

People want access to their own genomic data, even when uninterpretable

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The largest study to date of attitudes towards the use of genomic information shows that the majority of people want access to results from genome sequencing, even if these are not directly related to the condition for which the analysis has been undertaken. This applies even when the data are not health-related or are simply 'raw', a researcher will tell the annual conference of the European Society of Human Genetics today.

Dr Anna Middleton, a Principal Staff Scientist at the Wellcome Trust Sanger Institute, Cambridge, UK, will describe the results of a survey into the attitudes of the various groups involved in sequencing research - patients, public, [health professionals](#), and genomic researchers - towards the types of [genomic information](#) they would be interested in receiving. Just under 7000 people from 75 countries took part in an on-line survey, advertised on social and [traditional media](#), and by an email list-serve.

"We asked [participants](#) to imagine that they were taking part in sequencing research with the option to receive personal results, and carefully explained the sorts of results that might come from a sequencing study in ten short films. We found that 98% of participants wanted to know about genes linked to treatable conditions that were serious or life-threatening; they were still interested even if the chance of such a condition occurring was as low as 1%. What was important to them was being 'forewarned' about their future risk of disease so that they could take steps to protect their health. This makes sense, but we also found that 59% of those surveyed were interested in having access

to their own raw data, even though, on its own, it would tell them nothing useful about their future health. Participants perceived a value a value in raw data that may or may not exist: 'if the scientists know it, I'd like to know it too.' They felt the genomic information simply 'belonged to them' and thus they should be able to have access to it, even if the reality was that they would do nothing with it," Dr Middleton will say.

Participants appeared to be excited and positive about genomics, and they also wanted to be connected to the research process; for example, they were keen that genomic researchers should keep re-analysing their data and report to them if there were new findings. But they also recognised that scientists had an important job to do in doing good quality research; the work of answering a particular research question should not be side-tracked by a necessity to supply personalised results. Participants said they were willing to forego the return of individual findings if the delivery of such data compromised the ability of scientists to focus on the answer to a research question.

"It would now be very helpful to explore the value that people put on genomic data. For example, would they pay for an interpretation and, if so, how much?" says Dr Middleton. "Creating clinical-grade health information in a research setting requires funding, resources, and strong clinical connections to the health professionals who will deliver it, explain it, and follow up the patient. This may be out of reach for many researchers. So if research participants expect personalised results, but they also don't want researchers to compromise their research in order to deliver such results, then would they be willing to pay for these services?

"What we did in our research is explore what people say they might do in a hypothetical situation, and what we need to do next is explore the actual experience of research participants who are given personal results from sequencing research. We know already that some research participants ask for their raw sequence files and so it would be really

useful to follow such participants over time to see what they do with these. We also want to know more about the psychosocial impact of receiving genomic data and whether it has an emotional resonance that people didn't expect.

"Researchers have a responsibility not to harm their research participants, and if they are going to provide results, they need to do this in an ethical way. At the moment our genomics community agrees that if researchers choose to return results that could potentially be clinically actionable these need to be confirmed in a clinically accredited laboratory before they are returned, and there should be a clinician available to share the information with the patient and to provide screening services if necessary. For research participants who ask for their raw sequence data (that by their very nature, come with no interpretation), then they should be given a clear explanation of the limits of these data together with some signposts to services that they can access for interpretation and support. Without this there is a risk that research participants will turn up at the door of their GP and ask them what it all means." Dr Middleton will say.

"Whilst I feel that autonomy is important, and research participants do have the right to their own data, should they want them, we also have a responsibility to explain the reality of the difficulties with interpretation - and to do this without misleading people. By allowing research participants access to raw sequence data, they have the choice as to how these are explored and what sorts of information they would like to glean from them. However, they can only really do this when there is easy access to interpretation services that can be endorsed by health professionals and genomic researchers alike. Such services are not easily accessible currently and there is an urgent need to address this if sharing raw sequence data becomes a reality. Some of our participants mistakenly thought they could put their data into Google and an interpretation would pop out. Researchers mustn't leave their

participants stranded, so they should only share raw sequence data together with an explanation of what can be done with this. We also have to think carefully about the potential impact of this on health services," she will conclude.

Provided by European Society of Human Genetics

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