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Abstract

Our paper interrogates the ethics of digital pandemic surveillance from Indigenous perspectives. The COVID-19 pandemic has shown that Indigenous peoples are among the communities most negatively affected by pandemic infectious disease spread. Similarly to other racialized subpopulations, Indigenous people have faced strikingly high mortality rates from COVID-19 owing to structural marginalization and related comorbidities, and these high rates have been exacerbated by past and present colonial dominance. At the same time, digital pandemic surveillance technologies, which have been promoted as effective tools for mitigating a pandemic, carry risks for Indigenous subpopulations that warrant an urgent and thorough investigation. Building on decolonial scholarship and debates about Indigenous data sovereignty, we argue that should Indigenous communities wish to implement digital pandemic surveillance, then they must have ownership over these technologies, including agency over their own health data, how data are collected and stored, and who will have access to the data. Ideally, these tools should be designed by Indigenous peoples themselves to ensure compatibility with Indigenous cultures, ethics and languages and the protection of Indigenous lives, health and wellbeing.

KEYWORDS
agency, colonialism, digital health technologies, health justice, Indigenous data sovereignty, pandemic surveillance, vulnerability

1 | INTRODUCTION

Digital tracing systems have become prominent strategies to mitigate the spread of infectious diseases, as recently demonstrated in the use of contact-tracing apps in the COVID-19 pandemic.[1] In this paper, we interrogate the ethical implications of these technologies for Indigenous peoples from Native American perspectives.[2] Our paper responds to evidence regarding the high levels of vulnerability of Indigenous populations in a pandemic context; poor epidemiological data collection practices with respect to Indigenous health; and

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[1]Ienca, M., & Vayena, E. (2020). On the responsible use of digital data to tackle the COVID-19 pandemic. *Nature Medicine, 26*(4), 463–464; Lucivero, F., Hallowell, N., Johnson, S., Prainsack, B., Samuel, G., & Sharon, T. (2020). COVID-19 and contact tracing apps: Ethical challenges for a social experiment on a global scale. *Journal of Bioethical Inquiry, 17*(4), 835–839. doi:10.1007/s11673-020-10016-9

[2]The terms Indigenous and Native American are not one and the same. The term Indigenous is broader and references all pre-colonial peoples, including Native Americans, who have long-term ancestry within the North Canadian Arctic region, Canada, and the Americas.

a lack of debate about the ethical and social implications of digital pandemic surveillance from Indigenous perspectives.[3] We enquire whether digital technologies could help protect Indigenous lives in a pandemic context by bridging the gap on Indigenous peoples' data and mitigating the spread of an infectious disease, and under which circumstances.[4]

Our enquiry builds on theories of health justice,[5] which recognize the crucial impact of physical and social environments and structures on health. Indigenous scholars have argued that Indigenous health and wellbeing have long been undermined by colonialism and resulting systemic inequalities, and have identified decolonization as imperative in the survival and thriving of Indigenous peoples[6]. Many scholars hold that the process of decolonization requires that agency is given back to Indigenous peoples and communities so that Indigenous people have control over their lives and futures.[7] Agency has also been theorized to be crucial in the health context, as having agency enables Indigenous communities to increase self-determination, sovereignty, and control in the health sphere and improve the health and wellbeing of Indigenous people.[8]

Building on decolonial scholarship, we interrogate infectious disease tracing apps as potential tools for mitigating a pandemic in Indigenous communities, while also investigating concerns about the risks of data colonialism. In particular, we explore the devastating impact of the COVID-19 pandemic on Native American communities and its structural causes, and examine the conditions under which digital pandemic surveillance could protect Indigenous lives, health and wellbeing. In this enquiry, we connect debates about the ethics of COVID-19 apps with scholarship on Indigenous data sovereignty

(IDS),[9] which is centred around the requirement for Indigenous governance of Indigenous data. While the debates on IDS have articulated the importance of and demands for sovereignty with respect to Indigenous data, these concerns have gained new urgency in a global pandemic and warrant a further comprehensive investigation. Thus, we interrogate how the expansion of IDS within digital pandemic surveillance models would ensure health benefits and protections to Indigenous people. We argue that Indigenous peoples must have agency over their own health data and over how these data are administered and collected, which would, in turn, influence digital pandemic surveillance systems towards anti-colonial perspectives. Our enquiry focuses on an investigation of the implications of digital pandemic surveillance for Indigenous peoples in the United States, but our observations have broader implications for debates about the risks and benefits of digital pandemic surveillance for Indigenous peoples more broadly.

2 | NATIVE AMERICANS AND COVID-19

The vulnerability of Indigenous lives and health in an infectious disease context has most recently been manifested in the COVID-19 pandemic.[10] In the United States, Native Americans, together with other racialized subpopulations, have been affected by disproportionately high morbidity and mortality rates from COVID-19—between June 2020 and March 2021, at least one in every 490 Native Americans died in the pandemic, compared with one in 203 Latino, 559 Black, 1048 Asian, 1125 Pacific Islander and 2255 White people.[11] The Navajo Nation was particularly adversely affected, and

[3]Curtice, K., & Choo, E. (2020). Indigenous populations: Left behind in the COVID-19 response. Lancet, 395(10239), 1753. doi:10.1016/S0140-6736(20)31242-3; Cormack, D., & Kukutai, T. (2020, October 29). [BigDataSur-COVID] Pandemic paternalism: A reflection on Indigenous data from Aotearoa. Retrieved from https://data-activism.net/2020/10/bigdatasur-covid-pandemic-paternalism-a-reflection-on-indigenous-data-from-aotearoa/

[4]Our analysis is a result of an interdisciplinary collaboration between a digital humanities theorist (Tiara Roxanne) and a philosopher and bioethicist (Tereza Hendl). Roxanne is a Tarascan-Mestiza-Indigenous scholar, cyberfeminist and artist, whose work on data colonialism and digital colonialism explores colonial structures embedded within AI learning systems. Hendl's research is concerned with issues of justice, vulnerability, empowerment and solidarity, including in the digital health context. Her positionality and critical outlook on structural inequalities, imperial and colonial domination are informed by her experience of growing up in the then-Czechoslovakia when it was occupied by the Soviet Union and the Warsaw Pact armies and during the subseqent capitalist transformation as well as spending a part of her adult life in colonial Australia.

