

Endorsing Values through Participation: Facilitating Workshops for Participatory Value Elicitation in Two Different Contexts to Inform Sociotechnical Designs

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ABSTRACT

Legal measures such as the GDPR aim to regulate the collection and use of personal data for scientific or commercial purposes. However, these measures might not be enough to protect individual privacy. Moreover, it is rarely possible for individuals to participate in and contribute to regulatory strategies. Informed by this situation, we were challenged on how responsible data collection can be achieved considering individuals' values and needs. Based on our ongoing research in healthcare and urban mobility, we developed a two-step method: first, a workshop concept for participatory values elicitation, and second, an analysis procedure to examine the empirical data collected systematically. Our findings from the workshops show how values can inform sociotechnical designs.

KEYWORDS

Participatory design; value sensitive design; data donation

1 INTRODUCTION

Legal measures (e.g., GDPR) intend to regulate data practices for collecting, processing, and disclosing personal data for scientific or commercial purposes. However, due to our data-driven society, these regulations might be insufficient to protect the rights of individuals, as the responsibility for privacy is transferred from data users (e.g., institutions or companies) to data owners (e.g., individuals) [17]. Furthermore, data owners rarely can actively contribute to regulatory strategies helping to protect their privacy (see [20]). This situation calls for instruments considering individual values, competencies, and concerns that inform sociotechnical designs.

In our ongoing research, we faced similar challenges in the context of healthcare and urban mobility: In healthcare, the secondary

use of routinely collected patient data aims to improve personalized medicine through data-driven technologies; however, a large amount of patient data is required. One first step is the "broad consent" developed by all German university hospitals.¹ By signing the broad consent, patients agree to the cross-site or secondary use of their data without a predetermined medical research purpose. The specifications of the broad consent have been agreed upon by 52 German ethics committees for medical research and 18 German data protection authorities at the federal and state levels, but only one consultation group with patient representatives [21]. We hypothesize that this distribution may have led to asymmetries in participation when specifying the broad consent, assuming patients' values (e.g., regarding their autonomy and privacy) might have been bypassed.

In urban mobility, citizen science projects have emerged as a promising area for large-scale scientific research. For example, thousands of volunteers are often encouraged to donate their data through crowdsourcing activities to improve public transportation. However, volunteers are not always aware that they are sharing sensitive data (e.g., metadata in images or location data) when participating. Although citizen science aims to collect and connect data for the greater good of society, research (e.g., [6]) indicates that citizen science amplifies power asymmetries among stakeholders using the collected data (e.g., corporations or government agencies) probably disregarding citizens' privacy concerns.

By comparing the two cases, we argue that there is a need for directions to engage with and protect individuals' privacy by considering their values and needs in data donations. We emphasize that responsible data collection and use should be primary in healthcare and urban mobility. Hence, more participatory efforts should be realized, demonstrating how individual values can be elicited to support a design process [9].

Although HCI research offers a variety of research (see Section 2) to elicit values, we found that more guidance is needed on systematically exploring and examining individual values. As mentioned above, we faced challenges foregrounding values to inform responsible sociotechnical designs in two different contexts. In this regard,

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¹For more information, please visit: <https://www.medizininformatik-initiative.de/en/template-text-patient-consent-forms>

we are motivated to understand better how to work with and design for values. Therefore, we contribute a two-step method: First, a proposal for workshops for participatory value elicitation serving as a blueprint for unfolding values in a specific context, and second, an analysis for examining the empirical data collected from these workshops to arrive at design requirements informing the design of socially responsible technologies.

2 ADVOCATING VALUES THROUGH PARTICIPATION

Values reflect individuals' beliefs about what they perceive, for example, as good or bad, desirable or undesirable [1]. They can serve as *"bridges between the individual and the social"* [8]. By reviewing prevailing definitions of values (e.g., [12, 19]), Cheng and Fleischmann [5] conclude that values are *"guiding principles of what people consider important in life."*

Considering values through participation poses a particular challenge for researchers since participatory design (PD) in its tradition regards intrinsic values such as general, self-evident, and stable [13]. Moreover, given the goal of a (research) project, design processes may be influenced by the values researchers themselves behold [14]. Therefore, researchers should know their responsibilities in PD. Accordingly, PD expects a rethinking of the relationship between methods and participation [13], i.e., researchers need to choose and use methods carefully when working with values.

Stemming on PD as epistemological framing (see [2]), we further guided our ongoing research by the theoretically founded approach of value sensitive design (VSD) that accounts for human values throughout a design process focusing on morality and ethics [10]. Existing VSD methods support investigating the values of direct and indirect stakeholders (see [11]). For example, to identify value conflicts regarding mobile security and personal safety of youths and their parents [7], or enhance engagement for marginalized communities (e.g., elderly or disabled people) to inform more inclusive technologies [4].

However, VSD has faced several criticisms: For example, Le Dantec et al. [15] argue that VSD methods should be revised to focus more on value discovery instead of purely identifying them. This discovery should be the primary concern of a method that can be achieved through effective empirical inquiries, allowing researchers and participants to reflect critically on their values and incrementally refine them continually. Similarly, Borning and Muller [3] note that VSD could be enriched by realizing more participatory approaches among researchers (e.g., through collaboration regarding research materials for investigating values) to distill VSD methods. Iversen et al. [13] further discussed that it is not just about the methods used to capture participants' values but also how to work with values in a design process, as they can drive PD activities. The authors argue that values can be negotiated through dynamic and dialogic processes that foster values' emergence, development, and grounding regarding their use and acceptance in practice. Also, Leong and Iversen [16] show that values-led PD helps reveal meaningful alternatives, i.e., material or immaterial outcomes. Such alternatives materialize participants' values regarding technology design. The authors conclude that researchers should encounter

the challenge of connecting their expectations (e.g., of a project) to participants' values in pursuing a value-led PD.

