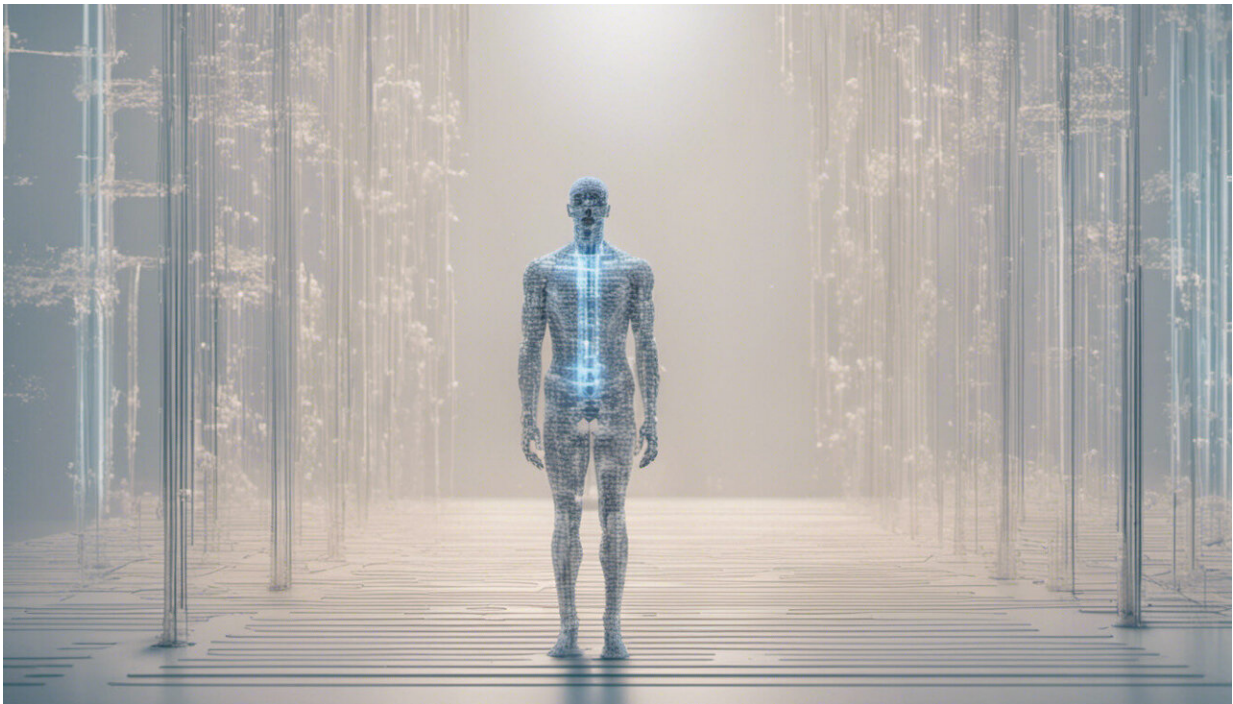# Google may get access to genomic patient data – here's why we should be concerned

July 4 2017, by Edward Hockings

Credit: AI-generated image (disclaimer)

Artificial intelligence is already being put to use in the NHS, with Google's AI firm DeepMind providing technology to help monitor patients. Now I have discovered that DeepMind has met with Genomic England – a company set up by the Department of Health to deliver the 100,000 Genomes Project – to discuss getting involved.

If this does indeed happen, it could help bring down costs and speed up genetic sequencing – potentially helping the science to flourish. But what are the risks of letting a private company have access to sensitive genetic data?

Genomic sequencing has huge potential – it could hold the key to improving our understanding of a range of diseases, including cancer, and eventually help find treatments for them. The 100,000 Genomes Project was set up by the government to sequence genomes of 100,000 people. And it won't stop there. A new report from the UK's chief medical officer, Sally Davies, is calling for an expansion of the project.

However, a statement by the Department of Health in response to a freedom of information (FoI) request I made in February reveals this decision has already been made. The department said in this response that the project will be integrated into a single national genomic database. The purpose of this will be to support "care and research, and the acceleration of industrial usage". Though it will "inevitably exceed the original 100,000 genomes, we do not anticipate that there will be a set target for how many genomes it should contain," the statement reads.

