PAN-CANADIAN
CANCER DATA
STRATEGY

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PAN-CANADIAN **CANCER DATA STRATEGY**

Contents

Executive Summary

High-quality data enables high-quality health care. But too often, data is incomplete, out of date or difficult to access. By committing to investing in Canada's cancer data ecosystem, we will be better able to support evidence-informed patient-centric care; innovative research; and effective healthcare service planning and delivery. An enhanced data ecosystem can also advance health equity by helping us better understand and respond to the health and cancer needs of communities that are underserved by the healthcare system.

The federal Working together to improve health care for Canadians plan was launched in 2023. Among other areas of focus, this plan highlights the importance of using data to improve the safety and quality of care. Initiatives such as the pan-Canadian Health Data Strategy (pCHDS) and the First Nations Data Governance Strategy are providing critical guidance to help establish an infrastructure that promotes access to better quality and more comprehensive data. Building on this foundation, the Canadian Partnership Against Cancer (the Partnership) and the Canadian Cancer Society (CCS) worked with provincial and territorial cancer agencies/programs and other partners throughout Canada's health and data systems to create a cancer-specific data strategy.

This pan-Canadian Cancer Data Strategy (cancer data strategy) will guide efforts to enhance the collection, integration and use of cancer data, focusing primarily on administrative data to support policy and planning, system-level clinical quality improvement, and health services and policy research. It complements and leverages the priorities and principles identified in the broader pCHDS and the Pan-Canadian Health Data Charter and acknowledges the collaboration underway between federal, provincial and territorial governments to improve health data. In addition, it aligns with the aims of the Shared Pan-Canadian Interoperability Roadmap to reduce data blocking and ease data portability, and to improve care coordination and

collaboration. The cancer data strategy also expands on the imperative to address cancer data noted in the Canadian Strategy for Cancer Control and supports efforts to respect and uphold First Nations, Inuit and Métis data sovereignty.

The cancer data strategy is starting from a place of strength with a mission to inspire and support the mobilization of data to improve cancer care access, experience and outcomes in Canada. It is based on broad cross-sector alignment on priorities for investment and an existing cancer data infrastructure that is more advanced than that of most other parts of the Canadian health system. This is thanks to the maturity of platforms like provincial cancer data systems and the Canadian Cancer Registry. At the same time, the cancer data strategy aims to address critical gaps that remain and advance improvements in:
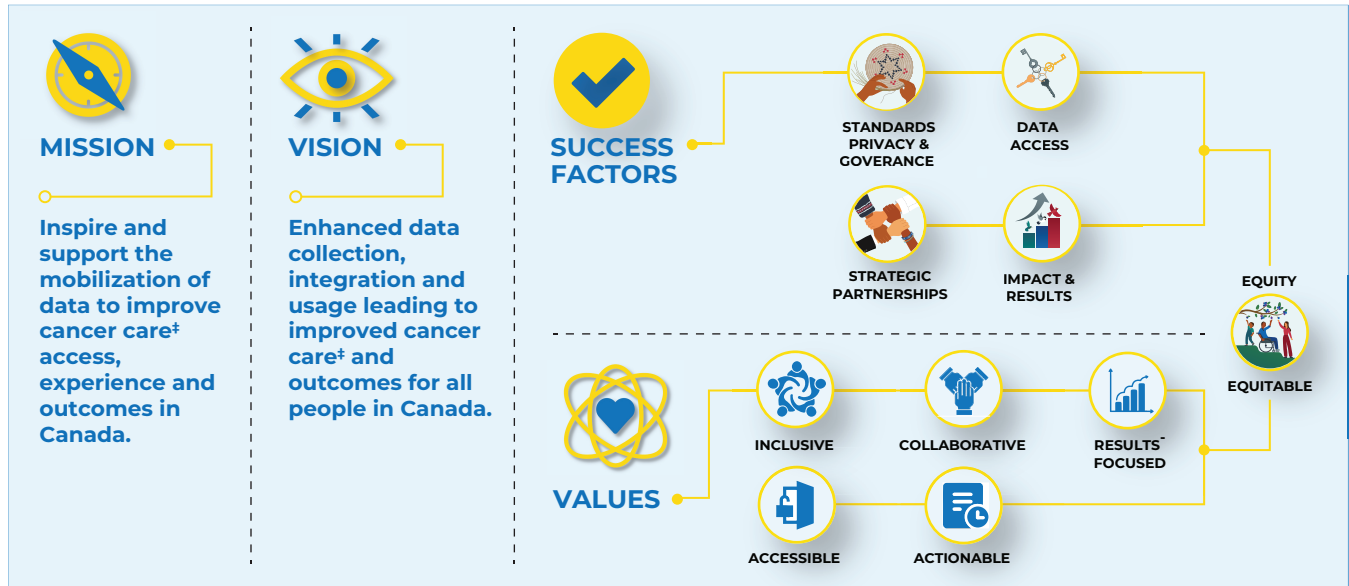
- integration of standardized identifiers for equity-deserving groups;

- support for First Nations, Inuit and Métis-governed efforts to build capacity for improved cancer data;

- timeliness and completeness of cancer data;

- accessibility of cancer data;

- comprehensive data capture for all parts of the cancer continuum;

- coordination of data integration and infrastructure initiatives.

