Applications to the CLSA & Considerations for Access/Use of Indigenous-Identified Data

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clsa élcv
Canadian Longitudinal Study on Aging
Étude longitudinale canadienne sur le vieillissement

Indigenous data in the CLSA

Baseline N=1879 (3.7% of CLSA participants)
- 1128 in comprehensive cohort
- 751 in tracking cohort

Indigenous Identifiers in CLSA Data

- Ethnicity

SDC_3   To which ethnic or cultural groups did your ancestors belong? (For example: French, Scottish, Chinese, East Indian.) **DO NOT READ LIST, MULTIPLE RESPONSES ALLOWED (EXCEPT IF 98 OR 99 ARE SELECTED), CODE ALL THAT APPLY**

INTERVIEWER NOTE: IF 'CANADIAN' IS THE ONLY RESPONSE, PROBE. IF THE PARTICIPANT HESITATES, DO NOT SUGGEST CANADIAN. IF THE PARTICIPANT ANSWERS ESKIMO, ENTER CODE 20 (INUIT).

SDC_ETHN_CA_COM	Canadian	01	SDC_ETHN_HE_COM	Hebrew	11
SDC_ETHN_FR_COM	French	02	SDC_ETHN_PL_COM	Polish	12
SDC_ETHN_EN_COM	English	03	SDC_ETHN_PT_COM	Portuguese	13
SDC_ETHN_DE_COM	German	04	SDC_ETHN_SA_COM	South Asian (e.g. East Indian, Pakistani, Sri Lankan)	14
SDC_ETHN_GD_COM	Scottish	05	SDC_ETHN_NO_COM	Norwegian	15
SDC_ETHN_GA_COM	Irish	06	SDC_ETHN_CY_COM	Welsh	16
SDC_ETHN_IT_COM	Italian	07	SDC_ETHN_SV_COM	Swedish	17
SDC_ETHN_UK_COM	Ukrainian	08	SDC_ETHN_AI_COM	North American Indian	18
SDC_ETHN_NL_COM	Dutch (Netherlands)	09	SDC_ETHN_ME_COM	Métis	19
SDC_ETHN_ZH_COM	Chinese	10	SDC_ETHN_IU_COM	Inuit	20
SDC_ETHN_OT_COM	Other	97	SDC_ETHN_DK_NA_COM	**[DO NOT READ]** Don't know/No answer	98
SDC_ETHN_OTSP_COM	Other (please specify: _____)*		SDC_ETHN_REFUSED_COM	**[DO NOT READ]** Refused	99

*Additional categories coded; refer to data dictionary

Indigenous Identifiers in CLSA Data

- Cultural / racial background

SDC_4   People living in Canada come from many different cultural and racial backgrounds. Are you…**READ LIST, MULTIPLE RESPONSES ALLOWED (EXCEPT IF 98 OR 99 ARE SELECTED), CODE ALL THAT APPLY**

SDC_CULT_WH_COM	White	01
SDC_CULT_ZH_COM	Chinese	02
SDC_CULT_SA_COM	South Asian (e.g., East Indian, Pakistani, Sri Lankan)	03
SDC_CULT_BL_COM	Black	04
SDC_CULT_FP_COM	Filipino	05
SDC_CULT_LA_COM	Latin American	06
SDC_CULT_SE_COM	Southeast Asian (e.g., Cambodian, Indonesian, Laotian, Vietnamese)	07
SDC_CULT_AR_COM	Arab	08
SDC_CULT_WA_COM	West Asian (e.g., Afghan, Iranian)	09
SDC_CULT_JA_COM	Japanese	10
SDC_CULT_KO_COM	Korean	11
SDC_CULT_AI_COM	North American Indian	12
SDC_CULT_IU_COM	Inuit	13
SDC_CULT_ME_COM	Métis	14
SDC_CULT_OT_COM	Other	97
SDC_CULT_OTSP_COM	Other (please specify: _____)	
SDC_CULT_DK_NA_COM	**[DO NOT READ]** Don't know/No answer	98
SDC_CULT_REFUSED_COM	**[DO NOT READ]** Refused	99

