DISCUSSION PAPER

Information Asymmetries in the Digital Sexual and Reproductive Health Space

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Contents

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INTRODUCTION

The proliferation of digital technologies in the health care context has important implications for fulfilment of the health-related Sustainable Development Goals ('SDGs'). This is particularly evident when it comes to the SDG targets relating to sexual and reproductive health ('SRH').[1] Technological developments offer an opportunity to expand the availability and accessibility of sexual and reproductive health services, especially for those populations that traditional health systems fail to reach. Digital technologies in the form of smartphone applications ('apps'), social media websites and other online platforms offer an important source of information about SRH for people living in communities where such topics remain taboo.[2] Access to accurate information is a key determinant of sexual and reproductive health. Indeed, SDG target 3.7 makes explicit reference to ensuring universal access to SRH information and education.[3] Platforms that provide information on topics like menstruation, contraception and HIV have enormous potential in contexts where social and cultural norms preclude open discussion of these issues, and may be especially useful for people who do not feel comfortable disclosing certain health issues to in-person providers for fear of being stigmatized.

While digital technologies have the potential to subvert traditional knowledge asymmetries between clinicians and patients in the health sector, information disparities between technology providers and the general user population impede meaningful access to the digital

COVID-19 is reshaping the way in which people access SRH services and information.[4] The pandemic has underscored the transformative potential of digital technologies in improving public health initiatives, yet it also raises a number of rights-based issues regarding equitable use of and access to such technologies. Chief amongst these is the power imbalance produced by information asymmetries between technology providers and users regarding how these technologies generate and disseminate content, collect, store and reuse personal data, and deploy algorithms to provide health advice and diagnoses. The aim of this paper is to make international organizations, including UN agencies and other stakeholders involved in the implementation of digital health strategies, aware of the ethical and human rights risks relating to information asymmetries in the context of digital technologies and SRH.

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[1] The key SDG targets that explicitly address sexual and reproductive health include SDG 3.7 ("By 2030, ensure universal access to sexual and reproductive health-care services, including for family planning, information and education, and the integration of reproductive health into national strategies and programmes") and SDG 5.6 ("Ensure universal access to sexual and reproductive health and reproductive rights as agreed in accordance with the Programme of Action of the International Conference on Population and Development and the Beijing Platform for Action and the outcome documents of their review conferences"); noting that other targets, such as SDG 3.3 ("By 2030, end the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases"), also fall within the sphere of sexual and reproductive health.

[2] *See* GIRL EFFECTS & WOMEN DELIVER, GOING ONLINE FOR SEXUAL AND REPRODUCTIVE HEALTH: MEANINGFULLY ENGAGING ADOLESCENT GIRLS AND YOUNG WOMEN FOR SMARTER DIGITAL INTERVENTIONS 12-15 (2020), https://womendeliver.org/wp-content/uploads/2020/08/Going-Online-for-Sexual-and-Reproductive-Health.pdf.

[3] U.N. DEPARTMENT OF ECONOMIC AND SOCIAL AFFAIRS, SUSTAINABLE DEVELOPMENT: GOAL 3, https://sdgs.un.org/goals/goal3 (last visited Jan. 18, 2021).

[4] Laura D. Lindberg et al., *Early Impacts of the COVID-19 Pandemic: Findings from the 2020 Guttmacher Survey of Reproductive Health Experiences*, GUTTMACHER INSTITUTE (Jun. 2020), https://www.guttmacher.org/report/early-impacts-covid-19-pandemic-findings-2020-guttmacher-survey-reproductive-health.

This paper embraces an understanding of the health system as a 'knowledge economy', in which physicians and other health care professionals serve as gatekeepers who exist to make available medical expertise to patients.[5] The discussion will primarily focus on digital technologies in the form of existing online platforms like Facebook, Twitter, Whatsapp and Google, which are increasingly becoming important sources of SRH information,[6] as well as SRH apps developed for smart phones. These platforms allow users to act as 'apomediators' in the digital health knowledge economy, facilitating the sharing and dissemination of SRH information on a broader scale.[7] They also give rise to some of the more egregious information asymmetry risks because they are often developed and operated by private entities with their own commercial interests and incentives. Given the global reach of these technologies, the scope of this paper is not limited to a specific set of countries, but it does focus on lower and middle-income countries ('LMICs') because they often have pluralistic health care systems in which participants are more heavily reliant on alternative sources of health information[8] and where the risks posed by information asymmetries may be higher because of lower digital literacy levels and inadequate health and technological infrastructure.

