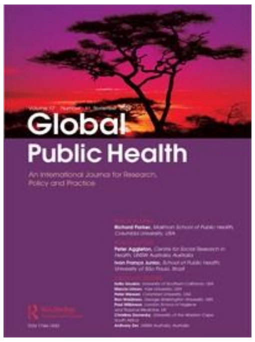

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RESEARCH ARTICLE

Indigenous sovereignty, data sourcing, and knowledge sharing for health

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ABSTRACT
In this article, we consider the impacts of the COVID-19 pandemic on Indigenous Peoples (IPs) by reporting on information-gathering work across two non-governmental and Indigenous organisations to compensate where federal systems failed. Strategies IPs have employed to understand and respond to the pandemic, and described here, include: collaborative efforts across communities intra- and internationally; open-source data platforms; and small-scale epidemiological research. Our review exposes the informational politics faced by Indigenous organisations and communities, and their struggle to pursue needed resources or protections while avoiding the critiques of 'post-neoliberal' and 'science denialism'. We conclude by suggesting ways that Indigenous communities improve our understanding of their needs during public health crises, and maintain both informational and medical self-governance.

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Indigenous; COVID-19; information; open-source data; crowd-sourcing

Introduction

Indigenous Peoples (IPs) have been among the most vulnerable to the COVID-19 coronavirus global pandemic for a number of reasons. Rural and remote settings are farthest from critical medical care and from certain sources of economic and food security. Likewise, many IPs are invisible within the statistics collected through state census counts or other health tracking offices because either Indigenous identity is not marked or because Indigenous communities are not included in those tracking efforts. For example in Mexico, a national institute dedicated to IPs (https://www.gob.mx/inpi) has generated some disaggregated data on IPs, but presents only summary data for all IPs by state, which erases the diverse needs of these various Peoples.[1] These gaps and erasures make IPs less likely to receive needed support.

IPs in the global South have denounced not only the paucity of disaggregated data on Indigenous experiences and vulnerability, but also the class privilege evident in official public health recommendations that assume access to resources such as abundant clean water and sanitation resources. The 'twin problems' of a lack of useful data on COVID in IPs and the risk to IP sovereignty that data gathering, dissemination, and applications can pose, have been evident throughout this pandemic and since before the U.N. Permanent Forum on Indigenous Issues first was created (Kukutai & Taylor, 2016, p. xxi).

Adequate public health protections are dependent on the information gathering and sharing capacities of IPs. However, histories of colonial medicine reveal how public health metrics have been used to incorporate and subjugate Indigenous bodies, rather than to heal (Adams, 2016; Briggs

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& Mantini-Briggs, 2016; Davis, 2017). Where IPs have achieved autonomy and self-governance in the modern era, they often struggle to remain visible at all within federal systems of care (Grundy-Warr & Lin, 2020; Yap & Watene, 2019). Reporting rates of infection among Native Americans up to 3.5 times higher than the U.S. average, Kemball argues that 'instances of statistical erasure and the obstacles placed between Native health organisations and the data they need to tackle the pandemic are … used to undermine Indigenous sovereignty' (Kemball, 2020). Likewise, Rodriguez describes these erasures in official public information as 'business logic … disguised as scientism', since a strategic lack of data on COVID rates allows, for example, logging and mining interests to proceed on the lands of already vulnerable communities (Rodríguez, 2020).

A 'statistical silence' on IP experience of COVID risks not only greater loss of life in these communities; such invisibility of IPs also ignores vast knowledge in health care, forms of cooperation and collective effort, ethnomedicines, and more (Artaraz et al., 2021; Morphy, 2016). Many Indigenous communities initiated their own, traditional preventive actions such as closing their own borders, establishing COVID-19 checkpoints, performing informative and communication campaigns, cancelling festivals, assemblies and congregations, and establishing mask requirements to prevent the virus from entering their territories (Cohen & Mata-Sánchez, 2021; Smith-Morris & DeLuca, 2020). As a result, a few Indigenous communities saw some protection. One year into the pandemic, 82 communities in the state of Oaxaca, Mexico, were still completely free of COVID-19 cases (Cherofsky & Juárez López, 2021). The Kuikuro community in Mato Grosso, Brazil, after 50% of the community got infected, still had no deaths by late August 2020 thanks to an improvised hospital in their territory and hiring medical personnel to attend to people who had been infected with the virus (Cherofsky & Juárez López, 2021; Dantas, 2020). Also in Brazil, in December 2020, the Ashaninka People became the only Indigenous People without COVID-19 cases in the state of Acre after adopting strict isolation measures for nine months (Cherofsky & Juárez López, 2021; Nascimento, 2020). And in the Ecuadorian Amazon, death rates from COVID-19 were low compared to the national average (Sirén et al., 2020). These positive reports merit recognition as well, if only to combat negative stereotypes about IPs that help fuel colonialistic state policies.

