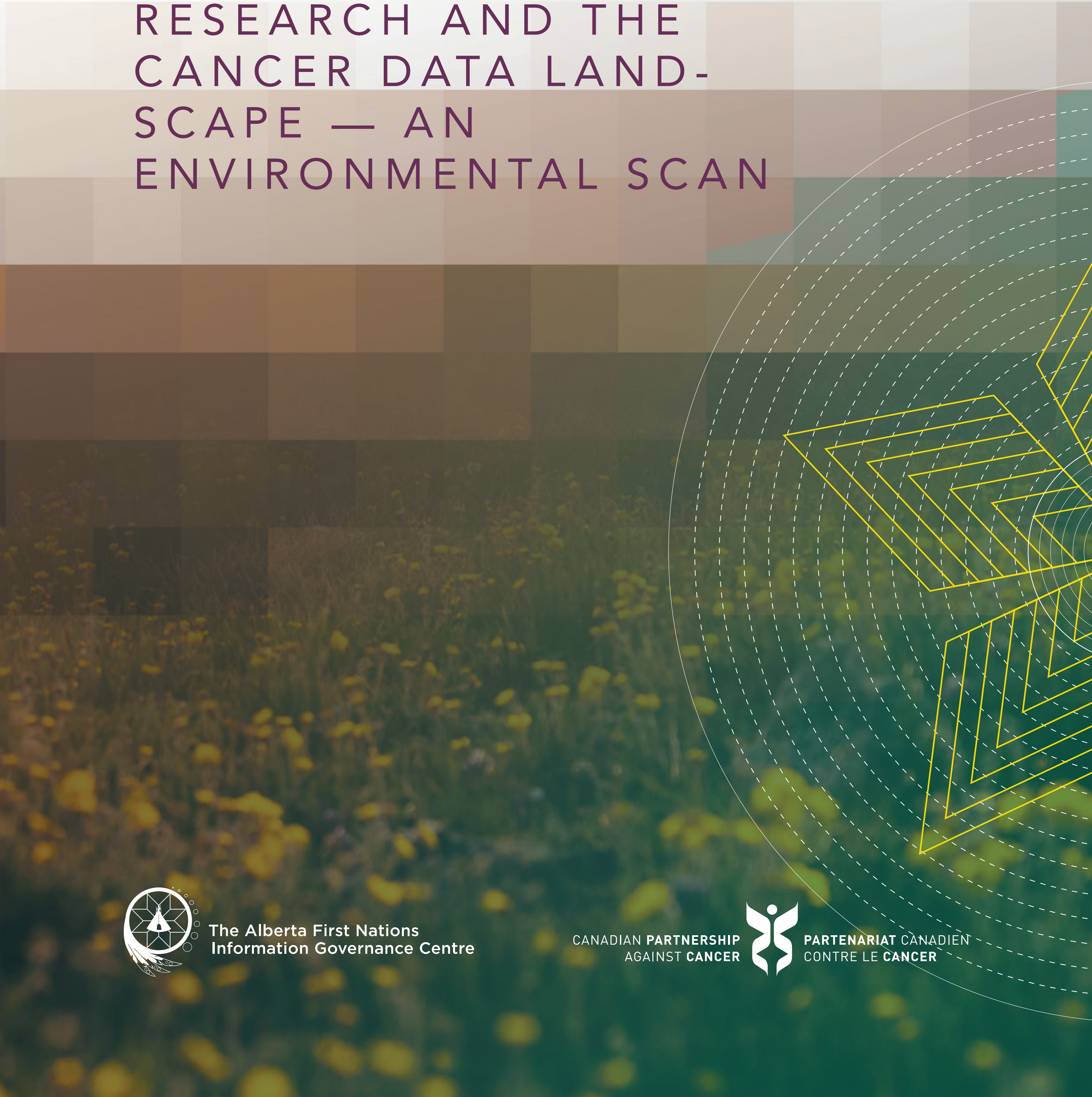
INDIGENOUS CANCER RESEARCH AND THE CANCER DATA LANDSCAPE — AN ENVIRONMENTAL SCAN



The Alberta First Nations
Information Governance Centre

CANADIAN PARTNERSHIP
AGAINST CANCER

PARTENARIAT CANADIEN
CONTRE LE CANCER

The Alberta First Nations
Information Governance Centre

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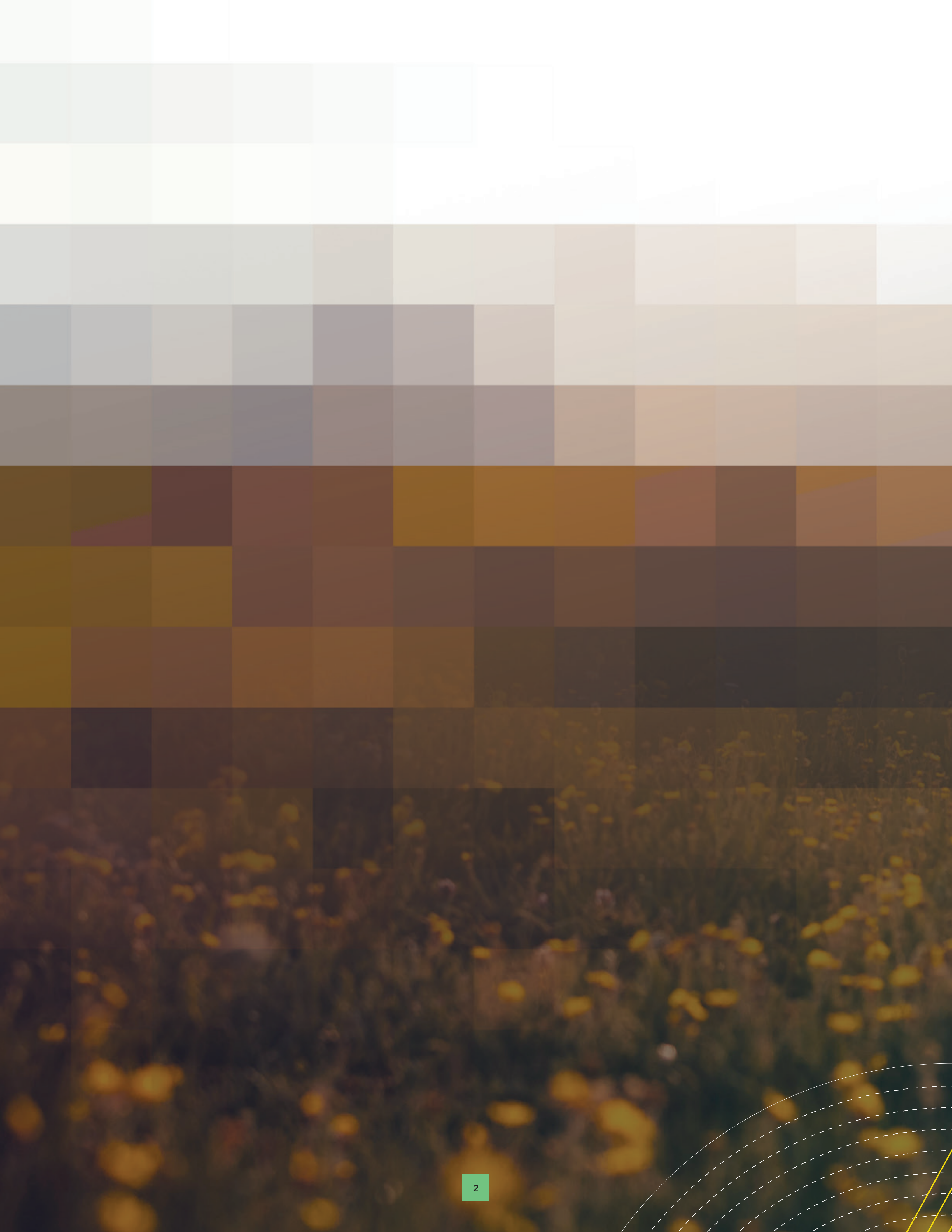


ACKNOWLEDGMENT

We honour and celebrate cancer patients from Indigenous communities and acknowledge their families; it is on their behalf that we do this work. We acknowledge Indigenous researchers who broke ground, included Indigenous thought and voice through research, and brought to light Indigenous perspectives from Indigenous cancer experiences and stories. We are indebted to the Knowledge Holders who have guided and walked with us on this discovery and learning journey.

The Canadian Partnership Against Cancer (CPAC) must be commended for having the integrity and courage to want to do better as an organization by developing their Strategic Priority 8 and to answer the Truth and Reconciliation Commission of Canada (TRC) Call to Action Article 19. In the words of TRC Commissioner Wilton Littlechild: *"… to go where there is no path and leave a trail for someone else, exercise a new right for humankind ... Not just to complain but offer solutions for consideration. Walk together on that journey." (March 30, 2022).*

EXECUTIVE SUMMARY

This work recognizes a vast diversity of perspectives that have yet to be fully comprehended within the field of cancer research, both nationally and internationally. Indigenous-governed data and cancer control research have not been fully realized yet, and it is erroneous to consider the lack of information as a gap within academic and scientific disciplines.

This Environmental Scan presents an applied Indigenous lens to reviewing the research conducted to date from the context of answering four specific broad questions. Grounded in the medicine wheel philosophy of a holistic approach, the mind, spirit, heart, and actions were applied to explore the Indigenous concept of data.

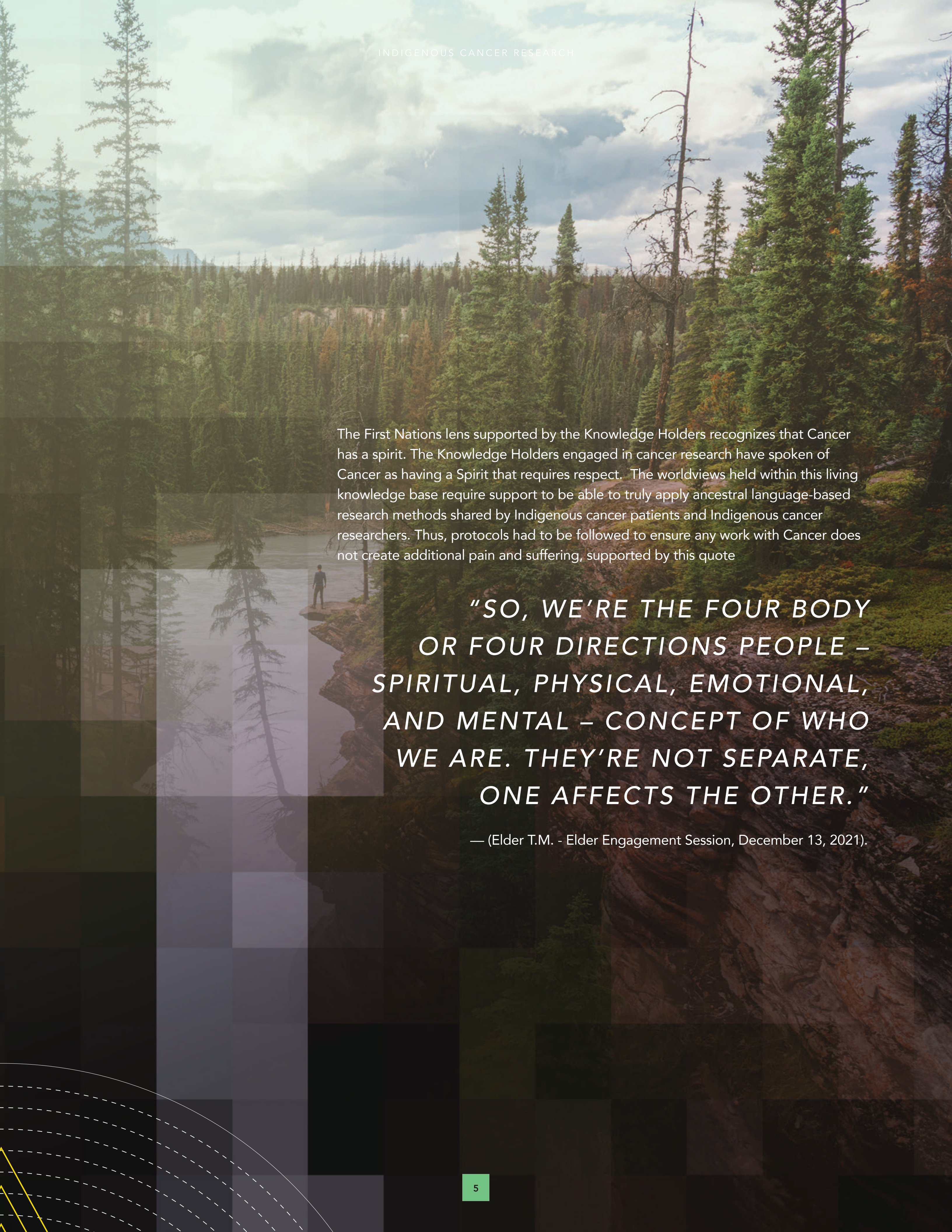
Specific questions utilized to focus the work were:

1. What is the current state of custodianship of Indigenous-governed cancer care data?
2. What is the current state of cancer care systems research re: Indigenous-specific and Indigenous-led?
3. What are the promising practices of cancer care data with/by researchers?
4. Where does the Canadian Partnership Against Cancer (CPAC) fit with Indigenous-governed data, research, and cancer care systems?

Given the diversity of perspectives on these topics, this environmental scan positions its work on the premise that cancer is recognized as having an energy and spirit of its own, which influences the research, and the data linked to it. Cancer touches all people worldwide, and the opportunity to present an Indigenous perspective through this environmental scan is an honour. This work focuses on the Indigenous population and language groups as a collective cancer journey. The diversity of approaches and methodologies in community-based cancer control research is a field of study that has not yet been fully realized. Each Indigenous population and language group has their own ancestral inquiry methods and living examination methodology. Indigenous-led research methodology holds promise for a new way of doing research and must be understood.

The unique approaches employed from an Indigenous perspective were:

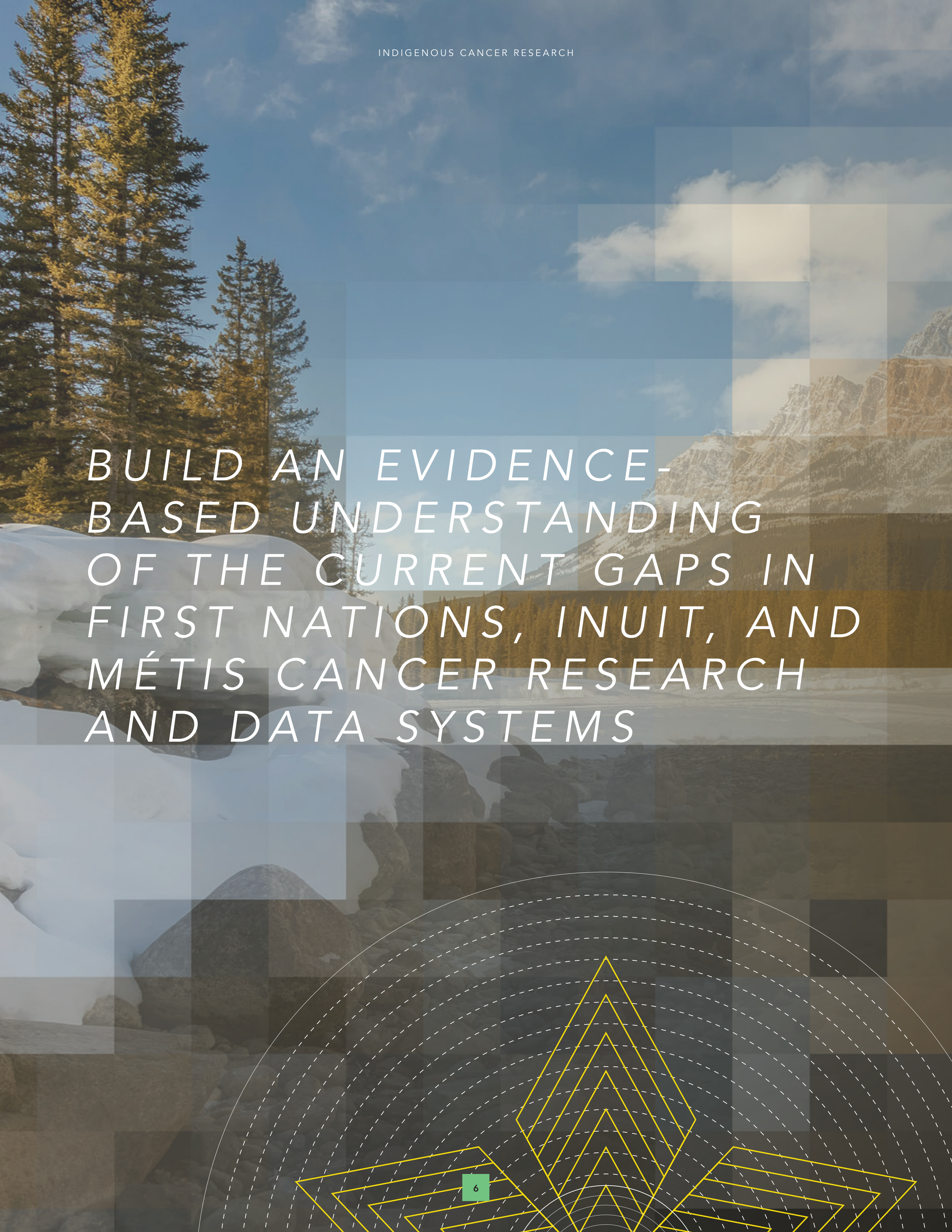
- Applying Indigenous protocols.
- Cultural knowledge and ways were applied to collaborative analysis processes.
- In keeping with the First Nations principles of OCAP®, an online survey specific to this project was created and conducted using a secure survey platform (Voxco)—the physical server for which is held securely at the Alberta FNIGC offices.
- A data robot (called Winston) was employed to identify and scan over sixty thousand (60,000) documents for relevance, prioritization, and quality.
- Focus groups and interviews (both national and international) were held via Zoom.
- An in-person Knowledge Holder engagement session comprised of Elders from many nations and areas informed the process and contributed to information verification.
- An extensive literature review was performed by multiple team members and analyzed using quantitative data artificial intelligence and qualitative analysis software (NVivo) with coding accuracy (inter-rater reliability) verified using Cohen's Kappa (κ).



The First Nations lens supported by the Knowledge Holders recognizes that Cancer has a spirit. The Knowledge Holders engaged in cancer research have spoken of Cancer as having a Spirit that requires respect. The worldviews held within this living knowledge base require support to be able to truly apply ancestral language-based research methods shared by Indigenous cancer patients and Indigenous cancer researchers. Thus, protocols had to be followed to ensure any work with Cancer does not create additional pain and suffering, supported by this quote

> *"SO, WE'RE THE FOUR BODY OR FOUR DIRECTIONS PEOPLE – SPIRITUAL, PHYSICAL, EMOTIONAL, AND MENTAL – CONCEPT OF WHO WE ARE. THEY'RE NOT SEPARATE, ONE AFFECTS THE OTHER."*

— (Elder T.M. - Elder Engagement Session, December 13, 2021).



BUILD AN EVIDENCE-BASED UNDERSTANDING OF THE CURRENT GAPS IN FIRST NATIONS, INUIT, AND MÉTIS CANCER RESEARCH AND DATA SYSTEMS

INTRODUCTION

First Nations, Inuit, and Métis partners continue to highlight the critical lack of Indigenous data and research to support cancer control. Through preliminary engagement, the Canadian Partnership Against Cancer (CPAC) has heard that Indigenous organizations and groups are working to manage ownership and data sharing through arrangements such as information governance bodies, data-sharing agreements with federal and provincial/territorial partners, and data linkages with cancer registries. Partners of Alberta FNIGC have indicated that the cancer burden must be measured using self-determined indicators, outcomes, and key metrics (such as wait times to diagnosis and travel times for assessment and treatment) to understand better trends, disparities, and gaps in cancer care.

Of particular concern is the increasing burden of cancer amongst Indigenous peoples, the way cancer is reported, and the need to rethink how cancer burdens are reported locally, nationally, and internationally.

In the absence of a national reporting system for Indigenous populations in Canada, cancer rates should be standardized beyond the provincial population to enhance an opportunity to compare rates across provinces.

There is currently no agreement on how best to enhance data standardization within provinces for improved comparability across Canadian regions. The same applies internationally. A recent paper by Moore et al. (2015) illustrated a most gallant effort to comparatively present the Indigenous cancer burden across four British colonial countries. Age-standardized incident cancer rates (excluding non-melanoma) were produced from the population-based cancer registries of New Zealand and three Australian states (Queensland, Western Australia, and the Northern Territory), one Canadian province (Alberta), and the United States Contract Health Service Delivery Areas. Of note is that only New Zealand produced national data for this study.

The environmental scan's purpose was to review foundational Canadian Cancer Research Alliance (CCRA) strategy and engagement documents, key content documents, academic literature, and grey literature, map partners and stakeholders, and provide an analysis of the current state of Indigenous-led research and data.

A primary aim of the environmental scan was to build an evidence-based understanding of the current gaps in First Nations, Inuit, and Métis cancer research and data systems. As described below, the activities of this phase were expected to identify areas of focus to inform the implementation of the Partnership's 2022-2027 business plan.

- Identify existing sources of First Nations, Inuit and Métis data (including research data), data holders, data access, variables, methodologies, and governance structures/agreements/policies.
- Identify priorities in cancer research for Indigenous populations by analyzing the current landscape of Indigenous health research and research governance.
- Identify and map key data and research leaders/organizations/stakeholders (First Nations, Inuit and Métis partners/researchers/data custodians, national Indigenous organizations, Canadian Indigenous Research Network Against Cancer, Indigenous information governance centers, federal research institutions, provincial/regional Indigenous governance centers, independent research organizations/academic institutions, cancer system partners).
- Identify and review key Canadian documents and literature (last ten years), along with identification and review of international best practices.
- Identify existing gaps, promising practices, and opportunities to support First Nations, Inuit, and Métis governed data and research.

OBJECTIVES

Guided by the following questions and the research team's expansive knowledge of cancer care systems, including connections with key stakeholders and knowledge holders within the Indigenous cancer research field, this report answers:

- **What is the current state of custodianship of Indigenous-governed cancer care data?**
- **What is the current state of cancer care systems research re: Indigenous-specific and Indigenous-led?**
- **What are the promising practices of cancer care data with/by researchers?**
- **Where does the Canadian Partnership Against Cancer (CPAC) fit with Indigenous-governed data, research, and cancer care systems?**

As recommended in the Request for Proposal (RFP), the work was carried out in a series of phases with key findings integrated into this final report. The phases of the project are as follows:

Phase 1 - Environmental Scanning

Review foundational CPAC/CCRA strategy and engagement documents, key content documents, academic literature and grey literature, map partner/stakeholders, and conduct a gap analysis by engaging key organizations.

Phase 2 - Engagement

Carry out key stakeholder engagement using multiple methods of inquiry, including digital platforms for an online survey, focus group sessions, and key informant interviews. A total of nine engagements (which included leaders in Indigenous cancer data and research) were undertaken. These engagement sessions targeted Indigenous data holders, First Nations, Inuit, and Métis partners, federal/provincial/territorial partners, CCRA, and leveraged existing CPAC engagement opportunities including CCRA meetings, existing indicator working groups, knowledge translation and exchange partner meetings, and advisory meetings.

Phase 3 - Gap Analysis

Phase 3 included activities to carry out a gap analysis of the current state of Indigenous-governed research and data systems. This process, which was iterative in nature, included activities and processes that often overlapped—e.g., the analysis of qualitative findings and the mapping process.

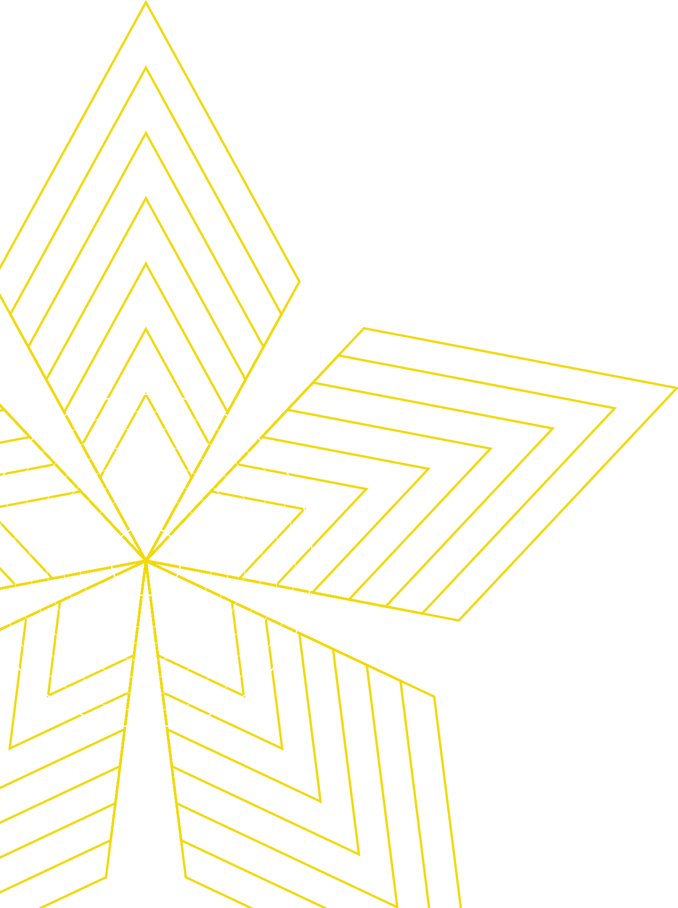
The Discussion section of this report focuses on responding to the following areas:

- To articulate the current state of Indigenous-governed research and data systems in the context of cancer control
- To map the cancer control data landscape in Canada for First Nations, Inuit, and Métis populations
- To identify key federal/provincial, organizational, and Indigenous community data users and data holders
- To identify and confirm gaps in First Nations, Inuit, and Métis data sources, data linkage processes, etc.
- To identify the desired state for Indigenous research and data governance with respect to cancer control
- To identify priorities, opportunities, and challenges concerning Indigenous research and data governance in cancer control – internationally, nationally, and regionally
- To articulate research and data governance capacities
- To describe infrastructure currently in place that could be leveraged
- To identify specific resources required to support Indigenous research and data governance

METHODOLOGY

ENVIRONMENTAL SCAN (LITERATURE REVIEW)

This research has used a mixed-methods approach to the environmental scan, applying both Western and Indigenous science principles. Western methods for conducting an environmental scan have been utilized to create outputs, including search plans, websites, database searches, and Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMAs). Indigenous methods were developed to conduct document analyses aligned with Indigenous science and knowledge to provide Indigenous perspectives of outcomes.



Indigenous Principles of Meta-Analysis

Indigenous principles applied to the environmental scan phase included:

- The core principle of respect is embedded in all aspects of Indigenous peoples' work. Recognizing that there are many types and bodies of knowledge, which come with protocols of handling and use, the team was conscientious about ensuring the respectful handling and use of data accessed and reviewed for this scan. This idea comes from the knowledge and understanding some of our team members have with handling medicine bundles. A body of knowledge is seen as a medicine bundle and thus demands the same level of respectful handling as a medicine bundle.
- The core principle of inclusiveness acknowledges the researchers' role and their gifts of applying mind, spirit, heart, and action in reviewing and exploring concepts and data. Inclusiveness provides the space for the four directions model and four aspects of human nature to be expressed and applied in a systematic way.
- The core principle of working together stems from our knowledge holders and keepers regularly reminding us that working together supports the best outcomes for any work linked to Indigenous peoples. By collaborating, working together and engaging stakeholders at multiple levels, the products represent diverse Indigenous groups.
- The core principle of humanitarianism refers to an Indigenous understanding of being connected by spirit and kinships and helping one another through sharing.
- The principle of comprehensiveness speaks to diverse knowledge systems and data and the strength of including diverse perspectives and bodies of knowledge/data.

