

**Karie Russell**  
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**Monday, December 1, 2024**  
**Podcast & Show Notes**  
**“Digital Dialogues: Data, Justice, and Indigenous Voices”**  
**Facilitation of a Virtual International Workshop**  
**HRSJ 5160 \_ Social Justice and Culture**  
**Joceline Andersen**

## Show Notes

### Episode Title: Digital Dialogues - Data, Justice, and Indigenous Voices

In this episode of Digital Dialogues, host Karie Russell will discuss an important question: How can Indigenous data sovereignty drive justice and self-determination for Indigenous communities? The idea behind this podcast is to tell the story of how Indigenous communities are rewriting the narrative about Indigenous data sovereignty, and to explore how Indigenous communities are flipping the oppressive narrative toward reclaiming their stories, protecting culture and traditions, and driving toward self-determination through ethical data practices.

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**Spotify Podcast link:** <https://open.spotify.com/episode/21weVILW71aPTgVqU9U6mR>

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## Key Concepts and Theory

### What is Indigenous Data Sovereignty?

Indigenous data sovereignty is not just about owning data—it's about self-determination. Walter et al. (2021) defines it as the right of Indigenous peoples to control the collection, access, analysis, interpretation, management, dissemination, and reuse of their data (p. 15).

What is self-determination? Indigenous peoples have been and continue to be resilient and have worked tirelessly to preserve and advance self-determination. Indigenous groups in Canada have laid the foundations for research processes and policies that highlight Indigenous ownership and stewardship of Indigenous data. (Walter et al., 2021, p.15). Example: The TRU Secwépemc Nation Research Ethics Guidelines which highlight that the knowledge or ideas created in

Secwépemc territory belong to the Secwépemc people. It also states that any research done in the Secwépemc Nation must have the Nation's approval. (Secwépemc Nation, n.d.)

Dr. Jennifer Walker (2016) goes on to highlight in Canada, it is a critical time for how Indigenous leadership will prioritize and translate Indigenous data governance principles into Indigenous data sovereignty practices towards improvements in policy, healthcare and wellbeing (p.84).

**What Is Self-Determination?** Indigenous Peoples have long been resilient, working tirelessly to preserve and advance self-determination. In Canada, Indigenous groups have laid the foundation for research processes and policies that emphasize their ownership and stewardship of data. Dr. Jennifer Walker (2016) notes that it is a critical time to prioritize and translate Indigenous data governance principles into practices that enhance policy, healthcare, and well-being (p. 84).

#### **Principles of Ethical Data Governance**

- **CARE Principles:** provide a framework for ethical data management include collective benefit, authority to control, responsibility, and ethics. (Walter et al., p.26).
- **OCAP Principles:** A system currently operational across five Canadian provinces, demonstrating a practical application of Indigenous data sovereignty which include ownership, control, access, and possession. (Walter et al., p.26).
- **FAIR Principles:** act as attributes for data policies and practices which include findable, accessible, interoperable, and reusable. (Walter et al., p.26).

Carroll et al. (2020) notes these principles are "designed to address historical power imbalances and create value for Indigenous data on a global scale" (p. 43).

**Governance in action:** Indigenous communities are increasingly aware of the implications of data in digital environments. Many are developing nation-specific research protocols that reflect their worldviews and protect their collective interests (Walter et al., 2021, p. 15).

Traditional data collection often prioritized deficits, creating narratives that focused on what was "lacking or wrong" (Walter et al., 2021, p. 15). By contrast, ethical data practices prioritize strength-based approaches that honor Indigenous perspectives.

## Case Studies

### 1. Historical Injustices: Canadian Nutritional Experiments (1942-1952)

Between 1942 and 1952, Canadian researchers conducted unethical experiments on over 1,300 Indigenous individuals, including 1,000 children. Researchers such as Frederick Tisdall, Percy Moore, and Lionel Bradley Pett saw the Indigenous people and children as 'test subjects', and the unethical nature of the experiments such as children being malnourished to observe the effects, even denying them dental care to study how malnutrition impacted oral health. These are all examples of the colonial research practices in Canada's history.

Consent was not obtained:

- As Rodriguez-Lonebear (2016) explains, these experiments reflected a view of Indigenous people as "test subjects" to be transformed into "more profitable assets to Canada" (p.60)
- Parents were not informed, and consent was never obtained.

