

COMMENTARY

# Ethical and Equitable Digital Health Research: Ensuring Self-Determination in Data Governance for Racialized Communities

Mozharul Islam<sup>1,2</sup>, Arafat A. Valiani<sup>3,4</sup>, Ranjan Datta<sup>5</sup>, Mohammad Chowdhury<sup>1,3</sup> and Tanvir C. Turin<sup>1,3</sup> 

<sup>1</sup>Department of Family Medicine, Cumming School of Medicine, University of Calgary, Calgary, AB, Canada, <sup>2</sup>Department of Sociology, Istanbul Sabahattin Zaim University, İstanbul, Türkiye, <sup>3</sup>Department of Community Health Sciences, Cumming School of Medicine, University of Calgary, Calgary, AB, Canada, <sup>4</sup>Department of History, Department of Indigenous, Race and Ethnic Studies, Global Health Program, University of Oregon, Eugene, OR, USA and <sup>5</sup>Canada Research Chair in Community Disaster Research at the Indigenous Studies, Department of Humanities, Mount Royal University, Calgary, Canada

**Corresponding author:** Tanvir C. Turin; Email: [turin.chowdhury@ucalgary.ca](mailto:turin.chowdhury@ucalgary.ca)

## Abstract

Recent studies highlight the need for ethical and equitable digital health research that protects the rights and interests of racialized communities. We argue for practices in digital health that promote data self-determination for these communities, especially in data collection and management. We suggest that researchers partner with racialized communities to curate data that reflects their wellness understandings and health priorities, and respects their consent over data use for policy and other outcomes. These data governance approach honors and builds on Indigenous Data Sovereignty (IDS) decolonial scholarship by Indigenous and non-Indigenous researchers and its adaptations to health research involving racialized communities from former European colonies in the global South. We discuss strategies to practice equity, diversity, inclusion, accessibility and decolonization (EDIAD) principles in digital health. We draw upon and adapt the concept of Precision Health Equity (PHE) to emphasize models of data sharing that are co-defined by racialized communities and researchers, and stress their shared governance and stewardship of data that is generated from digital health research. This paper contributes to an emerging research on equity issues in digital health and reducing health, institutional, and technological disparities. It also promotes the self-determination of racialized peoples through ethical data management.

**Keywords:** data governance; decolonization; digital health; digital technology; health equity; precision health equity; race; self-determination

## Introduction

The adoption of digital technologies in the field of health has accelerated at an incredible pace in the past two decades because of innovations introduced in the fields of data management, bioinformatics, and human genomics (among other fields pertinent to the health and life sciences). As evidenced by the coronavirus disease-2019 (COVID-19) pandemic (and continuing at the time of writing), some—but certainly not all—populations around the globe reaped the benefits of the digitalization in health that, for example, provided access to health facilities remotely.<sup>1</sup> Advances in digital technologies are largely viewed to be a productive resource in the health sciences, and thus their incorporation into its respective fields is expected to continue to increase. Nevertheless, digitalization of health may also create disparities between non-racialized and racialized populations in the global north, while adversely affecting

Mozharul Islam and Arafat A. Valiani contributed equally.

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populations of the global South as well.<sup>2,3</sup> Current research inquiring into the problem of inequality in digital health suggests that it is not technology itself but the individuals who, through their research and practices, may inadvertently contribute to unequal access to digital health services experienced by racialized population groups. The World Health Organization (WHO) has begun to address this problem in that it frames digital health to be an integral part of a society's health priorities that ought to be maintained in an ethical, equitable, and sustainable manner.<sup>4</sup> Despite this, the outcomes of using information technology in the field of health remain differentiated based on unequal socio-economic conditions of global populations and poor technological infrastructure within racialized communities.<sup>5,6</sup> Among several cited reasons that sustain such forms of inequality, racialized people typically do not have equal access to digital health services.<sup>7</sup> Therefore, multi-dimensional transdisciplinary research attentive to issues of equity, diversity, inclusion, accessibility and decolonization (EDIAD) seems to be urgently needed to ensure that racialized communities can equitably access digital health resources, practices, and commitments.<sup>8</sup>

