

Health Legacy Participant Information Sheet Summary

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Building a legacy of better health

The Health Legacy team invites you to join this important research study to improve the health of future generations. This information sheet will explain why the research is being done to help you decide whether to take part.

Joining Health Legacy is by invitation only and it involves attending one or two study visits at one of our research sites for a health assessment and to collect blood and saliva samples. Some people may also be asked to wear a glucose sensor and provide a urine sample. This document will describe in more detail what is involved.

Further information

Our team will be happy to answer any questions you have:

Email: HealthLegacyClinic@qmul.ac.uk

Visit: blackhealthlegacy.org

 This symbol means you can refer to our full Participant Information Sheet for additional information

Why join?



What is Health Legacy?

Health Legacy is a long-term research study that aims to improve our understanding of health and disease. It particularly focuses on people from diverse communities and backgrounds, many of whom do not often get involved in research. Health Legacy will involve men and women of different ages from Black African, Black Caribbean, white European and south Asian backgrounds.

Health Legacy will research medical problems such as type 2 diabetes, high blood pressure and kidney disease using genetic and health information. It will find out why some people are more or less likely to develop certain health conditions, respond to treatment, and whether certain tests used to monitor or diagnose conditions are accurate. By answering these questions, Health Legacy will help to improve the health of future generations through more precise approaches to the prevention, diagnosis and treatment of disease. Over time, Health Legacy will grow to address wider health issues, prioritised by the communities it serves.

Health Legacy is led by an experienced group of healthcare and research professionals who are passionate about improving health for everyone. We are based at Queen Mary University of London and the University of Exeter.



Why have I been invited to join Health Legacy?

You have been invited to join Health Legacy because you are aged 16 or above and you self-identify as coming from one of the following backgrounds:

- Black, Black British, Caribbean, African, Mixed or Multiple ethnic groups: White and Black African or White and Black Caribbean.
- Bangladeshi, British Bangladeshi, Pakistani, British Pakistani
- White, White British, White Irish and other White backgrounds

Health Legacy is partnering with other health research studies:

- Genes & Health: a study for British Bangladeshis and British Pakistanis
- Exeter 10,000 (EXTEND): a study of mostly white Europeans
- Black Health Legacy: a new study involving Black African and Black Caribbean people



Do I have to join Health Legacy?

No. It is completely up to you to decide whether or not you wish to join the study. If you do join the study, you are also free to withdraw at any time and do not have to give a reason. You can take as long as you need to decide if you want to join the study and are welcome to discuss your participation with family and friends.



What does joining Health Legacy involve?

- We will invite you to attend 1 or 2 study visits
- Study visits are usually at a hospital, GP surgery or clinical research facility, but sometimes it may be possible to arrange them online.
- Our research team will discuss details of the study and ask you to complete a consent form
- Study visits will be conducted by trained clinical and research professionals. We will ensure your privacy and dignity are maintained at all times.

We will reimburse volunteers £50 for the first 60 minutes of each study visit. For longer study visits, we will offer an additional £25/hour up to a maximum of £200 across two study visits. Reimbursement will be provided once all study visits are completed.

During our study visits, we will ask you to help as follows:



STUDY VISIT 1 (usually 30–60 mins, sometimes up to 2 hours):



- Complete a **brief questionnaire**: We will ask you to provide your NHS number, contact details (including email and mobile phone if available) and information about your health. This will help get our research started.

- Give a **saliva (spit) sample** into a sterile tube: we will take this sample to a specialist laboratory to extract DNA from it. This DNA sample will unlock important information from your genes. Have a blood test: We will take a maximum of 50ml (4 tablespoons) of blood from your arm using a small needle under sterile conditions. We may ask you to fast for up to 8 hours before your blood test. Please do not fast before your blood test unless we have asked you to do so. This sample will give us important information about your overall health, including checks of your blood cell counts, liver and kidney function, bone health, glucose (sugar) levels, hormone levels and nutritional status. We will use accredited NHS (or equivalent) laboratories for these tests. We will also take your blood samples research laboratory where we will prepare and analyse them to understand gene and cell function. We will look at RNA (the message from your DNA to make proteins), proteins and metabolites, and we may use other techniques that study how your cells work using specialist microscopes



- Undergo a **health assessment**: We will talk to you about your health now and in the past, including diagnoses, treatments, operations. We will also take some measurements of you, such as your height, weight, waist circumference, grip strength and blood pressure. We may also ask you some structured questions about your lifestyle (food intake, physical activity) overall functioning, memory, concentration and wellbeing.



