



GIDA-RDA COVID-19

Guidelines for Data Sharing Respecting Indigenous Data Sovereignty

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8. Indigenous Populations and Data Sharing

8.1 Focus and Description

Indigenous Peoples around the globe have diverse narratives of resilience and adaptability; however, they are also acutely impacted by the negative social, economic, environmental and health outcomes of COVID-19 ([UN Special Rapporteur on the rights of Indigenous Peoples, 2020](#)). As such, it is vital that Indigenous Peoples are included in all aspects of pandemic-related surveillance, research, research planning, and policy. Systemic policies, and historic and ongoing marginalisation, have led to Indigenous Peoples' mistrust of agencies and the data/research they produce. For example, Indigenous nation-specific COVID-19 data in the United States have been released by government entities without tribal permission and knowledge. These sensitive data continue to be accessed and reused without consent from Indigenous governing bodies by the media, researchers, non-governmental organisations, and others. Although this type of data usage is attempting to combat data invisibility of American Indians and Alaska Natives to address gaps, reporting of tribal-specific data is making tribes more visible in ways that can result in unintentional harm and ignores inherent Indigenous sovereign rights. Media perpetuation of mis-information and dis-information is amplifying confusion and harm to Indigenous Peoples.

To avoid increased distrust and harm, and to improve the quality and responsiveness of data activities, Indigenous data rights, priorities, and interests must be recognised in all COVID-19 research activities throughout the data lifecycle, and in ownership of any resulting innovations. We must also acknowledge that expressions of self-determination vary substantially across nation states due to conditions that also undermine the ability of Indigenous Peoples to govern data or enact sovereignty over data.

The Indigenous Data Guidelines within this document have emerged through global collaborations with Indigenous Peoples and Indigenous data governance advocates. They outline obligations for funders, governments, researchers, and data stewards in the collection, ownership, application, sharing, and dissemination of Indigenous data, specifically in relation to COVID-19 related issues. These Guidelines reflect and support Indigenous Data Sovereignty (see www.GIDA-global.org) and are underpinned by the United Nations Declaration on the Rights of Indigenous Peoples ([UNDRIP](#)). They do not supersede or replace existing Indigenous governance protocols or agreements developed (or under development) by Indigenous Peoples or nations. Rather, these Guidelines point to the need for Indigenous Peoples and nations to be engaged in governance *on their own terms* across COVID-19 data lifecycles and ecosystems. This demands proactive investment in Indigenous community-controlled data infrastructures to support communality capacity and resilience, and improve the flow of information for effective public health response.

The Indigenous Data Guidelines set out the minimum requirements for Indigenous-designed data approaches and standards, inclusive of Indigenous rights to data governance and decision-making within the planning and design of Indigenous data collection and sharing. The Indigenous Data Guidelines also highlight the inadequacy of personal and individual consent and data privacy protections. For Indigenous Peoples, collective consent and data privacy protections, supported via community-controlled data infrastructure, are essential to ethical Indigenous data practices.

These Indigenous Data Guidelines apply across all sections of the RDA COVID 19 Guidelines and Recommendations.

8.2 Scope

The CARE Principles for Indigenous Data Governance -- Collective benefit, Authority to control, Responsibility, Ethics -- (www.gida-global.org/care) set forth critical considerations for Indigenous rights and interests in data. Indigenous data, in general, comprise data, knowledge, and information that relate to Indigenous Peoples at both the individual and collective level, including data about lands and environment, people, and cultures. In the context of COVID-19, Indigenous data include data about COVID-19 testing (individual and community, e.g. wastewater), cases, hospitalisations, health service access, deaths, and comorbidities, as well as related Indigenous Knowledges about COVID-19, and data on the socioeconomic and environmental correlates and impacts of COVID-19. The CARE Principles provide a framework for the collection, storage, access, and use of Indigenous Peoples' data during the COVID-19 pandemic and beyond.