Recent studies examining the problem of introducing social justice principles to digital health emphasize the need for ethical and equitable digital health research that deliberately enacts safeguards of the rights and interests of racialized communities.<sup>9,10,11,12</sup> One facet of such forms of enactment concerns data collection, ownership, and its application; this literature stresses the need for data collection and interpretation to be organized around the goal of benefitting racialized peoples that such forms of evidence enumerate and quantify.<sup>13,14,15,16,17,18,19,20,21,22,23</sup>

Building on these insights, we argue for the adoption of practices in digital health that promote self-determination for racialized communities specifically as it concerns the data collection and management processes. We suggest that such an approach might enable institutional-based researchers to work in partnership with members of racialized communities to curate data in a manner that is aligned with the latter's cultural-historical understandings of wellness and their health priorities while also affording them the right to define and revise the terms of consent over the use of their data for policy formulation, among other outcomes of such forms of equitable data governance. Such an approach to data governance honors, recognizes, and strives to build on the insights from research on Indigenous Data Sovereignty (IDS), which is an innovative and important body of decolonial scholarship contributed by Indigenous and non-indigenous researchers. It also extends recent adaptations of IDS to the context of health research involving racialized communities, who hail from former European colonies primarily in the global South, regarding strategies by which to practice EDIAD principals in digital health.<sup>24,25,26,27,28,29,30</sup> Though discussed in the context of genetics and precision medicine/health, which we bracket here, Valiani *et al.*'s (2023) concept of Precision Health Equity (PHE) is germane to our argument about aligning the goals of racialized communities, that emphasize self-determination, with the collection and storage of digital data. Models of digital data collection aligned with the decolonial commitments of PHE foreground a model of data sharing that is co-defined by members of a participating racialized community and researchers which stresses their shared governance and stewardship of data generated from a study.<sup>31</sup>

This paper is part of a body of emerging research that focuses on issues of equity in digital health and reduces health, institutional, and technological disparities, and—vitaly—promotes the self-determination of racialized peoples through the ethical management of data. Below, we highlight the voices and needs of historically underprivileged racialized communities as it concerns knowledge production in digital health. In adopting such an approach to digital health, it is our aim to also blend together concerns about intersectionality and post- and de-coloniality elaborated in the social and behavioral sciences, which we are convinced provide a productive lens by which to assess if and how technological innovations in data science promote EDIAD.<sup>32,33</sup>

In describing what practical forms equity and self-determination in data governance might take below (also referred to as EDIAD), we argue that such decolonial approaches might promote digital health literacy and engagement as preliminary studies of digital health during the height of the COVID public health crisis demonstrate.<sup>34</sup> In addition, we also delineate different challenges faced by the racialized communities in their access to digital health research and data and then suggest possible directions in future research about digital health in manners that promote full, inclusive, and equitable participation of racialized people.

### Self-determination, equitable data governance, and its meanings for racialized communities

Studies focusing on digital literacy reveal the possible diversity of contexts in which digital health tools might be employed, thus revealing the conditions under which digital health technologies can be effectively introduced.<sup>35,36</sup> Opportunities for training and knowledge exchange in digital health which inheres a decolonial approach must enable the self-determination of racialized communities. In this respect, the promotion of digital health literacy is paramount because, as recent insights suggest, it can democratize access to the forms of knowledge that constitute health care systems.<sup>37,38,39</sup> According to current findings, digital health literacy has the potential to promote equity for racialized people by providing them with the tools to navigate digital interfaces, electronic records, and diagnostic results, etc.<sup>40,41,42</sup> For example, a randomized clinical trial run in 2022 indicated that Black women who sought treatment for insomnia were able to receive cognitive behavioral therapy when they were trained in how to engage with, and thus mediate, therapies that they received digitally.<sup>43</sup>

