2: GOOD DATA PRACTICES FOR INDIGENOUS DATA SOVEREIGNTY AND GOVERNANCE

RAYMOND LOVETT, VANESSA LEE, TAHU KUKUTAI, DONNA CORMACK, STEPHANIE CARROLL RAINIE AND JENNIFER WALKER

Introduction

Indigenous Data Sovereignty (IDS) and Indigenous Data Governance (IDG) are terms increasingly being used across community, research, policy and in practice. The IDS movement has emerged in response to poor data practices, from the conceptualisation of data items through to reporting of data about Indigenous peoples. This chapter aims to provide clarity concerning the definitions of IDS and IDG; provide an overview of the historical context in which IDS has emerged; and provide examples of IDS and IDG across the spectrum of community, policy and practice.

For Indigenous peoples, historical encounters with statistics have been fraught, and none more so than when involving official data produced as part of colonial attempts at statecraft. Governments in the settler states of Australasia and North America have amassed large amounts of data on their Indigenous populations to generate statistics as 'evidence' for population monitoring and policy interventions.[1] Set against this, Indigenous nations, communities and data activists have responded with their own agendas for 'good data'; Indigenous Data Sovereignty (IDS) and Indigenous Data Governance (IDG) movements are contemporary articulations of 'good data' and are the central focus of this chapter.

At the heart of IDS and IDG is the right of Indigenous peoples and nations to decide what data development occurs and the controls over the collection, governance, ownership, and application of data about their peoples, territories, lifeways and natural resources.[2] IDS is grounded in Indigenous understandings of sovereignty that challenge dominant 'data sovereignty' discourse and current practice, and is supported by global human rights instruments such as the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP). This chapter provides perspectives from Indigenous scholars across Australia, Aotearoa, and North America to explain the genesis and development of the IDS movement, acknowledging the nascent IDS movements outside these areas.[3] We begin with a brief discussion of the historical context of Indigenous statistics. We then discuss the defining elements of IDS and IDG, and

1   Tahu Kukutai and Maggie Walter, 'Recognition and Indigenizing Official Statistics: Reflections from Aotearoa New Zealand and Australia', *Statistical Journal of the IAOS* 31.2 (2015).

2   Tahu Kukutai and John Taylor, 'Data Sovereignty for Indigenous Peoples: Current Practice and Future Needs', in Tahu Kukutai and John Taylor (eds), *Indigenous Data Sovereignty: Towards an Agenda*, Canberra: ANU Press, 2016, pp. 1-25.

3   S. Carroll Rainie, M. Walter, P. Axelsson, M. Hudson, J. Walker and O. Figueroa-Rodríguez, 'Indigenous Data Sovereignty: Global Progression Roundtable', *North American and Indigenous Studies (NAISA) Tenth Annual Meeting*, Los Angeles 18 May 2018.

the development of country-specific IDS processes. We conclude with three examples of IDS and IDG in practice. The intent of this chapter is to inform others on how the application of IDS and IDG can lead to good data and good decision-making.

Defining Data

The idea of data is a broad concept, but in the context of this chapter, we define data as information that may be recorded in various forms. In the contemporary context, this mostly includes digital data. The Indigenous data ecosystem is extensive and includes data generated or held by Indigenous communities and organisations, governments, the public sector, international governmental organisations (IGOs), NGOs, research institutions and commercial entities. Therefore, the application of IDS and IDG crosses many boundaries.[4]

Defining Indigenous Data Sovereignty

'Data sovereignty' is the management of information in a way that aligns with the laws, practices and customs of a nation-state in which it is located.[5] In the Indigenous context this may manifest at the group (iwi(tribe)/mob/Maori) levels.