Indigenous Principles of Environmental Scan Meta Analysis

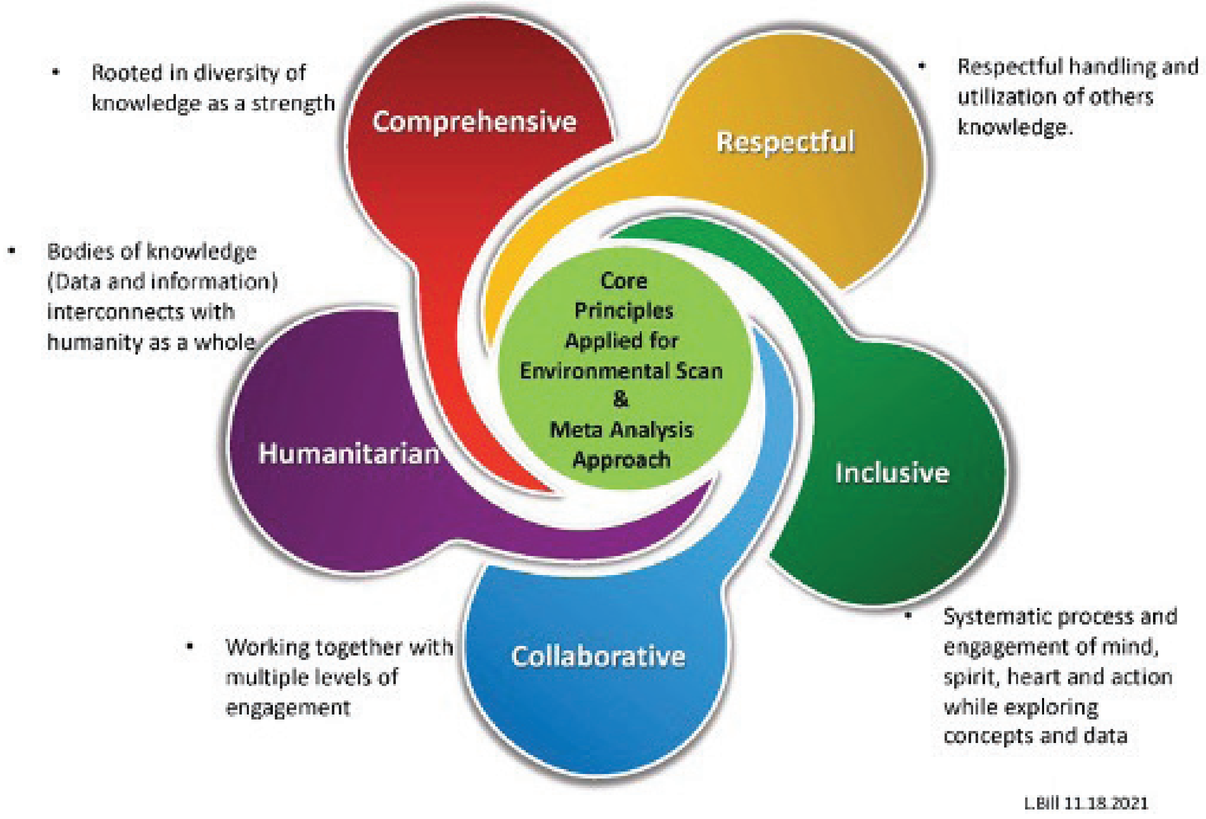


Diagram 01: Indigenous Principles applied within the Environmental Scan

Four Stream Approach

The Four Stream Approach offers a comprehensive framework for integrating Indigenous methodologies into research by recognizing the importance of contextual interpretation and a deep understanding of Indigenous principles. Here's a brief overview of each of the four streams:

1. **Spirit Essence of Data:** This stream emphasizes the intrinsic value and sacred nature of data, viewing it as more than just information. It reflects the spiritual aspects and cultural significance embedded in the data, encouraging researchers to approach data with respect and mindfulness.
2. **Life of Data:** This stream considers the lifecycle of data, from its collection and usage to its ongoing impact and legacy. It highlights data's dynamic nature and acknowledges its role in preserving cultural narratives and contributing to ongoing Indigenous knowledge systems.
3. **Datasets and Structures:** This focuses on the organization and framework of data. It involves the technical aspects of data management, ensuring that Indigenous perspectives guide how data is categorized, stored, and accessed, maintaining cultural integrity within structural and systemic considerations.
4. **Worldview, Translation, and Interpretation:** This stream ensures that data is interpreted and translated through an Indigenous lens. It underscores the importance of context and cultural nuances, promoting interpretations that resonate with Indigenous worldviews and ensuring that outcomes are meaningful and relevant to Indigenous communities.

Together, these streams provide a holistic approach to research that respects and integrates Indigenous methodologies, offering insights that align with Indigenous worldviews and values.

Four Stream Environmental Scan Design

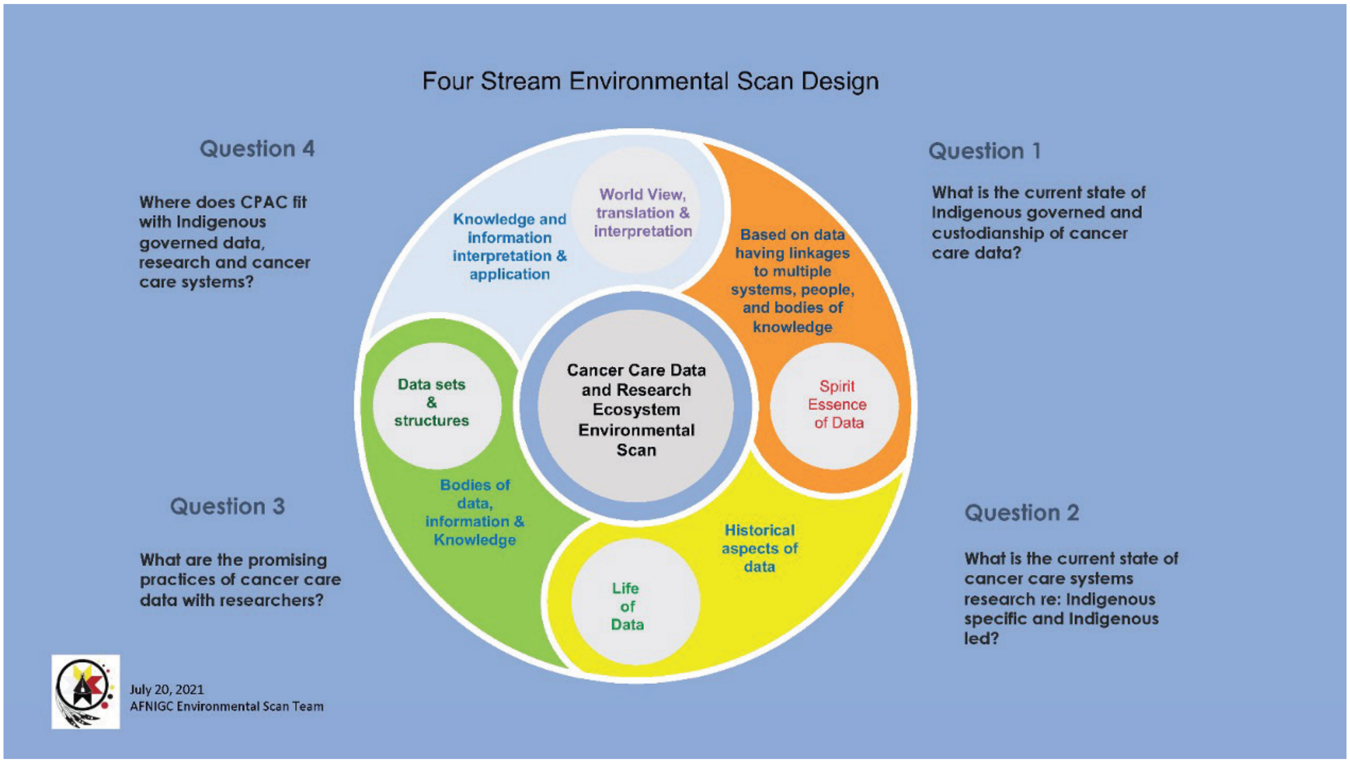


Diagram 02: Four Stream Approach

Aims and Guiding Questions of the Environmental Scan Methodology

The environmental scan aims were structured around the four key questions in Diagram 2, designed to uncover gaps and opportunities within the realm of Indigenous cancer research.

Current State Assessment: This question sought to evaluate the existing landscape of Indigenous-governed data and research systems specific to cancer control. It aimed to identify strengths, weaknesses, and the overall framework in which these systems operated.

Promising Practices Identification: This question focused on uncovering examples of successful cancer control initiatives that are driven by Indigenous researchers and data custodians. By highlighting these practices, the scan can facilitate the sharing of effective strategies and methodologies among Indigenous communities and researchers.

Opportunity Assessment: This question explored potential short-term, medium-term, and long-term opportunities for building partnerships that can strengthen Indigenous-governed research and data systems. It recognized the need for collaborative efforts to enhance the capacity and effectiveness of these systems in addressing cancer control in Indigenous populations.

Informing Implementation: The first aim and fourth question focused on aligning the Canadian Partnership Against Cancer (CPAC) 2022-2027 Business Plan with the needs of partners involved in Indigenous health. It sought to establish a responsive framework that integrates First Nations, Inuit, and Métis (FNIM)-governed research and data systems within the broader health system.

Synthesis and Integration: The second aim was to blend insights gathered from various engagements into a coherent understanding of Indigenous-governed research data systems. It emphasized identifying effective practices in cancer control and data research that are led by Indigenous communities.

Inclusion/Exclusion Criteria

STEP 1
Content Review for Inclusion/Exclusion

Inclusion Criteria:
The review included published literature, dissertations, conference proceedings, case studies, commentaries, reports, guidelines, policy or data-sharing agreements, declarations, position statements, strategies, and action plans written in English.

Documents analyzed through NVivo focused on cancer-related topics (cancer, cancer control, cancer care, cancer data, cancer prevention, cancer screening, and cancer survivorship) and at least one of the following:

- Indigenous-led governance, self-governance, or community leadership
- Data systems, management, frameworks, models, or research design
- Research/data best practices, protocols, principles, and ethical guidelines
- Relationships, collaborations, and consultations with Indigenous scholars, organizations, communities, or individuals
- Data and research enhancement, education, mobilization, and capacity-building
- Data privacy, protection, sharing, and reclamation
- Cultural protocols, practices, and safety

Exclusion Criteria:
Documents were excluded if they did not contain specific actions addressing Indigenous-led data and research governance or:

- Lacked focus on cancer-related topics
- Were published before 2011 (except for key Indigenous documents on data and research governance)
- Did not involve Indigenous data or research with Indigenous populations
- Did not include engagement with Indigenous partners
- Focused on Indigenous populations outside Canada, Australia, New Zealand, or the United States

STEP 2
Content Review for NVivo Analysis

Documents were assessed for inclusion using the following primary questions:

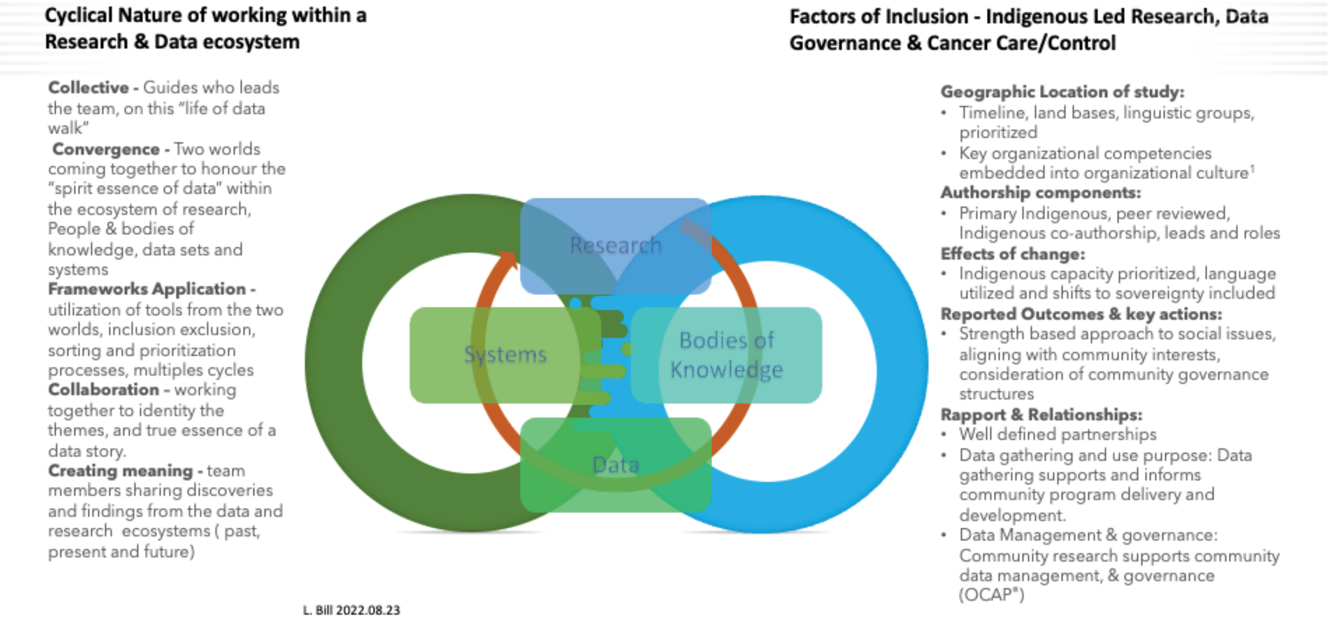
1. Does the document outline principle-based criteria supporting Indigenous-led research and data governance, such as alignment with OCAP®, Principles of Ethical Métis Research, or Respectful & Beneficial Research for all Inuit?
2. Does it specifically focus on cancer-related topics, including cancer control, care, data, prevention, screening, or survivorship?

If a document met these criteria, additional questions were considered:

- What is the study's geographic location, and does it prioritize timeline, land acknowledgment, and linguistic group?
- Does it identify Indigenous primary authorship, peer-reviewed contributions, leadership, or partnerships?
- Does it discuss Indigenous capacity-building, language use, or shifts toward sovereignty?
- Are key outcomes or actions reported, such as alignment with Indigenous community health plans?
- Does it address partnership-building and rapport in research collaborations?
- Is data gathered to inform program delivery and services for Indigenous communities?
- Does it discuss community-led research, data management, or governance?

Additional Indigenous knowledge and theory criteria, based on a four-stream directional model, were applied to deepen the understanding of "Indigenous-led Research Governance in Cancer Control." The graphic below describes these considerations.

Four Directions Philosophical Considerations of Inclusion and Exclusion Criteria



Cyclical Nature of working within a Research & Data ecosystem

Collective - Guides who leads the team, on this "life of data walk"
Convergence - Two worlds coming together to honour the "spirit essence of data" within the ecosystem of research, People & bodies of knowledge, data sets and systems
Frameworks Application - utilization of tools from the two worlds, inclusion exclusion, sorting and prioritization processes, multiples cycles
Collaboration - working together to identity the themes, and true essence of a data story.
Creating meaning - team members sharing discoveries and findings from the data and research ecosystems (past, present and future)

Factors of Inclusion - Indigenous Led Research, Data Governance & Cancer Care/Control

Geographic Location of study:
- Timeline, land bases, linguistic groups, prioritized
- Key organizational competencies embedded into organizational culture[1]

Authorship components:
- Primary Indigenous, peer reviewed, Indigenous co-authorship, leads and roles

Effects of change:
- Indigenous capacity prioritized, language utilized and shifts to sovereignty included

Reported Outcomes & key actions:
- Strength based approach to social issues, aligning with community interests, consideration of community governance structures

Rapport & Relationships:
- Well defined partnerships
- Data gathering and use purpose: Data gathering supports and informs community program delivery and development.
- Data Management & governance: Community research supports community data management, & governance (OCAP®)

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Diagram 03: Inclusion/Exclusion Criteria

Subject Classification and Key Terms

To guide the environmental scan, a structured approach was taken, beginning with the development of a comprehensive search strategy. A search table was created, covering the period from 2010 to the present, with key terms and phrases relevant to the study. An Excel tracking document was developed to log reviewed resources and identify stakeholders for potential engagement through surveys, focus groups, or interviews. The environmental scan activities were defined, including website searches, online document searches, and university library/database searches.

The second phase focused on website and online document searches. Initial broad searches using terms like "Indigenous data systems" were conducted and tracked in Excel. These searches were then refined to ensure greater specificity, helping to identify key stakeholder organizations, relevant frameworks, and potential participants for further engagement.

University library and database searches played a crucial role in gathering targeted information. Searches focused on Indigenous groups, including First Nations, Inuit, and Métis, and key terms related to cancer, data governance, frameworks, policies, and best practices. A review of key organizational resources, including grey literature, was conducted. Additionally, multiple Google searches combined relevant terms to expand the scope of findings. Government and non-government cancer control agencies, as well as Indigenous health organizations, were specifically targeted. Literature searches using PubMed and Web of Science (2010–present) helped identify recent research on Indigenous-led data and research governance in cancer control.

A grant funder website scan was also conducted, covering the years 2011–2021. This included funding bodies from Canada (Canadian Institutes of Health Research), Australia (National Health and Medical Research Council, Cancer Australia, Australian Research Council), New Zealand (Health Research Council New Zealand), and the United States (National Institutes of Health).

Finally, exclusion criteria were applied to ensure relevance. Documents that did not contain specific actions addressing Indigenous-led data and research governance were excluded from the scan. This approach ensured that the findings focused on meaningful contributions to Indigenous-led research and data governance in cancer control.

SEARCH TYPE	KEY TERMS	FOCUS AREAS
Website/Online Literature/ Database Searches	Indigenous, Inuit, Métis, First Nation, Aboriginal, Torres Strait Islander, Māori, Native American, American Indian, Alaskan Native, Aleut, American Native Continental Ancestry Group	Initial search on Indigenous research governance and governance design
Bucket 1 – Governance & Research Agreements	Cancer, cancer research, genetic research, trauma, survivorship, psychosocial aspects	Data governance, research governance, research design, data systems, stewardship, access, and sovereignty
Bucket 2 – Structural	Frameworks, models, policies, agreements, declarations, strategies, action plans	Governance structures and management strategies
Bucket 3 – Data Systems & Sets	Tumour data banks, screening data banks	Types of data and their applications in research
Bucket 4 – Multimedia Data	Focus groups, videos, modules, tutorials, peer-reviewed articles, books, journals, virtual and face-to-face engagement	Multimedia formats for knowledge sharing
Bucket 5 – Cancer & Research	Canada, Australia, US New Zealand	International comparisons and best practices

Table 01: Subject Classification and Key Terms

Knowledge mobilization programs such as Citavi were used to manage large numbers of documents and information. Additionally, this assisted in the development of the Environmental Scan PRISMA as shown below.

Literature Review

1435 articles sorted and assessed for relevance,

1291 were excluded following and inclusion exclusion criteria process

63 articles/studies were qualitatively analyzed for this project

Diagram 05: Literature Review

Literature Review Results

The Literature Review produced the following results:

NAME	DESCRIPTIONS	SOURCES	REFERENCES
Best or Promising Practices	Best/Promising practices; Data/Research governance practices; Data/Research governance recommendations	29	79
Cultural competency components		13	21
Cancer Control	Data/research focuses on Indigenous populations; cancer data; cancer research; cancer-specific; cancer screening; cancer prevention	25	42
Cancer frameworks, principles, agreements, protocols		8	20
First Nations Women's Indigenous Cancer Health		3	5
Psychosocial		14	22
Screening		8	23
Survivorship	How Indigenous populations are living with the burden of Cancer	15	39
Types of Studies	Cancer studies, epidemiology, incidence, surveillance of FNIM	17	29
Data Governance	Data and/or Research governance OR Data and/or Research sovereignty OR Management OR Control. Statements of "Declaration," "Position," "Policy." Research Protocol; Data Sharing Agreements; Governance Strategy or Action Plan; Governance is a priority; Legislation is available to govern collection and use of data.	13	25
Compliance		5	5
Legislation		1	3
Policies		11	19
Privacy		4	4

NAME	DESCRIPTIONS	SOURCES	REFERENCES
Protection		3	4
Quality Controls		7	9
Data Management	Storage/back-up; Mining; Archiving; Life Cycle; Security; Data Management Plans; Best Practice.	11	24
Archiving		1	1
Best Practices		4	10
FNIM Transformation		5	6
Data Management Plans		4	5
Life Cycle		1	1
Mining		4	5
Security		0	0
Storage — Back-up		1	1
Data Narrative	Indigenous perspectives; Elder/Knowledge Holder review of findings; Holistic worldviews are part of analysis; Social/Indigenous determinants are identified.	7	11
Academic vs. Indigenous World Views		6	7
Community Collaboration	Alignment with community priorities; evidence of community co-analysis; Indigenous-led; Indigenous-designed; undertakes or identifies Indigenous protocols; research is community-based.	18	34
Community Narrative	Indigenous perspectives; Elder/Knowledge holder review of findings; holistic world views are part of the analysis; social/Indigenous determinants are identified.	9	16
Lived Experience		13	22
FNIM & Data		7	10
Indigenous language engagement		8	8

NAME	DESCRIPTIONS	SOURCES	REFERENCES
Worldview & spirituality	Researchers who acknowledge the Indigenous worldview and spirituality of the people and land.	11	22
History of Data		6	7
Equity		13	18
Humanitarian		3	4
Inequities		24	48
Data Research & Research Data	Identify research question; Research objective achieved/not achieved; Evidence supports the outcomes; New evidence/ information needs are identified to achieve change.	13	27
Indigenous cancer data collection		21	37
Infrastructures		8	12
Indigenous community organization		1	1
Innovation		4	5
Intersections with international sectors		14	25
Indigenous worldview cultural cancer approaches		8	16
Data Sharing	Indigenous-specific principles - OCAP®, Inuit Research Ethics, Metis Research Ethics; Data ownership; Data control; Data access; Data possession; Data storage.	6	7
Copyrights		1	1
Data Sovereignty		11	17
Data-sharing agreements, protocols, principles		4	4
Indigenous Cancer frameworks		2	2
Intellectual Property		0	0

NAME	DESCRIPTIONS	SOURCES	REFERENCES
OCAP® Alignment	Indigenous-specific principles - OCAP®, Inuit research ethics, Metis research ethics; data ownership; data control; data access; data possession; data storage.	7	9
Proprietary		2	2
Data Systems	Existing Data Sets, Data stewardship, Data access, Data Storage + Types of Data (tumour banks, screening datasets); Data linkages are required; Indigenous identifiers are used; Bio-samples are collected or used.	9	19
Applications		3	5
Inputs-Outputs		3	3
Types and Access by FNIM	Types and access by FNIM; Inputs-Outputs: Applications.	2	2
Ethical Considerations	Ethical space; ethical boards; research review committees.	6	15
Great Quotes		11	32
Methodologies		20	50
Integrated Methodologies		11	16
Research protocols for community engagement	Identifying strategies that have been workshopped using lived knowledge of how to engage at the community level.	7	14
Indigenous protocols		2	3
Opportunities	Opportunities to support Indigenous-led data/research governance; what/who can inform change; who are potential partners; solutions to barriers for Indigenous-led governance or change are identified; facilitators for Indigenous data sovereignty are identified; next steps in Indigenous-led data /research governance.	18	42
Partnerships		2	3
Potential Partnerships		1	2
Other	Miscellaneous items of interest that don't seem to fit the existing nodes - to be parsed later.	7	8
Research Principles	Research principles, guidelines, etc.	2	15

NAME	DESCRIPTIONS	SOURCES	REFERENCES
Study Design	Qualitative; quantitative; mixed methods; clinical trial; methodologies-RTC; Indigenous methodologies; community-based methodologies.	10	21
Threats of Gaps	Threats/gaps to Indigenous data and research governance; challenges to Indigenous governance.	19	42

KNOWLEDGE HOLDER/ ELDER ENGAGEMENT

All Indigenous research undertaken by Alberta FNIGC is initiated by prayer, song, protocol, ceremony, and the actions of reciprocity. Alberta FNIGC positions the Knowledge Holders to guide the process of spirit-led data access. This practice is always initiated through protocol and ceremony. Alberta FNGIC upholds ancestral ways of collecting and ceremonially accessing sacred knowledge systems and datasets, such as the approach used for medicinal plant harvesting knowledge.

Alberta FNIGC maintains relationships with a core group of Elders/Knowledge Holders from each Treaty region of Alberta, all of whom were invited to participate in the Engagement session. Additional Elders/Knowledge Holders from across the West were also asked to participate. There were 15 who attended the in-person session, some from as far away as British Columbia and the Northwest Territories.

During the three-day session, participants were asked to focus on the following thoughts:

- What does Indigenous-led research governance look like to you?
- What are your perspectives on indicators and defined measures of value in cancer control?
- What traditional oral transmission components are essential for oncology care provider training and education and how can these be implemented?

Most participants also chose to share their cancer journeys - be it their own, that of someone close to them, or at a community level.

There were note-takers in the room, and the sessions were recorded for verbatim transcription.

Knowledge Holder Engagement Results

A distinct commonality arose out of the Knowledge Holders Environmental Scan Engagement. Each one was a Cancer survivor, and in their own languages, they were precise in their guidance and direction. The following key themes were emphasized:

- Sustain the spiritual nature of oral traditions.
- Non-Indigenous researchers are challenged in how Indigenous people are with the universe.
- Western medicine is confronted by ancient knowledge.
- Maintain intergenerational ancestral knowledge transfer.
- Indigenous people have been doctors all along, using traditional and spiritual pathways and processes.
- Establish international linkages with other Indigenous groups.
- Oncology regulations deny family, yet family is medicine.
- Work from the similarities between Indigenous and Western health and medicine.
- Oral tradition and living knowledge are in the stories.
- Support ancestral research and traditional data such as medicinal plant knowledge.
- The Spirit of knowledge is found in oral history.
- Indigenous governance practices come directly from the oral systems.
- Smudging creates a safe space to speak and follow protocol.
- Use the circle as a venue; Elders are required to sit in those circles; the Elder is our oral policy.
- There are differences between the Indigenous oral system and Western written knowledge.
- The oral system validates and authenticates.
- Reciprocity is central.
- Collective knowledge building (e.g., Elders talk builds human capacity).
- Oral tradition is at least as valid as written.
- Living philosophies of governance are perfected through ceremony.

FOCUS GROUPS AND INTERVIEWS

Engagement sessions used an open dialogue process following established processes for respectful engagement, such as an opening with prayer followed by participant introductions. These processes allowed each participant to situate themselves in Indigenous research and data, enabling everyone to drive the conversation given the specific populations and contexts from which they work with Indigenous people.

Focus Group/Interview activities included a set of engagements based on the findings and thematic outcomes of the Environmental Scan/Literature Review. The purpose of these activities was to engage key stakeholders with a vested interest in Indigenous research and data governance (from within the context of cancer control) with the aim of identifying gaps/threats, successes, and challenges in implementing Indigenous-governed research and data system frameworks and models.

This included identifying principles, best/promising practices, ongoing research to develop and implement Indigenous research and data governance, potential solutions, and opportunities for the Partnership to address the cancer burden in Indigenous populations. Opportunities may include collaborative partnerships designed to create parameters for data collection, including standardized metrics in Indigenous cancer control.

Using a multi-pronged approach to engagement, the Project Team conducted a series of knowledge and information-gathering sessions with research leaders, organizations, and stakeholders in First Nations research and data systems. Described in the 'Key Stakeholder Engagement Strategies' section below, activities include an online survey, focus groups, interviews, and presentations of engagement outcomes with the Partnership's Advisories for the purposes of dialogue on current and desired states of Indigenous-governed research and data systems.

Key stakeholder engagement strategies:
We reviewed the key stakeholder survey by developing interview questions and reviewed the survey participant groups for gaps, research and data governance systems, best practices, etc., with National Key Organizations, the Partnership 29 Initiatives, and others.

The engagement map below illustrates the complexity of the many levels of engagement undertaken for this project. The goal was to explore all areas of interest to provide a well-rounded and extensive perspective of Indigenous-led data and research governance in cancer control.

