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A genetic passport for all? Qualitative analysis of the Belgian online DNA debate

DRAFT VERSION (STILL IN PROGRESS)

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Executive summary

Confronted with the idea of a genetic passport for all citizens, participants from the online Belgian DNA debate expressed several central values, related concerns and motivations, but most importantly, a sense of vulnerability. Policymakers, experts and stakeholders in genomics should consider citizens' vulnerabilities to maintain the public trust and support in genomics.

1 Introduction

Short historical context/overview of population-based genetic screenings (newborn screening, etc. in which countries? from when? And the like).

Technological progress in genomics spurs to extend the list of conditions and the number of people to be tested, which raises the question of whether a genetic passport for all citizens could be established one day. This poses new ethical, legal and social issues that should be debated among the general public.

In 2019-2020, Sciensano – the scientific Institute of Public Health in Belgium – organised an online DNA debate on genomic information usage with one specific question on the eventuality of a genetic passport for all citizens. To our knowledge, this study is the first to explore the perspectives, values, concerns and motivations of the general public, from a qualitative approach, regarding a genetic passport for all. Aside from raising public awareness, the ultimate goal of the DNA debate was to produce recommendations on genomic information usage based on citizens' perspectives. Those recommendations were presented to health policymakers, related experts and stakeholders during a final symposium.

2 Methods

The Belgian DNA debate was an online deliberative platform to study Belgian citizens' opinions about the ethical, legal and social issues (ELSI) of genomic information usage in society. The central question – How should we use genomic information – was divided into five sub-questions on the online platform to structure and facilitate the debate among participants. The sub-questions were:

1) What encourages you to learn more about your DNA, or what dissuades you from doing it? Why?

2) What motivates you to share your DNA data, or what stops you from doing so? Why?

3) A genetic passport for all: a good idea or not? Why?

4) How would DNA be used in your ideal society? What applications should be avoided? Why?

5) Do you want to share another idea about how we should deal with DNA in society?

All Belgian citizens could participate voluntarily by creating a pseudonymised account on the dedicated website (dnadebat.be/debatadn.be). The open call to participate was disseminated through Belgian information channels, for instance, in national media, newsletters from partners and high school teachers' groups on Facebook. On the website, participants were informed about the main issues at stake through a short video, an interactive test (What society would you live in if everybody thought like you about genomics?) and an information booklet to encourage well-informed and balanced opinions. Besides, a pedagogical dossier helped teachers from about 75 high schools organise the debate in their classrooms. It also explained how to post contributions from students on the deliberative platform.

In total, 1127 citizens voiced 1258 opinions and comments on the five sub-questions about genomic information usage. The organising team moderated each opinion to exclude offensive language and trolling, but at little as possible to allow all opinions to be heard. Participants' opinions were imported with their initial questions into the NVivo 12 software to perform an inductive thematic analysis on how we should use genomic information in society. Three researchers performed the data analysis, with one of them focusing on the question of the genetic passport. This article presents participants' central values, their related concerns and motivations regarding the idea of a genetic passport for all citizens. However, since participants could answer all the questions on the deliberative platform simultaneously, we bore in mind the influence of the general research question and other sub-questions on the issue of the genetic passport.

3 Results

3.1.1 Participants' understanding of the genetic passport

No specific definition of the genetic passport was provided. It was left up to the participants to fill in this concept and subsequently express in these circumstances their values, concerns and motivations regarding genomic information usage. They generally understood it as an official electronic record containing all available genomic information of an individual, and for some, all medical and health information too. This passport would be established through diagnostic and predictive genomic testing, either in adulthood or by birth. In the latter case, one could interpret it as the expansion of newborn screening.

The data analysis took the influence of how participants interpreted the genetic passport on their opinions into account. For instance, some were against its creation because they thought it would be accessible to anyone, such as a travel passport (value = privacy), while they only supported the use of genomic information for medical purposes (motivation = improving health). If this interpretation of what could be one day a genetic passport is not factually correct, the values, concerns and motivations citizens expressed in this regard are still of great interest to health policymakers, experts and stakeholders related to genomics.

3.2 Arguments of participants to support a genetic passport

1) Advances in personalised medicine and scientific research: According to participants, a genetic passport for all would provide a global understanding of each individual and the population's health, enable the discovery and increase the knowledge of diseases and, consequently, improve personalised diagnostics, treatments and prevention for all citizens. This was the most supported added value of the genetic passport, showing that participants considered the genome a common good whose use could help many others.

2) More efficient patient management since healthcare providers would access all relevant health, medical and genetic information of patients more directly. Some also argued that an updated genetic passport would reduce private and public expenditures caused by abuse of medical examination and prescription of unappropriated treatment.

3) Encouraging genomic information usage for forensic purposes (although a minority strongly opposed this): Participants expected that the genetic passport would facilitate the search for criminals, maybe dissuade potential offenders from acting and, thereby, improve national security.

3.3 Arguments of participants to be suspicious of or opposed against the genetic passport

3.3.1 A sense of vulnerability due to distrust and fear of losing control

a. Governments and private companies already know too much about individuals by collecting and storing large amounts of personal data every day. Participants argued that a genetic passport for all would exacerbate the control over and tracing of populations, rendering individuals and their relatives vulnerable and diminishing their liberty and agency (e.g. put pressure on individuals to take their genetic information into account).

