

My Data, My Body, My Rights

An initiative to protect and promote data rights in the use of digital technology for sexual and reproductive health.

Problem Statement

Digital health¹ is transforming our daily lives. In high income countries, and increasingly in low- and middle-income countries (LMICs) more people are turning to search engines, apps, social media, telehealth, chatbots, wearables, and more to obtain health information, practice self-care, and access health services. When designed, deployed, and regulated in the right way, these digital health interventions hold promise to positively impact health outcomes.

However, to access and use these increasingly ubiquitous technologies, we are required to check away access to our data about our bodies, which is being shared, bought, and sold – without transparency, adequate regulation, or full understanding of where it ends up and for what purpose. This jeopardizes our basic human rights – namely the rights to bodily autonomy, security, and safety.

The stakes for those using digital technology for sexual and reproductive health² are particularly high both in terms of benefits and risks. This is due to the complex social and power dynamics inherent in this highly sensitive and stigmatized subject area. LGBTQIA+ people face additional challenges and hostilities in accessing SRH care and legal protections³ and thus may be more likely to experience similar abuse with regards to their health data rights.

Examples of SRH data rights violations abound - from law enforcement in [Nebraska](#) and [Idaho](#) using data as a form of evidence to prosecute women for having an abortion, to a suite of [fertility and pregnancy apps](#) misleading consumers and selling/ sharing their personal data, to girls in Kenya being targeted with ineffective contraception after using a menstruation App⁴.

Our legal systems and institutions are struggling to keep pace with this technology. While the field of academia is playing an important role in theorizing potential harms, and risk mitigation strategies, there is an urgent need for the many stakeholders at the intersection of this work to

¹ <https://www.fda.gov/medical-devices/digital-health-center-excellence/what-digital-health>

² <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6927830/>

³ <https://www.unfpa.org/equality-dignity-and-rights-lgbtqia-people>

⁴ Example from conference “The Personal is Political: Re-imagining Data Governance in the context of Digital Health” March 8, 2023 <https://www.genderhealthhub.org/articles/the-personal-is-political-re-imagining-data-governance-in-the-context-of-digital-health/>

develop co-created policy-level recommendations and pathways to action to balance the potential benefits and consequences.

It is unconscionable that we must trade away our right to bodily autonomy to access basic health information and services. How we – collectively and individually – respond to these challenges determines whether digital health interventions can have a positive impact without compromising basic principles of health as a human right.⁵

Hypothesis

As the line between our physical and digital selves becomes increasingly blurry, sexual and reproductive data rights must be safeguarded as a key lever of bodily autonomy and gender equality.

Solution Approach

There is an urgent need to protect our right to bodily autonomy when accessing basic health information and services through technology.

Kati Collective and Panorama propose to bring stakeholders together at the intersection of this issue to respond to these challenges through policy and action that ensures digital sexual and reproductive health interventions provide promised benefits without compromising basic principles of health and bodily autonomy as human rights.

Protecting rights to bodily autonomy when accessing health services digitally will take diverse partners across sectors working together. For the field to reach the next level of action, it will need an infusion of more robust public and private funding, increased awareness, recognition and elevation as a global priority.

We intend to engage in a two-year process with the goal of developing a global framework and standards for sexual and reproductive health data rights using a process that builds a coalition of diverse partners poised to engage in policy advocacy rather than creating a new entity.

Proposed activities include conducting a landscape analysis to understand SRH and data privacy policy frameworks and standards, learning directly from lived experience experts through key informant interviews, enabling cross-sector strategy development and knowledge sharing and elevating the issue with different key audiences.

After the initial literature review and landscape analysis, we aim to co-create and galvanize a global coalition of multi-sectoral stakeholders to develop a strategic set of guidelines for digital health rights. This coalition will include lived experience experts, technology companies, policymakers, health service providers, medical community researchers, service users, SRH organizations, and data privacy rights organizations. The purpose of this interactive coalition

⁵ [https://www.who.int/news-room/fact-sheets/detail/human-rights-and-health#:~:text=The%20WHO%20Constitution%20\(1946\)%20envisages,acceptable%2C%20and%20affordable%20health%20care.](https://www.who.int/news-room/fact-sheets/detail/human-rights-and-health#:~:text=The%20WHO%20Constitution%20(1946)%20envisages,acceptable%2C%20and%20affordable%20health%20care.)

will be to mobilize, invigorate, and accelerate the field's impact and action toward ensuring sexual and reproductive health data privacy.

About Our Partnership

Kati Collective and Panorama have joined forces to tackle this significant problem together. Each organization brings to the table unique but complementary skills, relationships, networks, structures, and approaches to building a lasting solution.

Kati Collective is a global consulting collaborative focused on understanding, analyzing, and advancing equity. For this initiative, Kati will leverage robust existing relationships across the digital SRH ecosystem (including with tech industry leaders, international NGOs, ministries of health, and more) and first-hand experience working with digital SRH at scale. Additionally, the Kati team has comprehensive experience in successfully creating and managing large global learning communities/ communities of practice across digital and health.

Panorama is a social impact nonprofit that empowers changemakers through radical collaboration. Panorama adds extensive expertise in building platforms for collaboration within and across issues and sectors to maximize collective impact on pressing global challenges. Recently, Panorama launched the Image-Based Sexual Abuse Initiative supports a platform for coordination, collaboration, and convening amongst lived experience experts, direct service providers, advocates, non-governmental organizations, academics, tech companies, law enforcement agencies, and other stakeholders working to combat the nonconsensual creation and distribution of intimate imagery.

Please get in touch with us!

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