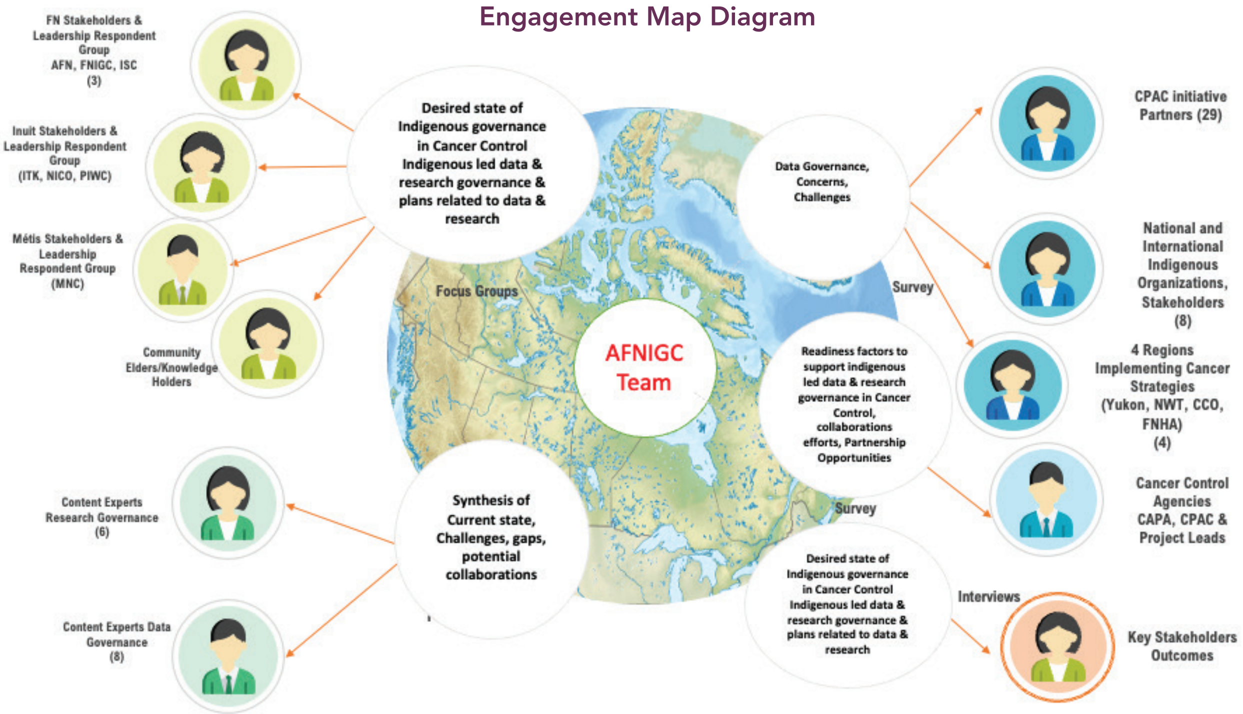


Diagram 06: Engagement Map

Focus Groups and Interview Results

Below is a summary of thematic responses from participants during the engagement sessions, which included six focus groups (two International, one research content expert, one First Nations, one Métis, and one Inuit) and four key stakeholder interviews. It is important to note that questions for focus group participants were chosen depending on the group and focus of the session.

For example, questions asked of Indigenous research content experts were necessarily different from those asked of Indigenous data experts to gain a clear picture of how Indigenous-led governance has evolved in recent years and the impacts on both Indigenous research and Indigenous data, while the same or consistent questions were asked of critical stakeholders during those interviews. Overall, 13 topics emerged as specific areas of importance spoken to by the participants, and many diverse responses were given from within the contexts of the Indigenous group, organization, and individual.

Summary Responses

What kinds of Indigenous principles are being applied to the research process?

International Focus Group responses:
Incorporating Indigenous principles in the genomic space, which is *"a heavily problematic space...and one of the areas that needs such strong Indigenous influence to ensure that the promise of all the benefits that are supposed to come from that approach to medicine will reach Indigenous communities and not actually widen equity gaps."*

In the cancer space specifically, it is about building the infrastructure of what that might look like. *"We have a Māori co-leader helping to incorporate Indigenous principles and our non-Māori colleagues are doing a lot of the technical bioinformatic infrastructure and genomic sequencing. They're just focusing on those technical issues and allowing us to shake the infrastructure and how it's going to be useful and safe and appropriate for Māori so that Māori can engage with it in a safe way."*

Challenges included the idea that the genomic space still sits in the research space with the goal to move it into the clinic and clinical engagement that would exist in the context of a patient. To build that infrastructure with quantitative data, participatory active learning, and participation or an active learning approach is required where participants in the study are not only getting the genome sequencing but there is a way of understanding their experiences of the entire process in a more reiterative process.

International partners also spoke about Australia's INTER Partner Indigenous-led Data and Research Governance and the work involving constant tension between Indigenous worldviews and perspectives while working within a Westernized framework. This included funders' requirements and thinking through how to be grounded in Indigenous ways of doing business. *"What I found the most challenging is that it's just this like complete refusal to see us or to see that we are worth being counted and so it's really easy to do nothing when they don't know how big the problem is because they're not counting it."*

Another noted challenge was how industry impacts data, including tobacco. So, while researchers must be able to talk about the problem, solutions also need to advocate from many different levels and give the General Practitioners, pathology sector, and the government ways in which they can see their role in providing data sources and reporting on key statistics that can make a difference for Indigenous people.

Further, true partnerships with Indigenous people must include strong and equitable Indigenous leadership that enables the voices of Indigenous people to be heard to understand our journey and from where we have come. This includes the importance of why Indigenous status is critical to inclusivity about what is happening at an individual community level, but also the Indigenous group level. This may also be considered respecting Indigenous priorities in data and research.

What promising practices have emerged or been applied to the research?

International colleagues reported the following promising practices:

- Reporting the equity gap—absolute and relative equity gap.
- The census collects a standardized ethnicity question, which is our denominator.
- Equity-focused reporting, which is recording the Indigenous results first and then recording the equity gap between the Indigenous and the majority white population.
- Promoting utility-based governance practice—Indigenous governance, either Indigenous-led or in partnership.
- Accurate cancer incidents and mortality data through cancer registry and IHS linkage.
- Engage Indigenous people around the most appropriate approach and what they need to consider.
- A new and emerging opportunity exists in Indigenous data governance and data sovereignty for lung cancer screening programs.

Canadian key stakeholder responses:

- A key goal is to make sure that someone can access treatment so that they can be tested for cancer and catch cancer early.
- A "Safe Spaces" program outcome is to provide a map of places with ratings to navigate and find a safe space with positive ratings for Indigenous people to seek care.
- Health navigators and the need to document all these experiences to identify issues within the healthcare system.
- Moving more towards data-driven decision-making and collecting that type of data, e.g., collecting and archiving the urban experience, with their distinctions-based approach.
- A client-centered approach to collecting disaggregated data that is, of course, consensual.
- National Association of Friendship Centres (NAFC) collecting very high-quality data and working with them to respect their data sovereignty. At the same time, we enter relationships with them that can leverage data for designing programs or measurable outputs.
- Working across our memberships and from different levels of center membership.
- Pulling leadership from local, regional, and national levels to get as many perspectives as possible and coming together to discuss these issues, e.g., ensuring we bring our data together, collecting the same data and using the same standards.
- Asking these different levels of governance, "What does data sovereignty look like?"
- Working to ensure different groups can be data owners and asking if that involves technology and training.
- Committing to strategic plans and staying on target in terms of timelines.
- Using standard cancer data, analysis, and outcomes and keeping up-to-date data to see what and when clinical practices change and when there are changes in the system.
- Needing Indigenous leadership at the highest level of the institutions that have the authority to grant access to data.

Are there any specific Indigenous-governed data sources or research frameworks that have been developed that could be identified, specifically, as Indigenous?

Minimal responses were provided on this topic – one during an international focus group and one during a key stakeholder interview. The international respondent stated: [New Zealand has two frameworks] Te Mana Raraunga, which is the Indigenous Data Sovereignty Framework and He Pikinga Waiora, which is based on implementation science (HPWcommunity.com).

A Canadian key stakeholder stated: Frameworks were talked about in terms of their value as part of a national data strategy with standards and definitions, which appears as a high-level business glossary where terms are defined, but at a technical level, database applications appear as data dictionaries. It was noted that this approach can enable comparability across communities, nations and even countries at some point. Also, flexibility was reported to be key in having standards of what we collect, why we are collecting it, what we are trying to do, and how we want to share our stories.

What are the challenges and opportunities that arise out of your research work?

Respondents from all engagement sessions noted multiple challenges and future opportunities in their research. Themes from international participants included:

- Undercounts remain low at 20 to 30% of all Māori being misclassified as New Zealand European; it is a simple fix of providing a national mandatory online training course for the data collectors.
- Matching databases up with hospital and primary care databases is taking way too long due to challenges around silos - having a more holistic kind of approach could recognize that people have lives and that people don't just have one [health issue] at a time.
- We have not incorporated Indigenous treatments into [healthcare], especially into cancer care and need to be flexible in using both qualitative and quantitative expertise as part of the research team – New Zealand is trialing a program for 'Gold Standard Indigenous Cancer Care.'
- There is an institutional struggle to figure out how to capture ethnicity data and understanding why you are collecting that data, what it is that you're trying to use it for, and thinking out the processes of what to do with the information, etc.
- Graduating researchers to a point where they think more about what they do with their data and concluding that there is a path where you clearly need to employ an Indigenous researcher on your team to bring that lens.
- Involving all parties to think about including screening along with other services. We know that screening is difficult for Indigenous populations for a variety of reasons, and screening for everybody has been very difficult with COVID-19, but it can save a lot of lives with colonoscopies, mammograms, pap smears, etc.
- Less than 1% of the population is American Indian, Alaska Native, and Hawaiian, and when we do analyses of morbidity, they can't separate out for us, so it's difficult to find out the epidemiology.
- Problems with small numbers cause us to aggregate a bunch of states together to report AI/AN cancer incidence rates and count without breaking any confidentiality.
- Different data for cancer incidence sits in a different place than screening data.
- Too few [Indigenous] researchers pose a lack of insight around specific data or data governance with a lack of accountability by governments, which then falls to the

responsibility of Indigenous researchers or practitioners, as governments see this as an Indigenous problem, but that we can't literally do it all.
- Indigenous clinical cancer researchers are needed, and we often get called on for lots of different things, so organizations must take some responsibility.
- Opportunities include working with interested groups to help move our agenda forward, e.g., a national bowel cancer screening project for Indigenous people in the same department as cervical screening, using the same sort of Indigenous co-design and engagement.
- Changing institutional visions leaves responsibilities largely on individuals, and then when the individual moves on, you lose ground.
- How research gaps are identified and different ways of doing that through dialogue with [Indigenous] groups.

Thematic responses from Canadian participants are as follows:
- Indigenous organizations' capacity and institutional lack of capacity for collecting data and designing culturally safe and strengths-based standards.
- There is a risk with institutions setting the standards as it perpetuates the colonial harms in the way data collection systems are designed, so understanding that they are not the experts in collecting data safely and designing those questions.
- Current work on strengths-based indicator development and cultural safety measurement is an opportunity for sharing best practices between institutions and Indigenous people.
- Working to create a policy that respects data sovereignty, but it could just as easily be creating a data quality policy to say don't use this data and don't share it because it's so terrible and it's not useful.
- Need to go far beyond only respecting OCAP® and redesigning the systems to better capture data that truly identifies health and wellness for Indigenous communities.
- Dealing with Canada's national statistical agency, Statistics Canada, and the Statistics Act still limits what we can do, and, in a sense, can erase policy that respects Indigenous data sovereignty.
- Partnerships with us as a national collaborating center because our mandate is knowledge dissemination, and there could be a role for us in knowledge translation with a broad reach across the country, e.g., transportation issues from an equity perspective and a reality perspective of how we get Indigenous people better access.
- Partnership opportunities regarding Northern challenges are similar but different, so there are piggy-backing opportunities in terms of advocating and lobbying for change by using allies to get the change happening.
- The approach or the how to interview the Southern Inuit is the same in terms of methodology and has the same essence for interviewing Inuit in the North, but the challenge is being able to locate a large enough group who will come together and are willing and able to converse about cancer.
- Federal responsibility for First Nations and Métis is not the same for Inuit, so Inuit do not pursue those dollars for research, and it's important to know what and how to access these dollars.
- A barrier to any research at the community level is navigating funding because it's confusing, and there are a lot of corporate research dollars that could be accessed but never get publicized and reach the community level.
- Inuit land claim agreements have the power to negotiate Inuit impact and benefits agreements to include funding from industry to support any research that would lead to the discovery of issues and solutions and potential impacts on Inuit people, including health, e.g., H-Pylori and stomach cancer in the North.
- The National Association of Friendship Centres (NAFC) "Safe Spaces" program is looking to expand nationally, and there is an opportunity to document urban Indigenous experiences with the healthcare system, including seeking cancer care to identify needed changes, including the opportunity to explore navigating the landscape and finding those places that are safe for urban Indigenous people to access healthcare.
- Addressing National Inquiry into Missing and Murdered Indigenous Women and Girls and 2S+ 'Calls to Action' including improved data quality and articulating what makes an individual distinct so that you capture their experience, as well as asking for self-identification that includes a gender lens as well as the diversity of what it means to be in that gender lens.
- Location of data to know where Indigenous people

are located, where their Homeland territories are and disaggregated data that captures intersectionality.

- Developing suitable data categories, e.g., developing data or data categories through a gendered lens that allows for multiple answers so an individual does not have to choose one identity, even though the individual may possess an identity with multiple facets – which, at a basic level, could be somebody who has both First Nation and Métis identity.
- Working with seniors - elders who might have fears around accessing healthcare to dispel myths around issues such as access, e.g., the Friendship Centre movement is identifying a 'Trailblazer Friendship Centre' with a beneficial program that documents detailed experiences and/or best practices for other centers to use and benefit from learnings to leverage regional and national level uptake.
- Ensuring national expansion is data-driven by learning from the best practices across the country to inform programs and program design and program outcomes and using data to learn about what is happening on the ground, what services are being offered, what services are effective, and who is coming to access service.
- There is a push toward data because there is a burden to it, and it can be seen to get in the way of service delivery, so the opportunity is to reframe data as a service to let us know what supports are needed and how we can get those supports and target those supports to have the most impact.
- Creating champions is important to bring communities on board in research and data work; for example, people collecting data need to be the champions to talk about the benefits of the research and data and make those benefits visible to the community.
- Communities should be able to point towards a [project] and talk about why the initiative took place and what happened, so the design needs to be rooted in the community and community outcomes.
- There is a need to identify persistent issues, such as support required for communities in research and data for developing a data strategy and then engagement with various stakeholders, whether it is the board, our Senate of Elders, or the Youth Council.
- NAFC forum recommendations include a Health Navigator at each Friendship Centre who is an expert in the healthcare system and able to talk to [Indigenous] people in a way that engenders trust and supports self-care.
- There is a potential opportunity to learn from a pilot project that's working on database applications for Friendship Centres, by Friendship Centres, leading to creating a pathway where Friendship Centres can share their experiences.
- Data can be dated, and stories or opinions that are shared or surveys are not any less valuable and need to be treated with respect, and we need to steward it properly and adhere to the OCAP® principles.
- Genomics is an exploding field, and as an Indigenous [researcher/health practitioner] in cancer care, it is exploding in terms of its positive impact and applies across multiple disciplines and pretty much every discipline in medicine. However, in the cancer world, we need to grow our understanding of the disease of cancer, the risks of cancer, how to predict risk, how to assist with diagnosis, how it's created new treatment plans, and has a massive impact on outcomes.
- We need to face genomics research if we are going to go into that space where, historically, there have been many mistakes made, e.g., significant egregious examples of genomic research gone wrong.
- Genomic research has additional risks that we have to recognize and have to talk about and explain what it means, and how we are going to protect blood samples and genomic data.
- Genomics needs to be treated with the utmost respect, and it needs to be governed by Indigenous people for Indigenous people and with Indigenous people building on governance discussions and dialogues.

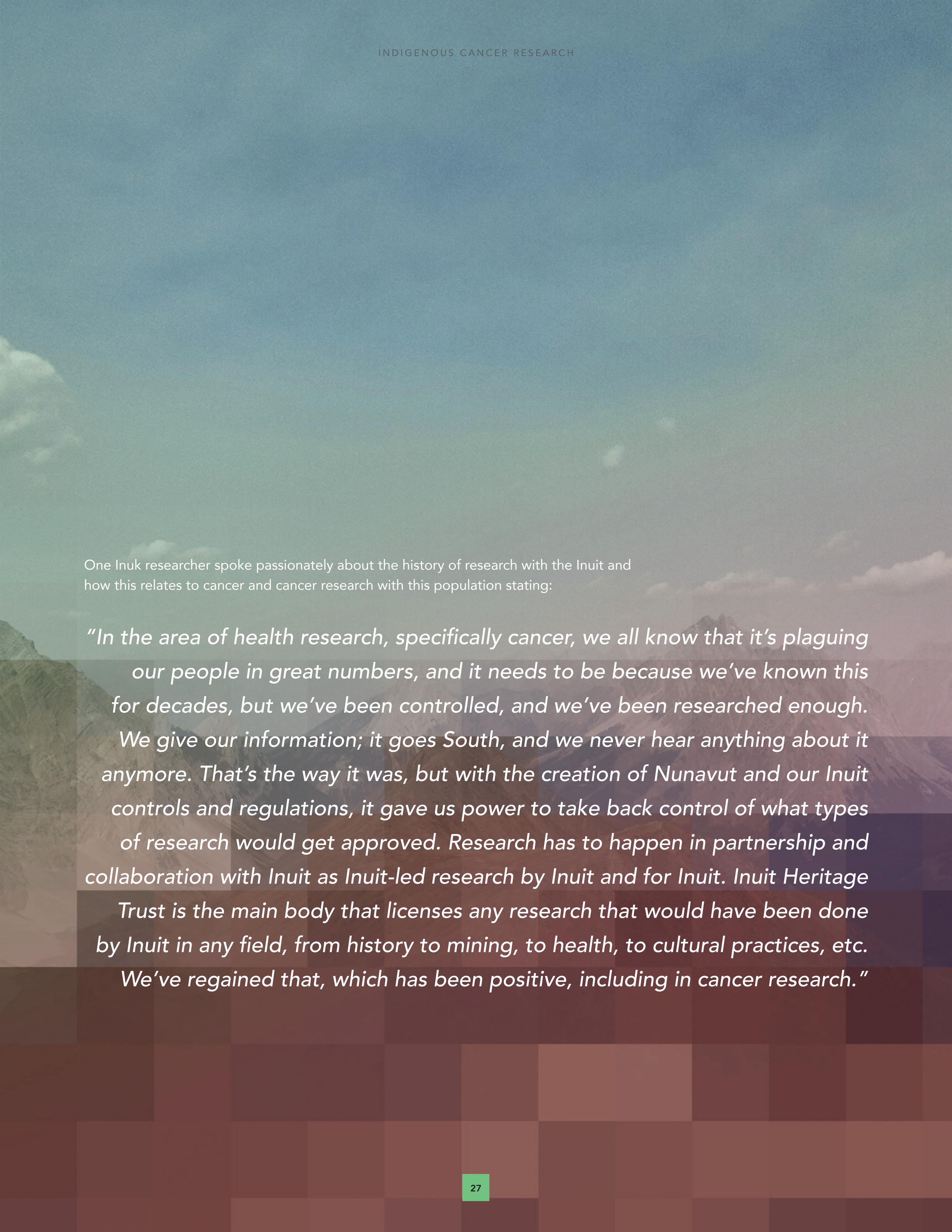
Regarding the significance of genomic research and data and the need for Indigenous-led governance, one key stakeholder stated: *"There is power in DNA that can have a significant impact on what was the DNA of your mother or your father or your great grandparents or your great grandchildren to come. There's an essence of community. It's the essence of family and it needs to be respected for what it is and what it could mean and what communities and what Indigenous people want it to mean."*

What significant changes have you seen in your career with Indigenous-led research?

Indigenous research experts and stakeholder interview participants spoke about changes in Indigenous-led research.

Inuit participants responded to this question extensively. Responses are provided below.

- [Indigenous research] went from there being no Indigenous health researchers to quite a number developed over the years and through budget provided by the Canadian Institutes of Health Research, which took a few years to get and the idea of creating an Indigenous research institute to having an actual Institute.
- At the same time, we may be standing still in a way regarding the difficulty with a particular government that is in place and access to provincial and federal resources, making it difficult to engage the community long-term because your work with the community moves along for an extended period and then crashes when governments slash funding and all the research capacity built basically disappears.
- Back in the days as an Indigenous researcher doing biomedical research, it was my aim to get Indigenous students into biomedical research, and we've made a lot of progress toward two or three hundred Indigenous health researchers in Canada now with advanced degrees.
- There's been progress in general that [could be considered] a reconciliation through the realization that resources need to be shared, but progress is slow and comes and goes, dependent on the political movements of the day.
- There's been tremendous progress made toward Indigenous-led research with allyship to support Indigenous researchers, and CIHR-IIPH has developed many Indigenous researchers to undertake various research studies both in academic institutions and in community-based organizations.
- Research governance should be highlighted for the very innovative work that started with the Canadian Aids Network, for example, and the Canadian Aboriginal AIDS Network where they became holders of funding from CIHR and now we have other FNIM organizations that apply for and hold monies, which is a significant change that's occurred.
- A challenge moving forward is that we're growing more researchers, but the specifics of the various institutes need researchers focused on specific areas, including cancer.
- We must give due consideration to the large number of Indigenous researchers focused on the social and cultural aspects of health services, but we may not have representation in the clinical streams and in the biological sciences.
- Investments are required to build those data repositories to inform communicable diseases or non-communicable diseases, and the health services concerning those various conditions, but this needs to come from a focus on the upstream approaches in terms of wellness, social determinants of health, etc.,
- Funding percentages that have been achieved are by no means at a level where it's addressing equity, and more needs to be allocated to evolving a multitude of different types of research networks to avoid over-taxing our Indigenous networks that exist in each of the provincial and territorial areas, such as the NEIHR Centers and we need to grow our research networks for specific issues, [including cancer].
- One challenge is our experience in cancer has shown that there are not many Indigenous cancer researchers, which results in difficulty in acquiring funding to do Indigenous cancer research.
- Access to secondary or administrative data is still very problematic and is dictated by provincial types of organizations, which are not housed within Indigenous organizations.
- A lot of work and huge investments are critical for research organizations like the Institute for Clinical Evaluative Sciences (ICES) to roll data together in which they're using Indigenous identifiers, but they are running into the problem of what an Indigenous identifier is, who defines the Indigenous identifier, and are there agreements across various groups within that group on the identifier?
- Investments are needed to create an Indigenous task force that works alongside other task forces, including prevention, which includes cancers and works to identify the data that is being abstracted from the various databases.



One Inuk researcher spoke passionately about the history of research with the Inuit and how this relates to cancer and cancer research with this population stating:

> *"In the area of health research, specifically cancer, we all know that it's plaguing our people in great numbers, and it needs to be because we've known this for decades, but we've been controlled, and we've been researched enough. We give our information; it goes South, and we never hear anything about it anymore. That's the way it was, but with the creation of Nunavut and our Inuit controls and regulations, it gave us power to take back control of what types of research would get approved. Research has to happen in partnership and collaboration with Inuit as Inuit-led research by Inuit and for Inuit. Inuit Heritage Trust is the main body that licenses any research that would have been done by Inuit in any field, from history to mining, to health, to cultural practices, etc. We've regained that, which has been positive, including in cancer research."*

- The Truth and Reconciliation Commission has laid a lot of groundwork for nation-to-nation relationships to be more fertile.
- Health research policy work by Indigenous scholars has brought forward the amount of racism that exists in healthcare systems and should lead everyone to ask themselves what kinds of policy change and health system changes are required to address Indigenous health inequities because of colonial experience and how we need to educate systems to support change.
- Cultural safety and anti-Indigenous racism training at the point of care is needed to provide healthcare practitioners with skills to support Indigenous patients, families, and communities.
- Evidence from diverse knowledge systems is different, and you need to look at these knowledge systems to see whether the two systems talk to each other to find an interface where they can communicate and learn from one another.
- Iqaluit Health Research Center, located in Iqaluit, focuses solely on Inuit health research within Nunavut to develop programs based on research, including how we can support the health and well-being of all Nunavut who must leave the territory to come down south for cancer care.
- Inuit researchers are needed to educate researchers about everything from methodology to how Inuit need to be involved in everything and how to approach research with community elders.
- Inuit researchers who speak our language are needed, plus the understanding that we are all related and our families are connected to engage Inuit in research and open the door to being involved in the research, which includes patience with the elders, getting out the proper information, asking for their guidance and ownership over the research and what is going to happen in the research.
- Engaging Inuit in research comes down to the methodology, putting people at ease and giving them some ownership.
- It's crucial to include Inuit people, mainly women, who have cancer and moved south to Edmonton because there are no healthcare and services in Nunavut in research, so we can hear if they're getting better treatment or how they are doing on their path or cancer journey.
- There is a huge gap related to how to interpret Inuit data and how to support Inuit to put forward recommendations for health and wellness because using an Indigenous (Inuit) research methodology may only be accepted at the university as long as a Western method is used as well and as long as the data gathered would be presented in a Western format and so Inuit research is not then analyzed to articulate how Inuit look at a situation differently from what Western academics and people who are data-driven do and how they interpret the findings.
- How Inuit look at wellness and illness and how we rate success is completely different with two different worldviews that must reconcile and produce two different interpretations [of the research and data].
- One challenge is that too often, research is focused on Northern Inuit, but there's a third of us that live in the South, and we often become this invisible population, and there's this dynamic between North and South which neglects Inuit in the South in any kind of research.

How have changes in Indigenous-led research influenced the design of research by researchers, organizations, and communities?

Indigenous research content experts and key stakeholder interview participants provided a great amount of feedback on this topic. Responses are summarized here.

- Community partners are looking to do research that can provide scientific knowledge [required and understood] in government circles to expand and support [program sustainability] with an approach to apply for grants and share funding, but this is not widespread, and programs like the CIHR-NEIHR are still needed to help these kinds of partnerships move forward.
- The strategy for patient-oriented research (SPOR) within each province is largely made of provincial government agencies that hold data for academics and patient partners in general, but funding is needed for provincial Indigenous organizations to take part in research [from a place of Indigenous] governance.
- Research Governance in the context of cancer research is becoming a very important topic as it affects FNIM peoples as much as diabetes or kidney disease, and you need not only Indigenous governance over primary data but also over secondary data. However, how we link most of the cancer data and probably most other kinds of data is held by the government agencies, so we need to involve Partners for Engagement and Knowledge Exchange (PEKE) to lead that governance.
- Pre-research funding is needed to help develop grants in the first place to support Indigenous participation and using an approach to simply say for every research project that comes in, unless you fund a body that can go out as a pre-research project to communities and ask questions about interest in the research, then, sorry we have limited capacity, and you can't allow the systems to rob you of all your capacity; therefore the research question itself is one way that changes in Indigenous-led research has influenced the design of research by researchers, organizations and communities.
- Underlying infrastructure resources are not being shared by universities, and the ethics requirements of many institutes are not Indigenous, so a lot of researchers find a way to tick off the boxes without Indigenous participation, which is not research-driven by and supported by the community because there is little to no Indigenous voice in the research.
- Addressing continuity of infrastructure, including the limitations of academia and community organizations, is needed to have a strong Indigenous presence in research, including ongoing engagement processes as communities evolve and change because you may lose capacity and end up starting from the beginning again.
- As a Métis researcher in an [Indigenous] organization, it is my job to provide them with the kind of knowledge needed to make policy decisions, but what's happening is that organizations are picking out individuals to sit on committees for issues like this, which provides a single perspective; whereas you need an overall governance perspective of [FNIM] health needs that can inform what you're doing, not only in research, but health admin and clinical work as well, but that still does not connect me to the policy if you don't have Indigenous governance systems sending that information up to governments and there's no infrastructure in Canada for that to happen.
- Métis should drive Métis research from across the country, so there needs to be the collective ability to look at what our big issue questions are that need to be answered to result in a change in health status.
- Formalized commitments by governments that consider readiness are needed to come to agreements that include funding regarding upstream and downstream [research impacts] based on engagement to nurture an understanding of the importance of Indigenous data governance.
- Some things have remained the same, and when [the Centre] was proposed, we started to talk with Indigenous public health people who were working in the field across the country and to non-Indigenous people who were doing Indigenous public health research, and we brought them together and asked them, "how should we govern ourselves? What should we work on?" That gave us our principles and topic areas to work in, and then we formed a national advisory committee and a strategic plan, which is governance.