Defining Indigenous Data Governance

Data governance is the power and authority over the design, ownership, access to and use of data. The governance of data has emerged as a highly contested area of debate between Indigenous peoples and the states within which they reside. For Indigenous peoples, whose traditional modes of governance were disrupted by western modes of democratic governance, re-asserting themselves through self-determined governance structures is critical. Ownership of governance structures commences at the development stage, and continues through the ethics application stage and through the collection, analysis and reporting of data, and through policy translation. Indigenous peoples' ownership is integral to autonomy.

Historical context of Data Sovereignty

Indigenous peoples have always been data collectors and protectors. Data gathering and preservation existed in most, if not all, Indigenous cultures in the form of art and pictorial calendars (e.g. Lakota winter counts), chants, songs, the recitation of genealogies and other cultural practices that have been passed on across generations. With colonisation these practices were disrupted (and often heavily censured), but not extinguished. In many contexts, the census was an indispensable tool of colonisation; indeed, the census has long been tied to the exercise of power and statecraft.[6] The word 'census' comes from the Latin word 'censere',

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4   Ibid.

5   C Matthew Snipp, 'What Does Data Sovereignty Imply: What Does It Look Like?', in Tahu Kukutai and John Taylor (eds), *Indigenous Data Sovereignty: Towards an Agenda*, Canberra: ANU Press, 2016, pp. 39-55.

6   David I Kertzer and Dominique Arel, 'Censuses, Identity Formation, and the Struggle for Political Power', *Census and identity: The politics of race, ethnicity, and language in national censuses* 1 (2002).

which means to tax or assess, and the origins of the census coincide with the rise of early Chinese, Egyptian and Roman states and their extraction of resources from the population, either through taxation, labour or military conscription.[7] With the expansion of colonial powers into new lands, the census facilitated the surveillance and control of Indigenous peoples and their lands, and political projects of segregation and/or assimilation. In Aotearoa NZ, for example, the counting of 'half-castes' in 19th and early 20th century censuses was clearly linked to colonial policies of racial amalgamation.[8] Across what is currently Canada, representatives of the British Crown and the Canadian government have undertaken counts and established lists of Indigenous people since before Canadian Confederation in 1867. Colonial legislation, in the form of the Indian Act (1876 to present), has resulted in registration lists of First Nations and Inuit peoples, termed the 'Indian Register'.[9]

In Australia, a long-standing committee advised on government held data pertaining to Aboriginal and Torres Strait Islander people. The Australian Institute of Health and Welfare (AIHW) in conjunction with the Australian Bureau of Statistics (ABS) convened the National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data (NAGATSIHID). The main role of NAGATSIHID was to provide strategic advice to the Australian Health Ministers Advisory Council (AHMAC) on Indigenous health data issues as part of a national strategy towards closing the data gap in life expectancy between Indigenous and non-Indigenous people.[10] However, in 2017 this group was disbanded in a review of committees, and the gap remains. There is now no national level mechanism to advise on the use of Indigenous health information. As a result, Aboriginal and Torres Strait Islander voices in the process are minimal, at a time of policy change surrounding government administrative data, including increasing the availability and improving the use of data in Australia.[11]

One of the more egregious contemporary examples of the misuse of Indigenous data is the well-known Havasupai case.[12] In 2004, concerns escalated in Arizona and nationwide in the United States related to biological samples collected from the Havasupai Tribe, with human subject violations cited.[13] In the 1990s, an Arizona State University researcher conducted

7   Kukutai and Taylor, 'Data Sovereignty for Indigenous Peoples: Current Practice and Future Needs'.

8   Kukutai and Walter, 'Recognition and Indigenizing Official Statistics: Reflections from Aotearoa New Zealand and Australia'.

9   'Indian Act (R.S.C. C. I-5),' (1985).

10   AIHW, 'National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data: Strategic Plan 2010-2015', Canberra, 2011; C. Coleman, B. Elias, V. Lee, J. Smylie, J. Waldon, F.S. Hodge, and I. Ring, 'International Group for Indigenous Health Measurement: Recommendations for best practice for estimation of Indigenous mortality'. *Statistical Journal of the IAOS* 32 (2016): 729-738, 729, DOI: 10.3233/SJI-161023.

