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RESEARCH ARTICLE

Data diaries: Self-reported chronicles on online health platforms and the challenges for technology assessment

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Abstract • This research article explores the ethical, social, and economic implications of online health platforms that promote participatory models of data collection and use. These platforms, often hailed as enablers for democratization of healthcare, also raise significant concerns about privacy and the commodification and exploitation of data. Based on qualitative interviews and a literature review, this study examines how such platforms influence global healthcare dynamics. While these platforms foster user empowerment, they also create environments where new forms of surveillance may emerge. This article emphasizes the importance of addressing these concerns through rigorous technology assessment, particularly in regions governed by strict data protection regulations such as the General Data Protection Regulation (GDPR) in Europe. By examining the socio-ethical challenges posed by these platforms, the study identifies ways to ensure that the benefits of participatory platforms are distributed equitably and ethically.

Daten-Tagebücher: Selbstberichte auf Online-Gesundheitsplattformen und die Herausforderungen für die Technikfolgenabschätzung

Zusammenfassung • *Dieser Forschungsartikel untersucht die ethischen, sozialen und wirtschaftlichen Auswirkungen von Online-Gesundheitsplattformen, die partizipative Modelle der Datensammlung und -nutzung fördern. Diese Plattformen, die oft als Wegbereiter für die Demokratisierung des Gesundheitswesens gepriesen werden, werfen auch erhebliche Bedenken hinsichtlich des Datenschutzes, der Kommerzialisierung von Daten und der Datenausbeutung auf. Auf der Grundlage qualitativer Interviews und einer Literaturrecherche untersucht diese Studie, wie solche Plattformen die globale Dynamik im Gesundheitswesen beeinflussen. Während diese Plattformen das Empowerment der Nutzer fördern, schaffen sie gleichzeitig Umgebungen, in denen neue Formen der Überwachung entstehen können. In diesem Artikel wird betont, wie wichtig es ist, diese Bedenken durch eine rigorose Technikfolgenabschätzung zu adressieren, insbesondere in Regionen, in denen strenge Datenschutzbestimmungen wie die Datenschutz-Grundverordnung (DSGVO) in Europa gelten. Anhand der Untersuchung der sozioethischen Herausforderungen, die diese Plattformen mit sich bringen, zeigt die Studie Wege auf, wie sichergestellt werden kann, dass die Vorteile partizipativer Plattformen gerecht und ethisch vertretbar verteilt werden.*

Keywords • *participatory health platforms, self-reporting, data privacy, technology assessment, ethical implications*

Introduction

In recent years, participatory online health platforms have become increasingly important in shaping how personal health data is gathered, shared, and applied in medical research and patient care. These platforms, which include patient communities such as PatientsLikeMe and direct-to-consumer genetic testing services like 23andMe, are often celebrated for empowering individuals to contribute actively to healthcare knowledge and improve health outcomes. However, while they offer users a sense of agency, these platforms also raise profound ethical concerns, particularly regarding data privacy and the commodification of personal health information (Kaplan et al. 2019).

The adoption of these platforms varies significantly across different regions. In the United States and the United Kingdom, such platforms have become integral to many patients' healthcare journeys. Conversely, in regions like Europe, strict regulations, such as the General Data Protection Regulation (GDPR), and cultural differences surrounding data sharing have led to more limited use. In Asia, platforms are growing rapidly, but their ethical implications are still under-examined (Shukla et al. 2018).

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The goal of this study is to explore the complex moral economy of participatory health platforms and their implications for technology assessment (TA). By analyzing qualitative interviews with users and reviewing existing literature, this study investigates how these platforms simultaneously promote empowerment and create new risks related to exploitation and surveillance. This paper also discusses the role of data protection regulations like the GDPR, and how they shape the way these platforms function in different regions.

The goal of this study is to explore the complex moral economy of participatory health platforms and their implications for technology assessment.

Methods

This study uses a qualitative research design, combining interviews with active users of participatory health platforms and a critical literature review. The research was conducted from 2019 to 2021, with interviews focusing on users of the PatientsLikeMe platform, a global health community that allows users to share health experiences, treatment data, and personal stories. This study aimed to capture the diverse experiences of users in managing their health data and navigating privacy concerns.

