

Taking a Value Perspective on Medical Data Donation Through Participatory Workshops

Claudia Müller-Birn
Freie Universität Berlin
Berlin, Germany
clmb@inf.fu-berlin.de

David Leimstädtner
Freie Universität Berlin
Berlin, Germany
david.leimstaedner@fu-berlin.de

Peter Sörries
Freie Universität Berlin
Berlin, Germany
peter.soerries@fu-berlin.de

ABSTRACT

Clinical patient data is a valuable resource for data-driven medical research. However, discussions around personal data privacy highlight the urgency of designing user interfaces that communicate the possibilities and limitations of the data security used when sharing personal health data. To better understand patients' values regarding medical data sharing, we developed a methodical approach for value-centered participatory workshops. This approach is inspired by two strains, *value-sensitive design* and *reflective design*, to reveal values related to a data donation process in the medical field. The data collected in the workshop (the first of three) will be used to derive design recommendations to improve data donation processes.

KEYWORDS

Value-sensitive design; reflective design; participatory design; values; data donation; medical domain

1 PROTECTING PERSONAL HEALTH DATA

Individualized medicine promises a data-driven approach to medical research. Routinely collected clinical patient data (e.g., electronic health records, biospecimens) are part of these data collections. However, such data collections need to fulfill legal requirements (e.g., concerning patient consent as required by the GDPR) and medical considerations (e.g., anonymization severely limits the utility of data). Thus, the Digital Health Care Act was enacted in 2019, providing the ground for collecting and centrally storing health data in research data centers. However, the Digital Health Care Act has raised much criticism. For example, it provides inadequate data protection standards (pseudonymization only) and lacks a right of objection for patients. Therefore, the public discussion oscillates between concerns about personal data protection, especially for vulnerable people, such as those with a rare or stigmatizing condition, on the one hand, and the need for improving the international competitiveness of the German health care system, on the other hand. These discussions show a particular urgency to design user interfaces that communicate the possibilities and limits of the employed data security when sharing personal health data, such as clinical data. We are convinced that to preserve individual privacy,

patients should regularly and consciously think about their privacy concerns, understand the potential consequences of data sharing, and have options to act on to what extent they share the data. Such empowerment can inform considerable societal discussions about further needed legal regulations. However, this calls not only for more transparency of the employed security technology but also for enabling reflection on privacy decisions [8].

In our ongoing research, we focus on the complex interplay of educating privacy literacy, transparently communicating the risks of data sharing, and supporting reflective decision-making [7]. Our starting point is the investigation of patients' decision-making processes regarding data donation and situation-specific, partly diverging attitudes and a variety of concerns, i.e., values, regarding the disclosure of health data. With our research, we seek to understand better how value-driven stakeholder participation can inform a more responsible socio-technical design of a medical data donation process. For this, we conceptualized and conducted participatory workshops to reveal the existing values of patients regarding data donation.

2 VALUE-SENSITIVE DESIGN OF DATA DONATION

Two strains of research inspired our participatory workshop primarily: *value-sensitive design* [3] and *reflective design* [5]. Value-sensitive design (VSD) is a theoretically grounded approach to systematically identifying stakeholders' values, needs, and concerns in technology design [3]. *Values* can be defined as desirable, worthwhile, or positive goals that transcend specific situations and can be applied generally to social life [6]. In the context of VSD, universal values such as trust, autonomy, privacy, and sustainability can be used. In addition to these often societal informed goals, each person has values of their own, depending on what is important to that person in life. VSD provides several methods for including these values explicitly in the design process [2]. Nathan et al. [4], for example, introduce "value scenarios," which are narratives that provide an analytical tool to consider values in technologies. However, even though VSD provides a variety of methods that help to consider values in design work practically, Shilton [6] argues that there have been few evaluations of how existing approaches (e.g., the "Envisioning Cards" [1]) can be applied outside of an academic context. We share this argument since our initial goal of adopting an existing workshop concept from VSD was not feasible. Thus, we incorporated a strong reflective design perspective into our methodological apparatus. Reflective design helps to explore the values of people and situations, for example, in participatory workshops or co-creation activities (e.g., [10]). The close collaboration between

Permission to make digital or hard copies of part or all of this work for personal or classroom use is granted without fee provided that copies are not made or distributed for profit or commercial advantage and that copies bear this notice and the full citation on the first page. Copyrights for third-party components of this work must be honored. For all other uses, contact the owner/author(s).

Veröffentlicht durch die Gesellschaft für Informatik e.V.
in K. Marky, U. Grünefeld & T. Kosch (Hrsg.):
Mensch und Computer 2022 – Workshopband, 04.-07. September 2022, Darmstadt
© 2022 Copyright held by the owner/author(s).
<https://doi.org/10.18420/muc2022-ws02-235>

stakeholders and designers brings out initially unconscious values, and design becomes a process of inquiry. Through such an approach, boundaries and holistic implications of a design are reflected from the beginning of the design process [5]. For example, Wong and Mulligan [9] highlight that by following this approach, technology design can be sensitive to socio-cultural differences and particularities.

