



Presentation of research

Project Title: User-centered, legal-ethical, and technical collective consent models for genomic data sharing in the EU

Objectives: Genetic data is highly sensitive due to the interconnected nature of the data, and if it is shared openly it may lead to identifying serial killers, disease inference, or genetic discrimination. Though it has been proposed, no digital collective consent exists yet as there are complex issues including legal-ethical considerations, technical properties such as interoperability and transparency, and core concepts such as trust that all must work together to support user rights. There are also different types of groups, for example genetic families or ethnic minorities. To address these issues, we are working on a qualitative and quantitative mixed methods grounded in health and genomic data to 1) Propose consent model(s) for collective decision making in real-life cases and 2) Study model's elements that enhance trust and transparency. Methods include an interdisciplinary literature review, user studies and expert interviews to assess user attitudes, and co-designing to build interoperable models of consent.

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March 2nd 2023 at 1 p.m
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