- When we started, we certainly didn't have all the social-political contexts because it didn't exist in the world of cancer, cancer research, and cancer in the community. What is the community really facing? What are the challenges for them? And then, what are the big topic areas that people are working on and researching? Is there a marriage between the two, or should some of that work be informed by Indigenous views and Indigenous ideas?
- I still draw on the Royal Commission on Aboriginal Peoples (RCAP) when I look at topics, and it's important to stay current with the contexts in which you are working by budgeting and planning for emerging priorities in strategic plans – I call this a bridging priority so that I can be responsive to Indigenous people and communities.
- Research involving Indigenous peoples or communities needs to, at least from the very beginning, be Indigenous-led, and increasing efforts are required to be empowered in a way where we can start to ask questions that we couldn't or didn't have a voice to before.
- When it comes to Indigenous-led research and the concept of time - is it measured in minutes, seconds, days, weeks, months, or years? And tools such as a Gantt chart should be measured more by what you're hoping to achieve rather than being focused on time, and even granting agencies are being forced to understand this because the entire research world came to a halt [with the pandemic], and then they had to listen.
- At NAFC, we have policy workers and researchers, and part of our work is to do our own research that can include specific topics around cancer or healthcare with a part of that initiative being connecting our policy and our researchers to the data being collected.
- It's important to have conversations about leveraging data in a respectful way with the people who are collecting data to develop data findings that can be used at the local level for advocacy, for answering questions and/or strategic questions, or for financial compensation to build more capacity and connections between policy research and the data collection.
- Collecting disaggregated data can be very burdensome because you're collecting data as a service, where for every service, you're collecting information about clients who come in; however, having each Centre collect that data is exciting because it would really shine a light on the urban Indigenous experience.

One Indigenous researcher spoke about the flipside of change and how Indigenous-led research influenced the understanding of non-Indigenous researchers, including granting agencies, by stating:

"It took a pandemic... for granting agencies to stop and understand that there are more important things than deadlines and timelines or best estimates of when you think something will be done. Suddenly, research came to a halt, and that led to basic scientists being impacted when universities shut down and no one was allowed on campus... and the research labs stopped, and you couldn't get on a plane, and all of the big research gatherings didn't happen. While granting agencies weren't overly forthcoming with extra money, that is never what Indigenous researchers were asking for when it came to Indigenous-led research, but instead, we have asked for more time to do more engagement and time for the communities to be ready for this process, and we need the time because of [events in the community] or [seasons of the year] and non-Indigenous researchers were certainly not talking about these challenges and the need for time."

What influences or movements in Indigenous health research policy, specifically, have you noted?

- In Manitoba, Cancer Care developed a Métis population database, which included 90,000 Métis and enabled a cancer prevalence study that set up an innovative data-sharing agreement process with specific protocols on how the data would move with Métis as the first signatory and a security system in terms of community security and privacy.
- Policies need to be in place to secure funding over the long term, and we must be careful in the future as there needs to be stable funding that can be rolled across fiscal lines, maybe in five-year windows.
- I found I could not do community-based Métis research out of a university office, so I moved my whole research program into the community and the research itself is only one small part of what needs to be done, while knowledge translation and community engagement are the bigger part.
- CIHR-IAPH created the construct of knowledge translation that then moved it forward to be worked to become what it is today.
- It's very simple - if the people don't ask the question, then they don't want the answer, and if you're not in the community, and your research is not being led by what your Métis governing body has in policy and what their needs are to be able to move that policy and move access to funding health needs, then you don't have that connection.
- You also need to be a part of figuring out answers by analyzing what that data is saying, and that's when things start to happen at the community level - it's their data and the Métis need to analyze the data so that it's interpreted according to Métis policy needs and so research needs to be more than space in the academy, it's about a whole infrastructure that allows the organization to compete for CIHR and public health funds from all kinds of different sources of data that are used to answer the questions being asked by the Métis.
- What I see is an evolution of structures and where it really needs to go with some progress at CIHR that allows for direct payments to Indigenous organizations on some of their grants, but the majority are still held by non-Indigenous academics, mostly senior academics at our major institutions or universities.
- Individual First Nations and Métis communities have very few resources, and probably Métis Nation Settlements (MNS) have even less, so they would like to be partners, and they would like to work on research projects, but they don't have the human resources needed, and we have realized that a lot of other people have devoted line-item budgets in our latest grants for them to take part, but it's still not adequate.
- Universities...have made a lot of statements about reconciliation and Indigenization, yet the real crux of the matter is that universities are not sharing resources, and they receive about 20% of the entire CIHR institute budgets over and above what's awarded in the form of indirect costs to support researchers and their administration.
- Policy-directed research is important, and who gets to interpret the policy is important, so there needs to be that space in research, and FNIM organizations need to be part of that, e.g., we have tried to get CIHR to do an equity approach to funding, which would have been more than 4.6% of the budget and we shouldn't give up on the idea of equity where the budget should be closer to 10%, not 5%.
- There is a need to invest in health and health policies research from a policy perspective, and money should be allocated to be able to research both within our academic institution and within our provincial and federal spaces that are distinctions-based with a First Nations and a Métis and an Inuit space and not a pan-Indigenous approach where everyone sits in the same space.

- To drive policy, we have to have policy organizations adequately funded as well as researchers to academically generate thoughts and publish them and be invited to various groups to help shape policy with organized Indigenous policy organizations, as opposed to getting dictated by large umbrella organizations that serve the Canadian provincial population and Indigenous needs becomes a tag on.
- Equity needs to be defined, and the allocation to Indigenous equity needs to be identified so individuals can invest time and study the politics from within the contexts of specific healthcare needs.

- To create system change around an issue, do a review, and then if that review reveals something, do focus groups to ground truths in the community with patients who are experiencing challenges to develop a profile of the issues and host a webinar or a podcast to drive the need that way - produce a fact sheet or a policy brief to share with government officials, provincial governments, and federal government or those who hold power around this, e.g., transportation is a huge challenge for Northern health and it isn't just cancer.
- Increasing interest in Indigenous research in many areas, cancer being one of them, hasn't been matched by a jump in Indigenous scholars, Indigenous faculty, Indigenous capacity building to the point that the jump matches the capacity so the work may not be done by Indigenous people, but it needs to be done in a culturally safe way with the right purpose in mind.
- As First Nations Health Authority Chair in cancer and wellness, we have been working on [developing policy] matched with the development of an Indigenous cancer strategy in British Columbia and CPAC has been a critical partner, and we recognize the limitations that it does not include Métis or Inuit, but with First Nations, a lot of the partnership are developing with the ministry of health and the BC cancer registry or BC cancer with their registry to do data linkages which is overseen by governance within the First Nations Health Authority because the BC cancer registry has no Indigenous identifiers.
- Power and the ability to answer the questions posed by First Nations communities and the leadership in BC has enabled the First Nations client file, which is basically the registry of status First Nations in British Columbia and is a starting point where we can look at some of the questions in terms of prevalence, incidents, survival and mortality rates of First Nation and cancer.
- Strict policies are in place for data access and how it is governed in combination with the First Nations Health Authority and the Ministry of Health, which provides significant snapshots and trends for some of the basic questions about cancer.
- Métis Nation BC is also working on this capacity, and as the First Nations Health Authority (FNHA) chair, I would be happy to share our experiences.
- The big issue right now is equitable access to healthcare and how adverse experiences can be a barrier to accessing healthcare, so helping people navigate healthcare has identified issues regarding creating a safe space for people to go and having a navigator or someone who can go with them and address aftercare or take them to treatments, etc.
- The federal government uses a distinctions-based approach, which can mean urban Indigenous peoples are unseen because they do not account for the geographic location of their home community or territory or other factors with self-identification, not just ethnicity.

It is important to collect disaggregated data that looks at what makes somebody distinct and ensures that intersectionality is being recorded so people don't fall through the cracks.

An Inuk Elder spoke to the influence of policies on the realities for Inuit with cancer in the South: *"[As Inuit] we have all the procedures and legislation and regulations, but that doesn't make it easy to be able to do research because you still need the relationships and trust building that needs to happen on the ground and sometimes people down here, especially those with health concerns just want to be able to quietly deal with their health issues and not make it known."*

Is there some specific terminology that you would apply that's different from a Western approach? If you didn't have a Western institution, what would be different about research?

International focus group respondents spoke to this theme. Australian participants talked about INTER Partner Indigenous-led Data and Research Governance and what Indigenous researchers refer to as Indigenous methods, such as yarning and iterative analysis approaches. Examples provided were research on 'Indigenous wellbeing indicators.' Utilizing a collaborative yarning, iterative-based approach, an Indigenous researcher group reviewed the data, which then was inclusive of young persons from the Torres Straight Islanders and older Aboriginal persons from different parts of the country. These life experiences are different, and different views and different experiences from different points in time [are gathered], which is more than just collecting data. These ideas were reflected in the following quote:

Indigenous governance in approaches to research, whether quantitative or qualitative, was talked about as providing the opportunity for early and ongoing analysis to those with no research background and allowing for those voices to come in with that data. This is viewed as part of "maintaining a good spirit as an Indigenous researcher," which is about allowing for that relationality within the work that we do regarding the relationships that are developed and how they operate, whether that be with the participants or with your governance group or with other researchers.

> *"We're not grounded in a theoretical framework. We're meant to be totally neutral. Which obviously is not real.... In the last few years, learning about the different theoretical frameworks you can work within, but also the way in which you can be grounded in your Indigenous worldview can play out in the quantitative way and makes the analysis so much better. People often talk about doing a strengths-based approach, but that's just an outcome that reduces what we do in some ways. Doing strengths-based work is important, but some sort of framework of theory around the quantum work provides opportunities for collaborative discussions and joint analysis and provides opportunities moving forward on how quantum or epidemiology hasn't realistically portrayed us but re-reduced out the humanness of Indigenous peoples in many ways."*

Do you have specific comments on data governance?

One international participant addressed this question along with several Indigenous data experts from Canada. The international speaker stated:

"Data governance doesn't seem to be the same kind of issue in the US. Our main source of data for just the socio-demographics of American Indians and Alaska Natives is the US census. Done every 10 years, it's not done in conjunction but on the advisement of the National Congress of American Indians, which is a group composed of the tribal leaders of all the federally recognized tribes. It's resulted in hiring census enumerators on reservations who speak the language, and there's a separate budget for advertising materials. There is data available to all the tribes, and whether that comes quickly or is pooled over various years depends on a lot of things. But that's been done as far as data governance of specific tribes for specific people. It's not quite the same thing because, in the US, all the federally recognized tribes are already sovereign nations."

Indigenous counterparts in Canada talked about the following opportunities:

- Regions are really at various stages but being able to share each other's experiences would be beneficial – even to the point of the creation of the data-sharing agreement or that process.
- There are lessons that can be shared that are similar in regions where they've already done research and data linkage, as well as the technical lessons of learnings.
- Recognizing that certain populations are not included and having an overall understanding of the limitations of data linkage—the Indian Registry is not the gold standard for identifying First Nations.
- One thing to build on is that there are lots of different models for capacity building and connecting an individual community or organization to its data—models where an individual community member has been seconded to the Institute for Clinical Evaluative Sciences (ICES) so they can access the data directly for their community, or we have organizations that have seconded a person.
- A national-level infrastructure across Canada for data centers, like Manitoba Center for Health Policy, Population Health BC, and ICES, so that they can facilitate multi-regional analysis without sharing data because they have trouble sharing data.
- We established an Indigenous Health Data Training Program where we work in collaboration with an organization, and there are two things embedded in this, including multiple sessions on how to use the data and how to understand the data, and how to work with ICES data.
- Training data governance at the national level because we've done a good job regionally and have trained some data experts in each region, with FNIGC and the national table of FNIGC, and good work with CIHR, board members of the CIHR-IIPH, and the college of reviewers—but we need to grow that beyond just these small groups for community people to do this in a way that makes sense to them.

One Indigenous data expert talked specifically about the case of cancer:

"It's not going anywhere. In fact, it's getting worse as we have more prominence, and as Indigenous people are further and further away from their original diets and their original medicines. We are reliant on Western medicine, especially for this disease process.... One thing that we're missing, and we're not talking about, is Indigenous people have not participated in any genomic science research, and all Western medicines are geared towards Western European DNA, not ours. I think we need to ask this question."

Do you have recommendations for needed changes for Indigenous-led data governance in relation to Indigenous health research overall, but specifically around cancer?

Both Indigenous focus groups and stakeholder interviews provided recommendations specific to cancer and cancer data summarized as follows:

- Recommendations pertain to changes in legislation regarding legislation on information regimes, such as the Privacy and Access to Information Act and in relation to the future development/co-development of distinctions-based Indigenous health legislation – and the importance of integrating [Indigenous] data sovereignty to take precedence, such that First Nations can access their information and use and control it.
- Identifying data challenges regarding COVID-19, including its variables, across regions in terms of the capacity to identify [Indigenous people] in administrative data sets, as some regions recognize there are differences in how we try to do this whether it's data linking through the Indian registry, whether it's having a direct relationship with the health authority or whether it's being able to do your own census so that you can create linkages to that information in administrative data sets.
- Education for researchers and government members, specifically on the inherent rights of Indigenous people, United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP), and Treaty rights, as well as for Indigenous community members to be able to understand the value of data due to the history and distress around research, which has created a hesitancy to self-identify even for COVID-19 data.
- There is a need for more First Nations trained in data sciences or data management alongside the need for infrastructure and connectivity.
- Governance for administrative data sets, whether it is Statistics Canada or other data sets that would have been created for research where First Nations/Indigenous people have been an identifier.
- Engagement work needs to happen to be able to get some idea of how structures need to look so that we are avoiding situations where we can't work with the information that's potentially already there even though there is engagement with Indigenous communities and partnerships, but there's just no process or structure in place for any of the organizations that are holding data.
- Building a data dashboard and having directors work together to learn how they can share data or make better use of their administrative data at the community level.
- Funding and capacity for communities to develop data-sharing agreements amongst themselves so that they are not so afraid of sharing data with each other and that they can feel secure and comfortable by helping them set up those infrastructures that they trust.
- Indigenous-led governance requires infrastructure in place that is not just the hardware but includes individuals trained in Western systems of thinking but grounded in our Indigenous ways of knowing.
- Looking at and interpreting data from an Indigenous worldview is needed, but what we are doing right now is looking at administrative data as disease processes at certain points in time that we can count as an event, missing the important pieces of how to heal as Indigenous people.
- Looking at everything that is interfering with my ability to be [Blackfoot] and even my own colonial thinking because colonial thinking is not all negative.
- When we're working with our people and because they've never had this information in front of them, yet they have timely data in front of them that they can make sense of, centralize, and use instead of what's happening where we are transferring data to our funders with the hope that somehow a report will come back to us eventually that we can do effective planning and evidence-based priority setting and measuring to see if we're on the right track of helping people to heal.
- Everybody outside of us knows everything about us, but they interpret and speak about us from a Western context, e.g., Blackfoot communities have an opioid crisis with 91 reported deaths, yet nobody is paying attention to the 7,000 people who attended a Sundance ceremony for prayers, for healing, for that connection to their clan families, to each other, and our ancestral teachings about our ancestral ways of life.
- Legislation that does not interfere with our ability to govern ourselves the way that we need to approach governance in the same way that we care for our knowledge as it transfers from one generation to the next would produce the most secure, best data governance system in the world.
- A funding formula with bad data is not possible, and we do not even know what it's going to cost or the resources it's going to cost to close the [equity] gap because we're not there, yet the responsibility of closing this gap has been given to First Nations.

- Being [Indigenous] without interference is being used to create an Indigenous data system where we trust ourselves and know how to care for data, how to care for ancestral, ancient knowledge and transfer that from one generation to the next as experts who are not looking at this from within colonial contexts.
- There is a need to label Indigenous data and data sets as Indigenous so that we know what governance to place on top and have a healthy skepticism of intention so data can be used in ways that are trust building and being very clear and making sure that we have ownership and control of that intention and the processes.
- Linking federal and provincial data for integration that is critical to answering good questions about cancer and about other issues that are connected to cancer, which requires data with clear First Nations and Métis governance, but then when we want to integrate NIHB data or other data, it's a federal fight to get other kinds of data that are required and needed to answer the questions.
- Acknowledging the complexity of different governance models is important to have data governance agreements and agreements for groups that do not want others speaking for their data requires that we start internally with the specific group.
- Governance models are needed to figure out if we are talking about building Nations and Nation-based governance: Are we talking about First Nations-based governance? That includes over 600 First Nation communities! Or are we talking about Nations that existed before the Indian act?
- There is a need to think critically about the ways that people are identified as Indigenous, whether First Nations or not, because this raises different governance questions. Working at ICES with the data, if we're using a registry, it's very clear if it is First Nations, but using a data set where people self-identify as First Nations, Inuit, or Métis is less clear in terms of governance and the governance should [perhaps] be determining the type of data being used.
- Multiple healthcare systems in Canada pose challenges in merging data from two provinces to make a bigger program, and provinces and territories also do not link the Indigenous populations.
- Additional funding for capacity and skills building in genomic data and cancers, including the ongoing work of FNHA and the Métis Settlement Nation BC (MSNBC) to look at the Indigenous Background Variant Library (IBVL) and the silent genomes to look at cancer.
- First Nations data governance strategy has a lot of the answers or important next steps, but Inuit and Métis appear to be much farther behind, with the most important issue being a lack of capacity with Institutions and staff who can negotiate data sharing agreements, analyze and work with the data, etc.
- Policy development on the part of the cancer care authorities is needed to provide clarity in the long term, which should be thought about when a research project is designed, including what will happen to the data after the project.
- More broadly, there needs to be thinking about how to deal with short-term issues such as: What are the rules for access? What are the rules for the destruction of data?
- Mainstream organizations need to figure out how they can respect Indigenous data sovereignty principles, what data they hold, what the protections are, and the procedures around it, etc.
- There is potential for sharing best practices and mutual advice through conversations that piggyback on other events, including conferences, e.g., hosting a data sovereignty conference with a section for mainstream organizations and governmental organizations to speak and help each other learn from best practices.
- The timeliness of health data is a real issue that affects the utility of administrative health data, and how we typically approach this with other organizations is to have data-sharing agreements that are longstanding and in place and renewed from year to year so that legal processes don't slow the process down when it comes to accessing and sharing data.
- Providing a secure access environment with tools that can securely send data to their own hard drives is now available through cloud-based technology that allows researchers to go in and access only the data for which they have permission and data sharing agreements to access.
- From the perspective of data requests that come in through researchers for administrative data, there is a secure destruction policy with a timeframe committed to it, and if researchers require the data beyond the original destruction date, they must apply once again.
- Developing policy to protect and respect OCAP® principles by and for those providing the data and data requests from researchers at the time of destruction to create a plan that is aligned with current policy about projects, including projects where parameters have changed.
- Share expertise regarding geography and how to protect community data that requires very technical aspects and a lot of work to figure out how to deal with census geography and postal code geography.

Do you have any other comments around the identification?

Identifiers in Indigenous research regarding data was of particular concern for data experts and is exemplified in the statement:

"Getting to the root of what has really harmed us as a people about the sensitivity around identification and because the Indian Act is still the longest standing racist legislation in the world, it's even harsher than Hitler's genocidal legislation, and we are still using that as our guide, by law, on how we can identify an Indigenous person in this country. ...we've seen great harm and the outcomes of what those harms cases such as Sharon McIvor, Bill C-31 that really destroyed families as it removed families from being able to identify or receive care or services, even for other family members because they chose to marry a non-Indigenous person."

Further issues were identified as follows:

- Indigenous people need to be at the table and to be in those systems because Western individuals do not have the same understanding of the sensitivities that can cause harm to Indigenous people as a population group, e.g., non-Indigenous researchers will use the Indian Registry as an identifier and not look at the potential harm of the data.
- Special attention and sensitivity are required to be prepared for self-identification because we haven't dealt with systemic racism in healthcare systems, and [Indigenous] health legislation is not going to eliminate systemic racism in health systems because it doesn't lead to Indigenous governance over hospitals and services.
- Vital statistics data needs to be cleaned up, and Indigenous people themselves need to decolonize the data through having legislation that continues to cause harm in our communities removed, e.g., our own membership lists don't recognize Bill-C31s or the Sharon McIvor's of the world.
- Regarding practices and processes, there is a tendency to not build a lot of time in for engagement and capacity building, as evidenced by increased communities becoming aware of OCAP® and understanding research, and if you don't build that time into improving capacity, you're wasting your time because either it won't start or it won't finish.
- Practices and processes are required for the use of data as an ongoing process that looks at how communities and people access their data and the processes needed for that, as well as for researchers who are working with communities' data.
- Tools, including training and capacity building, are important and need to be led by more complex processes that work for Indigenous Nations and communities.
- Decisions about data linkage are complex, but those practices and processes on access and ownership must also be considered to ensure better data utilization.
- Using cancer data with information where you can identify [Indigenous individuals] needs to build in time for the engagement so that those who have been engaged throughout the process can appreciate the value of the information collected and then continue doing more work in that area.
- Mistrust is a challenge that needs to be dealt with by having [Indigenous communities] govern and say what they would like to see come from the research.
- Sharing and disseminating information so that it is accessible to those who need it, e.g., COVID-19 modelling was being done, and it just caused more fear because it didn't go as planned and thought needs to go into how the information is being disseminated so that it makes sense and avoids causing harm.

One key stakeholder identified the challenge of accessing existing data holdings that were previously set up as more difficult than accessing data from a new research project that will collect data that did not exist before. In the case of new data collection, researchers may have existing protocols and agreements to address issues important to Indigenous people, such as ownership, etc.

What has been your experience pertaining to the linking of different pieces of data and useability by yourselves, your teams, or researchers, seeking to apply and utilize data?

One international participant talked about the involvement of government leadership in relation to data linkage, stating information about a forum called the Iwi - the National Iwi Chairs Forum, which has not all the Iwi or tribes in New Zealand, but 72 of them. The forum has an independent leadership group specific to take leadership in data linkage and is called an Indigenous data IOG, including interested influential positions from the government at national and regional levels. This enables influence at all levels of the government system, regional system, and health system, which report back to tribe members about retaining data and creating sustainable systems – future-focused, sustainable systems where they have full, unfettered authority through a memorandum of understanding with crown agencies in New Zealand.

Another national stakeholder organization spoke extensively on this topic to state that... the organization has three ways of identifying Indigenous people in the healthcare data sets, including self-identification, individuals who are asked during a registration process if they are First Nations, Inuit, or Métis, and by geography or where an individual resides with a postal code that is a reserve or Indigenous community. The challenge is that these approaches miss more than half the population. Regarding data linkage, challenges in methodology are related to the use of census data and people who self-identify, e.g., those who participate in the census.

Other responses included:
Currently, [our organization] has no plans to do analytical work, including data linkage and uses an approach to Indigenous health data as a supportive function to facilitate work with an FNIMs organization wanting to do data linkage. Their role is not the analysis but providing partners with data; instead, they facilitate conversations with other mainstream health data holders around Indigenous data sovereignty and OCAP®. The stakeholder questions who has authority and then tries to align our policies and apply OCAP®.

The stakeholder has completed a new internal policy on the release and disclosure of data that can identify Indigenous individuals and communities with the understanding that the organization will house Indigenous identifiable data. There are many data quality issues, a primary one being that much of the data is not group-specific or distinctions-based, making the data not particularly useful to those who own the data. To protect Indigenous people and their data, [our organization] has an internal policy that disallows the release of data that can identify either Indigenous individuals or communities via certain geography variables without that request being accompanied by approvals from an appropriate Indigenous authority. This has also led to the challenge of identifying those authorities and evaluating that approval, which is much more challenging in practice than on paper.

One stakeholder organization suggests working to identify advisors who can support organizations (data holders) in evaluating those approvals, supporting governance, and working to understand how to respect data governance and data sovereignty alongside how to apply the policy. Other benefits can include conversations around interpretations of the data and moving to mandatory training for all staff on data sovereignty.

What are your policies and standards pertaining to storage and management?

Only one stakeholder, the Canadian Institute for Health Information, addressed this question in depth. This organization reported to have a single public-facing document: Path Forward. They reported that an additional internal policy exists around the release of data, which is a form and a policy around data out but not around data in. Much of the data is dated (20 years), and several datasets have Indigenous identifiers. CIHI gathers or receives data from the provinces and territories and sets some standards for how it should be collected. Standards for race-based and Indigenous identifiable data are expected to be available in March 2023, along with a guide specifying how to collect and safely store data, as well as information on data governance. They explained that one reason to provide this is that self-identification in healthcare settings can be risky, and people are uncomfortable undertaking these activities for reasons around engagement.

GAP ANALYSIS — MAPPING EXERCISES

Automated searches of relevant documents

The project team decided to use publicly available data from Google Scholar to carry out a more expansive search of possible results for the environmental scan.

An automated method of collecting data was used to capture search results from Google Scholar based on certain queries. The results were then analyzed to see if they fit the project's inclusion/exclusion criteria. Most of the studies collected through this search did not fit the project inclusion criteria and were rejected.

Search queries included the following:

- Canada cancer screening data banks
- Canada tumour data bank
- FNIM cancer registry
- FNIM cancer databases
- FNIM cancer data systems
- Inuit cancer registry data - Canada Research
- "Indigenous-led" cancer data storage database registry
- "Indigenous-led" cancer research database registry
- First Nations, Inuit, and Métis cancer registry data Canada

The program captured the results of the above search queries and stored them in a database. Then, the project processes established for the environmental scan, including the inclusion/exclusion criteria, were carried out.

CANADIAN CANCER RESEARCH SURVEY (CCRS) DATA

This activity aimed to analyze a list of cancer research projects provided to the project team by CPAC that was compiled from the Canadian Cancer Research Survey (CCRS) from 2005 to 2019 that were related to First Nations, Inuit, and Métis. The projects were checked to see if they were led by Indigenous researchers or in partnership with Indigenous researchers.

The entire list of CCRS FNIM projects contained 297 individual projects. This list was filtered to collect data that fits into two different buckets. The first bucket related to projects that had an institute priority of Health Services and Policy Research, and the second bucket contained projects that had a thematic group of 7, 8, or 9, which are: Wholistic Health and Wellbeing, Indigenous Ways of Knowing, and Knowledge translation.

Bucket 1: Health Services and Policy Research

To get the relevant projects for this bucket, the research team first filtered data in the CCRS FNIM projects to get a list of all studies that have "Health Services and Policy Research" in any of these columns:

- Primary Institute
- Institute Priority 2
- Institute Priority 3
- Institute Priority 4

Once that was completed, duplicate studies were removed by checking for a unique "CCRA_ID."

The above steps resulted in a list of 46 unique projects.

In a first review of the filtered projects:

- 16 of the projects were Indigenous-led or in partnership with Indigenous researchers.
- Four of the projects were not clear whether they were Indigenous-led or not.
- 26 of the projects were not Indigenous-led or in partnership with Indigenous researchers.

In a second review of the filtered projects:

- 14 of the projects were considered Indigenous-led or in partnership with Indigenous researchers.
- 32 of the projects were not considered Indigenous-led or in partnership with Indigenous researchers.

Bucket 2: Thematic group of 7, 8, or 9

To get the relevant projects for this bucket, we filtered data from the CCRS FNIM projects list based on projects that have these topics as one of the provisional thematic groups (group 1 or group 2):

- 07-Wholistic Health and Wellbeing
- 08-Indigenous Ways of Knowing
- 09-Knowledge translation

Once that was completed, duplicate studies were removed by checking for a unique "CCRA_ID."

The above steps resulted in a list of 95 unique projects.

In a first review of the filtered projects:

- 51 projects were Indigenous-led or in partnership with Indigenous researchers.
- 19 of the projects were not sure whether they were Indigenous-led or not.
- 25 of the projects were not Indigenous-led or in partnership with Indigenous researchers.

In a second review of the filtered projects:

- 61 of the projects were considered Indigenous-led or in partnership with Indigenous researchers.
- 34 of the projects were not considered Indigenous-led or in partnership with Indigenous researchers.

CANADIAN CANCER RESEARCH SURVEY (CCRS) EQUITY

The Alberta First Nations Information Governance Centre (Alberta FNIGC) Indigenous-Led Data and Research Governance Project Team agreed to provide the Canadian Partnership Against Cancer with a breakdown of CCRS 2005 - 2019 funded projects relevant to Indigenous people and equity. This section outlines the process and outcomes for this task. Results are shown in the Appendices.

