



[REDACTED]
Dawson Hall
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London EC1M 6BQ
0207 882 5922

[REDACTED]
21 December 2018

Dear [REDACTED]

Your email of 6 December 2017

I refer to your email of 6 December 2017 under the Freedom of Information Act 2000 (FOIA). Your email has been passed to me to deal with. I set out our response to your question in the Annex to this letter:

If you have any queries about this letter, please contact me. If you are dissatisfied with the handling of your request, you have the right to ask for an internal review. Internal review requests should be submitted within two months of the date of receipt of the response to your original letter and should be addressed to:

Grant Stapleton
Senior Information Responsible Officer
Genomics England

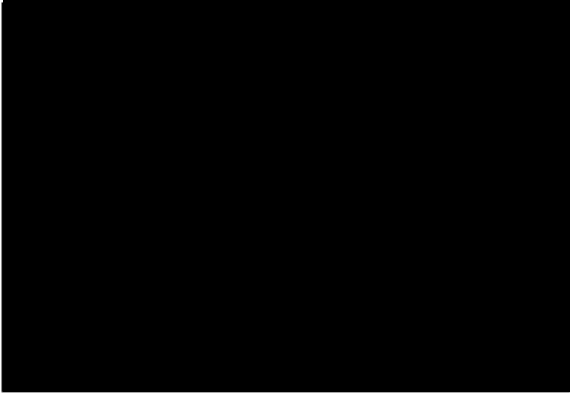
Email: grant.stapleton@genomicsengland.co.uk

If you are not content with the outcome of your complaint, you may apply directly to the Information Commissioner (ICO) for a decision. Generally, the ICO cannot make a decision unless you have exhausted the complaints procedure provided by the Department. The ICO can be contacted at:

The Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF

Kind regards

Yours sincerely





Annex

Q: Please can you release statistics on the number of results that have been returned to clinical teams and to patients and the time between a sample being collected and the results returned to the patient e.g average, shortest, longest.

When we began the 100,000 Genomes there was no pipeline for analysis the data from whole genome sequencing and so we had to build one. Over the past year, a great deal of work has been put into the development of an automated 'pipeline'. Without this, the 100,000 Genomes Project would not be able to deliver reports back to the NHS at the scale needed.

As of the 8th December, we have sent 3,417 whole genome reports back to the NHS recruiting sites and their clinical teams and this number will increase considerably throughout 2018. These reports contain findings for 7,231 genomes. At this point, the reports are then validated (checked) locally at the NHS labs before any relevant findings can be fed back to participants.

It's difficult to estimate a turnaround time for results as each individual patient is complex and for most participants, it will usually be a year or more before results are returned at this stage but we are working hard to clear the backlog. Some can take longer.

We are aware that many families are still waiting for results and are in the process of writing to them with an update and to give them the opportunity to check where their sample is in the process.

