

Shared Decision Making – Down’s, Edwards’ and Patau’s Syndromes

Next clinical review date March 2018

Deciding what to do about Down’s, Edwards’ and Patau’s Syndromes

This short decision aid is to help women and their partners who, after having a screening test, find they have an increased chance of having a baby with Down’s, Edwards’ or Patau’s syndromes to decide whether or not to have a diagnostic test.

The two initial options for women making this decision are:

Have no diagnostic test. This means continuing the pregnancy knowing from their screening result that they have an increased chance their baby has Down’s, Edwards’ or Patau’s syndromes. Women will still be offered the usual tests throughout the pregnancy that screen their health and that of their baby. The anomaly scan may identify anomalies associated with Edwards’ Syndrome and Patau’s Syndrome in many but not all cases. The anomaly scan will identify congenital anomalies associated with Down’s Syndrome in less than half of the affected pregnancies. Without a diagnostic test, prospective mothers will not know for certain whether or not their baby has one of these conditions until after the baby is born.

Choose to have a diagnostic test to tell for certain whether or not the baby has Down’s, Edwards’ or Patau’s syndromes.

There is then a need further discussion with your Obstetrician or midwife about which diagnostic test to have. There are two different diagnostic procedures, chorionic villus sampling (CVS) and amniocentesis. Both tests have a chance of causing the pregnancy to miscarry. Up to 1 in 10 women will miscarry after amniocentesis or CVS. Women will be offered the usual tests throughout their continuing pregnancy that screen their health and that of their baby

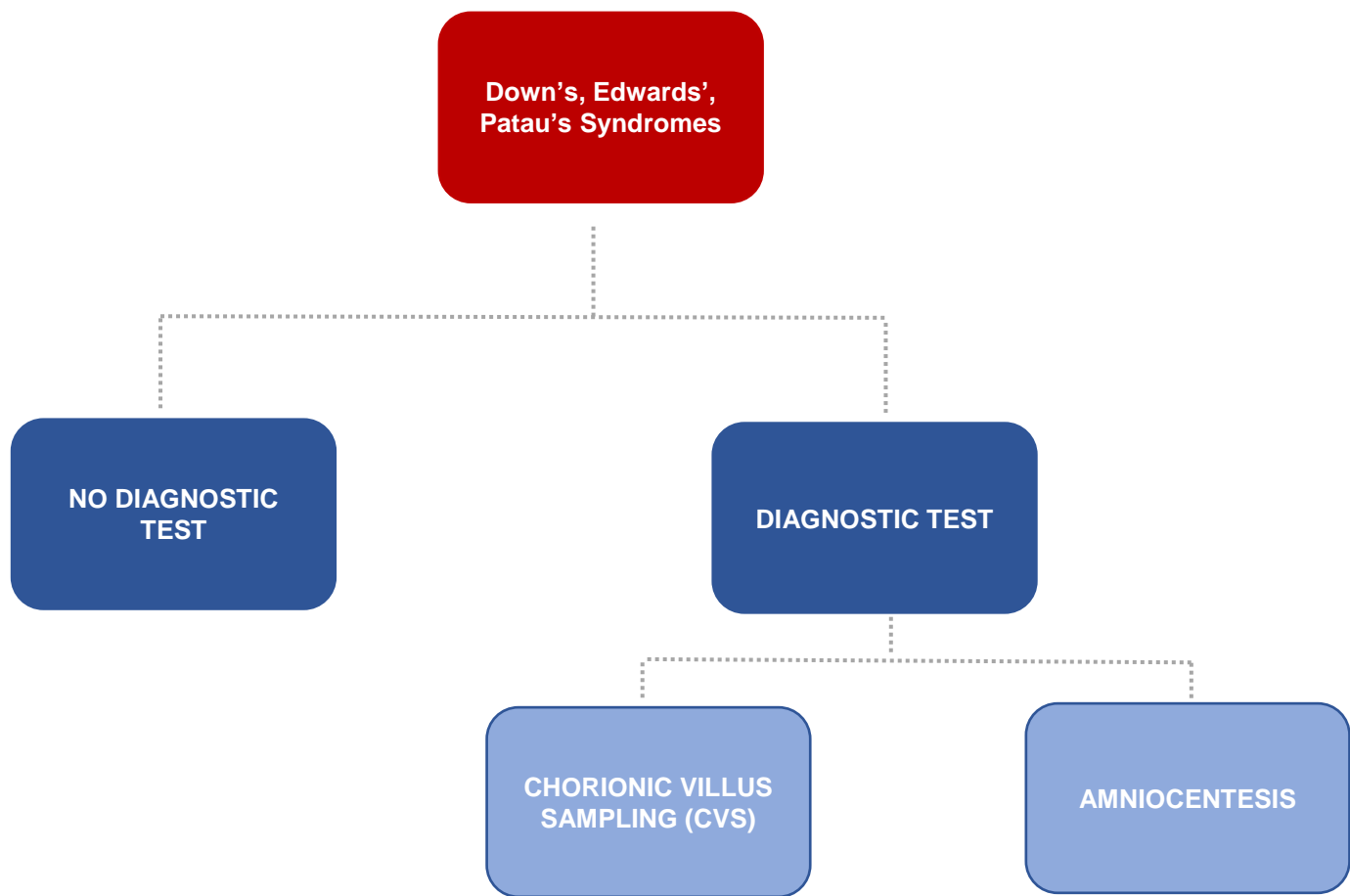
Women and their partners can find making this decision difficult. The choice women make depends on their values and how they feel about the chances of having a baby with Down’s, Edwards’ or Patau’s syndromes or miscarrying a normal pregnancy. This decision aid will help you think about what is important to you and your partner when making this decision.

