

SIENNA genomics. European project to survey the public on ELSI in genomics



TYPE STATUS: Pilot LAST UPDATE: February 2020 EUROPE • DIAGNOSTIC & TREATMENT Genomics

OBJECTIVE & RATIONALE

OBJECTIVE Elaborate ethical frameworks for genomics. The main ethical frameworks that results from this project are code of conduct, proposals for enhancing the ethical and legal framework.

RATIONALE Create a stakeholder informed ethics.

KEY COMPONENTS / STEPS

- Workshops with stakeholders to have feedback.
- Phone survey of 15 minutes (5 minutes per technology) in 11 countries - 11 000 people in total.
- Panels of 2 hours with citizens in several countries (must find the exact number).

KEY CONTEXTUAL FACTORS

- The SIENNA project a Horizon 2020 initiative. The goal is to develop a stakeholder involved ethics framework for genomics (and human enhancement and robotics).

LESSONS LEARNED

- Too much amount of materials and information for participants of the panels - 2 hours per technology is clearly not enough.
- Because all panels occurred in the same time, organizers could not learn from their mistakes and improve the next panel.

CONTACT

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REFERENCES & DOCUMENTATION

- <https://sienna-project.eu/genomics/publications/>

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