Indigenous Identifiers in CLSA Data

- Languages spoken

'Aboriginal' is an option for each of these questions:
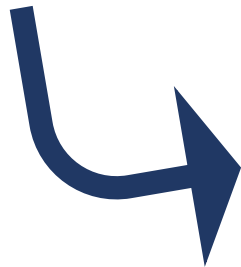
SDC_5 — In what languages can you conduct a conversation? **DO NOT READ LIST, MULTIPLE RESPONSES ALLOWED (EXCEPT IF 98 OR 99 ARE SELECTED), CODE ALL THAT APPLY**

SDC_6
SDC_LGMST_COM

What language do you speak <u>most often</u> at home? **[RECALL RESPONSES SELECTED AT SDC_5/SDC_LANG_COM] DO NOT READ LIST, CODE ONLY ONE RESPONSE**

SDC_7

What is the language that you first learned at home in childhood and can still understand? **DO NOT READ LIST, MULTIPLE RESPONSES ALLOWED (EXCEPT IF 98 OR 99 ARE SELECTED), CODE ALL THAT APPLY. IF PARTICIPANT CAN NO LONGER UNDERSTAND THE FIRST LANGUAGE LEARNED, MARK THE SECOND LANGUAGE LEARNED.**
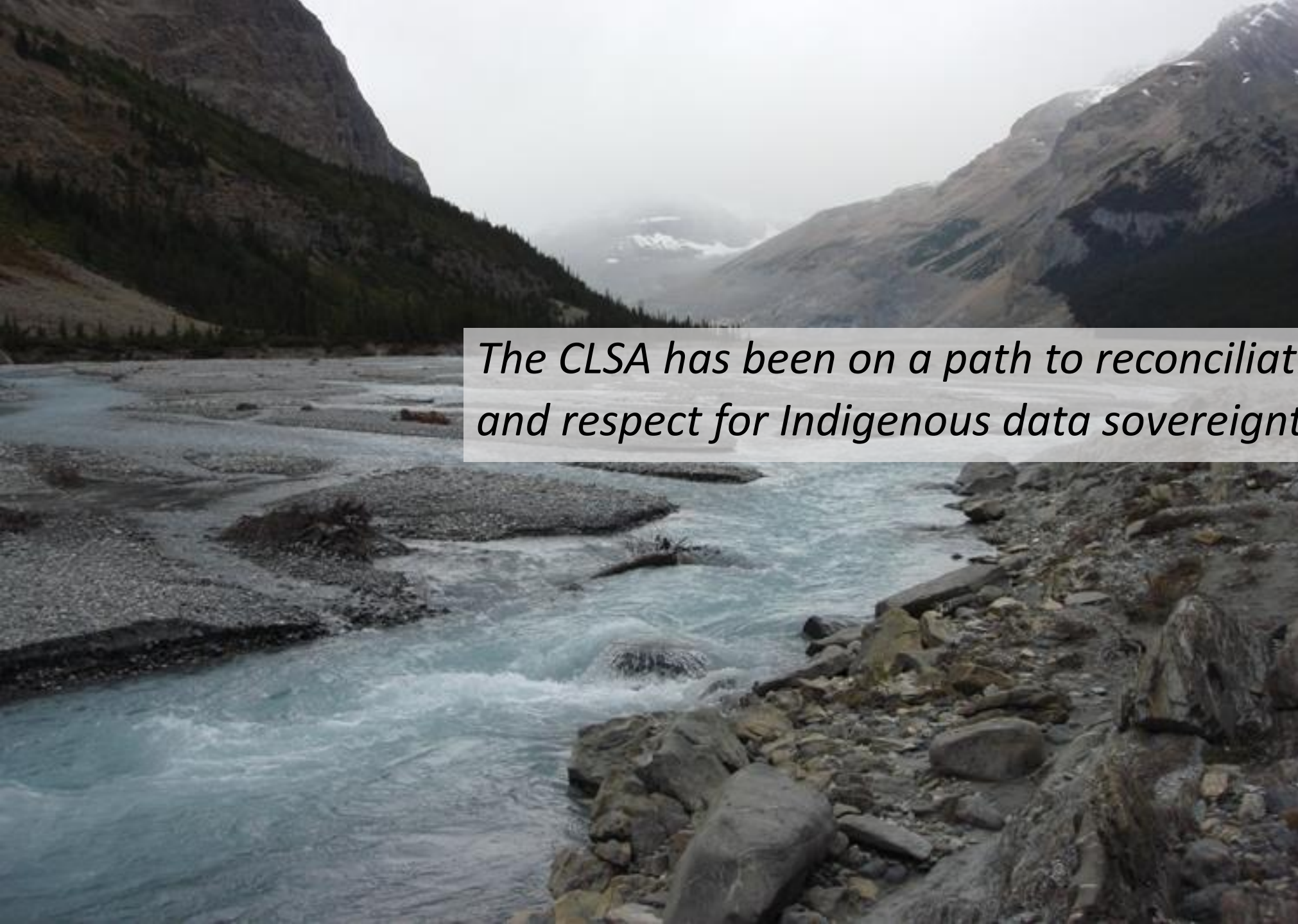
The CLSA has been on a path to reconciliation
and respect for Indigenous data sovereignty / governance