- Some people may be asked to give a **urine sample** and/or wear a small **glucose sensor**, similar to ones used by the NHS, on their arm for 14 days. A separate information sheet about glucose sensors will be provided if you are asked to wear one. These will help us understand more about the links between genes, health and disease. These are **OPTIONAL**.



STUDY VISIT 2: (usually 30–60 mins, sometimes up to 2 hours):



- **Completion of unfinished tasks** from study visit 1: if we haven't managed to finish all of our study in the first visit, we may wish to complete them in this visit.
- **Follow up of test results:** if any test results from study visit 1 need action, we will discuss these with you. For example, sometimes we discover a problem like anaemia or undiagnosed diabetes. If any of your results need further action, a medically-trained professional will discuss them with you at this visit and provide a written summary to you and your GP to guide the necessary action.



- **Removal of your glucose sensor:** if you had a glucose sensor put on in your first study visit, we will remove it. This is painless and quick, and there is more information in the Glucose Sensor Participant Information Document. We will also do a fingerprick blood test to measure your blood glucose level when your sensor is removed to check it has been accurate. This takes only a few seconds and causes only very brief discomfort and produces a few drops of blood.



- Some people may be asked to participate in a **qualitative interview**, where we will talk to you in depth about your health, experience of healthcare and participation research. This will help us find ways to make our discoveries have an impact in future NHS care and to make sure this is done in a way that people and patients find acceptable. This interview will take approximately 30–40 minutes and is **OPTIONAL**.



Can I know the results obtained from my samples?

If you are invited to join Health Legacy, you may ask to know (or alternatively, ask not to be told) why you were invited.

As the purpose for collecting your sample is for research, we will not routinely be able to provide results from the samples you give. Our genetic results are not produced with the same quality control checks as the NHS uses when it does genetic tests in routine clinical care. At present, we are unable to share your genetic results. However, if this changes, we will contact you to ask you if you would like to find out genetic information related

to your health. Some people may wish to learn more about where their ancestors came from through their genes. We hope to be able to offer you this information in the future, and we will contact you if this becomes possible.

If any test results obtained from your samples indicate that you require immediate medical treatment, a medically-trained professional will discuss these with you (by telephone or in study visit 2) and will provide you and your GP with a written summary.

What if I no longer want to be a volunteer?



You are free to withdraw from Health Legacy at any time without giving a reason. If you choose to withdraw, then you will not be contacted again, and unused stocks of samples held at Health Legacy will be disposed of. It will not be possible to dispose of samples already prepared for testing or to withdraw samples that have been distributed to other laboratories with whom Health Legacy collaborates. Information already obtained from your samples or health-related information that is in our research databases or laboratory records will have already been made anonymous, and it will not be possible to remove this. However, no new data will be added to the research databases or laboratory records from the moment the Health Legacy team has confirmed your withdrawal.

What are the risks and benefits of joining?



Benefits

You will be joining hundreds of other research volunteers to give the legacy of better health to your future generations. Your participation ensures new research discoveries benefit the health of people from diverse backgrounds equitably in the future.

As part of our research protocol, you will receive some health check information, such as your blood pressure, body mass index, or the results of some blood tests. This may provide you with information that helps you adopt healthy lifestyle behaviours or have further checks with your GP.

Risks

Wearing a glucose sensor has a low risk of developing a local skin reaction or infection. Some bruising, itchiness, redness and

bleeding at the site of sensor insertion may occur. In the unlikely event that this occurs, we will discuss this with you, and help you find appropriate treatment if required. Our Glucose Sensor Participant Information Document v1.1 11 Apr 2025 document contains answers to many common questions about wearing a glucose sensor that will also provide support to you.

Having a blood sample from your arm or fingertip taken can sometimes cause brief discomfort or bruising at the site where the blood was taken.

Some people can find it difficult or upsetting to answer questions about their health as it may trigger bad memories or worry. Our team is trained to ask questions carefully and sensitively. If you do get upset, the person doing the interview will be sympathetic and supportive. You can take a break or stop the study visit altogether.

Data confidentiality



What information and samples does Health Legacy collect for its research?