Women who have an increased chance of having a baby with Down’s, Edwards’ or Patau’s syndromes may be thinking about several decisions, including:

Do I need to know for certain whether or not the baby has Down’s, Edwards’ or Patau’s syndromes?

If I need to know for certain whether or not my baby has Down’s, Edwards’ or Patau’s syndromes, which diagnostic test is best for me?

If I knew for certain my baby has Down's, Edwards' or Patau's syndromes, would I want to continue with my pregnancy, or terminate it?



What are my options?

	No Test	Chorionic Villus Sampling (CVS)	Amniocentesis
What is the treatment?	<p>This means women do not have a diagnostic test to find out for certain if their baby does or does not have Down's, Edwards' or Patau's syndromes. Women will have the usual screening and health checks carried out in pregnancy.</p>	<p>This is a diagnostic test which can be carried out in pregnancy to find out if the baby had Down's, Edwards' or Patau's syndromes. A needle is guided through the abdomen (tummy) into the womb and a small amount of tissue taken from the placenta. The test tells women for certain whether or not the baby has Down's, Edwards' or Patau's syndromes. Some women say it is uncomfortable having the test.</p>	<p>This is a diagnostic test which can be carried out in pregnancy to find out if the baby had Down's, Edwards' or Patau's syndromes. A needle is guided through the abdomen (tummy) into the womb and a small amount of fluid surrounding the baby is withdrawn. The test tells women for certain whether or not the baby has Down's, Edwards' or Patau's syndromes. Some women say it is uncomfortable having the test.</p>

	No Test	Chorionic Villus Sampling (CVS)	Amniocentesis
What is the timing of the treatment?	Usual antenatal care continues throughout pregnancy. All pregnant women are offered an ultrasound scan between 19 and 20 weeks to check on the baby's physical development. If any problem is suspected, an amniocentesis can be offered at this stage.	CVS is usually carried out after 11 weeks of pregnancy.[10]	Amniocentesis is usually carried out after 15 weeks of pregnancy.[11]

	No Test	Chorionic Villus Sampling (CVS)	Amniocentesis
What is the recovery?	There are no procedures which require recovery in normal antenatal care.	Women are usually advised to take things easy for a day or two afterwards. There is no good evidence for resting in bed.	Women are usually advised to take things easy for a day or two afterwards. There is no good evidence for resting in bed.

