

Genetic Beta Cell Research Bank

Diagnostic Information Sheet for Consultees (V1 01/09/2017)

Information for consultees representing patients providing a blood sample for genetic testing at the Royal Devon & Exeter NHS Foundation Trust Molecular Genetics Service

Why am I being asked to read this?

You are attending an appointment with a person who, in the opinion of their doctor, is not able to provide written consent themselves. We therefore ask you to read this information and decide with the patient if they would be happy to consent to their sample being used for research and whether they would want to be involved in future research into their condition. A simplified schematic is provided below for you to help explain to the patient what is being asked.

What will happen to the patient's sample?

The blood sample will be sent to a laboratory at the Royal Devon & Exeter NHS Foundation Trust Hospital that specialises in identifying the genetic causes of diabetes and related conditions. Genetic material (DNA) will be extracted from their blood and diagnostic tests will be carried out to see if they have a known genetic condition. The DNA will be stored and may be tested in the future for new genetic causes of their condition. Any results will be referred to their doctor.

In addition to the testing done to understand the nature of their condition, we also ask for consent to use their sample for broader research into the causes and treatment of diabetes and related disorders. To protect their identity, the samples will only be labelled with codes and all research using these samples will need to be approved by an expert steering committee. This research may not directly benefit the patient but may help to improve the understanding, diagnosis and treatment of diabetes in the future.

How can they get involved in research into their condition?

If you provide contact details, the genetic research team at the Royal Devon & Exeter NHS Foundation Trust Hospital can let you know about studies looking into the causes and treatments of their condition.

How do I find out more?

For more information about genetic diabetes you can look at <http://www.diabetesgenes.org/content/maturity-onset-diabetes-young>

For more information, please contact: Maggie Shepherd on 01392 408261.

Simplified Information for Patients



Your doctor is going to send some of your blood to the lab to try and find out why you are not feeling well. Is it OK if we also give some of this blood to a scientist to find out more about why people get sick?