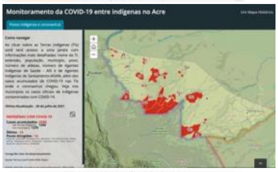
To contest these erasures from governmental health metrics, many IPs have developed their own responses to bolster information flows. These include not only prevention and educational resources on COVID (CONAIE, 2021) or medicinal plants (Vargas, 2021) often shared via community-controlled media (e.g. https://www.culturalsurvival.org/programs/community-media), but also research reports and open- or crowd-sourced counts of infections, deaths, and COVID-related harms to communities. Such data strategies often reflect the limitations in resources and professional training that IPs sustain, but reveal the strengths and resiliencies of local, Indigenous-led actions as well. And while the experiences of Indigenous groups with COVID have been reported in professional literature, to our knowledge none has grappled with the distinctive strategies in information politics employed by Indigenous communities. In their singular need to retain community autonomy and lifeways, Indigenous communities approach knowledge, data records, and COVID tracking in ways that challenge epidemiological orthodoxy. They raise the questions, Whose data count? And what forms of data can be taken into account?

In this discussion of IP data practices and sovereignty, we report on work across two non-governmental and Indigenous organisations during the COVID pandemic. These organisations worked with IPs to build locally-driven and non-standardizing yet credible evidence, baseline rates, and a history/documentation of COVID pandemic impacts. Such data practices have become crucial to both local-community purposes and larger-public knowledge of IP experience. In our discussion, we consider the implications of such open- and crowd-sourced data sets, and the informational politics in which Indigenous actors find themselves. We conclude by considering the 'perverse confluence' (Dagnino, 2007) of participatory politics and the colonising potential of epidemiological metrics for Indigenous lifeways (Smith-Morris & Epstein, 2014). To recognise and protect Indigenous forms of knowledge during a public health crisis, we seek public health encounters that prioritise relational responsibilities in health crises (Makere, 2005; Rylko-Bauer & Farmer, 2002) and rights-oriented strategies most relevant for IPs relational and place-based priorities in well-being.

Open- and crowd-sourced COVID mapping

If nation-states track epidemiological data on COVID-19, the data rarely capture or report findings specific to Indigenous Peoples (Curtice & Choo, 2020; Smith-Morris & DeLuca, 2020). But non-governmental and Indigenous organisations have worked to measure, follow, and address the pandemic in these most vulnerable communities using alternative sources of information. Open-source and crowd-sourced platforms have given IPs the capacity to build online maps of COVID cases, to track and characterise the experience of Indigenous communities with COVID, and to share this

Table 1. Examples of Indigenous organisation tracking maps.

Organisation/Description	Image of Page
Carlos Doviaza, a cartographer in Panama, used health ministry data to plot Indigenous cases of COVID. https://rainforestfoundation.org/covid-panama-gis-map/	
A story map by the Native Waters on Arid Lands project detailing impacts of the pandemic by region. https://storymaps.arcgis.com/stories/336825e7c44a494ab24c72f67e02814a	
The Pro-Indian Commission of Acre (CPI-Acre) shows the distribution of confirmed COVID-19 cases in Acre and more. https://cpiacre.org.br/?fbclid=IwAR3wnb5a-9cRDfReTEnIb_L86FqsjZQJb_zGTYJfhZDA0gPxDuHLGMiQxJE	
The Instituto Socioambiental initiative platform includes information on the availability of beds and respirators in all Brazilian municipalities. https://covid19.socioambiental.org/	
CONFENIAE in collaboration with San Francisco University of Quito USFQ, Aldea Foundation and Amazon Watch designed a tool monitoring the Indigenous territories of 11 nationalities of the Amazonian rainforest in Ecuador. https://confeniae.net/covid19	
Latinamerican map by UNAM in Mexico. http://www.nacionmulticultural.unam.mx/	
Cultural Survival open-source map shows both COVID cases by Indigenous community, but also COVID-related human rights violations. https://www.culturalsurvival.org/news/cultural-survival-launches-global-mapping-project-documenting-covid-19-indigenous-0	

information widely so that cooperative efforts might be supported. Recent examples of Indigenous Peoples and advocacy groups using mapping technology to document the crisis are shown in Table 1. As informational resources, these maps not only centralise information about COVID within Indigenous communities but they also disseminate preventive and case information to those seeking localised updates about the crisis. The technology enables Indigenous Peoples to share their own data, unfiltered by governments and other institutions, and to include reports on what they name as pandemic-related human rights violations in their communities.

One map, deployed as a COVID-19 tracking strategy by the organisation Cultural Survival (CS), used Google Maps technology to document both COVID-19 cases and related human and Indigenous rights violations (https://www.culturalsurvival.org/covid-19/tracking-indigenous-communities).[2] Through this tool, CS synthesised a wide range of information related to the experiences of Indigenous Peoples: the date that the first COVID-19 case was detected in each community; the number of cases and deaths over time; any press coverage, security measures, member stories and narratives; any abuses of authority against Indigenous Peoples' rights during the COVID-19 pandemic; and any abuses against Indigenous Peoples' lands during the COVID-19 pandemic.