The cancer data strategy includes:

- an organizing framework outlining the mission, vision, values and success factors defining the strategy;

- a set of priorities and facilitators that help drive action and investments;

- a section on the importance of First Nations, Inuit and Métis data sovereignty with examples of First Nations, Inuit and Métis-led efforts to improve data and data governance.
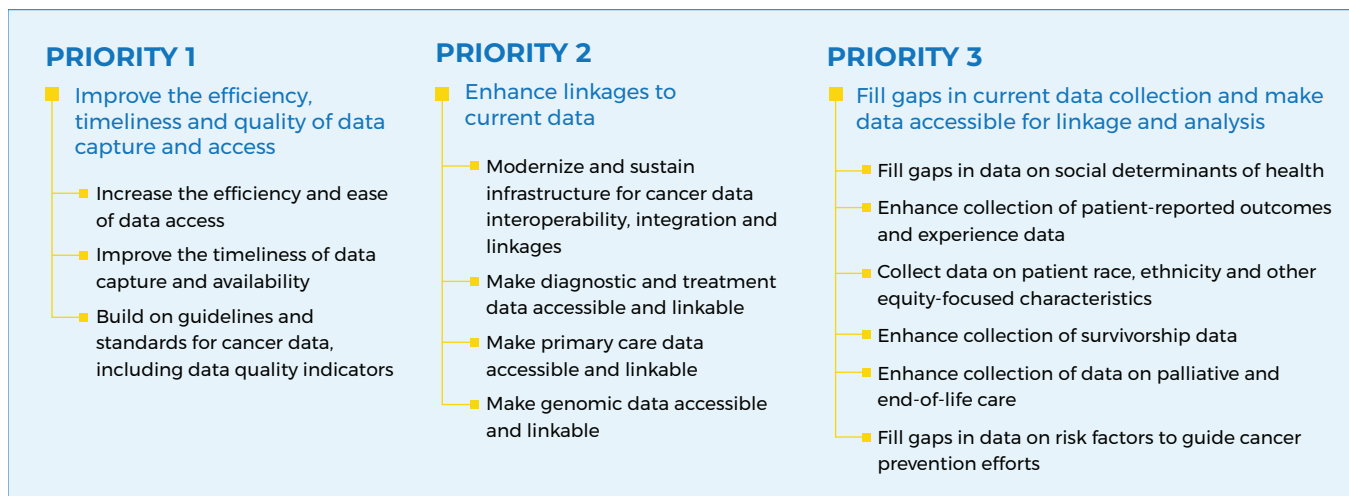
A framework to guide the strategy

Based on a broad engagement process, we developed the following strategic framework to serve as the foundation for this strategy:

MISSION

Inspire and support the mobilization of data to improve cancer care‡ access, experience and outcomes in Canada.

VISION

Enhanced data collection, integration and usage leading to improved cancer care‡ and outcomes for all people in Canada.

SUCCESS FACTORS

- STANDARDS PRIVACY & GOVERANCE
- DATA ACCESS
- STRATEGIC PARTNERSHIPS
- IMPACT & RESULTS
- EQUITY / EQUITABLE

VALUES

- INCLUSIVE
- COLLABORATIVE
- RESULTS FOCUSED
- ACCESSIBLE
- ACTIONABLE

Priority areas for investment

The health information landscape is vast, with many facets that are quickly evolving through innovations such as artificial intelligence and big data. Advancements in how data is collected and used are informing all aspects of the cancer continuum, from prevention and better understanding of genetic risks to new treatment methodologies.

Through engagement with key partners as well as patients and families, we identified the most critical data-related priorities and a set of facilitators needed to act on them. Advancing these priorities and facilitators will require concerted efforts and investment from partners throughout the health system.

PRIORITY 1

- Improve the efficiency, timeliness and quality of data capture and access
  - Increase the efficiency and ease of data access
  - Improve the timeliness of data capture and availability
  - Build on guidelines and standards for cancer data, including data quality indicators

PRIORITY 2

- Enhance linkages to current data
  - Modernize and sustain infrastructure for cancer data interoperability, integration and linkages
  - Make diagnostic and treatment data accessible and linkable
  - Make primary care data accessible and linkable
  - Make genomic data accessible and linkable

PRIORITY 3

- Fill gaps in current data collection and make data accessible for linkage and analysis
  - Fill gaps in data on social determinants of health
  - Enhance collection of patient-reported outcomes and experience data
  - Collect data on patient race, ethnicity and other equity-focused characteristics
  - Enhance collection of survivorship data
  - Enhance collection of data on palliative and end-of-life care
  - Fill gaps in data on risk factors to guide cancer prevention efforts

FACILITATORS

- Understanding the data landscape
- Building infrastructure and adequately resourcing it to support sustainability
- Improving data literacy amoung health system partners
- Elevating patient voice in planning/implementing data activities

Through engagement with this strategy, the cancer data community can help build a more cohesive cancer data ecosystem for the benefit of all people in Canada.

Support for First Nations, Inuit and Métis-governed data and data systems

The United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) affirms the rights of First Nations, Inuit and Métis to self-determination and self-government.[1] This requires efforts to respect, uphold and honour First Nations, Inuit and Métis data sovereignty so decisions about programs, services and policies can be based on high-quality, distinctions-based data.

As exposed by the pandemic, high-quality, disaggregated data is needed to understand the impact of health issues such as COVID-19 or cancer on First Nations, Inuit and Métis communities. In addition, most of the cancer data that does exist about First Nations, Inuit and Métis in Canada is currently held by other data stewards (e.g., governments, health organizations, hospitals, cancer centres). It is therefore critical that these data steward support actions that:

- facilitate improved data collection and reporting governed by First Nations, Inuit and Métis;
- promote First Nations, Inuit and Métis data governance and self-determination;
- establish relationships based on reciprocity, trust and respect.

