

A targeted approach to engage citizens in ELSI in genomics – the citizen forum



TYPE
STATUS

Implemented initiative

LAST
UPDATE

February 2020

BELGIUM • NATIONAL
Diagnostic & Treatment

OBJECTIVE & RATIONALE

Because genomics is becoming everybody's business, due to personalized medicine and the need for massive data sharing, there is a need to engage the public in discussion on the use of genomic information. Therefore, a citizen panel creates recommendations for interested politicians, with the help of experts of different backgrounds.

KEY COMPONENTS / STEPS

- **Issue Framing Workshop:** more than 50 Belgian and international experts and policymakers framed and identified the main ethical, legal, and societal issues that should be discussed during the citizen forum.
- **Citizen forum:** during three weekends, a panel of 32 citizens, selected to represent the most possible diverse group, debated and reflected on the ELSI, with the help of a professional team and resource persons with various expertise.
- **Stakeholder Workshop:** experts, policymakers, and other stakeholders analyzed how to implement the citizens' recommendations in the Belgian healthcare system, and identified major challenges to overcome and possible solutions.

KEY CONTEXTUAL FACTORS

- In 2016, Sciensano – the scientific institute of public health – organized focus groups with cancer patients to discuss ethical issues of genomic medicine. We learnt that their fears and worries about the uses of new genetic technologies (e.g. NGS) were relevant for the whole society, and exceeded the field of cancer. Following a request from the ministry of public health, we expanded this consultation to include the entire population, in the form of an in depth citizen forum.

MAIN IMPACTS / ADDED VALUE

- Generally speaking, the citizen forum provided policymakers, citizens, and experts with the opportunity to discuss together about sensitive issues and to learn from each other perspectives. The Minister of Public Health came in person with other members of the Ministry to listen to the citizens' recommendations and experts of different backgrounds analyzed how those recommendations could be implemented in the political field.

LESSONS LEARNED

- A good support, including financial, of relevant policymakers is needed because this kind of project is expensive and time-consuming.
- The forum unfolded in two languages (Dutch and French), but this linguistic barrier has been managed successfully thanks to instantaneous translations, bilingual participant, facilitators, and researchers.
- An academic study assessed the citizen forum based on participants' interviews and personal observation during the forum. They concluded that transparency, high-quality facilitation, and giving participants an active role in the process are key success factors of the citizen forum as a methodology.

CONTACT

Sciensano
Cancer Center
www-cancer.be
<https://www.sciensano.be/en>

REFERENCES & DOCUMENTATION

- Issue framing workshop report
- Informative
- Recommendations of the citizen panel
- Synthesis

More over
[IPAAC](#)
[Roadmap](#)