### 2. Te Mana Raraunga: Māori Data Sovereignty

**Commented [KR2]:** Content from script and sources: "In the United States, the US Department of the Interior, Indian Affairs (2019) states their mission as: "enhance the quality of life, to promote economic opportunity, and to carry out the responsibility to protect and improve the trust assets of American Indians, Indian tribes, and Alaska Natives" (Walter et al., 2021, p. 14). "Indigenous Services Canada proclaim that their vision is "to support and empower Indigenous Peoples to independently deliver services and address the socio-economic conditions in their communities" (Government of Canada 2019) and in Aotearoa New Zealand Te Puni Kōkiri Ministry of Māori Development (2019) states its mission is to "lead public policy for Māori; advise on Government-Māori relationships; provide guidance to government about policies affecting Māori wellbeing; and administer and monitor legislation". All policy frameworks also state, to varying degrees, that they undertake their policy role in collaboration with, and in the interests of, Indigenous Peoples". Referenced earlier, "The CARE Principles for Indigenous Data Governance (collective benefit, authority to control, responsibility, ethics). Reflecting the crucial role of data in advancing Indigenous innovation and self-determination, the CARE Principles are meant to affect change within external data stakeholders and the secondary use of data. The CARE Principles expand on mainstream principles, e.g., FAIR (findable, accessible, interoperable, reusable) concerned with data attributes (Wilkinson et al. 2016) to bring people and purpose into focus for data policies and practices. The CARE Principles enhance Indigenous

**Commented [KR3]:** Content from script and sources: Ian Mosby uncovered a dark history of medical research that targeted Indigenous children in Canada. Between 1942 and 1952, scientists conducted harmful experiments on more than 1,300 Indigenous people, with 1,000 of them being children. As Mosby himself described, "Last year, Ian Mosby, a food historian and postdoctoral fellow at the University of Guelph (Guelph, Ontario), revealed details of highly unethical nutrition experiments performed on Canadian Aboriginal children at six residential schools between 1942 and 1952 (p. 2) – our own medical atrocities." The experiments were run by well-known doctors like "Dr Percy Moore, the Indian Affairs Branch Superintendent of Medical Services, and Dr Frederick Tisdall, a famed nutritionist, a former president of the Canadian Paediatric Society and one of three paediatricians at The Hospital for Sick Children (Toronto, Ontario) who developed Pablum infant cereal in the 1930s." The research was incredibly cruel. Scientists deliberately kept children malnourished and studied their suffering. In their experiments, "control and treatment groups of malnourished children were denied adequate nutrition. In one experiment, the treatment group received supplements of riboflavin, thiamine and/or ascorbic acid supplements to determine whether these mitigated the problems – they did not."

The Māori Data Sovereignty Network in New Zealand is flipping the script which they have created framework to move away from deficit-based narrative toward a strength-based approach. Te Mana Raraunga is about redefining how data about their communities is collected and used. Instead of focusing solely on health problems, they're gathering data about cultural strength and community wellness. They're asking questions to break away from old narratives to tell their own stories which is very powerful.

The core principles of Te Mana Raraunga include:

- Self-determination (tino rangatiratanga): Māori control their data narratives.
- Cultural preservation: Data as a taonga (treasure, something precious) for protecting Māori language and identity.
- Challenging power structures: Shifting research control to Māori communities.

By reframing research questions to focus on strengths, Te Mana Raraunga demonstrates how culturally driven data governance can empower Indigenous communities (Sporle, 2021).

### Case Study 3. Indigenous Filmmakers Reshaping Narratives

Filmmakers like Kent Monkman, Caroline Monnet, Thirza Cuthand, and Michelle Latimer use archival footage to challenge colonial narratives:

- Sisters & Brothers (Monkman): Critiques colonial violence using the buffalo and the assimilation of Indigenous children in residential schools.
- Mobilize (Monnet): Demonstrates Indigenous resilience and adaptability using archived scenes from the past rural geography to a more modern urban setting.