[5]Powers, M., & Faden, R. (2019). Structural injustice: Power, advantage, and human rights. Oxford, U.K.: Oxford University Press; Venkatapuram, S. (2011). Health justice. Cambridge, U.K.: Polity Press; Chung, R. (2021). Structural health vulnerability: Health inequalities, structural and epistemic injustice. Journal of Social Philosophy, 52(2), 201–216. doi:10.1111/josp.12393; Sherwood, J. (2013). Colonisation – It's bad for your health: The context of Aboriginal health. Contemporary Nurse, 46(1), 28–40.

[6]Sherwood, op. cit. note 5; LaVallee, A., Van Styvendale, N., Innes, R. A., & Henry, R. (Eds.). (2018). Global Indigenous health: Reconciling the past, engaging the present, animating the future. Tucson, AZ: University of Arizona Press; Silburn, K., Reich, H., & Anderson, I. (Eds.). (2016). A global snapshot of Indigenous and tribal peoples' health: The Lancet-Lowitja Institute Collaboration. Melbourne: Lowitja Institute.

[7]McPhail-Bell, K., Bond, C., Brough, M., & Fredericks, B. (2015). "We don't tell people what to do": Ethical practice and Indigenous health promotion. Health Promotion Journal of Australia, 26(3), 195–199; Radu, I. (2018). Uschiniichisuu futures: Healing, empowerment, and agency among the Chisasibi cree youth. In R. Henry, A. LaVallee, N. Van Styvendale & R. A. Innes (Eds.), Global Indigenous health: Reconciling the past, engaging the present, animating the future (pp. 211–234). Tucson, AZ: University of Arizona Press.

[8]Ibid.

[9]Rainie, S. C, Kukutai, T., Walter, M., Figueroa-Rodríguez, O. L., Walker, J., & Axelsson, 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). Oxford: African Minds and International Development Research Centre; Carroll, S. R., Rodriguez-Lonebear, D., & Martinez, A. (2019). Indigenous data governance: Strategies from United States native nations. Data Science Journal, 18(31), 1–15; Lovett, R., Lee, V., Kukutai, T., Cormack, D., Rainie, S., & Walker, J. (2019). Good data practices for Indigenous data sovereignty and governance. In A. Daly, S. K. Devitt & M. Mann (Eds.), Good data (pp. 26–36). Institute of Network Cultures.

[10]Concerns have been raised about the disproportionate effect of COVID-19 on Indigenous communities across the world. For example, in Canada, Indigenous populations have been at higher risk of developing COVID-19, owing to structural marginalization—for example, 24% of Indigenous people living in urban areas were in poverty. Arriagada, P., Hahmann, T., & O'Donnell, V. (2020). Indigenous people in urban areas: Vulnerabilities to the socioeconomic impacts of COVID-19. Ottawa: Statistics Canada. Indigenous communities in Brazil have been particularly badly affected, and the government's response has generated fears of genocide of Indigenous people in the pandemic. Marcos, M. S., FitzGerald, G., Tickner, A. B., Behera, N. C., Pan, C., Shih, C. Y., & Shimizu, K. (2020). COVID-19, democracies, and (de)colonialities. Democratic Theory, 7(2), 82–93; Phillips, T. (2020, May 3). "We are on the eve of a genocide": Brazil urged to save Amazon tribes from COVID-19. The Guardian. Retrieved from https://www.theguardian.com/world/2020/may/03/eve-of-genocide-brazil-urged-save-amazon-tribes-covid-19-sebastiao-salgado.

[11]It is important to clarify that the data are incomplete, as 18 out of 51 states did not provide data regarding Indigenous deaths. APM Research Lab. (March 5, 2021). Color of coronavirus data file. Retrieved from https://www.apmresearchlab.org/covid/deaths-by-race. For more research on the systemic causes of high morbidity and mortality rates in racialized subpopulations, see Bhala, N., Curry, G., Martineau, A. R., Agyemang, C., & Bhopal, R. (2020). Sharpening the global focus on ethnicity and race in the time of COVID-19. Lancet, 395(10338), 1673–1676; Chowkwanyun, M., & Reed, A. L. (2020). Racial health disparities and Covid-19—Caution and context. New England Journal of Medicine, 383(3), 201–203. doi:10.1056/NEJMp2012910.

half way through 2020 had a COVID-19 infection rate higher than that of any U.S. state.[12]

However, the exact scale and impact of the pandemic in Indigenous communities is unclear and obscured by insufficient data collection and the exclusion of Indigenous communities from data sets and health policy analyses.[13] The Urban Indian Health Institute explains: 'Current standard data collection practices by many federal, state, and local entities effectively omit or misclassify American Indian and Alaska Native (AI/AN) populations, both urban and rural.'[14] To this day, there is a serious lack of precisely collected data regarding Indigenous COVID-19 morbidity and mortality rates.

