

About Consumer Genomics, Genetic Data Privacy and Ethics

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Abstract

The revolution of High-throughput Sequencing opens the way to personal genomics for millions of people. This technical breakthrough now reaches a new bottleneck: The ethical management of Genetic Data Privacy. Three key concepts are introduced here to overcome challenges of Genetic Data Privacy and unlock the true potential of personal genomics both for the benefit of individuals as well as for public health.

Keywords: Personal genomics; Genetic data privacy preferences; Electronic medical record

Abbreviations: HTS: High-Throughput Sequencing; IT: Information Technology; EMR: Electronic Medical Record; GDP: Genetic Data Privacy

Introduction

The massive and continuous drop in cost of DNA sequencing holds the promise of a precision medicine accessible to everyone. However, the adequate management of GDP requires new tools. Indeed, even though the relative standardisation of bioinformatics formats and analysis pipelines allow genetic analysts to build informative personalised genetic reports, the storage and reporting of these data requires new methods to respect the personal privacy preferences of each patient.

Short Communication

A friend of mine is part of the UK 100K Genome project [1]. Nothing surprising here; given the immense potential of this type of project to improve public and individual health; in both the short and long term. What was surprising was the reticence of project staff when he asked them to have access to his and his family's raw genetic sequences. Suffice to say at that stage one of his family members had a suspicion of an undiagnosed inherited disease and their data could contribute to establishing a diagnostic. So why not give him his own Genomic sequences?

In their interesting paper [2], Wright et al. list the different aspects of the logistical and ethico-legal considerations that explain the reticence to share genetic sequences with research participants.

They report an IT burden and cost issues, for instance, as sharing data was regrettably not initially planned in the project. Whatever the genomics study, we can never exclude that some of the Research participants will request access to their data. It seems appropriate to ask current research participants to financially compensate this additional cost to obtain their data and make sure that future projects will appropriately take this into consideration.

A key point is the risk of an error leading to a privacy breach. A necessary condition to hand over data would logically be a second non-ambiguous identification of sequences, such as a genomic fingerprint. On top of that, each person should give a fully informed consent to the reception of their genetic sequences and findings. Logically, Wright et al. conclude that returning individual genome sequence data to research participants is "logistically achievable and may also be morally desirable" but should be done under certain conditions including:

- Confirmation of data ownership
- Signing of consent form requests
- Careful evaluation of the personal, familial and societal impact

A key question remaining is how to handle these genetic data to both exploit their full medical potential AND respect GDP at any time? To do so, I propose to introduce 3 basic concepts.

Genetic Data Production and Use Follows Risks vs. Benefits Approach

Our Genome is a dynamic result that can be analysed again and again over a lifetime with increasingly sophisticated methods. For instance, genomic analyses can provide information to help avoiding our major health risks by revealing our main predispositions. In the same way, it could be used in an unethical way (Health Insurers, Marketers, etc.). As a result, the wider use of personal genomics requires an initial risk assessment as well as a careful management of GDP.

Genetic Data Privacy is a Shared and Transferable Asset

Identical twins shares the same DNA therefore are sharing the same GDP asset. More generally, genetic relatedness ("Distance") is a good way to quantify the degree of shared genetic data privacy between individuals. With genetic relatedness comes responsibilities. My right (including privacy) stops where yours begins. Indeed, once Genetic Data are disclosed, it is difficult to go back and it is also difficult to guarantee privacy in the longer term as future analysis methods could break data anonymity.

Genetic Data Privacy Profile Advantageously Could be Specified in Time and Genetic Distance

This profile could be standardised as Metadata linked to each EMR. Whatever the technical modalities, the need to define precisely the users

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profile in terms of Genetic Data is now more pressing than ever. It seems appropriate to perform a systematic stratification of Genetic data users' profiles and guarantee that the users' choice is both respected and kept confidential at all times.

To conclude, before guidelines are proposed and adopted by society, each one will have to make a clear personal choice and communicate it in an ethical way. We all have to decide if we are genetic data sharer or not; and, if yes, under which conditions given a standardised scale. With the transfer of personal genetic data comes, in turn, a transfer of responsibilities to handle these data with respect to ethico-legal considerations. New tools are obviously necessary to store our personal Genetic Data Privacy preferences as well as handling them in a secure way.

Conclusion

Several basic concepts are introduced to condition and safeguard genetic data and analyses. First, genetic data production and its use

follow Risks vs. Benefits approach to proportionate the analysis depth to the expected health benefits. Secondly, we claim that GDP is a shared and transferable asset that must be managed as a common property by persons genetically related. Thirdly, GDP must be specified in time and space (Genetic Distance) to determine objectively the limits of the GDP for everyone.

Conflicts of Interests

The author declares to be founder and CEO of the company CircaGene Ltd. He is also consultant for the following companies: DNA Electronics Holdings Ltd and DNAnudge Ltd.

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