**Commented [KR4]:** Content from script and sources: In their work, Kukutai et al. (2023) challenge traditional data collection approaches by advocating for an asset-based perspective through Te Mana Raraunga, the Maori Data Sovereignty Network. The network promotes a paradigm shift in research methodology, moving away from deficit-focused narratives to instead explore and highlight community strengths and cultural resilience. (Sporle, A., 2021, p.67)  
This approach reframes research questions to center on empowerment, asking transformative questions that highlight Indigenous community wellness, such as investigating the sources of collective strength and the ways cultural practices contribute to community vitality. The Māori Data Sovereignty Network in New Zealand demonstrates a transformative approach to data. Kukutai et al. (2023) emphasize their core principles (p.66):

- Self-determination (tino rangatiratanga) - Māori are no longer passive subjects of data collection, but active authors of their own narrative.
- Cultural preservation - Data is viewed as a taonga (treasure, something precious), with the goal of protecting and preserving Māori culture, language, and identity.
- Challenging existing power structures - They aim to shift from external researchers imposing preconceived notions to Māori communities defining what matters and how their story is told.
- Creating a global model for Indigenous data sovereignty - Te Mana Raraunga is a blueprint for Indigenous data sovereignty and leading by example the changes being made in New Zealand.

- **Bleed Down (Cuthand):** Explores colonial trauma through the affects of miss use of the land, wastelands they are relocated to, and the poor medical treatment which they received.
- **Nimmikaage (Latimer):** Reflects on displacement but the powerful reclaiming of female spiritual connection to culture, nature and traditions.

To enhance the script and create a more immersive experience for the podcast, the music from each short film was included. However, if the podcast is shared outside of this class, the music may need to be removed to comply with copyright infringement laws which has also been noted in the comment box.

#### 4. Aboriginal Health Data during COVID-19 – Note: not included with podcast.

Australian Aboriginal communities used health data to advocate for tailored pandemic responses, emphasizing holistic healing practices and culturally specific metrics. They established formal data-sharing agreements to ensure that data reflected Aboriginal priorities and values (Walter, 2018, p. 81).

#### Real-World Impacts

Empowering Indigenous communities through frameworks like OCAP and CARE Principles enables them to retain ownership and control over their data. This can directly influence policy, funding, and resource allocation. Initiatives such as Te Mana Raraunga showcase how self-determined data governance can drive transformative health and economic outcomes.

**Commented [KR5]:** Content from script: After viewing four short films, Sisters & Brothers by Kent Monkman, Mobilize by Caroline Monnet, Bleed Down by Thirza Cuthand, and lastly Nimmikaage by Michelle Latimer. Each creator has taken steps to change the narrative about Indigenous life by incorporating historical archived footage from the National Film Board used alongside their own personal perspective and cultural beliefs. These films aren't just artistic expressions; they are drawing from lived experiences captured on film to challenge mainstream ideas to offer their creative interpretation to tell a different story. Kent Monkman's "Sisters & Brothers" tells a story to critique the violence and assimilation caused by colonialism, blending historical footage with artistic licence it uses the archived images to tell two stories and how they are parallel to one another. One story about trying to tame the buffalo, and the second of the Indigenous children in the residential schools. The viewer has no choice but to look deeply into the eyes of the

**Commented [KR6]:** Content from script and sources: Australian Aboriginal communities used health data to advocate for tailored pandemic responses. Walter (2018) highlights their approach of "asserting their interests in relation to data" by:

- Establishing formal data-sharing agreements
- Measuring healing practices
- Tracking community-specific metrics
- Ensuring data reflects Aboriginal priorities and values (p. 81)

In Australia, Aboriginal communities used their health data to advocate for tailored pandemic responses. Dr. Tahu Kukutai and Dr. John Taylor, in their work "Indigenous Data Sovereignty: Toward an Agenda," share a powerful example from Australia much like their neighbours from New Zealand Te Mana Raraunga. When Aboriginal communities gained control over their health data during the COVID -19 pandemic to demand a say in how health

**Commented [KR7]:** Content from script and source:

Counter argument for real change: Some critics argue that these films are too abstract, and complex. They argue you can't just jump in and understand everything right away – you have to watch them a number of times. But here's the thing: that's not a weakness. That's the entire power of Indigenous storytelling. So, perhaps consider you're not just watching a movie, but you're being invited into a completely different way of understanding history, pain, and resilience. These filmmakers aren't interested in making something easily digestible for a mainstream audience. They're interested in telling their perspective of the truth.

Take films like Mobilize and Nimmikaage. They're not trying to spoon-feed you a narrative. They're using symbolism, abstract visuals—techniques that might seem confusing if you're looking through a traditional

For example, community-led health initiatives using their own data to secure funding for culturally relevant healthcare.

