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Can digital health democratize health care?

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Abstract

Much has been said about the potential of digital health technologies for democratizing health care. But how exactly is democratization with digital health technologies conceptualized and what does it involve? We investigate debates on the democratization of health care with digital health and identify that democratization is being envisioned as a matter of access to health information, health care, and patient empowerment. However, taking a closer look at the growing pool of empirical data on digital health, we argue that these technologies come short of materializing these goals, given the unequal health outcomes they facilitate. Building on this evidence, we argue that not only debates on democratization need to be connected to concerns of social determinants of health but also debates on the impact of digital health need to go far beyond democratization and engage with concerns of health justice.

KEYWORDS

decolonial justice, democratization, digital health, health justice, mHealth

1 | INTRODUCTION

Over the last decade, there has been much hype about digital health technologies and their potential to positively transform health care. According to the *Global Strategy on Digital Health 2020–2025* report of the World Health Organization (WHO), the utilization of digital health solutions "can revolutionize how people worldwide achieve higher standards of health and access services to promote and protect their health and well-being." The WHO holds that globally, digital health can assist both patients and health professionals in creating more evidence-based knowledge, therapeutics, decision-making, and self-management. Similar hopes are shared by the European Commission, which holds that

"person-centred approaches" to health and care can enable "citizens to assume responsibility for their health, improve their well-being and the quality of care, and contribute to sustainable health systems."

The high hopes regarding the positive impact of digital health have been echoed by advocates for the democratization of health care with digital health technologies. According to Wiederhold, a psychologist and director at the Virtual Reality Medical Centre, "we are on the leading edge of another revolution in health care, brought to you by the patient herself as she uses her phone for self-tracking." This notion of digital health as a revolutionary and democratizing health care through data-driven technology is strongly linked with the centering and empowering of the patient in the healthcare system. For example, Melanie Swan, 4 a technology

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¹World Health Organisation. (2021). Global strategy on digital health 2020–2025. https://apps.who.int/iris/bitstream/handle/10665/344249/9789240020924-eng.pdf

²Council of European Commission. (2018, n.p.). Communication from the commission to the European Parliament, the Council, the European Economic and Social committee and the Committee of the Regions on enabling the digital transformation of health and care in the Digital Single Market; empowering citizens and building a healthier society. https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=COM%3A2018%3A233%3AFIN

³Wiederhold B. K. (2012). Self-tracking: Better medicine through pattern recognition. Cyberpsychology, Behavior and Social Networking, 15(5), 235–236.

⁴Swan, M. (2012). Health 2050: The realization of personalized medicine through crowdsourcing, the quantified self, and the participatory biocitizen. *Journal of Personalized Medicine*, 2(3), 93–118.

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theorist, welcomes mobile health technologies,⁵ as an avenue to "institutional recasting" of health care from physician-facilitated to "consumer" centered, personalized, and participatory. She elaborates⁶ that "preventive medicine is inherently democratized with the individual as the center of action-taking with free or cheaply available mobile phone applications, online personal health records, and other increasingly inexpensive or sponsored self-tracking and monitoring solutions." The discourse of democratization through digital health celebrates these technologies as novel tools for ordinary people to gain control over their health.

Meanwhile, a growing pool of bioethics literature on responsible, socially sustainable, equitable and just innovation has emphasized that, to support health and well-being, health interventions and technologies need to fulfill a range of criteria that pertain to the safety, efficacy, and beneficence of health innovation. These criteria are important as they relate to the very credibility of health technologies as legible innovation with clinically substantiated potential for improving health. We believe that the research critically engaging with the criteria of health innovation is immensely relevant to debates on democratization, as it is crucial to investigate the quality of the technology and health services mediated by digital health technologies as part of the testing and proving of their potential for democratizing health care.

Scholars who have worked on socially sustainable health innovation have argued that all innovation pertaining to health and health care needs to provide health benefits, understood as ensuring of a reasonable likelihood of providing good health outcomes. Building on this literature, it can be extrapolated that digital health, which is to democratize healthcare, ought to not only ensure a reasonable likelihood of good and equitable health outcomes in individual users but also do so across diverse user populations within the target group, including on societal and global levels (whenever technology is used globally). Without ensuring this, the technology will fail to be inclusive, egalitarian and come short of delivering clinically appropriate and just health services to all.

Many scholars who have worked on concerns of health equity and justice have emphasized that to support these aims, health technologies and interventions need to be grounded in evidencebased clinical studies and data relevant to the specific bodies and health needs of all different population groups within the target population. The emphasis on intersectionality and just health outcomes builds on decades of scholarship that has engaged with the empirical evidence that historically, much of research, medicine and health care has treated the white western cisgender male body as the norm, and this legacy is ongoing and still shapes today's medical knowledge. 10 In light of this, it is crucial for digital health to provide safe, intersectionally relevant, efficacious and beneficent diagnostic information and health guidance to all users, as this is a prerequisite for ensuring equitable health benefits through digital health technologies. 11 Moreover, the need to work with heterogenous and debiased data sets is especially key in digital health as evidence has shown that automation magnifies inequalities owing to algorithmic oppression and discrimination. 12

Ensuring nondiscrimination and intersectional health benefits is crucial in the context of democratization as it would be difficult to conceive of digital health as a pathway to democratizing health, should digital health technologies not offer relevant and optimal health care to all. The notion of democratizing health care with a technology that would be irrelevant, not beneficent or even harmful to the health of some population groups would seem rather troubling. Such a case would also make little sense in terms of user empowerment as it is difficult to conceive of health technologies with discriminatory and harmful potential that could have a widely empowering impact. Building on the literature on viable health innovation. 13 we take it that the idea of patient empowerment through digital health is substantially connected to a reasonable likelihood of a health benefit from these technologies, as it is hard to imagine how technologies without such likelihood could meaningfully support patient decision-making or viable health management. As

⁵mHealth is a segment of digital health, involving a broad range of technologies, such as health information technology (IT), wearable devices, telehealth and telemedicine, and personalized medicine. Food and Drug Administration. (2020). What is Digital Health? https://www.fda.gov/medical-devices/digital-health-center-excellence/what-digital-health; According to the WHO, "Digital health expands the concept of eHealth to include digital consumers, with a wider range of smart-devices and connected equipment. It also encompasses other uses of digital technologies for health such as the Internet of things, artificial intelligence, big data and robotics." World Health Organisation, op. cit. note 1.

⁶Swan, op. cit. note 4.

⁷Lipworth, W., Stewart, C., & Kerridge, I. (2018). The need for beneficence and prudence in clinical innovation with autologous stem cells. *Perspectives in Biology and Medicine*, *61*(1), 90–105; Lipworth, W., & Axler, R. (2016). Towards a bioethics of innovation. *Journal of Medical Ethics*, 42(7), 445–449; Lipworth, W., Wiersma, M., Ghinea, N., Hendl, T., Kerridge, I., Lysaght, T., Munsie, M., RuRudge, C., Stewart, C., & Waldby, C. (2021). The oversight of clinical innovation in a medical marketplace. In G. Laurie, E. Dove, A. Ganguli-Mitra, C. McMillan, E. Postan, N. Sethi, & A. Sorbie (Eds.), *The Cambridge handbook of health research regulation* (pp. 287–295). Cambridge University Press; Greene, J. A. (2022). *The doctor who wasn't there: Technology, history, and the limits of telehealth.* University of Chicago Press. ⁸Lipworth, W., et al. (2018), op. cit. note 7; Hendl, T., Jansky, B., Seeliger, V., Shukla, A., & Wild, V. (2023). Ethical aspects of mHealth technologies: Challenges and opportunities. In R. Huss & C. Grass (Eds.), *Digital medicine* (pp. 101–128). Jenny Stanford Publisher.

⁹Criado-Perez, C. (2019). Invisible women: Exposing data bias in a world designed for men. Penguin; Ray, K. (2023). Black health: The social, political, and cultural determinants of Black people's health. Oxford University Press. Sowemimo, A. (2023). Divided: Racism, medicine and why we need to decolonise healthcare. Profile Books Ltd.

¹⁰Intersectionality is a concept which captures intersectional inequalities, whereby several levels of structural disadvantage intersect and generate specific patterns of discrimination in the healthcare context. Crenshaw, K. (1991). Mapping the margins: Intersectionality, identity politics, and violence against women of color. Stanford Law Review, 43(6), 1241–1299; Collins, P. H., & Bilge, S. (2016). Intersectionality. John Wiley & Sons; Kóczé, A. (2009). Missing intersectionality: Race/ethnicity, gender, and class in current research and policies on Romani women in Europe. https://cps.ceu.edu/sites/cps.ceu.edu/files/cps-policy-study-missing-intersectionality-2009.pdf.