For Health Legacy to make new discoveries that could improve the health of future generations, we need information about you. Health Legacy will work securely with health-related information about you from the NHS, and genetic information from your saliva sample. You can find more details about this information [here](#) or read our full participant information sheet. live in, or whether you smoke. The Health Legacy Executive will review what information we collect to ensure it has a direct link to health and addresses the aims of our study.



How will you protect my personal information?

In this research study we will use health related information about you from the NHS and genetic information from your saliva sample.

- We will only use information that we need for the research study.
- We will let very few people know your name or contact details, and only if they really need it for this study.
- Everyone involved in this study will keep your data safe and secure. We will also follow all privacy rules.
- At the end of the study we will save some of the data in case we need to check it.
- We will make sure no-one can work out who you are from the reports we write.

For more information on how we will ensure your confidentiality is maintained and what happens to the information that identifies you such as your name, date of birth, address and NHS number please follow this link to our website, or read our full participant information sheet.

Please note, we will not usually let your GP know that you have joined Health Legacy. However, if we discover something important about your health that needs action, we will discuss this with you and ask your permission to contact your GP.



Where will my information be stored?

Personal information that identifies you will be stored at Queen Mary University of London on secure servers (GDPR compliant with ISO27001 certification), accessible only by the Chief Investigator and core research team.

Anonymised health-related and genetic information will be stored in a Trusted Research Environment (GDPR compliant with ISO27001 certification). It will not be possible to export information out of the Trusted Research Environment without review by the Chief Investigator or an appropriately trained member of the core research team who will ensure that confidentiality is maintained.

We will allow approved researchers to work on Health Legacy information held in the Trusted Research Environment. To become an approved researcher, there will be a stringent review process by the Health Legacy Executive and Community Advisory Board. This will ensure the world's best researchers can contribute to our goals, whilst ensuring confidentiality and security of our study information.

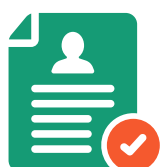
We will keep information for 5 years after the study has finished for ongoing analysis and audit, in line with the requirements of our Sponsor, Queen Mary University of London. After this, study information be anonymised and securely archived or destroyed.



Will you transfer my information or samples outside of Queen Mary University of London?

Sometimes we may need to transfer information or samples to external approved research sites and laboratories. These may be located in a hospital, university, non-profit institution or company. These transfers will only take place when absolutely necessary (for example to do a specialist analysis that cannot be done at Queen Mary University of London) and for health-related research studies that address the aims of Health Legacy. Transfers will only take place with a legal data sharing and/or material transfer agreement to ensure they are protected. We will not share identifiable information about you with external research sites and laboratories.

The research



What will happen to the results of Health Legacy?

The results from Health Legacy will be used to improve the prevention, diagnosis and treatment of disease in diverse populations in the UK and worldwide. We will share these results with the scientific and medical community, and with the public. We will use a range of channels to share this information, including written, online and video information. Under no circumstances will your name or identity be disclosed when the study results are shared in this way.



Who funds and sponsors Health Legacy?

Health Legacy is funded by the Wellcome Trust and receives additional funding support from the NHS Research Delivery Network. Queen Mary University of London is the Sponsor and Data Controller for Health Legacy.



What happens if I change my mind or have any complaints?

You are free to withdraw from Health Legacy at any time without giving reason. If you choose to withdraw, then you will not be contacted again, and unused stocks of samples held at Health Legacy will be disposed of. We will keep information about you that is already stored but not add more to it.

You can find more details on our website: www.qmul.ac.uk/wiph/centres/centre-for-primary-care/health-legacy/

The procedure for any complaints about the study is to contact the Chief Investigator, Professor Sarah Finer: healthlegacy@qmul.ac.uk



Where can I find out more?

The Health Legacy website (www.qmul.ac.uk/wiph/centres/centre-for-primary-care/health-legacy/) contains more information on:

- Who leads Health Legacy
- Who are our partners
- How the information and samples you are providing will help us in our research
- Our Privacy Policy and how we ensure your data is kept safe and your confidentiality is maintained
- What will happen to the results of Health Legacy
- Jargon buster and frequently asked questions
- News and updates

To find out more about how the NHS conducts research and protects your information, visit here: www.hra.nhs.uk/patientdataandresearch. To find out how Queen Mary University of London, our study sponsor and data controller, protects your data, email them: dataprotection@qmul.ac.uk

If you would like more information before deciding on your participation, or have any questions, you can contact the Health Legacy team by email: healthlegacy@qmul.ac.uk

Thank you for considering volunteering in Health Legacy.