

Genomic testing

patient consent form



| Details of patient being tested: | |
|----------------------------------|--|
| First name | |
| Surname | |
| Date of birth | |
| URN | |

| Parent/guardian/other representative (if applicable): | |
|---|--|
| First name | |
| Surname | |
| Date of birth | |
| Relationship | |

1. About the test

It is my choice for the above-named patient to have genomic testing by panel/exome/genome analysis to look for changes in genes that may be associated with:

Genomic test results are based on current knowledge, which may change in the future.

2. Potential outcomes

I understand:

- This test may find a cause for the condition(s).
- This test may not find a cause for the condition(s).
- The result may be of 'unknown significance', which means it cannot be understood today.
- There is a chance that genomic testing could find other medical conditions (incidental findings).
- This test will not predict all future health problems.
- Genomic testing may identify unexpected family relationships.
- Further testing or information sharing may be needed to finalise the result.

3. Results

I understand:

- I will be told the results by a health professional.
- I can choose not to be told about the results, but the report may still be included in the patient's medical record.
- Results may have implications for the health/genetic risks of the patient, and their family members.
- Results from these tests may affect the patient's ability to obtain some types of insurance.
- The results will be available to the team of health professionals involved in the patient's care.
- Results are confidential and may be released as specified in this form, or as allowed by law.

I give permission for the report to be shared with health professionals involved with the care of:

all relatives of the patient specific relatives: _____

The following individual can be given the results, if I am unable to be contacted:

Name: _____ Contact number: _____

4. Data and sample sharing

I understand and agree that the sample, genomic data and related health information may be shared and stored to help advance scientific knowledge (in a de-identified format – that is, without personal identifiers such as name and address).

5. Research

I provide consent to share the sample, genomic data and related health information of the patient for ethically approved research into the same or a related condition, where it remains possible to re-identify the patient. This allows relevant information to be returned to me where appropriate. There may not be a direct benefit to the patient and their family.

Yes No

6. Consent

I have had enough time to consider the information in this consent form and have:

- Had the opportunity to discuss genomic testing and its implications with a health professional.
- Been given access to information about genomic testing.
- Been able to ask questions until I am satisfied with the answers.
- Been offered a copy of this consent form.

I provide consent for genomic testing as summarised in this form.

Patient/Parent/Guardian signature: _____ Date: _____

Health professional signature: _____ Date: _____

Health professional name: _____

Consent for biological parents* undergoing duo/trio analysis (complete if applicable)

By signing below, we consent to genomic testing as described in this form for the purpose of assisting in the interpretation of the genomic results of our child (the patient named above).

Specifically we understand that the potential outcomes of the test described in section 2 (including incidental findings and unexpected family relationships), the sharing and implications of the result, including insurance implications (section 3), and the sharing and storage of the sample and genomic and health data (section 4) apply to the collection and analysis performed on our own samples.

| | BIOLOGICAL MOTHER | BIOLOGICAL FATHER |
|----------------|-------------------|-------------------|
| Name: | | |
| Date of birth: | | |
| Signature: | | |

**If both parents cannot sign one form, duplicate this form and ask each parent to sign a separate copy and submit both to the lab.*

Research consent

I provide consent to share my sample, genomic data and related health information for ethically-approved research into my child's condition, where it remains possible to re-identify me. This allows information to be returned to me where appropriate. There may not be a direct benefit to me or my family.

| | BIOLOGICAL MOTHER | BIOLOGICAL FATHER |
|-----------------------|--|--|
| Consent for research: | <input type="checkbox"/> No <input type="checkbox"/> Yes | <input type="checkbox"/> No <input type="checkbox"/> Yes |