¹¹Figueroa, C. A., Luo, T., Aguilera, A., & Lyles, C. R. (2021). The need for feminist intersectionality in digital health. *The Lancet Digital Health*, 3(8), e526–e533; Hendl, T., Jansky, B., & Wild, V. (2020). From design to data handling: Why mHealth needs a feminist perspective. In J. Loh & M. Coeckelbergh (Eds.), *Feminist philosophy of technology* (pp. 77–103). J.B. Metzler: Hendl, T., et al., op. cit. note 8.

¹²Noble, S. U. (2018). Algorithms of oppression: How search engines reinforce racism. New York University Press; Benjamin, R. (2019). Race after technology. Polity Press. Larrazabal, A. J., Nieto, N., Peterson, V., Milone, D. H., & Ferrante, E. (2020). Gender imbalance in medical imaging datasets produces biased classifiers for computer-aided diagnosis. Proceedings of the National Academy of Sciences, 117(23), 12592–12594.

¹³Lipworth, et al., (2018), op. cit. note 7; Lipworth & Axler, op. cit. note 7; Hendl, T., et al., op. cit. note 8; Lipworth et al. (2021), op. cit. note 7.

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such, the materialization of empowering and democratizing technology relies on the accuracy, clinical rigorousness, and intersectional efficacy of the health information and guidance generated by digital health. Furthermore, to be empowering in the health context, digital health technologies ought not be congruent with structural inequalities and material oppression, exacerbate user vulnerability and discrimination, or reinforce local and global health inequalities.¹⁴

The necessity for not replicating and magnifying global health inequalities is particularly crucial in regard to a technology that is expected to "revolutionize" health care across the world owing to its wide accessibility. A growing pool of scholarship has emphasized that any efforts toward improving worldwide health in ways that would address the needs of the most systematically oppressed and vulnerable populations need to engage with concerns of health justice and decoloniality. ¹⁵ In particular, the scholarship of indigenous experts has brought to the forefront the fundamental importance of critically engaging with eliminating persistent coloniality within sociopolitical structures, healthcare systems, as well as in the conduct of health innovation and scientific knowledge production. 16 Scholars working on decolonization in the health context¹⁷ have discussed a multitude of required shifts, including the transforming of research and medical practice in ways that will cease to be extractivist and will reach beyond western ontologies and epistemologies to respect and adjust to the ways of (well)being, conceptualizations of health and care of nonwestern, structurally oppressed, and under-served populations. Many have emphasized the need for steering health care toward the health needs of oppressed populations under their own leadership, to their own benefit, and to the fostering of traumainformed, community and culture-preserving health care, as for decolonizing communities coming back to culture is healing. 18 In the

context of digital health, scholars have raised concerns of (data) colonialism, problematizing methodologically white and western design that merely represents and often overlooks and excludes nonwestern and indigenous populations and their concerns of health and well-being. ¹⁹ The harms from colonial extractivism and misappropriation of indigenous tissue, DNA, and data have brought forward demands for Indigenous Data Sovereignty (IDS), centering of the agency and ownership of decolonizing populations over their own health information and healthcare measures. ²⁰ In light of these rich, urgent and ongoing debates, it would seem important for any debates on transforming health care and securing crucial high-quality health services for those who most need them to seriously engage with concerns of de/coloniality besides issues of democratization.

Before we get to explore such complexities in more depth, it is first important to ask how exactly is democratization of health care with digital health technologies envisioned and what does it entail? In this paper, we will take a closer look at interdisciplinary debates on the democratization of health care via digital health technologies to trace how democratization is conceptualized and what it involves. We observe that democratization is framed mainly in terms of access: to health information, health services, and patient empowerment. Building on research critically investigating innovation in health care,²¹ we investigate the assumptions that underlie the discourse on democratization and then test these assumptions against the evidence base. 22 We argue that a growing pool of evidence pointing at harm and lack of intersectional benefit challenges the notion that mHealth can democratize health care, locally and globally. In our view, this evidence suggests that not only debates on democratization need to be connected with concerns of social determinants of health but also debates on the transformation of health care through digital health ought to move beyond democratization toward justice and decolonization, in nonmetaphorical and material terms.

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¹⁵Powers, M., & Faden, R. R. (2006). Social justice: The moral foundations of public health and health policy. Oxford University Press; Venkatapuram, S. (2010). Global justice and the social determinants of health. Ethics & International Affairs, 24(2), 119–113; Venkatapuram, S. (2011). Health justice: An argument from the capabilities approach. Polity Press; Criado-Perez, op. cit. note 9; Chung, R. (2021). Structural health vulnerability: Health inequalities, structural and epistemic injustice. Journal of Social Philosophy, 52, 201–216; Bhakuni, H., & Abimbola, S. (2021). Epistemic injustice in academic global health. The Lancet Global Health, 9(10), e1465–e1470; TallBear, K. (2014). Standing with and speaking as faith: A feminist-indigenous approach to inquiry [Research note]. Journal of Research Practice, 10(2), Article N17.

¹⁶Sherwood, J. (2013). Colonisation - It's bad for your health: The context of Aboriginal health. Contemporary Nurse: A Journal for the Australian Nursing Profession. 46(1), 28-40; Sherwood, J., & Edwards, T. (2006). Decolonisation: A critical step for improving Aboriginal health. Contemporary Nurse: A Journal for the Australian Nursing Profession, 22(2), 178-190; Paradies, Y. (2016). Colonisation, racism and indigenous health. Journal of Population Research, 33(1), 83-96; Sowemimo, op. cit. note 9.

¹⁷Ibid; Fox, K. (2020). The illusion of inclusion-The "all of us" research program and Indigenous peoples' DNA. New England Journal of Medicine, 383(5), 411-413; TallBear, K. (2013). Native American DNA: Tribal belonging and the false promise of genetic science.
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¹⁸Tsosie, K. T., et al., op. cit. note 17; Urban Indian Health Institute. (2020). A historical trauma-informed approach to COVID-19-Urban Indian Health Institute. https://www.uihi.org/resources/a-historical-trauma-informed-approach-to-covid-19/; Asher BlackDeer, A. (2023a). Culture as treatment: A pathway toward indigenous health equity. *Healthy*

¹⁹Hendl, T., & Roxanne, T. (2022). Digital surveillance in a pandemic-response: What bioethics ought to learn from indigenous perspectives. *Bioethics*, 36(3), 305-312; Burnside, M., Haitana, T., Crocket, H. et al. (2023). Interviews with Indigenous Māori with type 1 diabetes using open-source automated insulin delivery in the CREATE randomised trial. *Journal of Diabetes Metabolism Disordoder*, 22, 861-871. https://doi.org/10.1007/s40200-023-01215-3.

²⁰Rainie, S. C., Kukutai, T., Walter, M. Figueroa-Rodríguez, O. L., Walker, J., & Axelson, P. (2019). Indigenous data sovereignty. In T. Davies, S. Walker, M. Rubinstein, & F. Perini (Eds.), *The state of an open data: Histories and horizons* (pp. 300–319). African Minds; Tsosie, K. T., et al, op. cit. note 17; TallBear, op. cit. note 15; Hendl & Roxanne, op. cit. note 19. ²¹Lipworth, W., et al., op. cit. note 7; Lipworth & Axler, op. cit. note 7; Lipworth, W., et al. (2021), op. cit. note 7; Hendl, T., Chung, R., & Wild, V. (2020). Pandemic surveillance and racialized subpopulations: Mitigating vulnerabilities in COVID-19 apps. *Journal of Bioethical*

²²Sjoding, M. W., Dickson, R. P., Iwashyna, T. J., Gay, S. E., & Valley, T. S. (2020). Racial bias in pulse oximetry measurement. New England Journal of Medicine, 383(25), 2477–2478; Rauscher, G. H., Khan, J. A., Berbaum, M. L., & Conant, E. F. (2013). Potentially missed detection with screening mammography: Does the quality of radiologist's interpretation vary by patient socioeconomic advantage/disadvantage? Annals of Epidemiology, 23(4), 210–214; Ledford, H. (2019). Millions of black people affected by racial bias in health-care algorithms. Nature, 574(7780), 608–610; Liao & Carbonell, op. cit. note 14.

2 | THE DISCOURSE OF DEMOCRATIZATION THROUGH DIGITAL HEALTH

In order to capture the descriptive discourse on the democratization of health care by digital health technologies, we have searched several databases (Google Scholar, PubMed, SCOPUS) with multiple search queries*. Our primary aim was not to conduct systematic review studies of scientific publications but rather critically examine the discourse that digital health technologies can democratize health care and, simultaneously, to analyze what democratization means in the context of digital health technologies. The findings in this paper are built upon a set of literature, including peer-reviewed papers, articles, reports, and so on, spanning across various disciplines, predominantly medicine, health technology development, science and technology studies, and health policy.²³ We have found that democratization of health care through digital health was framed most commonly as a matter of access to health information, health services, and patient empowerment. Next, we take a closer look at these three major themes.