The method for this exercise strove to be consistent with the Alberta FNIGC Project methodology for Indigenous-led data and research governance. Using the robot "Winston", an Equity Projects Methodology Diagram was created to depict the process and outcomes of steps 1 – 4, as discussed below.

Step 1: Relevant projects from the Canadian Cancer Research Survey (CCRS) 2005-2019 funding list under "04 - Equity in Access to Care" were identified. Projects were categorized into two spreadsheets: "TG_1 - Equity in Access to Care", which included 23 projects from Provisional Thematic Group 1, and "TG_2 - Equity in Access to Care", which included 15 projects from Provisional Thematic Group 2.

Step 2: Funded projects were then identified that included "Equity" in the title, abstract, or as a keyword. These projects were then placed in a spreadsheet named "Equity in Title, Abstract, KWs". This includes a total of 22 projects.

Step 3: All identified projects from TG_1, TG_2 and "Equity in Title, Abstract, KW" were placed into a single spreadsheet called "Deduplicated Equity Projects" and duplicate projects were removed. This includes a total of 52 projects.

Step 4: A first review was carried out of these 52 projects for their relevance to research that identified "equity in cancer control." Project Team members then carried out a second review to identify funded projects that further met the inclusion/exclusion criteria for Indigenous-led data and research governance. The results of these reviews are discussed in the final section. See the Appendix for "Equity Projects PRISMA."

FNIM Data maps

The goal was to prepare a visualization of the existing data and data sources about First Nations, Inuit, and Métis people to graphically show the current state of Indigenous-governed data and research systems and to showcase datasets that contain FNIM identifiers.

Documents identified throughout the project were reviewed and analyzed to determine what data products a particular province or territory might have about FNIM people.

Datasets that had a specific focus on cancer were marked with a star.

Mapping - Gap Analysis Results

CCRS Data: The results of this activity show that only a small number of FNIM-focused cancer projects are led by or in partnership with Indigenous researchers.
A total of 1,187 documents were reviewed. The initial review of titles and abstracts resulted in 38 documents that fit the inclusion criteria.

Following that, a second review was carried out on the 38 documents from the first review, and this resulted in two documents that were chosen to be included for full NVivo analysis, and to contribute to the recommendations in this report.

CCRS Equity: These activities revealed that 11 of the 296 CCRS 2005-2019 funded projects identified a focus on "equity in cancer control + Indigenous-led data and research governance." Results from both the first and second reviews identified the following outcomes:

- 13 funded projects identified a focus on "equity in cancer control."
- 30 funded projects did not identify a focus on "equity in cancer control."
- Nine funded projects were inconclusive in the first review and were included as part of the second review.

Detailed results for the second review identified the following outcomes:

- 11 funded projects identified a focus on "equity in cancer control + Indigenous-led data and research governance."
- 41 projects did not meet the inclusion/exclusion criteria of the second review.

Further, 15 of the 52 funded projects were identified as having no focus on Indigenous people and/or Indigenous people in Canada, with specific reference only to vulnerable or marginalized populations.

We suggest these be removed from the CCRS 2005-2019 FNIM-funded projects list. Finally, two of the 13 funded projects were dated 2009, which is beyond the project margins for Indigenous-led data and research governance and so they were removed to leave a total of 11 funded projects identified as having a focus on "equity in cancer control + Indigenous-led data and research governance." These include Cameron, B. (2009) and Mitchell, T. (2009).

FNIM Data maps: Three data maps were created from the above research showing data sources, registries, and data standards as they apply to First Nations, Inuit, and Métis people across the country. Find these in the appendix. These data maps visualize which provinces or territories are more developed in terms of storing Indigenous-specific ethnocultural information and which ones are not.

Furthermore, it is simple to see which provinces have agreed upon Data Standards regarding the storage of ethnocultural information. For example, only Newfoundland and Labrador, and British Columbia have fully agreed upon Data Standards that are implemented at all levels of government. All other provinces and territories have yet to agree upon a standardized way to store ethnocultural information.

These data maps also show how data about Indigenous people in Canada is disconnected. Indigenous people in a certain province or territory may be in the process of treating their cancer, but there is no single specific way of identifying Indigenous people within cancer datasets. More work needs to be done to properly connect the regional cancer registries with the relevant provincial or territorial Indigenous registry to better identify people within cancer datasets.

ONLINE SURVEY AND RESULTS

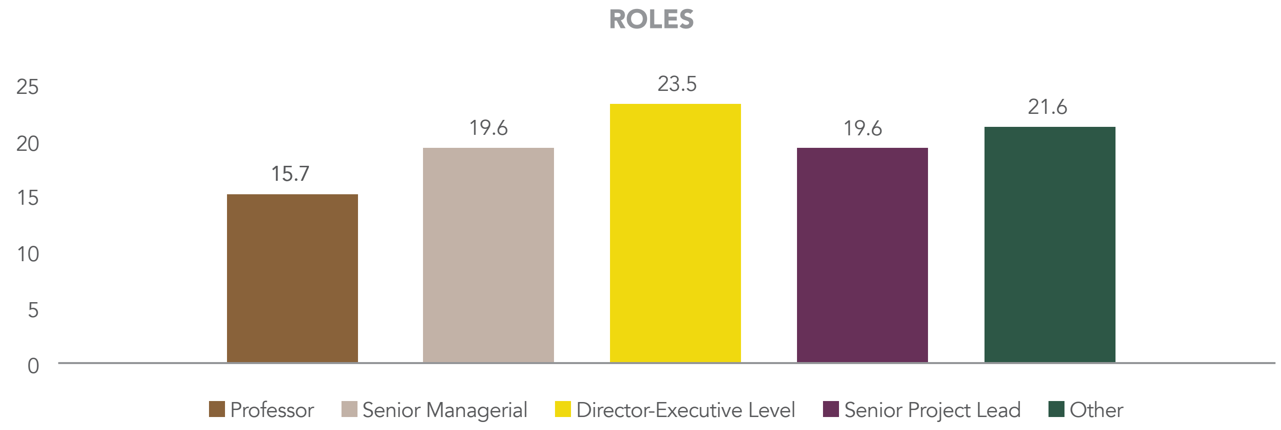
A survey was created using information gleaned from research documents for the Environmental Scan and included ideas from the research team and our funding team members. It was programmed, tested, and then deployed online using secure Canadian-based survey software, Voxco version 6.5. The data was saved while it was being entered by the respondent and stored on a secure physical server in the Alberta FNIGC offices with a redundant cloud backup. The only access to the data file was via secure login by a single analyst.

A list of individuals meeting certain Indigenous research criteria was created. An Excel contact workbook with categorized spreadsheets was developed and everyone was contacted via email with a link to the secure survey.

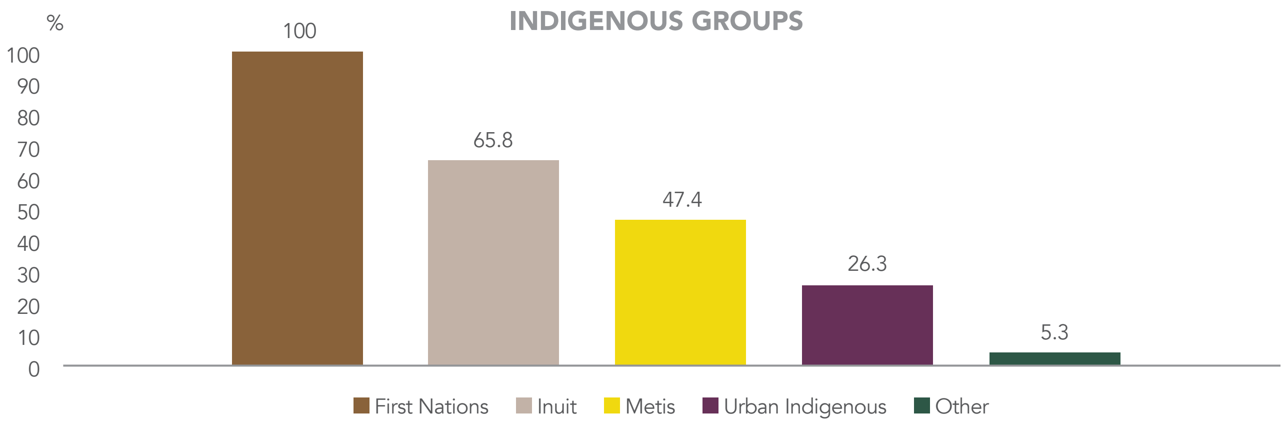
Email invitations were sent to 78 potential respondents. The campaign went on for 14 weeks. Those who participated in a given week were eligible for a $50 gift card draw of their choosing. Those who had not responded were reminded weekly.

General Information About Organizations Represented

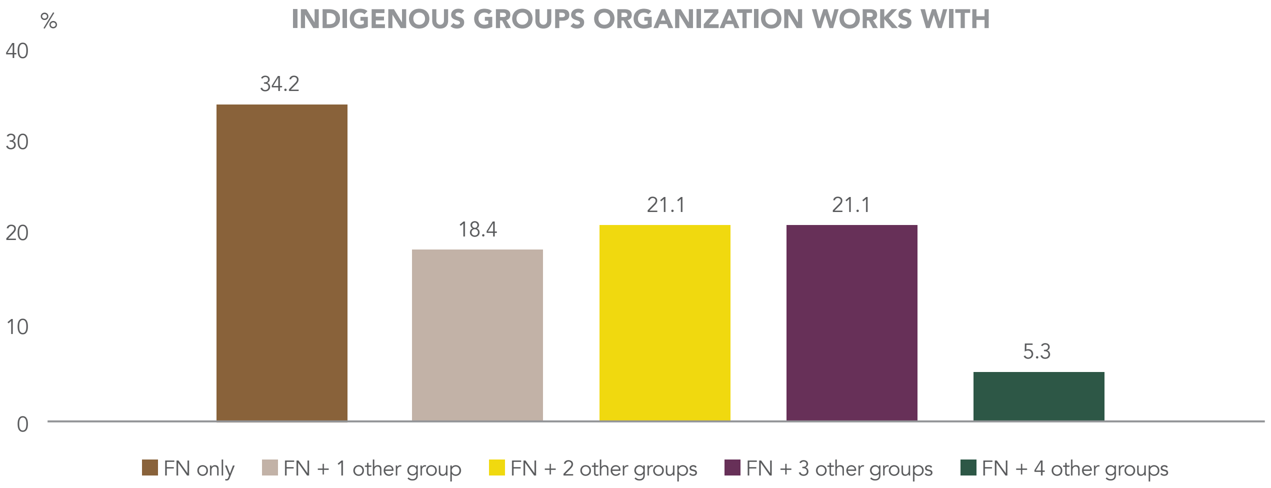
The following was the distribution of general roles fulfilled by the respondents:



Seventy six percent (76%) of respondents work with an organization that does research with Indigenous people. All 76% work with First Nations and to a lesser degree with other distinct Indigenous groups



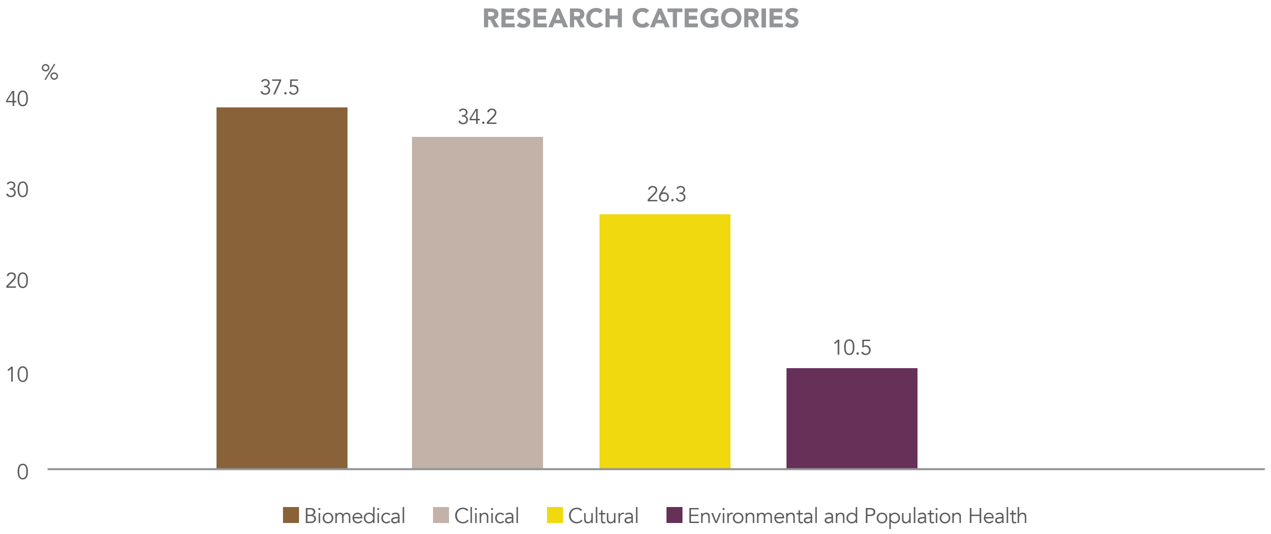
However, only 34% of respondents work purely with First Nations. The remaining organizations work with at least two and some with up to five Indigenous groups (First Nations, Inuit, Métis, Urban Indigenous, and "Other" which turned out to be Indigenous groups worldwide).



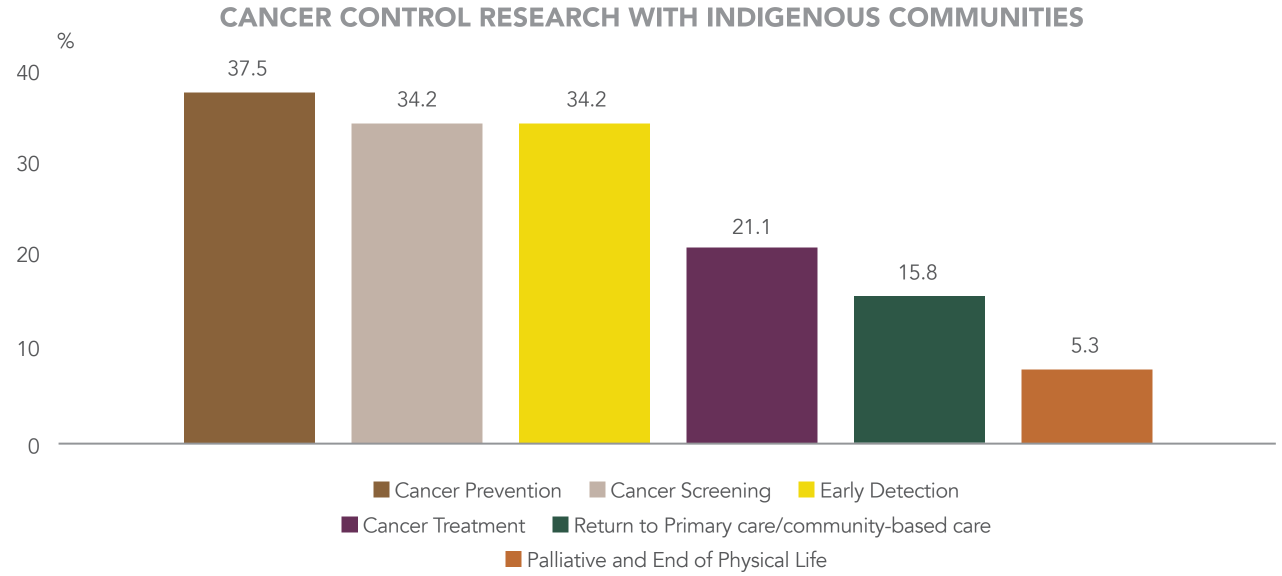
Of the individuals/organizations represented, 31% "have a mandate that includes Indigenous cancer control research."

Research Areas

Respondents could select from six categories (including "other") that best fit their research. Respondents had the option of selecting "as many as apply." The following four categories were endorsed.

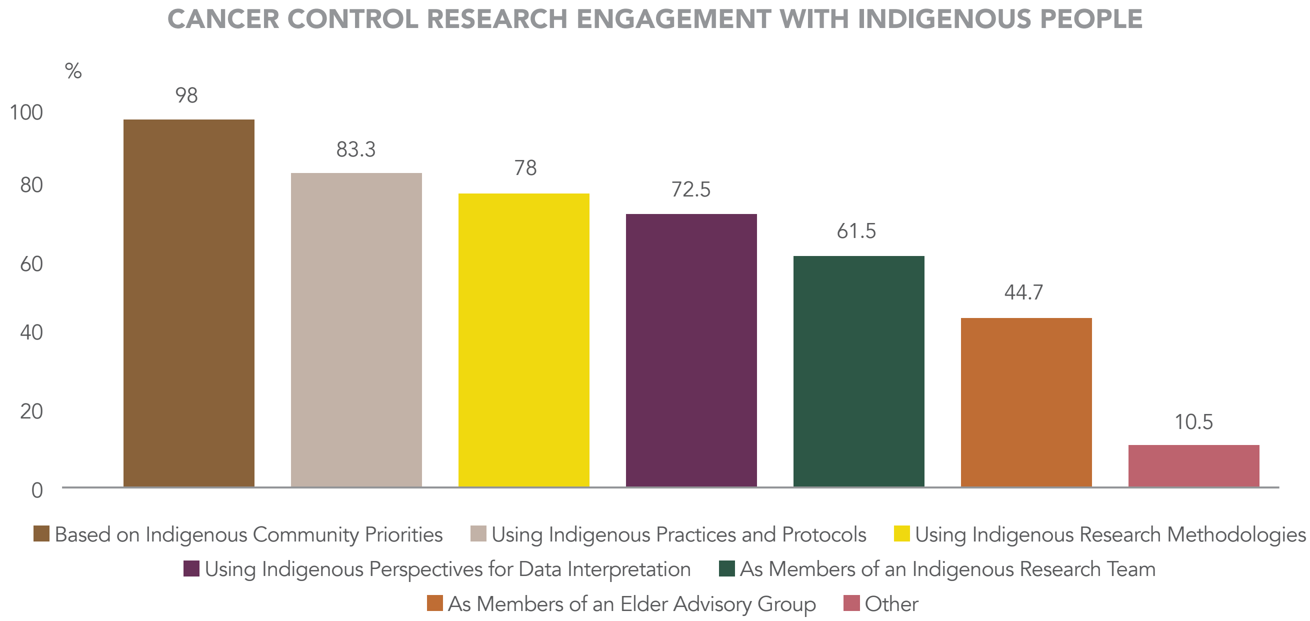


Respondents were also asked to describe their cancer control research with Indigenous communities. Eight categories were provided (including "other"), and respondents could again select as many categories as applied to them.



Engagement Practices

Respondents were asked how Indigenous people are engaged in their organization's cancer control research practices. As with previous questions, several categories were presented, and respondents could select as many as they felt were applicable. All categories were endorsed, including "other."



Each selection also had the option to provide additional information, which was then analyzed and coded into themes. Of the 45% who provided additional information, 71% stated that collaboration was an important part of their engagement process. The other two themes were cancer pathways improvement (12%) and data (18%).

Data

Respondents were asked several questions regarding data – whether they were able to access it, whether there was enough of it, and even whether the required data existed. The vast majority (71%) stated they were unable to access all the cancer control data needed to support their work. When asked what additional cancer control data would be the most helpful, the responses fell into four main categories:

What additional cancer control data would be the most helpful?

Identifiers	38.5%
Administrative data	34.6%
Community-level data	7.7%
Screening data	19.2%

Over half of the respondents (58%) stated that the data they require do not exist and two thirds (67%) stated that the available data do not meet their organization's cancer control research needs.

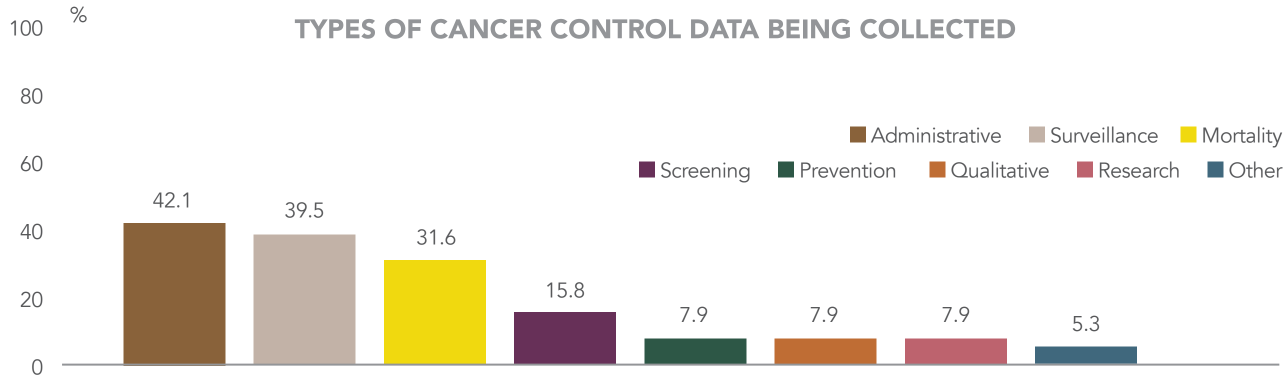
Methods for identifying Indigenous populations followed four major themes:

Self-identification	26.5%
Client Registry	41.2%
Data linkages	20.6%
Networking	11.8%

Fewer than half (39%) are doing work to develop measures in Indigenous cancer control. Of those who are developing measures, there are three main categories related to:

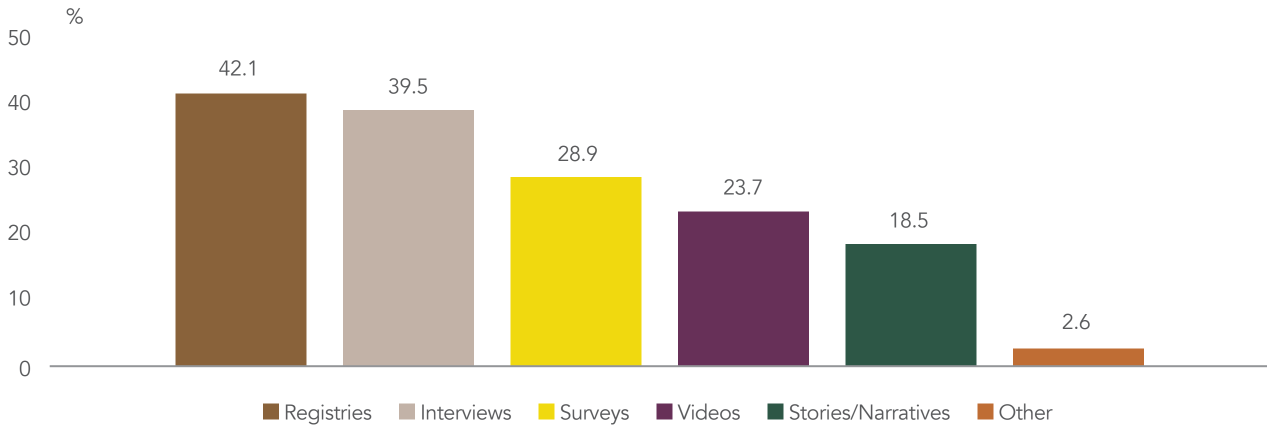
Frameworks	25.0%
Governance	20.0%
Baselines	40.0%
and then Other	15.0%

Forty-one percent (41%) of organizations are collecting data related to Indigenous cancer control. Of this 41%, the following types of data are being collected:


TYPES OF CANCER CONTROL DATA BEING COLLECTED

The methods used to collect these data are varied and include not only quantitative but also qualitative data

METHODS USED TO COLLECT INDIGENOUS CANCER CONTROL DATA



Data Management

Data management is an important aspect of research. It extends from the initial stages of collecting data to processing, availability, and even eventual destruction (where applicable). Respondents were asked about various aspects of their organization's data management plans. Fewer than half (44%) have a data management plan that includes cancer control data.

Further questions were asked about some data management processes and or policies. These were all open-ended questions, which were then coded into themes.

Data Storage Processes and/or Policies

Cancer Control	12.8%	**Sub-Themes**	
Partner Organization	17.9%		
Protocol/Governance	56.4%	Indigenous Principles	9.8%
Secure Server	12.8%	Under Development	5.9%

Data Privacy Processes and/or Policies

Data-sharing Agreements	19.4%	**Sub-Themes**	
Protected Files/Policy/Governance	67.7%		
Review Ethics Board	12.9%	Indigenous Principles/Protocol	13.7%

Data Security Processes and/or Policies

Data-sharing Agreements	18.5%	**Sub-Themes**	
Protected Files/Policy/Governance	70.4%		
Review Ethics Board	11.1%	Indigenous Ethics/Principles	9.8%
		Under Development	3.9%

Data Protection Processes and/or Policies

Data-sharing Agreements	14.8%	**Sub-Themes**	
Protected Files/Policy/Governance	70.4%		
Review Ethics Board	14.8%	Indigenous Principles	9.8%
		Under Development	5.9%
		Governance	2.0%

Data Linkage Processes and/or Policies

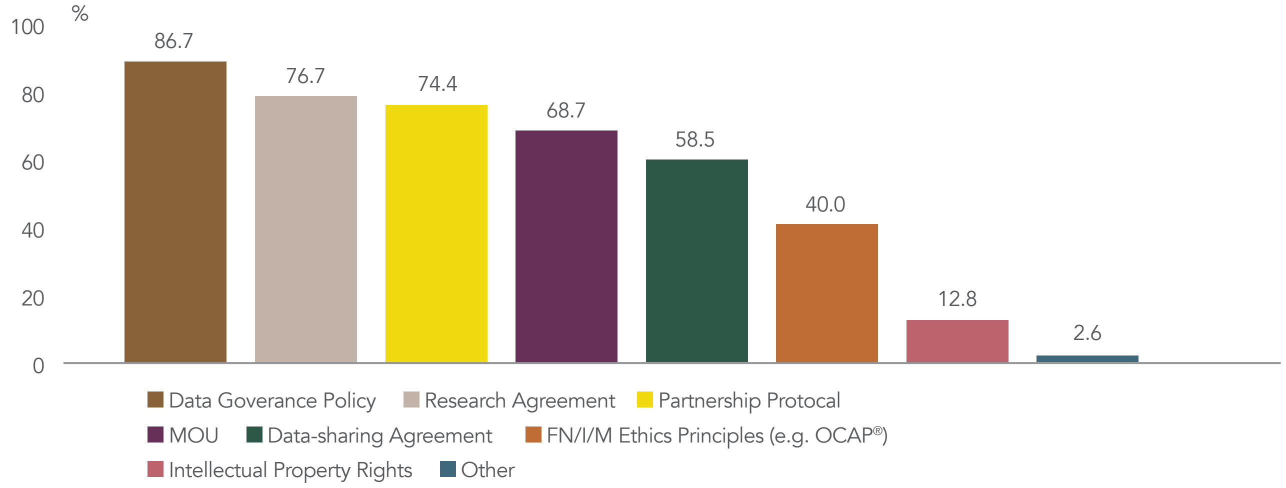
Data-sharing Agreements	18.8%	**Sub-Themes**	
Protected Files/Policy/Governance	68.8%		
Review Ethics Board	12.5%	Indigenous Principles	7.8%
		Governance	3.9%

Just over half (51.3%) of respondents said their organization has process or policy documents that they are willing to share with others. A few gave links to online documents, but most said to contact them, and they would be happy to share.

Research Partnerships

Respondents were asked about the implementation of standard policies or processes for research partnerships. Eight options were presented, including "other." Respondents could select "all that apply" to their organization.