Initial conversations

Initial design of CLSA did not include co-design with Indigenous researchers or communities
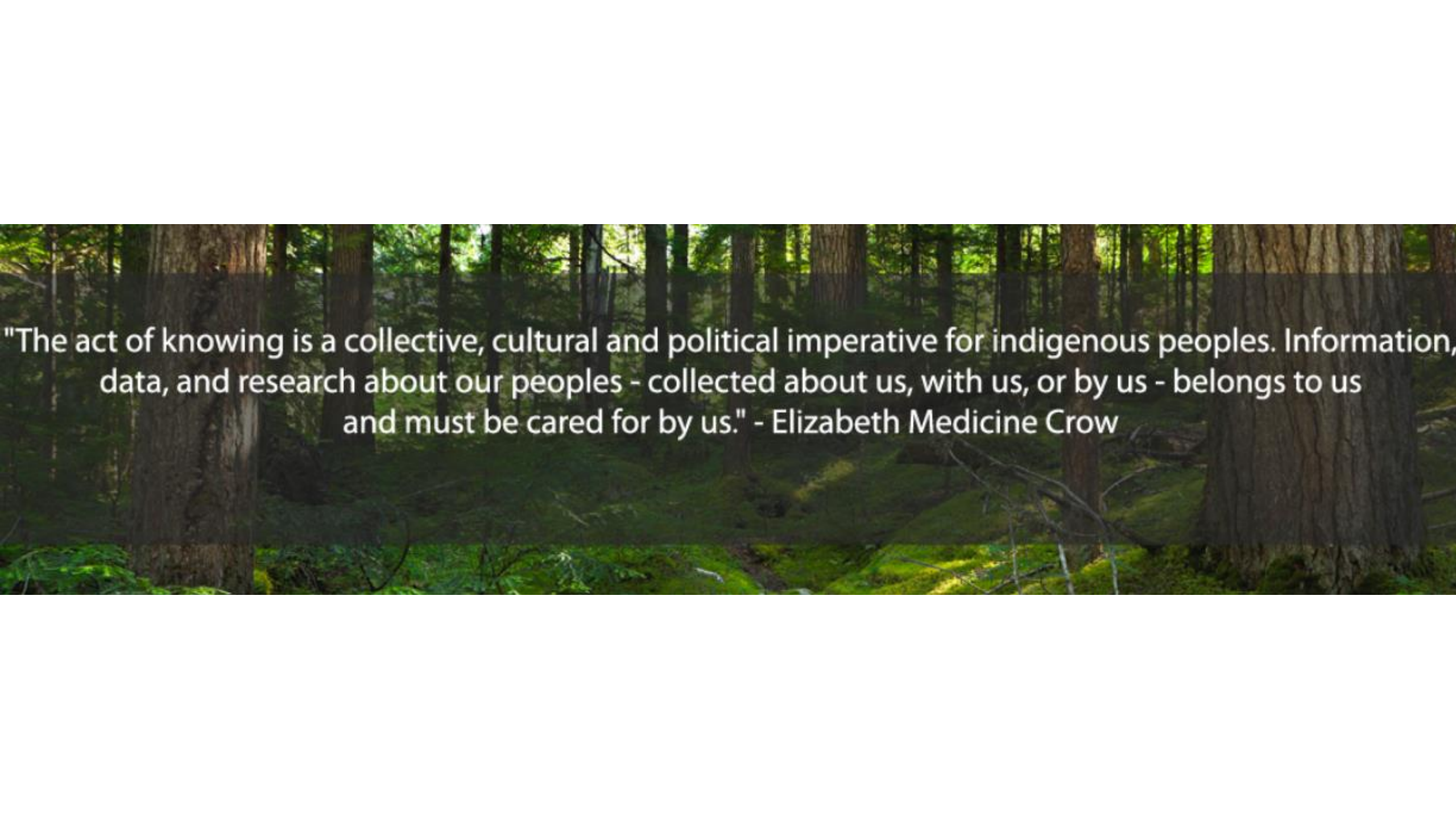
In 2018, Indigenous dementia researchers in the CCNA saw a presentation by CLSA that highlighted the number of people with Indigenous identity in the baseline