2.1 | Access to health information

The discourse on democratization of health care through digital health perceives technologies as crucial tools enabling access to health information beyond traditional healthcare settings. The Democratisation of Health Care report by Stanford Medicine states that "One day, perhaps soon, this expertise [sophisticated medical expertise] will live in our smart devices—readily accessible, whenever and wherever it's needed." According to this view, health care is democratized through patients' increasing access to health data, decreasing their dependency on health professionals for health guidance. On this account, digital health encourages the spread of medical knowledge in unprecedented ways, with the patient placed at the center of this process²⁴: "The net result is that the public now has access to medical data, both personal and general, in ways it never has before: 93% of hospitals and health systems enable patients to access their health data, interact with health data, and obtain health services."

In a digitally democratized healthcare system, patients are imagined to have access to medical expertise through digital health devices, independently of time and special constraints. This accessibility of health information is perceived as particularly beneficent to globally and structurally disadvantaged patients: "This kind of access could have an enormously positive impact on global health, especially for patients who lack high-quality care close to home." 25

Some research on democratization with digital health associates greater accessibility of health information with easier lab measurements and diagnostic possibilities. Some scholars emphasize democratization on the level of ensuring the accessibility of diagnosis for "the masses"—for example, medical practitioners Bosea and Saxon²⁶ hold that "new diagnostic consumer devices" are "fundamentally changing the way we diagnose disease by promoting virtual diagnosis outside of the traditional brick-and-mortar clinic. Instead of waiting for a clinic visit for diagnosis, patients are coming with a diagnosis in hand." They further hold that digital health is revolutionary in the health context because "device data introduces concrete objective information into the discussion."²⁷ According to them, as the devices "become universally adopted, they will define a new universal truth."28 In their view, the shift to digitization of health is democratizing owing to the wide accessibility of the technology: "The sacred power of diagnosis now lies in the literal hands of the everyman."29 On their account, the wide adoption of such devices will represent a cultural revolution, bringing a new way of viewing human health.

Others discuss the democratizing of access to diagnostics both in patients and health professionals. Wood et al.³⁰ elaborate

In principle, a mobile phone camera can take the place of advanced laboratory-based spectrometers and match their quantitation and multiplexing capability via innovative engineering. These efforts are acting to democratize access to otherwise costly laboratory equipment and reduce the training needed to interpret test results, e.g., via automated RDT measurements.

Hence, democratization is also framed in terms of an increasing technological capacity and accessibility of diagnostic measurements and information facilitated by mobile phones and other digital health technologies, which then enable the flow of health information to patients.

Greater access to health information through digital health technologies is further framed as a gateway to better decisionmaking and greater control over one's health. In particular, digital health is perceived as a technology that can provide new and better

²³Stanford Medicine. (2018). Health trends report: The democratisation of health care. https://med.stanford.edu/dean/healthtrends.html; Burnside, M., Crocket, H., Mayo, M., Pickering, J., Tappe, A., & de Bock, M. (2020). Do-it-yourself automated insulin delivery: A leading example of the democratization of medicine. *Journal of Diabetes Science and Technology*, 14(5), 878–882; Ozcan A. (2014). Mobile phones democratize and cultivate next-generation imaging, diagnostics and measurement tools. *Lab Chip*, 14(17), 3187–3194; Meskó, B., Drobni, Z., Bényei, É., Gergely, B., & Győrffy, Z. (2017). Digital health is a cultural transformation of traditional healthcare. *mHealth*, 3(38), 1–8; Roth, P. H., & Bruni, T. (2022). Participation, empowerment, and evidence in the current discourse on personalized medicine: A critique of "democratizing healthcare." *Science*, *Technology*, & *Human Values*, 47(5), 1033–1056; Wood, C. S., Thomas, M. R., Budd, J., Mashamba-Thompson, T. P., Herbst, K., Pillay, D., Peeling, R. W., Johnson, A. M., McKendry, R. A., & Stevens, M. M. (2019). Taking connected mobile-health diagnostics of infectious diseases to the field. *Nature*, 566(7745), 467–474.

 $^{^{24}\}mbox{Stanford Medicine, op. cit. note 23, p. 3.}$

²⁵lbid.

²⁶Bose, R., & Saxon, L. A. (2019). The democratization of diagnosis: Bringing the power of medical diagnosis to the masses. *EClinical Medicine*. 8, 6–7.

²⁷lbid: 6.

²⁸Bose & Saxon, op. cit. note 23, p. 7.

²⁹lbid.

³⁰Wood, C. S., et al., op. cit. note 23, p. 469.

diagnostic information.³¹ Patients' decision-making is then strongly linked with preventive health care and self-management. For example, the Stanford Medicine report states that democratization "promises a world in which patients-armed with data, technology, and access to expertise—can take charge of their own well-being and manage their own health."32

2.2 Access to health care

A major role in debates on democratization through digital health is attributed to access to health care. Digital health is described as technology facilitating the accessibility of health services at lower costs.³³ For example, Hernández-Neuta et al. have stated that the "high level of seamless connectivity, portability, and robust functionality integrated on these devices hold high promise in democratizing and decentralizing quality health care."34 According to them, the technological features of digital health technologies allow for the collection and processing of large sums of data and more precise diagnostic techniques. The cost effectiveness of digital health then allows for its employment in structurally impoverished parts of the world, rural areas remote from laboratories and medical facilities and within populations who previously have not had access to health care. Proponents of the digital transformation of health care, such as Mesko et al., 35 note that "healthcare systems worldwide are becoming financially unsustainable, a paradigm shift is imminent." In their view, such a paradigm shift includes the shift in the provision of care toward a more accessible digital mode.

Some scholars emphasized that digital health can also provide access to health care of higher quality. For example, Steinhubel et al. hold that mHealth technologies can "transform the mode and quality of clinical research and health care on a global scale" owing to their computing capabilities and connectivity. These scholars further suggest that mHealth can improve the comprehension of human physiological variation:

> Unimpeded by geographical boundaries, smartphonelinked wearable sensors, point-of-need diagnostic devices, and medical-grade imaging, all built around real-time data streams and supported by automated decision-support tools, will enable care and enhance our understanding of physiological variability.³⁶

On this view, mHealth might contribute to the advancement of health knowledge as well as health care.

2.3 Access to patient empowerment

In the scholarship on democratization through digital health technologies, greater access to information, decision-making, and health services subsequently enables access to patient empowerment, which further reinforces the increasingly central position of the patient within the healthcare system. Steinhubl and his colleagues³⁷ hold that "empowering patients with accessibility to and ownership of their own medical data reverses the predominantly one-way dynamic of today's healthcare system." In their view, technologies such as mHealth place "the consumer at the center of their healthcare network."

Access to health information is particularly perceived as enabling a more egalitarian doctor-patient relationship and a stronger standing of the patient within the healthcare system. According to Mesko et al.,³⁸ digital health represents "the cultural transformation of how disruptive technologies that provide digital and objective data accessible to both caregivers and patients leads to an equal-level doctor-patient relationship with shared decision-making and the democratization of care." On this account, digital health is seen as a novel source of "objective" information, which undermines the monopole of the doctor as a traditional bearer of a more subjective medical judgment and elevates the patient toward an equal position with healthcare professionals. According to the Stanford Medicine Report³⁹ "patients no longer get all of their healthcare information from the physician. This one-to-one relationship between the expert and patient is giving way to a multiplicity of information-sharing relationships." As such, access to digitally generated data is envisioned as the core leveler of the patients' position in the discourse of democratization with digital health. In this view, patients are no longer dependent on one source of health information, but they "are now engaged with the wider healthcare system in more complex forms of information sharing."40 At times, digital health is even envisioned as a potential substitute of doctor-patient interactions: "in many cases, these technologies can complement, or even replace, interactions with healthcare professionals."41

As a consequence of digitization of health, patients are perceived as more engaged in the health context and ultimately, empowered. In her paper "Health 2050: Preventive Medicine," Swan⁴² argues that mHealth represents a warranted futuristic shift in that the patient becomes the real "nexus of action-taking and empowerment." According to her, the shift signifies a move away from "fix-it-witha-pill mentality" toward "the empowered role of the biocitizen in achieving the personalized preventive medicine of the future." In her view, the shift to digital health is framed as unequivocally positive, in that it enables preventive and personalized and participation-centric

³¹Ozcan, op. cit. note 23; Wood, C. S., et al., op. cit. note 23.