Moreover, the evidence of the disproportionate burden of the pandemic on Indigenous people is being erased through racial misclassification. A *Guardian* news report released during the first peak of COVID-19 in April 2020 reveals the inaccuracies regarding how the data were collected and categorized:

> About 80% of state health departments have released some racial demographic data, which has already revealed stark disparities in the impact of Covid-19 in black and Latinx communities. But of those states, almost half did not explicitly include Native Americans in their breakdowns and instead categorized them under the label "other."[15]

A recent report in *Science*[16] called the data on Native Americans 'a national disgrace' and cited Abigail Echo-Hawk, a citizen of the Pawnee Nation of Oklahoma and director of the Urban Indian Health Institute: 'I see being eliminated in the data as an ongoing part of the continuing genocide of American Indians and Alaska Natives. If you eliminate us in the data, we no longer exist.' In her reflection on Native Americans' erasure from COVID-19 datasets, Echo-Hawk clearly perceives the practice as part of the broader colonial project of marginalizing and eradicating Indigenous lives.[17]

The socio-economic conditions in which Native Americans currently live in the United States make them more prone to contracting the virus. Indigenous people live in multigenerational housing, meaning that it was nearly impossible to isolate during the peak spread of the virus.[18] In addition, while handwashing is a core preventive measure, Indigenous (as well as Black and Latinx) households are more likely to lack complete plumbing than White households.[19] In the Navajo nation, a third of the community lacks access to running water, making proper hygiene a challenge. Close and Stone, who work at a critical access hospital in rural eastern Arizona, explain:

> Several families in our community set up camping tents in their yards to quarantine infected household members, but the sharing of bathrooms and eating utensils contributed to secondary household attack rates above 80%. Nearly every household here includes a grandparent, and many include a great-grandparent. It's rare to encounter a patient with Covid-19 who doesn't live with at least one high-risk person.[20]

Socioeconomic marginalization and lack of healthcare and infrastructure for tribal nations have also created conditions in which Indigenous people are more likely to die when contracting the virus.[21] Many scholars have argued that structural disadvantage has led to comorbidities in racialized people, which are behind the high mortality rates in these subpopulations.[22] Native Americans currently have the highest rates of diabetes in the United States, which is a comorbidity that places them at a disproportionately higher risk for severe complications and fatal outcomes related to COVID-19.[23] In a recent investigation of correlates of early COVID-19 infection rates in Native American populations, Rodriguez-Lonebear and her colleagues argue that 'With inadequate public health infrastructure, limited medical resources, and high rates of poverty, communities on Indian reservations are poorly equipped to manage a pandemic such as COVID-19.'[24]

The evidence regarding the living conditions of Native American populations highlights the systemic disadvantage and colonial oppression located within broader social structures, including

[12]Crepelle and Murtazashvili noted that this was particularly striking considering population density: 'The Navajo Nation encompasses over 27,000 square miles and has a population of about 150,000 people. By contrast, New York City, where most of New York's COVID-19 cases are concentrated, has 8 million plus residents in just over 300 square miles.' Crepelle, A., & Murtazashvili, I. (2020). *COVID-19, Indian reservations, and self-determination* (pp. 1–8). Arlington: Mercatus Center at George Mason University, p. 1.

[13]Insufficient and poorly disaggregated data collection, particularly regarding race and ethnicity, is a common problem in epidemiology, which has been met with more criticism since the outbreak of the COVID-19 pandemic. Hendl, T., Chung, R., & Wild, V. (2020). Pandemic surveillance and racialized subpopulations: Mitigating vulnerabilities in COVID-19 apps. *Bioethical Inquiry*, 17(4), 829–834. Problematic data collection practices are especially concerning in Indigenous populations, owing to structures of colonial oppression. Curtice & Choo, op. cit. note 3.

[14]Urban Indian Health Institute. (2020). *Best practices for American Indian and Alaska Native data collection*, Retrieved from https://www.uihi.org/resources/best-practices-for-american-indian-and-alaska-native-data-collection/

[15]Nagle, R. (2020, 24 Apr). Native Americans being left out of US coronavirus data and labelled as "other." *The Guardian*. Retrieved from https://www.theguardian.com/us-news/2020/apr/24/us-native-americans-left-out-coronavirus-data

[16]Wade, L. (2020, 24 Sep). COVID-19 data on Native Americans is "a national disgrace." This scientist is fighting to be counted. *Science*. Retrieved from https://www.sciencemag.org/news/2020/09/covid-19-data-native-americans-national-disgrace-scientist-fighting-be-counted

[17]In the same piece, Echo-Hawk is cited to state that the US system "has built a perfect environment to kill us in a pandemic." Wade, op. cit. note 16.

[18]Close, R. M., & Stone, M. J. (2020). Contact tracing for Native Americans in rural Arizona. *New England Journal of Medicine*, 383(3), e15(1)–e15(2).

[19]Ibid.; De Soto, J., & Hakim, S. (2020). Medical basis for increased susceptibility of COVID-19 among the Navajo and other Indigenous tribes. *Journal of Biomedical Research and Reviews*, 3(1), 37–41. Rodriguez-Lonebear, D., Barceló, N. E., Akee, R., & Carroll, S. R. (2020). American Indian reservations and COVID-19: Correlates of early infection rates in the pandemic. *Journal of Public Health & Management Practice*, 26(4), 371–377.

[20]Close & Stone, op. cit. note 18.

[21]Close & Stone, op. cit. note 18; De Soto & Hakim, op. cit. note 19; Rodriguez-Lonebear et al., op. cit. note 19.

[22]Bhala et al., op. cit. note 11; Chowkwanyun & Reed, op. cit. note 11.