Participant recruitment

Twenty participants were recruited through PatientsLikeMe between March 2019 and May 2021. The participants were selected based on their level of engagement with the platform, varying from light contributors to highly active users who frequently logged symptoms, treatments, and health outcomes. Recruitment was conducted online through open invitations on the platform, and all participants provided informed consent.

Data collection

The interviews, each lasting between 60 and 90 minutes, were conducted via video conferencing platforms due to the restrictions imposed by the COVID-19 pandemic. Interview questions focused on participants' experiences with data sharing, their perceptions of privacy, and their understanding of how their health data was used by the platform. Participants were also asked about their motivations for participating in the platform and any concerns they had about the commodification of their personal health data.

Ethical considerations

The interviews were pseudonymized to protect participants' identities, and all personal data was stored securely in accordance with GDPR regulations. Given the sensitive nature of health data, particular attention was paid to data security, both during the interviews and in the subsequent analysis.

Data analysis

The interview data were analyzed using a grounded theory approach informed by Charmaz's constructivist approach, which discusses the co-production of meaning between participants and researchers (Charmaz 2014). This involved coding the transcripts for key themes and patterns. The coding process was iterative, with themes such as empowerment, privacy concerns, and the commodification of health data emerging from the data. The literature review complemented the interview findings by contextualizing these themes within broader ethical discussions surrounding participatory health platforms. Particular attention was paid to how GDPR, and similar regulations in other regions, influence users' experiences and perceptions of privacy on these platforms.

Literature review: self-reporting and the moral economy of online health platforms

Since the 21st century, patient self-reporting, especially sharing experiential knowledge, has been promoted as a valuable resource for medical research and patient empowerment (Goetz 2008; Mahr 2017) Although often seen as new, this approach overlooks the long tradition of patients sharing experiences, historically known as anamnesis. Self-reported data has gained traction, especially in the context of 'P4-medicine'—focused on prediction, prevention, participation, and personalization (Hood 2013).

Participatory self-reporting practices, such as fitness tracking and social health networks, are key elements of a "New Social Contract for Medical Innovation" (Horne et al. 2015), suggesting that participatory data can democratize research and shift healthcare from reactive to proactive. Such data collection helps address chronic diseases by empowering patients and enhancing care quality through broader research initiatives, offering unprecedented insights into disease patterns, treatments, and prevention (Sands 2020).

The concept of moral economy - where social action is driven by shared values, ethical responsibilities and mutual expectations (Thompson 1966) - is, in my view, a central feature of participatory health platforms. In the context of online health platforms, moral economy refers to how users share data not just for personal gain, but as a contribution to the broader social good, cultivating a sense of ethical duty and collective responsibility (Tu and Gao 2021). This framing emphasizes data sharing as an altruistic act that resonates with social activism and a perceived moral obligation to advance health knowledge. However, these platforms are not entirely altruistic; commercial interests are deeply embedded. For example, platforms such as 23andMe encourage users to explore their genetic data while simultaneously building massive databases for both research and commercial purposes (Guerrini et al. 2020).

Self-reported data serves various purposes: advancing research, meeting market demands, and satisfying curiosity, raising ethical concerns about privacy, data commodification, and exploitation under the guise of empowerment (Househ et al. 2018). As self-reporting grows, it is essential to examine its societal impacts and ensure benefits are equitably distributed (Landers et al. 2024). As Lindsey Whitmore notes, participatory platforms foster encounters with the 'biological self', producing autonomy, identity, and agency, while embedding users in profit-driven data systems (Whitmore 2012). This moral economy of self-reporting reframes data sharing as both empowerment and moral obligation, appealing to users' desire to contribute to the public good while often simultaneously serving commercial goals.

Yet, questions remain about who truly benefits. Self-reporting framed as a moral duty can obscure underlying market interests and power dynamics. While these platforms blur the lines between altruism and exploitation, critically examining their ethical implications is vital to ensure the moral economy benefits all participants. Users report empowerment through sharing health information, connecting with others, and contributing to research, all of which offer significant "lifeworld-value" (Mahr 2021). The health sociologist Deborah Lupton also highlights how self-tracking and self-reporting empower users by fostering autonomy over their health data and narratives, replacing older models of compliance in healthcare (Lupton 2016).

