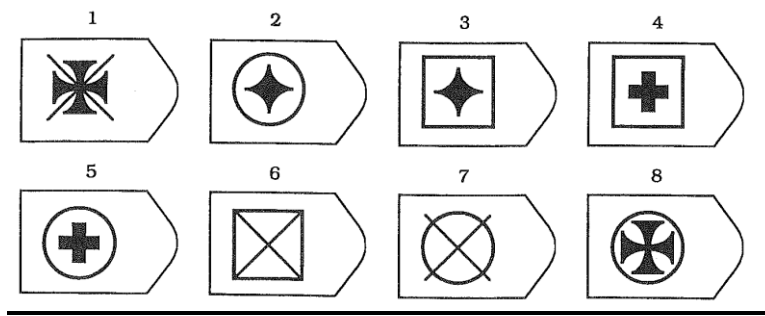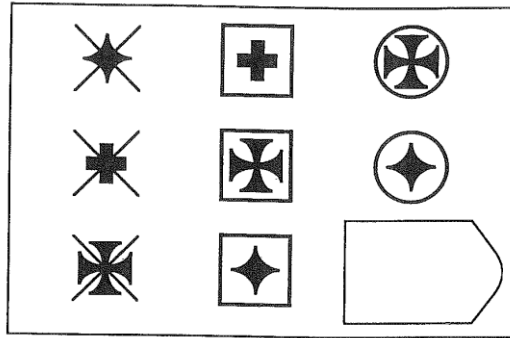
6)
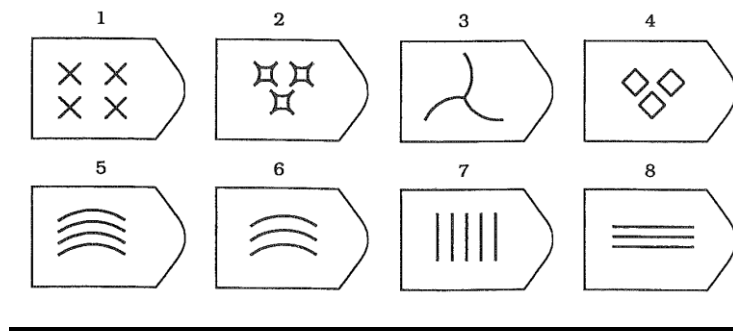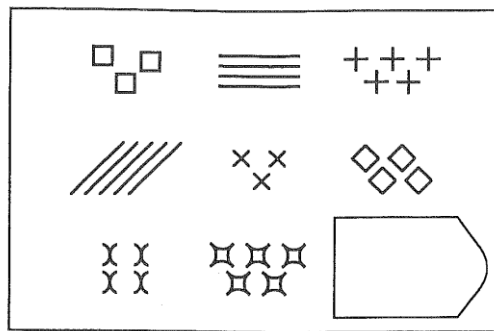
7)
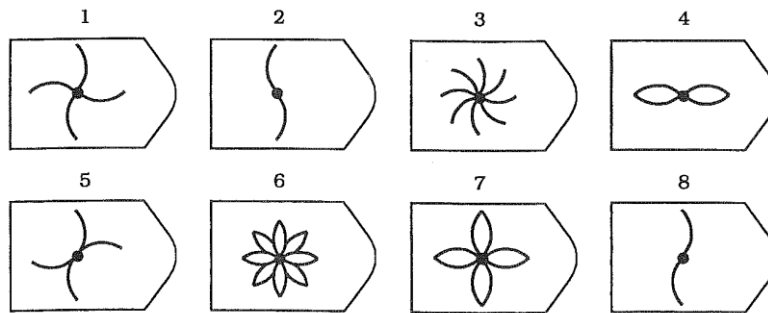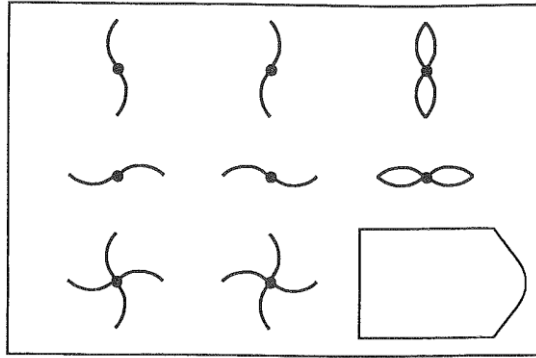