By working together and respecting First Nations, Inuit and Métis knowledge and worldviews, progress can be made to collect high-quality, distinctions-based data that can help close the health equity gaps that exist between First Nations, Inuit and Métis communities and non-Indigenous communities.

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‡For this strategy, care refers to and includes prevention, early detection and screening, diagnosis, treatment, supportive and palliative care, recovery and survivorship, and end-of-life care.

Message from the CEOs

Data has the power to transform cancer care. It provides critical information that helps shape approaches to cancer screening, diagnosis, treatment and services, and informs policies that affect the health of Canadians. But when it comes to cancer data in Canada, there are many gaps. To save and improve more lives, we must do a better job of consistently collecting complete and high-quality cancer data, linking relevant data sets, and making it easily accessible to those who need it.

Together the Canadian Partnership Against Cancer and the Canadian Cancer Society worked with partners across the cancer community—including provincial and territorial cancer agencies and programs; healthcare organizations; First Nations, Inuit and Métis partners; researchers; policymakers, and people with lived cancer experience—to create this pan-Canadian Cancer Data Strategy. The strategy aims to guide efforts to enhance the collection, integration and use of cancer data in Canada.

Fulfilling the goals identified in the cancer data strategy will be a team effort. We call on health administrators, researchers and academic institutions, and federal and provincial and territorial policymakers to engage with this strategy and join together to implement its priorities. Working collaboratively, we can build a more cohesive cancer data ecosystem that benefits all people in Canada and is nimble enough to respond to future needs. We also invite this group to continue to share their voices and perspectives to help us enhance and update this first iteration of the strategy. We are committed to continuing to engage with key partners to plan implementation efforts.

The launch of this pan-Canadian Cancer Data Strategy complements other data-focused initiatives stemming from the federal Working together to improve health care for Canadians plan, such as the Pan-Canadian Health Data Strategy[2]. Additionally, in recent health transfer funding agreements, the federal government has called on the provinces and territories to endorse the Pan-Canadian Health Data Charter and adopt common standards and policies related to data as outlined in the

Shared Pan-Canadian Interoperability Roadmap. The cancer data strategy aligns with the principles of the pan-Canadian Health Data Strategy and Interoperability Roadmap in addressing the circumstances, barriers and needs specific to the cancer care ecosystem. It builds on a solid foundation of existing cancer data to advance our priorities and make measurable progress quickly, offering a roadmap for other healthcare communities to follow.

A coordinated cancer data strategy is more important now than ever. In the face of the COVID-19 pandemic, health inequities were exacerbated, highlighting the limited data available to allow those in the cancer care ecosystem to understand the impacts on those affected by the disease. We believe that, if widely adopted and supported with the right investments, the pan-Canadian Cancer Data Strategy will help change the future of cancer in Canada. It will give us a better understanding of which cancers are most prevalent among specific populations, what socioeconomic factors have the greatest impact on outcomes and more. In turn, this will help us improve the patient experience through prevention, diagnosis, treatment, survivorship, and palliative and end-of-life care with better planning, decisions and innovations—all while protecting individual privacy and respecting the data sovereignty of First Nations, Inuit and Métis peoples.

On behalf of our partners involved in the development of this strategy, the Canadian Partnership Against Cancer and the Canadian Cancer Society invite all members of the cancer data community to join the effort to improve cancer data in Canada. Together, we can harness the power of data to build the cancer care system of tomorrow, today.

Dr. Craig Earle
CEO, Canadian Partnership Against Cancer

Andrea Seale
CEO, Canadian Cancer Society

Why data matters for cancer care

The fact that high-quality data is critical to supporting good decisions is a self-evident truth. "High quality" generally means timely, accurate, complete, comprehensive, standardized, relevant (fit-for-purpose) and accessible. But what is high-quality data in the context of health and cancer care?

- For **individual patients and their clinical care teams**, it is data that provides clear information on diagnosis, test results, treatments, patient experience and outcome measures, and other relevant documentation.

- For **researchers and clinical scientists**, it is data that allows them to study, understand and contribute to the latest results of basic science, clinical trials and health services research.

- For **policy makers, planners and administrators,** it is data that informs decisions to improve the availability, quality, equity and outcomes of healthcare services.

- For **First Nations, Inuit and Métis governments and organizations,** it is data that allows them to serve the interests of their communities and over which they maintain sovereignty and control.

In the Canadian cancer care landscape, a lot of useful data is collected at local levels (by hospitals, cancer centres, clinics, labs and pharmacies; by research teams and organizations; by provincial/territorial and federal governments, data agencies and public health programs). Some of that data collection is organized, standardized and managed centrally in ways that make it accessible to various users. Examples include provincial cancer registries and the Canadian Cancer Registry (CCR).[3] But other cancer data is collected locally with little or no standardization or without the ability to access it and link it to other data sets in ways that increase its value. Even data that is organized and made available centrally (through the cancer registries, for example) is not always as timely, complete and comprehensive as it could be.

