

Supporting pregnant women to decide whether to have a screening test for Down's syndrome

The MAGIC team – Newcastle

This case study describes how the team in Newcastle working on the Health Foundation's MAGIC programme to implement shared decision making developed a new approach to supporting pregnant women to decide whether or not to have a screening test for Down's syndrome.

All women are offered a screening test for Down's syndrome in pregnancy. The steps involved in screening for Down's syndrome are:

- A screening test is offered at 11 - 20 weeks
- If an increased risk is indicated, a diagnostic test is offered
- If the diagnostic test indicates Down's syndrome or another foetal abnormality, counselling is offered to support a decision on whether to continue the pregnancy

The obstetrics team at Newcastle Hospitals wanted to develop a support tool to help women and their partners decide whether to have this test that can detect an increased risk of Down's syndrome. This support tool could address two issues:

- To help people consider the possible consequences of a positive screening test
- The proportion of women choosing to undergo the screening test for Down's is higher in the North East of England than in other parts of the country - the national average for uptake is 50% and latest figures for the Newcastle area in 2011/12 were 62%.

What we did

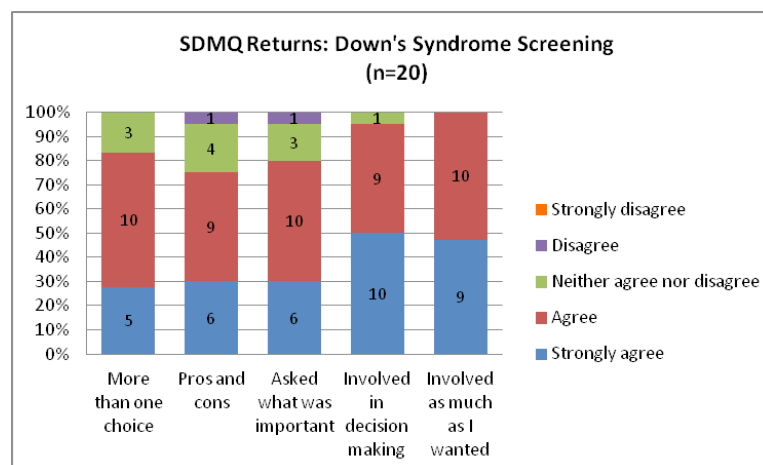
Finding out about people's experience

In March 2011 a baseline patient survey based on the Shared Decision Making Questionnaire (developed during the MAGIC Programme) was undertaken to gauge the level of involvement people felt they had had in making choices about whether to have screening for Down's syndrome.

The questionnaire asked people to grade how strongly they agreed or disagreed with the following statements:

Deciding whether to accept screening for Down's syndrome: Shared decision making questionnaire (SDMQ)	
1.	I was told that there was more than one choice
2.	I was told about the pros and cons of each choice
3.	I was asked what was important to me
4.	I was involved in making decisions
5.	I was involved as much as I wanted to be

The survey found:



Developing a tool to help people make decisions

Between April and July 2011 a first draft of a decision support tool was created collaboratively between community and hospital midwives and service users.

Feedback from women service users included positive comments such as:

- *"I didn't know I had a choice, I thought everyone had the test. This tool has helped me to make a decision."*
- *"This really helped us both to look at the pros and cons and to think about what we would do if the test came back high risk"*

Feedback from community midwives was also positive and comments included:

- *‘This is a Women focused tool’*
- *‘Helped to focus discussion’*
- *‘Promotes continuity in what we all (midwives) say and do, and can therefore play a part in training student midwives’*
- *‘An easy way of creating documented evidence of what has been discussed’*
- *‘Useful as a method of obtaining consent for screening before the scan or to identify those who remained undecided and who will benefit from further discussion’*

Piloting the tool

Between September and December 2011 the draft tool was piloted with twenty women. The patient survey based on the SDM Questionnaire was repeated and results before and after pilot use of the decision support tool were compared.

Analysis demonstrated that women felt more involved, understood the options and pros and cons had been discussed. On average prior to using the tool only 75% had felt involved and informed compared to almost 100% who had used the tool. (see table below)

Further testing and refinement

In October 2011 a National quality assurance pilot was carried out by the National Screening Committee who commended the use of the screening tool and recommended that it continue as good practice. The tool continued to be developed from January to March 2012 based on patient and midwife feedback.

March 2012 to date

- Use of the tool has been extended to all thirty Community Midwives in the Newcastle locality
- The tool is now included in all Personal Maternity Packs (PMR) which is given to women at booking (Newcastle women only at present which is approximately 42% of overall bookings, 3,750 women). The packs have been updated to emphasise involvement and values.
- Feedback from the Director of ARC (Antenatal Results and Choices – a national charity) has been sought and some modifications made to make the tool more user-friendly
- Plan to train community midwives in the wider North East community i.e. outside Newcastle, to use the tool, and roll out use to women from localities outside Newcastle, whose preference is to have their baby in Newcastle Hospitals.

