Principles and components of digital health policy processes

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Access

Enabling more young women and queer persons to enjoy universal, acceptable, affordable, unconditional, open, meaningful and equal access to digital health platforms

Information

Supporting and protecting unrestricted access to information relevant to young people including young women and queer persons, particularly information on sexual and reproductive health and rights, pleasure, safe abortion, access to justice, and LGBTIQ issues. This includes diversity in languages, abilities, interests and contexts
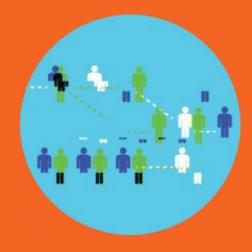
Usage

Young people in all their diversity have the right to code, design, adapt and critically and sustainably use and reclaim technology as a platform for digital health, as well as to challenge the cultures of ageism, sexism and discrimination in all digital health related policy spaces

Consent

Calling on the need to build an ethics and politics of consent into the culture, design, policies and terms of service of digital health platforms. Young people's health and well-being agency lies in their ability to make informed decisions on what aspects of their health to share and discuss online

Governance

We believe in challenging the patriarchal spaces and processes that control health data governance, as well as putting more feminists and queers at the decision-making tables. We want to democratise policy making affecting health and digital health processes (including internet governance and SRHR) as well as diffuse ownership of and power in global and local networks

Privacy & data

We support the right to privacy and to full control over sensitive and personal health data and information online at all levels. We reject practices by states and private companies to use data for profit and to manipulate behaviour online. Surveillance is the historical tool of patriarchy, used to control and restrict young women's bodies and health choices. We pay equal attention to surveillance practices by individuals, the private sector, the state and non-state actors

Anonymity

We defend the right to be anonymous and reject all claims to restrict anonymity online, particularly with regards to health records and personal health decisions. Anonymity enables our freedom of expression online, especially when it comes to breaking taboos of sexuality and heteronormativity, experimenting with gender identity, and enabling safety for women and queer persons affected by discrimination

Violence

We call on all stakeholders, including users, health providers, policy makers and the private sector, to address the issue of health related online harassment: the attacks, threats, intimidation and policing experienced by young women and queers are real, harmful and alarming, and are part of the broader issue of gender-based violence. It is our collective responsibility to address this through digital health policy processes

Implications and ethical issues in digital health: the case of SRHR

1.Data oligarchs are impinging on reproductive privacy

Health data is highly sensitive private information. Yet, it is still regarded as an outstanding case in data governance[4] because it requires legislation that is specific to the health sector, thus leading to a fragmented regulatory framework where health data is shared, sold, and interfered with by commercials and government alike. As health data apps have become ubiquitous and even strongly encouraged to harness the advent of telemedicine and virtual access to health services, a massive data broker industry surged using secret algorithms that can easily profile user's health status and undermine their decisional and reproductive privacy [5].

2. The uptake of digital health technology is not addressing gender digital divides

The global Covid-19 crisis taught the world how to overcome disruptions in healthcare services caused by mobility restrictions which led to the accelerated uptake of digital health technology and related interventions. Little the world knew this shift needed to happen within an environment that is concerned with the existing and widespread inequality in access, use and engagement with digital technologies [6] whereby women are excluded mainly and put at further risk of exposure to harmful practices such as overriding consent, privacy violations, online gender-based violence. The development of digital health technology is not a stand-alone process; for that, it must take shape and meaning in a context that addresses the barriers preventing two billion women [7] from the digital revolution.

3. The digital surveillance of abortion-seekers is a state watchdog in the making

The digital surveillance of vulnerable groups, including abortion seekers, is no old news; however, the implications are more harrowing considering the use of forensic tools by police and non-state actors that can efficiently turn medical staff and pregnant providers into criminal investigators without prior consent [8]. The Surveillance Technology Oversight Project released a white paper that corroborates cases where law enforcement workers used geofence to obtain search histories from pregnant women's devices without a warrant. The police and prosecutors used the records to charge potential abortion seekers with second-degree murder following a miscarriage. In a post-Roe era, the deployment of digital surveillance techniques to track and cast queries about miscarriages, including benign medical questions, can eventually lead to an arrest through deliberate tactics to harass pregnant women and chill their exercise of reproductive rights.

4. Innovation is way ahead the reproductive justice movement

While the tech motto "move fast and break things" [9] is driving innovative solutions at an unprecedented pace, the reproductive justice movement (a.k.a; networks and constituencies working on broader sexual reproductive health and rights (SRHR)) is slowly getting the hang of tech savviness. Moving fast often comes at the compromised cost of ethics and safety, which contradicts the "do-no-harm" guiding principle of reproductive justice. For both parties to find common ground, it is essential to acknowledge the power dynamics that are playing out. The innovation hubris cannot keep on assuming it knows best; it must carefully start listening to survivors and users to understand and respond to their needs.

5. The apparatus of reproductive ad censorship is sprawling on social media platforms

In October 2022, META amended its sexual health advertising policies to include ads that promote sexual health, wellness and reproductive products and services, ensuring the Center for Intimacy Justice (CIJ)'s investigative report and advocacy to change META's systemic rejections of women's health advertisements[10]. Among others, the report shed light on cases where META allowed health ads about male pleasure when it systematically rejected ads on products addressing the effects of menopause or pain relief during sex. The apparatus of reproductive ad censorship is not happening in a vacuum; it is sprawling in a setting of gender-biased, sexualised and out-of-context algorithmic processes, moderation training and overall content governance.

Our health, our devices, our choices

Inclusive, equitable and diverse digital health policy processes can not only amplify opportunities for young people including young women and queers to reclaim technology for their bodily autonomy. It also offers a pathway to address intimidation, suppression, and surveillance both offline and online and promote greater gender equality and reproductive justice