

What happens to your samples...

1. Information is collected



Medical files

Health data from the NHS and other organisations

Genomes

A full set of human genes

Symptoms and measurements

2. Information is analysed



3. Findings are sent to your doctor. Data is securely stored for analysis by researchers.



When can I expect results?

Never before has genomic sequencing on this scale been attempted in a health service. It is taking longer than was first thought. It has been more difficult than was expected to collect and analyse so much data.

We know how important results are. Results are now beginning to be returned to people who took part in the early part of the Project. But for some, it will still be a year or more before results are returned. For people joining now we're not expecting results to be returned in a few months. It is likely to be a year or more before you hear anything.

But as the knowledge grows and Project gathers pace – this will get quicker. By the end of the Project it will take just a few months to get results.

How will I get my results?

Results are first sent to your hospital to check. They run tests to confirm any findings. It is the hospital where you took part that will give you your results. They will contact you as they would with any other test results, usually by letter or phone.

In many cases no clear answer will be found at first. Your hospital will let you know if nothing was found. But researchers will keep looking and any new results will be given to your hospital as soon as they are available.

Additional findings will be returned later, separately to any findings related to your rare condition.

What happens after a result?

Once you have a result, you may have many questions. Your hospital team are the best people to help with any medical queries. If you get a 'negative' result – nothing was found - it doesn't mean it's the end of the road. Genomics England will keep looking. Your data will stay in the Project.

As the knowledge and understanding of genomics grows, it is possible a diagnosis may be found in the future. And everyone who takes part in the Project is contributing to research which will help others in the future.

To read about all the research taking place, see www.bit.ly/genome-research

Support

Whether a diagnosis is found or not, you may need support for yourself and your family.

There are many organisations that can help. Charities, patient support groups and forums can offer support and advice. Some organisations can connect you to other people who have the same condition as you – even if it doesn't have a name.

For a full list see www.bit.ly/genome-contact