These gaps have real consequences. When COVID-19 hit, difficulties in accessing high-quality, disaggregated health data limited the effectiveness of pandemic response across the country, as well as healthcare delivery beyond the pandemic-specific response. The pandemic also magnified existing deficiencies in the healthcare system overall, shining a spotlight on systemic inequities and the inability to properly measure health outcomes and other indicators. This highlighted the critical need for equity-related data to be routinely collected so policies, programs and services can be designed for those who need it most.

To help address some of these challenges, in 2020, the federal government and its health agencies established an expert advisory group to develop the Pan-Canadian Health Data Strategy (pCHDS).[2] At a high level, the pCHDS aims to:

- modernize health data collection, sharing and interoperability across critical health data supply chains;

- streamline and update the approach to privacy and access for the digital age;

- clarify accountability and health data governance to bring meaningful change in the way governments share data;

- establish a policy framework that supports appropriate data exchange, reuse and collaboration, balanced with security, confidentiality and respect for privacy.

The priorities of the pCHDS are being advanced through the health data commitments agreed to by the federal, provincial, and territorial governments as part of the Working together to improve health care for Canadians plan (Working together plan). The pCHDS makes several recommendations to enhance the use of data throughout the health system. (See Appendix 3 for the full list of recommendations). Data commitments in recent bilateral healthcare agreements and the work being led by the Canadian Institute for Health Information (CIHI), Canada Health Infoway (CHI), Statistics Canada, the Public Health Agency of Canada (PHAC), as well as provincial and territorial partners to advance the pCHDS are positive steps forward. While these recommendations and efforts offer tremendous potential for health system transformation, they do not specifically address the data-related needs unique to the cancer ecosystem.

Why a cancer-specific data strategy?

Cancer is the leading cause of death in Canada. A study published[4] in May 2022 estimated that more than 230,000 people would be diagnosed with cancer in 2022, and 85,000 people would die from the disease. Better access to high-quality cancer data is needed to deliver improved and more equitable cancer outcomes in Canada, particularly in the aftermath of system-wide crises like the COVID-19 pandemic.

Timely access to high-quality cancer data brings several key benefits, including:

- better and faster response to cancer system challenges, both chronic and emerging;

- improved patient experience and outcomes;

- more informed response to pandemic recovery and policy, research, and healthcare questions;

- breaking down of silos to maximize efficiency and align objectives across the health system.

While a significant amount of data regarding cancer patients and their treatment is currently collected in Canada, there are opportunities to substantially improve the value of that data, including:

- making it more timely;

- enhancing its completeness by encompassing all relevant phases of the cancer experience (including the currently undermeasured aspects before definitive diagnosis, after treatment, and during palliative and end-of-life care);

- reducing barriers to accessing cancer data including improved reciprocity in partnerships to ensure First Nations, Inuit and Métis have access to data about their communities;

- improving standardization and comparability across jurisdictions and data systems;

- supporting better coordination of decentralized data initiatives;

- enabling identification of First Nations, Inuit and Métis and equity-deserving groups, including people who are racialized, are immigrants, are 2SLGBTQI+, are disabled and others, so data is available to inform efforts to close health equity gaps;

- better support for First Nations, Inuit, and Métis-governed cancer data.

What is cancer data?

Cancer data refers to patient-and population-based data and information that is relevant to the cancer continuum. It includes provincial/territorial and federal administrative data sets, data sets for major research studies and programs, relevant digital health data sets, and more.

What is timely data?

Timeliness is contextual and depends on how data is collected and how it is intended to be used. In a clinical setting, timeliness could be a matter of minutes, hours or days. When being used to inform strategic planning decisions, timeliness could be a matter of months. Data quality standards should identify appropriate timeframes for data collection and reporting with agreed-upon targets.

Building on progress

We are not starting from scratch. A great deal of work has already been done to enhance the health and cancer data ecosystem. For example, the recent bilateral health transfer agreements between the federal government and provinces/territories includes data-related commitments such as the creation of new health data indicators and support for a new centre of excellence on health worker data. These initiatives can help enable the priorities and initiatives coming out of the pCHDS. Several jurisdictions, including Alberta, British Columbia, Newfoundland and Labrador, Nova Scotia, and Saskatchewan, have also implemented or are in the process of implementing new electronic medical records or digital health platforms.

In 2021, the Canadian Cancer Research Alliance (supported by the Canadian Cancer Society, the Canadian Partnership Against Cancer, the Canadian Institutes of Health Research Institute of Cancer Research, Genome Canada and the Ontario Institute for Cancer Research) published a set of recommendations[5] to enhance cancer health service planning and policy research, including several recommendations calling for more cohesive data infrastructure across the country.

The Canadian Cancer Registry[3] is a prime example of a successful initiative, offering a pan-Canadian platform that is well organized and has many systems in place to link a variety of key data points. Multiple other projects and platforms have also been developed to facilitate the use of cancer data, including the CanPath Portal[6] and Health Data Research Network Canada.[7] However, many of these projects would benefit from better coordination and tighter integration with each other.

For First Nations, Inuit and Métis, efforts to advance data sovereignty—that is, "the right [of First Nations, Inuit and Métis Peoples] to determine the means of collection, access, analysis, interpretation, management, dissemination and reuse of data pertaining to Indigenous people from whom it has been derived, or to whom it relates"[8]—are underway. The First Nations Data Governance Strategy[8] "envisions a First Nations-led national network of regional information governance centres equipped with the knowledge, skills and infrastructure to serve the information needs of First Nations peoples and communities." The Métis National Council[9] is also in the process of establishing a national Métis data development and governance strategy, and Inuit Tapiriit Kanatami is developing a national Inuit data strategy.[10] These efforts will enable a future where First Nations, Inuit and Métis Peoples' rights to data sovereignty are respected, upheld and honoured. In addition, improving data collection and reporting are opportunities to work toward eliminating racism against First Nations, Inuit and Métis in healthcare settings.

