

Improving COVID-19 data protocols for Indigenous peoples in the U.S. and Canada: A public-media-based cross-national comparison

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Abstract

In response to current calls by the World Health Organization and United Nations to prioritize data processes regarding COVID-19 and its impact on Indigenous Peoples worldwide, this exploratory paper aims to briefly identify barriers regarding data processes for Indigenous communities impacted by COVID-19 in Canada and the U.S. Built on emergent themes contributed by current research, the research conducted qualitatively public media analysis to address communication, distrust, and community participation as issues, barriers, and solutions for thorough and accurate data processes. Funding has been a long-term existing and primary issue in addressing these three themes. Federal governments of both countries could better support the Indigenous communities by providing adequate funding, following through with their pledges of support, and sharing detailed, accumulated data with tribal authorities, and tribal epidemiologists. Better communication among federal, state/provincial, and Indigenous community authorities would improve data collection and analysis. Stimulating bottom-up community participation in COVID-19 efforts, not only promotes the data processes in Indigenous communities, but also empowers the local communities' leadership to develop solution-based responses. This cross-national pilot research sheds light on the necessity of international collaboration advancing Indigenous communities' health and well-being in both disaster and non-disaster settings.

Introduction

At the beginning of August 2020, the COVID-19 pandemic had wreaked havoc on 188 nations worldwide, resulting in approximately 700 thousand deaths and more than 18 million people infected (JHU, 2020). Most high-income countries (e.g. Canada and Australia), which have been hit harder than their developing peers, have been moving into the reopening stages (Baragona,

2020). The U.S., however, has been experiencing a continual and significant surge eclipsing the initial swell in cases due to various social, cultural, economic, and political reasons (Almasy, 2020). In the U.S., and arguably Canada, “long-standing systemic health and social inequities have put some members of racial and ethnic minority groups at increased risk of getting COVID-19 or experiencing severe illness, regardless of age” (Centers for Disease Control & Protection [CDC], 2020a, p.1). CDC data indicates that between March and June 12, 2020 adjusted hospitalization rates for Native Americans were five times higher, than their white counterparts. As such, the appropriate collection and processing of minority COVID-19 data is crucial to coming to accurate conclusions and determining best practices for lowering infection rates, hospitalizations, and deaths.

Extreme events always have catastrophic influence on vulnerable and marginalized groups (Wu, & Karabanow, 2020). In the U.S. and Canada, the Native American community, presenting a relatively high percentage in the total population, including American Indians and Alaska Natives (AIAN), Native Hawaiians, Pacific Islanders in the U.S. and First Nations, Inuit, and Métis in Canada, are some of the most vulnerable and marginalized groups of the developed world. Though there are other terms, for brevity, “Indigenous Peoples” is the consistent term used here for these groups. In non-disaster settings, Indigenous communities in both countries have suffered a gamut of harsh realities ranging from limited healthcare, social services, housing, employment, and a scarcity of natural resources (e.g. water and food security) (Ashworth, 2018). Although the COVID-19 pandemic has further compromised their already extremely vulnerable status, the Indigenous-specified public health related data are still unclear (Jones et al., 2018; NCCAH, 2013). CNN reports that in May, the Navajo Nation surpassed New York in COVID-19 infections (Silverman et. al., 2020). The misalignment between government objectives and COVID-19 realities among Indigenous communities is the impetus to deeply examine the public health data processing and related issues through a cross-national comparison approach between the U.S. and Canada.

Conceptual Framework and Research Question

International health organizations and practitioners are calling for more inclusion and more efficient data processes to better understand the impact of COVID-19 on Indigenous Peoples (UN, 2020; WHO, 2020). This research aims to identify barriers regarding collecting, analyzing, and

disseminating data regarding coronavirus-affected Indigenous Peoples in the U. S. and Canada. As shown in Figure 1., the literature review yields to three specific emerging themes ultimately identified as barriers to accessing and assessing COVID data between the different levels of the two governments, and authorities in Indigenous communities. The examination of data reports relevant to Indigenous Peoples, and the impact of the COVID-19 pandemic, provides a unique cross-national platform to deeply examine the relationships among these three themes within one event, and guides this research to further identify the barriers towards data processes in Indigenous communities.