Access to good quality data is a key driver for the implementation of the FAIR principles – Findable, Accessible, Interoperable, Reusable ([Wilkinson et al., 2016](#)). The FAIR principles are data-centric, supporting greater data findability, accessibility, interoperability and reusability. The FAIR principles facilitate increased data sharing among entities. However, they ignore relationships, power differentials and the historical conditions associated with the collection of data that impact ethical and socially responsible data use. The CARE Principles for Indigenous Data Governance speak to how data are used in ways that are purposeful and oriented towards enhancing the wellbeing of Indigenous Peoples. The CARE Principles can find expression alongside the FAIR principles across data lifecycles from collection to curation, from access to application.

8.3 Policy Recommendations and Guidelines

The CARE Principles for Indigenous Data Governance set a minimum standard for non-Indigenous policymakers, data stewards, researchers, aid groups, and others.

COLLECTIVE BENEFIT: “Data ecosystems shall be designed and function in ways that enable Indigenous Peoples to derive benefit from the data.”

- 1. “For inclusive development and innovation”**

Systemically, existing data ecosystems do not support meaningful inclusion of Indigenous data rights and interests, and when engaged Indigenous Peoples' input is often left out of decision-making, particularly when making data open ([Rainie et al. 2019](#)). Early conscious inclusion at all stages of data lifecycles (design, collection, access, analysis, reporting, storage, protection, use, and reuse of Indigenous data) and throughout data ecosystems (digital infrastructures, analytics, and applications) enhance benefits for Indigenous Peoples and minimize harms such as misrepresentation and dis-information.

- 2. “For improved governance and citizen engagement”**

In many countries, Indigenous Peoples are exposed to a higher risk of pandemic-related harm, both to their health and livelihoods. COVID-19 is impacting all communities and responses must recognise the importance of diverse knowledge systems in decision-making in order to advance culturally-informed pandemic policy planning and implementation. By involving Indigenous Peoples throughout the COVID-19 pandemic preparedness and response processes, there is an opportunity to limit negative outcomes and inform both current and future pandemic response planning.

- 3. “For equitable outcomes”**

Repositories that include data that are collected or used as part of COVID-19 analyses or responses must explicitly support Indigenous governance of Indigenous data and include provenance for all Indigenous data. All surveillance, research, and data should contribute to addressing Indigenous Peoples' concerns and questions to improve current and future responses, and to achieve equity.

AUTHORITY TO CONTROL: “Indigenous Peoples’ sovereign rights and interests in Indigenous data must be recognised and their authority to control such data be empowered. Indigenous data governance enables Indigenous Peoples and Nations, through their established governing bodies and mechanisms, to determine how Indigenous Peoples, as well as Indigenous lands, territories, resources, knowledges and geographical indicators, are represented and identified within data.”

1. “Recognising rights and interests”

Upholding Indigenous rights and interests demands recognition and engagement of Indigenous systems of government and decision-making. Indigenous Peoples’ and nations’ governing bodies must be formally engaged with prior to the development and implementation of policies and agreements pertaining to Indigenous data that clearly state if, how, and when Indigenous data are collected, analysed, accessed, used/reused, and reported. Permission to use and report on Indigenous Peoples and nations must be granted by appropriate and authorised Indigenous governing bodies. Disclosure of Indigenous information without permission is a violation of Indigenous sovereign rights and undermines Indigenous governance over matters that directly impact Indigenous Peoples.

2. “Data for governance”

Indigenous leadership concerning data collection, ownership, storage, sharing, and use is the defining concept of Indigenous data sovereignty ([Kukutai and Taylor 2016](#)). Indigenous Peoples are in the best position to assess their own needs, priorities, and strengths and are informed by Indigenous responses to COVID-19 (see, for example, [Māori Response Action Plan](#), also see [AIPP COVID-19 Response](#)). As such, Indigenous Peoples need to be supported to lead and/or participate in the design of COVID-19 data systems that involve the collection, analysis, and sharing of Indigenous data. Given that the identification of Indigenous Peoples in data collections has too often led to serious harm and/or stigma, Indigenous Peoples should be able to exercise governance over COVID-19 data that derive from them, individually or collectively, regardless of who collects the data (e.g. government, private sector, researchers), or where they are held. This includes Indigenous data that are de-identified or anonymised for the purpose of sharing.

3. “Governance of data”

Existing Indigenous governance protocols, including those related to decision-making over Indigenous data, must be recognised and adhered to during the COVID-19 pandemic. Indigenous governing bodies must continue to be involved in decision-making on data matters that impact their peoples and nations to ensure collective benefit and minimise harm from Indigenous data.

