

Sickle Cell and Thalassaemia Blood Group Genotyping Programme



What are sickle cell and thalassaemia?

Sickle cell disorder and thalassaemia are both genetic disorders of haemoglobin, the oxygen-carrying molecule in blood. In sickle cell disorder, the red blood cells become damaged and sticky, blocking blood vessels, causing “crises”. In thalassaemia, people cannot produce enough haemoglobin, causing severe anaemia. For both disorders, people often need regular blood transfusions to keep them healthy.

What are blood groups and what is blood group matching?

Red blood cells have labels on their surfaces, known as antigens or blood groups. We inherit our blood groups from our parents and different people have different blood groups.

There are over 300 different blood groups, although the most important/well known ones are A, B, O and AB plus RhD positive and RhD negative. These are known as the basic blood groups. The donor blood selected for transfusion matches the basic blood groups as standard. Blood for people with sickle cell, thalassaemia and, in some cases, rare inherited anaemias is matched for a small number of additional groups but is not matched for the full extended blood groups.

How is blood matched now?

Before a person receives a transfusion, they have a blood sample taken, which will be processed by a hospital laboratory to check their basic blood group if they are a 'regular' patient. For someone with sickle cell or thalassaemia, they would have their partially extended blood group checked. When the blood laboratory team choose blood for patients, they check that the blood group of the donor matches their blood groups as closely as possible.

How do we find out the blood groups for donors and patients?

We use a technique involving antibodies, known as serology, to detect blood groups. This works well for the basic blood groups, but for testing more of the blood groups (known as extended blood group testing) we need a different technique. This is because serology is time-consuming and expensive and we do not have the antibodies or resources to test all the different blood groups of patients and donors. Also we cannot use serology if people have had a recent transfusion.

Why would it help to perform extended blood group testing on our patients and donors?

Each time we transfuse a person, even if we match the basic blood groups, there is a chance that the person can form a new antibody if the extended blood groups are not matched. Antibodies can cause reactions which may be severe and make it difficult to find the right blood for patients in the future. Unfortunately, this happens more often for people with sickle cell and thalassaemia.

What is the new technology?

Blood groups can also be tested using DNA from blood samples. This is known as blood group genotyping. NHSBT has used this technology for a while but up until now, it has been a slow and expensive test. Working with an international group of scientists and industry, NHSBT has developed a new fast and cost-effective test. NHS England are funding NHSBT to offer this new test alongside testing for bone marrow type (human leucocyte antigen – HLA). We have called this the sickle cell and thalassaemia blood group genotyping programme.

How would this new technology help patients?

NHSBT is running a similar programme in blood donors. Using the blood group types from donors and patients should allow the NHS, in the future, to provide the best possible blood match for patients, reducing the risk of forming antibodies. For those patients that already have antibodies, it should be easier and quicker to find suitable blood for transfusion. By also testing HLA, people who are potentially eligible for stem cell / bone marrow transplant will have taken the first step to see if they have a related HLA-matched donor.

We can't say when we expect extended matching to be available for those patients who may benefit. But, as more of the patients and the donors have their blood group genotyped, it will be increasingly possible to provide better matched blood.

How can I have my sickle cell and thalassaemia blood group genotyping test done? What is involved?

The blood group genotyping test requires a single sample tube of blood that can be taken at the same time you have a blood test. However, it can only be taken in hospital. The test will be explained to you and, if you agree, they will confirm your consent on the test request form. The samples and request form will be sent to NHSBT for testing. The result will be available to the hospital laboratory team on the regular system they use to access NHSBT results. In many hospitals, the team will put the results on the hospital laboratory system so your clinical team can see these results and share them with you.

Following testing, there is often some of your blood sample left over. The law allows NHSBT to use this, and the information associated with it, anonymously for quality control (making sure our tests are working correctly), education or training relating to human health, or ethics committee-approved research. Samples may be stored as part of required archiving protocols to enable further investigation for your benefit. This practice helps NHSBT maintain accurate testing procedures and improve its knowledge, and so provide the best possible care for all patients now and in the future. If you do not want your sample to be used for these purposes, you should tell your clinical team so that they can tell NHSBT. NHSBT will respect your wishes and dispose of any samples they no longer need.

It is the responsibility of the requester submitting your sample to ensure informed consent has been obtained for all tests, including genetic tests in accordance with current guidance and legislation.

If you are unsure about any aspects of your treatment/care, ask your treating clinical team to explain.

NHS Blood and Transplant

NHS Blood and Transplant (NHSBT) saves and improves lives by providing a safe, reliable and efficient supply of blood and associated services to the NHS in England. We are also the organ donor organisation for the UK and are responsible for matching and allocating donated organs. We rely on thousands of members of the public who voluntarily donate their blood, organs, tissues and stem cells.

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