8)
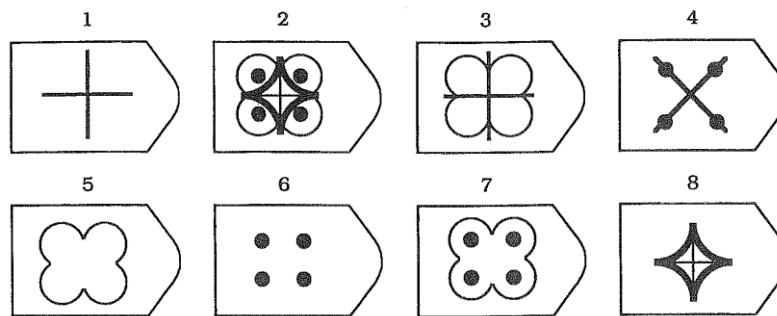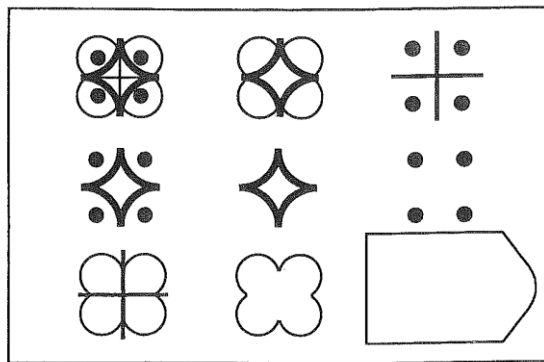
9)
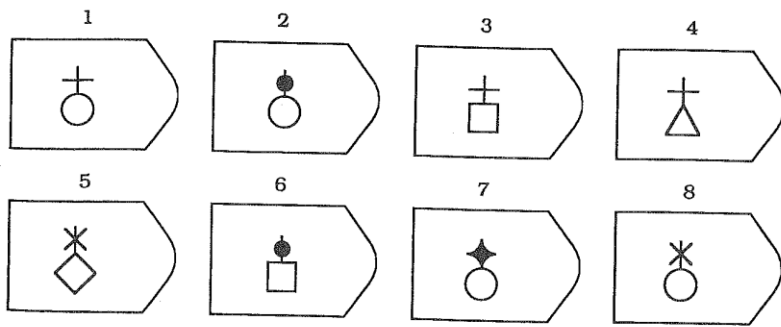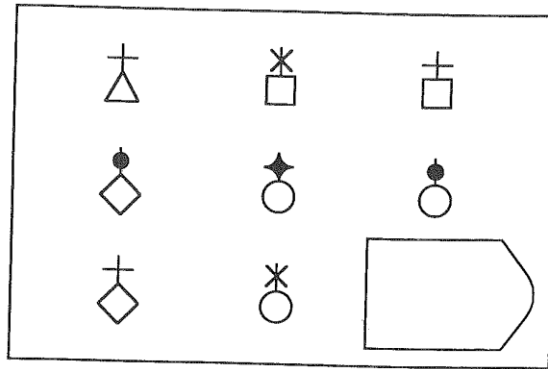
What am I like?