Qualitative analysis: user perspectives on participatory health data collection

In the interviews, a recurring theme was the empowerment users felt by sharing their health experiences and data within the PatientsLikeMe community, with the concept of a moral economy (as I would describe it) emerging as a significant motivator. Many participants noted that contributing data enabled them to take an active role in managing their health, fostering a sense of agency often lacking in traditional healthcare contexts. This collective ethos aligns with Charmaz's constructivist grounded theory approach, as participants not only experienced personal empowerment but also recognized the broader social impact of their contributions in co-producing both knowledge (through the interview process) and a part of the social world itself. As one 52-year-old woman with multiple sclerosis shared, "When I log my symptoms and treatments, I feel like I'm doing something positive—not just for myself, but for others too. It's like I'm part of a collective effort to find better ways to manage this disease."

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Another participant, a 45-year-old man with Parkinson's disease, echoed this sentiment, stating, "Before PatientsLikeMe, I felt isolated and overwhelmed. But now, by sharing my experiences and seeing what others are going through, I feel less alone. It's empowering to know that my data could help someone else find a treatment that works for them." These reflections not only underscore individual empowerment but also reveal a shared moral commitment to contribute to a public good, capturing how moral economy serves as an intrinsic driver in these participatory spaces.

Patients as co-researchers in a moral economy

For many users, the role of co-researcher became a source of pride, reflecting the shift from passive recipients of care to active contributors in scientific knowledge production. This role exemplifies the grounded theory approach of theorizing based on participant experiences, and it aligns with a moral economy wherein individuals view their health data as a shared resource for advancing public health. Seventeen participants explicitly described this shift. For instance, a 39-year-old user with fibromyalgia shared, "I never thought of myself as someone who could contribute to research. But now I realize that my daily logs, my pain levels, my treatment successes and failures—they're all data that researchers can use. I'm not just a patient; I'm a part of the research process." Another participant, a 60-year-old woman with diabetes, reflected on the moral responsibility tied to this role, noting, "I feel a responsibility to be as accurate as possible with my reports because I know that this data is being used in studies. It's a powerful feeling to know that my experiences could lead to better outcomes for others."

Privacy concerns in a commodifying health landscape

Despite these positive aspects, many interviewees voiced concerns over the privacy and security of their data. This tension between personal altruism and the potential for data commodification is a fundamental aspect of moral economy on these platforms, revealing ethical challenges within the constructivist framework. Some participants feared that third-party entities, like pharmaceutical companies or insurers, might misuse their health information. A 58-year-old participant who had shared her data for over five years noted, "I love being part of this community, but I always worry about who else is seeing my data. I don't want it to end up in the wrong hands, or worse, be used against me in some way." Another participant, a 47-year-old man with a rare autoimmune disorder, expressed similar concerns: "I trust the platform, but once the data is out there, it's out there. You can't take it back, and you have no control over how it's used. That's a scary thought." These reflections highlight the moral ambiguity users navigate, as their contributions, intended for the collective good, may be exploited in ways that challenge their original altruistic intentions.

Questioning impact: critical perspectives on moral economy

Not all participants viewed their contributions as unequivocally positive, with some questioning the actual impact and effectiveness of their participation. This critical perspective aligns with Charmaz's grounded theory emphasis on emergent, data-driven theorizing and underscores the need for transparency in the moral economy of data sharing. A 50-year-old woman with chronic fatigue syndrome voiced her skepticism: "We're told that our data is helping to advance research, but I've never seen any tangible outcomes from it. I've been contributing for years, and I'm still waiting for that breakthrough that's supposed to come from all this shared information." Similarly, a 38-year-old man with epilepsy questioned the value of his participation: "I get that there's a lot of promise in what we're doing here, but sometimes it feels like we're just giving away our data with little in return. The platform benefits, the researchers benefit, but what do we get? Maybe some community support, but beyond that, I'm not sure." These insights underscore the need for greater transparency from platforms like PatientsLikeMe regarding how user data is utilized and the concrete outcomes of these contributions, reinforcing a constructivist approach grounded in participants' experiences and expectations.

