

Patient first name:	
Patient last name:	
Date of birth (dd/mm/yyyy):	
NHS number: (or Postcode, if not known)	

## Record of discussion regarding testing for genetic causes of fetal anomalies

***This form relates to the person being tested.***

*All of the statements below remain relevant even if the test relates to someone other than yourself, for example your baby. One form is required for each parent being tested.*

***I have discussed exome sequencing with my health professional and understand that:***

1. This test includes genes with current evidence for a causal link with structural problems in a baby that can be detected by imaging. It does not include genes linked to conditions that only present after birth, for example developmental delay or autism.
2. Prenatal imaging does not allow us to examine the baby in as much detail as we can after birth. In some cases, more information after delivery will prompt further tests that may enable a genetic diagnosis.

***Family and wider implications***

3. The results of my test may have implications for me and members of my family, including revealing information about a child's biological parents. I understand that my results may also be used to help the healthcare of members of my family and others nationally and internationally. This could be done in discussion with me or through a process that will not personally identify me.

***Uncertainty***

4. The results of my test may have findings that are uncertain and not yet fully understood. To decide whether findings are significant for myself or others, my data may be compared to other patients' results across the country and internationally. I understand that as new knowledge becomes available this could change what my results mean for me and my treatment over time.

***Unexpected information***

5. The results of my test may also reveal unexpected results that are not related to why I am having this test. These may be found by chance and I may need further tests or investigations to understand their significance.

***DNA storage***

6. Normal NHS laboratory practice is to store the DNA extracted from my sample even after my current testing is complete. My DNA might be used for future analysis and/or to ensure that other testing (for example that of family members) is of high quality.

***Data storage***

7. The data from my test will be securely stored so that it can be looked at again in the future if necessary.

***Health records***

8. Results from my test will be part of my patient record, only available to healthcare professionals.

***Service evaluation and audit***

9. As this is a new test in the NHS it is important to monitor how the test is performing. To do this healthcare professionals may need to collect relevant information about me from my medical record after my test result, or to look at information about my test. Any data collected will be stored in a way that does not personally identify me.

***Research***

10. I understand that I may have the opportunity to take part in research which may benefit myself or others, now or in the future. If relevant opportunities arise, I consent to being contacted to discuss these.

For any further questions, my healthcare professional can provide information. More information regarding genetic testing and how my data is protected can be found at <https://www.nhs.uk/conditions/genetics/>.

**Please sign on page 2 to confirm your agreement to testing.**

Patient first name:	
Patient last name:	
Date of birth (dd/mm/yyyy):	
NHS number: (or Postcode, if not known)	



## Confirmation of your genetic test and research choices:

I confirm that I have had the opportunity to discuss information about testing for genetic causes of fetal anomalies by exome sequencing and potential research opportunities.

A. I confirm that I have had the opportunity to discuss information about testing for genetic causes of fetal anomalies by exome sequencing and agree to testing (circle your answer)  
YES | NO

B. I agree to being contacted to discuss relevant research opportunities in future YES | NO

<b>Patient name:</b>  .....	<b>Signature:</b>  .....	<b>Date:</b> (dd/mm/yyyy)  ...../...../.....
<b>If applicable:</b>		
<b>Parent / Guardian / Consultee name:</b> (amend as appropriate)  .....	<b>Signature:</b>  .....	<b>Date:</b> (dd/mm/yyyy)  ...../...../.....

## Healthcare professional use only:

To be completed by the healthcare professional recording the patient's choices

Healthcare professional name:	Signature:	Date:
		(dd/mm/yyyy)
.....	.....	...../...../.....

<b>Hospital number:</b>		
<b>Patient category:</b>	Adult (signed by themselves)	
	Adult lacking capacity (signed by consultee)	
<b>Responsible clinician:</b>		