IMPLEMENTATION OF STANDARD POLICIES OR PROCESSES FOR RESEARCH PARTNERSHIPS

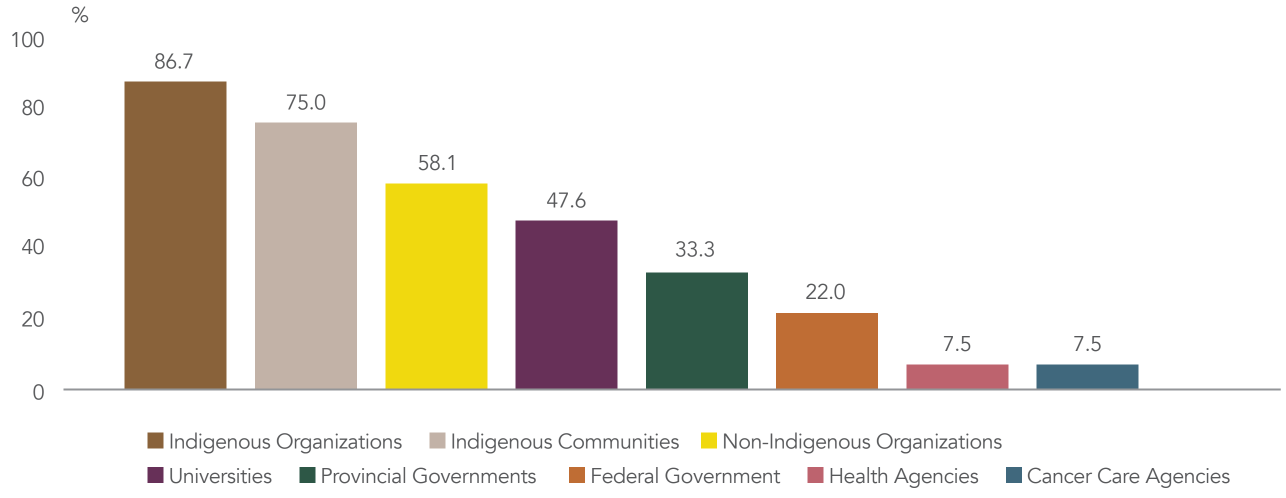


Respondents were asked about which Indigenous-specific ethics guidelines or principles their organization uses.

First Nations Principles of OCAP®	57.5%
Guiding Inuit Qaujimanituqangit Principles	35.0%
Principles of Ethical Métis Research	20.0%
Other	5.3%

Data-sharing agreements are an important part of research partnerships. Respondents were asked about their data-sharing agreements – again, they could select "all that apply."

USE OF DATA SHARING AGREEMENTS



Best Practices

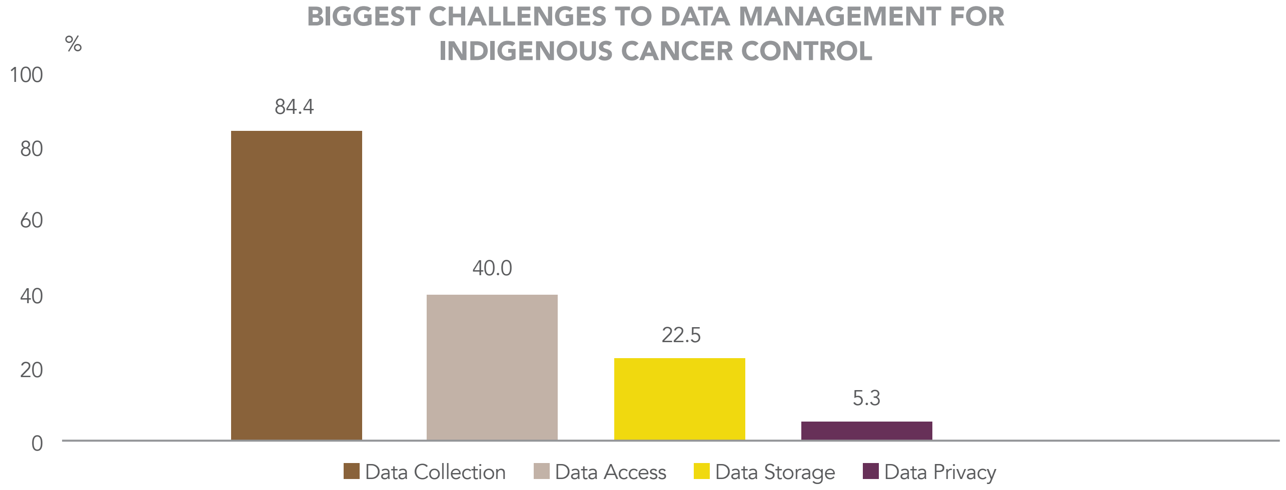
Respondents were asked to identify one or two best practices in Indigenous-led data and research governance. This was an open-ended question, and 45 of the 51 respondents provided an answer. These responses were coded into four major themes plus "other."

Community ownership/community driven	31.6%
Indigenous principles/governance	28.9%
Collaboration	21.1%
Indigenous research methodology	15.8%
Other	2.6%

Challenges

Respondents were asked to identify their biggest challenges to data management for Indigenous cancer control and explain any strategies their organization may use to address these challenges.

Seven options were provided for data management challenges, but only four were endorsed. No respondents had data security or protection challenges, and none provided any other possible challenges.



Strategies to address these challenges fell into three main categories. The top two were data governance/management (26.9%) and collaboration (42.3%).

Only 29 respondents were able to provide concrete answers to the biggest challenges in cancer control research with Indigenous populations. The biggest challenge was capacity, with almost half (44.8%) stating this was an issue. Governance/standards were also an issue at 24.1%, and the remaining 31.0% of respondents had a variety of "other" concerns ranging from access to remote communities to "time required to sort out steps." These could not be fit into any cohesive themes.

The strategies used to address these challenges revolve around collaboration (79.2%) and resources (20.8%).

The Future

Respondents were asked to think about what data systems and research systems could look like in the next five years if everything was done perfectly. The specific series of questions were:

In the next five years, if we do everything perfectly and improve current Indigenous data systems in cancer control:
  - *What would that future data system look like?*
  - *What problems would be solved?*
  - *How would data be shared?*
  - *How would people be identified?*

The same was asked for research systems.

Respondents commented that these were tough questions but good to think about. Many of the answers provided validated the gaps that they are currently experiencing – i.e., in five years those gaps would be gone.

Future Data Systems

Future data systems would provide access to data and allow for data linkages or other means to identify Indigenous individuals using good governance practices.

This would solve the current data access problems, lack of data linkages, and governance practices to facilitate evidence for action. One respondent wrote a perfect synopsis:

> *"Resources, programs, and services would be more effectively targeted. Indigenous people would get diagnosed with cancer earlier when treatment would be more effective. Indigenous people would have improved access to treatment, less Indigenous people would die and/or have their lives impacted by cancer."*

Data would be shared using governance and protocols, and people would either self-identify or be identified using various means of governance.

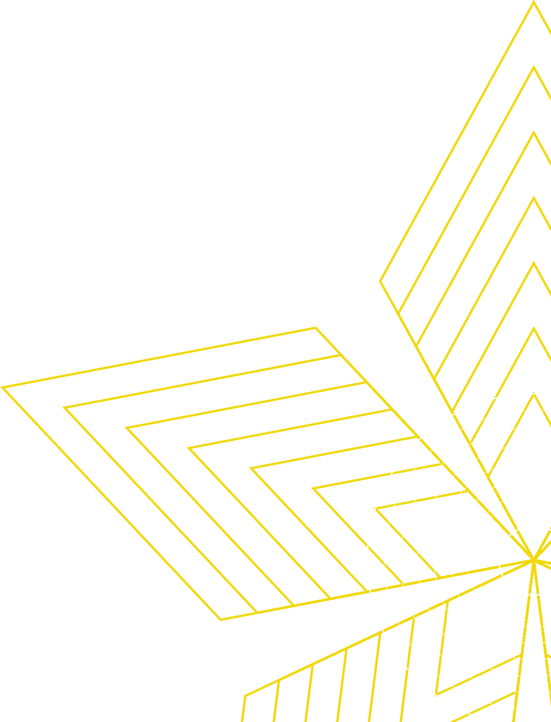
Future Research Systems

Future research systems would include Indigenous partnerships (including leadership) and improved capacity to facilitate evidence to action.

This would solve the current problems of lack of governance practices and capacity. Evidence to action could be facilitated. A respondent summed this up as follows:

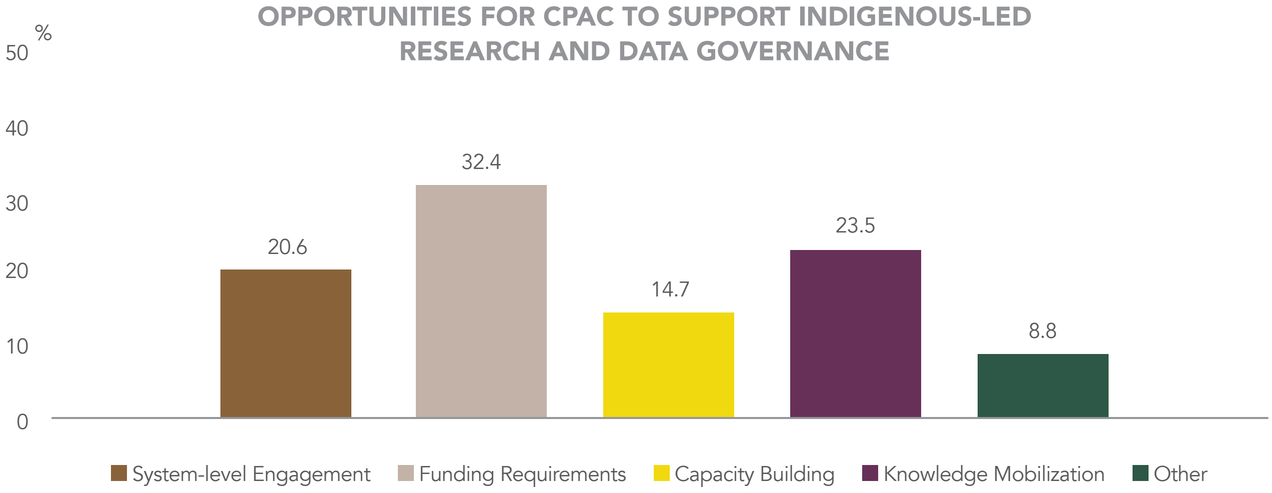
> *"It would meet the identified needs of Indigenous communities and leaders and Indigenous organizations, and groups would have the knowledge and capacity to fully utilize the system. There would be recognition that Indigenous forms of data gathering and knowledge sharing, although not scientifically rigorous by academic standards, is valuable to informing Indigenous needs and ways of being."*

Data would be shared using sound data governance/data management protocols, and there would be data-sharing agreements. People would either self-identify, there would be a system that would aid in identification, or identification would be project-based.



Opportunities for CPAC

Respondents provided feedback on opportunities they could see for CPAC to support Indigenous-led research and data governance. Of the 51 total respondents 38 (or 75%) chose to provide input. Their responses were coded into four major themes, plus "other."



OPPORTUNITIES FOR CPAC TO SUPPORT INDIGENOUS-LED RESEARCH AND DATA GOVERNANCE

DISCUSSION

Indigenous academics, scholars, and language-based communities co-created a spirited body of scholarship asserting compassionate leadership around research governance. Four main themes emerge within the literature in the verbalization of Cancer Research with Indigenous populations: transformation of Indigenous-led research, language-based data sovereignty, Indigenous cancer infrastructure, innovative research and international intersection.

TRANSFORMATION OF INDIGENOUS-LED RESEARCH

Good data is at the heart of respectful research governance. Cultural ethical standards enforced by the Knowledge Holders are strict and exact, high moral ways of inquiry (Scott. et al., 2020). The ancestral values guide the ethical transformation in how research is governed and can be traced back to the data sovereignty movement (Carroll et al., 2020; Walter & Carroll, 2021). Indigenous research, as it emerges and is actualized as a community-based approach, operates within the principles of good governance (Walter & Carroll, 2021).

Indigenous researchers are organizing opportunities with thematic dialogic research and community research gatherings. Like the Labrador gatherings, with a target audience of invited universities and the academic research community to hear firsthand their needs and process "called Naalak, an Inuk word that means "to listen and to pay close attention," the gathering created a dynamic moment of respect and understanding of how to work better together and support one another in research with Indigenous peoples on Indigenous lands" (Bull et al., 2019, p. 2). When communities take a leadership research role, data benefits their community and is the truest form of governance when they decide together (Bull et al., 2019). Data collected is also used to measure, monitor, and evaluate the health delivery of healthcare systems in meeting the well-being of Indigenous populations (OCC, 2019).

In Australia, a research community used a jury approach to ensure that the research undertaken by the service was in the community's interests and that the assessment of 'community interest and benefit' would be determined by the local Indigenous community (Bond et al., 2016). Transformation occurs when the Indigenous population's values and rights are infused, guiding the shared research decision-making process.

LANGUAGE-BASED DATA SOVEREIGNTY

Historically, research about Indigenous peoples has been unbalanced (Jull et. al., 2019; Kukutai & Taylor (2016b); Rodriquez-Lonebear, 2016). The injustice of exclusion is the energy that formed the eventual creation of the First Nations Information Governance Centre (FNIGC) to articulate the grounding OCAP® (FNIGC, p. 139). A pivotal date in Language-based communities is 1994 when the Federal Government launched the three major national longitudinal health surveys, and First Nations on reserve were omitted from this important gathering of data. The First Nations Regional Health Survey (RHS) was formed, and then this work was taken over by the RHS Steering Committee. An Indigenous research space was created when FNIGC was installed to support data and information sovereignty. The four guiding principles of ownership, control, access and possession assisted the articulation of research frameworks for ethical research (Hayward, 2021). A researcher's role is to be in service to the community's interests, and the duty of 'community interest and benefit' is determined by the local Indigenous community (Bond et al., 2016). An example of community-led and cutting-edge sovereign research governance structures is a partnership with the BC First Nations Data Governance Initiative (BCFNDGI) and UBC Advanced Research Computing (ARC); working to establish a BC First Nations Information Governance Centre. The voices of the people are heard, and BCFNDGI has a four-year evolving review and evaluation process.

Indigenous Cancer Infrastructure

All Community engagement in research and community-level research governance articles that underwent detailed extraction were reviewed for content on an Indigenous research approach. Community engagement in activities related to data management and on the development or implementation of community-level mechanisms for guiding or regulating research (Woodbury, et. a. 2019).

A peoples data movement collectively formed around Indigenous Data Sovereignty (IDS) arises out of a history of reclaiming (FNIGC, 2022; Kukutai, T. & Taylor, J, 2016; Smith, 2016, p.120; Raine et al., 2019). IDS represents the struggle and the diligence of the ancestors' commitment to actualize self-determination. The scholarship on the theme of Indigenous data sovereignty is relatively new. Language-based communities know the pain and suffering of the cancer spirit. Knowledge Holders conscientiously held space to envision a future where Indigenous cancer research unfolds all they envisioned within the talking circle.

A critical Indigenous-led cancer control community framework is required to fully support an Indigenous-led process within the Partnership to help build a cultural infrastructure. This goal is collaborative in nature. It is a community-based approach, as articulated by the Knowledge Holders in the Engagement Session. To truly influence Indigenous cancer research design and where language-based research methodologies become commonplace, if not implemented "When research is conducted without the voice of the community, key elements or indicators may be excluded." Data resources for communities, if not generated by Indigenous research processes and applying Western research methodologies, will not benefit the community. It is creating the wholeness that aligns with Indigenous populations and language-based communities, a humanitarian shift where "Good data. Data that is developed by and with and for communities, data that reflects Indigenous worldview, and data that is both relevant to communities and agreeable to policymakers" (Alberta FNIGC , 2022). Infrastructure that is supportive of cultural approaches is necessary and conducive to fostering an internal relationship to data.

Data governance leaders have emerged within Indigenous populations. In the far north, the Nunatukavut Community Council (NCC) asserted the inherent right to govern their own data research and research data infrastructure, and they have jurisdiction over research conducted within their communities and traditional territory. The NCC created the Research, Education and Culture (REC) department to strengthen Nunatukavut's research policy; they began to initiate, lead and collaborate in the local research infrastructure shift moving towards sovereignty and in the sector of research are designing and implementing their own data generation agenda.

Another prime example of the establishment of a data governance framework is the signing of the British Columbia Tripartite Framework Agreement on First Nations Health Governance. Each First Nation community was a part of the process, and educational engagement sessions informed the communities of the implementation process. Iterative tools like the Data Governance framework were developed (www.fnha.ca). This toolkit has six core elements: 1. Data Governance Vision and Principles, 2. Governance Structure, 3. Accountability Mechanism, 4. Data Governance Policy, 5. Privacy and Security Policy, and 6. Legal Instruments. Sovereignty data governance tools outline strategic community governance structures complete with nine principles to guide the implementation of locally conceptualized models. Indigenous toolkits create internal capacity within governance sectors such as cancer health systems and are applicable in all areas. Regarding managing and accessing data, a Data Governance Board oversees the administration and regulation. Each First Nations community effectively becomes a data custodian for the collective with stringent data access protocols. Local data governance agreements and information sharing agreements strengthen infrastructure linked to people and lands.

Innovative research and International Intersection

There are key moments when Indigenous people's human rights are affirmed and address inequities, such as in 2007, when the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) became the altering mechanism for the Indigenous research governance movement. The limited state of Indigenous cancer research with Indigenous language-based peoples in a global community is at the phase of a fledging poised to take flight. National and international cancer researchers comprise a handful of people working on behalf of their ancestors and people. Indigenous research networks such as CANZUS (Canada, Australia, New Zealand, and the United States) are essential as the sites of international intersections are analogous to kinship.

National and international networks are indispensable for researchers working in the field of cancer control. Thematic gatherings like the World Indigenous Cancer Conference (WICC) retrieve knowledge that has been suppressed or would support peer group systems of knowledge sharing. Networks reconnect at all levels. One cancer research group, the Canadian Indigenous Research Network Against Cancer (CIRNAC), was formed to enhance and address cancer research and data poverty.

A common theme is a consensus; the Indigenous community and its members are the ones who decide how they will treat their data and create local leadership around research and data (Caroll et al., 2016). Responsibility is placed upon the doorstep of Indigenous communities considering overwhelming social determinants of health. This is problematic on many levels, yet the grounding essence of self-determination is that communities are further burdened as they face different social determinations of health. The accumulation of data and on whom data has been generated unfolds critical factors related to research governance. The health disparities of Indigenous peoples can be traced to a history of colonial dominance and suppressive research (Witham et al., 2022). Ultimately, the role of research governance is to attend to unequal power distribution and imbalance in amassing data (Carroll et al., 2018).

Respectful relationships within any given library section of Indigenous-authored academic and literary works is a small section. This literature review of Indigenous scholarship leading Research Governance presented leading cancer scholars and organizations. Ethicalness exists as a foundational value embedded within the knowledge systems of each language community. It is natural that ethics be positioned as a core tenet of research governance.

CULTURAL DATA ACCESS

Within First Nations communities, it is clear who the data rights holders are. Government organizations that fund projects stipulate who owns data in funding agreements. Most of the time, it is the funder. However, this is changing. Herein lies the duality in how data is treated and accessed! During this environmental scan engagement, the Knowledge Holders, in their clarity, narrated multiple points in the shared roles between orality and reciprocity as key issues to be further examined.

Reciprocity is an Indigenous research process and can assume multiple forms. As a protocol, it is the mutual action of give and take. In the Indigenous research community, the role of reciprocity unfolds as a two-way process. For instance, the act of reciprocity is when one makes a concerted effort to learn and understand the cultural background of someone they are working with or researching. Another Indigenous-led research layer is orality. Orality is the gift bestowed by the lines of ancestry. It is a profound living knowledge base. Indigenous language serves as a spiritual conduit, as orality is the vessel that carries traditional knowledge systems, like medicinal plant knowledge data sets. Access to data is a spiritual and foundational protocol through prayer and ceremony within the Indigenous language. It must be acknowledged that different levels exist to access Indigenous data. There are specific protocols amongst each land-based language groups across Canada, acknowledging the great diversity. As a matter of principle and adherence to ancient process, the Alberta First Nations Information Governance Centre feasts the spirit of data and the ancestors who support this work. This acknowledgement of how data is managed and treated highlights the duality in understanding access from an Indigenous-led research process.

Now, wider society is more familiar with the Western dominant historical research approach. There is a place for scientific and Indigenous-led research to co-exist. Western science operates in a present or real-time data collection, such as cancer, mortality, epidemiology, and surveillance rates. More importantly, how data is accessed, collected, managed, and treated is completely different. Reciprocity does not yet exist within this dominant research arena. However, this environmental scan indicates the desire to approach data in a meaningful way that aligns with the communities it serves. Existing as if nothing has changed is slothful in an era of reconciliation. The business of upholding, supporting, and collaborating with Indigenous-led research is evolving into transformative spaces, signalling a healing journey.

Orality, Knowledge, and Traditional Dataset Presentation

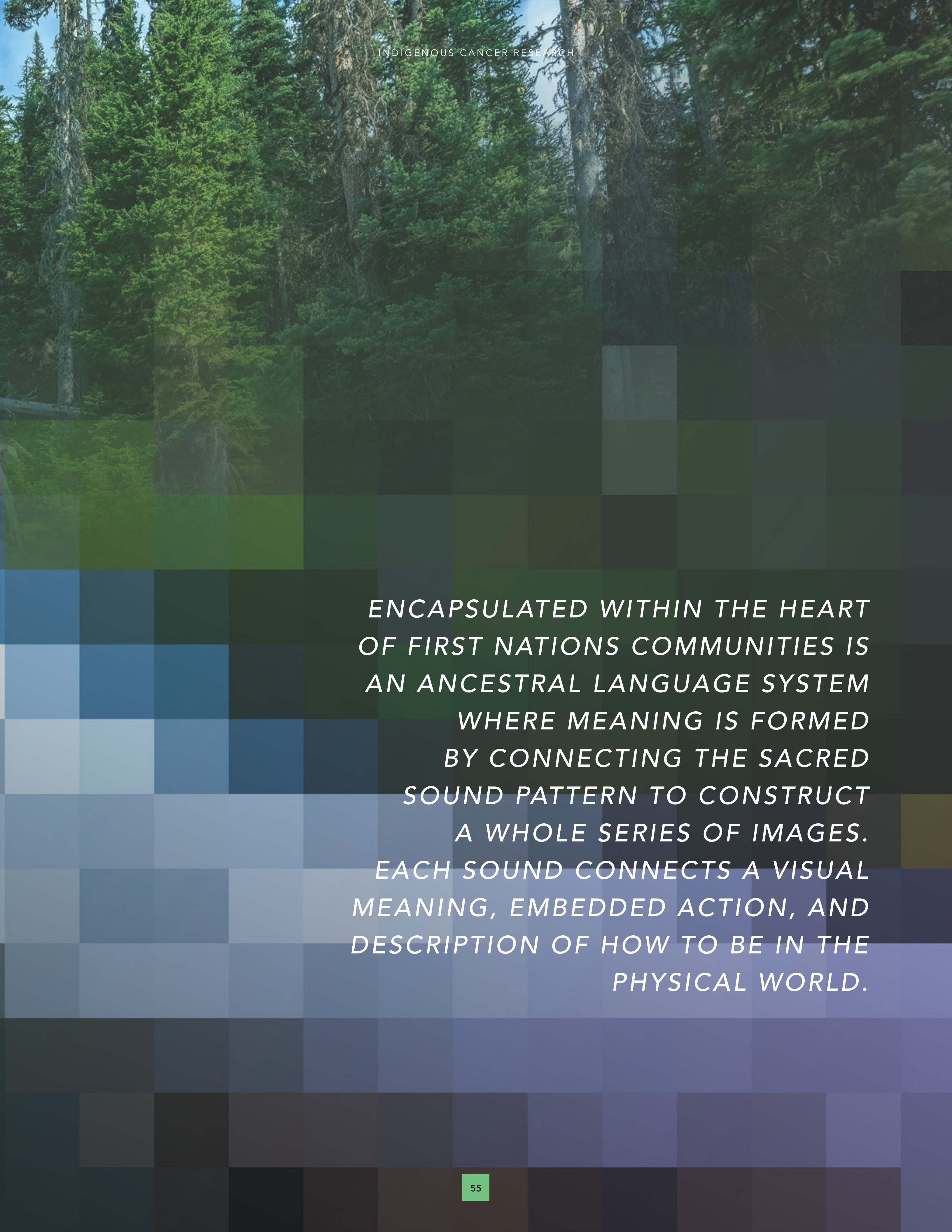
Finding a faint pulse in the current state of Indigenous-governed research and data practices within First Nations, Inuit, and Métis communities is indicative of the level of work yet to be accomplished. Tremendous willing teamwork revealed that First Nations, Inuit and Métis communities practice ancestral roles of stewardship and caretaking in the governance of their people's land-based data. Across Canada, dynamic language groups and communities emerged as lead warriors in the restoration and identification of their land-based informed Indigenous Data Sovereignty (IDS) processes, deep collaborative initiatives, and multifaceted partnerships. In doing so, these communities nationally and internationally transformed Indigenous data governance.

A critical starting point in the project initiation was the opening prayer. Its guiding intentions solidified the nature of the work at hand. Immediately, the moral responsibility of giving back in equal measure was positioned, for Alberta FNIGC its existence is based upon upholding sovereignty in all of its forms. There is an issue surrounding the lack, non-existent or understanding of reciprocity in the way research has been conducted. Reciprocity as a norm function is a caretaking practice of a mutual exchange at spiritual and material dimensions.

Encapsulated within the heart of First Nations communities is an ancestral language system where meaning is formed by connecting the sacred sound pattern to construct a whole series of images. Each sound connects a visual meaning, embedded action, and description of how to be in the physical world. Indigenous languages are recognized as a living being imbued with spirit. Each word verbalizes inherent roles and responsibilities as a land-based people. Where each word expresses a living methodology. Contained within these terms are states of being, foundational instructions, or teachings that articulate our humanness within the natural world—a continuous responsibility. Indigenous language carries the capability for speakers to make meaning in real-time and applies to that moment. Indigenous languages are not like English. Orality is an oral structure of making meaning. Knowledge Holders move forward and maintain ancestral knowledge datasets-bodies of knowledge into the next generation. This deep collaborative knowledge system nurtures teachings of how to bring a community into balance and how to move forward into the next generation. Teachings transfer responsibility and philosophy of the people, continuously binding with everything within the universe and continuously maintaining a whole community. A living total community structure engages and practices ancestral word-sound-actions in a deeply collaborative way. This is the merging of the spirit of data and language that the Alberta First Nations Information Governance Centre steadfastly upholds. Data is alive and imbued with spirit and brought forth into the present time and is recorded and created for future generations to access through spirit.

Clearly accessing data sets or knowledge systems is an internal process where the mind, body, and spirit and actions are embedded in the process. A relational approach exists in how orality is used to extract from a living knowledge system. This reciprocal relationship is comprised of many levels, and the role between the data source and the researcher is a ceremonial space.

In this philosophy, the researcher engages with the data source in a respectful and reciprocal manner, often recognizing the process as a kind of ceremony. This approach values the data source as a living system, acknowledging its complexity and the layers of meaning within it. It also highlights the importance of the relational dynamics between the researcher and the knowledge source, where learning is not just about extraction but about meaningful interaction and mutual respect.



ENCAPSULATED WITHIN THE HEART OF FIRST NATIONS COMMUNITIES IS AN ANCESTRAL LANGUAGE SYSTEM WHERE MEANING IS FORMED BY CONNECTING THE SACRED SOUND PATTERN TO CONSTRUCT A WHOLE SERIES OF IMAGES. EACH SOUND CONNECTS A VISUAL MEANING, EMBEDDED ACTION, AND DESCRIPTION OF HOW TO BE IN THE PHYSICAL WORLD.

CONCLUSIONS

The Indigenous cancer research landscape is a relatively small territory, with only a few Indigenous scientists specializing in this field. Western-oriented academic research systems continue to compartmentalize community data, with no room, place, or space for true recognition of the importance and role of Indigenous bodies of knowledge. This absence of Indigenous research and inquiry methodologies through a Western dominance imposed upon cancer research with Indigenous people has reinforced a perpetuation of deficit models. This has contributed to a "one-size-fits-all" approach to research and data, leading to inappropriate or limited perspectives being applied to the experiences and outcomes of language-based communities that possess their own knowledge systems and worldviews.

There is a disconnect between the original Indigenous wholistic, ceremonial ways of inquiry/knowledge and colonial methods. Indigenous methods of inquiry and knowledge remain but are suppressed by Western methodologies that are ineffective in Indigenous communities and with Indigenous people. This begs the question: *How can one provide solutions to Indigenous challenges and issues regarding ill health without accounting for or considering their philosophies of health, including the four aspects of self or the ancestral healing methodologies in achieving whole health?*

INDIGENOUS IDENTIFIERS IN COLLECTING ACCURATE DATA

Indigenous populations remain invisible within the multiple data systems, which continue to hold Indigenous population's data without access protocols or opportunities for linkages with ethnicity identifiers. Indigenous people feel unaccounted for—it is no wonder Indigenous populations feel invisible within a system.