³²Stanford Medicine, op. cit. note 23, p. 3.

³³Stanford Medicine, op. cit. note 23; World Health Organisation, op cit. note 1.

³⁴Hernández-Neuta, I., Neumann, F., Brightmeyer, J., Ba Tis, T., Madaboosi, N., Wei, Q., Ozcan, A., & Nilsson, M. (2019), Smartphone-based clinical diagnostics: Towards democratization of evidence-based health care. Journal of Internal Medicine, 285(1), 19-39. 35 Meskó, B., et al., op. cit. note 23, p. 1.

³⁶Steinhubl, S. R., Muse, E. D., & Topol, E. J. (2015). The emerging field of mobile health. Science Translational Medicine, 7(283), 283rv3.

³⁷ Ibid

³⁸Meskó, B., et al., op. cit. note 23, p. 1.

³⁹Stanford Medicine, op. cit. note 23, p. 3.

⁴¹Rosenbloom, S. T. (2016). Person-generated health and wellness data for health care. Journal of the American Medical Informatics Association, 23(3), 438-439.

⁴²Swan, op. cit. note 4.

medicine. She holds that "personalized preventive medicine could be critical to solving public health challenges at their causal root." 43

3 | DISCUSSION: THE VAGUENESS OF DEMOCRATIZATION

As is becoming clear from our summary, in the discourse on democratization through digital health, democratization is predominantly conceptualized through the access to an unlimited flow of health data. Medical humanities theorists Phil Roth and Tommaso Bruni have called this notion of democratization "empowerment through information,"44 further equated with making informed decisions about one's health. In their critique of the discourse of "democratizing health care" in debates on personalized medicine, they argue that democratization has become a buzzword. Their analysis builds on the "politics of buzzwords" by Bernadette Bensaude Vincent. 45 who argued that buzzwords serve to "generate" matters of concern and play an important role in trying to build consensus" and to "mobilize people by setting attractive goals and agendas." Exploring how the term "democratizing health care" is used in the context of digital health, Roth and Bruni argue that the discourse of democratizing is, in fact, a rhetorical strategy to encourage the extensive everyday use of these technologies. They further argue that the catchphrase belittles the political idea of "democracy" and ends up merely meaning "increase in access" to information technology. In their view, the notion of democratization as presented in the discourse on democratizing health care through digital health is predominantly characterized by vagueness.

We agree with much of Roth and Bruni's critique of the discourse on democratization for its vagueness. In our inquiry, we observe the hypothesis that digital health facilitates democratization in that access to information, health services, decision-making, and control over one's health lead to patient empowerment and a stronger position of patients in doctor patient-relationship and the healthcare system. Yet, much of the scholarship on democratization stays on the level of predictive promises, without providing empirical evidence substantiating the claims that democratization is occurring, for whom and under which conditions. These observations echo what Schmietow and Marckmann⁴⁶ have argued about the vagueness of debates on the potential of mHealth to enhance self-determination, empowerment, and health literacy and facilitate "democratized participatory health and medicine."

As we have shown above, in the discourse on democratization through digital health, patients are imagined predominantly as health consumers "armed" with digital data. However, concerns of

the quality of the health technologies, health data, and health care delivered via digital health technologies are seldom investigated or even thematized, both in the literature advocating for democratization through digital health health critiques. And yet, concerns of whether and how well digital health addresses the health needs of the diverse users across the target population are crucial for debates on whether it can empower the users and materialize the potential for democratizing health care. Next, we will look at empirical evidence regarding the health impact of digital health technologies and discuss what this evidence means for the claims about the potential of digital health for democratizing health care.

4 | EVIDENCE BASED ON THE IMPACT OF DIGITAL HEALTH AND ITS IMPLICATIONS FOR THE DEMOCRATIZATION OF HEALTHCARE

A growing pool of evidence has shown that a variety of digital health technologies, machine learning systems, and medical artificial intelligence (AI) come short of providing rigorous health information and health services. Much research shows that many technologies, such as health apps or machine learning systems used in medicine, have not been trained on heterogeneous data and are thus not serving whole subpopulations and, subsequently, not suitable for use across the population as a whole or globally.

Many studies have shown that Al platforms are commonly trained with data skewed toward a partial segment of the population and as a consequence, deliver poor, false, and potentially harmful results. For example, a recent large-scale study⁴⁹ has shown that Al systems working with medical imaging data sets fail to deliver correct diagnosis in women, owing to the over-representation of male data in publicly available X-ray image databases and deep neural network architectures. Larrazabal and her colleagues⁵⁰ note that "a consistent decrease in performance is observed when using male patients for

⁴³lbid: 93.

⁴⁴Roth & Bruni, op. cit. note 23.

⁴⁵Bensaude Vincent, B. (2014). The politics of buzzwords at the interface of technoscience, market and society: The case of 'public engagement in science.' *Public Understanding of Science*, 23(3), 238–253.

⁴⁶Schmietow, B., & Marckmann, G. (2019). Mobile health ethics and the expanding role of autonomy. *Medicine, Health Care and Philosophy*, 22(4), 623–630.

 $^{^{47}}$ Swan, op. cit. note 4; Stanford Medicine, op. cit. note 23; Steinhubl, S. R., et al., op. cit. note 36.

⁴⁸Roth & Bruni, op. cit. note 23; Fiske, A., Buyx, A., & Prainsack, B. (2020). The double-edged sword of digital self-care: Physician perspectives from Northern Germany. *Social Science & Medicine* (1982). 260. 113174.

⁴⁹Larrazabal, A. J., et al., op. cit. note 12.

⁵⁰The downside of the study is that it works with a strictly binary conceptualization of gender, which reproduces the normative and unsubstantiated idea that sex and gender are strictly binary categories. The binary also reproduces a biologically deterministic notion of gender as unambiguously following from sex, which erases transgender and genderqueer people. This binary notion of sex/gender has been critiqued as socially reinforced and empirically unfounded, given the large pool of evidence that sex and gender exist on a spectrum and continuum, see Hendl, T., & Browne, T. K. (2022). Gender: Ongoing debates and future directions. In *The Routledge handbook of feminist bioethics* (pp. 151–166). Routledge. The replication of the sex/gender binary in Al platforms and machine learning has been critiqued by many scholars, see for example, Scheuerman, M. K., Wade, K., Lustig, C., & Brubaker, J. (2020). How we've taught algorithms to see identity: Constructing race and gender in image databases for facial analysis. *Proceedings of the ACM on Human-Computer Interaction*, 4(CSCW1), 1–35; Scheuerman, M. K., Pape, M., & Hanna, A. (2021). Autoessentialization: Gender in automated facial analysis as extended colonial project. *Big Data & Society*, 8(2), n.p.

training and female for testing (and vice-versa)." At times, the distortion in the data begins at the clinic and continues through the healthcare referral process. Research on the implications of skewed data sets conducted in mammography screening⁵¹ shows that clinicians spend less time particularly with socioeconomically disadvantaged and negatively racialized women. These groups of women then may not be referred to specialists and their diagnostic images will thus not reach into databases, which are used to train machine learning systems. The absence of the training data might in turn have a disproportionately detrimental impact on the same population groups, as conditions that might be population specific or more prevalent in particular groups (e.g., owing to socioeconomic deprivation) will not be well documented and thus harder to detect, and this effect will likely be further magnified through algorithmic discrimination. ⁵²

These issues point toward intersectional inequalities, with interlocking levels of structural disadvantage-such as based on gender, racialization, and class-that result in specific and exacerbated patterns of discrimination in the healthcare context. 53 As such, these issues and their institutionalized structural character raise concerns over the potential of automation and digitalization to democratize health and foster patient empowerment. In particular, the systemic failure of clinical research and standard medicine to produce relevant data in already structurally vulnerable populations, issues subsequently magnified through algorithmic oppression, undermines the expectations that digital health has widely democratizing effects that enable marginalized and excluded patients to participate in high-quality health care. In particular, it is becoming clear that technologies which come short of producing populationspecific, relevant, clinically justified and accurate diagnostic data cannot facilitate viable health choices and enhance patient decisionmaking.

