

# Information on Genetic Testing and Consent

## Information for patients

### Why have genetic testing?

There are a number of reasons why genetic testing may be offered:

- To confirm a diagnosis of a genetic disorder
- To test for a genetic disorder known in the family
- To allow risk reducing options or screening to be offered as some disorders can predispose to certain health problems such as cancer or heart disease
- To test an unborn baby for a genetic disorder if suspected due to clinical information or family history.

### Genetic testing and consent

Genetic testing is always your choice and there is no set time to carry out testing, you can come back to it at any time.

### How is the test carried out?

The most common way to do genetic testing is using a blood sample. Your DNA (genetic material) is then extracted from the blood and the testing is carried out on the DNA.

It can take several months for the results to be available depending on the individual test.

Your clinician will advise you on how long your results will take.

### Results

The results of your test will be explained either by letter, phone, or consultation.

This information will be shared with other health professionals who need it to provide health care, including your GP.

### Your records will be kept confidential

The results of your test can have implications for members of your family. It may be useful to share information with their genetic department.

### Family information

The interpretation of genetic information will depend on the accuracy of the family information given to the clinician.

Difficulties in interpreting test results may arise when the parents of a child are different from those reported: for example, non-paternity may be detected with some genetic tests.

## DNA storage

After genetic testing is completed, there is often DNA left over. It is our normal laboratory practice to store this unused DNA. This is because in the future (months or years) new tests may become available and the laboratory can then carry out additional testing.

Additionally, the lab may occasionally use stored DNA to check laboratory techniques or as a 'quality control' for testing other family members.

If you would rather the laboratory **did not** store your unused DNA, you can indicate this on your consent form. The clinician who is taking consent will highlight this option for you.

## Genetic testing and insurance

Currently there is an agreement between the insurance companies and the genetic community that the results of genetic tests cannot be used to raise premiums. However, it is unclear whether this agreement will be maintained indefinitely. If you would like further information, we have a leaflet called "*Insurance and Genetics*" or the Genetic Alliance website has up to date information: [www.geneticalliance.org.uk/information/living-with-a-genetic-condition/insurance-and-genetic-conditions/](http://www.geneticalliance.org.uk/information/living-with-a-genetic-condition/insurance-and-genetic-conditions/)

Alternatively check with the ABI directly at [www.abi.org.uk/data-and-resources/tools-and-resources/genetics/genetics-faqs/](http://www.abi.org.uk/data-and-resources/tools-and-resources/genetics/genetics-faqs/)

## Further information

It is important to understand that although genetic testing is usually accurate, as with all testing, some inaccuracies may occur. Genetic research is ongoing and new research may mean that the interpretation of the test results may change over time.

You can check with the department for updated genetic information and counselling that you feel you need at any time, for example, in making personal decisions about pregnancy.

It would be helpful to notify the South East of Scotland Clinical Genetics Service of any change of your address.

### Your local genetics service:

South East of Scotland Clinical Genetic Services  
Molecular Medicine Centre  
Western General Hospital  
Crewe Road South  
Edinburgh  
EH4 2XU

Telephone: 0131 537 1116