e-CohortE: A French solution to genetic data ownership

Henri-Corto Stoeklé
Marc Bollet
Aurélie Cobat
Philippe Charlier
Oudy Ch. Bloch
Jérôme Flatot
Clément Draghi
Valérie Tolyan
Christian Hervé
Pierre Desvaux
Laurent Uzan
Michaël Grynberg
Alexandre Alcaïs
Alain Tolédano
Guillaume Vogt

Video Abstract

Keywords: Clinical Genetics, e-CohortE, 23andMe, Ancestry DNA, MyHeritage, cohort, France, two-sided market, healthcare, genomics, recherche impliquant la personne humaine (RIPH), national health insurance system, personal data, electronic consent, recruitment, research protocol, genotyping, French law, sequencing, doctor-patient relationship

Posted Date: December 23rd, 2019

DOI: https://doi.org/10.21203/rs.2.19677/v1

Abstract

Genetic testing companies hold data for tens of millions of consumers who have paid, online, for genetic information, without consulting a doctor. This information encodes more than just ancestry; it also captures aspects of wellbeing as well as traits or predispositions for which test quality is often poor. These private companies are strictly prohibited in France. But that hasn't stopped French research teams from working with them, or French people from paying for illegal tests over the Internet. So how can France keep control over its own genetic data? Our solution is e-CohortE. Designed to achieve the same ends sought by genetic testing companies, but legally and more effectively, e-CohortEs would correspond to a specific and legal French research protocol of RIPH. RIPH sponsors currently address only a few questions on a single topic and then terminate a cohort. Like two-sided markets, e-CohortEs would involve multi-subject questionnaires to determine the easiest genetic factors to identify and to accelerate the discovery of more complex genetic factors through genomics. The topics addressed—from cancers to physical and behavioral traits—would be determined independently for each e-CohortE sponsor. Unlike two-sided markets, e-CohortEs would provide participants with high-quality information about susceptibility factors for health, physical traits, wellbeing, or ancestry free-of-charge. And any medical predispositions detected would be managed within the framework of the French national health insurance system, which is accessible to all. And the best part: anyone could participate in an e-CohortE. Participants would be recruited by physicians, who would explain that the aim of the e-CohortE is "to conduct genomic studies associated with multi-subject questionnaires". Participants would sign an electronic consent form and answer a short set of original questions and possibly others determined by the physician's specialty. Following this first consultation, participants would receive an identifier and password allowing them to log onto the website and answer other questions if they wish. Participants would know the source of the question and could choose whether to respond. The goal would be to increase the numbers of topics, participants, and collaborators over time and space. Participants, physicians, and collaborators could pose their own questions to the e-CohortE using the existing infrastructure. And anyone could create an e-CohortE addressing topics of interest to them. But different e-CohortEs would be able to work together, to achieve a critical mass for large studies or for legal collaboration with foreign companies—always with the consent of the participants. e-CohortEs offer institutions a unique opportunity to accelerate research and facilitate collaboration with internal and external partners. Above all, with e-CohortEs, any country could retain control over its genetic data and stimulate high-quality genetic research—all at no charge to participants.