Many studies have shown that the impact of racial inequalities is magnified through digital health. Research on medical AI has identified that black Americans with sickle cell anemia have been over-diagnosed and needlessly treated for diabetes based on data from clinical studies that exclude them. S4 Serious concerns have been raised in radiology, with several studies showing that negatively racialized patients have been under-diagnosed and thus deprived of health care. Alarmingly, research has shown that algorithmic discrimination in medical AI has deprived millions of black patients of access to health care in the United States, as instead of interpreting their health data, an algorithm was inferring their diagnosis based on their lower health spending, which was in itself

lower due to racial discrimination and the lack of referral of negatively racialized patients to specialists. Furthermore, a recently designed Google dermatology app has been found to be almost entirely calibrated to white skin, with only 2.7% of data samples of the second darkest skin type (type V). In consequence, the app will likely wrongly diagnose or over-diagnose patients with darker skin tones. In spite of the glaring gaps in the training data, the app was certified as class one medical tool in the European Union. This rich evidence of intersectional inequalities embedded into medical AI and digital health raises serious worries regarding the lack of rigorous assessment and testing of the technology for intersectional and equitable health benefits. This generates concerns about not only the quality of the design process of the technology but also the approval and certification processes for digital health.

Indeed, structural inequalities have been shown to have shaped both the training data and the design of digital health technology. For example, the pulse oximeter, a mobile health technology which attaches on a person's finger like a clothes peg and measures oxygen saturation, was shown to provide incorrect measurements in patients with darker skin tones.⁵⁸ The tool was used for triage during the COVID-19 pandemic, with harmful and presumably also lethal impact in non-White patients. The tool was found to have been tested and calibrated for a white male subpopulation and three times more often failed to identify hypoxemia in black patients.⁵⁹ The skewed design also raises subsequent concerns regarding the negative impact on women, especially black and brown women-who, on average, have smaller fingers than men, on whom the tool was designed and tested on. A more heterogenous design is also crucial more broadly for everyone beyond the normative sex/gender binary categories, as both sex and gender exist on a spectrum and continuum, and humans have diverse bodies and needs.⁶⁰ Given the discriminatory design of the pulse oximeter, the device has been identified as a striking example of a digital health technology exacerbating the vulnerability of already structurally oppressed population groups and congruent with material oppression.⁶¹

The now robustly documented issues of gender and racial disparities integrated into digital health and the risk of intersectionally unequal effects should raise alarm in debates on the democratizing potential of the technologies. The initial hype that preventive medicine will be necessarily democratized through personalization and the centering of the individual empowered through data and able to take charge of their health is now contrasted with a growing pool of evidence that digital health technologies are designed and trained toward the persistent

⁵¹lbid.

⁵²Benjamin, op. cit. note 12; Noble, op. cit. note 12.

⁵³Hendl, T., et al., op cit. note 8; Sowemimo, op. cit. note 9; Collins & Bilge, op. cit. note 10; Kóczé, op. cit. note 10; Figueroa, C. A., et al., op. cit. note 11; Sherwood, op. cit. note 16; Paradies, op. cit. note 16; BlackDeer (2023a, 2023b), op. cit. note 18.

⁵⁴Selbst, A., & Barocas, S. (2017). Al now 2017 report. https://ainowinstitute.org/Al_Now_ 2017_Report.pdf.

⁵⁵Rauscher, G. H., Khan, J. A., Berbaum, M. L., & Conant, E. F. (2013). Potentially missed detection with screening mammography: Does the quality of radiologist's interpretation vary by patient socioeconomic advantage/disadvantage? *Annals of Epidemiology*, 23, 210–214.

⁵⁶Ledford, op. cit. note 22.

⁵⁷Daneshjou, R., Smith, M. P., Sun, M. D., Rotemberg, V., & Zou, J. (2021). Lack of transparency and potential bias in artificial intelligence data sets and algorithms: A scoping review. JAMA Dermatology. 157(11), 1362–1369.

⁵⁸Sjoding, M. W., et al., op. cit. note 22; Liao & Carbonell, op. cit. note 14; Hendl, T., et al., op. cit. note 8; Keller, M. D., Harrison-Smith, B., Patil, C., & Arefin, M. S. (2022). Skin colour affects the accuracy of medical oxygen sensors. *Nature*, 610(7932), 449–451.

⁶⁰Hendl & Browne, op. cit. note 45.

⁶¹Liao & Carbonell, op. cit. note 14; Hendl, T., et al., op. cit. note 8.

.4678519, 2024, 6, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/bioe.13266 by Universita

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onditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons

normative conceptualization of the individual through normative androcentric whiteness. A closer look at the implications of methodologically and structurally sexist and racist health technologies suggests that they have discriminatory and materially oppressive rather than democratizing impact.

Last but not least, some digital health technologies have been demonstrated to come short of addressing the actual root causes of health problems. A recent study has shown⁶² that this is the case of the majority of apps responding to violence against women (VAW). VAW represents a major and preventable global health problem, predominantly perpetrated by men and experienced by one-third of the global female population, disproportionately black, indigenous, and fellow negatively racialized women as well as transgender women.⁶³ A systematic review⁶⁴ of apps responding to VAW has found that 82.46% of the reviewed apps were directed only at victims (survivors and potential victims) and most offered one-off emergency and avoidance "solutions," instead of systemic approaches that would address and prevent the global health problem of VAW and its social and political determinants, such as gender-unjust social structures and norms. Eisenhut and her colleagues⁶⁵ thus argue that the technology needs to be subordinated to the overall aims of preventing violence against women and girls, which requires the changing of social norms that enable gender-based violence. Without such changes, most of the apps against VAW will not only fail to eliminate the health problems they claim to be addressing but also remain congruent with material oppression owing to their perpetuation of epistemic injustice. 66 More generally, the case of apps responding to VAW illustrates that the mere access to digital health "solutions" does not necessarily address particular health problems. Rather factors such as the quality of digital health technologies, the targets, functions and aims, and their integration within broader social and health politics are crucial in evaluations of the role of digital health in improving health care.

The growing pool of evidence of harm from digital health, some of which we have discussed above, is even more concerning considering the lack of empirical evidence that would prove that digital health technologies do facilitate equitable and just health outcomes, locally and globally.⁶⁷ In our previous research,⁶⁸ we have emphasized that "for the most part, the hopes and expectations associated with mHealth cannot clearly be substantiated with empirical evidence, especially with regard to long-term and population effects." Rowland et al.⁶⁹ point out that a current search for "mHealth" in the pubmed database of scholarly articles generates over 30,000 hits but only a handful of clinical scenarios where use of mHealth apps is supported by the highest levels of evidence. Concerns regarding evidence basis and quality standards of digital health are even more pressing, owing to a current lack of robust and clear regulations to guide manufacturers, providers, and users. Scholars have argued⁷⁰ that these issues are further alarming as neither the regulatory frameworks nor a large portion of the research on digital health pay attention to the need for assessing the safety, efficacy, and health benefits through an intersectional lens, which would evaluate the impact and health outcomes of digital health in various different user populations, that is, without falsely assuming that one mould fits all.

One of the key justifications for democratizing health care with digital health, relating to the immense rise in the accessibility of mobile phones and the possibility of scaling mobile health apps supported by wireless sensors⁷¹ and smartphone apps, has been critiqued. In particular, the current use of smartphone apps in individual, clinical, and population settings, along with the push toward developing and integrating app-based solutions into health care, have been criticized on the ground of insufficient evidence regarding their efficacy and proof of positive contribution to improving health. Skorburg and Yam, in the context of growing interest in digital mental health (DMH) solutions (such as smartphone apps and AI chatbots), raise the question, "Do DMH technologies demonstrably improve mental health outcomes?"72 Contextualizing the importance of this fundamental question on digital mental health, they particularly highlight the case of smartphone apps and lack of empirical evidence and rigorous evaluation of their efficacy for in treatment of mental health problems. While the authors discuss the limited literature and clinical evidence through meta-analyses and systematic reviews on the efficacy of the apps, they also mention that plenty of DMH apps available in the market are not evidence

⁶²Eisenhut, K., Sauerborn, E., García-Moreno, C., & Wild, V. (2020). Mobile applications addressing violence against women: A systematic review. *BMJ Global Health*, *5*(4), e001954.
⁶³August, S., Bear, T., Bourgeois, R., Bouvier, R., Chacaby, M. O. A., Downtown Eastside Power of Women Group, Gingell, S., Good, M., Harjo, K., Hunt, S., Innes, R. A., Jacobs, B., Kappo, T., Kappo, T., Kinoshameg, K., Knott, K., Lamouche, S., Lawless, J.-A., Leo, D., Leonard, K. T., Livingston, A.-M., Macdougall, B., Maracle, S., Navarro, J., Okemaysim-Sicotte, D. R., Win, P. P. S., Reece, R., Robertson, K., Simpson, L. B., Starr, B., Stout, M. K. D., Christine Sy W., & Wilson, A. (2018). *Keetsahnak/our missing and murdered indigenous sisters*. University of Alberta; Hague, G., & Mullender, A. (2006). Who listens? The voices of domestic violence survivors in service provision in the United Kingdom. *Violence Against Women*, *12*(6), 568–587; Krell, E. C. (2018). Is transmisogyny killing trans women of color? Black trans feminisms and the exigencies of white femininity. *Transgender Studies Quarterly*, *4*(2), 226–242.