PREVALENCE OF RACISM IN THE HEALTH SYSTEM

Grounded in our belief that there is an urgency to address Indigenous peoples' cancer grief, we recognize that there continues to be many discriminatory encounters for Indigenous cancer patients that go unchecked within the cancer system involving basic human rights. Notwithstanding Indigenous rights to health (Article #28 of the United Nations Declaration on the Rights of Indigenous Peoples), Indigenous populations must be aware of the input they have in their treatment plan in navigating their cancer journey. The truth facing the medical health care system is that it is not a place of trust; a humanitarian approach is required to address the cancer grief within Indigenous populations.

FINAL THOUGHTS

A significant outcome of this environmental scan is the persistence of the Western system in using a lens that ignores or misunderstands Indigenous conceptualizations of health and healing. This is further supported through the engagement and dialogue sessions with FNIM Knowledge Holders, content experts, and researchers. Orality is the life source of knowledge working from spirit and interconnection. A return to the ancestors' original methods of inquiry and Indigenous methodologies of examination would do much to adjust for the wholeness of health and healing. Indigenous people would then be unencumbered by a research process that is not their own and a medical system that does not acknowledge their ancestral ways of healing.

"We never lost it. Never did. And we're still very sacred with the strength of the knowledge of our ancestors. We still have them, and they are with us to guide us this way. How we've sustained a lot of information awareness." (Elder D.D. Elder Engagement Session, December 13, 2021).

RECOMMENDATIONS

The following is a list of recommendations that emerged consistently during a review of the environmental scan relevant documents regarding data systems:

DATA RECOMMENDATIONS

Data Recommendation #1:

Fund a project to collaborate, discuss, and agree on a standardized way to store Indigenous identifier information in data systems across all provinces and territories in Canada.

There is no single, standardized, Canada-wide way of storing Indigenous identifier information, leading to difficulty linking data between provinces and territories. This would allow for easier linking of FNIM data across multiple datasets, allowing for more detailed and accurate care to be provided and improving the kinds of research that can be carried out.

A standardized data type that is agreed upon as acceptable to use across the country would decrease organizations' worries about asking for this information.

A standardized data type would make it easier for EMR software vendors to add this data type as a feature to their software and allow healthcare providers to easily keep track of their patient's information.

This standardized data type should allow for intersectional choices, allowing a person to make multiple selections of the First Nations, Inuit, and Métis options and possibly choosing which community they associate with.

For this standard to be effective, communities in each province and territory need to agree on and approve a data standard that would work for them within their own province or territory. Only then could a national standard be implemented because the input of Indigenous communities across Canada has approved it from the ground up.

A good starting point would be to look at the Newfoundland and Labrador Indigenous Administrative Data Identifier Standard or the BC Aboriginal Administrative Data Standard.

Data Recommendation #2:

Fund a project to identify how regional cancer organizations collect or link Indigenous identifiers to their screening, diagnostic, treatment, or survivorship data, and ponder how to share this data across the country.

Discuss with provincial and territorial cancer registries to more specifically identify how they collect or link Indigenous identifiers. This could be expanded to include provincial and territorial hospitals or hospital networks.

Identify how these organizations collect and store Indigenous identifiers, if they do at all. Identify the specific ways that organizations share their data and how they use it.

Find information about how linkages are carried out exactly. What data points do they link on? What goals do they have with the identifiers? How do they keep these identifiers updated?

Do they have an Indigenous data governance committee? Are there Indigenous people on that committee? Knowing how each province and territory collects and links these Indigenous identifiers would enable future opportunities related to sharing data with Indigenous communities.

If communities could share their membership and residency lists on a monthly or quarterly basis with the province or territory (agreed upon through Data Sharing Agreements that embody the OCAP® principles), that would allow for an additional data source which could then be used along with the existing sources of information and identifiers.

Data Recommendation #3:

Begin discussing and creating Data-Sharing Agreement templates specific to Indigenous communities in a province or territory. These agreements allow communities to securely share member data with regional and/or national cancer organizations and/or researchers. Begin working on data-sharing agreement templates for communities and PT cancer care organizations. See what kind of sharing they would allow. How would the data storage work? FNIGC regional organizations may be involved in storing data for communities if they are unable to do it themselves.

Make funding available for communities or FNIGC regional organizations to work on data-sharing agreements. Find out if communities want to store the data themselves or if they would be agreeable with regional FNIGC organizations doing so.

Work with communities to help them develop their own data sharing or data access policies and define how they can begin sharing data with others. Help them figure out best practices in terms of data storage, access, security, privacy, OCAP®.

Enable communities to share their own health and cancer data with other communities to facilitate research projects and allow researchers to connect with communities to easily access their data.

A standardized way of carrying out research when using Indigenous ethnocultural identifiers in provinces and territories must be figured out. If there were a straightforward process that all researchers could use when conducting research, the numbers that researchers would come to would be more accurate and reliable because the process is fully vetted and approved. Otherwise, researchers might be carrying out their own data linkages and filters, which may not fully include all individuals who should be included in their dataset, resulting in less accurate results and poor-quality research.

Data Recommendation #4:

Work towards making Indigenous cancer data more available to Indigenous communities and providing education and training to those communities so they can check in on and assist their own members along their cancer journey.

One aspect of reconciliation is giving communities the opportunity to be self-reliant and independent. More data about community members should be shared with their communities so that their communities can be involved in the care that their members receive.

Provide Indigenous communities with more disaggregated data instead of purely aggregated data so that communities can have more detailed, accurate data to make more informed decisions. Making data more available and educating communities on how to best access it. Possibly providing an Indigenous epidemiologist to work with communities to help them better understand the health of their members and to provide ideas on programs and services that the community could work on to improve the health of their members.

This also works backwards by enabling community healthcare organizations to share their data with provincial and territorial organizations so that all the healthcare services provided to the patient are tracked and reported on and that all responsible organizations can see that the journey is going well.

Provincial cancer care organizations could create community-specific reports and share them with communities to report how many community members have been screened for cancer, how many are getting treatment, etc. This would make it easier for communities to know how many of their members are getting the healthcare they need.

Involving communities in the reporting process would also enable more customized metrics and measurements the community wants to track.

For example, create an “Indigenous cancer data set,” “Indigenous cancer dashboard,” or “Indigenous cancer metrics” that are developed with communities, are open, and allow communities to pick and choose which metrics they want to measure. Allow communities to share this data in aggregate form or only share metrics about their community’s stats on certain cancer metrics. This would allow provincial or territorial cancer organizations to know which communities might need more help and which communities are doing well.

Create a portal for community members to browse and download the most recent reports and data for their community. Make all relevant government data available to that community through this one portal.

Standardize how communities can ingest data, so they do not have to talk to countless people in different departments and organizations to procure all relevant data.

Set up tools for communities to more easily and securely access data from government sources. A portal to connect communities and government so that cases never fall through the cracks and are followed up on properly.

RESEARCH RECOMMENDATIONS

Research Recommendation #1:

Collaborate with Indigenous researchers and organizations and create a list of Indigenous-focused data definitions, measurements, and indicators to develop a centralized repository of metrics that communities can refer to so they can consider and create their own ways of measuring the success and healthiness of their members.

One topic that keeps coming up in the research and discussions is that every time a new project is started, everyone on the project must agree on the meaning of certain data-focused words. If there were a central list of definitions that Indigenous researchers could agree on, it would speed up the communication between researchers and communities.

Furthermore, making a list of Indigenous-created metrics and measurements and how to carry out the required calculations would expand the topic of Indigenous-led research and data governance. Indigenous individuals and communities have different ways of seeing and measuring health, so developing metrics that are aligned with the thoughts and beliefs of Indigenous communities in cultural, spiritual, and traditional ways would be a more inclusive way of gauging and reporting on Indigenous individuals' health.

This list of metrics could identify the most important cancer care metrics that communities care about and ensure that the data required to measure these stats are available to the communities themselves. Developing more Indigenous-focused health indicators and metrics in collaboration with communities could lead to a better understanding of healthiness in communities regarding cancer control.

Research Recommendation #2:

Fund more patient-focused and provider-focused Indigenous-led programs that assist patients along their cancer journey in a culturally safe way.

Patients need more navigator support.

Indigenous people access health services differently than the rest of Canada's general population, and the way that Indigenous people want to access this care should be accepted.

Racism in the healthcare system exists and still occurs today. In situations where patients are experiencing racism, they should be able to report their issues without worry and be able to have them resolved safely.

Ensure this whole process is transparent and that community members from across Canada can ask questions and provide feedback on the process to ensure their voice is heard.

Sometimes, patients are afraid of sharing their Indigenous status because they believe they may receive worse care. It would be valuable to investigate the fears that some Indigenous people have about self-identification and about their concerns in making their Indigenous status known to the healthcare system.

Ensure that people living in more remote communities are provided with more care and support.

Make healthcare providers more familiar with information about communities and Indigenous people. For example, if a doctor or nurse knows that someone comes from a certain community and they don't have certain healthcare facilities, that doctor might be able to change their treatment plan and customize it more for that person.

Research Recommendation #3:

Set up a system that automatically notifies and reminds Indigenous patients specifically about suggested screening opportunities to increase the number of patients who get screened for cancer and ensure that "no one is forgotten" or "falls through the cracks".

For these reasons, it would be valuable to have a provincial, territorial, or national program that automatically notifies and reminds individual patients about possible screening opportunities or other similar appointments.

Building a culturally safe and appropriate system for carrying out automated screening reminder communications would increase the number of patients getting screened for cancer and ensure that these people do not fall through the cracks.

It's possible that there could be an automated, online patient navigator that can help patients with questions about their cancer care journey. This software could access the patient's records and help patients know when their last appointment was, when their next one is, how to schedule transportation to the appointment (if required), allow patients to share complaints and feedback, and more.

This leads to better follow-up on patients throughout their cancer journey, ensuring that any available data about that patient and their cancer is available to the patient's other providers, whoever they may be.

For example, if a patient is in the "treatment" phase, why haven't there been any additional treatments recorded recently?

Automated care and follow-up for people who are diagnosed and for their change in each stage of cancer. For example, if someone is diagnosed with cancer, have they booked a follow-up appointment in time? Are they getting care? How long have they been in the diagnosed stage but have not started in the treatment stage yet?

Additional outreach about screening programs to Indigenous individuals and better collaboration with Indigenous communities would allow for earlier detection of cancer. More reminders, whether via direct physical mail, telephone calls, text messages, or email, can help increase compliance.

This could be connected with communities themselves, which could have someone in the community (such as a patient navigator) alerted when a certain member needs help. For example, a report for the community that details individuals who were screened more than x number of years ago and that they should get something scheduled soon.

Research Recommendation #4:

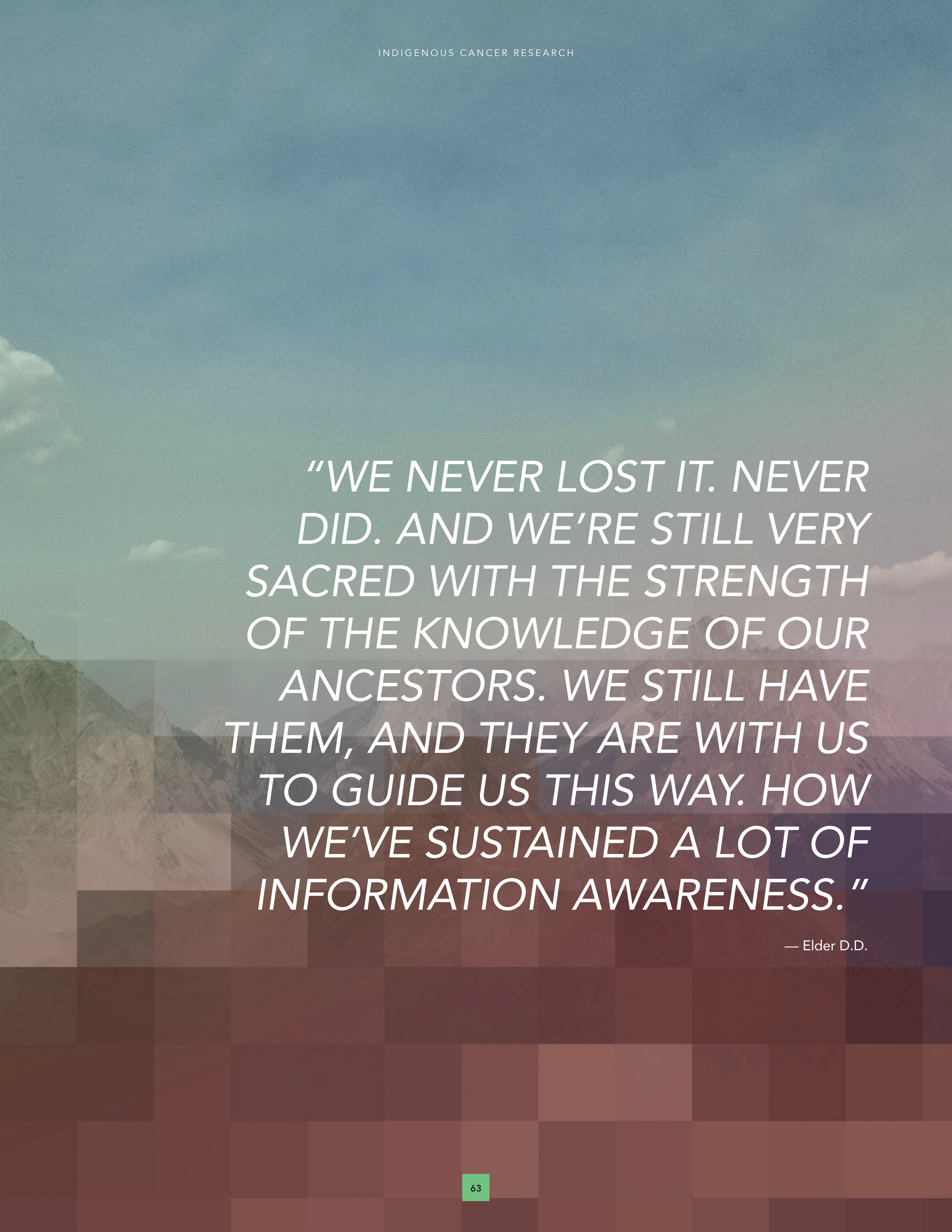
Make more funding available to Indigenous researchers, projects, communities, and organizations in order to allow for more Indigenous-led cancer data research projects.

More community-led data and research projects need to be funded. Of the 300 research studies from the CCRS list, there are only 11 studies which are focused on Data and Research (~4%). If communities were given a chance to improve their statistical capacity and employ their own community members in these sorts of data initiatives, communities would be able to better determine their own future and improve their capacity to self-govern while also generating more accurate and quality data that may be used at different stages of the cancer care lifecycle.

Provide communities with training and assistance about privacy and security to ensure that they can keep all new data safely and securely. For example, ensure that communities have a standardized process for verifying and approving access to people's data.

Have more funding available for Indigenous data analysts, epidemiologists, researchers, and scientists so that more Indigenous people are involved in the entire data ecosystem.

Make this funding more available and known to communities and community organizations. Set up a mailing list for specific communities and send them funding opportunities as they arise. Currently, it is hard to know when new funding is available.



> “WE NEVER LOST IT. NEVER DID. AND WE’RE STILL VERY SACRED WITH THE STRENGTH OF THE KNOWLEDGE OF OUR ANCESTORS. WE STILL HAVE THEM, AND THEY ARE WITH US TO GUIDE US THIS WAY. HOW WE’VE SUSTAINED A LOT OF INFORMATION AWARENESS.”
>
> — Elder D.D.

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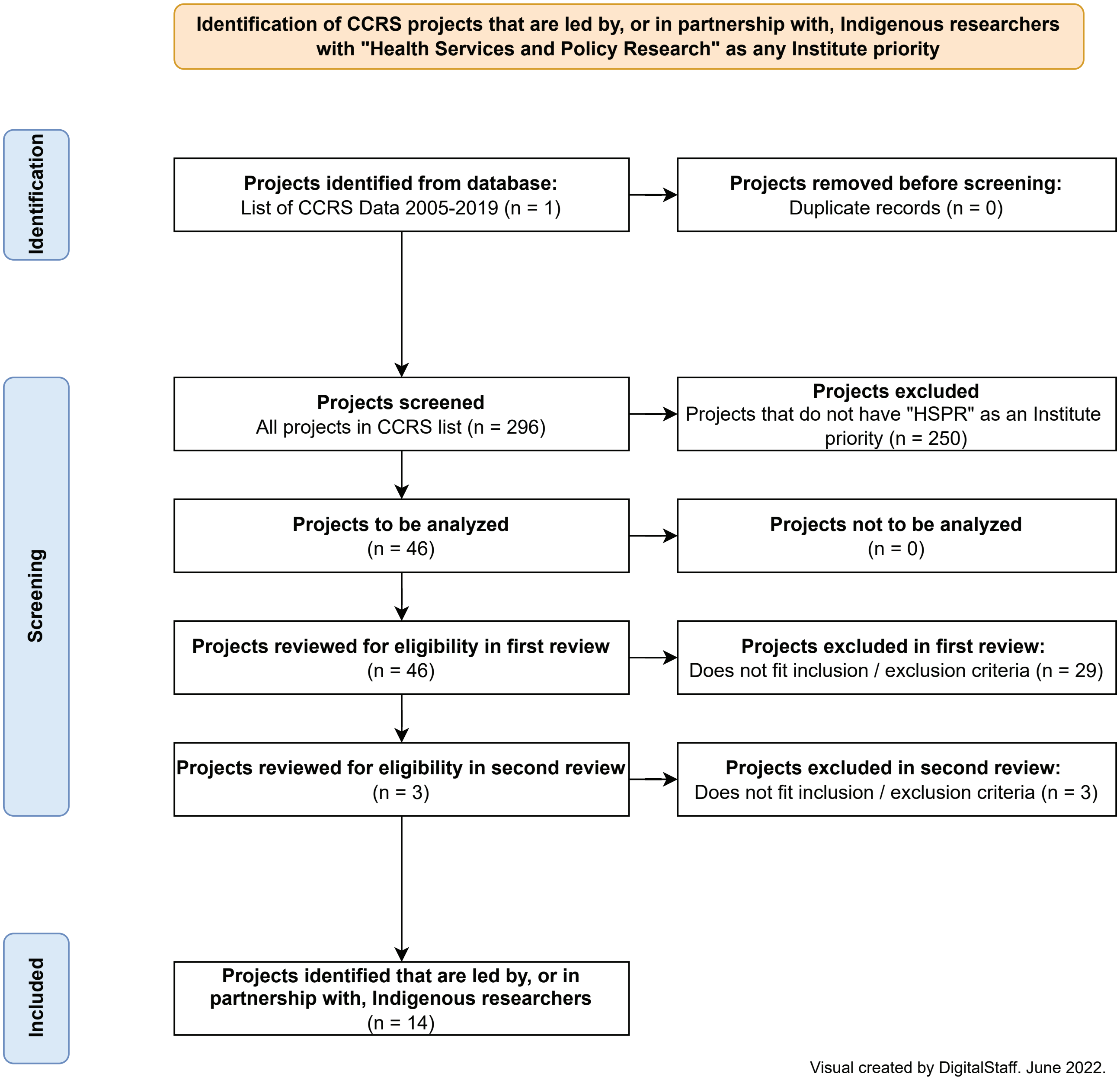
APPENDICES

- **Appendix 1a:** CCRS Health Services and Policy Research - Bucket 1 – PRISMA
- **Appendix 1b:** CCRS Health Services and Policy Research - Bucket 1 – Methodology
- **Appendix 2a:** CCRS Thematic Groups 7, 8, 9 - Bucket 2 – PRISMA
- **Appendix 2b:** CCRS Thematic Groups 7, 8, 9 - Bucket 2 – Methodology
- **Appendix 3a:** CCRS Equity Projects PRISMA
- **Appendix 3b:** CCRS Equity Projects – Methodology
- **Appendix 4:** First Nations Data Map
- **Appendix 5:** Inuit Data Map
- **Appendix 6:** Métis Data Map

APPENDIX 1A
CCRS HEALTH SERVICES AND POLICY RESEARCH - BUCKET 1 - PRISMA

Alberta First Nations Information Governance Centre project: Indigenous-led data and research governance

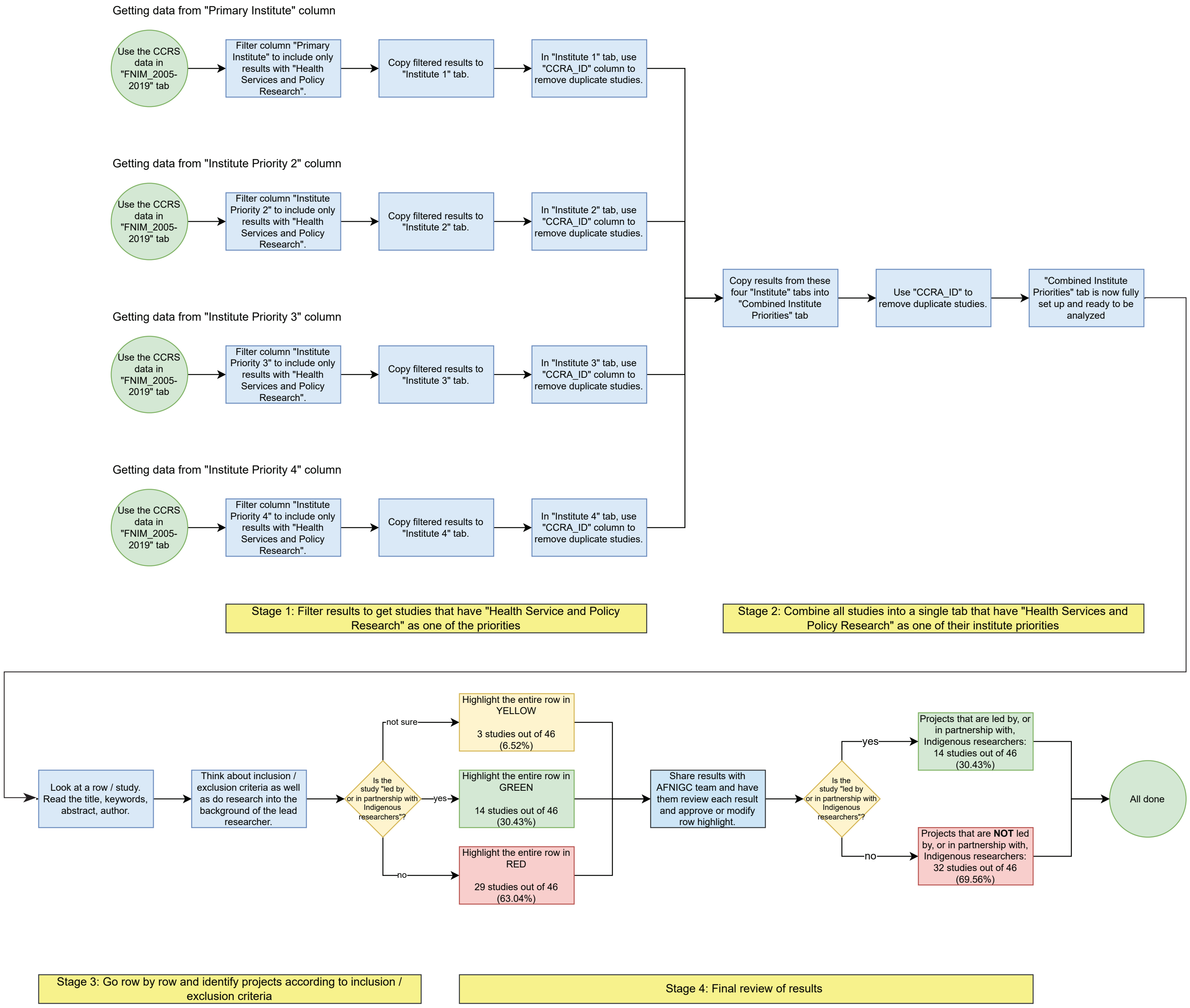


Visual created by DigitalStaff. June 2022.

APPENDIX 1B
CCRS HEALTH SERVICES AND POLICY RESEARCH - BUCKET 1 - METHODOLOGY

Alberta First Nations Information Governance Centre project: Indigenous-led data and research governance

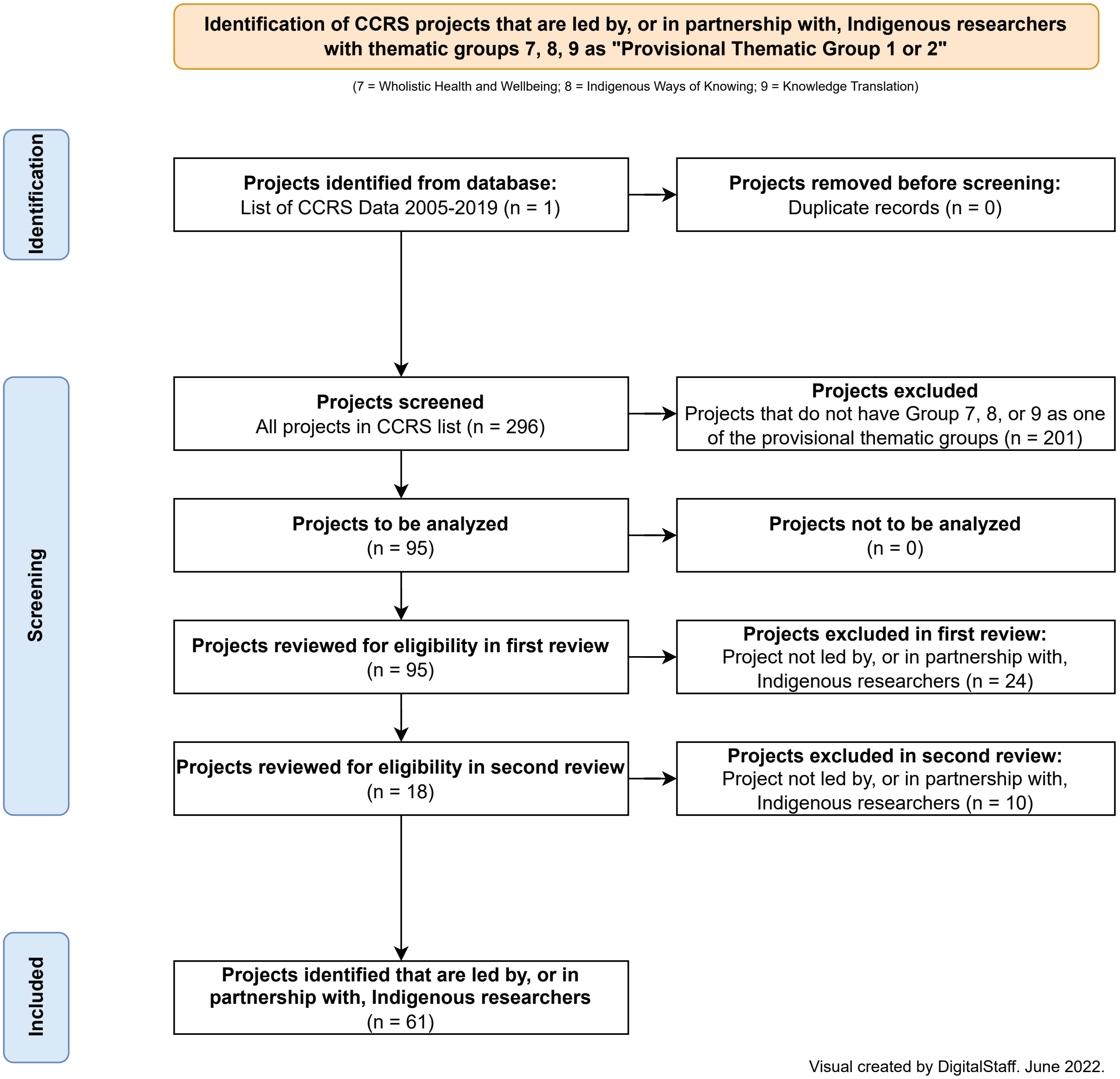
Methodology to review and identify projects led by, or in partnership with, Indigenous researchers from CCRS 2005 - 2019 list of projects that have "Health Services and Policy Research" identified as an Institute priority



Visual created by DigitalStaff. April 2022.