Reports aggregated in the map reflect a wide variety of sources including: Indigenous community leadership or spokespersons; published reports by nonprofit Indigenous rights organisations (e.g. Cultural Survival, Minority Rights Group International, Survival International, Forest Peoples Programme, International Work Group for Indigenous Affairs); news organisations (e.g. Mongabay, Associated Press, National Public Radio); mainstream media outlets (e.g. NBC, CNN, CBS, Washington Post, New York Times, BBC, The Guardian); national or local news organisations (e.g. Hindustan Times, The Hindu, Mexico News Daily, The New Zealand Herald); international organisations (e.g. United Nations Development Programme; Unrepresented Nations and Peoples Organization; Food and Agriculture Organization); and international news organisations (e.g. Voice of America, Deutsche Welle, World Is One News). Many of the news articles also include quotes from Indigenous persons and/or representatives of Indigenous communities.

Between July 1, 2020 and July 15, 2021, the map curated a total of 178,442 cases and 7,630 deaths across 6 continents (see Table 2). In addition, a total of 162 cases of human rights and/or Indigenous rights abuses were recorded. To understand trends in the types, sources, and topics of information in these entries, we coded and analyzed these 162 entries. First, we discuss six categories of human rights concerns; we then address the strengths and weaknesses in the data sources and the implications of this type of crowd-sourced, participatory tool for Indigenous health.

(1) *COVID-19-related mobility restrictions*. The most common harm to Indigenous Peoples has been to their freedom of movement (e.g. forced lockdowns, closed borders, etc.). While such restrictions are not limited to Indigenous Peoples, their applications have frequently been more harmful to the lifeways of Indigenous Peoples due to assumptions about the placement, timing, and duration of these strategies. Harms described in posts (and linked public-access articles) include increases in unemployment that have led to losses of livelihoods and greater food insecurity (e.g. decline of the tourism industry). For example, lockdowns and other health

Table 2. Summary statistics of CS COVID-19 map entries.

Continent/Region	# of Entries	# of cases reported	# of deaths reported
North America	55	54,463	4,612
South America	15	25,738	847
Asia	58	96,469	2,131
Africa	25	509	0/unknown
Europe	4	1,126	40
Oceania/Australia	5	137	0/unknown
TOTAL	162	178,442	7,630

and safety protocols due to the pandemic in Uganda negatively impact the Batwa Indigenous Peoples by impeding access to forests and forested areas (which are considered Batwa ancestral lands that they have depended on for survival) for foraging, markets for trading and employment opportunities, and agricultural fields for food production (OHCHR, 2020; Uganda, 2020). These effects often contribute to food insecurity, which has meant that many Batwa must now rely on food aid to survive and are left increasingly vulnerable (OHCHR, 2020). Furthermore, even where Indigenous communities enact restrictions, the extractive companies on or near their lands do not, thus enacting exploitative violence at the same time they bring infectious agents to the area via workers.

(2) *Violations related to living conditions and access to basic resources*. These reported impacts take various forms including lost access to healthcare, work, education, running water or electricity, Internet, and to information. The Kanak of New Caledonia are marginalised by food and housing insecurity, poor sanitation in their communities, unequal access to education, poor housing with questionable structural quality and disparities, and disproportionately high rates of incarceration. These issues have been exacerbated during the pandemic for the Kanaks, some of whom currently reported living in 'squats' in New Caledonia's capital, without a reliable source of clean water, electricity, or waste removal (Lin, 2020). An oil spill in the Ecuadorian provinces of ORellana and Sucumbios in April 2020 combined both environmental disaster with increased COVID impact due to lost food and safe water (Henriquez-Trujillo et al., 2021).

(3) *Violence*. Violence in many forms – including gender-based or sexual violence, military or police violence, or physical attacks targeting Indigenous Peoples – have been worsened in some cases due to pandemic conditions. Ethnic armed conflicts in Kachin State of Myanmar endanger many Kachin Indigenous Peoples, and many have become internally displaced persons (IDPs) being held in IDP camps, many of which host poor living conditions and high rates of COVID infection (Fishbein, 2020; Hkawng et al., 2020).

(4) *Government and legal issues*. Reports on the failures, repression, or persecution enacted by governments were the fourth most common category. An example comes from the Duma- gat-Remontado Indigenous Peoples of the Philippines; the government has been ignoringthe suffering and situations of the Indigenous Peoples during the pandemic and only sent a minimal emergency subsidy that 'barely helped families get by' (Flores-Obanil, 2020). In addition, some local Indigenous Peoples have already been restricted by the government from accessing the lands or bodies of water near their lands and thus are losing their livelihoods; much of this is due to the planned construction of the Kaliwa Dam, which is to be built on Indigenous lands but does not have the consent of the Dumagat-Remontado (Flores-Obanil, 2020). The government has prioritised the unlawful construction of the Kaliwa Dam over providing aid to Indigenous communities and, since the pandemic, militarisation in the area. Correspondingly, violence and harassment from the police and military have increased (ibid.).