11   Productivity Commission, 'Data Availability and Use: Overview & Recommendations', Canberra, 2017.

12   Katherine Drabiak-Syed, 'Lessons from Havasupai Tribe V. Arizona State University Board of Regents: Recognizing Group, Cultural, and Dignity Harms as Legitimate Risks Warranting Integration into Research Practice', *J. Health & Biomedical L.* 6 (2010).

13   Christina M Pacheco et al, 'Moving Forward: Breaking the Cycle of Mistrust between American Indians and Researchers' *American journal of public health* 103.12 (2013): Rebecca Tsosie, *Cultural Challenges to Biotechnology: Native American Genetic Resources and the Concept of Cultural Harm,* Los Angeles: SAGE Publications, 2007.

a genetics of diabetes study with the Havasupai Tribe, taking DNA samples from over 400 tribal members with consent for primary use of the biological materials. The study failed to find a genetic link to diabetes. Later, the researcher directed secondary analyses of the DNA samples with respect to schizophrenia. When this secondary use of specimens came to light, the tribe filed a lawsuit alleging lack of informed consent and misuse of genetic materials. The lawsuit settled out of court, but lasting damage to research relationships as well as a ban on genetics research at Havasupai and other tribes remain.

Contemporary IDS was pioneered by the work of Canadian First Nations communities. In 1995, tired of non-Indigenous data users assuming the mantle of unbiased experts and speaking with authority about First Nations realities, data sovereignty was demanded as a prerequisite for a government health survey in First Nations communities. A new model was developed by First Nations that established First Nations' collective and broad-based control of their own data. This model became known as OCAP® with the acronym trademarked to prevent its use except by First Nations[14]. In this acronym the O is Ownership; C is the Control First Nations hold on how the data are collected, used and disclosed; A is Access, whereby First Nations have access to any data about them; and P is Possession whereby all First Nations data fall within First Nations' jurisdiction. Since the establishment of OCAP® principles by First Nations, similar and adapted sets of principles have emerged in other Indigenous groups within Canada. For example, the recent National Inuit Strategy on Research establishes Inuit ownership, control and access with respect to Inuit data and information. To some degree, these principles are now acknowledged by federal departments and agencies, such as Statistics Canada. These principles are primarily used in the area of data collection, but not in the analysis of existing data collected through the census or other government surveys.

Emergence of IDS movements

Indigenous groups across the world have increasingly become engaged in the data space in response to historical practice and to guide good practice going forward. This has included the establishment of country specific networks including the US Indigenous Data Sovereignty Network (USIDSN) to support IDS through data-driven research, policy advocacy, and education. The Aotearoa New Zealand-based Te Mana Raraunga - Maori Data Sovereignty Network, was formed in 2015,[15] and argues that data that are collected about Indigenous people should be subjected to the laws of the nation from which it is collected, including tribal nations. The First Nations Information Governance Centre advocates for and coordinates Indigenous data governance efforts for First Nations in Canada; the Maiam nayri Wingara Aboriginal and Torres Strait Islander Data Sovereignty Collective in Australia was formed in early 2017[16] to develop Aboriginal and Torres Strait Islander data sovereignty principles and to identify Aboriginal and Torres Strait Islander strategic data assets.

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14   The First Nations Information Governance Centre, 'Ownership, Control, Access and Possession (Ocap™): The Path to First Nations Information Governance', Ottawa: The First Nations Information Governance Centre, 2014.

15   Te Mana Raraunga, 'Te Mana Raraunga - Maori Data Sovereignty Network Charter', https://www.temanararaunga.maori.nz/tutohinga/.

16   AIATSIS, *National Indigenous Research Conference* 2017.

The intent of these groups is to advocate for rights (informed by UNDRIP) using data to inform development.