Efforts have also been made to advance the collection of health equity data. Black Health Matters COVID-19 is a national survey developed by and for African/Black individuals and communities to understand the impacts of the pandemic on African/Black communities in Canada and transnationally.[11] Another example is work led by CIHI to develop minimum standards for the safe collection of race-based and First Nations, Inuit and Métis identity data in health care.[12] This work included engagements with federal and provincial/territorial governments; researchers; clinicians; organizations that represent racialized communities; and First Nations, Inuit and Métis organizations. These efforts can help better understand inequities in care experiences, access and outcomes, and can inform interventions to eliminate racism and advance health equity.

Developing a pan-Canadian Cancer Data Strategy

The Canadian Partnership Against Cancer (the Partnership) and the Canadian Cancer Society (CCS) worked with the provincial cancer agencies/programs and other partners throughout the Canadian cancer system to create a strategy that will guide efforts to enhance the collection, integration and use of cancer data. This pan-Canadian Cancer Data Strategy complements and builds on the priorities and principles identified in the pCHDS. While the pCHDS is focused on broad, foundational infrastructure changes, this cancer data strategy is a tactical, cancer-specific strategy designed to guide the development of initiatives that can be implemented quickly by leveraging and building on existing cancer data infrastructure.

In that regard, the cancer data strategy is starting from a place of strength, with broad cross-sector alignment on the priorities for investment and a data infrastructure that is more advanced than that of most other parts of the Canadian health system, thanks to the maturity of platforms like the CCR. The strength of that platform and the lessons we have already learned from it position us well to build on those strengths and showcase the difference high-quality data can make. By being able to demonstrate quick wins that have significant impact within five years, the cancer data strategy can serve as a testing ground for other health data strategies, with sectors across the health system applying our learnings to improve their own approaches to data.

Who contributed to the pan-Canadian Cancer Data Strategy?

The cancer data strategy was developed in collaboration with a wide range of cancer system partners, including:

- patient and family advisors
- First Nations, Inuit and Métis partners
- cancer system health leaders
- research organizations and funders
- provincial and territorial cancer agencies and programs
- pan-Canadian health organizations

For more on how the strategy was developed, see "Appendix 2: How the strategic framework was developed".

A framework to guide the strategy

The Partnership and CCS conducted a broad engagement process to create a strategic framework that would form the foundation of the cancer data strategy. The process included working sessions and facilitated discussions with organizations and partners within and beyond the cancer care system. The strategic framework was developed with their input, refined with their feedback, and finalized with insight from patient and family advisors. It consists of the following mission, vision, values and success factors, providing a structure that policy makers, researchers, academic institutions, healthcare system partners and others can align with and use to guide cancer data improvements in Canada.

Mission

Inspire and support the mobilization of data to improve cancer care‡ access, experience and outcomes in Canada.

Vision

Enhanced data collection, integration and use leading to improved cancer care‡ and outcomes for all people in Canada.

Values

- **Inclusive:** Work with partners across Canada—representing a diversity of experiences and perspectives—using a variety of engagement methods to ensure communities (especially equity-deserving groups) have a meaningful say in the systems that affect them.

- **Equitable:** Take a differentiated, intentional approach to address the diverse needs of our partners, and work to achieve respectful processes, equality of opportunity and equitable outcomes.

- **Collaborative:** Work together to find the best approaches to support partners, populations and others to gain access to, fluency with or use of data—including financial support and resources.

- **Results-focused:** Focus on prioritizing initiatives that will have clear, beneficial impacts for people in Canada.

- **Accessible:** Remove barriers to accessing data and focus on access to portable data.

- **Actionable:** Through training, access and other activities, place making positive change at the heart of all initiatives, ensuring partners are able to use timely data to enhance their decision-making in the interest of patient care.

‡ For this strategy, care refers to and includes prevention, early detection and screening, diagnosis, treatment, supportive and palliative care, recovery and survivorship, and end-of-life care.

Success factors

The following factors represent key elements that are critical to the success of the cancer data strategy:

Strategic partnerships

Strategic partnerships will enable the cancer data strategy to:

- build diverse, effective, cross-jurisdictional and cross-sectoral partnerships while advancing pan-Canadian priorities;

- encourage private–public sector partnerships to accelerate uptake and implementation of priorities, including adoption of innovation and new technologies;

- actively engage all partners, including data holders, data users and organizations that represent equity-deserving communities, to understand and support their diverse needs, identify areas of alignment, build trustworthy relationships, and be transparent about shared goals;

- provide clarity about who data users should engage with to access linked data sets;

- acknowledge the strength of data sovereignty assertions of First Nations, Inuit and Métis partners, and support their data governance and application efforts in a collaborative manner;

- recognize community-driven and Nation-based approaches to data management and governance, including the First Nations Data Governance Strategy, as well as a national Métis data development and governance strategy and a national Inuit data strategy, which are under development.

