Health Data Democratization in Austria: Patients' Perspective

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Abstract. Health data democratization requires a transparent, protected, and interoperable data-sharing environment. We conducted a co-creation workshop with patients living with chronic diseases and relevant stakeholders to explore their opinion on health data democratization, ownership, and sharing in Austria. Participants showed their willingness to share their health data for clinical and research purposes; provided that appropriate transparency and data protection measures are provided.

Keywords. Datasharing, healthcare democratization, mHealth

1. Introduction

During the last decade, mobile health (mHealth) has played an essential role in realizing participatory medicine, in which the patient's voice is vital for their healthcare management [1]. This necessitates the integration of mHealth data (patient-generated health data) and the National Electronic Health Record (called ELGA in Austria). This connected health model accelerates the adoption of health data democratization- that aims at enabling wider access to health data by all stakeholders for better shared-decision making[2]- in which data sharing is a prerequisite[3]. In Europe, there is a high potential and willingness to have better citizens' access to and sharing of health data reported through the DigitalHealthEurope project [4]. In this work, we aim to explore the patients' opinions on health data democratization, ownership, and sharing in Austria. Accordingly, we organized a workshop with patients living with chronic diseases to co-identify the inhibiting and enabling factors for health data sharing in Austria, based on their expertise in using mhealth apps and/or ELGA in managing their disease.

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2. Methods

In April 2021, we conducted an online co-creation 3-hour workshop with 9 patients living with chronic diseases, 6 stakeholders (interdisciplinary experts in digital health), and a representative from ELGA. Before the workshop, we sent background material and videos on ELGA and General Data Protection Regulation (GDPR) to set the participants' backgrounds. The workshop started with a presentation on the status quo of health data management in Austria. This was followed by the co-creation of content in small groups of 4-5 participants (rotated each 20 min) and facilitated by a moderator to discuss three topics, namely, 1) Definition of health data, 2) Needs and access to health data, and 3) Motivation and incentives for data sharing. The groups discussed these topics by answering three guided questions for each topic. The workshop ended with the facilitators' presentations on each topic. This was followed by collecting open questions and prioritizing/disagreement of proposed solutions (utilizing a Padlet digital notice board for each topic). After the workshop, the 3 Padlet boards were analyzed to conclude the main findings and recommendations.

3. Results

Participants showed willingness to share health data for clinical and research purposes, provided that concerns on data privacy, fear of discrimination, or abuse of commercial benefits are resolved. They also showed great interest in having more transparent and enhanced communication with ELGA services. A new model for data altruism, including data-sharing incentives, was highly recommended. The actions to be taken to enable willingness to share health data are: 1) handle shared data transparently, 2) introduce a national awareness program for data sharing, 3) strengthen the citizen's engagement and empowerment programs, 4) develop user-friendly tools for data governance, and 5) create incentives and recognition program for data sharing. These results are also highly aligned with the outputs of DigitalHealthEurope project [4].

4. Discussion and Conclusions

Connected health has created opportunities for realizing preventive and personalized healthcare services. Citizens' empowerment and engagement in data sharing and healthcare democratization will be crucial game-changer for future medicine.

References

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