United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP)

UNDRIP was the result of a quarter of a century work to develop minimum standards to protect Indigenous peoples' rights. After a series of changes to the draft (initially submitted in 1994), the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) was adopted by the General Assembly on 13 September 2007.[17] A majority of 144 states voted in favour, four voted against (notably Australia, New Zealand, Canada and the United States), and 11 abstained.[18] Australia did not adopt the declaration until 2009, even though it played a key role in the development of the United Nations' Declaration of Human Rights.[19] Aotearoa and the United States adopted the Declaration the following year in 2010.[20] Canada issued a Statement of Support in November 2010, but the Minister of Indigenous and Northern Affairs did not announce Canada's full commitment until May 2016.[21]

Article 18 of the UNDRIP specifies that 'Indigenous peoples have the right to participate in decision-making in matters which affect their rights, through representatives chosen by themselves in accordance with their own procedures, as well as to maintain and develop their own Indigenous decision-making institutions'.[22] Article 19 stipulates that states are required to 'consult and cooperate in good faith with Indigenous peoples through their own representative institutions in order to obtain their free, prior and informed consent before adopting and implementing legislative or administrative measures that may affect them'.[23] As Tauli-Corpuz suggests,[24] measures are needed to gauge Indigenous peoples access and ownership of land, how they participate in decision-making and control on their development and application processes, and control over the data and knowledge. In the same foundational publication, Kukutai and Taylor highlight that to give 'practical effect' to UNDRIP, Indigenous peoples should assert (and are asserting) control of data from nation states.[25] Both UNDRIP articles require data to appropriately inform legislative and administrative decisions.

17   Kukutai and Taylor, 'Data Sovereignty for Indigenous Peoples: Current Practice and Future Needs'.
18   United Nations, 'The United Nations Declaration on the Rights of Indigenous Peoples', 2008 https://www.un.org/development/desa/indigenouspeoples/declaration-on-the-rights-of-indigenous-peoples.html.
19   Australian Human Rights Commission, 'Australia and the Universal Declaration on Human Rights', https://www.humanrights.gov.au/publications/australia-and-niversaldeclaration-human-rights.
20   N.B In 2010, the State Department released, 'Announcement of U.S. Support for the United Nations Declaration on the Rights of Indigenous Peoples'. To read the full statement, go to http://www.achp.gov/docs/US%20Support%20for%20Declaration%2012-10.pdf.
21   Indigenous and Northern Affairs, 'United Nations Declaration on the Rights of Indigenous Peoples', Government of Canada, https://www.aadnc-aandc.gc.ca/eng/1309374407406/1309374458958.
22   Nations, 'The United Nations Declaration on the Rights of Indigenous Peoples'.
23   Ibid.
24   Kukutai and Taylor, 'Data Sovereignty for Indigenous Peoples: Current Practice and Future Needs'.
25   Ibid.

Based on the groundwork from First Nations in Canada and with additional impetus provided through UNDRIP, Indigenous groups have, over time, developed principles specific to their IDS context.

IDS principles in the Asia Pacific and North American States
Research Data Alliance (RDA) International Indigenous Data Sovereignty Interest Group
Generate recommendations for principles and best practices in IDS (currently in the principles development phase).
Aotearoa/NZ. Te Mana Raraunga, the Maori Data Sovereignty Network
Whakapapa and whanaungatanga: Recognising the connectedness between the material, natural and spiritual worlds *Rangatiratanga*: Iwi(tribal)/Maori rights to own, access, control and possess data from them or about them and their environs *Kotahitanga*: Collective vision and unity of purpose *Manaakitanga*: Ethical data use to progress iwi/Maori aspirations for wellbeing *Kaitiakitanga*: Sustainable data stewardship
United States - US Indigenous Data Sovereignty Network (USIDSN)
The USIDSN is in the principles development phase. Draft principles include recognition of inherent sovereignty; protection of Indigenous data; a commitment to aligning with Indigenous values for intergenerational collective wellbeing; a focus on relationships between Indigenous nations and other stakeholders; for IDG; and the honouring of Indigenous knowledge.
Canada (First Nations) - OCAP®
Ownership of data **C**ontrol - First Nations hold on how the data are collected, used and disclosed, **A**ccess - whereby First Nations have access to any data about them **P**ossession - whereby all First Nations data fall within First Nations jurisdiction

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Australia - Maiam nayri Wingara

Maiam nayri Wingara is the most recent of the IDS groups and has recently developed their principles.<26>

Table 1 - IDS principles in the Asia Pacific and North American States.