Standards, privacy and governance

Clearly defined data quality standards and data governance mechanisms aligned with the pCHDS will enable the cancer data strategy to:

- create a structure to guide implementation activities and support all partners in achieving the strategy's vision;

- encourage the adoption of leading practices in data governance and the development of a common set of definitions and standards to assure the quality of data being captured and shared;

- promote platform interoperability between systems and jurisdictions that is aligned with the Interoperability Roadmap;

- explore standards to enhance data access while supporting partners to work together to respect existing data governance, privacy and legislative frameworks—because establishing data transparency will be important to building and maintaining trust;

- align with First Nations principles of OCAP®[13] (ownership, control, access, possession), as well as Inuit and Métis data governance principles.

Data access

Data access will enable the cancer data strategy to:

- support a system that respects data governance and ownership by adhering to leading practices and principles, such as FAIR[14] (data is findable, accessible, interoperable and reusable), CARE Principles for Indigenous Data Governance[15] and TRUST Principles for digital repositories;[16]

- help all partners understand what data is available to them, how they can use and interpret it, and how it can help them achieve their organizational goals;

- improve timely and efficient access to administrative data, research data and other types of cancer care data;

- support all partners to develop agreements that achieve collective goals while balancing enhanced data access with privacy requirements;

- support data linkage and sharing with First Nations, Inuit or Métis governments and organizations for enhanced Peoples-specific cancer data.

Equity

A focus on equity will enable the cancer data strategy to:

- develop a system that includes and supports equity-deserving communities and communities that are underserved to build analytic capacity;

- adhere to First Nations principles of OCAP®[13] as well as Inuit and Métis data governance principles, respect the cultural sensitivity of data, and build appropriate processes rooted in trust to advance First Nations, Inuit and Métis-led cancer data systems;

- capture key equity stratifiers in a way that promotes self-identification and is consistent across data sets, providing standardized processes and definitions to guide data collection (refer to the Engagement, Governance, Access, and Protection (EGAP) framework);

- be inclusive and transparent, and consider language, access and representation.

Impact and results

A focus on impact and results will enable the cancer data strategy to:

- promote results-focused activities that consider the short, medium and long terms while aligning with other strategies (such as the pCHDS) to build and maintain momentum for improvements to cancer data and better outcomes for all people affected by cancer;

- inform policies, programs and services that can benefit equity-deserving populations and First Nations, Inuit and Métis to support progress toward closing health equity gaps;

- support partners to build analytical and data capacity, capability and fluency for actionable insights;

- develop innovative, results-focused funding models, incentives and requirements to support data access that respects all partners;

- develop a clear knowledge translation process to publicize the successes, lessons learned and impacts of the strategy in a way that is easy to understand, interactive and representative of the collective efforts and impacts across the continuum of cancer care.

Priority areas for investment

Achieving the vision of this strategy will require concerted efforts and investment from partners throughout the cancer system. Through underlined engagement with a wide range of system partners, we identified the most critical priorities and a set of facilitators that must be put in place to deliver on them. The Working together plan is a key enabler of the cancer data strategy priorities, grounded in improving integrated healthcare for people in Canada by modernizing how health information is collected, shared, and used.

Note that the health and cancer information and technology landscape is vast and diverse, spanning many domains. These include the rapidly emerging role of artificial intelligence (AI) and big data, as well as access to and sharing of personal health information though mobile technologies including wearables and remote monitoring devices. While acknowledging this wide landscape, we focused on short- to medium-term priorities in administrative, research and clinical data that will support decisions in policy, planning and research, as well as system-level clinical quality improvement.

By adhering to the values and harnessing the success factors of the strategy, taking action on these priorities will enhance data collection, integration and use to improve cancer control and outcomes for all people in Canada.

Priorities

Three priorities can be actioned to advance the cancer data strategy:

- improve the efficiency, timeliness and quality of data capture and access
- enhance linkages to current data
- fill gaps in current data collection and make data accessible for linkage and analysis

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Priority 1: Improve the efficiency, timeliness and quality of data capture and access

Advancing this priority will make it easier to capture data in current data systems and to access data that has already been collected. The strategy recommends the following actions:

Increase the efficiency and ease of data access*

Health system partners should work together to enhance timely and efficient access to cancer data (including research data sets such as those produced by clinical trials, etc.) for decision makers, clinicians and administrators. This is in keeping with the principles of data liberation and stewardship (vs. custodianship) called for in the pCHDS.

Improve the timeliness of data capture and availability

Health system partners should establish streamlined processes and leverage innovative technologies to enable timely identification and coding of diagnostic, prognostic and treatment data in cancer registries and other key data assets. Aligned with the pCHDS, this needs to include mechanisms that promote digitization and electronic interfaces with source records to reduce reliance on increasingly constrained human resource-intensive approaches. This includes further advancement of electronic synoptic reporting and the use of natural language processing and other AI-based solutions.

Build on guidelines and standards for cancer data, including data quality indicators

Health system partners should work together to build on, strengthen and sustain data governance mechanisms that produce agreed-upon common standards and protocols for data collection and sharing. Leveraging strategic partnerships and existing work (e.g., work of the Canadian Council of Cancer Registries[3]) will improve consistency and comparability by enabling expanded pan-Canadian comparisons and benchmarking.

Partners should routinely report on data quality indicators with agreed-upon standardized definitions and calculation methods that, when appropriate, are aligned internationally. These efforts must include engagement with First Nations, Inuit and Métis to advance data collection that is respectful of data sovereignty principles and data sharing to support Nation- and community-driven priorities.

