Data of/by/for the People – Designing Participatory Approaches to Data Governance

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ABSTRACT

Current frameworks of data governance often fail to account for the plurality of the publics they are required to safeguard. Several alternative structures are emerging to democratise and rethink data governance to involve and protect people and their fundamental rights. This 1-day workshop will bring together HCI researchers, practitioners and designers working in areas of privacy, law, policy, social science and community practice to solidify the role of design in engaging communities with deliberate data practices which embed varied lived experiences into new technological developments. Critically addressing issues of care and meaningful representation, we aim to reflect on the impact of collective action and participation in datafied socio-technical infrastructures. To consolidate this research community, the intended workshop outcome is a visual map of the emerging landscape of alternative, community-led governance models, and a set of critically informed guidelines on best practices for design in this field.

CCS CONCEPTS

• **Human-centered computing**; • **Human computer interaction (HCI)**;

KEYWORDS

Data governance, privacy, data justice, care, data ethics, participatory and speculative design methods

1 BACKGROUND

'Data governance' has been extensively discussed from technical and legal perspectives, often focusing on strengthening data flows, data quality, and GDPR-compliance. However, a fundamental challenge remains – citizens and users are commonly left out of the conversation. In most cases, those at the production end of the data hardly have a say in how their data gets collected and used. Furthermore, mechanisms of data privacy and governance often focus on individual responsibility and awareness. A practical example is the case of informed consent for data processing, where Renaud et al. [36] argue that it is not fair or reasonable to put privacy and data responsibilities on to users without sufficient support. However, users are often left unsupported in making informed decisions when they are not afforded the knowledge or capacity to do so [25], [48], let alone contest any decisions made about them.

With each new development of technology, such as smart technologies, AI and Mixed Reality, we see an increasing and more complex level of data collection and sharing integrating into everyday life. This brings with it an increase in privacy issues for people and communities, creates a bigger gap in understanding, and reduces the ability for informed consent and accurate representation [5]. In response to the inadequacies of popularised approaches to data ethics, and informed by concepts such as 'data justice' [45], a number of alternative data governance structures have emerged with the aim of restructuring how data is managed through more participatory, community-led and inclusive approaches. Some of these approaches attempt to conceptualise data as commons, inspired by the foundational work of Elinor Ostrom on the community governance and management of the commons [34], [44]. The data as commons approach aims to suggest an alternative governance model, that will redistribute the value of data back to its communities by collectively deciding on how and under which conditions and purposes data should be collected, used and reused. Effective data governance not only requires collaborations among multiple

public and private stakeholders, but it also requires new methods of mapping individual and collective harms, agency, and power. Alternative data governance structures range from Data Cooperatives [33] where people can volunteer their data and collaboratively pool it, with the aim to provide more agency and control for individuals to use or sell the data for their benefit [7], [32], to Data Trusts [13], to the utilisation of Data Stewardship as an internal organisational structure that enables organisations to delegate the responsibility to data "stewards" [20], [32]. There are also Data Unions which can bargain over measures to collectively protect privacy or share data with third parties [40]. These types of approaches challenge the status quo by enabling people to be part of the decision-making process and have more control over their data. It positions data collection and sharing as something that can be mutually beneficial, not just extractive for capitalist gain. Research focused on such perspectives has proposed alternative data epistemologies separated from Western approaches [37], indigenous perspectives [15], criticism of data colonialism [10] and with manifestos against data universalism [29].

People use and experience technology differently due to demographic, cultural and socio-economic factors resulting in uneven levels of risks or online harms [1]. There is a considerably increased impact on the more vulnerable groups in our society [3], [4], [19], [35], [42], [43], [44], [47] which need to be addressed and acknowledged when developing alternative data governance structures as different communities require different approaches to include and support a plurality of voices, knowledges and experiences. By moving towards more participatory, plural and community-led data governance, it is important to engage with communities to explore possible future models and support the design of structures that work for them. The challenge is ensuring people can meaningfully and critically engage with their data, identifying points of intervention for negotiating new forms of control and oversight. We also need to ensure that participatory approaches are not tokenistic or extractive, particularly with those in vulnerable positions in the existing socio-technical and economic infrastructure. They should not perpetuate existing power relations, so careful consideration for the time and resources needed to support equitable approaches is key.