Indigenous Data Sovereignty and Governance in practice

Here we present examples of IDS and IDG in practice. The first example from Australia concerns both IDS and IDG.

Australia

The Mayi Kuwayu: The National Study of Aboriginal and Torres Strait Islander Wellbeing (meaning 'to follow Aboriginal people' in Ngiyampaa language) is a national Aboriginal and Torres Strait Islander longitudinal study. The aim of the study is to develop national-level cultural indicators and examine how culture interacts with health and wellbeing. It is publicly funded research and is housed at the Australian National University (ANU) in Australia.[27] The study development processes are designed to adhere to IDS and IDG. The data development considerations in the Mayi Kuwayu Study include:

- Development of new data items that represent cultural expression and practice (data of importance to Aboriginal and Torres Strait Islander peoples).

- The Australian Code for the Responsible Conduct of Research (the Code), that requires research data ownership and storage to be described.

- Research ethics[28] and intellectual property,[29] to acknowledge the sources of information and those who have contributed to the research. If Indigenous knowledge contributes to intellectual property, recognising the contribution, where appropriate, by transferring or sharing intellectual property and any benefits that result from the research'.[30]

- An Indigenous Data Governance group that develops data access and release protocols based on IDS principles.

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26   Maiam nayri Wingara and the Australian Indigenous Governance Institute, *Indigenous Data Sovereignty Summit and Indigenous Data Sovereignty Communique,* Canberra, 2018, www.maiamnayriwingara.org.
27   KA Thurber, R Jones, J Chapman et al, 'Our Cultures Count: Mayi Kuwayu - the National Longitudinal Study of Aboriginal and Torres Strait Islander Wellbeing', *BMJ Open* (in press, 2018).
28   AIATSIS, 'Gerais Guidelines for Ethical Research in Australian Indigenous Studies' Canberra: Australian Institute of Aboriginal and Torres Strait Islander Studies, 2012.
29   Australian National University, 'Intellectual Property Policy', https://policies.anu.edu.au/ppl/document/ANUP_003603.
30   AIATSIS, 'Gerais Guidelines for Ethical Research in Australian Indigenous Studies'.

The Mayi Kuwayu Study has developed a number of mechanisms to address many of the existing data processes identified above. This includes ensuring Aboriginal and Torres Strait Islander leadership and management of the study from the outset, through leadership of the study by majority Aboriginal Chief Investigators and research staff. Further, in the development of cultural data items, the research team undertook 24 focus groups with a diverse range of Aboriginal and Torres Strait islander groups across Australia, embedding their feedback into priorities for measurement while also seeking suggestions on cultural appropriateness of questions and methods.

In the MK Study, ongoing data collection and ownership of the data set is shared between the research institute and participants under institutional policy (and its use is currently governed by the Study's Governance group that includes investigators and representatives from Aboriginal institutional project partners and community). Further, the research team and study governance group are developing protocols for data storage, access, analysis, and dissemination.

Aotearoa (New Zealand)

Aotearoa NZ is one of the world's most advanced digital nations.[31] Data is seen as a key national strategic asset,[32] and several key policy and legislative initiatives are underway to facilitate easier data sharing and linkage. A flagship project is the Integrated Data Infrastructure (IDI), a world-leading research database under the stewardship of Statistics New Zealand that contains de-identified data (including Maori data) from more than 50 surveys and administrative datasets across the state, research and NGO sectors. With a greater focus on data-driven policy-making has come an increased interest in how 'social license'[33] can enable more flexible data sharing without explicit individual consent. Missing from these innovations, however, are robust models of data governance and ethics, value creation and benefit-sharing to enhance 'good data' and 'good outcomes'.

