Practical ethics and prenatal screening

Scientific and medical developments often raise important ethical questions. Professor of bioethics Rebecca Bennett explores what is meant by ethics and provides a practical way of evaluating ethical issues you might encounter both within and outside your studies

Ask people 'what is ethics?' and you are likely to get several different replies. Most agree that ethics has to do with the question of how we should behave, and what choices we should make about how we live our lives. However, how individuals answer the question 'how should we behave?' differs greatly and may include reference to religions, intuitive feelings, professional codes of practice, laws and policy, and cultural norms.

Deaf debate

Consider the following question: 'Is it ethically acceptable to allow hearing-impaired parents undergoing fertility treatment to use preimplantation genetic diagnosis to choose to implant an embryo that will also be hearing-impaired?' You might find it useful to look at the news article in Further reading on page 10 to help you to think about this.

Blood test in pregnancy — part of the screening for Down's syndrome

People with Down's syndrome have an extra copy of chromosome 21

The following questions can be used to address any ethical issue:

- What is your answer to this question? (There is no right answer so really consider what you think is the most ethically defensible answer.)
- Can you explain why you answer this way?
- What would you say to someone who answered this question differently to convince them that your answer is more ethically defensible?

Let's consider another issue in some detail so that you can apply this approach to another question.

Screening for Down's syndrome during pregnancy

Down's syndrome is a condition caused by an extra copy of chromosome 21. Children with Down's syndrome usually have distinguishing facial features, learn and process information more slowly than other children, and may have heart defects and other health problems — the phenotype is diverse. Some women want to know in pregnancy whether the fetus they are carrying has Down's syndrome. Some may want the option to end the pregnancy with a termination. Others find the information helpful when preparing for the birth of a baby with the condition.

In the UK, screening for Down's syndrome began in the 1980s. Since the 2000s the screening offered has been a combined test comprising a blood test that detects certain hormones and proteins associated with a higher chance of Down's syndrome and another test that involves taking a measurement from an ultrasound scan. This combined test is a screening test. It does not give a definite diagnosis, only an indication of the likelihood that a fetus has Down's syndrome. Further tests are needed to give a more accurate diagnosis. These involve taking a small sample of placenta or some of the fluid around the fetus. These further diagnostic tests are more accurate and known as 'invasive' tests. A needle is used to collect the material to be tested and so it involves a small risk of miscarriage.

A new test for Down's syndrome

In 2008, there was great excitement in the press as a test for Down's syndrome was discovered that is much safer than

existing diagnostic tests. This non-invasive prenatal testing is a blood test and does not increase the risk of miscarriage. It tests for fragments of fetal DNA in the pregnant woman's blood (see BIOLOGICAL SCIENCES REVIEW, Vol. 31, No. 1, pp. 38–41). This test is also more reliable than the combined screening test, at around 98% accuracy.

While the announcement of the development of this new safer test for Down's syndrome was celebrated by many as a positive scientific and medical breakthrough, news of the new test also caused a great deal of negative comment and controversy. The development of the test became the focus of social media campaigns by groups such as 'Don't screen us out', and was featured in a BBC documentary *A World Without Down's Syndrome?* as a source of concern. It continues to be a focus for debate.

Despite these concerns, in April 2018 the new non-invasive test was introduced in Wales as part of the existing Down's syndrome screening programmes and was offered to women identified by the combined test as being at high risk of carrying a fetus with Down's syndrome. The new test was introduced as a screening test, not a diagnostic test — it is recommended that any results from this test should be confirmed using the standard invasive diagnostic tests. The plan is to introduce the test in a similar way in England soon. The advantages of adding the test to the screening programme is that it will give women a more accurate assessment of their risk than the combined test, so fewer women will need the more risky invasive diagnostic test.

Why are people concerned about this test?

It is easy to see why those living with Down's syndrome and their families and friends would find the apparent enthusiasm for a new, effective screening test and the rush to adopt it problematic and even offensive. If you have Down's syndrome or have a loved one with Down's syndrome, talk of more 'efficient' screening of this condition in pregnancy seems to send a message that the NHS is trying to 'screen out' people like you and others with Down's syndrome.

However, in response to these criticisms, those proposing the introduction of the new test would argue that the new screening test does not really change much, as it is being added to the screening programme that has been running for years. Those supporting the introduction argue that the aim of this new screening test is not to 'screen out' Down's syndrome but to improve the existing screening programme, allowing access to more reliable and less risky information about the pregnancy and thus enhancing women's choices.

Is screening for Down's syndrome ethically problematic?

