

DATA JUSTICE AND COVID-19:

GLOBAL PERSPECTIVES

Data Justice and COVID-19: Global Perspectives
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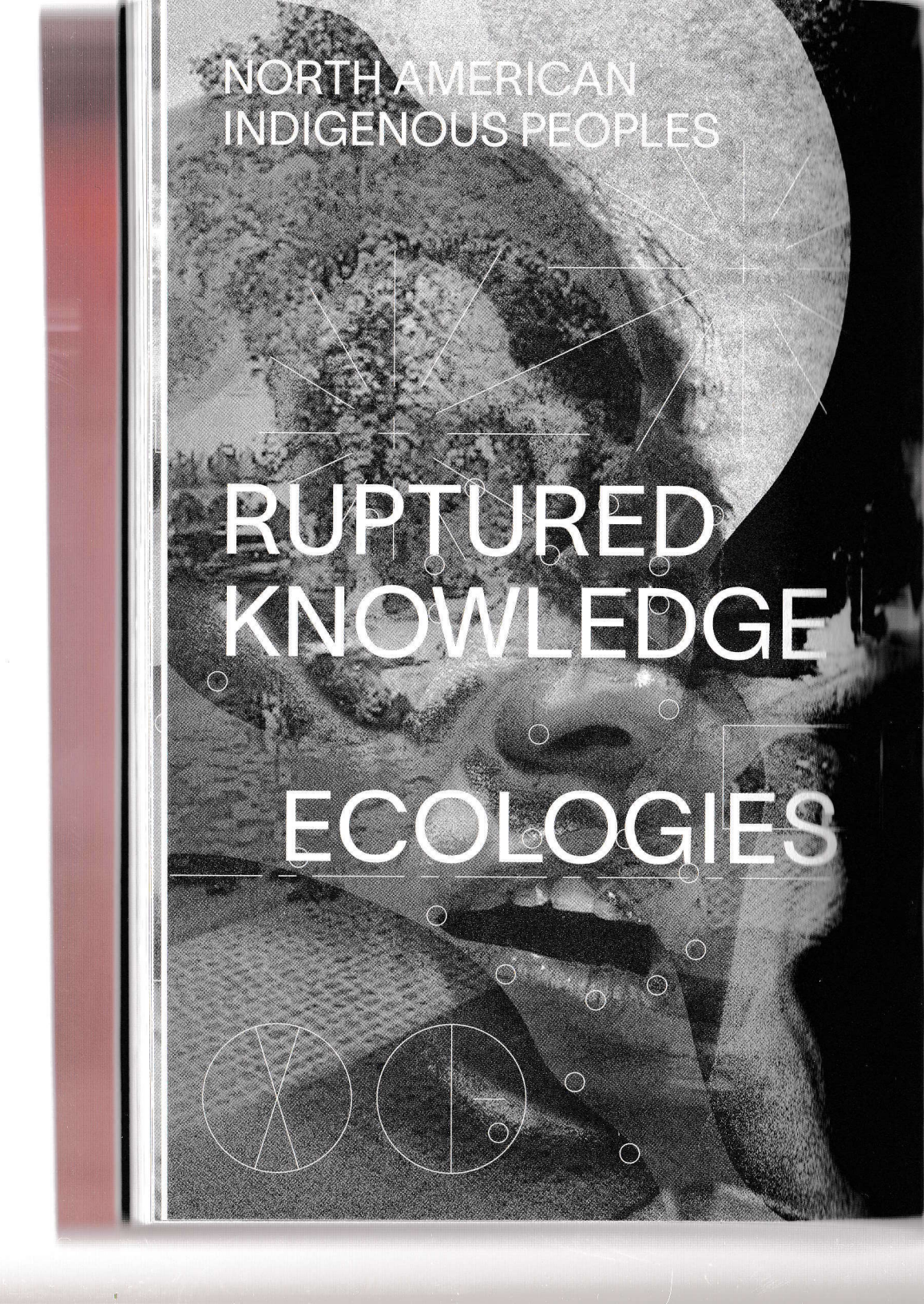
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NORTH AMERICAN
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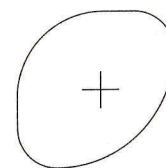
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ECOLOGIES

