



Volunteering for genetic blood type testing

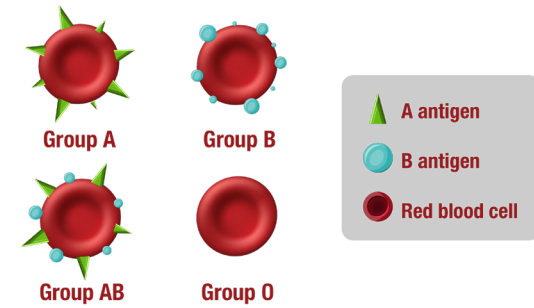
Thank you for giving blood. The Scottish National Blood Transfusion Service (SNBTS) are asking a limited number of blood donors to take part in an exciting new project on genetic blood group testing, a technique which allows scientists to extend the amount of blood groups they can identify.

What are blood groups?

As of September 2022, 43 different human blood group systems are recognised by the International Society of Blood Transfusion (ISBT). The two most commonly used blood group systems are ABO (ie whether your blood is type A, B, AB or O) and RhD (ie whether your blood is type positive or type negative). These two blood groups are used together to give a more precise description of your blood, so it can be matched for blood transfusions. However, there are also a number of other ways of classifying blood which are less commonly known about outside the scientific community. When these are used, even more precise matches can be made between donor and patient.

What differentiates blood groups?

Each blood group has different combinations of sugars and proteins attached to the red blood cells. These are called 'antigens', and they are the markers which are used to work out someone's blood groups. We inherit our blood antigens genetically from our parents,



and different people have different sets of blood groups.

You can read more about this at www.haemmatch.co.uk.

Why is matching blood important?

Most blood transfusions are matched based on the ABO and RhD groups. However, if someone needs ongoing transfusions, blood works best when it closely matches their own types for other groups too. This is because a patient may form an antibody (an active immune cell) against an antigen if the red cells of the donor have an antigen that is different to their own. Antibody formation can be dangerous, because if the patient is later transfused with blood containing the antigen that caused the antibody to form there is a risk that the immune system of the patient will attack the transfused cells, causing a reaction that can be harmful.





What is the BGC project?

The Blood transfusion Genomics Consortium (BGC) is an international partnership between blood services, research institutions and industry leaders. The aim of this group is to improve the safety and efficiency of blood and platelet transfusion matching by introducing DNA testing into routine transfusion practice.

When you become a blood donor, SNBTS test your blood to work out your blood group. This is so we can match your donation to be compatible with the blood group of the patient. This is performed using traditional laboratory techniques.

Recent advances in DNA testing mean it is now a proven method for determining blood types. Moreover, all necessary information can be uncovered by a single DNA test, rather than the multiple tests that are currently needed. This means that, in theory, DNA testing should be quicker and more efficient than traditional testing, allowing SNBTS and the consortium to obtain more information on extended donor blood types, and helping find closer matches with the patients who need it. However, the project is being undertaken to work out whether it is feasible to scale up DNA testing for an entire population of blood donors in a real world context.

As part of this consortium, SNBTS are working with other blood services, including those from England, New York, and Canada. We are also working in partnership with academic hospitals in Cambridge (UK) and Boston (United States), as well as a commercial scientific company (Thermo Fisher Scientific) to develop these genetic testing systems for the benefit of patients worldwide. Find out more at www.bgc.io

What does it involve?

Donors will be asked to donate a small blood sample at the same time as your regular blood donation. We will ask for your consent to carry out genetic testing for blood group types on this donation. The genetic testing will reveal your blood

group information and support development of new methods of matching blood between donors and recipients. Donors who sign up to this project will be listed in a confidential BGC database. This database may be used in the future to identify your donated blood as a suitable match for a patient with a specific requirement for matched blood. The database contents will be anonymised (ie any information identifying particular people will be removed) but will contain your blood type results as determined by genetic testing as well as the blood type information from previous traditional testing. We will share this anonymised information about your blood group with the consortium to allow comparison between both sets of data.



Additional Q&A

What will I need to do if I decide to take part?

You will donate a small sample of blood (3 to 4 teaspoonfuls) at the same time as your blood donation (no extra needle required) and give permission for us to test some of your DNA for blood typing from this blood sample. We will be testing for the presence of genes that determine which antigens your blood cells have. This will allow us to identify donors with specific types of blood to meet the needs of patients who rely on blood transfusions.

What should I do next?

If you are interested in taking part, please speak with one of our donor team, who will be happy to give you more information.

If you're not interested, that's fine - please keep giving blood as usual.

Who can join the BGC project?

SNBTS are recruiting volunteer blood donors to join the BGC database of donors, whose blood types are determined using new genetic techniques. By joining, you will be helping develop these new testing and matching techniques which aim to improve our knowledge of blood group types and help to provide more detailed matching between donors and recipients of blood and platelets.

Do I have to join the BGC project?

It is completely up to you to decide whether or not you wish to join. If you wish/agree to join, you will be free to withdraw at any time and without having to give a reason.

What will happen if I agree to participate in the BGC project?

You will:

- read and sign a consent form.
- donate a small sample of blood (3-4 teaspoons), which will be taken from your usual blood donation without the need for an additional needle
- allow us to collect, store and analyse a sample

of your DNA for blood group typing and use this along with the blood group information we already hold on you to test and validate these new genotyping techniques and for matching your donations to potential recipients in the future.



Samples

Data and communication

What will happen to samples I give?