Adopting approaches that embrace EDIAD in data collection, and in the management and application of data are vital to the promotion of self-determination of racialized communities in the practice of digital health. Because the EDIAD approaches adopted in this essay strive to both honor and contribute to existing bodies of relevant and allied knowledge, we turn to the findings regarding IDS advanced by social and health scientists which are particularly relevant as it concerns the rights, interests and ethical obligations of collecting data about peoples colonized by European imperial powers. Tahu Kukutai and John Taylor's (2016) seminal study identifies data control, data quality, and comprehensiveness of racialized data as being central to data governance that promotes the self-determination of racialized peoples and sovereignty in the context of Aboriginal and Indigenous peoples. As postcolonial historians comprehensively document, the classification, collection, dissemination, ownership, and impact of demographic data collected by European colonial states (and their postcolonial incarnations also) have created several contradictions historically, particularly related to the aims of creating such forms of quantitative knowledge.<sup>44,45,46,47,48</sup> The COVID-19 pandemic revealed the problematic nature of such data, and the institutional-based methods on which it depends, underlining how health data about Black, Indigenous, Asian, South Asian, Caribbean, and other racialized groups has typically been collected and analyzed with reference to academic and broader public health concerns which, in many cases, have been privileged over consistently providing benefits and access to treatments to racialized and Indigenous communities.<sup>49</sup>

The findings of C. Matthew Snipp (2016) suggest that data collection, curation, and access, approached in a manner that is aligned with EDIAD, can afford members of racialized communities with the power to determine who should be counted among them, what their interests and priorities data collection and curation serves, and how data libraries might be accessed, by whom and over what kind of time horizon. Historically, institutional data collections have been monopolized by state institutions, often colonial ones, which thus has historically constrained demographic data collection and it remains a legacy that constrains the prospect for truly digital health that is aligned with EDIAD.<sup>50</sup> As a concept, IDS powerfully redefines the locus of authority over the collection, use, and access of data, relocating it to Indigenous nations, their territories, and in alignment with their ways of life. IDS does not presume to construct a template, or 'one size fits all', prescription. Indeed, the meaning of IDS rightfully differs between communities varying as it might on, for example, how a respective community and its polity defines the aims, rights, and responsibilities of community-based data and information.<sup>51,52</sup> In all, IDS proposes a decolonial approach to data collection, storage, and access which seeks to provincialize the dominance of the data-dependent nation-state system privileging instead, the priorities, benefits, and knowledge cultures of more local racialized communities.

While Kukutai and Taylor's original interventions focused largely on demographic data, we foresee future research in digital health acknowledging and contributing to explorations of IDS by extending its spirit, which is grounded in notions of sovereignty for communities historically subjected to colonial rule, to the self-determination of racialized communities.<sup>53,54,55,56</sup> In making such a suggestion, we are convinced that such an adaptation would be productive, and aligned with EDIAD commitments, particularly as it concerns the ownership and handling of biomedical data for the purpose of promoting

health equity. In this regard, personal health-related data of racialized communities have a purpose for both the health outcomes for racialized individuals (and families) and broader public health initiatives and thus are at the forefront of research about EDID and digital health.<sup>57</sup> Such debates are diverse, ranging in a number of relevant topics falling under the coupled rubric of sovereignty and self-determination ranging from definitions of data sovereignty and how it differs from other visions of sovereignty, such as cyber sovereignty, internet sovereignty, digital sovereignty, national sovereignty, and socio-political sovereignty.<sup>58</sup>

Recent studies about data self-determination and sovereignty interrogate the institutionalized practice in which data governance has typically been the sole jurisdiction of national states.<sup>59,60</sup> These studies offer a reconsideration of both the authority of the governments over data as well as the place of IDS within such an established system of 'data power'.<sup>61,62</sup> Floridi's (2020) findings recommend the necessity to systematically research data sovereignty to nurture scholarly discussions among researchers working on data self-determination and sovereignty while also including policymakers to ground commitments, protocols, and practices of EDIAD-informed data governance in established institutions, authorities and, ultimately, the state. In this regard, Winandy (2011)<sup>63</sup> used an example of the German Electronic Health Card (eHC) system, which ensures authentication, authorization, and audit mechanisms for local communities to achieve data autonomy over their health-related data; the eHC has made strides in placing control over access to health data in the hands of local communities. In our view, the case of the eHC is a powerful one that exemplifies the purchase of approaches that share affinities with EDIAD commitments that privilege principals of community-centered autonomy, control, power, and privacy of health-related digital data.<sup>64</sup> Similarly, such forms of data governance also enable local communities to control and verify the geolocation of their data.<sup>65,66,67</sup>

