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Title

Using Personal (Pharmaco)Genomic Data within Primary Care: Two Mixed-Method Studies for Stakeholder Engagement

Priority 1 (Research Category)

Genetics

Presenters

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Abstract

The ongoing health crises calls for more personalized approaches to healthcare. (Pharmaco)genomic medicine, a vital component of these personalization strategies, is increasingly applied in risk assessment, prevention, prognostication, and therapeutic targeting. Several challenges to its implementation in existing healthcare contexts remain, including robust clinical data infrastructures, clinical and ethical standards, and patient education. Two studies were conducted to better comprehend what an implementation of personalized treatments might look like. The first study evaluates stakeholders' perspectives, including healthcare users and professionals, on personalized genomic medicine and the Personal Genetic Locker (PGL), a personal health data space. A mixed-methods design (surveys, interviews, focus groups) was used. Several meta-themes were generated: (i) Participants were interested in genomic information, (ii) Participants valued data control, robust infrastructure, and sharing data with non-commercial stakeholders. (iii) Autonomy was a central concern for all participants. Identified limits to individual autonomy included obligations towards others and healthcare professionals' duty to prevent medical harm. (iv) Relatedly, institutional and interpersonal trust is highly significant for genomic medicine. Additionally, focus group participants were asked to evaluate the characteristics and functionalities of the PGL. In the second study we piloted a PGL in a hospital setting. This pilot also had a mixed-method design (using surveys and interviews in combination with a demonstration of the pilot) for the use of a PGL for pharmacogenetics. The following themes were seen as added value by the medical professionals: (i) The PGL application itself makes the translation of pharmacogenetic standards into a format usable by prescribers. (ii) Knowledge from outside the organization (in this case in the field of pharmacogenetics) can be applied within the local clinical process. (iii) The information within the application can also be used within the electronic health record of the patient. The solution thus connects to existing developments and environments.

To conclude, we formulate recommendations based on the opinions of a diverse set of stakeholders for implementing genomic medicine in the Belgian and Dutch healthcare context as it relates to EU personalized health and health data strategies.