Showcase the success of initiatives like Te Mana Raraunga in Aotearoa/New Zealand, highlighting the benefits such as self-determined health research and economic strategies.

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### Scalability of Data Sovereignty

Indigenous data sovereignty can be expanded through:

- Technological enablers (encryption open-source platforms)
- Cross-cultural adaptation of frameworks
- Collaborative partnerships
- Policy integration
- Education and capacity building

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### Conclusion / Call to Action

Support Indigenous data sovereignty by:

- Listening to Indigenous voices
- Advocating for ethical data practices
- Recognizing data as a narrative, not just numbers

Close by inviting to visit website to view sources

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**Commented [KR8]:** Content from script and source. The scalability of Data sovereignty isn't just a local concept. It's a blue print for global change.

One possibility is Technology for example has so much potential - such as open-source platforms that are encrypted - — are tools that can turn data protection into a superpower for remote and under-resourced communities where they can store, manage, and protect their data securely.

Another possibility is cross-cultural adaptation. Countries like Canada and New Zealand aren't just creating frameworks—as shared earlier they are creating blueprints such as The OCAP® principles and CARE guidelines. These aren't just local policies. They're templates that Indigenous groups worldwide can adapt to their unique cultural contexts.

Though - Collaboration is at the heart of it and the multiplier. Universities, governments, NGOs—They are amplifying Indigenous data sovereignty through conferences, journal publications, and their research while also sharing their approaches. Just imagine what would happen if these principles were imbedded into global frameworks like the UN Declaration on the Rights of Indigenous Peoples.

Let's imagine the possibilities for Real change which could come from the power gained through new policies. When data sovereignty principles can be written into legal code, they become real protections. So for example if An OCAP® policy in a health ministry were to be written – it would mean every Indigenous community gets the same strong data rights. But where the real magic could take ...

**Commented [KR9]:** Fictional statement as I do not have a website.

Additional resources would include the full set of resources, along with the following if there was a website:

Belcourt, M. (Director). (2015). Nimmikaage (She Dances for People) [Film]. National Film Board of Canada. [https://www.nfb.ca/film/nimmikaage\\_she\\_dances\\_for\\_people/](https://www.nfb.ca/film/nimmikaage_she_dances_for_people/)

Desjarlais, E. (Director). (2016). Etlinisigu'niet (Bleed Down) [Film]. National Film Board of Canada. [https://www.nfb.ca/film/etlinsigu\\_niet\\_bleed\\_down/](https://www.nfb.ca/film/etlinsigu_niet_bleed_down/)

First Nations Information Governance Centre. (n.d.). The First Nations principles of OCAP®. <https://fnigc.ca/ocap-training/>

Global Indigenous Data Alliance (GIDA). (n.d.). CARE Principles. <https://www.gida-global.org/care>

Monkman, K. (Director). (2015). Sisters & Brothers [Film]. National Film Board of Canada. [https://www.nfb.ca/film/sisters\\_brothers/](https://www.nfb.ca/film/sisters_brothers/)

Monnet, C. (Director). (2015). Mobilize [Film]. National Film Board of Canada. <https://www.nfb.ca/film/mobilize/>

**Show Notes Disclaimer:** This podcast and the show notes are based on the research conducted by Karie Russell for educational purposes only. As a non-Indigenous individual, my goal is to use digital media to raise awareness and foster meaningful engagement on the topics of data sovereignty and self-determination. This podcast aims to promote the integration of data sovereignty principles into legislation, embedding them within policy frameworks.

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Walter, M. (2018). Indigenous data sovereignty. In T. Kukutai & J. Taylor (Eds.), *Indigenous data sovereignty: Toward an agenda* (pp. 257–278). ANU Press.  
<https://doi.org/10.22459/CAEPR38.11.2016.13>

### **Additional Resources**

Belcourt, M. (Director). (2015). *Nimmikaage (She Dances for People)* [Film]. National Film Board of Canada. Retrieved from  
[https://www.nfb.ca/film/nimmikaage\\_she\\_dances\\_for\\_people/](https://www.nfb.ca/film/nimmikaage_she_dances_for_people/)

Desjarlais, E. (Director). (2016). *Etlinisigu'niet (Bleed Down)* [Film]. National Film Board of Canada. Retrieved from [https://www.nfb.ca/film/etlinisigu\\_niet\\_bleed\\_down/](https://www.nfb.ca/film/etlinisigu_niet_bleed_down/)

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