The way in which this screening test is offered to all pregnant women is seen by some as ethically problematic. Respecting individuals' choices is seen as being very important in modern medical ethics, even if this means that we have to respect choices we might think are unpalatable. This is because in modern democratic societies we accept that people may have very different priorities, cultural and religious beliefs, and one of the main things that most people value is the ability to choose how they live their own lives. As a result, when an adult has any medical test or procedure, great lengths are usually taken to ensure that they want the test, that they have, and understand, all the relevant information about the risks and benefits of taking the test, and that they are not being pressured to have it.

It has been argued that screening programmes for Down's syndrome put pressure on women to accept screening. The fact that the screening is routinely offered to all pregnant women sends the message that testing for Down's syndrome is the recommended course of action, and that this makes non-take-up more difficult. Women are often not aware that the screening is optional. The information and guidance given to women can be biased towards a recommendation of termination of pregnancy. It has therefore been argued that screening for Down's syndrome does not conform to the usual requirements for voluntary, informed consent for any medical screening, testing or procedure.

If we are serious about valuing the choices of all individuals, including pregnant women, then we should offer tests for Down's syndrome in a way that allows women to make a choice, based on balanced information, without pressure to accept the test. In this way, women can choose whether or not screening and testing for Down's syndrome is right for them. There will be those who really want this information but there will be those who do not want to know. Most importantly, the choice of any woman to terminate her pregnancy or not should be her choice and one that she is able to make with accurate information and without pressure.

Is Down's syndrome screening a special case?

There are those who argue that while we should *usually* ensure that choices to accept screening, testing or any other medical procedure are voluntary and not pressured, screening for Down's syndrome is a special case where the usual rules should not apply. Knowing whether or not your fetus has Down's syndrome is, in this view, so important that a little pressure to ensure a high uptake of screening is justified. There are other exceptions to the usual rule of voluntariness that might provide some support for this argument. For instance, pressure is put on parents to vaccinate children and smoking is banned in certain places. But these exceptions to the rule are usually justified on the basis of preventing harm to others.

Does screening for Down's syndrome prevent harm to anyone?

Is a child with Down's syndrome being harmed by being brought to birth? Many people would receive the news that their fetus has Down's syndrome as a terrible blow, but does the birth of a child with Down's syndrome necessarily harm anyone? Children with Down's syndrome are as likely as anyone else to have a life they value. No child is 'saved' from having Down's syndrome by routine screening or testing — they are either born with it or not born at all. Identifying a fetus with Down's syndrome in pregnancy may prevent that fetus from being born, but if a termination is not chosen and the child is born, there is no sense in which that child has been harmed by the decision not to terminate the pregnancy.

Further reading

Clare Murphy, 'Is it wrong to select a deaf embryo', BBC News online, 10 March 2008: **http://tinyurl.com/knavdx**

Heidi Ledford, 'Blood test for Down's syndrome unveiled', *Nature*, 6 October 2008: **http://tinyurl.com/y58sa6r5**

Nuffield Council on Bioethics, 'Non-invasive prenatal testing: ethical issues' (2017): **http://tinyurl.com/y43arwqj**

NHS leaflet, 'Screening tests for your baby' (2014, updated 2019): **http://tinyurl.com/y6h6pjoo**

Harriet Sherwood, 'Down's syndrome test could see condition disappear, C of E warns', *Guardian*, 19 January 2018: **http://tinyurl.com/y9h2lsqw**

Useful website

The campaign group 'Don't screen us out':
http://dontscreenusout.org

Many prospective parents would view the extra challenges raised by having a child with Down's syndrome as harmful to them. But there will also be those who would find pressure to screen for Down's syndrome harmful both in terms of reducing their free choice and in the message that screening sends about Down's syndrome and those who are affected by it.

What do you think?

Do you think making screening for Down's syndrome routine in pregnancy is justified if this means that some women may feel pressured into being tested?

When you answer this question try add to the strength of your answer by also answering the two questions mentioned earlier:

- Can you explain why you answer this way?
- What would you say to someone who answered this question differently to convince them that your answer is more ethically defensible?

If you would like more information about ethics more generally or screening for Down's syndrome there is further reading above or do contact me by email.

Professor Rebecca Bennett is a professor of bioethics at The University of Manchester. She has been teaching and writing on ethics for 26 years and has developed many online courses in this area. She was the ethics consultant on the BBC documentary *A World without Down's?* If you have a question about ethics or about screening in pregnancy, contact her at **Rebecca.Bennett@manchester.ac.uk**