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European survey: citizens' attitudes on personalized medicine, genetic testing and health data sharing – design and delivery

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ABSTRACT

In the transformative landscape of healthcare, personalized medicine emerges as a pivotal shift, harnessing genetic, environmental and lifestyle data to tailor medical treatments for enhanced outcomes and cost efficiency. Central to its success is public engagement and consent to share health data amidst rising data privacy concerns. To investigate European public opinion on this paradigm, we executed a comprehensive cross-sectional survey to capture the general public's views on personalized medicine and data-sharing modalities, including digital tools and electronic records. The survey was distributed in eight major European Union countries and the results aim at guiding future policymaking and trust-building measures for secure health data exchange. This article delineates our methodological approach, whereby survey findings will be expounded in subsequent publications.

1. Background

In an era marked by unprecedented advances in biomedical science and technology, personalized medicine has emerged as a transformative paradigm in healthcare, promising to revolutionize how we prevent, diagnose and treat diseases. Unlike the one-size-fits-all approach of traditional medicine, personalized medicine better tailors medical interventions to the individual patient's unique genetic, environmental and lifestyle profiles. Targeted therapies are a well-established reality in modern oncology, where complex biological markers of cancer, including genetic and epigenetic changes, can influence cancer behavior and patient response to treatment. This profound shift from a population-based to an individualized approach can also significantly enhance the efficacy and safety of medical treatments, thereby offering new hope to patients and opportunities for the healthcare industry [1,2].

Adopting personalized medicine represents a pivotal moment in the evolution of healthcare systems worldwide. With a growing body of evidence demonstrating its capacity to improve patient outcomes and reduce healthcare costs, healthcare providers, policymakers and researchers increasingly recognize its importance [3,4]. This paradigm shift has led to a burgeoning ecosystem of precision diagnostics, targeted therapies and data-driven healthcare delivery systems. However, the successful implementation of personalized medicine critically hinges upon the active participation of citizens and positive attitudes toward sharing their health data [5].

In light of the growing awareness and criticism of data privacy issues among the public, it is evident that trust plays a crucial role in the context of data sharing in personalized medicine [6,7]. Therefore, surveying citizens' attitudes towards personalized medicine and health data sharing becomes even more crucial. By building on earlier research, such as the Your DNA Your Say (YDYS) project [8] and a survey targeting the Italian public [9], we addressed issues concerning the general public's perceptions and attitudes toward genetic testing, as well as various means of health data sharing, including healthcare records and data-generating apps. The gathered comprehensive and up-to-date insights on public perceptions, concerns and expectations regarding personalized medicine and health data sharing will be invaluable in shaping policies and practices that address these

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concerns and help foster a trustworthy healthcare data-sharing environment. The survey was conducted as part of the 'European network staff eXchange for integrating precision health in the Health Care Systems' (ExACT) project, funded by the European Union's (EU's) Horizon 2020 research and innovation program, RISE Marie Curie Actions, aimed at providing an overview of EU-wide attitudes on personalized medicine and health data sharing. Moreover, this survey is part of the activities of a project financed by the Italian Center for Disease Prevention and Control of the Ministry of Health aimed at drafting an Italian Genomic Strategy and guaranteeing national support for the European initiative 1 + Million Genomes (1 + MG) and Beyond 1 + MG (B1MG).

2. Survey design

The survey design involved five researchers from Amsterdam UMC in The Netherlands and Università Cattolica del Sacro Cuore in Rome, Italy: R Pastorino, C van El, FA Causio, F Beccia and S Boccia. All communications happened in English, and the first version of the survey was in English. The survey was conceptualized from scratch, building upon previous studies conducted in the two centers on related subjects, such as knowledge and attitudes regarding genetic testing and other examples retrieved in the literature [9,10]. The survey was divided into four modules: A) 'Knowledge and views', B) 'Data use and sharing', C) 'Governance', and D) 'Citizens' needs'. Each section had short introductory sections informing the respondents before investigating their viewpoints on these aspects.

The final version was validated by experts in both institutions and submitted to the ethical review boards of Amsterdam UMC, which did not object to the study (reference 2022.0214), and Fondazione Policlinico Universitario Agostino Gemelli IRCCS in Rome, where it was approved with ID 5047.

3. Survey composition & description

We designed a branching survey to ensure the optimal delivery of questions to the respondents [11]. The survey comprised 37 questions distributed across four main modules, with an estimated response time of 12 min. The questions were single-choice, multiple-choice and 5-item Likert scale questions. The survey text is available in the Supplemental Material.

