VCGS
Leaders in Genetic Health

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Genomic testing
patient consent form

Details of person being tested:	
First name	
Surname	
Date of birth	
URN	

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

Statement

This molecular test has been explained to me by a health professional and I have been given the test information sheet. I understand that my / my child's / my relative's DNA will be tested for genes associated with (type of condition):

_____

Only genetic changes (variants) in genes known to be associated with the condition above will be analysed and interpreted in the first instance. This test is NOT a general health test and will not identify all gene changes that could contribute to health problems in the future.

I understand:

1. The potential outcomes of the test, including the potential risks and benefits, as outlined in the relevant patient information sheet.
2. Knowledge about genetic conditions is likely to improve in the future. If new information comes to the attention of the laboratory that alters the meaning of the result for my / my child's / my relative's health, the laboratory may inform my / my child's / my relative's healthcare provider of this. Alternatively, I can ask my healthcare provider to contact the laboratory to check if such information has become available.
3. There is a small chance that genetic variants may be identified that are associated with an unrelated condition that may develop in the future, or that may reveal carrier status of an unrelated condition. In this circumstance, my / my child's / my relative's healthcare provider will arrange appropriate follow up care, as necessary.
4. The result can be used to facilitate the counselling and testing of other family members.
5. My / my child's / my relative's DNA sample and genomic data will be stored by the testing laboratory in accordance with national laboratory guidelines.
6. The genomic data and associated healthcare information can be used and disclosed in accordance with the applicable health privacy laws.
7. The result and associated health information will be stored by my healthcare provider and may be made available for my / my child's / my relative's ongoing treatment and healthcare.
8. My / my child's / my relative's genomic data and health information may be shared, **in a way that does not identify** myself / my child / my relative (anonymised), for the purpose of advancing knowledge generally, including understanding of genetic variation in humans. I understand that I / my child / my relative are unlikely to gain any personal benefit from this and will not be notified if the information is shared.
9. I may be contacted to obtain my consent for the use and disclosure of my / my child's / my relative's DNA, genomic data and associated health information for other purposes not specified above.

Additional use of DNA and genomic data (see examples in Table 1 below)

Please specify if you agree or not to the following. Not agreeing will not affect your access to this test.

10. ☐ I agree ☐ I do not agree

for my / my child's / my relative's DNA, genomic data and health information to be shared after testing, for additional activities that may benefit my / my child's / my relative's healthcare. If you agree, your **identified** information will be used.

If you do not agree, your information will not be used for additional activities.

_____ Date:_____

Signature of patient/guardian/other representative

In the event that I am not able to be contacted, the following individual(s) can be given my result:

_____ _____

Name, Address & Phone Relationship to tested individual

Health Professional Statement:

I have explained the potential clinical utility (including the risks and benefits) of the requested test, as well as the clinical implications of not undergoing the test, and answered questions asked of me by the patient and/or the patient's guardian or authorised representative.

_____ Date:_____

Signature of health professional

Identified and anonymised health information:

Your health information can exist in two main forms: identified and anonymised (or de-identified).

Identified information means that someone is able to identify you. They have access to your name and/or other personal details.

Anonymised or de-identified information has had your personal details removed. Someone using anonymised information does not know who it came from.

Examples of how identifying information may be used

Examples of how identified information can be used are listed below. These may reveal information that is important to your health, or the health of your blood relatives. All important information will be returned to you.

Table 1: Examples of use
Activities to better understand the cause or management of your condition
For example, your doctor may share your information with international groups trying to identify genetic variants common to people who all have the same condition. The greater the number of patients with the same condition and the same genetic variants, the more likely the genetic variants are to contribute to the condition.
Research to identify new genes associated with your condition
Research opportunities aimed at finding the cause of your condition may be offered. This may involve a re-analysis of your genomic data. With your permission, your doctor and the laboratory could share your information, meaning researchers may not need to re-sequence your DNA and you would not need to provide another sample.
Trying to understand what a specific genetic variant does in the cells of the body
To help clarify whether the genetic variant affects cell functioning, the laboratory may ask for your information so they can do further work that may provide clues to the role of the genetic variant