

# Health Legacy Participant Information Sheet

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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](mailto:HealthLegacyClinic@qmul.ac.uk)

Visit: [blackhealthlegacy.org](http://blackhealthlegacy.org)

# Why join?

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# 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, 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, 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:

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## 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 to a 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**.



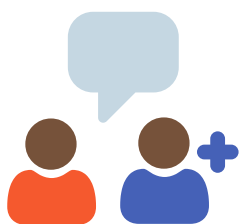
## **STUDY VISIT 2:** (usually 30–60 mins, sometimes up to 2 hours):



- **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**. Our Participant Interview Information Document contains further information about how the interview will be conducted.



## **Can I know the results from my study 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

## How will we protect your information?



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

For Health Legacy to make new discoveries, we need information about your health and genes:

**Health-related information:** we will securely collect information from NHS General Practices and Hospitals; other healthcare organisations and providers; registers and records held by the NHS including NHS Digital, NHS Central Register, NHS England, NHS Personal Demographics Service, Department of Health, and Office for National Statistics for the duration of the study. This includes diagnoses, clinical measurements, test results, and treatments recorded during your lifetime. We will collect information on determinants of health which includes social and environmental factors linked to health, such as air

pollution or socioeconomic deprivation levels in the area you 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.

**Genetic information:** your saliva sample contains DNA which we will extract in a laboratory. From this DNA, we can study your genetic code to explore the links between genes and health. Everyone's genes are different, and it is possible to see particular patterns in people's genes according to where their ancestors come from. We will use scientific techniques such as genotyping and gene sequencing to study these patterns and make discoveries that will have direct relevance to diverse communities. Any spare saliva sample will be stored securely for future testing in this study.



### **Will anyone else have access to my information?**

Best ethical and legal practice will be followed to ensure all information collected about you will be handled in confidence. Only the Chief Investigator and the core study team at Queen Mary University of London will have access to identifiable information about you, and this will be stored safely. Anyone provided access to your information for research purposes only will be trained in data protection, cyber security and information governance. Please note, we will not usually let your GP know that you have joined Health Legacy. However, in the unlikely situation that we discover something important about your health that needs action, we will discuss this with you and ask your permission to contact your GP.



### **How will we use information about you?**

We will need to use information from you and other sources such as NHS General Practices and Hospitals; other healthcare organisations and providers; and registers and records held by the NHS including NHS Digital, NHS Central Register, NHS England, NHS Personal Demographics Service, Department of Health, and Office for National Statistics for this research project. This information will include your:

- Name
- Date of birth
- Address
- NHS number
- Health-related information for e.g. medical conditions, treatments
- Questionnaire

People will use this information to do the research or check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

Queen Mary University of London is the sponsor of the research.

Queen Mary University of London is responsible for looking after your information. We will share your information related to this research project with the following types of organisation:

- Approved research sites and laboratories. These may be located in a:
  - Hospital
  - University
  - Non-profit institution
  - Company

We will keep all information about you safe and secure by:

- Strictly controlling who has access to your information and samples.
- Using information that identifies you only when absolutely necessary, and by a very limited number of individuals in the core team with appropriate training.
- Giving your samples and information anonymous, unique study numbers so that you cannot be identified by researchers working with Health Legacy outside the core team.
- Using the highest security research data storage facilities (a “Trusted Research Environment”) with robust data security and confidentiality procedures.

- Only allowing the transfer of samples and information outside our research sites when necessary, and only to facilities that have been approved by Health Legacy and under a legal agreement with Queen Mary University of London. These transfers will only happen once a legal data sharing and/or material transfer agreement is in place to ensure they are protected. We will not share identifiable information about you with external research sites and laboratories.

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### **International transfers**

We may share information about you and/or samples outside the UK for research-related purposes to:

- Allow Health Legacy-approved researchers/research organisations to undertake studies that will benefit the wider population around the world.
- We may also do this because we need to carry out tests and analyses that might not be available in the UK if required.