This prompted discussion with Indigenous organizations about data use and access

An initial data request for all Indigenous-identified CLSA data to be cared for under Indigenous governance was submitted. It was not approved.

"The act of knowing is a collective, cultural and political imperative for indigenous peoples. Information, data, and research about our peoples - collected about us, with us, or by us - belongs to us and must be cared for by us." - Elizabeth Medicine Crow

Analyzing CLSA Data in Partnership with NWAC

In 2019, researchers from NWAC and academic partners analyzed Indigenous-identified CLSA data with a group of 16 older Indigenous people and Elders from across Canada.

Significant concerns were presented by NWAC to CLSA

| Data governance | Representation and sampling | Relevance of content |

In 2020, CLSA hosted a gathering of Indigenous organizations and researchers.

The outcome was a pause on accessing Indigenous-identified data.

Access to Indigenous-identified data was paused until a path that respects both research ethics requirements and indigenous data sovereignty principles could be determined.

The CLSA's Commitments

- The CLSA is committed to supporting research that benefits all people living in Canada.

- The **CLSA is committed to ensuring all research involving First Nations, Métis and Inuit peoples is conducted in a manner that respects Indigenous data governance principles and rights**, including researcher responsibilities to uphold those same principles and rights in their research activities.

Research Ethics: What does TCPS 2 (2022) have to say?

- Article 9.1

"Where the research is likely to affect the welfare of an Indigenous community, or communities, to which prospective participants belong, **researchers shall seek engagement with the relevant community**. The conditions under which engagement is required include, but are not limited to:… **d. research in which Indigenous identity or membership in an Indigenous community is used as a variable for the purpose of analysis of the research data…**"

- Article 9.2

"The nature and extent of community engagement in a project shall be **determined jointly by the researcher and the relevant community** and shall be **appropriate to community characteristics and the nature of the research.**"

Article 4 – right to **autonomy** and **self-government**

Article 5 – right to maintain and strengthen **distinct** political, legal, economic, social and cultural **institutions**

Article 15 (i) – right to dignity and **diversity** of cultures traditions, histories and aspirations which shall be appropriately reflected in education and **public information**

Article 18 – right to participate in decision-making in matters that would affect rights…and to develop indigenous **decision-making institutions**

Article 19 – States shall…obtain **free, prior and informed consent** before adopting and implementing legislative or administrative measures that may affect them

Article 23 – right to determine and develop **priorities and strategies**…and to administer **programs** through their own institutions if possible

Article 31 – right to maintain, control, protect and develop **intellectual property**

Article 33 – right to **determine their own identity or membership**. Right to determine structures and select membership of their institutions
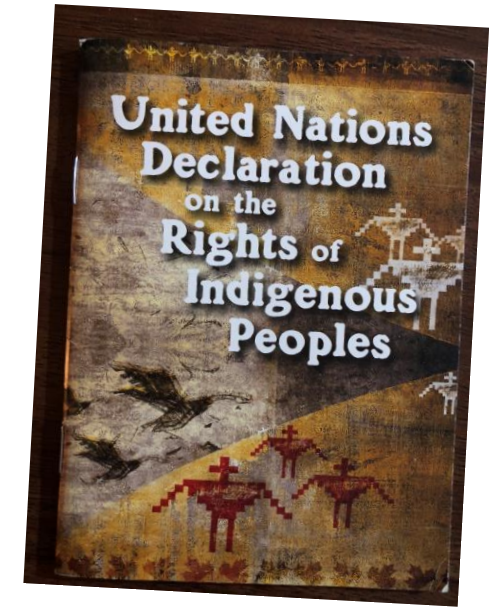
2007