[23]Urban Indian Health Institute. (2020). *Special diabetes program for Indians (SDPI): Mitigating COVID-19 risk*. Retrieved from https://www.uihi.org/resources/special-diabetes-program-for-indians-sdpi-mitigating-covid-19-risk/. Fang, L., Karakiulakis, G., & Roth, M. (2020). Are patients with hypertension and diabetes mellitus at increased risk for COVID-19 infection? *Lancet Respiratory Medicine*, 8(4), e21. doi:10.1016/s2213-2600(20)30116-8

[24]Rodriguez-Lonebear et al., op. cit. note 19.

healthcare systems and interventions. It also suggests the need to meditate on ways in which the structural disadvantage ought to be eliminated from the system and domains shaped by oppression, such as healthcare and federal funding, multi-generational housing, and the severe deficiency of basic needs for hygiene and overall health. The structural conditions of Native American lives call for urgent solutions, which would protect the health and wellbeing of Indigenous peoples, with respect to COVID-19 as well as other infectious diseases that might emerge in the future.

3 | DIGITAL PANDEMIC SURVEILLANCE AND ITS RISKS TO INDIGENOUS PEOPLE

Since the outbreak of the COVID-19 pandemic, there has been much emphasis on digital pandemic surveillance as a mode of suppressing the spread of the disease. In particular, COVID-19 tracing apps have gained much traction in debates about infection tracing.[25] These technologies have assisted in providing necessary information regarding high- and low-risk areas and alerted users about the need to get tested. However, digital pandemic surveillance has also gained much attention for its potential to exacerbate the vulnerabilities of structurally marginalized subpopulations, particularly racialized people.[26]

Digital pandemic surveillance technologies give rise to various ethical questions with respect to how the data are handled and stored and who has access to them.[27] In COVID-19 contact-tracing apps, even when geolocation data are self-reported and anonymized, some schemes involve data storage in centralized databases run by state authorities. For example, proximity tracing technology, such as the PEPP-PT,[28] has been welcomed as privacy-maintaining technology for its use of Bluetooth for contact tracing, rather than geolocation data. Nevertheless, alongside a decentralized version of the technology, which holds user IDs locally on their smartphones,[29] a centralized version has been developed, which involves storing data on servers controlled by state (health) authorities and which has been

met with criticism for the potential access to data by governments.[30] Particular concerns have been raised in regard to how data will be handled and the implications for users.[31]

Some have raised concerns that centralized versions of digital pandemic surveillance data can exacerbate the vulnerabilities in structurally marginalized subpopulations.[32] Hendl, Chung and Wild[33] have argued that while COVID-19 apps promise to decrease infection rates, if they are not designed and executed carefully, they could exacerbate situational vulnerabilities in structurally disadvantaged subpopulations as well as creating pathogenic vulnerabilities,[34] generated in contexts where pre-existing vulnerability is magnified by oppression.[35] In their view, rich evidence that COVID-19 measures have led to the disproportionate policing and criminalization of racialized people in many countries across the world raises serious concerns about the ethical implications and risks involved in digital pandemic surveillance.[36] These risks are exacerbated in Indigenous populations, owing to the legacy of colonialism, genocide and racial oppression.[37]

Moreover, the risk that digital pandemic surveillance will intensify the already omnipresent oppression of Native Americans has

[25]World Health Organization (WHO). (2020). *Guidelines on ethical issues in public health surveillance*. Retrieved from https://www.who.int/ethics/publications/public-health-surveillance/en/

[26]Benjamin, R. (2020). *Black skin, white masks: Racism, vulnerability and refuting black pathology*. Department of African American Studies, Princeton University, April 15, 2020. Retrieved from https://aas.princeton.edu/news/black-skin-white-masks-racism-vulnerability-refuting-black-pathology?fbclid=IwAR3Hufh0-ZKmLb5GucR2Nwahi8Utzc0ZDFocqYwBvG2vArELv6mcgQ-63xY. Hendl et al., op. cit. note 13.

[27]Ienca & Vayena, op. cit. note 1; Ranisch, R., Nijsingh, N., Ballantyne, A., van Bergen, A., Buyx, A., Friedrich, O., ... Wild, V. (2020). Digital contact-tracing: Ethical guidance for trustworthy surveillance tools. *Ethics and Information Technology*, 23, 285–294. doi:10.1007/s10676-020-09566-8; Bock, K., Kühne, C. R., Mühlhoff, R., Ost, M. R., Pohle, J., & Rehak, R. (2020). *Data protection impact assessment for the Corona App*. Berlin: Alexander von Humboldt Institute for Internet and Society. Retrieved from https://www.hiig.de/publication/data-protection-impact-assessment-for-the-corona-app/

[28]Pan-European Privacy-Preserving Proximity Tracing (PEPP-PT). (2020). *Overview: How we preserve privacy and maintain security*. Retrieved from https://www.pepp-pt.org/content.

[29]Troncoso, C., Payer, M., Hubaux, J.-P., Salathé, M., Larus, J., Bugnion, E., ... Pereira, J. (2020). *Decentralized privacy-preserving proximity tracing*. Retrieved from https://github.com/DP-3T/documents/blob/master/DP3T%20White%20Paper.pdf

[30]Bock et al., op. cit. note 27; Ada Lovelace Institute. (2020). *COVID-19 rapid evidence review: Exit through the app store?* Retrieved from https://www.adalovelaceinstitute.org/our-work/covid-19/covid-19-exit-through-the-app-store/; Joint Statement. (2020). *Joint statement on contact tracing*. Retrieved from https://drive.google.com/file/d/1OQg2dxPu-x-RZzETlpV3lFa259Nrpk1J/view

[31]Hendl et al., op. cit. note 13; Lucivero et al., op. cit. note 1.

[32]Hendl et al., op. cit. note 13; Schaefer, O., & Ballantyne, A. (2020, May 4). Downloading COVID-19 contact tracing apps is a moral obligation. *Journal of Medical Ethics Blog*. Retrieved from https://blogs.bmj.com/medical-ethics/2020/05/04/downloading-covid-19-contact-tracing-apps-is-a-moral-obligation/ [accessed Jun 4, 2020].