### Current scenarios and challenges of digital data

Previous research on race and information technology suggests that unequal access, defined broadly, to digital devices reproduces social forms of inequality because access to computers and the internet is, in fact, a conduit for racialized communities to access information.<sup>68</sup> These studies also indicate that as long as marginalized groups are not empowered to deploy digital technology (which is part of the definition of digital technology access), existing inequalities are likely to be reproduced—or even exacerbated—because these communities remain unable to learn about technological innovations.<sup>69</sup> Ruha Benjamin also stresses that technological advances impact almost every dimension of a modern individual's economic, political, social, and cultural life; we extend this observation to an individual's family and community also. Racialized people have historically participated in health research or data collection processes often without becoming fully informed of the risks to their health, privacy, or potential outcomes of the research data.<sup>70,71,72</sup> While one study seemed to suggest that African Americans and Latinx peoples are considerably more active in using the internet than white people,<sup>73</sup> a series of studies counter such a claim indicating that there exists a digital divide in personal technology consisting of a racialized boundary that separates low and high-tech access.<sup>74,75,76</sup> Similarly, Nakamura (2002) interrogates the dual presumptions that assert that Asian Americans have a natural proclivity towards digital culture, and Black Americans comparatively 'do not'; their findings indicate that such conclusions reify 'race theories' in which Asians are viewed as a 'model minority', capable of modern practices (like technology use) and placed higher in a hierarchy of races, at the bottom of which are typically—and reprehensively—located Black Americans. Although the findings on race and information technology support a utopian ideology of a race-free culture of digital technology, that will reduce the social differences between the racialized communities, through universal access to digital information,<sup>77-78</sup> Nelson (2002) posits that racism in technology is a structural barrier and it is considered a liability and a significant source of exclusion in digital life.

Building on these findings in the study of race and information technology, we emphasize that engagement with digital technology is a central challenge for racial and ethnic minority groups striving to attain equal benefits in the context of digital health. For example, a study of online smoking termination

programs found that racial and ethnic minority groups were less likely than non-racialized individuals to create an account in such programs; Black Americans in particular were less likely than non-racialized individuals to log into such programs that was underwritten (and therefore offered free) by National Cancer Institute.<sup>79,80</sup> Therefore, we suggest that future research on equitable access to digital health develop a deeper understanding of the manners in which racialized communities engage with digital health technologies; the findings of such inquiries might explain how members of these communities might be better included and thus be afforded the tools and opportunities to engage with digital health.<sup>81,82,83</sup>

### Ethics and equity in research: Optimal practical guidelines and implementation process

As we have argued, a lack of knowledge about digital technology is one important barrier to access to digital research and design experienced by racialized communities and thus an impediment to benefiting from innovations in digital health.<sup>84</sup> Existing insights suggest that the employment of community-based participatory research (CBPR) design can ensure that interventions of digital health, and its associated tools, address the needs of the racialized people particularly because when community participants engage in the design of research, they are empowered to determine the research outputs that are most meaningful to them and their community members.<sup>85</sup> Collaborative research design also has the potential to equally engage both the researchers and community members in such a way that the research process becomes engaging and a learning opportunity for all participants, and thus far more effective.<sup>86,87,88,89</sup> In this regard, research focusing on knowledge about and engagement with digital health tools ought to explore how community health workers, providers, receivers, and other health-related organizations can utilize their strategies best and build communication techniques and digital tools so that they can ensure equal benefits of digital health services for all the community people.<sup>90</sup> The effectiveness of participatory research models has been affirmed in the University of Pittsburgh, where Equity Design Thinking has been pioneered particularly for its facility.<sup>91,92,93</sup>