Beyond individual consent → Importance of collective consent

CARE Principles for Indigenous Data Governance

Global Indigenous Data Alliance. (2019). CARE principles for Indigenous data governance. GIDA https://www. gida-global. org/care.

Carroll, S. R., Garba, I., Figueroa-Rodríguez, O. L., Holbrook, J., Lovett, R., Materechera, S., Parsons, M., Raseroka, D.R., Rowe, R., Sara, R., Walker, J.D., Anderson, J., & Hudson, M.(2020). The CARE Principles for Indigenous Data Governance. *Data Science Journal*, *19*(1).
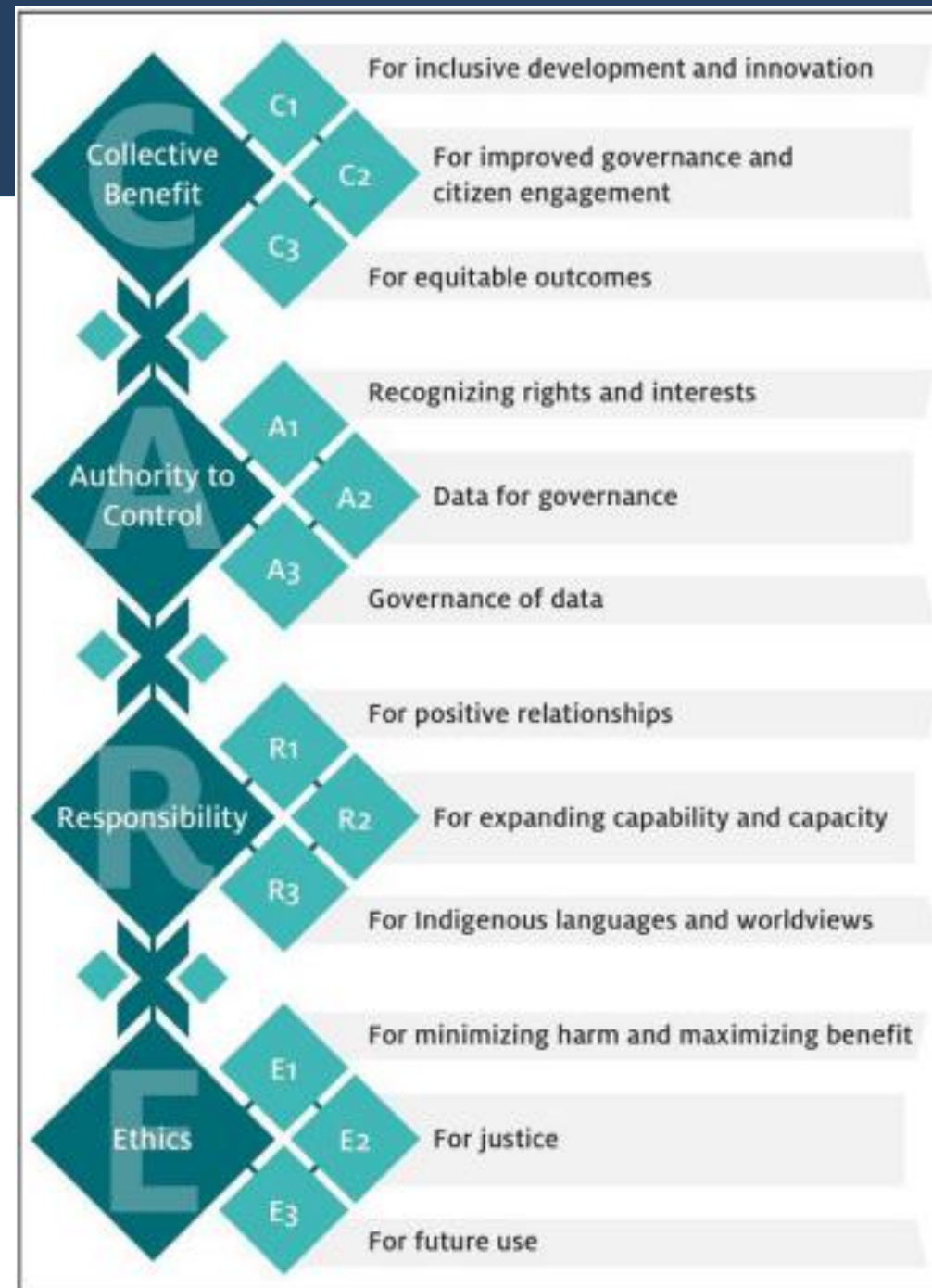
CARE Principles for Indigenous Data Governance