This paper argues that, while digital technologies have the potential to subvert traditional knowledge asymmetries between clinicians and patients in the health sector, information disparities between technology providers and the general user population impede meaningful access to the digital health knowledge economy. This undermines the proper enjoyment of sexual and reproductive rights, which is necessary for attainment of the SDGs. In support of this argument, it makes the following claims: (1) in the digital era, technology providers function as gatekeepers of crucial SRH information. This poses a threat to sexual and reproductive rights because technology providers are not commercially incentivized to slow the spread of inaccurate health information. These platforms also withhold important educational content that is arbitrarily classified as sexually explicit; (2) the inscrutability of algorithms underlying digital technologies means that users do not understand how their data is used and processed to generate SRH-related content and advice; and (3) the illusion of algorithmic authority places technology providers and developers in a position to dictate norms surrounding SRH in a way that is opaque to users. The paper concludes by making recommendations as to how information asymmetries may be addressed by international organizations to better support the SRH-related SDGs in a manner that conforms to international human rights and ethical principles.

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[5] Gerald Bloom et al., *ICTs and the Challenge of Health System Transition in Low and Middle-Income Countries,* 13 GLOBALIZATION & HEALTH 1, 2 (2017).

[6] *See eg,* Linda Waldman et al., *'We Have the Internet in Our Hands': Bangladeshi College Students' Use of ICTs for Health Information*, 14 GLOBALIZATION & HEALTH 1, 7 (2018); Constanze Pfeiffer et al., *The Use of Social Media Among Adolescents in Dar es Salaam and Mtwara, Tanzania*, 22 REPROD. HEALTH MATTERS 178, 182-84 (2014); GIRL EFFECTS & WOMEN DELIVER, GOING ONLINE FOR SEXUAL AND REPRODUCTIVE HEALTH: MEANINGFULLY ENGAGING ADOLESCENT GIRLS AND YOUNG WOMEN FOR SMARTER DIGITAL INTERVENTIONS 12-15 (2020), https://womendeliver.org/wp-content/uploads/2020/08/Going-Online-for-Sexual-and-Reproductive-Health.pdf.

[7] Gunther Eysenbach, *Credibility of Health Information and Digital Media: New Perspectives and Implications for Youth*, *in* DIGITAL MEDIA, YOUTH AND CREDIBILITY 123, 129-130 (Miriam J. Metzger & J. Flanagin eds., 2008).

[8] Gerald Bloom et al., *ICTs and the Challenge of Health System Transition in Low and Middle-Income Countries,* 13 GLOBALIZATION & HEALTH 1, 3 (2017).

A Rights-Based Approach to Sexual and Reproductive Health

The discourse surrounding the relationship between SRH, human rights and sustainable development has evolved significantly over the last few decades. The 1994 International Conference on Population Development ('ICPD') Programme of Action marked a monumental paradigm shift in the way that the international community thought about SRH.[9] It was the first time that reproductive rights were acknowledged as an integral part of the international human rights framework.[10] Access to family planning services, for instance, was treated as a means of empowering women to take control of their own reproduction instead of as a population control issue.[11] The Beijing Platform for Action, adopted the following year, sought to afford greater attention to sexual health and rights.[12] Since then, advocates have sought to realize a more expansive sexual and reproductive health and rights agenda, which was reflected in the efforts of advocates in the lead up to the adoption of the SDGs.[13] Unlike the Millennium Development Goals ('MDGs'), the SDGs capture a broader understanding of SRH, veering away from a much narrower focus on maternal mortality.[14] International human rights are 'embedded in the architecture of the SDGs'[15] and SRH-related rights permeate the various targets and indicators.[16] Goals 3 and 6 contain targets that explicitly refer to SRH but, because the SDGs are intended to be read as 'integrated and indivisible',[17] improving SRH globally necessarily entails initiatives that touch on multiple goals and targets.