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Ethical considerations: balancing contribution and privacy

The ethical dilemmas participants faced in deciding what and how much to share reveal deeper questions about the balance of contribution and privacy within a moral economy. While many users felt a strong desire to contribute to the public good, they also grappled with the risks associated with data sharing, particularly in a commercially-driven digital health landscape. A 42-year-old mother of two who uses the platform to manage her migraines noted her internal conflict: "I want to help—I really do. But every time I hit that 'share' button, I wonder if I'm doing the right thing. Am I helping others, or am I putting myself at risk?" As these ethical considerations intersect with commercial interests, some users expressed skepticism about the platforms' true motivations. One participant bluntly stated, "I know they say it's about helping people, but let's be real—it's also about making money. That's fine, but I wish they were more transparent about it." These reflections further exemplify the challenges inherent in a moral economy where personal altruism intersects with organizational profit motives.

Lifeworld-value as a driver of engagement

Despite these challenges, the concept of 'lifeworld-value'—the meaningful impact of participation on users' everyday lives—emerged as a key motivator for continued engagement. This concept reflects how moral economy transcends mere data contribution, becoming a source of personal fulfillment and a way for participants to integrate themselves within a broader social cause. A 55-year-old cancer survivor encapsulated this sentiment: "Participating in PatientsLikeMe has given me a sense of purpose. It's not just about managing my health; it's about being part of something bigger. That's priceless."

In sum, these interviews illustrate the complex interplay between empowerment, privacy, and ethical considerations in the moral economy of participatory health data sharing. While users appreciate the agency and community these platforms provide, they also confront significant concerns regarding data security and the potential exploitation of their personal information. As participatory platforms continue to evolve, addressing these concerns will be essential to ensuring that the moral economy truly benefits all participants, as underscored by the constructivist approach to grounded theory, which demands a nuanced understanding of the lived experiences and values that shape user engagement.

Discussion: navigating the ethical landscape of self-reporting in digital health

This study highlights the complex interplay between empowerment, privacy, and commercialization in participatory health platforms. As these platforms continue to evolve, they offer both significant opportunities and challenges for users, researchers, and policymakers. The findings suggest that while participatory health platforms such as PatientsLikeMe provide users with a sense of empowerment and control over their health data, they also raise important ethical concerns, particularly regarding data privacy and the commodification of personal information.

Regional differences and regulatory contexts

In the United States and United Kingdom, such platforms have flourished, largely due to less stringent data protection laws compared to Europe. In contrast, in the European Union, the GDPR imposes significant restrictions on how personal health data can be collected, stored, and used. This regulatory framework has limited the expansion of participatory platforms in Europe, where transparency and explicit consent are mandatory (Pourrez et al. 2020).

The GDPR is designed to protect individuals from the exploitation of their personal data, but it also creates a barrier for companies that seek to monetize health data under the guise of empowerment. As one participant in the study noted, "I trust the platform, but once the data is out there, it's out there. You can't take it back, and you have no control over how it's used." This sentiment underscores the tension between the promise of democratizing health research and the risk of data commodification.

In regions like Asia, where health data platforms are rapidly emerging, the regulatory environment is still evolving. Ethical issues around data privacy and commercialization are less clearly defined, making it crucial for future research to examine how these platforms operate in different cultural and regulatory contexts (Marin 2017). The current study shows that the ethical challenges of participatory platforms are not confined to any single region but are global in scope, demanding a nuanced understanding of regional laws, cultural attitudes, and market dynamics.

Empowerment versus exploitation

One of the central findings of this study is the dual role of participatory platforms in both empowering users and exposing them to potential exploitation. On the one hand, users of platforms like PatientsLikeMe expressed a sense of agency in contributing to scientific research and sharing their health experiences with others. This aligns with broader trends in healthcare that emphasize patient engagement and the active role of individuals in managing their health. However, the study also reveals significant concerns about the extent to which these platforms benefit users versus corporations.

For example, while users were generally positive about their ability to share data and connect with others, many participants questioned the ultimate outcomes of their contributions. As one participant with chronic fatigue syndrome put it, "We're told that our data is helping to advance research, but I've never seen any tangible outcomes from it." This critical perspective suggests that while platforms may market themselves as tools of empowerment, the true beneficiaries may be the companies and researchers who profit from user data.

The moral economy of self-reporting

The concept of a 'moral economy' of self-reporting emerged as a key theme in this study. Participatory platforms often frame data sharing as a moral obligation, appealing to users' altruism and desire to contribute to the public good. This framing can obscure the commercial interests of the platforms, which profit from the data users provide. The moral economy thus functions as a tool for legitimizing the commodification of health data while downplaying the risks of exploitation.

