What happens to your information?

Genes & Health

1 Join Genes & Health

- Complete and sign a consent form
- Fill out a short questionnaire
- Give a saliva sample – just spit into a tube!

Unique barcode ensures you cannot be identified

2 We organise your information

- We scan your form and questionnaire
- Scanned information is kept safe on secure computer systems at Queen Mary University of London
- Paper copies are securely archived

3 We securely access your health information

- We convert your NHS number to a digital key so that you cannot be recognised
- We share this digital key with trusted NHS partners to connect to your NHS health information

NHS

4 We process and analyse your saliva sample

- Your saliva sample is taken to our laboratories at Queen Mary University of London
- Our laboratory team extract DNA from your saliva
- We work with trusted and approved laboratories to convert your DNA into genetic information

Genes & Health Trusted Research Environment

ISO27001-CERTIFIED

5 We secure your information securely

- We join your questionnaire, NHS health information and genetic information using your digital key and barcode
- All this information is kept in a special, highly secure system – the **Trusted Research Environment**
- Your name and identity are never stored here

6 Your information helps us to make important discoveries

- Researchers log in to the Trusted Research Environment to analyse health and genetic information
- All our researchers are approved by the study leads, follow strict data access rules and have data security training
- Our researchers cannot see your name or reveal your identity

Queen Mary University of London

Genes & Health and the study Sponsor and Data Controller, Queen Mary University of London, are responsible for keeping your study information and samples safe and secure. We take this responsibility very seriously. We work in strict accordance with UK Research Governance Framework for Health and Social Care, Data Protection Act (2018) and General Data Protection Regulation and we have legally-binding agreements with all of our research partners to ensure your information is fully protected.