IN INDIAN COUNTRY

Marisa Elena Duarte

Fundamentally, the concept of data justice is ideal: it presupposes a reasonable state of information equity, where factual evidence and knowledge are thoughtfully integrated into decision-making. Sadly, for over two centuries before COVID-19, Indigenous peoples of North America have existed in a state of epistemic injustice. Even the points of negotiable agreement between sovereign tribes or *pueblos indígenas* and North American federal and state / provincial governments are clouded by misinformation and colonial disinformation about Indigenous rights and customs, land claims and boundaries, and rules around intellectual property and privacy. Nationalist systems subjugate Indigenous philosophies while excluding Indigenous families and communities from decision-making roles in public education, health care, and media. Specifically, in the US, leaders in sovereign Native nations have been excluded from decision-making roles around crafting the Coronavirus Aid, Relief, and Economic Security (CARES) Act, which distributes billions of dollars to Americans and health care institutions. In Mexico, leaders of *pueblos autónomos* are not included in local health surveillance efforts. In Canada, leaders of sovereign First Nations have had to demand essential resources through parallel



governmental processes. While Indigenous leaders demand representation and participation, COVID-19 is exacerbating existing structural inequities in each of these contexts.

Lack of robust Internet and media infrastructure, accurate and precise epidemiological data and analyses, culturally relevant public health messaging, and means of data-sharing toward informed decision-making are contributing to the spread of COVID-19 through a number of Indigenous communities.

- Bigotry and ignorance amplify the stigmatisation of Indigenous peoples whose communities are suffering from outbreaks.¹ Where histories of redlining—including containment on reservations, reserves, and in remote pueblos—prevent Indigenous children from obtaining basic educational support, K-12 students rely on homework-by-mail to keep up with daily coursework.²

While technologically advanced societies hope for a vaccine, Indigenous government leadership struggles for inclusion in the negotiations between the federal governments and private industries that make PPE, clinical care equipment, vaccinations, and antiviral drugs deliverable and affordable through reputable institutions.³ For some Indigenous leaders, this means working through intergovernmental bodies to pressure federal authorities to consider their treaty responsibilities to tribes. For others, it means working with non-governmental organisations, university labs, and mutual aid collectives to direct personnel, food, and PPE to tribal organisations. For others, it means writing letters to congressional or provincial representatives, and speaking with reliable journalists who can spread awareness of the crisis through media.

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- Considerations of data justice in Indigenous contexts require reflection on the range of information ecologies of Indigenous North America.⁴ Presently, Indigenous knowledge—including information, datasets, and intellectual and cultural property created by and about Indigenous peoples—circulates through institutions such as tribal administrative offices, libraries and archives, museums, non-profit cultural centres, health centres, schools and universities, private corporations, and federal agencies via digital and analogue infrastructures and platforms. When information infrastructures work well

in terms of technical capacity, procedural routine, and skilled personnel, decision-makers can transmit, receive, craft, and push data, information, and knowledge through analogue and digital networks of humans and devices.

Regional epidemiological centres as well as tribal health centres typically have the means of receiving and sharing limited types of information relevant to clinical care and Indigenous community health. However, the first waves of COVID-19 outbreaks affected various regions so rapidly that prior means of communicating health information—including reliable health surveillance data and culturally targeted public health messaging—were quickly overwhelmed. In some regions, health providers have no training or systematic method for documenting cases of COVID-19 presenting in tribal clinics.

Through most of Mexico, health providers in *pueblos indigenas* have no tools for systematically counting and reporting cases of COVID-19 in areas with limited information and communication technologies. In the US and Canada, some tribal governments retain their own epidemiological data, whereas others report cases to states or provinces, and then rely on state health department or university epidemiological analyses. Divergent chains of reporting COVID-19 cases have resulted in different epidemiological calculations, where some account for spread through reservations and reserve communities, and some merely provide abstract analyses divorced from Indigenous geographies.

The relationship between (1) the functionality of institutional data-sharing assemblages and interfaces, (2) the capacity of individuals and institutions to create and disseminate health surveillance analyses and public health messaging at point of need, (3) practices of informed leadership, and (4) information integrity in a knowledge environment characterise any knowledge ecology structured around Indigenous health care. However, anecdotes emerging out of the waves of regional COVID-19 outbreaks throughout North America have revealed the weakened capacities of Indigenous communities' and governments' data-sharing infrastructures. Notably, these anecdotes reveal limitations

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of technical capacity, data-sharing procedures, and skilled personnel who can assure the functionality of ICTs and data-sharing platforms as well as rapidly synthesise information for various stakeholders.