(5) *Marginalization and discrimination*. Since Indigenous marginalisation and discrimination are ongoing, these COVID-related events were identified as occuring in person or physically (as in not treating Indigenous Peoples with respect, equality, or dignity or treating them as inferior in some way), but these forms of violation can also happen at the level of policy – for example, by not formally recognising Indigenous Peoples' rights. This is evidenced by the experience of the Mangyan Indigenous Peoples of the Philippines; the Mangyan Indigenous Peoples have been experiencing discrimination, as they are being negatively perceived as 'primitive' and 'dirty and uncivilized' (Bociaga, 2020). This discrimination has been exacerbated by the COVID-19 pandemic; the Mangyans rarely have access to adequate social services, and in the era of the pandemic, they are being overlooked by the government in the delivery of COVID-19 relief supplies and assistance (Bociaga, 2020). Similarly, the Dayak Indigenous Peoples of Borneo experience stigmatisation and structural racism, which have been reinforced

by the effects of the pandemic; these prejudiced views of the Dayak have also resulted in the passing of the Omnibus Bill by the Indonesian parliament, a bill which would allow Indigenous lands to be encroached upon and exploited for profit and threaten the livelihoods of the Dayak (Lundström, 2021).

(6) *Land encroachment and destruction.* Land encroachment and destruction often have to do with unlawful encroachment by governments, corporations and/or extractive industries, or law enforcement organisations. The violation of the right to Free, Prior, and Informed Consent became more common during the pandemic, as experienced by the Ogiek Indigenous Peoples of Kenya (IWGIA, 2020). In July of 2020, over 100 Ogiek families were forcefully evicted from their ancestral lands by the Kenya Forest Service (KFS), and their traditional houses and structures destroyed (Bhalla, 2020; IWGIA, 2020; Life, 2020). These evictions took place amid a rise in COVID-19 cases and deaths in Kenya; the displacement of the Ogiek people increased their vulnerability to COVID-19, as they faced a lack of shelter and resources and were unable to implement preventative measures such as social distancing (Life, 2020). The Kenya Forest Service is now demarcating the area as restricted forest areas where human presence is forbidden, even though these are ancestral Ogiek territories recognised in a 2017 ruling by the African Court on Human and Peoples' Rights (IWGIA, 2020).

A second example comes from the Chepang Indigenous Peoples of Nepal. Multiple Chepang families living in the Chitwan National Park lost their homes, money, and identity documents in forced evictions by the Nepal government forces (Ganguly, 2020; Samiti, 2020; "Kenya Flouts African Court Judgment, Continues to Evict Ogiek in the Midst of COVID-19 Pandemic,", 2020). These evictions were carried out amid the pandemic in Nepal, when the ability to shelter at home was critical (Samiti, 2020); furthermore, the Chepang have been historically marginalised and as a result have little access to basic services such as healthcare, drinking water, electricity, and more, putting them at even greater risk for COVID-19 in addition to the loss of their homes (Chepang, 2020; Samiti, 2020). Tapia et al. have also documented disease outbreaks in Indigenous territors of the central and southern part of the Ecuadorian Amazon region, mainly in *Pastaza* and *Morona Santiago* provinces, nearest the illegal activities of Balsa timber harvesting companies (Tapia et al., 2021).

These six major categories of harm reported in the Cultural Survival COVID-19 map are drawn from open-source and crowd-sourced data. In those data sources, case reports were not always verified by public health specialists, whether tribal or non-tribal. Out of concern for quality and completeness of information, communities and Indigenous organisations therefore strive to collect reliable and precise data of their own. We next consider the research efforts of Indigenous organisations to collect and validate their own public health data.

Indigenous organisation research

A second, major source of information for and about IPs is their own research projects. These projects are often smaller in scale, and must labour to gain acknowledgement from powerful government sources whose agendas may be better served by contradicting Indigenous research. To address these concerns, and to illustrate how Indigenous communities address these concerns, we summarise a study on morbidity and mortality conducted in a sample of Kichwa Indigenous communities in Ecuador.

The Confederation of Indigenous Nationalities of the Ecuadorian Amazon (CONFENIAE) and Inty Anka Taripak Research Association designed and conducted a quantitative estimate of morbidity and mortality among 13 Kichwa Indigenous communities in the Ecuadorian Amazon (Sirén et al., 2020). Their study also captured information on how these communities coped with the pandemic, including the use of various medicinal plants for treating COVID-19, being successful. A team of researchers from CONFENIAE made a quantitative estimate of the mortality caused by COVID-19 in Kichwa Indigenous communities in Ecuadorian Amazonia, and described how people in these communities have coped with the pandemic. Thirteen Kichwa Indigenous communities in the Ecuadorian Amazonia, with a total of approximately 10,300 inhabitants, were contacted and assessed for COVID case data. Communities ranged from peri-urban communities to remote villages far from the road network. A total of 34 subjects (n = 34) in one community were given a COVID antibody test, and interviews were completed with several community leaders.