Maori have often been at the sharp end of intrusive data surveillance and misuse but have well-tested 'tikanga' (ethics, processes, principles) around the protection and sharing of knowledge for collective benefit that can be readily adapted to digital data environments. Maori Data Sovereignty (MDS) advocates are developing a number of tikanga-based solutions including: models of Maori/iwi (tribal) data governance for the IDI and wider government ecosystem; 'cultural license' as the 'social license' alternative for community acceptability of data use; and a Maori Data Audit Tool to assess organisational readiness to incorporate MDS principles. Many of the assumptions underpinning old and emerging data ecosystems rest on Anglo-European

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31 N.B Aotearoa is part of the D7 network of the world's most advanced digital nations. The others are: Estonia, Israel, South Korea, United Kingdom, Canada and Uruguay.

32 N.B. The strategic importance of data ecosystems in Aotearoa NZ is reflected in government strategies such as the Data Futures Partnership, the Government ICT Strategy, Open Government Data Programme and the establishment of a Social Investment Unit; research initiatives such as the New Zealand Law Foundation Information Law & Policy Project and the Virtual Health Information Network (VHIN); and the recent appointments of a Government Chief Digital Officer and Chief Data Steward.

33 See, for example: http://datafutures.co.nz/our-work-2/talking-to-new-zealanders/.

legal concepts, such as individual privacy and ownership, which translate poorly into the big and open data environments. What is needed is a radically different way of conceptualising rights that relate to massive quantities of data and the value that can be extracted from. The direct beneficiaries of the 'data revolution' have largely been data producers and controllers, not the individuals and collectives from which data are drawn. IDS and MDS demands clear lines of accountability and benefit sharing; at the heart of these demands is a call for power sharing. Seen this way, the potential benefits of embedding MDS principles across government data ecosystems extend beyond Maori to include the wider public.

As a result of the rapidity of changes in data capabilities and technology, there can be a tension between responding to technological imperatives and to changes being driven by other actors (e.g. Government and corporations) and focusing on Maori aspirations and priorities. The MDS space is also a creative space where there is potential for Maori to (re-)imagine relationships and practices that realise Maori aspirations for data sovereignty, including those that may operate outside currently existing structures.

North America

One of the landmark results of the establishment of OCAP® principles in Canada has been the multiphase First Nations Regional Health Survey, which is designed, implemented and analyzed by First Nations organizations in Canada.[34] A coordinating national organization, the First Nations Information Governance Centre was established to lead the efforts to expand this First Nations-driven survey approach to education, labour and employment and other key areas.

Across Canada, each of the three distinct Indigenous Peoples in Canada (First Nations, Métis and Inuit) have also asserted sovereignty over the data that are held about their encounters with the provincial health system.[35] This has resulted in a mosaic of relationships, Data Sharing Agreements, and Data Governance Agreements in each Canadian province to ensure that decisions about the use and sharing of First Nations, Inuit, and Métis data are made by the respective governance organizations.

Conclusions

While the IDS movement has emerged in response to poor data practices and exclusion, IDS and IDG provide opportunities to reconfigure current approaches to data, including embedding good governance of Indigenous data that supports self-determination and wellbeing for Indigenous communities. Good data, including good data governance, are necessary to ensure Indigenous peoples benefit from current and future data practices and to mitigate the potential for continued harm. IDS movements also support broader transformative aims of developing Indigenous-owned and controlled data infrastructures, protocols and community capabilities that lie beyond the reach of nation states and corporations.

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34   See: http://fnigc.ca/our-work/regional-health-survey/about-rhs.html.
35   Evelyn Pyper et al, 'Walking the Path Together: Indigenous Health Data at Ices', *Healthcare Quarterly* 20.4 (2018).

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