Furthermore, overall, systemic health inequities are compounded by federal abrogation of Indigenous treaty rights. In Canada, on March 23, 2020, the Assembly of First Nations executed a motion to declare a state of emergency with regard to the COVID-19 pandemic, including a call for federal, provincial, territorial, and municipal governments to systematically increase funding, support, and resources to First Nations, especially to remote and isolated communities. The state of emergency insists that 'First Nations leadership be fully and meaningfully involved at the decision-making tables in the development of all plans, legislation, policies, budget allocations and regulations regarding the COVID-19 pandemic federally and provincially, inclusive of the epidemiological datasets, budgetary spreadsheets, and other datasets that First Nations leaders can analyse with regard for the institutional capacities within their own governments.'⁵

The need to promulgate informed leadership as part of a state of emergency reveals existing structural inequities impeding the actionability of Indigenous data sovereignty, that is, the deliberate negotiated sharing of datasets across Indigenous and non-Indigenous institutions toward Indigenous well-being. In this context, Indigenous data sovereignty demands the dissemination of methodically assembled datasets affecting Indigenous well-being and livelihood across secure channels toward reputable and authoritative Indigenous institutions for analysis in accordance with Native scientific methodologies and tribal-centric policy-making.

However, in the midst of a fearful sociopolitical environment laden with governmental inequities, the means of carrying this out are challenged. Indigenous communities throughout Canada, the US, and Mexico are relying on non-profit organisations, grassroots activist collectives, and mutual aid organisations to raise emergency funds at a faster rate than governments can provide. Members of tribal communities and *pueblos indígenas* who are formally educated in

science, technology, policy, and health are voluntarily rapidly analysing, interpreting, and translating statistical analyses and mass media news updates about the virus, rates of transmission, fatalities, and economic impacts for their families, communities, and governments. The on-the-ground stories emerging out of First Nations communities reveal the depth of these challenges. In April the Yukon government, in support of a number of women's shelters and Indigenous health organisations, delivered 325 cell phones with 4-month service plans to women fleeing abusive relationships.⁶ The effort is complicated by prior evidence showing that cyberstalking predicates abusive acts and assaults against First Nations women and girls.⁷

The effort is also complicated by digital divide research that shows the limitations of charitable efforts that drop unsustainable Internet-ready devices and services into marginalised communities. For example, in this scenario, how will the recipients of these much-needed cell phones afford the comparable data plan after the subsidised 4-month period, particularly in light of the scientific likelihood that social distancing will need to occur for years until a vaccine is globally distributed, and employment options increase? While there is no doubt that these efforts are immediately appreciated, when it comes to data justice for First Nations and Metis peoples, subsidised cell phones and WiFi hotspots are like band-aids amidst the systemic and structural racism, including environmental racism, that marginalises Indigenous peoples through Canada's era of Truth and Reconciliation.

Meanwhile, in the US, President Trump's racist rhetoric and anti-scientific propaganda inflames the existing public health crisis in Indian Country. The lack of coherent messaging about COVID-19 from the White House has resulted in what US journalists are calling an infodemic: a parallel scourge of misinformation and disinformation about COVID-19 that is resulting in increasing viral spread as well as racist acts against social groups such as Asians and Asian-Americans (Trump refers to COVID-19 as the 'China virus'), and highly affected populations who already endure structural health inequities and systematic racism, including African Americans, Latinos, and Native Americans.

Since April 2020, Navajo Nation has been a hotspot for regional outbreaks that, due to the lack of social distancing and public health education, are moving through tribal and non-tribal communities across four states. Partisan politics fuels the outbreaks. While in New Mexico Democratic Governor Michelle Lujan extends periods of social distancing and storefront closures, and sends state resources to regional hospitals and clinics, attorneys are suing Arizona Republican leadership for massaging health data indicators in support of 're-opening the state', allowing for the operations of nursing homes state-wide as well as storefronts near Navajo Nation with little to no public health enforcement measures.⁸

Navajo Nation covers a massive territory, and multiple federal, state, and local health service providers, Internet service providers, chapter houses and district governments, and schools and colleges provide different levels of care to the region. Significant health information gaps occur through the lack of consistent epidemiological data-sharing and analyses across these institutions, including the state governments, Indian Health Services, regional private hospitals and clinics, and non-profit organisations. The lack of fibre optic cable to homes and anchor institutions both impedes deployment of emergency Internet hotspots in key locations, and makes it difficult or impossible for families to share information without traveling and speaking in person. Local authority figures, including fundamentalist church and spiritual leaders, white supremacist political movement leaders, and family leaders who are simply ignorant about what a virus is and how it is transmitted, disseminate misinformation and disinformation with fatal consequences.

