Clinical Genetic Service leaflet reference: 090

South East of Scotland Genetic Service
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Long QT Syndrome Predictive Testing Information Leaflet

A gene alteration has been identified in your family that is thought to explain your family history of Long QT Syndrome (LQTS). This means that a test is available for you, to see if you have this gene alteration and if you have an increased risk of developing LQTS.

- **If you carry the gene change**, this confirms a diagnosis of LQTS in you and you are therefore at risk of developing symptoms of this syndrome. Your children and future children are at a 1 in 2 (50%) risk of inheriting the gene change

- **If you do not carry the gene change**, your risk of developing LQTS is similar to other people in the general population and your children would not be at increased risk of inheriting the condition.

If you are found to have the gene change we would refer you to cardiology for regular follow up and management of your clinical risk.

Plan of action going forward

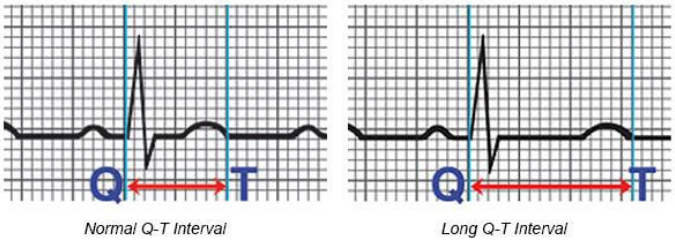
Please tick as appropriate		Enter details
	You have decided to proceed with testing. We have made the following arrangements for you to receive the results.	
	A follow up appointment has been arranged on	
	You have decided to get back in touch when you feel ready to proceed with testing.	

Following testing, results are usually available within 6 weeks. Results are confirmed in writing to you and copied to your referring clinician/GP.

You were seen by:	Genetic Counsellor	Patient label
Date:		

Long QT syndrome

Long QT syndrome (LQTS) can cause disturbances in the electrical system of your heart, leading to an abnormal heart rhythm called an arrhythmia. This can sometimes be seen on an electrocardiogram (ECG) recording as a lengthening of the time period of a particular part of the heartbeat cycle, known as the 'QT interval'.



Symptoms can include unexplained fainting, seizures or a sudden cardiac arrest.

Long QT syndrome can be inherited (due to an altered gene) or acquired (usually due to QT prolonging medication).

It is common for individuals in the same family with inherited LQTS to have different experiences of the syndrome. Some may have a normal QT interval and not have any symptoms; some may have a very abnormal QT interval but no symptoms; and some may have a very abnormal QT interval and episodes of abnormal heart rhythm that put them at risk. It is therefore important to identify those at risk so individualised care can be provided.

Several investigations may be required before a diagnosis of LQTS is confirmed. If your genetic test identifies that you have inherited LQTS you will be referred to Cardiology who may arrange several investigations. The most common test is an ECG which provides a recording of electrical signals in your heart. As signs of LQT can be infrequent, sometimes additional investigations are required e.g. repeated ECGs, exercise stress test and holter monitoring over a period of time. Genetic testing can also be utilised to help confirm a diagnosis of LQTS and to provide clarification of familial risk. Once one person in the family is confirmed to have the condition they will be offered genetic testing. If this testing identifies the genetic cause for their LQTS then other people in the family can have a genetic test to see if they have the condition or not.

For more information and links to support organisations you can look at the website: Network for Inherited Cardiac Conditions Scotland (NICCS) at **www.niccs.scot.nhs.uk/**

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A limitation of the genetic test *is that just like much of medical science, we cannot yet know with certainty all the factors that influence health. There is very small chance that current classification of a gene variant may change as more information becomes available. This may change the clinical diagnosis, prognosis or treatment you receive.*