



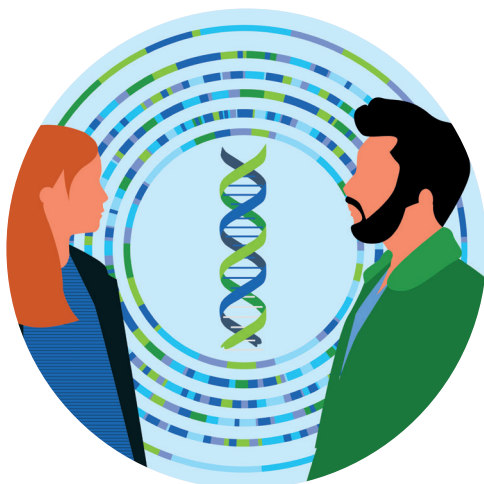
National Genomic Research Library



When you are offered a genomic test, you also have the opportunity to decide if your (and/or your child's or relative's) genome sequence and health data can be donated to the National Genomic Research Library, to be used for ongoing medical research.

What is the National Genomic Research Library?

The Library is a secure national database managed by Genomics England, a company set up and owned by the UK Department of Health and Social Care. It allows approved researchers to access data and samples to study conditions and look for new treatments that might help you and others now or in the future.



What is included in the National Genomic Research Library?

Importantly, your data in the Library is kept in secure systems and is de-identified, meaning any information that could personally identify you is removed and replaced with an individual reference number. Data includes information about your genomic test, your genomic sequence, and electronic copies of your health records that will continue to be collected.

The Library already contains data from tens of thousands of individuals, with their consent. Everyone is unique, and being able to compare genomic and health data from many individuals all in one place provides researchers with a greater opportunity to better understand diseases, find diagnoses and develop new treatments.

How would my data be used and kept safe?

The Library is only accessible to researchers who are trying to better understand diseases and how to treat them. They must be approved by Genomics England, and through an independent review committee that includes clinical experts and participants.

Researchers may come from hospitals, universities, charities or healthcare companies (such as drug companies) from all over the world, because pooling data and sharing knowledge gives the best chance of new discoveries. Your data is never used by insurers, for marketing purposes or for speculative searches.

The data stays within a secure environment where all research activity is continually monitored. A committee within Genomics England reviews any summary data or findings that could come out of this environment so that this can be done safely and with strict controls.

Additional information about how Genomics England use your data is available at: www.genomicsengland.co.uk/privacy-policy



You can find out more information and FAQs at:

www.genomicsengland.co.uk/patients-participants/data



Will you contact me again?

You may be contacted occasionally for further information, to tell you about other research opportunities, or if something is identified through research that is relevant for you or your care, such as a diagnosis. The process for re-contacting you is managed by Genomics England together with the NHS.

What if I don't want to take part?

It is your decision whether you want to take part in the National Genomic Research Library, and you can withdraw at any time. If you say 'no', it will not affect your care by the NHS or continued participation in any other research projects you are involved with.



We think it is important that people see what has been achieved thanks to their data donation, and updates about research are made available on the Genomics England [website](#).