Priority 2: Enhance linkages to current data

Advancing this priority will improve the ability to draw on data from multiple (federated) data sets by enhancing interoperability; promoting the use of standardized identifiers; and ensuring various data sets are accessible, ready for analysis and easily linkable. These actions will use innovative technologies to enable seamless use and integration of data elements available across all relevant data systems and are not intended to develop new or combined physical databases. The strategy recommends the following actions:

Modernize and sustain infrastructure for cancer data interoperability, integration and linkages

Provincial/territorial and federal partners (e.g., Statistics Canada, CIHI) should continue to work collaboratively to build and maintain infrastructure for cancer data interoperability, using innovative technologies and strategic partnerships to support modernization. Among other benefits, integrated access to data across sectors and data systems will allow for comprehensive analysis of the patient experience and facilitate actionable insights and informed decision-making. Being able to link data across the healthcare system also requires common technical and data standards to support interoperability between care sectors, organizations and providers. These are leading efforts under the Shared pan-Canadian Interoperability Roadmap with a goal to reduce data blocking and ease data portability, improving care coordination and collaboration. Enabling cross-analysis between cancer-specific and socio-demographic data systems will also support understanding of the impact of social determinants of health, risk factors and other equity-relevant factors on cancer control access and outcomes, including the economic burden of cancer. Efforts led by First Nations and Métis organizations and governments are currently underway to link First Nations and Métis citizenship registries with existing health data sets. These efforts will enable access to Peoples-specific data that can inform the development of culturally safe policies, programs and services. A sustainability plan should be built to keep the linkages up to date.

Make diagnostic and treatment data accessible and linkable

To provide a more complete picture of patients' cancer care experience, screening, diagnostic and treatment data should be linkable with the CCR[3] and other cancer data systems. This data should include:

- screening and diagnostic data (e.g., lab, pathology, cancer imaging)

- cancer-related acute hospital ambulatory encounters (e.g., acute inpatient, emergency department visits, day procedures)

- treatment data (e.g., surgery, chemotherapy [IV and oral], radiation)

- diagnostic and therapeutic trial data

Make primary care data accessible and linkable*

Linking primary care data with other data systems is critical, as primary care is often the first point of contact for patients experiencing cancer symptoms or diagnosis. It is also where they return to upon discharge from specialist care for follow-up and survivorship supports. Better integration of electronic medical record data from primary care with cancer system data will improve the effectiveness and experience of care for patients in these key transitions. Access to data from other data systems, such as immunization registries, could support primary care providers in their practice for delivering cancer preventive supports.

Make genomic data accessible and linkable *
The genomic data that currently resides in genomic, research and clinical databases (such as CanPath,[6] Canada's largest population health cohort) should be linkable with the CCR[3] and other cancer data systems. This will support researchers to improve understanding of the biology of cancer and accelerate progress in precision oncology.

Priority 3:
Fill gaps in current data collection and make data accessible for linkage and analysis

Advancing this priority will make data available about individuals in Canada seeking care across the cancer control continuum and about important parts of the cancer experience that are not represented in current data sets. Without this data, and without linking it to other cancer data systems, we have an incomplete picture of the effects of cancer on equity-deserving groups and of opportunities or challenges in key domains of the cancer control continuum. The strategy recommends the following actions, which represent enhanced or net-new data collection to expand the comprehensiveness of available data: expand the comprehensiveness of available data:

Fill gaps in data on social determinants of health
Health system partners should create mechanisms to collect relevant social determinants of health parameters[17] (e.g., income, education, physical environments), integrate it with cancer data systems, and link it to the CCR or otherwise make it available for analysis. This should be done in a way that supports cancer care access and outcomes and fills gaps in reporting.

Enhance collection of patient-reported outcomes and experience data *
Collection and integration of patient-reported outcomes is important to inform a wholistic approach to clinical decision-making and to support care that is responsive to each specific patient's needs, including physical, mental, emotional and spiritual. The collection and integration of patient-reported experience measures is another important enabler of person-centred care. It can provide insights on patient experiences with racism, discrimination, marginalization and stigma in the healthcare system. Such insights help assess progress made toward eliminating racism against First Nations, Inuit and Métis and racialized communities in Canada, as well as other forms of discrimination, marginalization and stigma.

Collect data on patient race, ethnicity and other equity-focused characteristics
This data will help better understand the experiences of equity-deserving populations as they navigate the healthcare system. It can be used to identify and address inequities in access to care, experience and outcomes that result from racism, discrimination and other systemic factors. In addition, it is important to support First Nations, Inuit and Métis-driven efforts to collect data, access existing data and advance data linkages to inform Nation- and community-based approaches to improve cancer care.

As the public system starts to collect data on race, ethnicity, gender, sexual orientation, disability and other identifiers of equity-deserving populations, mechanisms should be put in place to enable linkages to databases such as the CCR, CIHI data holdings and research data sets. Strategic collaborations with key partners (e.g., organizations that represent equity-deserving populations; First Nations, Inuit and Métis partners; CIHI; Statistics Canada) will enable initiatives to build on previous work and expertise. These collaborations could also support the development and promotion of new standard equity stratifiers for use in data collection, analysis and performance reporting.

Enhance collection of survivorship data *
The collection of data on patient needs (including patient-reported outcomes) and access to follow-up care and community-based supports in the post-treatment/survivorship phase should be expanded. This data should be linked to the CCR to better understand factors affecting cancer experience post-treatment and identify where gaps or unmet needs remain.

