Black Health Legacy
Participant Information Sheet

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Building a legacy of better health

The Black Health Legacy team invites you to join this important research study for Black, Black African and Black Caribbean people to improve the healthof future generations. This information sheet will explain why the research is being done to help you decide whether to take part.

You can also find out more information by visiting our website: blackhealthlegacy.org/participantinformation

Joining Black Health Legacy is easy and involves:

- Filling in a short questionnaire
- Providing a saliva sample

You can join online from home or at one of our research sites across the UK.

Further information

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

Email: healthlegacy@qmul.ac.uk
Visit: blackhealthlegacy.org

Queen Mary University of London

Why join?

Data confidentiality

The research

Why join?

What is Black Health Legacy?

Black Health Legacy is a long-term research study for Black, Black African and Black Caribbean people that aims to improve our understanding of health and disease. In the past, people from Black, Black African and Black Caribbean backgrounds have not been well represented in research studies, and this means that important discoveries and breakthrough treatments may not help them.

Black Health Legacy will research medical problems such as type 2 diabetes, high blood pressure and kidney disease which affect many Black, Black African and Black Caribbean people. It will work in close partnership with Black, Black African and Black Caribbean communities to shape its work and to bring health benefits to future generations.

We are led by an experienced group of healthcare and research professionals who are passionate about improving health for all Black, Black African and Black Caribbean people in the UK. Our leadership team includes representatives from Black, Black African and Black Caribbean communities.

Black Health Legacy aims to recruit up to 2500 people in the first 2 years. Our long-term ambition is to involve 100,000 people in the study and become the UK's largest health research programme from Black, Black African and Black Caribbean backgrounds. Our goal is to create a legacy of better health for all, and we are inviting you to help us by joining Black Health Legacy.

You can find out more at: blackhealthlegacy.org

Why have I been invited to join?

You have been invited to join because:

- You are aged 16 or above
- You live in England
- You identify as Black, Black African, Black Caribbean or Mixed ethnic background that includes Black African or Black Caribbean.

Do I have to take part?

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 will I need to do?

Joining is easy and takes around 10 minutes! If you agree to join Black Health Legacy, you will be asked to read and sign a consent form giving us permission to:

1

Gather some information about you in a **short questionnaire**

2

Collect a **saliva (spit) sample** from you in a sterile tube. We will use this to study DNA and the links between genes and health

3

Securely access **health-related information** about you that is routinely collected by organisations such as the NHS

4

Invite you to participate in **future optional research studies** up to 4 times a year, using information saved from this study

You can find out more about all of these steps and why they are needed by reading on. We will also tell you more about the protections we put in place to keep your information and samples secure. For more information about joining the study visit: blackhealthlegacy.org

We will offer you a £15 voucher to reimburse you for your time.

What are the risks and benefits of joining?

Joining Black Health Legacy will involve you donating a small sample of your saliva (spit). This can be done in your home or elsewhere. There is no risk in doing this.

You will be joining thousands of other Black, Black African and Black Caribbean volunteers to give the legacy of better health to your future generations by supporting health research for health conditions that are important to our community.

At some of our recruitment sites, we may offer you a routine health check such as blood pressure or blood glucose measurement or signpost you to NHS health information. This is optional and not part of our research.

Data confidentiality

How will we protect your information?

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

For Black Health Legacy to make new discoveries that could improve the health of future generations of Black, Black African, Black Caribbean people, 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 Black Health Legacy Executive and Community Advisory Board 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 Black, Black African and Black Caribbean people. Any spare saliva sample will be stored securely for future testing in this study.

Who will 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 Black 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 or
  - 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 being sent to the laboratories and information anonymous, unique study numbers so that you cannot be identified by researchers working with Black 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 Black 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.

International transfers

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

- Allow Black Health Legacy-approved researchers/research organisations to undertake studies that will benefit the wider population around the world.
- 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:

- Black Health Legacy approved research teams, including those at:
  - Academic organisations
  - Healthcare providers
  - Medical charities
  - Laboratories
  - Life sciences partners
- 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 information for 5 years after the study has finished. The study data will then be fully anonymised and securely archived or destroyed.

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.

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
- By asking one of the research team
- By sending an email to healthlegacy@qmul.ac.uk
- By emailing the sponsor: data-protection@qmul.ac.uk
- On our website: https://www.blackhealthlegacy.org/

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.

What will happen to my saliva 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 name or any other information that can identify will not be sent to the laboratory. Some of the saliva samples will be securely stored for the duration of the study 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 within a hospital, university, non-profit institution or a company laboratory within and/or outside the EU. All unused samples at the end of the study will be destroyed.

The research

Who will do research with Black Health Legacy?

- We want to bring the world's best researchers to Black Health Legacy to help us to improve the health of future generations of Black, Black African and Black Caribbean people. We will only do this in a way that keeps your information safe.
- We invite applications to work with Black Health Legacy from approved researchers. We will have a stringent review process for all applications involving the Black Health Legacy Executive and Community Advisory Board. Further information can be found at blackhealthlegacy.org.
- External researchers working with Black 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 Black Health Legacy?

The results of Black Health Legacy research will help improve the prevention, diagnosis and treatment of disease among Black people 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 Black Health Legacy will be identified as the source of the material.

We will share updates and summaries of our research with you in a newsletter sent to securely by SMS and/or email. You will be given the option to opt-out of receiving these newsletters if you wish.

Black 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. Black 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 Black Health Legacy?

Black 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 Black Health Legacy.

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

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

You are free to withdraw from Black 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 Black Health Legacy will be disposed of. We will keep information about you that is already stored but not add more to it.

You have the right to ask us to remove, change or delete data we hold about you for the purposes of the study. If this means we cannot use your data to do the research, we may not be able to do so. If this is the case, we will tell you why we cannot do this.

You can find more details at: blackhealthlegacy.org

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 Black Health Legacy website contains more information on:

- Who leads Black 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
- How Black, Black African and Black Caribbean people are helping to make Black Health Legacy a study for them
- What will happen to the results of Black 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: 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 Black Health Legacy team by email: healthlegacy@qmul.ac.uk

Thank you for considering to volunteer in Black Health Legacy.

Additional information

Black Health Legacy jargon buster

Ancestry	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
Anonymised	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.
Black Health Legacy Community Advisory Board	Our study has been shaped and guided from the beginning by members of the Black, Black African and Black Caribbean community. 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 Black Health Legacy works sensitively and effectively with the people it represents and prioritises work that is important to them.
Data	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.
Gene	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
Gene sequencing	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.

General Data Protection Regulation (GDPR), 2018	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.
Genome	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.
Genotyping	This is a technology that detects small genetic differences in your genetic code. It uses prior knowledge of the genetic differences that are 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.
Health-related information	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.
Identifiable information	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.
ISO27001 certification	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.
Trusted research environment (TRE)	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.