[33]Hendl et al., op. cit. note 13.

[34]Rogers, W., Mackenzie, C., & Dodds, S. (2012). Why bioethics needs a concept of vulnerability. *International Journal of Feminist Approaches to Bioethics*, 5(2), 11–38.

[35]Hendl et al., op. cit. note 13, use the taxonomy of vulnerability developed by Rogers, Mackenzie and Dodds, who distinguish between *inherent* vulnerability, stemming from one's corporeality; *situational* vulnerability, arising from one's personal, social, political, economic, or environmental situatedness as an individual or member of a group; and *pathogenic* vulnerability, emerging in sociopolitical contexts where a pre-existing vulnerability is multiplied by oppression or injustice.

[36]Hendl et al. argue: 'In order to meet the goal of infection control, it seems important to prioritize the most confidential and vulnerability mitigating COVID-19 technology—that is, technology without geolocation data tracing and with decentralized data storage and access.' Hendl et al., op. cit. note 13, p. 831.

[37]The authors are committed to the practice of conscientious refusal in refusing to educate the reader on the history of colonial violence. Should the reader lack background information on past and present socio-political manifestations and impacts of colonialism, they are invited to do the work of familiarizing themselves with the subject by researching the rich and plentiful scholarship on colonialism and structural racism. The authors find it particularly problematic that members of structurally marginalized groups are constantly required to provide evidence to 'prove' socio-political oppression in 'debates' about the impact or even the very existence of the said oppression. As descendants and members of populations who have been subjected to colonial and imperialist violence, and as scholars who have been systemically othered in Western-dominated academia on the grounds of their racial and/or ethnic background and migrant status, our refusal to perform such tasks is a political act. This refusal builds on a long history of anticolonial and feminist scholarship and resistance. Lorde, A. (1984). *Sister outsider: Essays and speeches*. Trumansburg, NY: Crossing Press; Tuck, E., & Yang, K. W. (2014). R-words: Refusing research. In D. Paris & M. T. Winn (Eds.), *Humanizing research: Decolonizing qualitative inquiry with youth and communities* (pp. 223–248). Thousand Oaks, Calif: SAGE Publications; Tlostanova, M. (2015). Can the Post-Soviet think? On coloniality of knowledge, external imperial and double colonial difference. *Intersections*, 1(2), 38–58; Smith, L. T. (2012). Decolonizing methodologies. London: Zed Books; Simpson, A. (2017). The ruse of consent and the anatomy of "refusal": Cases from Indigenous North America and Australia. *Postcolonial Studies*, 20(1), 18–33; Koobak, R., Tlostanova, M., & Thapar-Björkert, S. (2021). *Postcolonial and postsocialist dialogues: Intersections, opacities, challenges in feminist theorizing and practice*. New York: Routledge.

significant implications for the uptake of these technologies in Native communities, owing to potentially low trust in digital health interventions among Indigenous peoples. Eckenwiller argues that trust is a moral good that is characteristically relational.[38] Similarly, Krishnamurthy argues that the lack of trust that others will act justly is a reasonable belief in the context of inequality.[39] The fact that Native Americans have been subjected to genocide, including through the intentional spread of infectious diseases,[40] means that they lack the historical experience and empirical evidence that would give them good reasons to trust health interventions and technologies designed without them and/or recommended by colonial governments, which have placed them in harm's way.

This lack of good reasons to trust in non-Indigenous health interventions is particularly understandable considering the effects of data colonialism, which has exacerbated the vulnerabilities of colonized and racialized people.[41] There is much evidence that data have been used against Indigenous populations.[42] For example, the U.S. census began in 1790 but excluded Native Americans through to 1850 and did not count those living in reservations until 1900.[43] In this way, data were used to justify the invasion and settlement of presumably available empty land. Thus, many Indigenous scholars argue that the census was a crucial tool of colonization, linked with the exercise of power and statecraft.[44]

Indeed, the exclusion and erasure of Indigenous people and communities in standard data-collecting practices and their continuous omission and/or obliteration from data reinforce Indigenous invisibility over time and exacerbate its impact. For example, much research has raised concerns about the detrimental impact of the lack of (ethically sourced and governed) Indigenous genomic data in data banks for medical research or clinical trials.[45] This gap means that many specifics of particular health conditions have not been researched in Indigenous people, and appropriate

therapies might be unknown and/or their safety and efficacy be uncertain, as many pharmaceutical or technological remedies have not been researched and tested in Indigenous subpopulations. Indeed, these gaps and omissions are continuously replicated, and their implications might become magnified as contemporary clinical research could still be utilizing older biobank samples and datasets. Crucial data on previous infectious disease epidemics might also be missing, as Indigenous people may have been omitted from data collection owing to issues such as the lack of access to health services and the availability of contact tracers in Indigenous communities.[46]

Some argue that the problems with Indigenous erasure as well as the abuse of data for colonialism gained new strength with digitization. As digital platforms often utilize data from old datasets for training purposes, Indigenous erasure is reinforced on digital platforms. Furthermore, the practice of codification replicates Indigenous marginalization. Roxanne argues:

> As AI codes Indigenous bodies according to its colonial input, it also classifies these communities into a marginalized digital data set, the asterisk, the code. As AI codes the marginalized Indigenous body, it reproduces historical erasure of Indigeneity which necessitates an interference.[47]

According to Roxanne, codification further dehumanizes and colonizes the Indigenous body.[48] She argues that digital platforms are structured by normative whiteness, and Indigenous bodies are merely re-presented and interpreted through a white colonial gaze. This in turn creates an endless feedback loop, effectively reinforcing settler colonial domination.