Results

Eleven of the 13 communities examined had widespread contagion during the period between January 2020 and September 2020. In most of these communities, few precautions to avoid contagion were in practice. The first cases with symptoms typical of COVID-19 appeared in these communities between February and June, with most communities reporting onset in April. On average, the peak of disease prevalence occurred one month after the first case and was followed by rapid decline. By August, there were few or no new cases reported across all communities. Antibody testing in one community produced a 77% positivity rate, while a total of 14 deaths from COVID-19 were recorded by direct observation by local researcher assistants, a mortality rate of 0.14% for the population. This figure is approximately twice as high as the national Ecuadorian mortality rate. Many people in the 13 communities attribute recovery from COVID-19 to the use of various medicinal plants including *Zingiber officinale, Maytenus* spp., and *Mansoa Alliacea* (Vargas, 2021). These three principal, medicinal plants in used in these communities, and used during treatment of COVID-19 symptoms, contain compounds that affect the production and action of cytokines, which are inflammatory mediators. COVID-19 is characterised as a cytokine release syndrome induced by a cytokine storm (Hirano & Murakami, 2020; Mahmudpour et al., 2020). Researchers argued that other factors that may have contributed to low mortality in these communities are the low prevalence of obesity, high level of physical activity, cross-immunity acquired by frequent exposure to other viral infections and the young age (over half under the age of 15) of the population (Henriquez-Trujillo et al., 2021).

This study further represents capacity for robust information gathering and case tracking *within* approaches that respect Indigenous autonomy and community self-preservation. Such efforts and the organisations that make them offer profound lessons not only for prevention and treatment of infectious pandemics in Indigenous communities, but for ethical engagement and knowledge production and sharing. Turning to these larger benefits, we next discuss the relationship of these community- and crowd-based strategies for Indigenous health.

Discussion: Data sourcing, sharing knowledge, and collaboration for indigenous health

The tracking of health events in communities without public health infrastructure, such as small, remote, or marginalised Indigenous communities, is laborious and requires relationships of trust in each community. Making the needs of these communities visible to sources of public health resources is a priority that must be weighed against such dangers as lost autonomy, unmet promises, and even infectious exposures through community visitors (Horse & Huyser, 2021). The ethics of these types of metric engagements is not a new subject of concern, but the COVID pandemic has warranted broader awareness of the unique informational positionalities of Indigenous Peoples.

The knowledge politics surrounding unofficial, media-driven, and crowdsourced data like those used in the Cultural Survival map may be the only forms of information available to/on Indigenous communities. Yet establishing the validity of ‘unofficial’ media-driven and crowdsourced data can be difficult (Ozkan et al., 2018). The emergence of Indigenous Data Sovereignty movements has helped guide many IPs toward stronger control and more self-determined use of available data

(Daly, Mann, and Devitt 2019). Indigenous organisations like Cultural Survival, which built the map-based platform for Indigenous COVID tracking discussed above, or CONFENIAE, whose staff conducted prevalence estimates and collected narratives of local experience, fill important positions in the web of public health communication. \In their role as communications facilitators, these organisations contribute to knowledge transfer and skill sharing in ways that traditional scientific research can seldom accomplish (Keane et al., 2017).

While the advantages and benefits of scientific rigour in epidemiological sciences are clear, these traits of scientific practice may not be the priority for these communities and organisations. The first concern of Indigenous communities is typically member health followed by maintaining sovereignty and self-determination. Thus, while NGOs may be crucial in the process of reaching and partnering with Indigenous communities for health studies, they also carry an enormous responsibility to avoid colonising or acculturative strategies and products. As Whittaker's dynamic view of multiculturalist politics in Milpa Alta exposes, 'naive researchers risk causing considerable damage in entering this complex, politically charged context … such as by associating themselves with particular groups, by publishing knowledge without permission, and by exploiting, neglecting, or disrespecting the people they work with' (Whittaker, 2020, p. 175). The subtle forms of authority conveyed in popular health metrics – such as mortality attributed to COVID, rather than to colonial relations and neoliberal marginalisation and impoverishment – are a constant threat to Indigenous lifeways (Junge, 2012; Paradies, 2020).

To remove these threats, epidemiologists and public health officials must expand their tolerance for smaller-scale forms of data, including validated eyewitness accounts, local and culturally-relevant measures of harm, and local structures and authorities in prevention (Briggs & Mantini-Briggs, 2016; Prussing, 2018, 2020; Prussing & Newbury, 2016; Smith-Morris, 2017). Scientists who are willing to confront the errors and bias within their own enterprises will be crucial allies to Indigenous Peoples who rely on these heterogeneous, and heterodox, forms of information. For example, scientific litmus tests of replicability and generalizability will be less important for many small-scale projects than relational care and lifelong bonds and places of connection.