2 DESIGN APPROACHES FOR GOVERNANCE

Alternative economic governance models are often facing scalability issues, and lack adoption or appropriation of these governance models by the market currently reducing their potential. While these civil society initiatives on governing data 'otherwise' are currently remaining on the margin of regulatory efforts, we argue for rethinking the role of design methods for participation in sketching out alternative spaces for engagement and impact. Design methods can provide creative, playful and speculative approaches to engage in conversation, build knowledge, co-design and explore alternative futures. Approaches like participatory design and co-design aim to collaborate with participants to embed their lived experience in the process [17]. Other design approaches may create more tangible and visual ways to frame complex topics for ease of understanding and for relatable discussions. To explore data privacy, consent and governance and support participants to interactively

engage in these topics, HCI and design researchers have explored creative approaches such as metaphors [1], [30], ideation cards [24], imaginaries [2] and interactive installations [31]. Framing data and governance in accessible and playful ways enables people to focus on their notions of and relationships with data practices and systems without the need for technical or theoretical understanding. This allows audiences to engage and envision new experiences or practices and emphasizes designers' role in speculating emergent and near-future data scenarios [41] to explore possible future challenges that rapidly developing technologies may pose for policy making, law and regulation. These approaches range from design and prototyping for policy [21], [22] and speculative policy making [38] to legal futuring [11] and legal provocations [46]. This workshop aims to explore the opportunities and challenges of using design in this context to engage communities with data practices and embed varied lived experiences into new technology developments.

3 WORKSHOP THEMES

This section outlines key themes of the workshop to move towards participatory models of data governance from principles to on-the-ground practices of participatory data governance:

3.1 Emerging practices and models of data governance

The increasing levels of datafication and possible harms posed to individuals and communities at large, has given rise to a growing need to move away from dominant, extractive models of data collection. Several attempts are being made to reconfigure power and agency among private, public, and civil actors in the governance ecosystem, placing the citizens as 'key actors' within it [28]. Models such as 'data cooperatives' enable alternative and consolidated forms of data ownership that protects a collective's data rights and sovereignty. In attempts to comply with regulations such as GDPR and the EU AI act, public and private organisations are increasingly democratising their internal data governance structures to involve multiple stakeholders and disciplines. The emergence of 'data intermediaries' [6], involvement in citizen assemblies [18] and civic participation [39], are a few examples. At the same time, several bottom-up, community-driven interventions are being observed to take back control over data [23]. While progress has been made to democratise data governance to better represent citizens' interests, these models exist within a larger surveillance economy and thus, are subject to continuous friction. Additionally, new models can perpetuate inequities if blindly adopted and not approached with critical reflexivity. How can we map the emerging forms, practices, contexts, actors and challenges of data governance models to better understand the landscape?

3.2 Embedding care in data governance models, processes or practices

Addressing vulnerabilities or capabilities shows there is a desire to position people and their needs as the driver of the design process for technology and data, challenging the mainstream systems mostly driven and shaped by economic motivations. Current research is exploring how innovation and technology can be shaped

around key principles of belonging, care and repair based on metrics of human wellbeing [8]. Other researchers are developing privacy frameworks around care by supporting control and awareness [27], while considering peoples capabilities to protect themselves online [12]. Other efforts are exploring a privacy framework that foregrounds vulnerability to shape the design process, informed by intersectional feminist theories [26]. It is important to understand the barriers or assets that people and communities may have to access technology, as these approaches can inform the development of alternative data governance models, building infrastructure based around care principles. Thus, how can design methods embed care principles within the design process of data governance for and with communities?

3.3 Meaningful spaces for engagement and representation

It can be challenging to engage people around data governance in a meaningful way due to its complex nature and level of knowledge needed. There is an opportunity to explore how designers can support meaningful collaborations with people and communities to investigate, critique and design alternative data governance approaches, engage participants through visualisation, installations, role play, speculative scenarios or metaphors. Data governance needs to be approached from a pluralist view, so that marginalised communities are included in its design and development, ensuring that diverse backgrounds [14], [16] are represented and that infrastructure is created around these communities' specific needs, epistemologies and interests. Design methods can provide bespoke, adaptable tools to engage and co-design with marginalised or vulnerable communities, embedding their lived experience within the process [9]. How can design support underrepresented voices to be better integrated within data governance? What are the challenges to meaningfully engage people and communities with it and what makes people stop engaging?

4 AIMS AND ANTICIPATED OUTCOMES OF THE WORKSHOP

This workshop brings together HCI researchers, practitioners and designers working in areas of privacy, law, policy, social science and community practice who are exploring participatory data governance and design methods with communities. Building an international and interdisciplinary community we will identify effective ways that design can support communities to engage and develop alternative models. During the workshop we will discuss existing and emerging design approaches and case studies in visual mapping activities to form a common and shared basis on how to put theories into practice. We will explore key aspects of care, diverse representation and meaningful spaces; and reflect on opportunities, challenges and tensions we face. In summary, together we will develop a set of recommendations for design methods for developing alternative and participatory data governance to be published as white paper for comments. In addition, a map of emerging practices and case studies will offer insights into working with different communities. We aim to further establish data governance as important field in the design community when working with data of/by/for the people.

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