NHS
Blood and Transplant

Volunteering for the BBMR Healthy Donor Research Panel

Participating in research

Thank you for joining the British Bone Marrow Registry (BBMR). Our records indicate that when you joined you signified your willingness to be approached about potentially participating in research.

We are getting in touch with you now to see if you would like to volunteer to be part of a group of BBMR donors that would occasionally be contacted to see if they are willing to take part in specific biomedical research studies. You can either tell us straight away if you are not interested or, if you do decide to join the group, you can withdraw your consent and be removed at any time. You are also under no obligation to be involved in any future research opportunities we may contact you about. Once part of the group, you can choose to be involved or decline each research study opportunity.

There are lots of great reasons to participate in research. Some common reasons for people choosing to participate include:

- contributing to medical science
- learning more about health and health research
- wanting to help improve treatment options for patients with a variety of conditions

If you agree, we will contact you from time to time to see if you wish to participate in specific research studies. For each study, we will provide you with a participant information sheet to enable you to be fully informed about what is being asked of you, so you can decide whether you want to participate or not. Studies might involve, for example, us going through research questionnaires with you, obtaining blood samples from you, testing new medical devices (e.g., evaluating how well a new filter that removes cholesterol from your blood works), or even collecting cells from you via a process called apheresis.

Joining the BBMR Healthy Donor Research Panel

Joining the BBMR research donor panel is easy. All it takes is your agreement during a telephone conversation or your confirmation by email. After that, we will contact you from time to time to ask you whether you are interested in participating in specific research studies. If you do want to participate, we will let you know exactly what this entails and we may ask you to attend one of our clinics in person so we can talk through what participation means. You may be asked to sign a study-specific consent form.

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Frequently asked questions

What is apheresis?

Apheresis is a safe and well-proven medical technique which we use to collect stem cells for regular donations by BBMR donors. The blood of a donor is passed through a machine that separates out one constituent and returns the remainder to the circulation. One such constituent is white blood cells (also known as peripheral blood mononuclear cells, lymphocytes, T cells, B cells, natural killer cells, monocytes, and dendritic cells). These are immune cells that can be removed by an apheresis process called leukapheresis. They are particularly interesting to researchers and apheresis can provide them in huge numbers.

If you undergo apheresis, we will need to arrange for you to have a full medical and undergo infectious disease marker testing, e.g., for HIV, hepatitis B and C. Occasionally recent travel may mean we need to test you for West Nile virus, malaria, or Chagas disease as well.

Will my donated cells be used in research involving animals?

When research involving animals is planned, the proposed study is reviewed carefully by an independent ethics committee and only approved to proceed if the benefits to the advancement of science are thought to justify the use of animals and there is no alternative option. Researchers must also hold a licence issued by the Home Office before testing on animals is allowed. You will be told explicitly if there is a possibility your cells will be used in research with animals, for which you would need to provide specific consent, and you can of course decide not to participate in such studies.

What are ‘cell lines’ and will my donation be used to create them?

Researchers do occasionally create a cell culture developed from a single cell and therefore consisting of cells with a uniform genetic make-up. They are sometimes ‘immortalised’ which means they can be indefinitely long-lived and are genetically identical to a donor. If you were willing for this to happen, you would need to give full informed consent which would involve us providing you with sufficient detailed background study information to enable you to decide whether to give permission or not to participate.

Will my donated material undergo DNA analysis?

DNA analysis is a common part of modern scientific research as so much can be learned from genetic testing. Your DNA has already been partly analysed once when you joined the BBMR (tissue typing or human leucocyte antigen / ‘HLA’ analysis), to help us match you as a potential stem cell donor for a patient. However, there are many different kinds of DNA analysis, and you would be given specific information and asked to give specific consent to this kind of testing, if it was deemed necessary as part of a research study.

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Is my personal information, including my test results, kept confidential?

If you agree to participate in research, BBMR will process and share only pseudonymised (no personal identifying data will be divulged) information with researchers, both in the UK and possibly worldwide. This may include your test results and will be done in such a way as to be compliant with the 2018 Data Protection Act. NHSBT's full privacy policy can be found here: **https://www.nhsbt.nhs.uk/privacy/**

Will I get paid?

Some research studies we will tell you about will offer payment, which can vary depending on what's involved and expected from you. Some studies do not offer payment, but we will at the very least reimburse your expenses, including any loss of earnings incurred because of research-related visits to our centres or clinics. It's important to find out about the inconvenience and risks involved before you sign up, and to carefully weigh up whether you wish to take part.

Bear in mind:

- it can be time-consuming – you may be expected to attend a number of screening and follow-up sessions
- there may be restrictions on what you can and cannot do – for example, you may be asked not to eat, or not to drink alcohol, for a period of time
- you may experience unknown side effects from the apheresis or medical device if either of these are part of the study
- the following regarding reimbursement may not apply if it is agreed you will be paid a lump sum for participating in a research study (i.e., the lump sum may be inclusive of loss of earnings, travel related to participation, etc.)

For reimbursement, you will be given a form to record your expenses. Please bear in mind that only receipted items can be claimed for regarding subsistence and travel-related expenses (so please keep all receipts from research-participation-related transactions where BBMR have not paid upfront on your behalf for submission to us at BBMR).

Will my cells be transplanted?

If we collect cells from you for research purposes, they won't be directly transplanted into a patient. Your cells may be used to create new biological drugs, however. One example is an immunotherapy called chimeric antigen receptor cell therapy (CAR-T). CAR-T therapies might be created from your cells to fight the cancer cells affecting patients in a clinical trial. Developers of such drugs can be private companies with commercial interests. BBMR/NHSBT may receive income from researchers, though as we are a not-for-profit organisation, any income will be reinvested back into the NHS.