Module A: Knowledge and Views consisted of six main questions that assess respondents' baseline knowledge and perspectives on personalized medicine concepts, including various genetic testing applications. Additionally, this module features three branching sections for an in-depth exploration of respondents' viewpoints based on their initial responses.

Module B: Data Use and Sharing, is further divided into three distinct sections to explore attitudes towards various forms of data sharing: Section 1, 'Sharing Data from Health Care Dossiers and Records', comprises two questions to uncover individuals' attitudes and practices regarding sharing health data derived from their medical records; Section 2, 'Donating Health Data to a Research Institute or Biobank', includes seven questions, this section probes respondents about their willingness to donate health data to research institutions or biobanks, delving into motivations, concerns and perspectives; Section 3, 'Actively Contributing Health Data via Apps', encompasses five questions centered around respondents' experiences and inclinations to actively contribute their health data through mobile applications or similar platforms. It seeks to understand the factors driving or hindering such participation.

Module C, Governance, encompasses five questions to assess respondents' opinions on personalized medicine's regulatory and ethical aspects. Module D: Citizens' Needs, examines how respondents perceive personalized medicine and their access to information.

4. Survey translation

To ensure the best possible distribution relating to regions in Europe, the survey was translated into Dutch, Italian, French, Spanish, German, Polish, Hungarian and Romanian. The translation was performed by either native language speakers in the issuing institutions or by professional translators hired by the authors.

5. Survey distribution

Researchers agreed to contract the private company YouGov to distribute the survey on their platform. YouGov is a global public opinion and data company whose platform complies with the highest standards for quality and research while ensuring participant privacy. YouGov's methodology is compliant with GDPR standards and is detailed on their website (https://yougov.co.uk/about/panel-methodology). The survey distribution lasted approximately 2 weeks during April 2023. Respondents are invited to participate in a YouGov survey based on their demographic information. They can complete the survey on the YouGov platform using their credentials. There is no time limit for filling out the survey, and participants can pause and resume as needed. Upon completion, participants receive a small nonmonetary token of appreciation as compensation.

6. Limitations

Despite the efforts to design and deliver this survey in the best way possible, some limitations should be considered: the study was conducted online, potentially introducing a

bias toward individuals comfortable with internet usage. The survey was translated into a restricted number of languages, excluding individuals from different countries or linguistic backgrounds. The survey was not designed to be representative of the entire European population, limiting the generalizability of findings to other regions or countries. Participants' responses were self-reported, which could introduce inaccuracies or dishonesty.

7. Conclusion

This paper outlines the development of our cross-sectional online survey, which assesses European citizens' attitudes toward personalized medicine and health data sharing. Administered to the general public across eight EU countries, the survey provides insights for future policymaking. Given the pivotal role of personalized medicine and health data sharing in shaping healthcare's future, this survey addresses knowledge gaps in the field. This project represents the most extensive study to date on public perspectives on genomic data sharing in the EU.

8. Future perspective

In the future, personalized medicine is poised to revolutionize healthcare by tailoring treatments to individual patients, enhancing effectiveness and well-being. As evidence of its benefits accumulates, we anticipate increased acceptance among healthcare providers and policymakers, further driving its integration into mainstream healthcare systems. These developments foster a dynamic ecosystem of precision diagnostics, therapies and data-driven healthcare solutions. The critical elements of building and maintaining trust in data sharing must be emphasized to help ensure its success, including transparency and robust privacy protection. Ongoing research and policy development will be pivotal in shaping the path forward. This survey contributes by addressing these topics in several papers, presenting the general European perspective, and subsequently diving deeper into the general public's perspectives towards health apps and data sharing, biobanks and research institutes, and their literacy and needs.

Executive summary

- A collaborative cross-sectional online survey was developed by researchers from Università Cattolica del Sacro Cuore and Amsterdam UMC to assess European Union (EU) citizens' attitudes toward personalized medicine and genomic data sharing.
- Structured into four thematic modules comprising 37 questions in total, the survey comprehensively addressed individuals' knowledge, attitudes towards data sharing, governance issues and perceived personal needs related to personalized medicine.
- Translations into eight European languages were undertaken to ensure broad accessibility, with distribution managed by a private company, ensuring high-quality research standards and privacy compliance.

- The survey aims to inform and shape policy on personalized medicine by capturing a snapshot of current EU views, with an outlook on enhancing healthcare through data-driven and patient-tailored approaches.
- While providing valuable insights for EU policymaking in healthcare, the survey acknowledges limitations such as potential online user bias, language restrictions and self-reported data accuracy.

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