The central role of health care and public health in nation-building requires that ethical scientists combat iniquitous information strategies (Waitzkin, 2015). The global public health community supports this agenda by modifying its scientific information flows via several priorities:

1. Gather Local Data. Information gathering during public health emergencies is crucial, and data from Indigenous communities must be gathered where possible, where and when researchers are welcome. While all data must be clearly marked for their strength and weaknesses, the dissemination of information on Indigenous experiences and needs should not be enslaved to academic or scientific discourses about replicability or generalizability. Open- and crowd-sourced data conveying local details should be marked, but welcomed, especially when validated or more rigorously vetted forms of data or not available.
2. Value Heterogeneous Forms of Data. Major institutions of science with reputations for reliability of data can show leadership in the use of broader types of knowledge, including forms of data that reflect diverse needs and capacities of local settings. For example, while anecdotal or unverified case reports may not satisfy standards for inclusion in certain information platforms, these 'possible cases' or 'grey data' may merit a separate category or other platforms. Such strategies would allow the thousands of cases in marginalised communities to receive desperately needed attention
3. Extend Data Collaborations. Scientific and medical communities should collaborate with Indigenous organisations and communities on public health information at multiple levels, including: the generation and dissemination of case data; coordination of resources in response to those data; and decision-making that impacts communities. Scientific ethics demand responsible stewardship of information which, for IPs, means local data-based decision-making, resource-generation, and information-sharing.

4. Respect IP Data Sovereignty. Information about Indigenous communities, once gathered, may not become the 'property' of researchers. Repeat consents from individuals and communal bodies may be necessary (Smith-Morris, 2007).

In conclusion, global pandemics are not separate from the broader societal and survival challenges that Indigenous Peoples battle every day. Likewise, an imperious and colonising attitude toward data cannot be separated from the ethnocidal harm that scientific erasures create. The COVID pandemic illustrates this intricate but dissoluble connection. For their rights to be protected, IPs must be visible in state metrics, engaged collaboratively in data collection and interpretation, and their consent and sovereignty respected. This may require a de-privileging of canonical ways of vetting information, and reformed ideas about data ownership. A public health crisis must not become justification for the reversal of hard-won IP rights and may, instead, be an opportunity to expand Indigenous data sovereignty and capacities.

Notes

1. For example, the INPI Report for November 2021 acknowledges 65 Indigenous Peoples in Mexico but the public health data presented later in the same report is aggregated by states. IP statistics are embedded and overlapping within those state designations, making it impossible to determine their community-specific needs.
2. It is beyond the scope of this article to summarise the character and scope of Indigenous rights, the complexity of violations now recognised by the United Nations and other international bodies, or the relationship between these rights and Indigenous health. Key concerns include physical safety, territorial security, place-based communal sovereignty, reduced or dis-interest in capitalist or technological incorporation, inadequate access to public health infrastructures, invisibility within over-arching federal safety net systems, and limited networks of communication.

Disclosure statement

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References

Adams, V. (2016). *Metrics: What counts in global health*. Duke University Press.

Artaraz, K., Calestani, M., & Trueba, M. L. (2021). Introduction: Vivir bien/Buen vivir and post-neoliberal Development paths in Latin America: Scope, strategies, and the realities of implementation. *Latin American Perspectives*, *48*(3), 4–16. https://doi.org/10.1177/0094582X211009461

Bhalla, N. (2020). Kenya's forest communities face eviction from ancestral lands - even during pandemic. In Thomson Reuters Foundation News.

Bociaga, R. (2020, August 7). For the Philippines' Mangyans, COVID-19 extends a long history of discrimination. https://news.mongabay.com/2020/08/for-the-philippines-mangyans-covid-19-extends-a-long-history-of-discrimination/.

Briggs, C. L., & Mantini-Briggs, C. (2016). *Tell me why my children died*. Duke University Press.

Chepang, B. (2020, April 21). Chepangs face a humanitarian crisis *The Kathmandu Post*. https://kathmandupost.com/columns/2020/04/21/chepangs-face-a-humanitarian-crisis.

Cherofsky, J., & Juárez López, B. n. M. (2021). COVID in Indigenous Peoples: One Year Into the Pandemic. https://www.culturalsurvival.org/news/covid-19-en-pueblos-indigenas-un-ano-de-la-pandemia-datos-nuevas-variantes-y-vacunas.

Cohen, J. H., & Mata-Sánchez, N. D. (2021). Challenges, inequalities and COVID-19: Examples from indigenous oaxaca, Mexico. *Global Public Health*, *16*(4), 639–649. https://doi.org/10.1080/17441692.2020.1868548

CONAIE, E., CONFENIAE, and CONAICE. (2021). Indicaciones para prevenir el Coronavirus en comunidades Afroecuatorianas. In.

Curtice, K., & Choo, E. (2020). Indigenous populations: Left behind in the COVID-19 response. *The Lancet*, *395* (10239), 1753. https://doi.org/10.1016/S0140-6736(20)31242-3

Dagnino, E. (2007). Citizenship: A perverse confluence. *Development in Practice*, *17*(4–5), 549–556. https://doi.org/10.1080/09614520701469534

Daly, Angela, Monique Mann, and S. Kate Devitt. (2019). *Good data*. Lulu. com.