For each sentence below, please circle (1-5) how well the sentence describes you. For example, if an item does not describe you very well, circle number "1". If the item does describe you very well, circle number "5". Use the scale below to score your answers:

1= Very unlike me **2**= A bit unlike me **3**= Not sure **4**= A bit like me **5**= Very like me

1. I prefer difficult problems to simple problems. (Very unlike me)   **1**   **2**   **3**   **4**   **5**   (Very like me)
2. I like to be in charge when a situation needs a lot of thinking. (Very unlike me)   **1**   **2**   **3**   **4**   **5**   (Very like me)
3. Thinking is not my idea of fun. (Very unlike me)   **1**   **2**   **3**   **4**   **5**   (Very like me)
4. I would rather do something that uses little thought than something that will test my thinking. (Very unlike me)   **1**   **2**   **3**   **4**   **5**   (Very like me)
5. I try to think ahead and keep away from situations where there is a likely chance I will have to think hard about something. (Very unlike me)   **1**   **2**   **3**   **4**   **5**   (Very like me)
6. I enjoy thinking hard for long hours. (Very unlike me)   **1**   **2**   **3**   **4**   **5**   (Very like me)
7. I only think as hard as I have to. (Very unlike me)   **1**   **2**   **3**   **4**   **5**   (Very like me)
8. I prefer to think about small daily projects than long term ones. (Very unlike me)   **1**   **2**   **3**   **4**   **5**   (Very like me)
9. I like tasks that need little thought once I have learned them. (Very unlike me)   **1**   **2**   **3**   **4**   **5**   (Very like me)
10. The idea of using thought, to make my way to the top, interests me. (Very unlike me)   **1**   **2**   **3**   **4**   **5**   (Very like me)
11. I really enjoy a task that involves coming up with new answers to problems. (Very unlike me)   **1**   **2**   **3**   **4**   **5**   (Very like me)
12. Learning new ways to think is not very exciting to me. (Very unlike me)   **1**   **2**   **3**   **4**   **5**   (Very like me)

13. I prefer my life to be filled with puzzles I must solve. (Very unlike me)   **1**   **2**   **3**   **4**   **5**   (Very like me)
14. The idea of thinking "outside the box" interests me. (Very unlike me)   **1**   **2**   **3**   **4**   **5**   (Very like me)
15. I would prefer a task that is difficult and important to one that is not as important and does not need much thought. (Very unlike me)   **1**   **2**   **3**   **4**   **5**   (Very like me)
16. I feel relief rather than enjoyment after finishing a task that needs a lot of mental effort. (Very unlike me)   **1**   **2**   **3**   **4**   **5**   (Very like me)
17. It's enough for me that something gets the job done; I don't care how or why it works. (Very unlike me)   **1**   **2**   **3**   **4**   **5**   (Very like me)
18. I usually end up thinking about problems even when they do not affect me. (Very unlike me)   **1**   **2**   **3**   **4**   **5**   (Very like me)

What I know about Down syndrome

This study is interested in your understanding of the Down syndrome information that was given to you in routine booking appointments. Please read the following questions and draw a circle round the answer you think is correct from the options provided:

1) Please circle which of the following you think causes Down syndrome? *(More than one item can be circled)*
   a. A chromosomal abnormality – where the baby has developed differently than usual
   b. It is hereditary - runs in families
   c. Result of physical injury
   d. Result of emotional trauma
   e. Don't know

2) Please circle which of the following statements you think are true: *(More than one item can be circled)*
   a. The chances of having a child with Down syndrome can be affected by how old the mother is
   b. Someone with Down syndrome can have a learning disability
   c. Someone with Down syndrome can have lasting relationships
   d. Someone with Down syndrome can obtain paid jobs
   e. Someone with Down syndrome can live on their own

3) What do you think a low risk screening result means? *(Please only circle one item)*
   a. The baby definitely has Down syndrome
   b. The baby has a high chance of having Down syndrome
   c. The baby might have Down syndrome
   d. The baby has a low chance of having Down syndrome
   e. The baby definitely does not have Down syndrome
   f. Don't know

4) Is screening for Down syndrome compulsory? *(Please only circle one item)*

   a. Yes

   b. No

   c. Don't know

5) If you opt for the blood test to screen for Down syndrome when will it be performed? *(Please only circle one item)*

   a. When you are between 7-10 weeks pregnant

   b. When you are between 11-14 weeks pregnant

   c. When you are between 15-18 weeks pregnant

   d. When you are between 19-22 weeks pregnant

   e. Don't know

6) How many unborn babies affected by Down Syndrome will be picked up by screening tests? *(Please only circle one item)*

   a. All of them

   b. 90% (90 in 100)

   c. 70% (70 in 100)

   d. 50 % (50 in 100)

   e. 30% (30 in 100)

   f. Don't know

About Me

1) Age:_____

2) What is you ethnic group? Please circle one option that best describes your ethnic group or background.