The costs of sequencing the genome on a national scale are prohibitive. The first human genome was sequenced at a cost of US$3bn. However, almost two decades later, Illumina, who are responsible for the sequencing side of the 100,000 Genomes Project, produced the first "$1,000 genome" – a staggering reduction in cost. Applying machine learning to genomics – that is, general artificial intelligence – has the potential to significantly reduce the costs further. By building a neural network, these algorithms can interpret huge amounts of genetic, health, and environmental data to predict a persons health status, such as their level of risk of heart attack.

DeepMind is already working with the NHS. As part of a partnership

with several NHS trusts, the company has built [various platforms](link), [an app](link) and a [machine learning system](link) to monitor patients in various ways, alerting clinical teams when they are at risk.

But it's been controversial. The company announced the first of these collaborations in February 2016, saying it was building an app to help hospital staff monitor patients with kidney disease. However, it later emerged that the agreement went far beyond this, giving DeepMind access to vast amounts of [patient data](link) – including, in one instance, 1.6m patient records. The Information Commissioner's Office ruled recently that the way patient data was shared by the Royal Free NHS Foundation Trust [violated UK privacy law](link).

Google's ambitions to digitise healthcare continue. I received a response to an FoI request in May which reveals that Google and Genomics England have met to discuss "using Google's DeepMind among other subjects" to analyse [genomic data](link).

Davies insists that <u>data could be anonymised</u>. The Department of Health always promise that medical data used in such initiatives will be anonymised, yet one of the reasons that Care.data (an initiative to store all patient data on a single database) was abandoned is that this was <u>shown to be untrue</u>. I <u>have also shown</u> that the department has misinformed the public about the level of access granted to commercial actors in the 100,000 Genome Project. In particular it said the data would be "pseudonymised" rather than anonymised, meaning there would still be information available such as age or geographical location.

The danger of personalisation

What would genomic information add to Google's already far-reaching database of individual information? A hint lies in its self-confessed aspiration to organise our lives for us. The algorithms "will get better, and we will get better at personalisation", <u>according to Eric Schmidt</u>, executive chairman of Google's parent company Alphabet. This will "enable Google users to ask the question, 'what shall I do tomorrow?', or 'what job shall I take?'".

With personalisation as their ultimate "goal", Google intend to use the machine learning algorithms which track our digital footprint and target users with personalised advertising based on their preferences. They also want to analyse health and genomic data to make predictions such as when a person <u>might develop bipolar disorder</u> or tell us what we should do with our lives.

Let us not forget that data, genomic or otherwise, is the <u>oil of the digital</u>

era. What is stopping genomic information from being captured, bought and sold? We cannot assume that people will make life choices based upon their "genetic profile" without undue pressure – commercial or governmental.

As for how genomic data might be used and what decisions will be taken about us, the mass surveillance by government agencies of their own citizens is a chilling reminder of the way information technology can be used. There is something unpalatable about everything being connected and everything being known.

When it comes to genetics, the implications are particularly frightening. For example, there is evidence of a link between genes and criminality. We know that 40% of sexual offending risk is down to genetic factors. A "single national knowledge base" as the one the UK government is aiming to create might therefore be used for broad genetic profiling. Although early intervention programmes that buy into genetically deterministic notions of "crime genes" are reductive, serious debate about policies involving genetic information will no doubt happen soon.

We can already see the beginnings of this in the United States. The bill Preserving Employee Wellness Programs Act – which has received strong backing from Republicans and business groups – would allow companies to require employees to undergo genetic testing. The results would be seen by employers, and should employees refuse to participate they would face significantly higher insurance costs.

Too much personalisation is likely to be intrusive. The challenge, then, will be to harness the potential of genomics while introducing measures to keep government and big business in check. The UK House of Commons Science and Technology Committee's inquiry on genomics and genome editing was cut short (due to the recent snap general election). Its recommendations for further lines of enquiry include

creating a quasi-independent body, which could be more attuned to broader, social and ethical concerns. This might introduce more balance at a pivotal time for the future of human genetic technologies.

This article was originally published on [The Conversation](#). Read the [original article](#).

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