Dantas, C. (2020). Aldeia do Alto Xingu improvisa hospital, contrata médica e tem mortalidade zero por Covid-19. In.

Davis, S. L. M. (2017). The uncounted: Politics of data and visibility in global health. *The International Journal of Human Rights*, *21*(8), 1144–1163. https://doi.org/10.1080/13642987.2017.1348707

Fishbein, A. (2020, April 19). Displaced Families in Myanmar's Kachin Fear Coronavirus Threat. *Al Jazeera*. https://www.aljazeera.com/news/2020/4/19/displaced-families-in-myanmars-kachin-fear-coronavirus-threat.

Flores-Obanil, C. (2020). The Pandemic's Hidden Casualty: Human Rights. In: The Diplomat.

Ganguly, M. (2020). Nepal Park Guards Accused of Persecuting Indigenous People. In: Human Rights Watch.

Grundy-Warr, C., & Lin, S. (2020). COVID-19 geopolitics: Silence and erasure in Cambodia and Myanmar in times of pandemic. *Eurasian Geography and Economics*, *61*(4–5), 493–510. https://doi.org/10.1080/15387216.2020.1780928

Henriquez-Trujillo, A. R., Ortiz-Prado, E., Rivera-Olivero, I. A., Nenquimo, N., Tapia, A., Anderson, M., Lozada, T., & Garcia-Bereguiain, M. A. (2021). COVID-19 outbreaks among isolated Amazonian indigenous people, Ecuador. *Bulletin of the World Health Organization*, *99*(7), 478. https://doi.org/10.2471/BLT.20.283028

Hirano, T., & Murakami, M. (2020). COVID-19: A new virus, but a familiar receptor and cytokine release syndrome. *Immunity*, *52*(5), 731–733. https://doi.org/10.1016/j.immuni.2020.04.003

Hkawng, J. T., Fishbein, E., & Nitta, Y. (2020). Myanmar's ethnic conflicts obstruct COVID-19 aid to minorities. In Nikkei Asia.

Horse, A. J. Y., & Huyser, K. R. (2021). Indigenous data sovereignty and COVID-19 data issues for American Indian and Alaska Native Tribes and populations. *Journal of Population Research*, 1–5. https://doi.org/10.1007/s12546-021-09261-5

IWGIA. (2020). Joint submission on the situation of the Ogiek to the Human Rights Council's 45th Session. In IWGIA.

Junge, B. (2012). NGOs as shadow pseudopublics: Grassroots community leaders' perceptions of change and continuity in Porto Alegre, Brazil. *American Ethnologist*, *39*(2), 407–424. https://doi.org/10.1111/j.1548-1425.2012.01372.x

Keane, M., Khupe, C., & Seehawer, M. (2017). Decolonising methodology: Who benefits from indigenous knowledge research? *Educational Research for Social Change*, *6*(1), 12–24. https://doi.org/10.17159/2221-4070/2017/v6i1a2

Kemball, A. (2020). Postapocalyptic Peoples? Covid-19, Public Health, and Native Americans. In. The Polyphony.

Kenya Flouts African Court Judgment, Continues to Evict Ogiek in the Midst of COVID-19 Pandemic. (2020, July 17). https://minorityrights.org/2020/07/17/ogiek-evictions/.

Kukutai, T., & Taylor, J. (2016). *Indigenous data sovereignty: Toward an agenda*. ANU press.

Life, L. i. (2020). Stop The Evictions Of Ogiek Peoples From Their Ancestral Lands In Kenya's Mau Forest. https://www.landislife.org/stop-the-evictions-of-ogiek-peoples-from-their-ancestral-lands-in-kenyas-mau-forest-695/.

Lin, C. (2020). Poverty in New Caledonia: The Kanak's Struggle. *Borgen Magazine*. https://www.borgenmagazine.com/poverty-new-caledonia/.

Lundström, K. (2021, February 25, 2021). Indonesia's Dayaks grapple with COVID-19, deforestation and development. https://southeastasiaglobe.com/dayak-group-indonesia/.

Mahmudpour, M., Roozbeh, J., Keshavarz, M., Farrokhi, S., & Nabipour, I. (2020). COVID-19 cytokine storm: The anger of inflammation. *Cytokine*, *133*, 155151. https://doi.org/10.1016/j.cyto.2020.155151

Makere, S.-H. (2005). Cultural studies, Indigenous knowledge and pedagogies of hope. *Policy Futures in Education*, *3* (2), 153–163. https://doi.org/10.2304/pfie.2005.3.2.4

Morphy, F. (2016). Indigenising demographic categories: A prolegomenon to indigenous data sovereignty. *Indigenous Data Sovereignty: Towards an Agenda*. TAHU KUKUTAIJOHN TAYLOR Series: Centre for Aboriginal Economic Policy Research (CAEPR) (Vol. 38, 99–115). ANU Press.