In this broader context, characterized by persistent and systemic colonial power inequalities, Indigenous people are more than justified in being wary of the introduction of non-Indigenous surveillance tools, including in a pandemic. They are also justified in practising informed refusal,[49] should they wish to avoid using digital pandemic surveillance tools. This has been recognized by some (albeit few) ethicists in debates about COVID-19 apps. Schaefer and Ballantyne argue that owing to the greater risks of surveillance for racialized subpopulations and Indigenous people in particular, privileged population groups carry greater moral responsibility for using contact-tracing apps.[50]

[38]Eckenwiler, L. (2020, October 22). *Producing and distributing Covid-19 commodities: What else for global justice?* Global health justice event series. Geneva Graduate Institute, Global Health Centre.

[39]Krishnamurthy, M. (2015). (White) tyranny and the democratic value of distrust. *Monist*, *98*(4), 391–406.

[40]Norgaard, K. M. (2019). *Salmon and acorns feed our people: Colonialism, nature, and social action*. New Brunswick, NJ: Rutgers University Press.

[41]Rainie et al., op. cit. note 9; Carroll et al., op. cit. note 9.

[42]Rainie et al., op. cit. note 9; Carroll et al., op. cit. note 9; Lujan, C. C. (2014). American Indians and Alaska Natives count: The US census bureau's efforts to enumerate the native population. *American Indian Quarterly*, *38*(3), 319–341; Roxanne, T. (2020). Data colonialism: Decolonial gestures of storytelling. *Donau Reader*, Donaufestival, 147–159.

[43]Lujan, op. cit note 42; Krieger, N. (2019). The US Census and the people's health: Public health engagement from enslavement and "Indians not taxed" to census tracts and health equity (1790–2018). *American Journal of Public Health*, *109*(8), 1092–1100. The practice of excluding Native Americans from the census is ongoing: Carroll, Rodriguez-Lonebear and Martinez argue that 'the US Census notoriously undercounts American Indian and Alaska Native peoples, particularly those living on tribal lands' and clarify that 'American Indians and Alaska Native peoples experienced the highest undercount (4.9%) of any racial or ethnic population in the 2010 Census.' Carroll et al., op. cit. note 9, p. 5.

[44]Ibid; Lovett et al., op. cit. note 9.

[45]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*. Minneapolis: University of Minnesota Press; Tsosie, K. T., Krystal S., Yracheta, J. M., Kolopenuk, J. A., & Geary, J. (2021). We have "gifted" enough: Indigenous genomic data sovereignty in precision medicine. *American Journal of Bioethics*, *21*(4), 72–75.

[46]Close & Stone, op. cit. note 18.

[47]Roxanne, T. (2019). Digital territory, digital flesh: Decoding the indigenous body. *A Peer-Reviewed Journal About*, *8*(1), 70–80, p. 71.

[48]Roxanne, T. (2020). Refusing representation. In H. Lichtenhäler (Ed.), *Wenn KI, dann feministisch-Impulse aus Wissenschaft und Aktivismus* (pp. 4336–4703). Hrsg. von netzforma* e.V.

[49]Simpson, A. (2017). The ruse of consent and the anatomy of "refusal": Cases from indigenous North America and Australia. *Postcolonial Studies*, *20*(1), 18–33; Benjamin, R. (2016). Informed refusal: Toward a justice-based bioethics. *Science, Technology & Human Values*, *41*(6), 967–990.

[50]Schaefer & Ballantyne, op. cit. note 32.

At the same time, if designed and governed in accordance with Indigenous cultural and ethical requirements[51] and the need for decolonization and health justice, contact-tracing apps and other digital pandemic surveillance technologies could play a role in mitigating a pandemic in Indigenous communities. For example, some of these technologies could help shine light on patterns of infection in Indigenous populations, who currently do not have at their disposal adequate data mapping the infection routes and impact of the pandemic that disproportionately affects them.[52] Many scholars concerned with the impact of the COVID-19 pandemic on Indigenous and racialized people have emphasized the importance of collecting and evaluating exact demographic data in the infectious disease context.[53] They have argued that precisely because the pandemic is not affecting the population in the same way, epidemiological data on COVID-19 infection and mortality are needed to capture the scale and forms of the inequalities entrenched and magnified by the pandemic. Hence, contact-tracing apps could play a role in filling some of the gaps in knowledge.

Furthermore, digital pandemic surveillance technologies could help raise awareness about infectious diseases and improve health prevention and care. Scholars have pointed out that prompt access to healthcare is limited in most rural areas in the United States, especially in remote tribal communities.[54] In this regard, digital health technologies have the potential to provide crucial health information and to connect users with essential health services, and, as such, improve Indigenous health-related decision-making.[55] The questions that remain to be answered are how to design, implement and maintain technologies that will be compatible with Indigenous ethics, avoid harming and further disadvantaging Indigenous populations, and ensure that digital pandemic surveillance will protect Indigenous lives and cultures.

4 | BIOETHICS, WESTERN BIAS AND LESSONS FROM INDIGENOUS CRITIQUES

So far, much of the discussion on the ethics of digital pandemic surveillance and COVID-19 apps has been Western-dominated.[56] Furthermore, many enquiries have focused largely on issues of

privacy, transparency, open-source code, data security and uptake,[57] and structural issues of justice have not been given adequate consideration. These investigations have been centred on and prioritized the epistemologies and ontologies of the Global North, which, as argued by Risam, is a practice that 'decenters those of Indigenous communities and the Global South.'[58] As such, this scholarship has certain power structures embedded within it, which contributes to the further marginalization of structurally oppressed perspectives, knowledges and people.