	No Test	Chorionic Villus Sampling (CVS)	Amniocentesis
What are the effects on pregnancy?	There are no additional risks to the baby from usual antenatal care, but there remains a background risk of miscarriage in all pregnancies.	CVS causes between 1 and 2 in every 100 women to miscarry.[12]	Amniocentesis causes 1 in 100 women to miscarry.[12]

	No Test	Chorionic Villus Sampling (CVS)	Amniocentesis
What is the knowledge from testing?	Women who decide not to have a diagnostic test will not know for sure if the baby has Down's, Edwards' or Patau's syndromes. They will know their chance of having a baby with Down's, Edwards' or Patau's syndromes from their screening result.	Women get either a positive or negative result. A positive result means the baby has Down's, Edwards' or Patau's syndromes. A negative result means the baby does not have Down's, Edwards' or Patau's syndromes. In a small number of cases a different abnormal chromosome pattern may be diagnosed.	Women get either a positive or negative result. A positive result means the baby has Down's, Edwards' or Patau's syndromes. A negative result means the baby does not have Down's, Edwards' or Patau's syndromes. In a small number of cases a different abnormal chromosome pattern may be diagnosed.

	No Test	Chorionic Villus Sampling (CVS)	Amniocentesis
What are the future decisions?	The health of women and their babies will continue to check throughout pregnancy. A further ultrasound scan is offered at 18-20 weeks, to check on the baby's physical development.	<p>Most women will get a negative diagnostic test result. The health of women and their babies will continue to be checked through pregnancy. A further ultrasound scan is offered at 18-20 weeks, to check on the baby's physical development.</p> <p>Women who get a positive diagnostic test result will decide whether they want to continue with or terminate their pregnancy.</p>	<p>Most women will get a negative diagnostic test result. The health of women and their babies will continue to be checked through pregnancy. A further ultrasound scan is offered at 18-20 weeks, to check on the baby's physical development.</p> <p>Women who get a positive diagnostic test result will decide whether they want to continue with or terminate their pregnancy.</p>

What are the pros and cons of each option?

People deciding about diagnostic testing for Down's, Edwards' or Patau's syndromes have different experiences and views.

Choosing the option that is best for that person means considering how each option will affect them.

Here are some questions people may want to consider about diagnostic testing for Down's, Edwards' or Patau's syndromes:

- How important is it for me to know for certain whether or not my baby has Down's, Edwards' or Patau's syndromes?
- Is knowing my chance of having a baby with Down's, Edwards' or Patau's syndromes from my screening test enough for me?
- Would I have this baby if it had Down's, Edwards' or Patau's syndromes?
- Would I have a termination of pregnancy if the baby had Down's, Edwards' or Patau's syndromes?
- Would I accept the chance of miscarriage in order to have a diagnostic test?
- If I have a diagnostic test, how important is it for me to have the one that will give the result as early as possible?
- If I have a diagnostic test, how important is it to me that it is the one with the least chance of miscarriage?

How do I get support to help me make a decision that is right for me?

People using this type of information say they understand the health problem and treatment choices more clearly, and why one treatment is better for them than another. They also say they can talk more confidently about their reasons for liking or not liking an option with health professionals, friends and family.

References

10. NHS Screening Programme Chorionic Villus Sampling. www.fetalanomalyscreening.nhs.uk

11. NHS Screening Programme Amniocentesis. Sampling. www.fetalanomalyscreening.nhs.uk

12. Royal College of Obstetricians and Gynaecologists. Amniocentesis and Chorionic Villus Sampling. Green-top Guideline No.8. June 2010.