If this happens, we will only share the information that is needed. We will also make sure you cannot be identified from the data that is shared, where possible. This may not be possible under certain circumstances – for instance, if you have a rare illness, it may still be possible to identify you. If your data is shared outside the UK, it will be with the following sorts of organisations:

- Health Legacy approved research teams, including those at:
  - Academic organisations
  - Healthcare providers
  - Medical charities
  - Laboratories
  - Industry partners Laboratories
- IT services or research facilities that offer services required for our health-related research that are only available or better outside the UK

We will make sure your data is protected. Anyone who accesses your data outside the UK must do what we tell them so that your data has a similar level of protection as it does under UK law. We will make sure your data is safe outside the UK by doing the following:

- The countries your data will be shared with have an adequacy decision in place. This means that we know their laws offer a similar level of protection to data protection laws in the UK.
- We use specific contracts approved for use in the UK which give personal data the same level of protection it has in the UK. For further details visit the Information Commissioner's Office (ICO) website: <https://ico.org.uk/for-organisations/uk-gdpr-guidance-and-resources/international-transfers/>
- We do not allow those who access your data outside the UK to use it for anything other than what our written contract with them says.
- We need other organisations to have appropriate security measures to protect your data which are consistent with the data security and confidentiality obligations we have. This includes having appropriate measures to protect your data against accidental loss and unauthorised access, use, changes or sharing.
- We have procedures in place to deal with any suspected personal data breach. We will tell you and applicable regulators when there has been a breach of your personal data when this is legally required. For further details about UK breach reporting rules visit the Information Commissioner's Office (ICO) website: <https://ico.org.uk/for-organisations/report-a-breach>

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### **How will we use information about you after the study ends?**

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can identify you as a study volunteer.

We will keep your study data for a minimum of 5 years. The study data will then be fully anonymised and securely archived or destroyed.

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### **What are my choices about how my information is used?**

- You can stop being part of the study at any time, without giving a reason but we will keep information about you that we already have.

- If you choose to stop taking part in the study, we would like to continue collecting information about your health from NHS central records. If you also object to this to happen, tell us and we will stop.
- You have the right to ask us to access, remove, change or delete data we hold about you for the purposes of the study. You can also object to our processing of your data. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this.
- If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study.

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### **Where can I find out more about how my information is used?**

You can find out more about how we use your information:

- At [www.hra.nhs.uk/patientdataandresearch](http://www.hra.nhs.uk/patientdataandresearch)
- By asking one of the research team
- By sending an email to: [HealthLegacyClinic@qmul.ac.uk](mailto:HealthLegacyClinic@qmul.ac.uk)
- By emailing the sponsor: [data-protection@qmul.ac.uk](mailto:data-protection@qmul.ac.uk)



### **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 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 will be anonymised and securely archived or destroyed.



## What will happen to my samples?

We will look after your saliva sample and store it safely – the sample will be labelled only with a unique code and sent to a specialist laboratory in London for analysis in order for us to understand your DNA.

Your blood sample will be labelled with the unique code and sent to the central laboratory where relevant tests will be carried out to help understand various blood measures.

Some of the saliva and blood sample will be securely stored in a dedicated storage space that will only be accessed by the research team members. The samples may be used by Queen Mary University of London and approved research facility within a hospital, university, non-profit institution or a company laboratory within and/or outside the EU. All unused sample at the end of the study will be destroyed.

## The research



### Who will do research with Health Legacy?

We want to bring the world's best researchers to Health Legacy to help us to improve the health of future generations

We will only do this in a way that keeps your information safe.

We invite applications to work with Health Legacy from approved researchers. We will have a stringent review process for all applications involving the Health Legacy Executive.

External researchers working with Health Legacy will not be given access to identifiable information about you. Instead, they will access your information after it has been assigned an anonymous code.

We will not send information out to external research teams. External research teams will access information via our Trusted Research Environment, accessible by 2-factor authentication and only after information governance training has been completed.



## What will happen to the results of Health Legacy?

The results of Health Legacy research will help improve the prevention, diagnosis and treatment of disease among diverse populations in the UK and worldwide.

To ensure that our research contributes to these developments, the results of our research will be made available to the scientific and medical community, policy members and the public through a range of outlets. This will include scientific publications, internet information (written and video), in press articles, social media, and project leaflets. Under no circumstances would your name or identity be disclosed in any published materials, although Health Legacy will be identified as the source of the material.

Health Legacy will work in partnership with approved researchers in the UK and worldwide across healthcare, academic and industry to bring important discoveries that can improve the health of future generations. Health Legacy is a not-for-profit project and neither you nor the study team will benefit financially from any discoveries that are made.



## 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.

Health Legacy is supported by a large network of NHS and community partners. For more information about our partners, please visit our website.