⁶⁴Eisenhut, K., et al., op. cit. note 62.

⁶⁵lbid.

⁶⁶Sauerborn, E., Eisenhut, K., Ganguli-Mitra, A., & Wild, V. (2022). Digitally supported public health interventions through the lens of structural injustice: The case of mobile apps responding to violence against women and girls. *Bioethics*, 36(1), 71–76.

⁶⁷Rowland, S. P., Fitzgerald, J. E., Holme, T., Powell, J., & McGregor, A. (2020). What is the clinical value of mHealth for patients? *NPJ Digital Medicine*, *3*(1), 1–6; Agarwal, P., Gordon, D., Griffith, J., Kithulegoda, N., Witteman, H. O., Sacha Bhatia, R., Kushniruk, A. W., Borycki, E. M., Lamothe, L., Springall E., & Shaw, J. (2021). Assessing the quality of mobile applications in chronic disease management: A scoping review. *NPJ Digital Medicine*, *4*(1), 1–8; Day, S., Shah, V., Kaganoff, S., Powelson, S., & Mathews, S. C. (2022). Assessing the clinical robustness of digital health startups: Cross-sectional observational analysis. *Journal of Medical Internet Research*, *24*(6), e37677.

⁶⁸Hendl, T., et al., op. cit. note 8, n.p.

⁶⁹Rowland, S. P., et al., op. cit. note 67.

⁷⁰Hendl, T., et al., op. cit. note 8; Sharon, T. (2020) Blind-sided by privacy? Digital contact tracing, the Apple/Google API and Big Tech's newfound role as global health policy makers. Ethics and Information Technology, 23(Suppl 1), 45–57.

⁷¹Jones, G. B., Bryant, A., & Wright, J. (2022). Democratizing global health care through scalable emergent (beyond the mobile) wireless technologies. *JMIR Biomedical Engineering*, 7(1), e31079.

⁷²Skorburg, J. A., & Yam, J. (2022). Is there an app for that? Ethical issues in the digital mental health response to COVID-19. *AJOB Neuroscience*, 13(3), 177–190.

based and fall short on providing empirical evidence as "rigorous evaluation is the exception rather than rule."

5 | DEMOCRATIZATION AND A NEOLIBERAL APPROACH TO HEALTH CARE

Overall, the empirical evidence discussed by us points at issues that undermine the tales about democratization through digital health. In particular, the general tale that digital health technologies can democratize health care, whereby democratization is perceived as a matter of providing access to health information, decision-making, health services, and patient empowerment, is challenged by a growing pool of empirical evidence documenting the risk of intersectional harm from these technologies. All the examples discussed above illustrate that algorithms and health technologies trained with skewed data fail to provide accurate health information, diagnosis, and therapeutic guidance. These failures, which have been shown to be rather common in the digital health context, will in turn undermine rather than enhance patient decision-making as inaccurate, and misleading health technologies will come short of providing whole population groups with viable and beneficent health options. Such technologies will undermine rather than facilitate patient empowerment in the health context, given that they will not provide adequate and equitable health benefits, from individual, population, and global perspectives.

Owing to the discriminatory and disempowering effects of a range of digital health technologies, it is currently difficult to conceive of digital health as capable of democratizing health care on a local and global scale. Given that the proven unequal impact and risk of harm from digital health replicates the same inequalities that have dominated western medicine and health care, these findings further suggest that just like standard health care, also digital health technologies designed and implemented in ways that are congruent with structural sexism, racism, and coloniality will reinforce material oppression and consequently exacerbate health inequalities. 73 These inequalities will undermine the democratizing potential of digital health. Even if various populations around the world had equal access to the technologies, only the minority of them, such as white western cisgender men, would be accessing such technologies with a high likelihood of being provided services tailored to their health needs. Meanwhile, the majority of the world's population might not even have a good chance that the information and health guidance provided to them through digital health will be safe, accurate, or beneficent to them.

Yet remarkably, the discourse on democratization through digital health does not so much consider the public and global health impact of digital health as it focuses predominantly on the individual. This brings to the forefront that within this discourse, democratization is envisioned through an individualistic framework: democratizing

health care with digital health is predominantly conceptualized as a matter of individual empowerment through a mere access to technology and absence of interference. As we have noted above, these debates on access are also largely disconnected from concerns of quality control of the accessed services. And while these debates disregard discrimination and structural inequalities magnified by digital health technologies, they emphasize the role of the individual in managing their health. Scholars have argued that the individualized notion of empowerment promoted by advocates for the wide use of digital health involves the "responsibilization" of the individual for their health outcomes.⁷⁴ This aspect is very strong in the democratization discourse: the individual user/patient is mainly debated as empowered by digital health toward self-management. Empowerment, predominantly envisioned as self-empowerment (e.g., through self-tracking), and health are conceptualized as largely decontextualized from society and patients' socioeconomic and political environment.⁷⁵

The overall strong emphasis on the improvement of health through self-management in debates on democratization through digital health is reminiscent of a neoliberal approach to health care, which promotes individualistic and market-place solutions to structural problems. ⁷⁶ As argued by Cosgrove and Karter ⁷⁷ in the context of mental health care:

In a neoliberal climate, markets give us truth and individuals are encouraged to be self-concerned agents rather than members of a polis. Thus, at the very moment that neoliberal policies transfer responsibility to individuals, there is a simultaneous increase in surveillance in order to reinstall certain patterns of human behavior.

Similarly, in debates on democratization through digital health, the idea of democratization is conceptualized as mere individual access and participation in self-management, that is, framed as self-empowering. Instead of receiving care from a robust healthcare system, the labor of health monitoring is outsourced to the very individual, who is then increasingly

⁷³Liao & Carbonell, op. cit. note 14; Sjoding, M. W., et al., op. cit. note 22; Ledford, op. cit. note 22; Hendl, T., et al., op. cit. note 8; Hendl & Roxanne, op. cit. note 19.

⁷⁴Kreitmair, K. (2019). Ethical dimensions of direct-to-consumer neurotechnologies. *AJOB Neuroscience*, 10(4), 152-166; Hendl, T., et al., op. cit. note 8; Schmietow & Marckmann, op. cit. note 46.

⁷⁵Sharon, op. cit. note 70; Ruckenstein, M., & Schüll, N. D. (2017). The datafication of health. The Annual Review of Anthropology, 46(1), 261–278; Lupton, D. (2015). Health promotion in the digital era: A critical commentary. Health Promotion International, 30(1), 174–183; Storeng, Fukuda-Parr, S., Mahajan, M., & Venkatapuram, S. (2021). Digital technology and the political determinants of health inequities: Special issue introduction. Global Policy, 12(S6), 5–11. Hendl, T., & Jansky, B. (2021). Tales of self-empowerment through digital health technologies: A closer look at 'Femtech.' Review of Social Economy, 80(1), 29–57.
⁷⁶Collins & Bilge, op. cit. note 10; Sharon, op. cit. note 70; Lupton, op. cit. note 75; Cosgrove, L., & Karter, J. M. (2018). The poison in the cure: Neoliberalism and contemporary movements in mental health. Theory & Psychology, 28(5), 669–683; MacLean, S., & Hatcher, S. (2019). Constructing the (healthy) neoliberal citizen: Using the walkthrough method "do" critical health communication research. Frontiers in Communication, 4, 1–14. https://doi.org/10.3389/fcomm.2019.00052; Numerato, D., Čada, K., & Honová, P. A. (2020). Citizenship, neoliberalism and healthcare. In J. Gabe, M. Cardano, & A. Genova, (Eds.), Health and illness in the neoliberal era in Europe (pp. 75–89). Emerald Publishing Limited.

⁷⁷Cosgrove & Karter, op. cit. note 76, p. 669.

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responsibilized with the monitoring of their health and their health outcomes. This responsibilization can not only be burdensome and unfair, given the impact of social determinants of health on health and well-being, but also troubling in light of the documented risk of harm from digital health technologies, which has discriminatory rather than democratizing effects. Indeed, scholars have critiqued that rather than being connected to proven user health interests, the hype about digital health has been largely intertwined with the interest in their implementation, including private and commercial interests; Roth and Bruni have gone so far to argue that the very discourse on democratization lacks substance and is rather driven by commercial interests and amounts to a marketing strategy.

Overall, the evidence of intersectional harm and unequal benefit from digital health technologies and the absence of proof of safety, efficacy, and beneficence of the technologies then necessarily raise broader questions and concerns about the conceptualization of democratization through digital health. In particular, what becomes palpable is the disconnect of debates on democratization from engagement with social and political determinants of health and broader concerns of justice.

