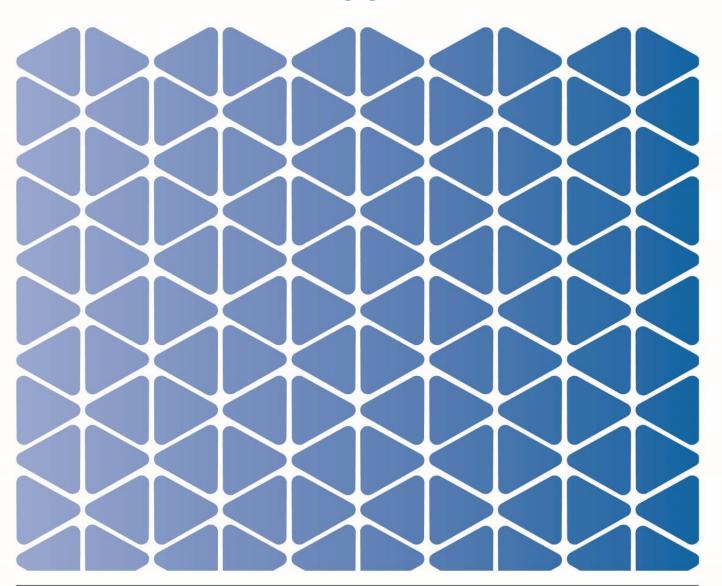




# **PATIENT INFORMATION**

# **FOLLOWING A HIGHER CHANCE COMBINED SCREENING OR QUAD RESULT**







## What does a 'higher chance' result mean?

This result does not mean your baby has Down's syndrome, Edward's syndrome or Patau's syndrome. In fact, most women who receive a result like this will **not** be carrying a baby with one of these conditions. This result means that your individual chance has been detected as higher than 1:150 therefore we are offering you the option of further testing to determine if your baby does have one of these conditions.

## An example of a higher chance result:

The chance of Down's syndrome is 1:100. This is the same as saying:

- There is a 1% chance your baby will have Down's syndrome or
- There is a 99% chance your baby does not have Down's syndrome or
- If there were 100 people stood in a room together there is a chance 1 of those people might have Down's syndrome.

| Your screening result i | nas snown you are at a nigi | ner chance of having a baby |
|-------------------------|-----------------------------|-----------------------------|
| with                    |                             |                             |
| The chance your baby    | has this condition is:      |                             |
| 1 in                    | Which is                    | %                           |

## What happens next?

We have discussed all of your options over the telephone/or in person with you and here is a summary of what was discussed:

- Take no action Continue with routine follow up in your pregnancy, accepting your higher chance result as this does not affect how you feel about continuing your pregnancy. You will have your mid trimester anomaly scan as planned at around 18-20 weeks and if any structural differences are seen on the scan you will be referred to our fetal medicine department. However, it is important to note that a scan cannot diagnose a chromosomal difference with your baby.
- Chorionic villus sampling (CVS) This can be carried out between the 11<sup>th</sup> and 14<sup>th</sup> week of your pregnancy. You will be referred to Birmingham Women's Hospital for this procedure and they will contact you directly. CVS is an invasive diagnostic test that carries a 1-2% chance of miscarriage but is extremely accurate. The failure rate with this test is <1%.

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- Amniocentesis This can be carried out locally at WRH from 15 weeks onwards. Amniocentesis is an invasive diagnostic test that carries a 1% chance of miscarriage but is extremely accurate. The differences in the specific procedures for CVS and amniocentesis have already been discussed with you over the phone but if you would like more specific information on these please get in touch. The failure rate with this test is <1% (i.e the chance of not obtaining a result is less than 1%)</li>
- NIPT Non Invasive Prenatal testing is a private screening blood test not currently available on the NHS costing £300-£500 depending on which provider you use. An advantage of this test is that it does not carry a miscarriage risk as it just requires a blood test from the mother however it is still classed as a screening test which will give you a 'highly likely' or 'highly unlikely' result. It has been proven that this test is 99.9% accurate for detecting Down's syndrome and 93-96% accurate for Edward's & Patau's syndrome as it is looking at the baby's own DNA. Should you wish to end your pregnancy based on the findings of a NIPT result you would require a CVS or Amniocentesis to confirm the results. If you do wish to go ahead with this option please contact ARC (Antenatal results & choices) 0845 077 2290 and they will give you a list of local recommended providers.

## Things to think about

- You can take as much time as you need to think about your options, we will not rush you into making any decisions. However we will contact you to offer further support unless you tell us otherwise.
- What will you do with the extra information from further testing? For example if it
  would not change how you feel about your pregnancy you may feel you don't
  want to take any further action and this is ok.
- If you do opt for NIPT we would be grateful if you could let us know the results as we don't automatically get informed of these.

If you have any further questions please contact the screening team on **01905 768945.** 

#### Useful websites –

www.arc-uk.org

https://www.nhs.uk/conditions/amniocentesis/

https://www.nhs.uk/conditions/chorionic-villus-sampling-cvs/

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If your symptoms or condition worsens, or if you are concerned about anything, please call your GP, 111, or 999.

### **Patient Experience**

We know that being admitted to hospital can be a difficult and unsettling time for you and your loved ones. If you have any questions or concerns, please do speak with a member of staff on the ward or in the relevant department who will do their best to answer your questions and reassure you.

#### **Feedback**

Feedback is really important and useful to us – it can tell us where we are working well and where improvements can be made. There are lots of ways you can share your experience with us including completing our Friends and Family Test – cards are available and can be posted on all wards, departments and clinics at our hospitals. We value your comments and feedback and thank you for taking the time to share this with us.

## Patient Advice and Liaison Service (PALS)

If you have any concerns or questions about your care, we advise you to talk with the nurse in charge or the department manager in the first instance as they are best placed to answer any questions or resolve concerns quickly. If the relevant member of staff is unable to help resolve your concern, you can contact the PALS Team. We offer informal help, advice or support about any aspect of hospital services & experiences.

Our PALS team will liaise with the various departments in our hospitals on your behalf, if you feel unable to do so, to resolve your problems and where appropriate refer to outside help.

If you are still unhappy you can contact the Complaints Department, who can investigate your concerns. You can make a complaint orally, electronically or in writing and we can advise and guide you through the complaints procedure.

#### **How to contact PALS:**

Telephone Patient Services: 0300 123 1732 or via email at: wah-tr.PET@nhs.net

## Opening times:

The PALS telephone lines are open Monday to Thursday from 8.30am to 4.30pm and Friday: 8.30am to 4.00pm. Please be aware that a voicemail service is in use at busy times, but messages will be returned as quickly as possible.

If you are unable to understand this leaflet, please communicate with a member of staff.

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