

Chief Investigator:
Dr Raghbir Ali
of Our Future Health

If you want to take part in the Our Future Health research programme, please read through the Participant Information Sheet dated 11/06/2024 (version 3.5) and read the following statements. To take part you need to agree to all the statements below. If you have any questions about the programme or taking part please contact our support team by emailing support@ourfuturehealth.org.uk or by calling 0808 501 5634.

By agreeing to take part in the Our Future Health Programme, I understand that:

FOR INFORMATION ONLY

1. Our Future Health will access, store and link to health-related records about me held by UK organisations across the four nations, including the NHS, and those providing health research services for the NHS. I understand that the records may include details about my current or previous health status, including any diagnoses and treatments I have received.

I understand that Our Future Health will also need to store and share some identifiable information with these organisations, such as my NHS number, name and date of birth, to enable Our Future Health to link this information with my health records and with the other information they hold about me.
2. As long as I remain in the programme, Our Future Health will continue to use my data and collect and use my linked health information for research and analysis over the course of my lifetime and beyond.
3. Blood samples that I give to Our Future Health will be stored and used for health-related research. I understand that my de-identified samples and data could be sent to approved processors outside the UK for analysis.
4. DNA (genetic information) will be extracted from my blood. I understand that my DNA will be analysed for health-related research using a technology called SNP array, and that other technologies might also be used, such as genome sequencing.
5. I will not automatically receive personal feedback from the research, but I will be contacted in the future and asked if I want to receive personal feedback arising from my samples or data.
6. Researchers approved to access and store the information collected by Our Future Health could be from academic organisations, charities or companies, in the UK or overseas.
7. Our Future Health may contact me again in the future, including to:
 - Send me news and updates about the research programme.
 - Ask me about my experiences of taking part.
 - Ask me to complete additional questionnaires.
 - Ask my permission to collect relevant information about me from other sources.
 - Invite me to give (further) biological samples including blood.
 - Invite me to attend an appointment for other assessments, such as imaging.
 - Ask if I would like to receive personal information arising from my samples or data.
 - Invite me to take part in other research studies. This may be based on health-related information about you, such as your genes, lifestyle habits or medical conditions.
8. I can withdraw from Our Future Health at any time without giving a reason. I understand that, if I leave Our Future Health, some research may have already taken place using my data and samples and this cannot be undone.

Additional information for participants joining Our Future Health through NHS Blood and Transplant (NHSBT) at a blood donation appointment.

By joining Our Future Health through my NHSBT blood donation appointment, I understand that:

- Our Future Health will share specific genetic information about me from my blood sample with NHSBT. This will include information about my red blood cells, platelet types, HLA subtypes and white blood cell groups.
- This data will be used to improve the matching process for people having transfusions and stem-cell and organ transplants and to help make products that can be used to support, the diagnosis, prevention, and treatment of diseases, laboratory work, education, and training.
- My personal identifiable information will be shared by Our Future Health with NHSBT to help link genetic information from my blood sample with my donor record.

I agree to take part in the Our Future Health research programme.

Participant name:

Electronic signature:

Date: