

Do international recommendations meet citizens' values and needs regarding genomic information?

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Conclusion

Genomics will impact the lives of many citizens, as it grows more and more important and even spreads beyond the scope of healthcare. Recommendations of international professional societies related to genomics, which are mainly based on expert opinion, should be informed by fundamental values and needs of well-informed citizens.

Introduction

At the request of the Belgian Minister of Public Health, Sciensano and the King Baudouin Foundation organized a citizen forum on the use of genomic information in healthcare and beyond (KBS, 2019). We compare some of the key values expressed during this forum with related recommendations of international professional societies, such as the European Society of Human Genetics. Do experts' guidelines meet society's expectations?

Methods

- A panel of 32 selected citizens debated and reflected on the ethical, legal and societal issues in genomics during three weekends, with the aim of producing political recommendations for the Minister of Public Health. Citizens were selected according to specific criteria (linguistic, gender, age, level of education, and so forth) to guarantee maximal diversity and a rich discussion. Experts of different backgrounds were invited to inform and challenge citizens of the panel. The final report of the citizen forum was approved by the panel and the expert committee who supervised the whole process.
- Here, we review the recommendations from the ESHG and analyse how they relate to the 3 key messages from the citizen forum regarding genomic data sharing. The main focus is on the recommendations on whole-genome sequencing in health care (Howard et al., 2015; van El et al., 2013).

Results

Citizens of the panel support genomic data sharing for the common good, which they define as scientific research that improves knowledge (on both prevention and diagnostics) to build a fair society where everyone has an equal opportunity to live healthy. However, their support hinges on three conditions, ranked in order of importance:

- **No genetic discrimination (insurance, bank and employer)**
- **Privacy protection (data governance)**
- **Individual's control on the uses of his/her genomic data and autonomy in decision-making (informed consent)**

Both the panel and the ESHG consider informed consent as a crucial tool to ensure an individual's autonomy in decision-making regarding diagnostic use, storage, and disclosure of genomic data in clinical and research settings. However, **to avoid misuses of genomic data and thereby maintain citizen and patient trust in genomics, informed consent is not enough**. Citizens demand fundamental protections beyond specific or broad consent procedures. For example, they require protection against genetic discrimination and undue privacy infringement.

For future documents, we recommend that **societal values** regarding the use of genomic information are equally taken into account.

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