Nascimento, A. (2020). Povo Ashaninka adota isolamento rígido há 9 meses e é o único do Acre sem registro de casos de Covid-19. In: Globo G1.

OHCHR. (2020). *Impact of COVID-19 on Batwa and Benet IPs Communities in Uganda*. https://www.ohchr.org/Documents/Issues/IPeoples/SR/COVID-19/IndigenousCSOs/UGANDAAfricanInternationalChristianMinistryandMinortyRightsGroupInternationalCOVID19Uganda.pdf.

Ozkan, T., Worrall, J. L., & Zettler, H. (2018). Validating media-driven and crowdsourced police shooting data: A research note. *Journal of Crime and Justice*, *41*(3), 334–345. https://doi.org/10.1080/0735648X.2017.1326831

Paradies, Y. (2020). Unsettling truths: Modernity,(de-) coloniality and Indigenous futures. *Postcolonial Studies*, *23*(4), 438–456. https://doi.org/10.1080/13688790.2020.1809069

Prussing, E. (2018). Critical epidemiology in action: Research for and by indigenous peoples. *SSM-population Health*, *6*, 98–106. https://doi.org/10.1016/j.ssmph.2018.09.003

Prussing, E. (2020). Through a critical lens: Expertise in epidemiology for and by indigenous peoples. *Science, Technology, & Human Values*, *45*(6), 1142–1167. https://doi.org/10.1177/0162243919887448

Prussing, E., & Newbury, E. (2016). Neoliberalism and indigenous knowledge: Māori health research and the cultural politics of New Zealand's "National Science Challenges". *Social Science & Medicine*, *150*, 57–66. https://doi.org/10.1016/j.socscimed.2015.12.012

Rodríguez, N. J. (2020). Indigenous and Black Peoples of Latin America Impacted by COVID-19. https://www.nacionmulticultural.unam.mx/pueblos-covid19/.

Rylko-Bauer, B., & Farmer, P. (2002). Managed care or managed inequality? A call for critiques of market-based medicine. *Medical Anthropology Quarterly*, *16*(4), 476–502. https://doi.org/10.1525/maq.2002.16.4.476

Samiti, R. S. (2020, July 22). Halt forced eviction of Chepang people *The Himalayan Times*. https://thehimalayantimes.com/nepal/halt-forced-eviction-of-chepang-people/.

Sirén, A., Uzendoski, M., Swanson, T., Jácome-Negrete, I., Sirén-Gualinga, E., Tapia, A., … Machoa, D. (2020). Resilience against the covid-19 pandemic among indigenous Kichwa communities in Ecuadorian Amazonia.

Smith-Morris, C. (2007). Autonomous individuals or self-determined communities? The changing ethics of research among Native Americans. *Human Organization*, *66*(3), 327–336. https://doi.org/10.17730/humo.66.3.qj157567773u2013

Smith-Morris, C. (2017). Epidemiological placism in public health emergencies: Ebola in two Dallas neighborhoods. *Social Science & Medicine*, *179*, 106–114. https://doi.org/10.1016/j.socscimed.2017.02.036

Smith-Morris, C., & DeLuca, D. (2020). CoronaVirus, Indigenous Peoples, and Global Advocacy. https://www.culturalsurvival.org/news/coronavirus-indigenous-peoples-and-global-advocacy.

Smith-Morris, C., & Epstein, J. (2014). Beyond cultural competency: Skill, reflexivity, and structure in successful tribal health care. *American Indian Culture & Research Journal*, *38*(1). https://doi.org/10.17953/aicr.38.1.euh77km830158413

Tapia, A., Garcés, B., & Montahuano, L. (2021). The Amazonian Indigenous communities fighting 'balsa wood fever' and COVID.

Uganda, U. O. f. B. D. i. (2020). Increased hunger and poverty among the Batwa amidst COVID-19 in Uganda. https://www.forestpeoples.org/en/increased-hunger-and-poverty-for-Batwa-in-Uganda-amid-covid-19.

Vargas, I. (2021). *Manuel de uso tradicional de plantas medicinales para la mitigación del COVID-19 en comunidades Kichwas Amazónicas*. CONFENIAE, Lanceros Digitales, and Internews. https://issuu.com/lancerosdigitales/docs/manual_plantas_covid19.

Waitzkin, H. (2015). Resistance and building an alternative future the struggle against privatization of health. In Howard Waitzkin (Ed.), *Medicine and public health at the end of empire* (pp. 183–201). Routledge.

Whittaker, C. (2020). Aztecs are not indigenous: Anthropology and the politics of indigeneity. *Annals of Anthropological Practice*, *44*(2), 173–179. https://doi.org/10.1111/napa.12147

Yap, M. L.-M., & Watene, K. (2019). The sustainable development goals (SDGs) and indigenous peoples: Another missed opportunity? *Journal of Human Development and Capabilities*, *20*(4), 451–467. https://doi.org/10.1080/19452829.2019.1574725