Collective Benefit.

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

    C1. For inclusive development and innovation
    C2. For improved governance and citizen engagement
    C3. For equitable outcomes

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.

    R1. For positive relationships
    R2. For expanding capability and capacity
    R3. For Indigenous languages and worldviews

Authority to Control.

Indigenous Peoples' rights and interests in Indigenous data must be recognized and their authority to control such data respected.

    A1. Recognizing rights and interests
    A2. Data for governance
    A3. Governance of data

Ethics.

Indigenous Peoples' rights and wellbeing should be the primary concern at all stages of the data life cycle and across the data ecosystem.

    E1. For minimizing harm and maximizing benefit
    E2. For justice
    E3. For future use

First Nations Data Governance Principles - OCAP®

- First Nations Information Governance Centre (FNICG)
- Refers to the rights of First Nations communities to own, protect and control how their information is used for research and other purposes

OWNERSHIP	CONTROL	ACCESS	POSSESSION

https://fnigc.ca/ocap-training/

A new pathway for CLSA:
Access to Indigenous-identified data

Summary of new requirements:

Meaningful and respectful **engagement** with relevant Indigenous Peoples when using/reporting on Indigenous identifiers

- Not sure where to start?
    - Training on building Indigenous community research partnerships: https://www.queensu.ca/indigenous/decolonizing-and-indigenizing/community-research-partnerships-training
    - Training on assessing Indigenous Research Engagement: https://iceclearning.fnuniv.ca/courses/indigenous-research-level-of-engagement-tool

Ideally: Indigenous **governance** of Indigenous-focused projects and research questions

Applying to access Indigenous-identified data in Magnolia

Abandon

Download ▾ | **Compare ▾** | **Show Record** | **Submit**

Instructions   Part 1   **Part 2**   Part 3   Total fees: $3000

Part 2 of 3: Data Checklist

Notes   Cohort & Longitudinal Analyses   **Indigenous Identifiers**   Core CLSA Data   Linked Data   Images and Raw Data   Geographic Indicators   COVID-19 Data   Mortality Data

Note to Applicant

[ ]

Please note that as per >Chapter 9: Research Involving the First Nations, Inuit and Métis Peoples of Canada of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, projects that include Indigenous identifiers will undergo an additional review to ensure that meaningful and respectful engagement with relevant Indigenous Peoples is integrated throughout the project.

Does your proposed project include the use of Indigenous (First Nations, Métis, Inuit) self-identifiers?

[Yes ▾]   **Undo**

Please include a description on how you intend to use Indigenous identifiers in your analyses and how you are involving Indigenous organizations, people and governing bodies in your project.

[ ]

← Return to the previous section   **Proceed to the next section →**

Data Access – Indigenous Identifiers

DSAC
- DSAC committee includes an Indigenous health researcher.
- Assess if the project demonstrates meaningful and respectful engagement with appropriate Indigenous group(s), people, organizations, and/or communities.

Data and Sample Access Committee & Scientific Management Team Review

Dataset Preparation & Release

- If approved, different sets of variables will be released for ethnicity, language, and culture which include Indigenous identifiers information.

≤ 12 weeks

Submission

1-page describing:
- How identifiers are used in analysis
- How meaningful & respectful engagement is integrated into the project

6-9 weeks

5-7 days

Final Report
- Describe how meaningful and respectful engagement was fostered into the project.