RESPONSIBILITY: “Those working with Indigenous data have a responsibility to share how those data are used to support Indigenous Peoples’ self-determination and collective benefit. Accountability requires meaningful and openly available evidence of these efforts and the benefits accruing to Indigenous Peoples.”

1. “For positive relationships”

Systemic changes must occur at all levels of government and within institutions that collect, use, or hold Indigenous data to ensure that policies and data sharing agreements are consistent with

Indigenous priorities, are co-determined with Indigenous Peoples, and recognise Indigenous rights to control their data.

2. “For expanding capability and capacity”

Indigenous Peoples and nations have often enacted strong, effective first line of responses and defences against COVID-19, proactive investment in Indigenous community-controlled data infrastructure is recommended in order to support community capacity and resilience, and improve the two-way flow of information essential for effective public health responses.

3. “For Indigenous languages and worldviews”

Indigenous knowledge and worldviews offer strength for localised contact tracing - local contact tracing data are more likely to be stored in repositories that are governed by Indigenous Peoples. Investments into decentralised contact tracing applications and infrastructure is needed to ensure that Indigenous Peoples can control data as well as narratives over their own contextualised realities.

ETHICS: “Indigenous Peoples’ rights and wellbeing should be the primary concern at all stages of the data life cycle and across the data ecosystem.”

1. “For minimising harm and maximising benefit”

Reporting of identifiable (e.g. ethnic, tribal affiliated, etc.) Indigenous COVID-19 data can contribute to racism and discrimination, hostility, reinforcement of negative stereotypes, and implicitly blame Indigenous Peoples and nations for the spread of COVID-19. Indigenous nations have the responsibility to provide for the safety and welfare of their peoples and nations by determining current and future use of their data, and how and with whom their information will be shared. This is to minimise harm and maximise any benefit that may result from public release of Indigenous-identified COVID-19 data and information. Permission to use and report identifiable Indigenous data by others (e.g. national and state government, researchers, media, etc.) must be granted by Indigenous governing bodies that have the authority to speak on behalf of Indigenous Peoples and nations before their Indigenous data are reported. Disclosure of this information without permission is a violation of Indigenous sovereign rights.

2. “For justice”

Indigenous data disaggregation is supported by Indigenous communities ([FNIGC, 2016](#)), the [United Nations Permanent Forum on Indigenous Issues \(2017\)](#), and by researchers ([Kukutai et al., 2015](#); [Madden et al., 2016](#)). Every effort should be made to collect data that enables Indigenous Peoples to be identified in relation to COVID-19 outcomes *should they desire it*, including the collection of ethnic and tribal identifiers. Non-reporting or aggregation of Indigenous findings into regional populations can disguise the urgent needs of Indigenous Peoples and is insufficient for monitoring the spread of COVID-19 for Indigenous Peoples. Whereas, appropriate reporting and disaggregation is a necessary condition that supports Indigenous visibility and decision-making. However, disaggregated data, without Indigenous governance risks: 1) violation of Indigenous Peoples and nations rights; 2) pejorative judgements from governments, the media, and the public; 3) improper extrapolation of dominant population findings into Indigenous populations; and 4) non-Indigenous algorithms being unreflectively applied to Indigenous data.

3. “For future use”

Indigenous data governance is also a prerequisite for determining appropriate future use of data. As contact tracing becomes a key tool to control COVID-19 there has been a noticeable shift from paper-based to electronic tracking, and to increased centralisation. Mobile phone proximity and/or location tracking is another tool being employed by nations and states to mitigate the



spread of COVID-19. While electronic tracking systems may have advantages in their ability to scale and include multiple inputs, they create an enduring record which in many countries do not as yet have an end date. These data, as well as other contact tracing data, can easily be repurposed for other activities. This form of function creep is of particular concern to Indigenous communities who recognise the immediate public health need but face deeper ongoing challenges associated with the use of surveillance as a tool of political oppression. Therefore, Indigenous governance throughout COVID-19 data ecosystems and lifecycles must be supported, including investments in Indigenous community data capacity and infrastructures.

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