Critical debates on (digital and data) colonialism and the implications for Indigenous lives suggest that bioethics ought to learn to conduct enquiries from positions that fundamentally integrate the concerns of structural justice. Indigenous experiences of, resistance to, and critiques of colonialism should prompt decolonial analyses of health interventions, technologies, policies and healthcare frameworks, particularly in a pandemic that has been magnifying global social and health inequalities.[59] Enquiries into the ethical aspects of digital pandemic surveillance technologies need to pay attention not only to power imbalances but also to how these structures of domination and inequality shape knowledge production in digital health technologies, as well as to the purposes of this knowledge and to how, by whom, and for whose benefit it is used.

Because persistent structural inequalities are embedded within digital technologies and surveillance systems, it is crucial to ask questions about accessibility and resources. What kind of technology is viable in Indigenous communities, including rural communities, and do most people have internet access, smart phones, etc.? What epistemological resources are provided to tribal nations that will help them take agency over their own data, and, more generally, understand the ways in which their data are being mined and used? Do these epistemological resources support Indigenous agency in the health context in ways that benefit Indigenous health and wellbeing?

These questions are the first steps towards building modes of epistemological resistance while enabling the sovereignty of Indigenous peoples. This move, however, must be articulated with caution owing to the embeddedness of colonialism within the digital platform, as modes of data mining and surveillance technologies continue to marginalize Indigenous peoples. Indigenous agency is an important concern when Indigenous data are distributed online, with respect to the need to combat ongoing forms of settler colonialism while amplifying Indigenous agency.

[51]However, many spheres relating to Indigenous ethics, including human to non-human relations, such as cosmology, storytelling or dance, are all sacred. We are, thus, intentionally not inquiring into them in this paper out of respect, and we perceive this approach as an important step in decolonising methodologies in bioethical research. Smith, op. cit. note 37.

[52]Urban Indian Health Institute., op. cit. note 14.

[53]Bhala et al., op. cit. note 11; Chowkwanyun & Reed, op. cit. note 11; Hendl et al., op. cit. note 13.

[54]Graves, J. M., Mackelprang, J. L., Amiri, S., & Abshire, D. A. (2020). Barriers to telemedicine implementation in Southwest tribal communities during COVID-19. *Journal of Rural Health*, 37(1), 239–241; Sidhu, S. S., Fore, C., Shore, J. H., & Tansey, E. (2017). Telemental health delivery for rural Native American populations in the United States. In H. Jefee-Bahloul, A. Barkil-Oteo & E. F. Augusterfer (Eds.), *Telemental health in resource-limited global settings* (pp. 161–180). Oxford, U.K.: Oxford University Press.

[55]Uddin Palas, J. U., Mahfuz, A., Quazi, A., Grunfeld, H., & Hasan, N. (2017). Linking Indigenous peoples' health-related decision making to information communication technology: Insights from an emerging economy. *International Technology Management Review*, 6(3), 64–81.

[56]Joint Statement, op. cit. note 30.

[57]Bock et al., op. cit. note 27; Ada Lovelace Institute, op. cit. note 30; Joint Statement, op. cit. note 30.

[58]According to Risam, invoking decolonization "encompasses epistemological dimensions because the political realities of colonization are interdependent with displacement of Indigenous epistemologies and ontologies. The existence of colonization relies on not only ongoing occupation of land but also occupation of regimes of knowledge erected to maintain and legitimate such occupation." Risam, R. (2018). Decolonizing the digital humanities in theory and practice. In J. Sayers (Ed.), *The Routledge companion to media studies and digital humanities* (pp. 78–86). New York: Routledge, p. 79.

[59]WHO, op. cit. note 25; Flood, C. M., MacDonell, V., Philpott, J., Thériault, S., Venkatapuram, S., & Fierlbeck, K. (2020). Overview of COVID-19: Old and new vulnerabilities. In C. M. Flood, V. MacDonell, J. Philpott, S. Thériault & S. Venkatapuram. (Eds.), *Vulnerable: The law, policy and ethics of COVID-19* (pp. 1–31). Ottawa, Canada: University of Ottawa Press.

Crucial lessons about the fundamental importance of Indigenous agency, ownership and control should already have been learnt from Indigenous critiques of the oppressive and ethically troubling sourcing and utilization of Indigenous data in 'precision medicine' and health research. Many Indigenous scholars, such as Kim TallBear, Keolu Fox, and Krystal Tsotsie and her colleagues,[60] have interrogated the appropriation and commodification of Indigenous data in genomics and DNA biobanks. They have argued that ownership and control of data and specimens have detrimental health and socioeconomic impacts.[61] According to these scholars, without explicit ownership and agency over their data, Indigenous communities face having their identities misconstrued, commodified and commercialized (e.g. as ancestry tests), in ways that not only fail to provide health and socioeconomic benefits to Indigenous communities but also exacerbe their oppression. This line of research should serve as a well-evidenced warning about the co-optation and biocolonial mining of Indigenous data perpetuated under the guise of 'health innovation.' As such, this scholarship provides crucial lessons about the urgent need for any current and future health research and technologies to break ties with the legacy and structures of oppression, including in the design, implementation and governance of emerging technologies and Indigenous data. Clearly, both decolonization and amplification of Indigenous (health) agency ought to play a core role in improving Indigenous health and wellbeing, and this recognition also ought to guide innovation in public health interventions.[62]

5 | INDIGENOUS DATA SOVEREIGNTY AND DIGITAL PANDEMIC SURVEILLANCE

The concept of IDS refers to the governance of Indigenous data.[63] Indigenous data encompasses information and knowledge about Indigenous individuals, collectives, entities, lifeways, cultures, lands and resources.[64] Too often, Indigenous data is mishandled in open-data arenas where data is governed and collected via open resources, which removes agency from Indigenous peoples, prolonging the destruction of settler colonialism. Tribal nations need data about their citizens, communities, lands, resources, and cultures to make informed decisions. However, few official statistics agencies make any

meaningful concession to Indigenous rights in relation to Indigenous data.[65] The need for spaces that support Indigenous agency and governance over Indigenous data is paramount for fighting modes of settler colonialism within digital spaces. Furthermore, conceptualizations of open data purely as digital data produce an area ripe for knowledge co-optation and the theft of Indigenous knowledge, as, for example, in cases where researchers or others who collect Indigenous knowledge about the environment (as opposed to digital data) digitize that knowledge and share it openly without consent or oversight of Indigenous peoples.[66]

Because IDS is being formed for and by Indigenous scholars, it is important to foster accessibility of information so that Indigenous communities can understand the data created for their health. Moreover, their understanding of how this data can assist them in protecting themselves against COVID-19 whilst preserving their Indigenous identity and cultures, individually or collectively, is equally important.