Administrative & Feasibility Review

Access Agreement Signed; Ethics Approval

Admin review
- Does the application use Indigenous identifiers? If yes, did the primary applicant complete the section on use and engagement?

Feasibility review
- Does the applicant clearly describe the of use Indigenous identifiers in their analyses and the engagement of Indigenous organizations, people and governing bodies in their project?

Ethics Approval (as per TCPS-2 Article 9.10)
- Did the primary applicant advise the REB(s) how they have engaged, or intend to engage, with Indigenous organizations, people and governing bodies?

Access Agreement
- Is there a provision for data sharing with Indigenous organizations or governing bodies?

Tips for Ethically Using and Reporting on Indigenous Data

- Conduct work in service to community that supports community priorities
- Respect existing Indigenous governance protocols
- Recognize and promote sovereignty by ensuring Indigenous direction and governance throughout
- Centre Indigenous values and communities in knowledge sharing
- Strengthen and build data capacity within communities
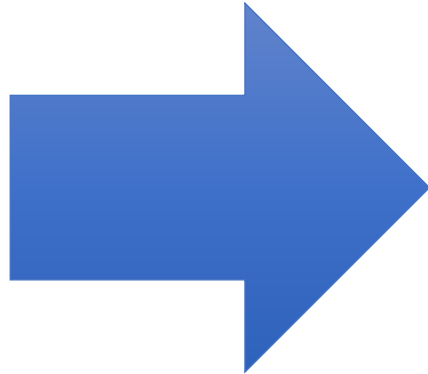- Build on strengths, not deficits

Where to next?

TWO CONDITIONS for Data Sovereignty

Decolonization of Data

Indigenous Data Governance

5Ds of Colonizing Indigenous Data

- Disparity
- Depravation
- Disadvantage
- Dysfunction
- Difference

- Classifies us as "problematic"
- Data used to rationalize dispossession & marginalization, and to perpetuate narratives of dependency

Walter (2016). "Data politics and Indigenous representation in Australian Statistics", in Kukutai and Taylor (eds) Indigenous Data Sovereignty: Toward an Agenda. 2016.
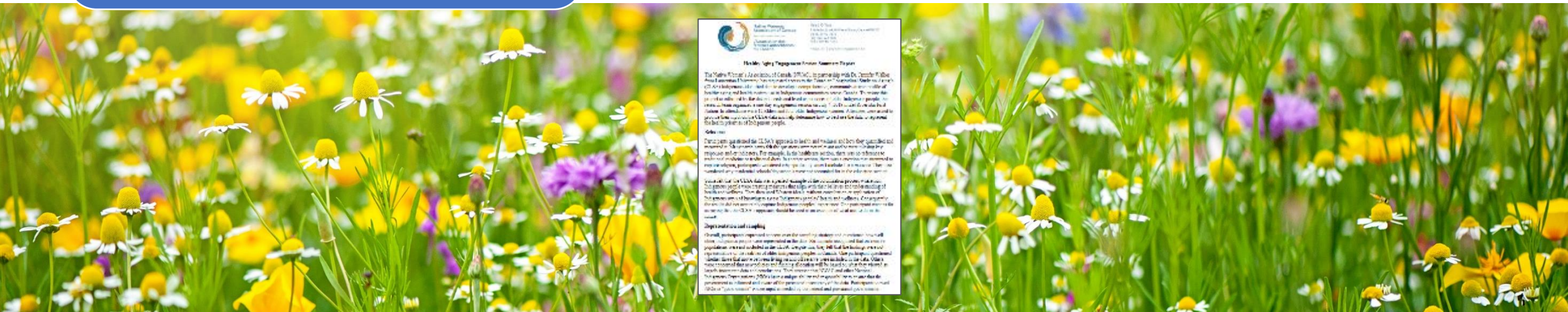
Next Steps – establishing a CLSA Indigenous Working Group

Relevance of Content

- *Asking questions that are relevant for First Nations, Inuit and Metis communities*

Representation and Sampling

- *Recruiting First Nations, Inuit, and Métis participants in a respectful and representative way*

Nia:wen

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