By incorporating these implications, we arrived at a method consisting of a workshop procedure to elicit values through active participation and a systematic approach to analyze and translate the empirical data gathered into design requirements informing our two contexts.

3 APPLYING OUR METHOD IN TWO DIFFERENT CONTEXTS

We arrived at a two-step method, first, to facilitate workshops for participatory value elicitation and second, an analysis to examine the empirical data gathered to systematically funnel participants' values into design requirements informing our design contexts, i.e., data donations in healthcare and urban mobility.

Workshop procedure and participant recruitment. Our workshop procedure enables participants to address their values in four sequential phases: Participants' values regarding a specific context are explored and collected individually in the first phase. Then, in the second phase, participants negotiate their values and assign them to stakeholders on a value map. The value map aims to contextualize participants' values regarding a specific context. Participants are prompted to imagine an idealized solution in subgroups in the third phase by creating value scenarios. Finally, participants reflect on their value scenarios articulating and illustrating why and how their solutions might improve a context.

In 2022 and 2023, we facilitated workshops (2.5 h; breaks excluded) regarding our two design contexts: In the first context of medical data donation, we worked closely with patients, physicians, and practitioners. Concerning medical data donation, we supposed that power asymmetries may have led to bypassing patients' values when specifying the broad consent. Thus, we aimed to understand better patients' values regarding the broad consent to inform patient-centered data donation processes. We conducted three workshops with a total of 16 participants. We invited patient advocates from vulnerable groups who we consider patients since they are characterized by their rare disease or those of a family member, and patients suffering from mental disorders who were in inpatient care of a psychosomatic department.

In the second context of mobility data donation, we collaborated with citizens, researchers (e.g., with expertise on digital self-determination and distributed security infrastructures), and public institutions focusing on urban mobility. We hypothesize that citizens are insufficiently informed about the possible consequences when donating their mobility data (e.g., for citizen science projects). Similar to our first context, we assume a power inequality between citizens and data-collecting institutions. Hence, we aimed to foreground citizens' values to enhance mobility data donations. Based on this, we conducted three workshops with a total of 13 participants. We recruited participants with varying educational backgrounds, fields of work, or motivations to participate (e.g., contributing to research).

Analysis and findings. To analyze the empirical data of each workshop, we conducted a qualitative content analysis [18]: In the first step, we used the value maps as a coding scheme, helping us

better understand how participants interpreted, substantiated, and contextualized their values. As a result, we arrived at categories defining participants' values. In the second step, we consulted the value scenarios to determine how participants materialized their values regarding an idealized solution for a specific context. We derived design requirements based on the value scenarios, which we refined by revising them with the categories from the first step.

Concerning the workshops on medical data donation, we arrived at design requirements that strongly incorporate patients' values: First, enhancing patients' reflective thinking on potential consequences of their data donation (e.g., no therapeutic measures when consent is rejected); second, a decision facilitator to foreground an ethical stance for patient-oriented decision-making. A decision facilitator (e.g., digitally implemented) can reduce hurdles in health-care data practices (e.g., by giving comprehensive information on technical terms); and finally, a data intermediary to enhance transparency and control even beyond a data donation (e.g., by allowing patients to withdraw the secondary use of their data).

In the workshops on mobility data donation, our findings reflect citizens' stance emphasizing that, first, citizens' self-governance should be maintained by the support of local infrastructures (e.g., close communication in communities improving individual data sharing); second, citizens' reflection on data donation should be improved by social interactions (e.g., technologies offering collaborative feedback supporting individuals' reflective decision-making when donating data); and finally, citizens' data sovereignty should be increased by disentangling data practices (e.g., data stewardship improving control over data on citizens' behalf).

To summarize, our results of the workshops in two different contexts yielded valuable insights. However, we experienced that participants in the workshops on mobility data donation were more open and creative in approaching each phase, i.e., activity, compared to those of the workshops on medical data donation. Regarding the latter, we attribute this to patients' lived experiences (e.g., medical histories or exhausting treatments) that might have influenced the activities (e.g., some participants felt pressured to do something wrong). Nonetheless, our results point to directions focusing on values that inform sociotechnical designs beyond legal and formal-ethical perspectives.

4 CONCLUSION AND FUTURE WORK

In this position paper, we present a two-step method to (1) elicit and (2) analyze and translate values into design requirements informing sociotechnical designs. PD, VSD, and research on value-led participation offered valuable implications for our approach. However, we argue that further investigation is needed to demonstrate the suitability of our method for design practice. A promising lens in design research is provided by the research through design (RtD) approach [22], emphasizing that an appropriate method includes different research examples to form knowledge, enable critical reflection, and justify its relevance. Regarding the latter, our method has already been applied in the context of online journalism platforms with experts in law and economy. Furthermore, we plan to conduct our method in the context of research data platforms considering researchers from different disciplines (e.g., humanities and natural sciences). We are also driven by the idea of making our

method available to researchers and practitioners. Accordingly, we are working on a toolkit that can be applied to different contexts. Besides a method guide, this toolkit will include research materials (e.g., activity descriptions) to facilitate and analyze workshops for participatory value elicitation.

We hope our work will demonstrate to policymakers that more participatory approaches are needed to define individual rights, especially for marginalized and vulnerable groups.

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