In both Canada and the United States significant breaches in research ethics protocols in internal review board-approved studies (IRB) involving Indigenous communities have resulted in the creation of significantly higher research standards for studies involving Indigenous and Aboriginal, and/or individuals and/or communities.<sup>94,95,96,97</sup> While we applaud these important reforms and acknowledge the research community's broad adoption of such protocols, Indigenous and racialized peoples remain unevenly included in such forms of research; and when they are, established IRB protocols are often insufficient in providing access to the benefits of such research particularly as it concerns new treatments or diagnostics.<sup>98,99,100,101</sup>

Again, the findings from researchers in and around the IDS space are a good starting place to explore strategies by which to achieve both inclusion and equity in digital health. In the late 1990s, researchers at the First Nations Information Governance Centre (FNIGC) conducted a health survey and, through reflections on how the data that would be produced and used, created OCAP® which is now a trademark held by the FNIGC and protocol to maintain Ownership, Control, Access and Possession of data pertaining to Indigenous peoples.<sup>102</sup> As an alternative to the growing open-data environment that is being endorsed in some scientific circles, though partially constrained by existing patient privacy constraints of course, CARE principals (Collective Benefit, Authority to Control, Responsibility, and Ethics) seek to safeguard the interests of Indigenous communities when it concerns data collection. These principles seek to complement FAIR principles which emphasize Findable, Accessible, Interoperable, and Reusable data curation and design.<sup>103</sup>

Though early in their explorations, scholars are investigating parallel problems of inclusion and equity in human genomics, precision medicine (PM) and precision health (PH) research that involves racialized communities suggest a productive pathway to equitable data governance.<sup>104,105,106</sup> The findings of these scholars acknowledge important strides in the field of human genomics and precision medicine, which depends in significant ways on digitally coded and organized genomic data, to include

racialized communities in studies in this increasingly important field. Importantly, these researchers identify a unique problem in which inclusion, while necessary, is insufficient in also providing equity to racialized groups that might be included in human genomics research. Specifically, they underscore the issue of data governance, emphasizing its co-sharing and stewardship, in contrast to conventional data ownership models that typically place control in the hands of university-based researchers (or the institutions with which they are affiliated).<sup>107-108</sup> We identify a comparable problem in initiatives that strive to include racialized communities in digital health and thus adapt the following prescription concerning equitable inclusion:

“the co-creation of governance protocols, structures, and timelines through a partnership between racialized community members and [digital health] researchers, perhaps also including policy makers and other entities funding such research”<sup>109</sup>

In our view, such an approach might genuinely enable the self-determination of racialized communities and thus make digital health both inclusive and equitable.

### Conclusion and recommendation

The equitable governance of health data pertaining to racialized communities is consequential for the design of EDIAD-committed digital health because it includes them in the research enterprise, inviting them to engage with, manage, control, and own their data, ultimately to improve health outcomes and health knowledge and training within these communities. We are convinced that self-determination in digital health research involving racialized communities can be achieved. We draw inspiration from, and seek to deepen partnerships with, the First Nations Information Governance Center(s) that lent Indigenous communities in Turtle Island significant control over information pertaining to them.<sup>110</sup> Future research in digital health can explore institutional solutions to achieve similar forms of jurisdiction over data about racialized peoples and its attendant knowledge practices. Digital health research committed to EDIAD principals must develop a path for the racialized communities to ensure their self-determination in the collection of their health data. We believe that it comprises awareness, participation, control, and utilization of their health data. In order to achieve this, we suggest the following principles be undertaken in the context of digital health research involving racialized communities particularly:

1. Recognition that full participation in research projects is essential to maintain equal rights of access to health services must be broadly recognized and institutionalized.
2. CBPR approaches must be substantively incorporated into research rendering racialized communities' partners in the enterprise. Equitable inclusion in research therefore requires that data-sharing and stewardship characterize governance models of the knowledge and data produced from research.
3. Research results must be published in a language understandable to the racialized people and returned to them on a schedule that is co-defined by researchers and community members/representatives.
4. As part of CBPR, it is optimal the aims of digital health research are aligned with the cultural-historical views of racialized community members regarding the body, disease, and wellness.
5. Research team members must respect other sensitive issues related to racialized communities' historical, geographical, and demographic factors.

**Competing Interest.** The authors has no competing interest to declare.

## Notes

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