   White

   1. British
   2. Irish
   3. Gypsy or Irish Traveler
   4. Any other White background, please describe _____

   Mixed

   5. White and Black Caribbean
   6. White and Black African
   7. White and Asian
   8. Any other Mixed / Multiple ethnic background, please describe _____

   Asian or Asian British

   9. Indian
   10. Pakistani
   11. Bangladeshi
   12. Chinese
   13. Any other Asian background, please describe _____

   Black or Black British

   14. Caribbean
   15. African
   16. Any other Black background, please describe _____

   Other Ethnic group, please describe _____

3) Is English your first language?   Yes   No

4) Do you have GCSE English Language?   Yes   No
   If you answered "yes", what grade did you obtain? _____

5) How long ago were you last in formal education? (such as school / college / university) _____

6) How many years in total have you spent in formal education? (from age 5+, such as school / college / university) _____

7) If you have had a previous pregnancy, did you have a booking appointment? *(a booking appointment is the first appointment you have with a midwife)*

    Yes I have had a booking appointment before

    No I did not have a booking appointment

    No, this is my first pregnancy

If you answered "yes I have had a booking appointment before", have you seen your current midwife at any previous booking appointments?

                  Yes   No

8) You will be asked to complete another short follow-up questionnaire that will take around 5 minutes to do. Could you please provide your home address as this questionnaire will be sent to your home address in a month's time. Please remember these details will be kept confidential and will not be seen by anyone other than myself. Once you have received and returned this short questionnaire, using the pre-paid envelope that will be provided, your participation in the study will be complete.

Home address:

House Number/Name _____

Street Name _____

Post Code _____

Or if you would prefer to have the questionnaire emailed to you please provide your email address: _____

Thank you for completing this questionnaire

Appendix 3. Questionnaire 2: Satisfaction

Participant no: _____

Title of Project: Presentation and women's understanding of information provided at antenatal booking appointments

Thank you for taking part in this study. Below is the final questionnaire that you agreed to receive. This questionnaire should take you about 5 minutes to complete. Once you have completed the questionnaire, please return it in the prepaid envelope provided.

1) How easy or difficult did you find it to follow the Down syndrome screening information that your midwife provided at your booking appointment? *(Please circle a number on the scale below)*

    Very Easy   Very Difficult
                    1   2   3   4   5

2) From the options below, please choose three that helped you learn most about Down syndrome. Show which of these three was the most helpful by circling the 1 next to it, show the next most helpful by circling the 2 next to it and show the third most helpful by circling the 3 next to it. Look at the example below, this person thought they had learnt most from a previous pregnancy, and then their midwife and then the leaflet, they have circled numbers 1, 2, and 3 to show this.

    Example:

a. What the midwife told me	**1**	**②**	**3**
b. Leaflet provided by midwife	**1**	**2**	**③**
c. What I found on the internet	**1**	**2**	**3**
d. From my friends/family	**1**	**2**	**3**
e. From a previous pregnancy	**①**	**2**	**3**
f. Other, please state _____	**1**	**2**	**3**

Now it is your turn:

a. What the midwife told me	**1**	**2**	**3**
b. Leaflet provided by midwife	**1**	**2**	**3**
c. What I found on the internet	**1**	**2**	**3**
d. From my friends/family	**1**	**2**	**3**
e. From a previous pregnancy	**1**	**2**	**3**
f. Other, please state _____	**1**	**2**	**3**