## 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/](http://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: [HealthLegacyClinic@qmul.ac.uk](mailto:HealthLegacyClinic@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/](http://www.qmul.ac.uk/wiph/centres/centre-for-primary-care/health-legacy/)) contains more information on

- How the information and samples you are providing will help us in our research
- Our privacy policy
- Frequently asked questions

You can also find out more about how the NHS conducts research and protects your information here: [www.hra.nhs.uk/information-about-patients/](http://www.hra.nhs.uk/information-about-patients/). You can also find out more about how Queen Mary University of London, our study sponsor and data controller, protects your data by emailing them: [dataprotection@qmul.ac.uk](mailto: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: [HealthLegacyClinic@qmul.ac.uk](mailto:HealthLegacyClinic@qmul.ac.uk)

**Thank you for considering volunteering in Health Legacy.**



## Additional information

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# Health Legacy jargon buster

|                                                        |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
|--------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Ancestry</b>                                        | Your ancestry tells the origin of your DNA code from your biological ancestors. Genetic ancestry can be put together with historical information to work out where in the world your ancestors came from. It is important to include people from a variety of different ancestry backgrounds in health research, because people from different ancestries have different patterns of genetic code and these can impact your risk of disease or how your body responds to different treatments |
| <b>Anonymised</b>                                      | Health Legacy will remove information that identifies you (“anonymise”) from our research database. Researchers working with Health Legacy who are not part of the core team will not be able to see identifiable information about you.                                                                                                                                                                                                                                                      |
| <b>Data</b>                                            | This is information about you, that might include personal information or anonymous information. In Health Legacy, we collect data to conduct our research, including health-related information, genetic information, or your questionnaire responses.                                                                                                                                                                                                                                       |
| <b>Gene</b>                                            | Your genes are like an instruction manual to help make proteins, the building blocks of our bodies. Genes control how our bodies look, grow and function                                                                                                                                                                                                                                                                                                                                      |
| <b>Gene sequencing</b>                                 | This is a detailed technology to study your genetic code. It works across large areas of your genome, allowing researchers to build detailed knowledge of how your genes influence your body. Genotyping is also done in a laboratory or NHS setting using DNA often collected saliva or blood.                                                                                                                                                                                               |
| <b>General Data Protection Regulation (GDPR), 2018</b> | This is the legal framework that sets guidelines for the collection and processing of personal information to ensure your data is protected. Health Legacy, and its sponsor, Queen Mary University of London carefully follow all of the rules and regulations set out by GDPR that are applicable to them.                                                                                                                                                                                   |

|                                               |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
|-----------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Genome</b>                                 | This is the complete set of DNA that your cells have. It includes the DNA that make up your genes as well as other stretches of DNA between your genes.                                                                                                                                                                                                                                                                                                                                     |
| <b>Genotyping</b>                             | This is a technology that detects small genetic differences in your genetic code. It uses prior knowledge of the genetic differences that can impact your physical characteristics or risk of disease to study these differences. Genotyping is done in a laboratory or NHS setting using DNA often collected saliva or blood.                                                                                                                                                              |
| <b>Health Legacy Community Advisory Board</b> | Our study has been shaped and guided from the beginning by members of the Black and Caribbean community, the Genes & Health Study and the Exeter EXTEND10,000 Study. Our community advisory board brings together a diverse group of individuals who are passionate about improving the health of future generations through research. They are ensuring that Health Legacy works sensitively and effectively with the people it represents and prioritises work that is important to them. |
| <b>Health-related information</b>             | This is the information we collect about you from organisations like the NHS and Office for National Statistics. This information tells us about your health, or things that affect your health. This information is collected when you see your GP or hospital doctor or attend for checkups. Health-related information helps us to make important discoveries that will improve the health of future generations.                                                                        |
| <b>Identifiable information</b>               | This is personal information that can identify you. Most research studies need to collect this information to run and monitor their research properly. Health Legacy will collect 4 pieces of identifiable information: your name, your date of birth, your address and your NHS number. Access to this information is limited to a very small number of people who need it to conduct and monitor the study, and it is kept securely and used only when absolutely necessary.              |
| <b>ISO27001 certification</b>                 | This is an international standard that demonstrates a high level of information security. Health Legacy stores its information in ISO27001 certified locations, and this shows our commitment to the highest level of information security.                                                                                                                                                                                                                                                 |
| <b>Trusted research environment (TRE)</b>     | TREs provide approved researchers with a single location to access study data, and it is a bit like a secure reference library. Making research data available through a TRE means that people can be confident that their personal data is accessed securely and their privacy is always protected.                                                                                                                                                                                        |