We arrived at a participatory workshop design consisting of three phases based on our theoretical considerations and a pilot study. The workshop enables a value-sensitive perspective on the value needs of the particular participating stakeholder group. In the first phase, the individual value context is ascertained, then located collectively in the second phase on a value map. Here, the goal is to create a shared conceptualization of important stakeholder values through reflection on a group level and reveal potential value conflicts between different stakeholder groups. In the final phase of the workshop, concrete requirements for providing informed consent are derived by developing value scenarios. These value scenarios represent an “ideal” data donation process by focusing on selected patient values.

3 VALUE-CENTERED PARTICIPATORY WORKSHOPS

So far, we have conducted one participatory workshop with a group of experts (three female and two male, self-reported). This expert group involved representatives from patient advocacy of vulnerable groups. We invited the participants to a neutral venue, where we conducted the full-day workshop (4,5 hrs, breaks excluded). This workshop (the first of three) produced empirical data on values that patients have as primary stakeholders when donating data in the medical context. We want to use the insights gathered to derive design recommendations for improving the data donation process, especially for consent forms.

ACKNOWLEDGMENTS

We thank the participants of the workshop and the reviewers for their valuable and insightful comments. This work is supported by

the Federal Ministry of Education and Research (grant 16SV8463: WerteRadar).

REFERENCES

- [1] Batya Friedman and David Hendry. 2012. The Envisioning Cards: A Toolkit for Catalyzing Humanistic and Technical Imaginations. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. Association for Computing Machinery, New York, NY, USA, 1145–1148. <https://doi.org/10.1145/2207676.2208562>
- [2] Batya Friedman, David G. Hendry, and Alan Borning. 2017. A Survey of Value Sensitive Design Methods. *Foundations and Trends® in Human-Computer Interaction* 11, 2 (2017), 63–125. <https://doi.org/10.1561/1100000015>
- [3] Batya Friedman, Peter H. Kahn, Alan Borning, and Alina Huldtgren. 2013. Value sensitive design and information systems. In *Early Engagement and New Technologies: Opening up the Laboratory*. Springer, Dordrecht, NL, 55–95.
- [4] Lisa P. Nathan, Predrag V. Klasnja, and Batya Friedman. 2007. Value Scenarios: A Technique for Envisioning Systemic Effects of New Technologies. In *CHI '07 Extended Abstracts on Human Factors in Computing Systems*. Association for Computing Machinery, New York, NY, USA, 2585–2590. <https://doi.org/10.1145/1240866.1241046>
- [5] Phoebe Sengers, Kirsten Boehner, Shay David, and Joseph 'Jofish' Kaye. 2005. Reflective Design. In *Proceedings of the 4th Decennial Conference on Critical Computing: Between Sense and Sensibility*. Association for Computing Machinery, New York, NY, USA, 49–58. <https://doi.org/10.1145/1094562.1094569>
- [6] Katie Shilton et al. 2018. Values and Ethics in Human-Computer Interaction. *Foundations and Trends® in Human-Computer Interaction* 12, 2 (2018), 107–171.
- [7] Peter Sörries, Claudia Müller-Birn, Katrin Glinka, Franziska Boenisch, Marian Margraf, Sabine Sayegh-Jodehl, and Matthias Rose. 2021. Privacy Needs Reflection: Conceptual Design Rationales for Privacy-Preserving Explanation User Interfaces. In *Mensch und Computer 2021 - Workshopband*, Carolin Wienrich, Philipp Wintersberger, and Benjamin Weyers (Eds.). Gesellschaft für Informatik e.V., Bonn, NW, DE, 7 pages. <https://doi.org/10.18420/muc2021-mci-wsc-389>
- [8] Arnout Terpstra, Alexander P. Schouten, Alwin de Rooij, and Ronald E. Leenes. 2019. Improving Privacy Choice through Design: How Designing for Reflection Could Support Privacy Self-Management. *First Monday* 24 (Jan 2019), 19 pages.
- [9] Richmond Y. Wong and Deirdre K. Mulligan. 2019. Bringing Design to the Privacy Table: Broadening “Design” in “Privacy by Design” Through the Lens of HCI. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*. Association for Computing Machinery, New York, NY, USA, 1–17. <https://doi.org/10.1145/3290605.3300492>
- [10] Daisy Yoo, Alina Huldtgren, Jill Palzkill Woelfer, David G. Hendry, and Batya Friedman. 2013. A Value Sensitive Action-Reflection Model: Evolving a Co-Design Space with Stakeholder and Designer Prompts. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. Association for Computing Machinery, New York, NY, USA, 419–428. <https://doi.org/10.1145/2470654.2470715>