Enhance collection of data on palliative and end-of-life care
Comprehensive data collection on access to and experience with the full range of palliative care is critical to making a full and responsive continuum of care available to cancer patients and their families. This data collection should begin from diagnosis of a life-limiting illness and include access to pain and symptom management, as well as psychosocial and other supports through to end-of-life care. This data should be linked to the CCR.

Fill gaps in data on risk factors to guide cancer prevention efforts
Risk factor data (e.g., tobacco use, HPV vaccination status) can provide a more comprehensive picture of the risk profile of individuals and populations. Capturing this data will provide invaluable insight into a crucial part of the cancer continuum and identify opportunities to improve prevention efforts. Drawing on strategic partnerships and existing initiatives, such as CanPath and the constituent provincial cohort projects, this data should be linked to the CCR and other data systems to enhance understanding of various cancer risk factors and guide cancer prevention activities.

In line with the actions above showcasing the importance of disaggregated data in driving insights that lead to real improvements, CIHI will lead a process in collaboration with provinces, territories and other experts to report on a list of common health indicators under the Working together plan that will demonstrate the progress being made towards our shared priorities in healthcare. Reporting on these standardized indicators could highlight how Canada is performing compared to international counterparts and reveal potential areas for improvement.

Facilitators

Several actions were determined to be foundational to supporting further initiatives to enhance the cancer data landscape in Canada. Addressing these foundational elements will enable the identified priorities to be effectively actioned, paving the way for success.

Understanding the data landscape

- **Developing and maintaining a publicly accessible inventory of cancer-relevant data holdings:** A knowledge resource should be developed, leveraging existing inventories, that describes the principal data sets relevant to cancer. This could include provincial/territorial and federal administrative data sets; First Nations, Inuit or Métis-governed data sets; data sets generated by research; and digital health system data sets. A decision framework should be built that clearly defines the inclusion and exclusion criteria for data sets included in the inventory. A sustainability plan will also be required to ensure the inventory remains current.

- **Conducting periodic gap analyses of current data holdings:** In support of the data inventory, data gaps should be identified based on needs and challenges related to access to and effective use of existing holdings. Regularly assessing the cancer data landscape with respect to the pillars identified in the pCHDS (governance, trust, policy, interoperability, capacity, literacy) will help identify gaps in cancer data holdings, including administrative, process and usage gaps. Identifying these gaps will support a collective and up-to-date understanding of where data is lacking and where data collection efforts need to be focused.

- **Developing and maintaining a user guide to support the use of cancer-relevant data holdings:** A knowledge resource should be developed that provides information on how researchers and cancer data users can access cancer-relevant data holdings. A sustainability plan will also be required to ensure the user guide remains current.

Building infrastructure and adequately resourcing it to support sustainability*

Investments should be made to build integration infrastructure across the ecosystem, using transformative technologies to increase data flow across sectors, organizations, researchers and others. With rapid advancements in technology, cancer data systems can be developed to support more real-time data flow across the cancer control continuum. These systems should be built to meet minimum standards, and sufficient resources should be allocated to maintain them, so they continue to deliver high-quality data. The pCHDS outlines several pillars and recommendations to address infrastructure needs, such as trust and interoperability and in particular, underlines the importance of data stewardship. Due to the uniqueness of cancer data, in that it is relatively well structured and supported, there may be opportunities under the cancer data strategy to advance more quickly toward the objectives of the pCHDS. The cancer data strategy will align with and leverage these outcomes to improve cancer data and the advances and lessons learned can also be applied to other aspects of the health data system.

Improving data literacy among health system partners*

Work should be done with organizations and strategies such as Canada Health Infoway, CIHI and the pCHDS to improve data literacy, including how data can be used and its limitations. A better understanding of data can be supported through a variety of methods that allow partners to contribute more meaningfully to data-related work. This may include, for example, improved understanding of data governance and accountability; the importance of First Nations, Inuit and Métis data sovereignty; or the benefits of data sharing agreements.

Elevating the patient voice in planning and implementing data activities*

Patient, family and caregiver voices must be embedded across all cancer data initiatives using culturally competent, tailored, resourced and supported engagement approaches. This will allow a better understanding of the lived experience of patients and families, particularly those who are part of underserved or equity-deserving groups. It will also enable initiatives to be grounded in their needs and priorities, supporting more equitable care access, experiences and outcomes. Engagement methods may vary based on project objectives (as informed by the International Association for Public Participation spectrum[18] but could include patient/family advisory panels, focus groups and surveys.

Support First Nations, Inuit and Métis-governed data and data systems

The United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) affirms the rights of First Nations, Inuit and Métis to self-determination and self-government.[1] This requires efforts to respect, uphold and honour First Nations, Inuit and Métis data sovereignty so decisions about programs, services and policies can be based on high-quality, distinctions-based data. There has been a growing movement supporting data sovereignty—that is, "the right of [First Nations, Inuit and Métis Peoples] to determine the means of collection, access, analysis, interpretation, manage-ment, dissemination and reuse of data pertaining to Indigenous people from whom it has been derived, or to whom it relates."[8] This movement has been amplified since the COVID-19 pandemic exposed the lack of high-quality, disaggregated data necessary to understand the impact of the pandemic on First Nations, Inuit and Métis communities.[19]

Support improved data collection and reporting governed by First Nations, Inuit, and Métis Peoples

Several of the Truth and Reconciliation Commission's Calls to Action highlight the need for data to report on progress toward reconciliation and toward closing the gaps in health outcomes between First Nations, