

The online DNA Debate: Belgian citizens' attitudes towards genomic data sharing



Chloé Mayeur
Marlies Saelaert
Wannes Van Hoof



Contact:
• + 32 479 018 602
• chloe.mayeur@sciensano.be
• www.sciensano.be



The online DNA Debate

Sciensano – The Belgian scientific Institute of Public Health – set up an online deliberative platform (www.dnadebat.be/debatadn.be), where 1127 Belgian citizens expressed their opinions about ethical issues concerning genomics, such as genomic data sharing. Citizens could voluntarily participate under a pseudonymized profile after being informed through a short video, an information booklet and an interactive test. A pedagogical dossier also helped about 75 high schools organize the debate in their classrooms.

Results

From the inductive thematic analysis we performed on citizens' opinions, we can assert that participants:

- Acknowledged the **individual and societal value of genomic data**. If the majority believed everybody should freely decide about their genomic data usage, a minority supported a genetic passport for all citizens, without exception.
- Wanted to **share their genomic data for medical, scientific and forensic purposes**, provided that:
 - ✓ **Privacy** is respected to **avoid discrimination** by insurers, employers and banks
 - ✓ **Traceability and control** are granted (knowing who uses their data, when, and why)

Take-home message

Participants supported a **soft precautionary approach** to genomic data sharing: its benefits depend on proportional protective measures to avert risks and harms.