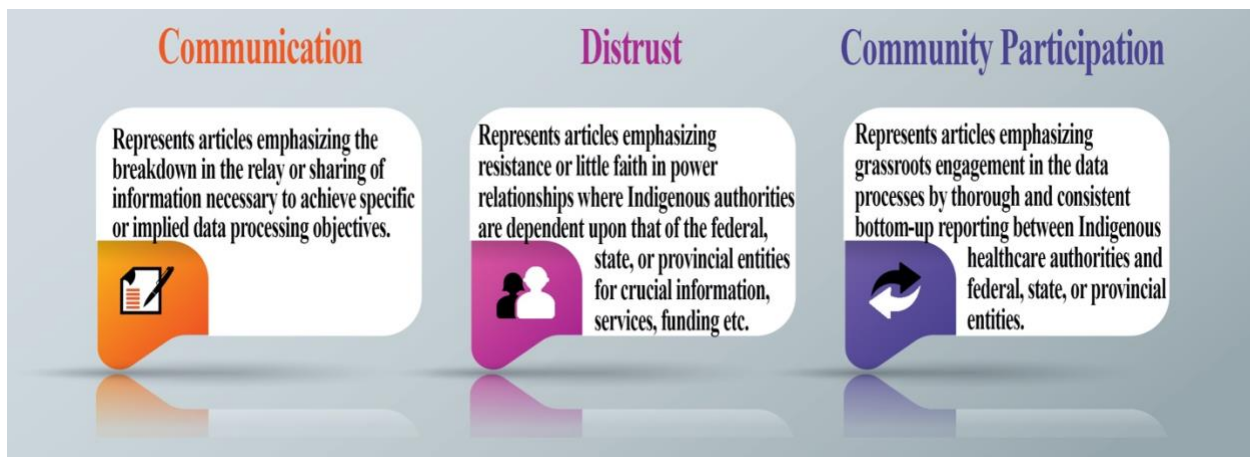


Figure 1. *Communication, Distrust and Community Participation in Indigenous Studies*

Research Design

Data Curation

This qualitative research focused on the top-ranked public media venues in both countries, which are the major source for COVID-19 information for the public (CBC Radio, 2020). In Canada, according to Feedspot (2020), the top three Canadian News websites are Canadian Broadcasting Corporation (CBC News), the Globe and Mail, and CTV News. The U.S. Federal Communications Commission identified three primary governmental news websites focused on COVID-19 information, Coronavirus.gov, CDC.gov/coronavirus, and USA.gov/coronavirus (FCC, 2020). Informally, the top three most competitive public media outlets in the U.S. for national news on COVID-19 are FOX News, CNN, and MSNBC (Statista, 2020). Despite this,

there were a few news reports related to data centralized within the three top-ranked news media venues.

Search Strategies

Website-based news articles are the major data resources that support this study. Two groups of keyword were established to identify news articles in the primarily consumed public media websites: Group 1 Indigenous: (“Aboriginal” OR “Native American” OR “American Indian” OR “First Nations” OR “Indigenous” OR “Inuit” OR “Métis” OR “Indians” OR “Alaska Natives” OR “Native Hawaiian” OR “Asian Pacific” and Group 2: COVID-19 (“COVID-19” OR “coronavirus”). This scope search will provide most of the documents including either one keyword from each group. For example, any articles consisting of “Indigenous” AND “COVID”, or “Inuit” AND “coronavirus” will be selected by the primary screen. The search period begins upon the first infected case was reported, January 21, 2020 in the U.S. (Schumaker, 2020) and January 25, 2020 in Canada (The Canadian Press, 2020a) respectively, and ends at 23: 59 ET on July 15, 2020. The authors included primary documents specifically related to data and its processes to support the arguments presented below but did not exhaust all sources given the brevity and time constraints related to publishing the special topic.

Data Analysis

Emerging theme strategies, supporting inductive and deductive coding approaches, are employed to compare and synthesize media article data from both countries. Most of these articles consist of the original reports from other resources, especially the governmental websites, which provide extra background and related information and form a comprehensive lens to examine and synthesize related data. Various differences and similarities between two countries including pandemic-related social, economic, and political reasons, were also imbedded in the data analysis, in order to develop independent and collective themes to facilitate the cross-national comparison. This article yields the scope of emerging themes to focus specifically on the issue of data processes in each country.