3) Would any of the following options have helped to improve your understanding of Down syndrome screening information given to you at booking interview? *(You can circle more than one answer)*

a) I would have understood better if the midwife had used simpler words

b) I would have understood better if the midwife had used a slower pace

c) I would have understood better if the midwife had spent more time talking to me about this topic

d) I would have understood better if the midwife had given more information on this topic

e) Other *(please state)* _____

f) No, I had a full understanding of Down syndrome information

4) How much do you think the information given by your midwife at your booking appointment helped you understand Down syndrome screening? *(Please circle a number on the scale below)*

Not at all   A lot

         1   2   3   4   5

5) How much do you think the Down syndrome screening information given by your midwife at your booking appointment made you think about your decision to accept or reject screening? *(Please circle a number on the scale below)*

Not at all   A lot

         1   2   3   4   5

Thank you for completing this questionnaire. Please return the questionnaire in the pre-paid envelope provided.

Appendix 4. Scoring Questionnaires

Cognitive ability and Down syndrome understanding questionnaire	Question	Response	Score
Proverbs *(Familiar* *Sayings)*	1. Don't cry over spilled milk.	A B C D	1 2 0 1
	Are you familiar with the above proverb?	Yes No	1 0
	2. Rome wasn't built in a day.	A B C D	1 0 2 1
	Are you familiar with the above proverb?	Yes No	1 0
	3. A drowning man will clutch a straw.	A B C D	0 1 2 1
	Are you familiar with the above proverb?	Yes No	1 0
	4. The sun shines upon all alike.	A B C D	1 2 0 1
	Are you familiar with the above proverb?	Yes No	1 0
	5. A rolling stone gathers no moss.	A B C D	1 0 2 1
	Are you familiar with the above proverb?	Yes No	1 0
Overall	**High Score = More abstract cognitive ability**	**Total**	**/10**
RSPM *(Shapes* *Puzzle)* The original matrices consist of 60 puzzles	1. A11	1 2 3 4 5 6	0 0 0 1 0 0
	2. B12	1 2 3 4	0 0 0 0

with 5 sets (A-E) containing 12 items each. The 9 items included were sampled from each set (Bilker et al. 2012)		5 6	1 0
	3. C4	1 2 3 4 5 6 7 8	0 0 0 0 0 0 0 1
	4. C12	1 2 3 4 5 6 7 8	0 1 0 0 0 0 0 0
	5. D7	1 2 3 4 5 6 7 8	0 0 0 0 1 0 0 0
	6. D12	1 2 3 4 5 6 7 8	0 0 0 0 0 1 0 0
	7. E1	1 2 3 4 5 6 7 8	0 0 0 0 0 0 1 0
	8. E5	1 2 3 4 5 6 7 8	1 0 0 0 0 0 0 0

	9. E7	1	1
		2	0
		3	0
		4	0
		5	0
		6	0
		7	0
		8	0
Overall	**High Score = More abstract cognitive ability**	**Total**	**/9**
Need for Cognition *(What am I like?)*	1. I prefer difficult problems to simple problems.	Very unlike me A bit unlike me Not sure A bit like me Very like me	1 2 3 4 5
	2. I like to be in charge when a situation needs a lot of thinking.	Very unlike me A bit unlike me Not sure A bit like me Very like me	1 2 3 4 5
	3. Thinking is not my idea of fun	Very unlike me A bit unlike me Not sure A bit like me Very like me	5 4 3 2 1
	4. I would rather do something that uses little thought than something that will test my thinking.	Very unlike me A bit unlike me Not sure A bit like me Very like me	5 4 3 2 1
	5. I try to think ahead and keep away from situations where there is a likely chance I will have to think hard about something.	Very unlike me A bit unlike me Not sure A bit like me Very like me	5 4 3 2 1
	6. I enjoy thinking hard for long hours.	Very unlike me A bit unlike me Not sure A bit like me Very like me	1 2 3 4 5
	7. I only think as hard as I have to.	Very unlike me A bit unlike me Not sure A bit like me Very like me	5 4 3 2 1
	8. I prefer to think about small daily projects than long term ones.	Very unlike me A bit unlike me Not sure A bit like me Very like me	5 4 3 2 1

