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What is happening?

Scotland has joined a UK Wide Genetic Testing Programme to improve future blood matching for patients with Sickle Cell Disorder, Thalassaemia and other rare inherited red cell disorders.

The Scottish National Blood Transfusion Service (SNBTS) will be offering access to the NHS Blood and Transplant (NHSBT) and NHS England blood group genotyping programme for patients in Scotland. This testing is available for patients living with inherited anaemias, including Sickle Cell Disorder (SCD), Thalassaemia, and other rare red cell disorders, who need regular blood transfusions for their health and well-being.

As part of a UK wide collaboration, the samples will be tested at NHSBT's Molecular Diagnostics Laboratory in Bristol, using a new testing array developed by the <u>Blood</u> <u>Transfusion Genomics Consortium (BGC) - www.bgc.io/</u>

Participation with testing through this programme will strengthen our continuing commitment to supporting patients in Scotland with Sickle Cell Disorder and other inherited anaemias who require transfusions.

What is the NHSBT/NHS England Blood Group Genotyping Programme for inherited red cell disorders?

NHS England (NHSE) is working with NHSBT on a new national programme of work to better identify blood groups for all current patients in England living with inherited anaemias including Sickle Cell Disorder and Thalassemia and transfusion dependent rare inherited red cell disorders. This test has now been made available to those living in Northern Ireland, Scotland and Wales through their respective national blood services.

The programme aims to use a DNA testing array, developed by the international Blood Transfusion Genomics Consortium, to provide extended blood group genotyping and HLA typing.

Through this programme, together with a programme that is being rolled out in the donor population in England, in the future it will be possible to identify better matched blood for transfusion and so reduce antibody formation.

Why do we need this?

Blood group genotyping is the **first step** towards providing better matched blood for patients requiring regular transfusions. Over time, this aims to reduce the likelihood and consequences of red cell allo-antibody formation.

Currently, we test all patients and donors for blood groups A, B, O, Rh D (to see if you are positive or negative). Blood for the patient groups listed above is also tested for other common groups such as K and Rh C, c, E, e. This is mainly performed using serological techniques.

Blood group genotyping is currently performed in Scotland for set clinical indications using a low throughput, low resolution (giving limited detail) technique. In this new programme, testing will be performed using a new high-throughput, high-resolution technique, which allows more samples to be tested and faster, giving greater detail than previously available.

Who is eligible for this testing in Scotland?

Patient with inherited anaemias who require or are likely to require blood transfusions.

Patient group examples include:

- Sickle Cell Disorder
- Transfusion-Dependent Thalassaemia
- Other rare inherited red cell disorders such as Diamond-Blackfan Anaemia Syndrome.

Please note that patients who have already had extended blood group typing performed by serological or genotyping techniques are still eligible for testing in this current programme.

When can patients get tested?

Testing will be available in Scotland from **10th December 2024** to **30th September 2025**.

What do clinical teams and blood banks need to do?

Clinical teams

- Please discuss this testing with eligible patients or their guardians when they attend clinic or for transfusion.
 - You can use our local patient information leaflet to support your discussion and/or you can signpost your patients to online information at <u>National Services</u> <u>Scotland's (NSS) Blood group genotyping webpage</u> (https://www.nss.nhs.scot/blood-tissues-and-cells/blood-group-genotyping-programme-in-scotland/)
 - Online information for clinicians and laboratory staff can be found on <u>NHS Blood</u> and <u>Transplant's Frequently Asked Questions webpage for Blood group</u> genotyping (<u>www.nhsbt.nhs.uk/what-we-do/clinical-and-research/blood-group-genotyping/hospital-and-lab-staff/frequently-asked-questions/</u>)
- If your patients, or their legal guardian/s consent to be tested, please complete the
 request form which can be found at
 https://www.nhsbt.nhs.uk/ibgrl/services/molecular-diagnostics/nhs-england-programme-for-haemoglobinopathy-blood-group-genotyping/
 - Guidance on completing the form can be found at <u>NSS' Blood group genotyping</u> webpage (https://www.nss.nhs.scot/blood-tissues-and-cells/blood-groupgenotyping-programme-in-scotland/blood-group-genotyping-programme-inscotland/)
 - You must tick the box to confirm that your patient has provided informed consent or your sample will not be sent to Bristol for testing. NHSBT do not test samples which do not have confirmation of consent.
- Document your discussion and patient's consent in your clinical notes
- Take the appropriate sample from your patient as follows:
 - o Adults or children over 12 years 6 ml EDTA
 - o Children 6 months 12 years 2 ml EDTA
 - o Children less than 6 months − 1 − 2 ml EDTA
- For hospitals that do NOT have an SNBTS run blood bank, take an additional Group and Save sample (see volume requirements above)
- Send the samples x 2 and fully completed form to your local blood bank

Blood banks

• Ensure blood forms completed correctly and samples correctly labelled. Contact the clinical team if not completed correctly e.g. consent box not completed.

- Contact clinical team if wrong or insufficient sample type sent.
- Guidance on completing the form can be found by visiting <u>NSS' Blood group</u> genotyping webpage (https://www.nss.nhs.scot/blood-tissues-and-cells/blood-group-genotyping-programme-in-scotland/blood-group-genotyping-programme-in-scotland/)
- Complete the required SNBTS referral form (NATF 1307 or NATF 1648)
 - For NATF 1307, write "Blood Group Genotyping Programme" on the "Reason for Referral" line
 - For NATF 1648, write "Blood Group Genotyping Programme" in the "Other"
 line in the "Reason for Referral" section
- Send correctly completed forms and samples to SNBTS Red Cell
 Immunohaematology laboratory at Gartnavel via routine transport arrangements.

What will SNBTS do?

- SNBTS' laboratory will extract the DNA from samples sent before sending to NHSBT's Bristol laboratory for testing.
- SNBTS will **not** process samples where patient consent is not confirmed or that do not satisfy sample acceptance criteria.
- Samples will be sent to NHSBT in batches.
- Results from NHSBT will be sent to SNBTS and will include advice on interpretation.
- SNBTS will send results to blood banks who will notify the requesting clinicians via established pathways.

When will results be available?

The turnaround time for return of results has not yet been confirmed by NHSBT. There may be several months between sending samples and receiving results.

Any patient who requires genotyping for clinical reasons (eg to resolve and identify an allo-antibody specificity for blood provision) should be discussed with their local SNBTS Consultant. If required, blood group genotyping can be performed using current standard tests (either by SNBTS or NHSBT) to help support timely and appropriate blood provision.

Does this mean that patients will get matched blood once my results are available?

This information is the **first step** towards providing better matched blood for patients. Improved matching will also require blood group genotyping to be performed on blood donors. This is a separate complementary programme of work currently being undertaken by NHSBT.

Where can I find more information about this testing programme?

More information can be found online by scanning the QR code or visiting <u>NSS' Blood group genotyping webpage</u> (https://www.nss.nhs.scot/blood-tissues-and-cells/blood-group-genotyping-programme-in-scotland/blood-group-genotyping-programme-in-scotland/)



Who can I contact for more information?

Scottish testing arrangements: nss.BGGenPrgTestEnquiries@nhs.scot