Responses to a modified SDM questionnaire survey asking about involvement in decision-making				
	Before using decision aid		After using decision aid	
	agree	disagree	agree	disagree
I was told I could choose whether to have the test	75%	25%	100%	0%
We talked about the pros and cons of deciding to take the test	75%	25%	95%	5%
I was asked what was important to me in making a decision	80%	20% (neither agree or disagree)	85%	15% (neither agree or disagree)

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- The tool, as a consent form, is filed in the Maternity Handheld Record once the woman has made a decision about screening (i.e. accept or decline) so that it can be seen by the sonographer who completes the screening test if required
 - Sonographers have reported that women appear to be more informed and more certain about whether or not to accept or decline testing. This appears to be saving some time as they do not have to consider all of the information again in-depth at the time of the scan
 - Plan to share good practice at the regional and national forums
 - The tool has been made available on the Trust intranet for users to access
 - Although only a small pilot, analysis of the early survey suggests that women felt better prepared, aware of choice and more involved in the decision as to accept or decline a screening test for Down's syndrome
 - The tool has support from the National Screening Committee who highlighted it as good practice in a QA pilot report
 - Use of the screening tool has become standard practice for women having their baby in Newcastle hospitals. This is due to the enthusiasm of the screening midwives and their ability to work with community colleagues to ensure the tool was of use to both service users and providers
 - A tool to support decision making about diagnostic testing for Down's syndrome (available when an increased risk has been identified by the screening test) is in use and midwives are being trained in its use
 - The tools described have been developed for local use however the team have been closely involved in developing the on-line national Patient Decision Aids for screening and diagnostic testing, available at <http://sdm.rightcare.nhs.uk/pda/>

Pilot decision support tool May 2013

The Newcastle upon Tyne Hospitals **NHS**
NHS Foundation Trust



Patient ID sticker

Do I want a screening test for Downs' syndrome?

Facts about the screening test.

- All women are offered a dating scan early in their pregnancy and then a scan at around 20 weeks to check that the baby is developing as expected.
- You will be offered a screening test for Down's syndrome. It is entirely your choice whether or not you decide to have this test.
- The screening test can detect up to 90 out of 100 (90%) of babies who have Down's syndrome. It can sometimes detect other rare chromosome abnormalities.
- Approximately 3 out of 100 (3%) of all women who have the screening test fall into the "increased risk" group even if the baby is not affected. An increased risk does not mean that your baby has Down's syndrome.
- If your results fall into the increased risk group you will be offered further tests.
- Occasionally, even when a woman is given a "low risk" result, the test may indicate the need to have extra scans throughout the pregnancy. This would be discussed with you in more detail at the time of the result.
- More information is available in the booklet "Screening tests for you and your baby" which is with your maternity information.

You have two choices:

1. You can choose to accept a screening test to find out if you are at increased risk of having a baby with Down's syndrome
2. You can choose to decline a screening test for Down's syndrome.

* Mother to sign below to indicate her preferred choice about screening:

Accept _____ Decline _____

You may find the brief decision aid on the reverse page useful to help you to make a decision that is right for you.

Further information is available at:

www.arc-uk.org

www.screening.nhs.uk

www.downs-syndrome.org.uk

What are some of the reasons for and against accepting the screening test?

Pros	Cons
<p>You may feel reassured if you are at “low risk” of having a baby with Down’s syndrome and therefore worry less throughout your pregnancy.</p> <p>If the result shows an “increased risk” you will be offered a diagnostic test (either Chorionic villus sampling (CVS) or amniocentesis) to find out for certain if your baby has Down’s syndrome.</p> <p>If you find out that your baby does have Down’s syndrome, this will give you time to prepare and find out more about the condition</p> <p>or</p> <p>You will have the option to end the pregnancy at an early stage if the baby is affected with Down’s syndrome or another chromosome abnormality (if you undergo the earlier diagnostic test, CVS).</p>	<p>You could have a low risk result and still have a baby with Down’s syndrome or other, unrelated abnormalities.</p> <p>If you fall into the “increased risk” group this might cause you anxiety. You would still need to have a diagnostic test to say for certain if the baby has Down’s Syndrome or not.</p> <p>The diagnostic test carries a risk of miscarriage (1 in 100 chance or 1%)</p>

What are some of the reasons for and against declining the screening test?

Pros	Cons
<p>You do not feel it is important for you to know if your baby has Down’s syndrome before he or she is born.</p> <p>Avoids the stress that you may feel if you have a high risk result</p> <p>You will still be offered a routine scan at 20 weeks which might detect a problem. If this is the case you may still have the option to have a diagnostic test.</p> <p>A diagnostic test at a later stage in pregnancy will still give you time to prepare if the baby is found to have Down’s syndrome.</p> <p>It would fit in with your religious and/or cultural beliefs.</p> <p>You do not wish to possibly make difficult decisions about diagnostic tests.</p>	<p>If you opt for a 20 week scan there is a small chance your baby may be found to have a major abnormality (e.g. a heart abnormality) or features that increase the risk of Down’s syndrome. If this were the case you would need to reconsider whether to have a diagnostic test.</p> <p>If a diagnostic test confirms a problem at this later stage you will be much further on in your pregnancy and a termination could mean you may need have to deliver the baby (vaginally). The option of an operation to terminate the pregnancy (under general anaesthetic) is not always available</p>