	9. I like tasks that need little thought once I have learned them.	Very unlike me A bit unlike me Not sure A bit like me Very like me	5 4 3 2 1
	10. The idea of using thought, to make my way to the top, interests me.	Very unlike me A bit unlike me Not sure A bit like me Very like me	1 2 3 4 5
	11. I really enjoy a task that involves coming up with new answers to problems.	Very unlike me A bit unlike me Not sure A bit like me Very like me	1 2 3 4 5
	12. Learning new ways to think is not very exciting to me.	Very unlike me A bit unlike me Not sure A bit like me Very like me	5 4 3 2 1
	13. I prefer my life to be filled with puzzles I must solve.	Very unlike me A bit unlike me Not sure A bit like me Very like me	1 2 3 4 5
	14. The idea of thinking "outside the box" interests me.	Very unlike me A bit unlike me Not sure A bit like me Very like me	1 2 3 4 5
	15. I would prefer a task that is difficult and important to one that is not as important and does not need much thought	Very unlike me A bit unlike me Not sure A bit like me Very like me	1 2 3 4 5
	16. I feel relief rather than enjoyment after finishing a task that needs a lot of mental effort	Very unlike me A bit unlike me Not sure A bit like me Very like me	5 4 3 2 1
	17. It's enough for me that something gets the job done; I don't care how or why it works.	Very unlike me A bit unlike me Not sure A bit like me Very like me	5 4 3 2 1
	18. I usually end up thinking about problems even when they do not affect me.	Very unlike me A bit unlike me Not sure A bit like me Very like me	1 2 3 4 5

Overall	High Score = High Need for Cognition	Total	/90
Down syndrome understanding questionnaire	1. Please circle which of the following you think causes Down syndrome	A B C D E	1 1 0 0 0
	2. Please circle which of the following statements you think are true	A B C D E	1 1 1 1 1
	3. What do you think a low risk screening result means?	A B C D E F	0 0 0 1 0 0
	4. Is screening for Down syndrome is compulsory?	Yes No Don't know	0 1 0
	5. If you opt for the blood test to screen for Down syndrome when will it be performed?	A B C D E	0 1 0 0 0
	6. How many unborn babies affected by Down Syndrome will be picked up by screening tests?	A B C D E F	0 0 1 0 0 0
Overall	**High Score = Better Understanding**	**Total**	**/11**

Satisfaction Questionnaire	Response	Score
1. How easy or difficult did you find it to follow the Down syndrome screening information that your midwife provided at your booking appointment? *(Lower score=better understanding)*	Very Easy Very Difficult	1 2 3 4 5
2. From the options below, please choose three that helped you learn most about Down syndrome.	Midwife Leaflet Internet Friends/family Previous pregnancy Other	1, 2, 3 1, 2, 3 1, 2, 3 1, 2, 3 1, 2, 3 1, 2, 3
3. Would any of the following options have helped to improve your	Simpler words Slower pace	1 1

understanding of Down syndrome screening information given to you at booking interview? *(Lower score=better understanding)*	Spent more time on this topic Given more information on this topic Other No	1 1 1 0
4. How much do you think the information given by your midwife at your booking appointment helped you understand Down syndrome screening? *(Higher score = better understanding)* **(reverse scores)**	Not at al A lot	1 (code 5) 2 (code 4) 3 (code 3) 4 (code 2) 5 (code 1)
5. How much do you think the Down syndrome screening information given by your midwife at your booking appointment made you think about your decision to accept or reject screening? *(Higher score = better outcome)* **(reverse scores)**	Not at all A lot	1 (code 5) 2 (code 4) 3 (code 3) 4 (code 2) 5 (code 1)