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Much of the news about what life with COVID-19 is like within and near Navajo Nation is distributed by independent Indigenous journalists in the region, who rely on their existing social networks to raise awareness of local challenges. Aspects of Navajo Nation's experience with COVID-19 reflect experiences in other sovereign Native nations throughout the US. Lummi Nation experienced outbreaks associated with intergenerational family gatherings. Though Oneida Nation and Menominee Nation issued shelter-in-place orders alongside the state of Wisconsin in early April,

within six weeks the state's Republican-led Supreme Court ruled that the governor's stay-at-home order was unlawful and unenforceable, effectively putting at risk millions of individuals, including tribal citizens.

In Mexico, on Sunday, March 8, the weekend before social distancing measures were announced by many US states, millions of women marched through cities and towns in protest of President Obrador's sexist response to systemic government mishandling of *femicidio*: significantly increasing cases of disappearances and assaults against women, including murders of feminists in particular.⁹ Indigenous feminists and leadership supported aspects of this protest; a number of those disappeared and murdered are Indigenous activists.¹⁰ Historically, Mexico's colonial ideology simultaneously subjugates women and Indigenous peoples through covert government-sponsored kidnappings and killings alongside corrupt church and government practices, including the withholding of hospital care and safe refuge, obfuscated or erroneous scientific datasets, withholding of technical reports, censorship of journalistic exposés, and general subjugation of information and knowledge pertaining to Indigenous peoples.

While Mexico is reporting the greatest number of COVID-19 cases in dense city centres such as Mexico City and Tijuana, scientists suggest that the government is not tracking or reporting the actual numbers of deaths, cases, and affected groups. Indeed, while the Mexican government closed the Mexico-US border in April to stem North-South contagion, the US and Mexican governments are now deporting hundreds of individuals likely exposed to COVID-19 in detention centres, most of whom are also Indigenous peoples from Chiapas and the Mayan communities in the borderland between Guatemala and Mexico.¹¹ Social stigmas compound lack of access to treatment and healthcare amongst the poorest sector of the national population. Officials are investigating the case of a Chiapas man who, in April, tested positive for the virus and shortly thereafter was found hanging from a tree outside his home in Ocosingo in an apparent suicide.¹²

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In response to the economic recession across the NAFTA governments, local shop owners are price-gouging. Women's weaving collectives in Chiapas, grassroots Indigenous advocacy groups, and binational tribes such as the Pascua Yaqui Tribe / Yaqui people of Sonora have been raising funds and sending resources to families and the *pueblos autónomos* so that families can afford food staples amidst increasing joblessness.

Disinformation and misinformation also shape the public health response. In March, a Mexican political cartoonist released an image of a rural student wearing a face mask and standing outside his home holding a book, looking at a far-away city shadowed by a giant WiFi signal. The student says, loosely translated, 'Pardon me, Teacher, but I cannot hear you.' In April, the Yaqui people of Sonora made national news for their insistence on continuing annual Easter ceremonial traditions in spite of shelter-in-place warnings.¹³ Advocates for Indigenous rights in Mexico have been supporting the cultural translation of public health messaging for the various Indigenous language communities throughout the country.

206 Throughout North America, only tribal governments with local technical and epidemiological expertise are maintaining and reporting datasets indicating numbers of cases and rates of transmission, and of those, very few are tracking cases in border towns and of individuals who are associated with the tribal community but who are not officially enrolled tribal citizens. One of the only ways for Indigenous leaders and health advocates to gather accurate and precise datasets is by reaching into their existing social networks to form secure data-sharing partnerships. Methods must include analyses of epidemiological data in light of Indigenous discernment of community social practices and norms, culturally informed contact tracing and public health education and messaging, local analyses of institutional barriers and opportunities, and tracing of viral spread through regions beyond government jurisdictions.

This approach requires a combination of relational skill, trustworthy productivity, political acumen, and scientific analytic expertise. It requires networks of teams who

can advocate for large structural changes, increase in infrastructure expenditures for Indigenous peoples and governments, and everyday social change through education and community awareness. By providing executive summaries of data-sharing activities and efforts with trusted policy-makers, in the future, authorities can advocate for the kinds of equitable data-sharing, research, and archival activities that need to occur through nation-to-nation negotiation between Canada, the US, Mexico, and *pueblos indígenas* and sovereign tribes. For now, though, throughout Indigenous North America, much of the work is about enduring and counteracting the brutality of the COVID-19 infodemic.