From a TA perspective, this raises important questions about the ethical frameworks governing these platforms. Current regulations, such as the GDPR, attempt to strike a balance between innovation and protection, but they may not be sufficient to address the growing commercialization of personal health data. As participatory health platforms continue to evolve, there is a pressing need for new ethical guidelines that can ensure that the benefits of data sharing are equitably distributed and that users' rights are protected.

> *Current regulations attempt to strike a balance between innovation and protection, but they may not be sufficient to address the growing commercialization of personal health data.*

Broadening the scope of participatory health platforms

In addition to PatientsLikeMe and 23andMe, the DiPEX (Database of Individual Patient Experiences) project represents another valuable example of participatory health platforms. DiPEX systematically collects and disseminates patient experiences with a range of health conditions, such as Alzheimer's disease and multiple sclerosis. Founded as part of an international network, DiPEX aims to enhance patient-centered care by making patient narratives freely available to the public, healthcare providers, and researchers. The platform not only collects patient stories but also contextualizes them with evidence-based resources, making it a valuable educational tool for healthcare professionals and an important resource for patients navigating similar conditions (A cura della redazione 2013; Mackey et al. 2014).

Unlike 23andMe, which primarily gathers genetic data for both personal exploration and scientific research, DiPEX emphasizes the qualitative richness of personal stories and aims to foster greater understanding of patient experiences. Moreover, DiPEX operates under strict ethical guidelines, reflecting a similar regulatory adherence to the GDPR in Europe, particularly concerning patient consent and privacy, which contrasts with the commercial models of data utilization seen in U.S.-based platforms like 23andMe.

The global landscape of participatory platforms is shaped by different regulatory environments, such as the GDPR in Europe, which offers strong protections for personal data. However, in other regions, the lack of robust data protection laws creates greater risks for users. This highlights the need for a more global approach to data governance, one that can adapt to the diverse regulatory and cultural contexts in which these platforms operate.

From a TA perspective, the rise of participatory health platforms presents both opportunities and challenges. TA must evolve to address the ethical and societal implications of these platforms, ensuring that they contribute positively to healthcare innovation while safeguarding users' rights. This will require new ethical frameworks and regulatory policies that can keep pace with the rapid evolution of digital health technologies (Petrakaki et al. 2021).

In conclusion, while participatory health platforms offer exciting possibilities for the future of healthcare, their success will ultimately depend on how well we navigate the ethical, legal, and societal challenges they present. By fostering a balanced approach to innovation and regulation, we can ensure that these platforms empower users without compromising their privacy or autonomy.

Technology assessment must evolve to address the ethical and societal implications of these platforms.

The role of technology assessment

The findings of this study have significant implications for TA, particularly in the context of participatory health platforms. TA must navigate the complex intersection of innovation, regulation, and public trust. The rise of these platforms presents both opportunities and challenges for TA practitioners. On the one hand, participatory platforms can democratize research by giving users a voice in health innovation. On the other hand, the commercialization of health data raises concerns about exploitation and the erosion of privacy.

TA must evolve to address these challenges. First, it must ensure that privacy and data security are prioritized, particularly in regions with less robust regulatory frameworks. Second, TA should evaluate the long-term societal impacts of these platforms, focusing on how they shape patient engagement, health outcomes, and access to care. Third, TA should consider the global implications of participatory platforms, recognizing that ethical concerns and regulatory responses will vary across regions. This requires a flexible and context-specific approach to TA, one that considers the diverse cultural and legal landscapes in which these platforms operate.

Conclusion

This study critically examined the dynamics of participatory health platforms, focusing on the ethical, social, and economic challenges they present. While these platforms hold significant potential to empower users and democratize health research, they also raise serious concerns about privacy, data commodification, and the balance between public good and corporate profit.

Participatory platforms, such as PatientsLikeMe and 23andMe, exemplify the dual nature of self-reporting in healthcare. On the one hand, they offer users a sense of agency and inclusion in scientific research, but on the other, they expose users to potential exploitation, particularly in the context of data commercialization. The moral economy of self-reporting encourages users to share their health data as a social good, but it often masks the commercial interests that drive these platforms.

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Research data

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