I do not think it is a good idea to make genetic passports for the population. It is no longer about cameras or fingerprints that can provide more safety. It's really about data that gives you information about your physical characteristics, personality, ethnic origin and much more. You bring yourself and your close and even distant family members into a vulnerable position when the government has insight into all your data. (Thread n°541)

b. Additionally, centralising genomic information within a genetic passport increases the risk that non-eligible actors outside healthcare, including insurers, employers, educational bodies, banks or any commercial company, use this information to categorise, discriminate or exclude people based on their genetic makeup or predispositions to incurable diseases. Participants esteemed unacceptable that their genetic passport could change the way people consider and treat them. A minority also feared that the genetic passport combined with personalised medicine lead to discrimination inside the healthcare system (e.g. reimbursement and access to care).

You classify people literally according to their health. […] People with severe diseases or incurable illnesses will be considered differently by society, amongst others by people who are healthy or better off. This causes a conflict between each other, which can break relationships (with family or friends.) Because people always prefer healthy people. […] And they cannot do anything about it. (Thread n°747)

3.3.2 The feeling of insecurity

Their sense of vulnerability and fear of abuses came from their feeling of insecurity. They had doubts about existing security systems and a sufficiently robust legal framework to protect them against the many potential misuses in various fields. Losing their privacy and control over their most personal information made them anxious.

Personally, it seems that too much information on these DNA passports opens up many ways to abuse them. Companies will always be able to make profits from such information, and it seems complicated to keep this information secret. Just the idea that all the information about me is stored somewhere (even things I might not know myself) gives me a feeling of being stuffy. (Thread n°1054)

For some participants, only qualified people having a special request in a determined context and bound by professional secrecy should use the genetic passport. Furthermore, it should only include a limited number of relevant health and genetic information (e.g. severe diseases) to reduce the risk of misuses.

3.3.3 The uncertainty

Uncertainty about current and future uses of the genetic passport made participants anxious since they considered this information the most personal and intimate one.

The biggest problem is that you are vulnerable. And not only you but your family too. You give away genetic information from you and your family. Who can handle it all? What will they do with it? This uncertainty alone should not be allowed to live. (Thread n°866)

3.3.4 The resulting need to empower individual autonomy and control

For all the above reasons, participants expressed the need to keep control of their genetic passport and requested some autonomy and transparency in its usages, such as knowing and deciding who has access, for which purpose, and the right to withdraw their decision (e.g. data deletion). Besides, after being informed about benefits and harms, participants considered they should freely decide to know (or not) the information contained in the genetic passport. These remarks highlight that participants also viewed the genome as an individual property. However, a disagreement persisted between participants considering the genetic passport a free choice through informed consent at adulthood and those favouring rendering it compulsory on every newborn to increase its utility.

4 Discussion

In general, participants either highly supported or highly opposed the idea of a genetic passport for all because they attributed an exaggerated power to genomic information, both positively or negatively. Some opponents believed that knowing their genome is tantamount to knowing everything about them, including their future and death. For their part, proponents thought the genetic passport would solve almost all ills at the individual and collective levels. To avoid factually wrong or excessive fears and hopes within the general population, informing them correctly and sufficiently about the possibilities and limits of genomics is crucial. Public engagement turns out to be an effective tool in this wise, especially when various experts in the field are involved in answering participants ‘questions before and during deliberations. Nevertheless, even factually wrong or exaggerated fears and motivations may hide valuable information that should be considered, such as values, needs, concerns and motivations.

The key and underlying concept to understand and make sense of the many other values, motivations and concerns expressed by participants is vulnerability. Their vulnerability regarding the idea of a genetic passport may have diverse but interrelated explanations.

First, they seemed to confuse genomic sequencing and interpretation of results as they believed sequencing the genome equals knowing everything about it. Some went a step further by saying the knowledge of their genome would reveal (nearly) everything about their past (e.g. genealogy), present (e.g. diagnosis, talents) and future (predispositions, death). Second, participants worried about losing control of such intimate information because, among other reasons, potential misuses of their genetic passport can negatively impact their distant and close relatives too. In other words, their feeling of vulnerability exceeds their person. Third, participants identified many potential misuses of their genetic passport in various fields since they distrusted governments, employers, insurances, banks and any commercial company. If the genetic passport may render individuals and their relatives more vulnerable, it also gives more power to people or institutions who could use this information against them. For example, forensic uses of this information could lead to extensive profiling where people with specific genetic features or predispositions, like aggressiveness, would become suspicious by default. The general distrust of participants in people potentially using their genomic information highlights the significance for health policymakers, experts and stakeholders in genomics to understand and take the concerns, values and motivations of the general public into account if they want their support in using their genomic information. Finally, uncertainty about potential current and future uses of the information contained in their genetic passport only reinforces their feelings of insecurity and vulnerability.

To our knowledge, this study is the first to explore the perspectives, values, concerns and motivations of the general public, from a qualitative approach, regarding a genetic passport for all.

Comparison with the literature review on vulnerability.

5 Conclusion

Confronted with the idea of a genetic passport for all citizens, participants from the online Belgian DNA debate expressed several central values, related concerns and motivations, but most importantly, a sense of vulnerability. Health policymakers, experts and stakeholders in genomics should consider citizens' feeling of vulnerability and its related values to maintain the public trust and support in genomics.

6 Data Availability Statement

The data supporting the findings of this study are available from the corresponding author upon reasonable request.

7 Acknowledgements

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9 Conflicts of interest

All authors have no conflict of interest to declare.