APPENDIX 2A
CCRS THEMATIC GROUPS 7, 8, 9 - BUCKET 2 - PRISMA

Alberta First Nations Information Governance Centre project: Indigenous-led data and research governance

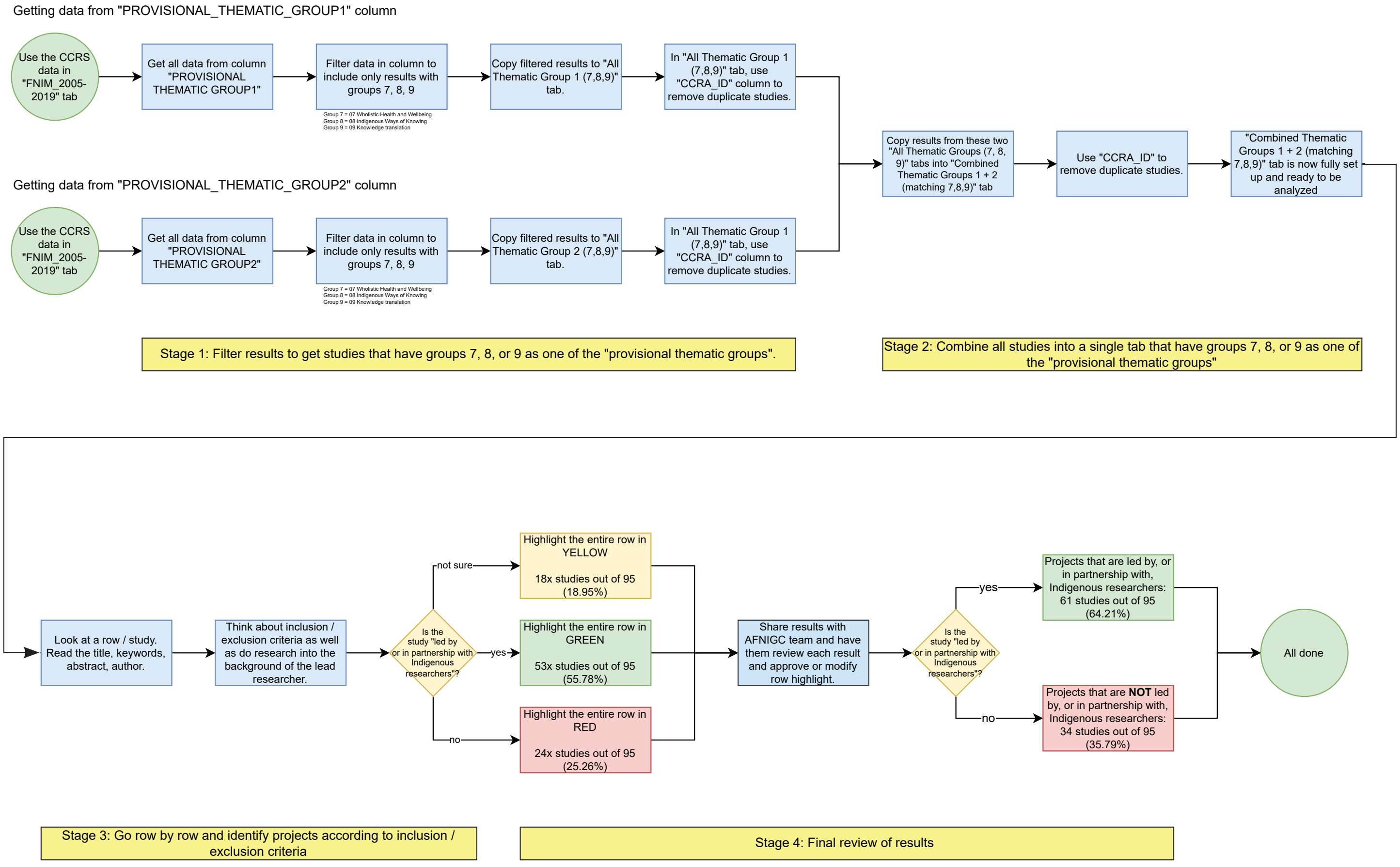


Visual created by DigitalStaff. June 2022.

APPENDIX 2B
CCRS THEMATIC GROUPS 7, 8, 9 - BUCKET 2 - METHODOLOGY

Alberta First Nations Information Governance Centre project: Indigenous-led data and research governance

Methodology to review and identify projects led by, or in partnership with, Indigenous researchers from CCRS 2005 - 2019 list of projects that have groups 7, 8, 9 identified as a Provisional Thematic Group



Getting data from "PROVISIONAL_THEMATIC_GROUP1" column

Use the CCRS data in "FNIM_2005-2019" tab

Get all data from column "PROVISIONAL THEMATIC GROUP1"

Filter data in column to include only results with groups 7, 8, 9

Group 7 = 07 Wholistic Health and Wellbeing
Group 8 = 08 Indigenous Ways of Knowing
Group 9 = 09 Knowledge translation

Copy filtered results to "All Thematic Group 1 (7,8,9)" tab.

In "All Thematic Group 1 (7,8,9)" tab, use "CCRA_ID" column to remove duplicate studies.

Getting data from "PROVISIONAL_THEMATIC_GROUP2" column

Use the CCRS data in "FNIM_2005-2019" tab

Get all data from column "PROVISIONAL THEMATIC GROUP2"

Filter data in column to include only results with groups 7, 8, 9

Group 7 = 07 Wholistic Health and Wellbeing
Group 8 = 08 Indigenous Ways of Knowing
Group 9 = 09 Knowledge translation

Copy filtered results to "All Thematic Group 2 (7,8,9)" tab.

In "All Thematic Group 1 (7,8,9)" tab, use "CCRA_ID" column to remove duplicate studies.

Copy results from these two "All Thematic Groups (7, 8, 9)" tabs into "Combined Thematic Groups 1 + 2 (matching 7,8,9)" tab

Use "CCRA_ID" to remove duplicate studies.

"Combined Thematic Groups 1 + 2 (matching 7,8,9)" tab is now fully set up and ready to be analyzed

Stage 1: Filter results to get studies that have groups 7, 8, or 9 as one of the "provisional thematic groups".

Stage 2: Combine all studies into a single tab that have groups 7, 8, or 9 as one of the "provisional thematic groups"

Look at a row / study. Read the title, keywords, abstract, author.

Think about inclusion / exclusion criteria as well as do research into the background of the lead researcher.

Is the study "led by or in partnership with Indigenous researchers"?

Highlight the entire row in YELLOW

18x studies out of 95 (18.95%)

Highlight the entire row in GREEN

53x studies out of 95 (55.78%)

Highlight the entire row in RED

24x studies out of 95 (25.26%)

Share results with AFNIGC team and have them review each result and approve or modify row highlight.

Is the study "led by or in partnership with Indigenous researchers"?

Projects that are led by, or in partnership with, Indigenous researchers: 61 studies out of 95 (64.21%)

Projects that are **NOT** led by, or in partnership with, Indigenous researchers: 34 studies out of 95 (35.79%)

All done

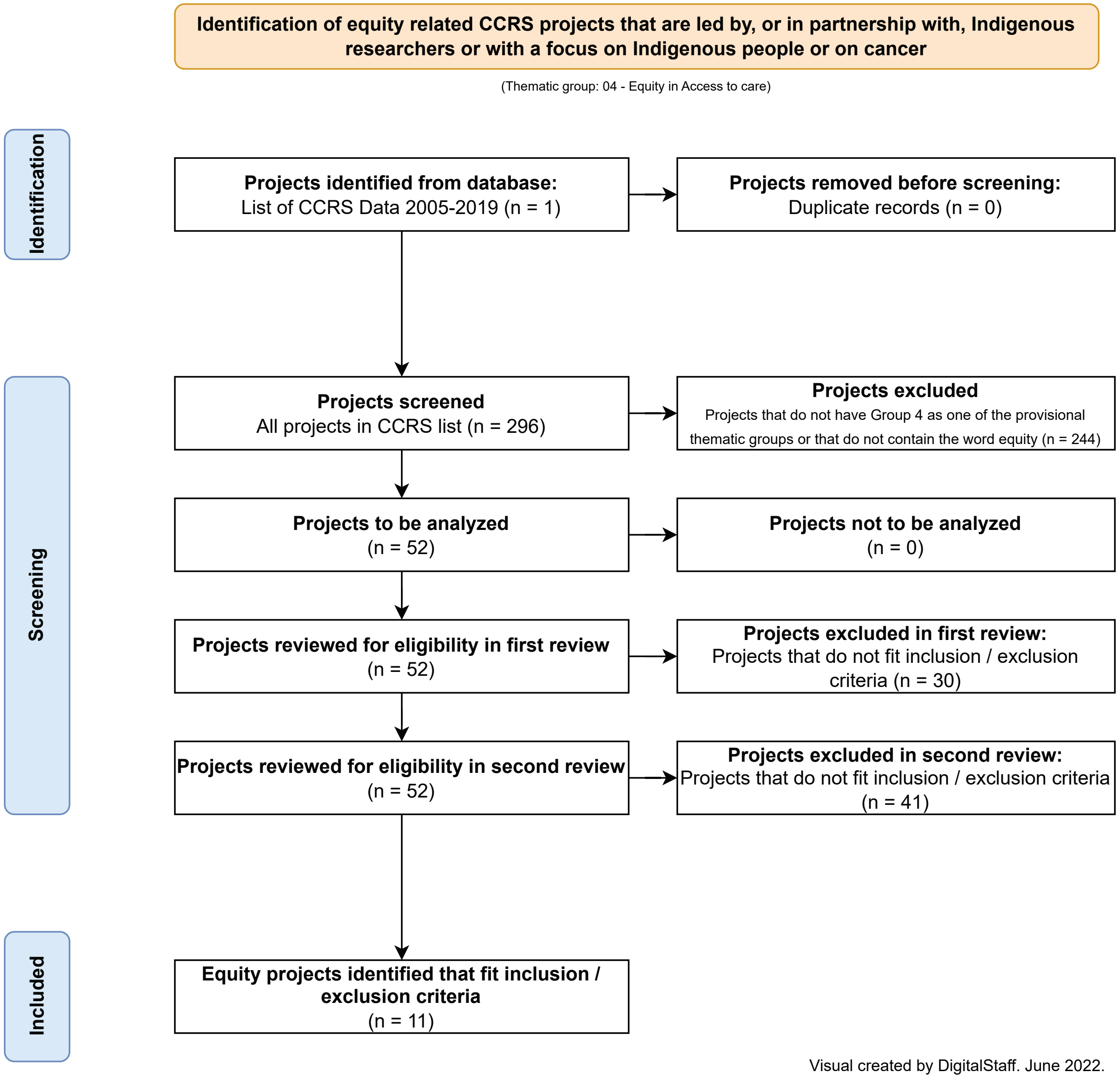
Stage 3: Go row by row and identify projects according to inclusion / exclusion criteria

Stage 4: Final review of results

Visual created by DigitalStaff. April 2022.

APPENDIX 3A
CCRS EQUITY PROJECTS PRISMA

Alberta First Nations Information Governance Centre project: Indigenous-led data and research governance

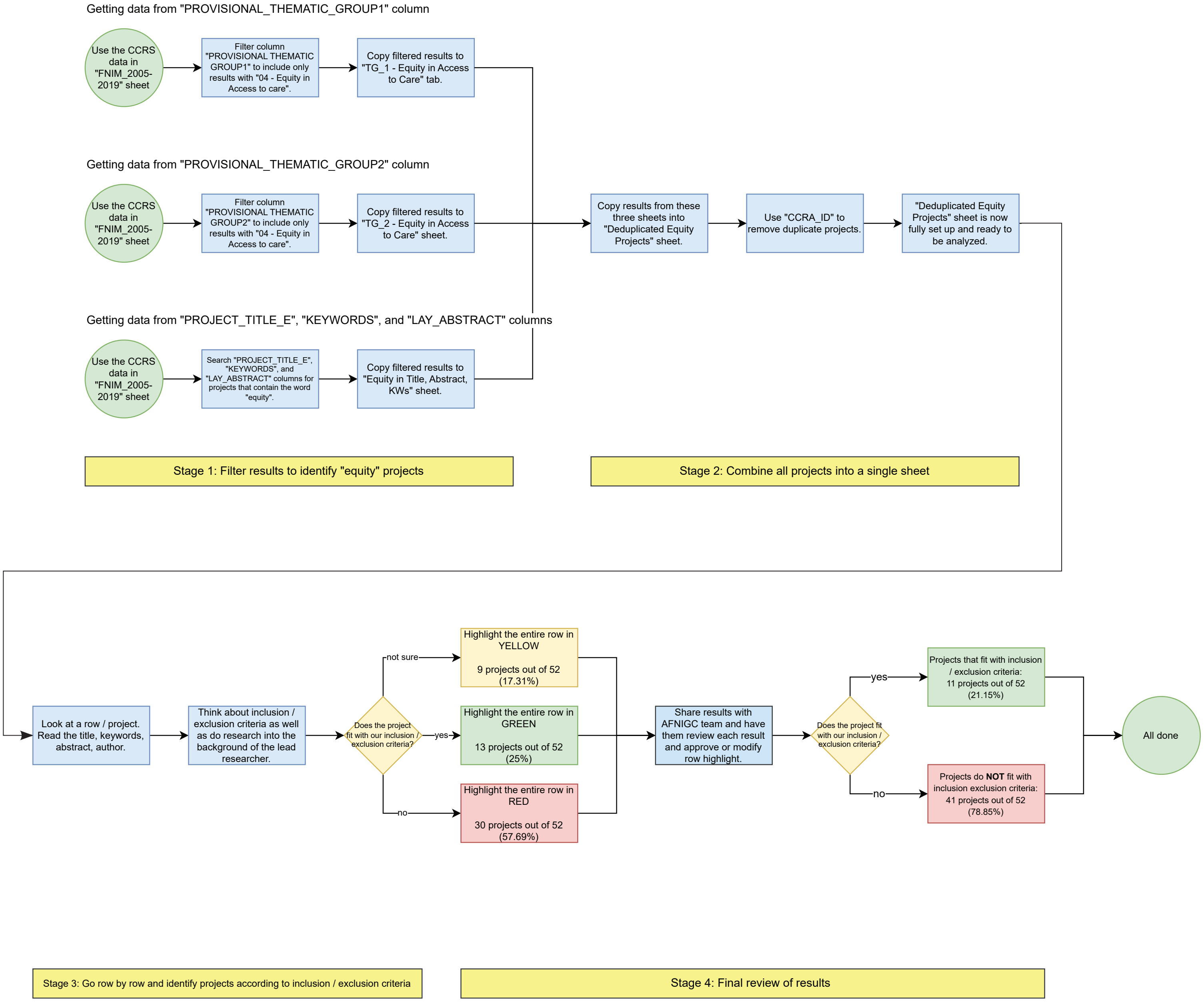


Visual created by DigitalStaff. June 2022.

APPENDIX 3B
CCRS EQUITY PROJECTS - METHODOLOGY

Alberta First Nations Information Governance Centre project: Indigenous-led data and research governance

Methodology to review and identify projects led by, or in partnership with, Indigenous researchers from CCRS 2005 - 2019 list of projects that have "Equity" identified as a thematic group or in the project title, abstract, or key words



Getting data from "PROVISIONAL_THEMATIC_GROUP1" column

Use the CCRS data in "FNIM_2005-2019" sheet

Filter column "PROVISIONAL THEMATIC GROUP1" to include only results with "04 - Equity in Access to care".

Copy filtered results to "TG_1 - Equity in Access to Care" tab.

Getting data from "PROVISIONAL_THEMATIC_GROUP2" column

Use the CCRS data in "FNIM_2005-2019" sheet

Filter column "PROVISIONAL THEMATIC GROUP2" to include only results with "04 - Equity in Access to care".

Copy filtered results to "TG_2 - Equity in Access to Care" sheet.

Copy results from these three sheets into "Deduplicated Equity Projects" sheet.

Use "CCRA_ID" to remove duplicate projects.

"Deduplicated Equity Projects" sheet is now fully set up and ready to be analyzed.

Getting data from "PROJECT_TITLE_E", "KEYWORDS", and "LAY_ABSTRACT" columns

Use the CCRS data in "FNIM_2005-2019" sheet

Search "PROJECT_TITLE_E", "KEYWORDS", and "LAY_ABSTRACT" columns for projects that contain the word "equity".

Copy filtered results to "Equity in Title, Abstract, KWs" sheet.

Stage 1: Filter results to identify "equity" projects

Stage 2: Combine all projects into a single sheet

Look at a row / project. Read the title, keywords, abstract, author.

Think about inclusion / exclusion criteria as well as do research into the background of the lead researcher.

Does the project fit with our inclusion / exclusion criteria?

not sure

Highlight the entire row in YELLOW

9 projects out of 52 (17.31%)

yes

Highlight the entire row in GREEN

13 projects out of 52 (25%)

no

Highlight the entire row in RED

30 projects out of 52 (57.69%)

Share results with AFNIGC team and have them review each result and approve or modify row highlight.

Does the project fit with our inclusion / exclusion criteria?

yes

Projects that fit with inclusion / exclusion criteria: 11 projects out of 52 (21.15%)

no

Projects do **NOT** fit with inclusion exclusion criteria: 41 projects out of 52 (78.85%)

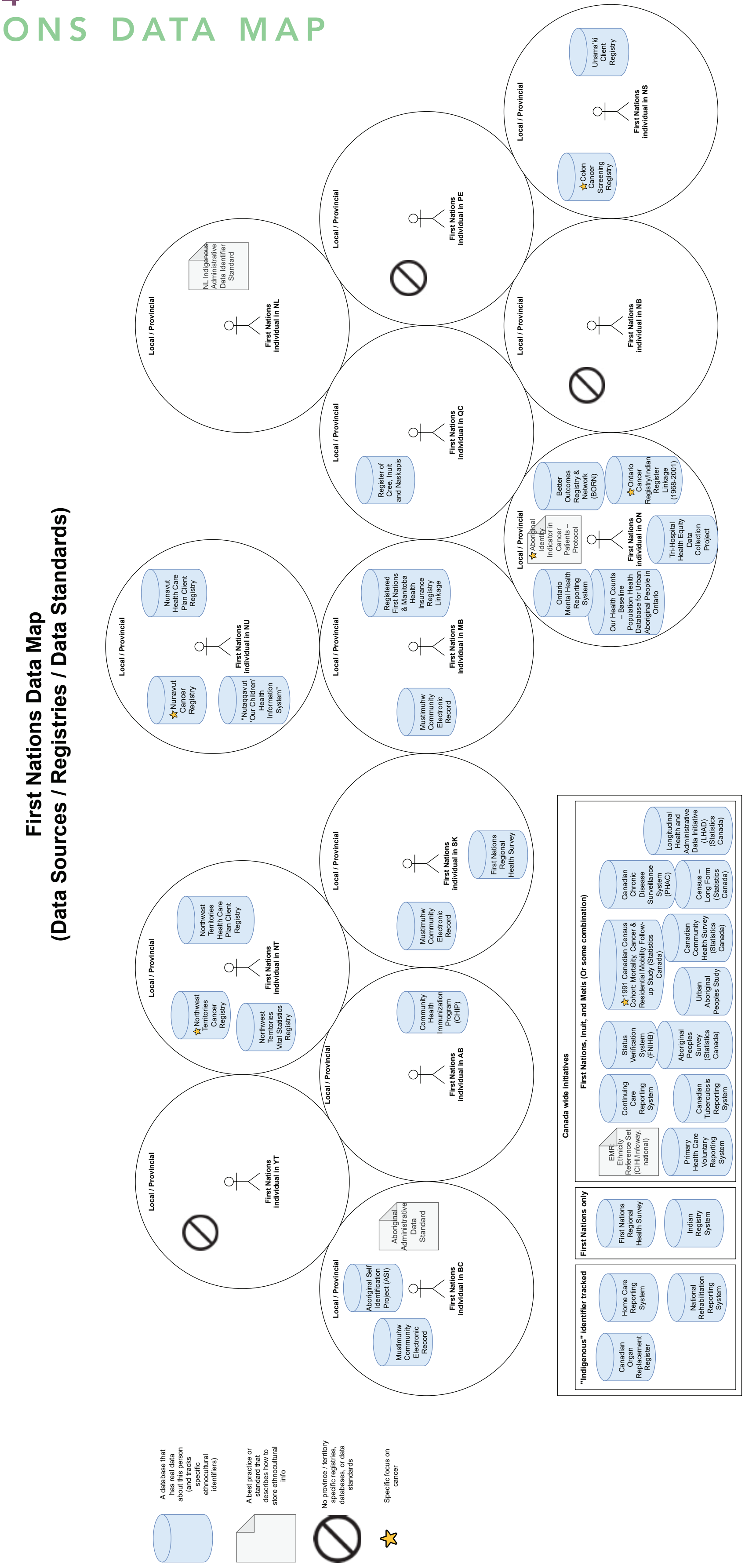
All done

Stage 3: Go row by row and identify projects according to inclusion / exclusion criteria

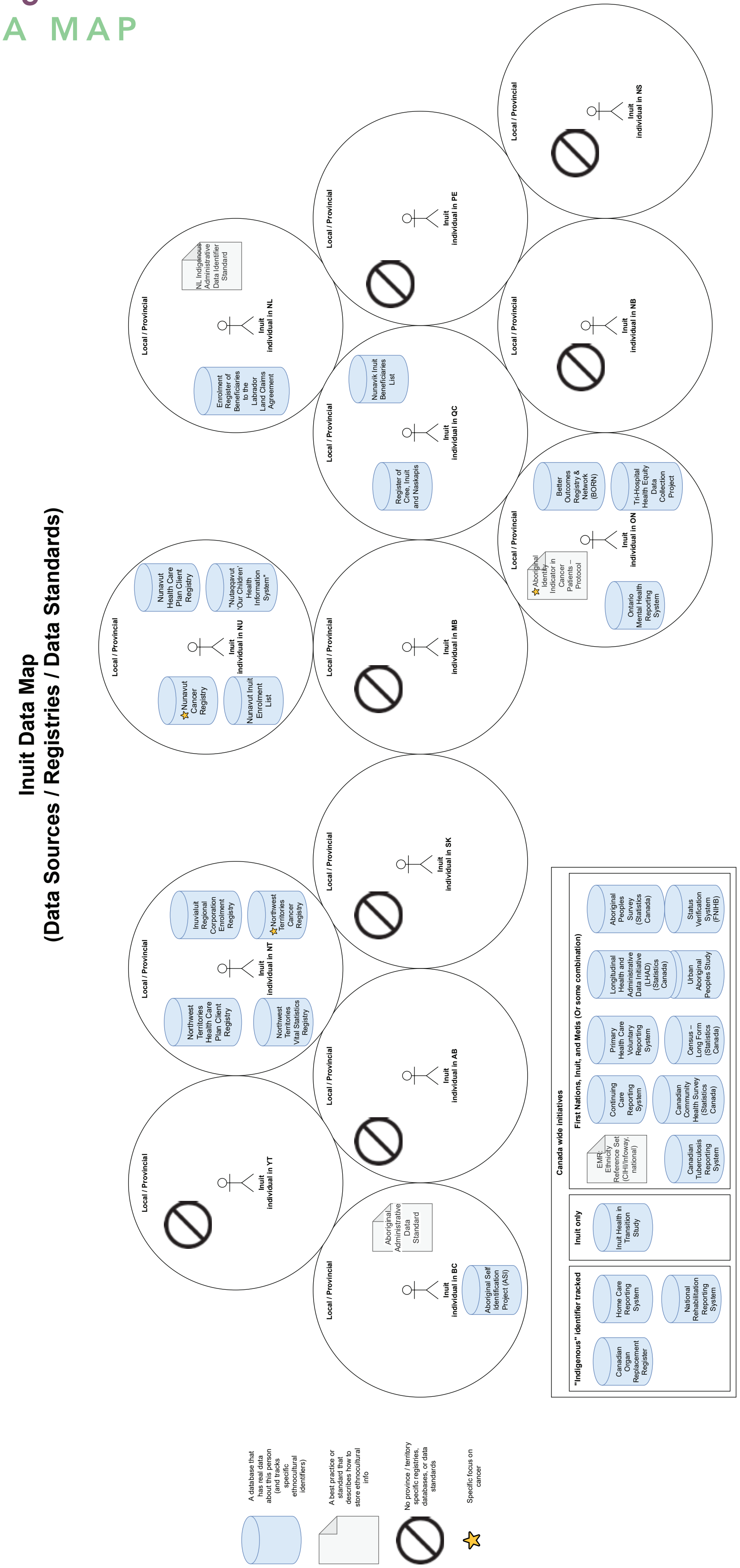
Stage 4: Final review of results

Visual created by DigitalStaff. June 2022.

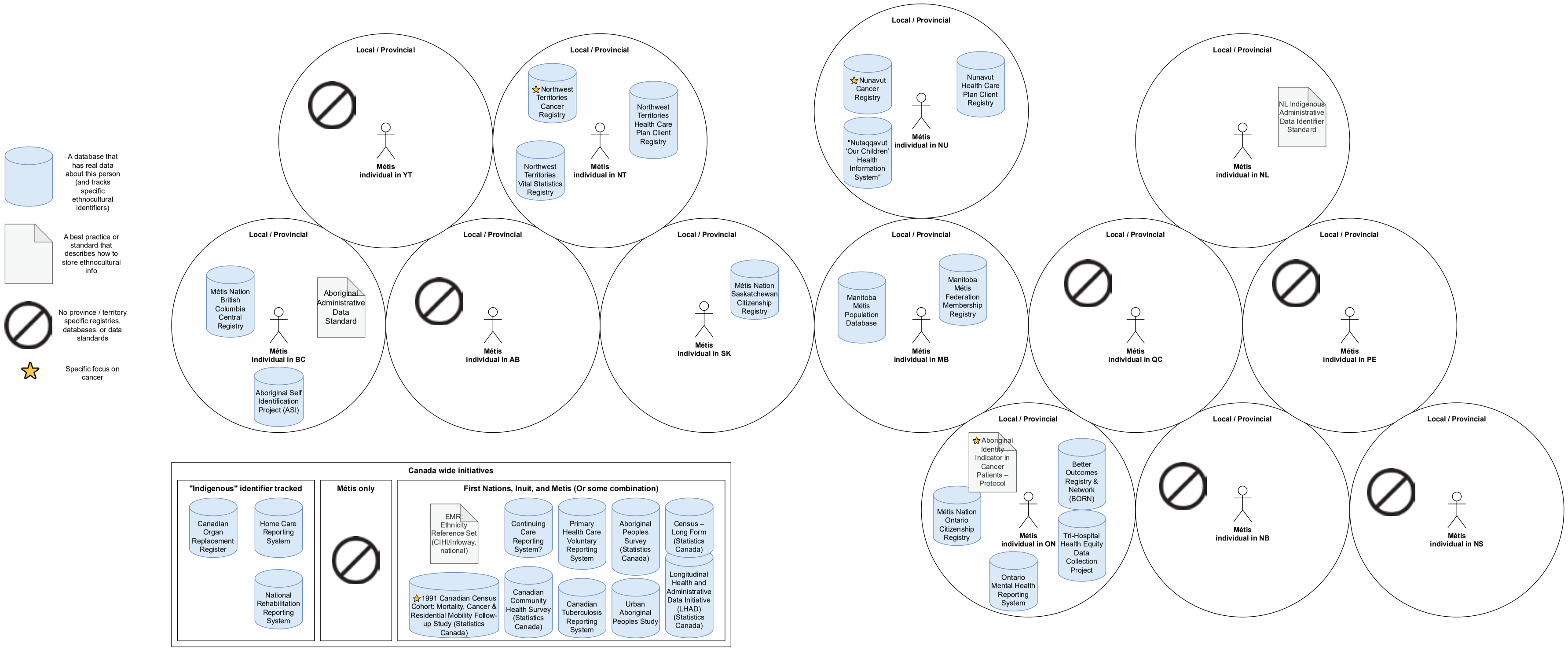
APPENDIX 4
FIRST NATIONS DATA MAP



APPENDIX 5
INUIT DATA MAP



Métis Data Map
(Data Sources / Registries / Data Standards)



NOTES

NOTES

INDIGENOUS CANCER RESEARCH AND THE CANCER DATA LANDSCAPE
– AN ENVIRONMENTAL SCAN

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