Issues and Barriers

Data Sharing: A Huge Difference Regarding Data Released Between the Federal Government Agencies and Community-Based Agencies Clearly Indicate the Data Gaps in Both Countries

Overall, in both countries, communication emerged as a pillar of the conceptual framework through which relations between federal governments, state, provincial, and local tribal authorities can be greatly improved. Bringing tribal entities to the table to engage in a more cooperative manner can help to create data driven solutions that impact both countries and their Indigenous populous. In Canada, according to Yellowhead Institute, a community-based First Nation-led think tank in Canada, released a report indicating that more than 465 indigenous COVID-19 cases among 42 communities across Canada with seven deaths on May 11, 2020 (Skye, 2020). At the same time, Indigenous Services Canada (ISC), a Canadian federal government department, officially announced that 183 cases on-reserve in five provinces with 2 deaths, which triggered the Yellowhead Institute's concern that the federal government agency of ISC might not have full capacity to reflect the entire landscape regarding the influence of COVID-19 on indigenous communities across Canada (Barrera & Deer, 2020).

In the U.S., similarly, tribal epidemiologists argue that federal and state entities are not as forthright in sharing data as the tribal entities and Indian Health Services (IHS). Thus, tribal health organizations and the IHS cannot portray a true overall status of the COVID-19 impacts on all Indigenous persons, rather than collecting limited data from those who seek clinical service within tribal lands. Such one-sided cooperation further worsens the distrust between Indigenous authorities and federal and state health organizations. Federal and state entities' are extremely vague in providing legitimate justification regarding denying IHS and other regional TECs access to the data, citing "privacy concerns" and even broadly challenging the "veracity" of tribal identity in some cases (Tahir and Cancryn, 2020, para.1). To example the lack of specificity in the data, the IHS website is reporting approximately 25,000 cases of COVID-19 across 12 regional TECs in the U.S. (IHS, 2020). However, in looking closer at the data there are indicators that point to data unreliability. Indeed, according to the Arizona State COVID-19 data, on July 15, 2020 there are 86,453 positive cases of COVID-19 in Maricopa County. Among those cases, only 3 percent are identified as AIAN. However, 54 percent of the cases are designated as racially/ethnically

“UNKNOWN,” which is about 46,700 people without a racial designation (Arizona DOHS, 2020). The category of “UNKNOWN” was designated across counties in Arizona and represents significant number of cases. These large gaps in specific data detail are indicative of the data collection throughout the states’ and their individual COVID-19 data sites. While some states do better in data collection and transparency, most state data sites are not consistent in identifying cases, nor are they consistent in defining the categories of data collected which can be addressed by resolving the following two barriers: top-down financial support, and bottom-up community participation.

Barrier 1 Top-Down Financial Support. When the Canadian data gap was discovered on May 11, 2020 (Deer, 2020), ISC immediately invested \$250,000 to advance data collection for COVID-19 affected Indigenous communities (Kirkup, 2020). This intensive governmental intervention strongly states that the Canadian federal government’s on-going efforts lean towards Indigenous communities. However, Indigenous authorities challenged the funding efforts and the untimely delivery of perishable data as inadequate (Wright, 2020). Canadian First Nations have experienced a long-term unfunded status, especially equal health service, threatening the trust foundation between community and governmental entities (Blackstock & Day, 2020). Indeed, 1918 Spanish Influenza claimed more than one third of Inuit population in the Province of Newfoundland and Labrador because of chronic overcrowding and limited medical supplies (Mercer, 2020). Pandemics do not respect geographic boundaries. Indigenous communities hope that the COVID-19 pandemic threat would justify increased governmental investment in redressing the inequities, better preparing the Indigenous community, and serving their residents (The Canadian Press, 2020b).