6 | FROM DEMOCRATIZATION TOWARD JUSTICE IN HEALTH

The discourse of democratization through digital health conceptualizes democratization as a mere matter of access, participation, and lack of interference with one's choices. Yet, the empirical evidence showing the (risk) of harm and lack of benefit from digital health points not only at the poor design and assessment of the technology but also more broadly toward the empirically substantiated observation that health is fundamentally socially shaped and political. Just consider the impact of gender inequality on women's health through men's violence against women, magnified by antitrans and racial oppression, as we discussed above. Amy have argued that in order to deliver intersectionally just health care, digital health needs to mitigate structural inequalities at all stages of development, design and use, as well as counter the ongoing legacy of gender and racial inequalities that has shaped medicine and health

care. ⁸² Yet, debates on democratization narrowed to issues of access/participation in digital health do not account for the nonideal sociopolitical conditions that impact one's health, and they also lack concern for quality control of health care in relation to population-specific health needs. ⁸³ Furthermore, the notion of empowerment through information, whereby mere data shall strengthen one's relation to health professionals as well as one's position within the healthcare system, does not account for the structural inequalities that have shaped medicine and health care, including digital health. ⁸⁴ This suggests that not only democratization in the health context ought to be conceptualized differently ⁸⁵ to account for social determinants of health but also debates on the impact of digital health need to go far beyond democratization and engage with concerns of health justice.

Given in particular the colonial legacy of medicine and health care as well as the detrimental impact of structural inequalities on the health of many populations in the majority world, it appears crucial that debates on health technologies and innovation would engage with concerns of local and global health justice. ⁸⁶ This is even more crucial considering the well-documented capacity of inconsiderately designed digital health for magnifying intersectional discrimination and health inequalities. The empirical evidence of (risk of) harm we have discussed above thus calls for a proactive engagement with the aims of antidiscrimination, as well as concerns with intersectional, decolonial, and global health justice. ⁸⁷ Such shift would not only require engagements with theory but also a broader concern with healthcare practice, its conditions, and implications. Such practical engagement is crucial to avoided falling into the traps of treating concerns of decolonization as yet another buzzword or as a metaphor

⁷⁸Sharon, T. (2017). Self-tracking for health and the quantified self: Re-articulating autonomy, solidarity and authenticity in an age of personalized healthcare. *Philosophy & Technology*, 30(1), 93–121; Hendl, T., et al., op. cit. note 8; Kreitmair, op. cit. note 74.

⁷⁹Roth & Bruni, op. cit. note 23; Hendl & Jansky, op. cit. note 75; Sharon, op. cit. note 70; Sharon, T. (2018). When digital health meets digital capitalism, how many common goods are at stake? *Big Data & Society*, 5(2), 205395171881903. https://doi.org/10.1177/2053951718819032; Kressbach, M. (2019). Period hacks: Menstruating in the big data paradigm. *Television and New Media*, 22, 1–21. Punzi, M. C., & Werner, M. (2020). Challenging the menstruation taboo one sale at a time: The role of social entrepreneurs in the period revolution. In C. Bobel, I. T. Winkler, B. Fahs, K. A. Hasson, E. Arveda Kissling, & T.-A. Roberts (Eds.), *The Palgrave handbook of critical menstruation studies* (pp. 833–850). Palgrave Macmillan.

⁸⁰Roth & Bruni, op. cit. note 23; Rubeis, G., Dubbala, K., & Metzler, I. (2022). "Democratizing" artificial intelligence in medicine and healthcare: Mapping the uses of an elusive term. Frontiers in Genetics, 13, 1–11. https://doi.org/10.3389/fgene.2022.902542.

⁸¹Eisenhut et al., op. cit. note 62.

⁸² Figueroa, C. A. et al., op. cit. note 11; Hendl, T., et al., op. cit. note 8.

⁸³Criado-Perez, op. cit. note 9; Kóczé, op. cit. note 10; Sowemimo, op. cit. note 9; Venkatapuram, op. cit. note 15; Sherwood, op. cit. note 16; Paradies, op. cit. note 16; BlackDeer (2023a, 2023b), op. cit. note 18.

⁸⁴lbid; Neff. (2019). The political economy of digital health. In Mark Graham & William H. Dutton (Eds.) *Society and the internet: How networks of information and communication are changing our lives* (2nd ed, pp. 281–292). Oxford University Press; Hendl, T., et al., op. cit. note 8; Figueroa, C. A., et al., op. cit. note 11; Sharon, op. cit. note 70; Hendl & Jansky, op. cit. note 75; Sharon, op. cit. note 79.

⁸⁵Collins, P. H. (2019). The difference that power makes: Intersectionality and participatory democracy. In O. Hankivsky & J. S. Jordan-Zachery (Eds.), *The Palgrave handbook of intersectionality in public policy* (pp. 167–192). Palgrave Macmillan; Banerjee, S. B. (2021). Decolonizing deliberative democracy: Perspectives from below. *Journal of Business Ethics*, 181, 283–299; Khader, S. J. (2019). Decolonizing Universalism: A transnational feminist ethic. Oxford University Press; de Ploeg, & de Ploeg, C. (2017). No democratisation without decolonisation: A testimony from the student movement in Amsterdam. *Tijdschrift Voor Genderstudies*, 20(3), 321–332.

⁸⁶Amrute, S., Singh, R., & Guzmán, R. L. (2022). A primer on Al in/from the majority world: An empirical site and a standpoint. https://doi.org/10.2139/ssrn.4199467.

⁸⁷Abimbola, F., Asthana, S., Cortes, C., Guinto, R., Jumbam, D., Louskieter, L., Kabubei, K., Munshi, S., Muraya, K., Okumu, F., Saha, S., Saluja, D., & Pai, M. (2021). Addressing power asymmetries in global health: Imperatives in the wake of the COVID-19 pandemic. *PLoS Medicine*, 18(4), e1003604; Mogaka, Stewart, J., & Bukusi, E. (2021). Why and for whom are we decolonising global health? *The Lancet Global Health*, 9(10), e1359–e1360; Khan, M., Abimbola, F., Aloudat, T., Capobianco, E., Hawkes, S., & Rahman-Shepherd, A. (2021). Decolonising global health in 2021: A roadmap to move from rhetoric to reform. *BMJ Global Health*, 6(3), e005604; Ferryman, K. (2021). The dangers of data colonialism in precision public health. *Global Policy*, 12(S6), 90–92. Mishra, R. K. (2021). The appropriated body: Biometrics regime, the digital state and healthcare in contemporary India. *Global Policy*, 12(S6), 55–64; Sowemimo, op. cit. note 9; Sherwood, op. cit. note 16; Sherwood & Edwards, op. cit. note 16; Hendl & Roxanne, op. cit. note 19.

To counter the inequalities and coloniality that have shaped and been reinforced through medicine and health care, it is crucial to prioritize the health needs of structurally marginalized and oppressed populations under their own leadership in the design of individual technologies in specific target geographical areas.⁸⁹ To this end, it would seem crucial to ensure that the development, design, and implementation process of digital health technologies will be led by experts from the populations who will be using them. As we have discussed above, particularly indigenous scholars from decolonizing communities have emphasized the fundamental importance of culture to health and well-being. 90 In contexts affected by colonial legacies, it will be important to support the design of digital health technologies under the leadership of decolonizing communities, grounded in their native ontologies and epistemologies and health priorities, to ensure adequate healthcare services responding to population-specific health needs.