This paper takes up the integrated, comprehensive definition of SRH originally proposed by the Guttmacher-*Lancet* Commission[18] and adopted by the United Nations Population Fund,[19] which conceives of good sexual and reproductive health as a 'state of complete physical, mental and social well-being in all matters relating to sexuality and the reproductive system'.[20] This includes the right to autonomy in SRH decision-making and to a safe and satisfying sex life.[21] The control that technology providers exert over a user's informational environment and the impenetrability of algorithmic processes underlying the production of SRH information create information asymmetries that inhibit the proper enjoyment of sexual and reproductive health and rights. They do so by undermining the ability of individuals and communities to make full and informed decisions regarding sex and reproduction and shaping the context in which those decisions are made.

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[9] UNFPA, Sexual and Reproductive Health and Rights: An Essential Element of Universal Health Coverage, Background Document for the Nairobi Summit on ICPD25 – Accelerating the Promise 15 (Nov. 2019), https://www.unfpa.org/sites/default/files/pub-pdf/SRHR_an_essential_element_of_UHC_2020_online.pdf.

[10] *Id.*

[11] *Id.*

[12] *See* U.N. Women, Beijing Declaration and Platform for Action: Beijing +5 Political Declaration and Outcome (2014), https://beijing20.unwomen.org/~/media/headquarters/attachments/sections/csw/pfa_e_final_web.pdf#page=61.

[13] Alicia Ely Yamin, *Power, Politics and Knowledge Claims: Sexual and Reproductive Health and Rights in the SDG Era,* 10 GLOBAL POL'Y 52, 54-55 (2019).

[14] *Id.* at 52.

[15] *Id.* at 55.

[16] *Id.*

[17] *Id.*

[18] Ann M. Starrs, *Accelerate Progress – Sexual and Reproductive Health and Rights For All: Report of the Guttmacher-Lancet Commission*, 391 THE LANCET 2642 (2018).

[19] UNFPA, Sexual and Reproductive Health and Rights: An Essential Element of Universal Health Coverage, Background Document for the Nairobi Summit on ICPD25 – Accelerating the Promise 8 (Nov. 2019), https://www.unfpa.org/sites/default/files/pub-pdf/SRHR_an_essential_element_of_UHC_2020_online.pdf.

[20] *Id.*

[21] *Id.*

Information asymmetries in the digital SRH sphere also implicate a number of other human rights. The quality of SRH information available on digital platforms impacts both the right to health and the right to freedom of expression,[22] while, the collection and use (or misuse) of personal data affects the right to privacy, the right to informational self-determination and, in cases where sensitive SRH data is shared, the right to non-discrimination. These rights are overlapping and multifaceted. To fully understand the threat that knowledge disparities pose to individual rights, we must consider a more expansive understanding of the content of these rights. The right to an adequate standard of health, for example, which is provided for in a number of international instruments such as the Universal Declaration of Human Rights, Article 25 and International Covenant on Economic, Social & Cultural Rights, Article 12, extends beyond the right to access health care to include some of the underlying determinants of health i.e., health-related education and information.[23] The conversation about the right to health also now includes questions regarding the extent to which people have the right to understand the underlying technologies used to provide health information and advice.[24] Freedom of expression includes the right to receive and impart information[25] and is guaranteed by the exchange of reliable information and ideas based on factual truths.[26] Disseminating misinformation or withholding information undermines this right by impeding the ability of individuals' to understand their informational environment.[27] The right to privacy and reproductive autonomy are frequently linked, especially in countries like the United States where the right to privacy serves as the constitutional foundation of reproductive rights. It also arises, albeit in a different form, in respect of digital technologies due to the vast troves of personal data collected and stored by different technologies.