We can test for the presence of genes that determine which antigens you have on your blood cells. Genes are made up of DNA. We will isolate, analyse and store a sample of your DNA from your donated blood and, using advanced laboratory techniques, we will determine your genetic blood types. This testing will take place in one of the four consortium laboratories in London, Brisbane, New York or Amsterdam). Researchers will compare the results from this testing with your existing blood typing data performed using standard laboratory techniques as part of the routine testing of your blood donation. Your personal details will stay within SNBTS and only anonymised samples and data will be shared with the BGC researchers. Your samples will be kept in a secure location.

What will happen to any data produced from the samples I give?

Anonymous data about you may be stored in an electronic archive and made available to researchers. This data will include the genetic information related to your blood type and the typing results performed routinely by SNBTS for correlation.

Researchers will have to make a request to access this data and explain how they will use it, ie. which research question they are trying to answer. This type of system is referred to as 'managed access'. Genuine researchers will be given access to the data for their research, and they will be reminded of their obligation to keep your data safe by accepting the

terms of a data transfer/access agreement.

Managed access requests could come from researchers who are working in the public and charitable sector (universities, research institutes etc) or in commercial companies, either in the UK or overseas.

Researchers share the results of their studies by means of reports or publications, which includes placing information/

data on the internet, in press articles, in project leaflets and through other media. Under no circumstances will information that identifies you personally be disclosed in any of these documents.

Only SNBTS will store information that allows you to be identified and linked to the blood group information, as required for matching your donations to recipients.



Will my details be kept confidential?

Yes. Best ethical and legal practice will be followed to make sure all information collected about you will be handled in confidence. Your samples will be labelled with a unique sample study number before being transferred to the laboratory for testing, and information from genetic and other tests will be stored

separately from your personal details. Access to your personal details will only be available to necessary SNBTS and NHS National Services Scotland (NSS) staff, and IT staff that manage our database. You will not be identified personally in any report or publication for research purposes.



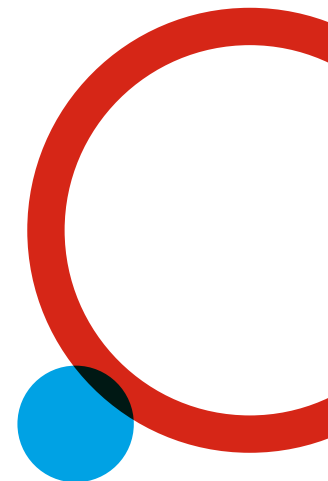
Transparency Statement under General Data Protection Regulation (GDPR)

The Cambridge University Hospitals NHS Foundation Trust is responsible for managing the UK based BGC – DNA sample bank. SNBTS will be using information from your donor records in order to carry out this study and will act as the data controller for your personal information. This means we are responsible for looking after your information and using it properly. SNBTS will keep identifiable information about you in relation to this project for a minimum period of 10 years (June 2033 in the first instance), and we may approach you to extend this. The results may be used to help identify you as a suitable donor for a

patient with specific matching requirements in the future.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible.

You can find out more about how we use your information at www.nss.nhs.scot/how-nss-works/data-protection/future



Risk and benefits of joining



What are the risks and disadvantages of joining the BGC project?

Joining the BGC project will involve donating a small sample of your blood at the time of blood donation. This will be taken from the blood donation sampling pouch and will not require an additional needle or procedure for you.

What are the benefits of joining the NIHR BioResource?

There will be no direct benefit to you, but you will be making a contribution to science and there may be a benefit to the future development of healthcare provision.

Results

Can I know the results obtained from my study samples?

The BGC consortium does not plan to provide feedback of genetic findings, but we will notify you if this changes.

Will any of the results obtained with my sample predict the risk of disease?

We will only be testing for genes related to blood group typing. We will not be testing for disease-associated genetic markers in this project.

What happens if an invention is made using my sample?

Your donated samples and related information are given as what is legally known as an 'absolute gift' (ie. without receiving payment and without conditions). The BGC is operating on a non-commercial basis, meaning it does not sell your sample to make a profit and will not allow anyone else who is working with the sample to do so either. However, if samples are made available to other research institutions or to commercial companies, a fee may be charged to cover the BGC operational costs.

In the future, your sample may help researchers in the public and commercial sector to make an invention, for example, develop a new product to diagnose or treat a disease. If an invention results from the research undertaken with your sample, you will not receive any compensation, recognition or payment. BGC members in the public sector may work together with commercial companies to develop inventions for the benefit of patient and donor care, and we hope that such products are brought into use to improve healthcare in the future.

Withdrawal process

What if I no longer want to be a member of the BGC Consortium database?

Volunteers are free to withdraw from the BGC project at any time without giving a reason. If you choose to withdraw:

- You will be asked to specify whether you would like us to destroy the sample(s) you have donated and which are stored at the central archive.
- It will not be possible to destroy samples already prepared or already distributed for testing.
- Your personal information will be kept in an archive within SNBTS so that a record remains of your initial consent and the withdrawal process.
- Should you wish, no further data will be retrieved from your donor health-related records and no new data from laboratory measurements will be added to the project database; pre-existing data will not be used in further analysis wherever possible.
- Pre-existing data and data that has already been distributed to other researchers cannot be destroyed.
- Once confirmation of your decision to withdraw is received, you will not be contacted again by the BGC.
- If the BGC is unable to confirm your decision, your sample(s) and data will be retained for future use, but you will not be contacted again.

Funding and sponsorship

Who funds and sponsors the BGC?

The BGC is a partnership between different national and regional blood services, research, and commercial organisations. Each member organisation funds their own sample collection and testing.

Cambridge University NHS Foundation Trust is the establishment responsible for the management of the BGC data and sample storage.

Further information

If you want more information before deciding or have any queries, please contact:

email us at nss.snbtsequiry@nhs.scot

visit www.scotblood.co.uk

or visit the consortium website at www.bgc.io



Contact us

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