Why I became the first person to donate my entire genome sequence to the public

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Credit: AI-generated image (disclaimer)

I had my complete genome sequenced a few years ago – all six billion base pairs of it. And rather than keeping it to myself, I became the first person in the world to make it publicly available by donating it to the Personal Genome Project UK, an organisation led by academic researchers. As anyone can access the data, the public can contribute to

analysing it – in collaboration with professional scientists.

I made my donation under "open consent", which is controversial. Four other people have done this since. It means that we agree for our personal data to be freely available to anyone and make no claim to privacy. The project does not stop at disseminating personal genome sequences but goes much further by linking the data with personal health records, information on traits and the environmental exposure of the individual.

It is this rich combination of information which makes the personal genome project initiative both unique and powerful.

Revealing data

The human genome sequence can also be considered the ultimate digital identifier – we will all have a unique sequence. Currently, most human genome data is kept anonymous and it is not generally possible to relate this data to the personal data of the subjects. But this greatly reduces the potential usefulness of it.

The more genomes we can link to additional information, the closer we will get to uncovering exactly which traits and conditions are linked to which genes. When we know this, the possibilities for treatment will be enormous. It will enable true, personalised medicine where we can predict diseases and know exactly which treatments each individual will respond to. Since scientific and medical research is continually making such discoveries, these can be shared with participants of the projects in the future through updated genome reports.

Many leading scientists consider that it is extremely difficult to keep genomic data anonymous. Although there are attempts to improve methods, there have been cases where anonymous subjects in research

papers have been readily identified – often through information such as age range, sex and postcode. So perhaps we need to give up on the idea that data can be perfectly anonymised for all eternity.

There are great things about joining the personal genome project. You get access to a team of leading genomics and bioinformatics researchers and you get to receive detailed reports on your personal genome. I have found my personal genome report to be very helpful. It has flagged up potential health risks, some of which I have followed up with my GP.

The data: You can read Colin's current genome report here

Another very useful finding is that I have several DNA variants that prevent me from metabolising or transporting many different prescription drugs. As a result, I know which drugs won't work on me and, in fact, one class of drug could be potentially fatal for me. Now that is good to know!

I would certainly encourage people to participate in the programme. Once there are hundreds of thousands or even millions of participants, the knowledge that we will gain about how our genomes influence our health, traits and behaviour will be unprecedented. While we can't predict exactly what we will learn, it is likely that we will gain insights into mental health conditions, drug metabolism, personal human nutrition, allergies, autoimmune conditions, longevity, diabetes, cardiovascular health and cancers.

Thorny issue

But I am also aware that getting one's personal genome sequenced is not for everyone – some people simply don't want to know, and feel that the information could cause them a lot of anxiety. No one should be made to feel under any compulsion to get their genome sequenced.

I did find out that I was at increased risk of a rare, unpleasant condition when having my genome sequenced and immediately I started developing symptoms. When medical tests finally revealed I didn't have the condition, the symptoms evaporated – showing that such information can cause psychosomatic symptoms.

Another issue that some may worry about is how the data could be used by private companies, including employers or insurance companies. Although the researchers haven't looked at things like genes linked to criminal activity, the raw data is there for anyone to analyse. While insurance companies are not currently allowed to make decisions based on genomics data, some might be concerned that this could change in the future.

Family is another important factor. After all, we share genes with our parents and children – and so may want to discuss the issues with them before publishing our genome. One other issue to bear in mind with genomic testing is that you may discover that one of your biological parents is not the person you thought they were. This happens in up to 10% cases.

I do understand that these things can be concerning for certain people. Indeed, I have considered them all but decided that, ultimately, being forewarned is being forearmed. By knowing you have an increased risk of a health condition you can act early – for example, by modifying one's diet or by requesting some medical tests through your doctor. That is the most important thing to me along with donating my genomic and health data for the greater public good.

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