The importance of context-specific knowledges, community leadership, and health expertise then suggests the need for more localized technology development. Much scholarship in science and technology studies and on social determinants of health shows that (health) inequalities dominant in particular social environments shape health technologies, which then generate unequal health outcomes.⁹¹ It follows that approaches to digital health and individual technologies that will be able to improve health and mitigate health disparities dominant in particular societies will also need to be more local and context-specific. For the design of intersectionally beneficent technologies in different geographical contexts, it will be important to seek more local and community-led approaches. This will also require different approaches from those enabled by the still dominant methodologically white design of digital health technologies in the West and then their offering for global application, at times with mere

particular approaches to redressing harm. As many underserved populations reside in the global South, this would then require investing into local health innovation. In a recent commentary, knowledge from the global South is in the global South; Seye Abimbola⁹⁴ specifically argues that "the primary function of knowledge platforms is connection," and in this regard, he continues that "it is far more important to strengthen and build global South knowledge platforms than it is to include global South voices on global North platforms." To this end, he argues that the global North platforms ought to be provincialized and global South platforms centralized. Abimbola argues this in the context of academic knowledge production, but we believe that his arguments offer much food for thought relevant to digital health platforms and how they produce knowledge about health. We think that Abimbola's observations are especially important in light of the fundamental link between social conditions, culture, and health,

codesign and additional "cultural translation" of technologies. 92 In

many cases, such approaches will not be sufficient because they seek

to implement health technologies into contexts and user populations

that have not shaped their development. As the agency and health

needs of various populations will be different in each geographical and

sociopolitical context, this will require more context- and population-

specific digital health solutions, also sensitive to issues of unequal

access to intersectionally beneficent (digital) health services. In

particular, in decolonizing societies, support is needed for the

development of digital health for indigenous communities under their own leadership and in line with requirements of IDS. 93 These efforts

will need to be embedded within local decolonial movements and their

How exactly to achieve the strengthening of innovation in peripheralized and decolonizing parts of the world in the digital health context remains to be investigated, especially by experts with direct insights from these world areas. Building on a growing pool of research that traces structural inequalities within the tech industry, it would seem important to further explore how to effectively counter the persistent white western male domination in the field and the structures of outsourcing and exploitation within the industry.96

emphasized by scholars from populations living with (post)colonial trauma

and communities requiring trauma-informed and culturally appropriate

health care for their well-being.95

 $^{^{88}\}mbox{The}$ need to understand decolonization as a process unsettling old hierarchies and power structures with impact on material reality is particularly crucial, given that decolonization of theory is not sufficient to make a palpable societal change or bring about real-world health justice. Sherwood & Edwards, op. cit. note 16; Khan, M., et al., op. cit. note 87; Tuck, E. & Yang, K. W. (2012). Decolonization is not a metaphor, Decolonization: Indigeneity, Education & Society, 1(1), 1-40,

⁸⁹TallBear, op. cit. note 15; Tsosie, K. T., et al, op. cit. note 17; Smith, L. T. (2012). Decolonizing methodologies. Zed Books; Koobak, R., Tlostanova, M., & Thapar-Björkert, S. (2021). Postcolonial and postsocialist dialogues: Intersections, opacities, challenges in feminist theorizing and practice. Routledge

⁹⁰ Sowemimo, op. cit. note 9; Sherwood, op. cit. note 16; Sherwood, & Edwards, op. cit. note 16; Smith, op. cit. note 89. The importance of "returning" to or embracing one's culture appears particularly fundamental as Indigenous communities have not only experienced the suppression of their culture and ways of life by colonial systems but also survived against genocides that almost annihilated their existence as peoples as well as depleted and damaged their cultural heritage. In such context, the return to culture has a connection to survival, continuation of life and thriving within it, see BlackDeer (2023a), op. cit. note 18. 91Powers, M., et al., op. cit. note 10; Venkatapuram, op. cit. note 15, p. 3; Paradies, op. cit. note 16; Criado-Perez, op. cit. note 9; Chung, op. cit. note 15; Costanza-Chock, S. (2020). Design justice: Community-led practices to build the worlds we need. The MIT Press. For example, Venkatapuram has argued that "People's health or 'clinical' health outcomes and their antecedent capabilities to be healthy are significantly socially produced." see Venkatapuram (2011: 3), op. cit. note 15. From this perspective, the systemic practice of designing technologies in ways that fail to counter or even consider intersectional racial, gender and colonial inequalities, reinforces the same inequalities and harms structurally oppressed population groups.

⁹²TallBear, op. cit. note 15; Hendl & Roxanne, op. cit. note 19; Smith, op. cit. note 89; Costanza-Chock on cit note 91: Gewin V (2023) Pack up the parachute: Why global north-south collaborations need to change. Nature, 619(7971), 885; Krishnan, A., Abdilla, A., Moon, A. J., Souza, C. A., Adamson, C., Lach, E. M., Ghazal, F., Fjeld, J., Taylor, J., Havens, J. C., Jayaram, M., Morrow, M., Rizk, N., Quijano, P. R., Çetin, R. B., Chatila, R., Dotan, R., Mhlambi, S., Jordan, S., & Rosenstock, S. (2021). Decolonial Al Manyfesto. https://manyfesto. ai/. Petrakaki, D., Chamakiotis, P., & Curto-Millet, D. (2023). From 'making up' professionals to epistemic colonialism: Digital health platforms in the Global South. Social Science & Medicine (1982), 321, 115787.

⁹³TallBear, op. cit. note 15; Tsosie, K. T., et al., op. cit. note 17; Hendl & Roxanne, op. cit. note 19: Rainie, S. C., et al., op. cit, note 20.

⁹⁴Abimbola, S. (2023), Knowledge from the global South is in the global South. Journal of Medical Ethics, 49(5), 337-338, p. 337.

⁹⁵BlackDeer (2023a, 2023b), op. cit. note 18.

⁹⁶Turner, K., Wood, D., & D'Ignazio, C. (2021). The abuse and misogynoir playbook. In A. Gupta, A. Royer, C. Wright, F. A. Khan, V. Heath, E. Galinkin, R. Khurana, M. Bergamaschi Ganapini, M. Fancy, M. Sweidan, M. Akif, & R. Butalid (Eds.), State of AI ethics report (January 2021) (pp. 15-34). Montreal Ethics Institute; Sacchetto, D., & Andrijasevic, R. (2015). Beyond China: Foxconn's assembly plants in Europe. South Atlantic Quarterly, 114(1), 215-224.

Research and media reporting have pointed at the systemic outsourcing of underpaid yet "essential" labor to countries across Africa, Asia, and Europe's East, in ways that have reinforced old power hierarchies and global socioeconomic inequalities. As observed by Gregg and Andrijasevic, "underpaid female and migrant labor, some of it located in electronics assembly plants in East Asia and Eastern Europe, is the labor that powers the internet and its necessary hardware."97 This suggests that the strengthening of the localization of tech development in peripheralized parts of the world needs to go hand in hand with the bettering of the conditions in the tech and digital health industries in ways that will counter (neo) colonial extractivism and data colonialism as well as support the health and well-being of people employed in the industries. Indeed, it appears troubling that the development and global maintenance of digital health and medical AI currently relies on exploited labor from various peripheralized societies under conditions which undermine their physical and mental health and socioeconomic prosperity.

The nonideal sociopolitical and material conditions within which digital health technologies are developed and implemented need to become a central part of debates on the social and ethical implications of digital health. Instead of abstract and largely decontextualized contemplations on digital health, debates on the potential of these technologies for the improvement of human health need to be reconnected with the material conditions of human lives in different areas of the world. This will require a deeper engagement with persistent local and global inequalities that have shaped health (care), issues of unequal digital health outcomes, and concerns of health justice. We shall add that our discussion in this paper does not aim to provide definitive solutions to the many complex issues raised in the digital health context or those not resolved within debates on democratization. Still, we hope that a closer engagement with concerns of local and global health justice proposed by us will enable finding more pathways to such solutions.

7 | CONCLUSION

Our paper has investigated debates on the democratization of health care through digital health. We have identified that these debates conceptualize democratization as a matter of access to health information, health care, and patient empowerment. As we have argued, the growing pool of evidence documenting the risk of harm and lack of intersectionally equitable benefit from many digital health

technologies, as well as their incapacity to address the roots of health problems, seriously undermine the tales about the potential of digital health for democratizing and positively transforming health care. Instead, a growing pool of evidence suggests that much of digital health currently perpetuates as well as magnifies unequal health outcomes and health inequalities in already structurally disadvantaged and oppressed populations. Building on this research evidence, we have argued that not only debates on democratization need to be connected with concerns of social and political determinants of health, but also they need to go beyond issues of democratization toward concerns of health justice. Given that different populations in various geographical and sociopolitical environments will have specific health needs, we contend that a shift toward more justice-oriented digital health solutions will require more local approaches led by under-served and decolonizing communities.

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⁹⁷See Gregg, M., & Andrijasevic, R. (2019). Virtually absent: The gendered histories andeconomies of digital labour. *Feminist Review*, 123(1), 1–7, p. 1. Furthermore, reporting has uncovered that technologies, such as ChatGPT have relied the outsourced labor to grossly exploited African workers, who were tasked with making these technologies safer for users, while being traumatized in the process to the detrimental impact on their health and wellbeing; See Perrigo, B. (2023, Jan 18). Exclusive: OpenAl Used Kenyan Workers on Less Than \$2 Per Hour to Make ChatGPT Less Toxic. *Time*. https://time.com/6247678/openaichatgpt-kenya-workers/. These global racialized and gendered labor inequalities and structures of exploitation emphasize the need for anticolonial approaches—that is, approaches that would prevent the perpetuation of (neo)colonial inequalities in the future—to technologies and the global tech industry.