The crucial importance of IDS for Indigenous peoples, for their health and wellbeing, has serious implications for debates about the design, implementation and maintenance of digital pandemic surveillance in Indigenous populations. Should Indigenous peoples wish for the implementation of digital pandemic surveillance technologies in their communities, then these technologies ought to be developed in ways that give Indigenous communities ownership over them, including the power to decide which data will be collected, how the data will be stored and who will have access to it. Ideally, these technologies should be designed by Indigenous peoples themselves to ensure that they incorporate Indigenous conceptualizations of health, are sensitive to cultural, spiritual and ethical needs and concerns in a particular Indigenous health context, and are available in Indigenous languages.[67] In this way, digital pandemic surveillance technologies stand a chance of being relevant and beneficial to Indigenous individuals, communities and of protecting their lives, health and wellbeing.

6 | CONCLUSION

We have explored the possibility of implementing digital pandemic surveillance technologies in Native American communities and argued that while these technologies attempt to assist in suppressing the COVID-19 pandemic, it is paramount that they are developed, implemented and maintained in ways that are consistent with Indigenous governance, meet requests for IDS, and are grounded in Indigenous cultures, ethics and needs. Our discussion suggests that further research is warranted in the ethics of data collection and the

[60]Fox, op. cit. note 45; Tallbear, op. cit. note 45; Tsosie et al., op. cit. note 45.

[61]Similar arguments regarding the harms and lack of benefit stemming from the exclusion, misrepresentation and systemic oppression of structurally marginalized subpopulations in data, medicine, healthcare and health research have been made concerning the intersectional oppression of women and fellow people marginalized on gender grounds, particularly those who have been racialized, within the social structures of white supremacist patriarchal domination (see Criado-Perez, C. (2019). *Invisible women: Exposing data bias in a world designed for men*. London: Chatto & Windus; Costanza-Chock, S. (2020). *Design justice: Community-led practices to build the worlds we need*. Cambridge, MA: MIT Press). This scholarship highlights the importance of intersectional justice in society, including in health technologies, medicine and healthcare more broadly.

[62]McPhail-Bell et al., op. cit. note 7; Radu, op. cit. note 7.

[63]Rainie et al., op. cit. note 9; Carroll et al., op. cit. note 9.

[64]Rainie et al., op. cit. note 9; Carroll et al., op. cit. note 9.

[65]Rainie, 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), p. 302.

[66]Rainie et al., op. cit. note 65, p. 304.

[67]Urban Indian Health Institute. (2020). *A historical trauma-informed approach to COVID-19 – Urban Indian Health Institute*. Retrieved from https://www.uihi.org/resources/a-historical-trauma-informed-approach-to-covid-19/

particular criteria that ought to guide it. In particular, enquiries into ethically appropriate and justice-enhancing ways of collecting data in digital health technologies in Indigenous communities and investigations of what different data collection practices do to Indigenous cultures and communities are warranted.[68] Further research also needs to explore which conceptualizations of health and wellbeing need to be embedded in digital health technologies in order to ensure that these technologies can serve Indigenous peoples well and protect their health.

However, our findings also suggest that it is important to avoid subscribing to tech solutionism.[69] The broader socioeconomic and health inequalities that Indigenous communities face are so severe that they warrant urgent responses. In such circumstances, communities need access to basic healthcare services. As Close and Stone very poignantly put it when describing their work in rural eastern Arizona:

> Covid-19 is a novel disease in need of novel approaches. But our experience has shown that there is no substitute for providing services according to the most basic principles of medicine and public health. In our current health care system, knocking on doors and talking to patients may be the most novel approach of all.[70]

Clearly, digital pandemic responses, no matter how novel and innovative, cannot succeed in suppressing the COVID-19 (or another) pandemic without the provision of health services, and any implementation of digital tools needs to go hand in hand with robust healthcare, sensitive to Indigenous health needs. Simultaneously, the dangers of Indigenous exclusion, misrepresentation and re-oppression in digital and data-driven public health interventions highlight the pressing need for advancing digital platforms towards incorporating Indigenous data in ways that accurately capture Indigenous lives and health concerns, promote Indigenous agency, and are consistent with Indigenous requirements for IDS.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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[68]It is particularly important to consider the alternatives to digital data collection and pandemic tracing, such as manual infection tracing, exploring and weighing their various social and ethical implications. As we have pointed out, the risks of omission of Indigenous patients in manual tracing can be high, especially owing to the lack of health infrastructure in Indigenous communities. Digital tracing might be easier and involve low risks of viral transmission as it is based on self-reporting, but the accessibility of smart phones could be an issue. However, as we have argued, significant risks from digital tracing can be associated with non-Indigenous design, governance and institutional access to data, which can all reinforce data colonialism. These risks ought to be thoroughly investigated and mitigated.
[69]Milan, S. (2020). Techno-solutionism and the standard human in the making of the COVID-19 pandemic. *Big Data & Society*, 7(2), doi:10.1177/2053951720966781.
[70]Close & Stone, op. cit. note 18.