In the U.S., historically, Indigenous Peoples have had a tumultuous relationship with the federal and state governments (Nelson, 2003). Federal and state laws have often clashed with Indigenous sovereignty over Indian Country (Doshi, 2020). Top-down oversight has led to scarcity in funding for initiatives that would mitigate the higher-risk in the COVID-19 pandemic (Akee, 2020). Recently, the federal government has responded to a lack of personal protective equipment (PPE), ventilators, and adequate plumbing for water resources (Hlavinka, 2020). For example, the Department of Health and Human Services announced that the CDC would “provide \$80 million in funding to tribes in support of our nation’s response to... COVID-19” through the Families First Coronavirus Response Act (HHS.gov, para.1). Congress and the Executive branches of

government signed H. R. 174 into law, featuring “strong provisions in support the priorities of tribal communities across Indian Country in response to the pandemic (National Congress of American Indians, 2020, para.1). Although these pledges have initiated a step in a positive direction, there is no evidence to support whether the governmental funding is enough, nor if it will continue consistently.

Top-down approach, especially the financial support from the federal government will fundamentally improve the community-based data collection. In both countries, a lack of funding has impacted the capacity of Indigenous authorities to provide adequate services for their communities, which has been worsened by the ongoing issue of Indigenous having little trust in the promises of federal and state agencies. Improving top-down interventions by meeting longstanding funding pledges can improve the quality of tribal life and foster more trust between government authorities and tribal residents.

Barrier 2: Bottom-Up Local Community Participation and Empowerment. In addition to government financial interventions, empowering Indigenous communities will form a bottom-up approach to support the data collection from the grassroots level. Indigenous Peoples in Canada and the U.S. have recognized that waiting for federal, state, or provincial resources puts them at further disadvantages, potentially missing the valuable window to stop the COVID-19 spread, and put more peers at risk (Richmond et al., 2020, Doshi, 2020). These communities also recognize that further development of their community-based efforts is critical for self-protection (Jones, 2020). For example, increasingly, provinces and territories in Canada have been entering into different stages of reopening and as such, Indigenous communities and tribal authorities are closely monitoring the summer travelers to avoid “the possible arrival of additional COVID-19[infections]” (CBC News, 2020a, para. 16).

In the U.S., some tribes have been critical of state and local governing bodies who have failed to issue lockdown protocols and have instituted their own checkpoints (Ortiz, 2020). Such fears have led many other tribal leaders in other states to impose their own lockdowns and issue curfew orders in the evenings (Doshi et al., 2020). The bottom-up approach highlights a third component of the conceptual framework of “community-participation.” Historically, long-term engagement with the natural and built environments strengthen the Indigenous People’s resilience capacity (Berkes & Turner, 2006). Community participation taps into the strengths of Indigenous People and emphasizes organic solutions. Some tribal-driven solutions in response to food

shortages during this pandemic include communities returning to Indian customs of seed saving, canning, and dehydrating food (Brown, 2020). Bottom-up approaches give tribal authorities more opportunities to lead community initiatives and provide proactive opportunities to problem-solve in addressing COVID-19.

Limitations and Conclusion

The data resources and language issues present the major limitations in this research. The research identified news articles from the top news companies in both countries rather than community-based public media, especially those based in the Indigenous communities. Although most valuable information released by these community-based media channels were also further developed by the major news companies, neglection is unavoidable. News stories related to gaps in COVID-19 data impacts on Indigenous communities, or people living outside of those communities were not concentrated in major news outlets in the U.S. The research only examined English documents, which potentially excluded the documents published in other languages, like French in Canada, and Spanish in the United States. Although the Indigenous language-based news articles were excluded in both countries, some valuable news articles were highly translated and covered by the major public media chosen in this study.

Our research indicates that the data protocols between federal, state, provincial, and tribal health authorities are inefficient because of disrupted communications, distrust, and inadequate funding despite funding commitments. Federal entities in Canada and the U. S. seem unwilling to share information effectively to provide tribal entities the kind of data detail that would mitigate community spread of COVID- 19. Tribal authorities and tribal epidemiologists believe data is somewhat manipulated in undercounting cases or using standards which deny claims of tribal membership. Additionally, the data process has been influenced by other factors (e.g. a need for data disaggregation, prioritizing collection of racial and ethnic demographic information, inclusion of remote Indigenous tribes in data collection). As the cases of COVID-19 infections rise worldwide, data driven responses are the primary means by which vulnerable Indigenous communities in tandem with the larger governments can eradicate the hospitalizations and death tolls in Indigenous communities.

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