It is difficult to fully grasp the potential cost of information asymmetries from a human rights perspective when focusing only on *individual* rights. Information asymmetries in the digital health space also risk undermining collective societal values (i.e., participatory democracy) that form the foundations of the international human rights regime.[28] As Karen Yeung argues, existing human rights language may be inadequate to capture the risks posed by technologies.[29] Firstly, because it is difficult to identify with any certainty the individual rights that are being violated when users do not understand how these technologies work.[30] And secondly, because information and power asymmetries in relation to complex technologies pose a threat to the 'broader and more amorphous moral, social and political culture and context in which advanced digital technologies operate'.[31] The

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[22] Karen Yeung, *A Study of the Implications of Advanced Digital Technologies (including AI Systems) for the Concept of Responsibility Within a Human Rights Framework*, MSI-AUT (2018) 05, 24 (Nov. 9, 2018), https://ssrn.com/abstract=3286027.

[23] WHO & OHCHR, The Right to Health: Factsheet No. 31, 3 https://www.ohchr.org/documents/publications/factsheet31.pdf.

[24] Matthew Fenech et al., Ethical, Social, and Political Challenges of Artificial Intelligence in Health, Future Advocacy 44 (2018), https://wellcome.org/sites/default/files/ai-in-health-ethical-social-political-challenges.pdf.

[25] Karen Yeung, *A Study of the Implications of Advanced Digital Technologies (including AI Systems) for the Concept of Responsibility Within a Human Rights Framework*, MSI-AUT (2018) 05, 24 (Nov. 9, 2018), https://ssrn.com/abstract=3286027.

[26] Forum on Information & Democracy, Working Group on Infodemics: Policy Framework 122-23 (Nov. 2020), https://informationdemocracy.org/wp-content/uploads/2020/11/ForumID_Report-on-infodemics_101120.pdf.

[27] *Id.*

[28] Karen Yeung, *A Study of the Implications of Advanced Digital Technologies (including AI Systems) for the Concept of Responsibility Within a Human Rights Framework*, MSI-AUT (2018) 05, 36 (Nov. 9, 2018), https://ssrn.com/abstract=3286027.

[29] *Id.*

[30] *Id.*

[31] *Id.*

potential dangers presented by digital technologies extend beyond infringing individual rights to molding the societal conditions under which individuals seek SRH information, advice and care. Thus, a rights-based discourse regarding information asymmetries and digital health must also consider the 'collective, aggregate and cumulative' risks that digital technologies may present.[32]

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[32] *Id.*

SRH and the Digital Health Knowledge Economy

The health care sector is characterized by vast knowledge disparities between clinical professionals and patients.[33] This is the case in many different industries involving service provision but is particularly consequential in the health care context due to the vital interests at stake. Gerald Bloom and colleagues argue that conceptualizing the health sector as a 'knowledge economy' provides a useful framework for understanding the formal and informal channels through which healthcare is provided, particularly in pluralistic health systems which are characteristic of many LMICs.[34] In a pluralistic health system, there are many different providers of health care that operate alongside the official health sector and individuals assume more responsibility for their own health.[35] Facilitating access to SRH in these countries is thus more heavily dependent on alternative sources of information and health services.[36] The health knowledge economy framing also emphasizes a multidimensional understanding of SRH as it embraces forms of health-related activities that fall outside the traditional bounds of disease diagnosis and determining the absence of infirmity and dysfunction.[37]

In the traditional health knowledge economy, clinical experts act as gatekeepers who control access to information and expertise about medicine and other forms of health care.[38] SRH presents a special case as there are many socio-cultural barriers that stand in the way of access to SRH-related information and care and a greater variety of actors that engage in gatekeeping practices, including teachers, community leaders and family members.[39] This is particularly true for adolescents in LMICs who shoulder the greatest SRH burden.[40] Digital technologies have the potential to subvert traditional information asymmetries in the SRH context by empowering individuals to take control of their own sexual and reproductive health through providing a forum in which to share SRH information and educational materials in a less hierarchical fashion. This is a process referred to as 'disintermediation'.[41] Digital platforms help transform users into 'apomediaries' who 'stand alongside' their peers, enabling peer-to-peer sharing of SRH content while preserving the autonomy and agency of individuals seeking health information.[42]

Digital platforms like Facebook, Twitter, Whatsapp, Google and Youtube are increasingly being used as sources of SRH information in countries where socio-cultural norms preclude open discussion of topics like contraception, menstruation and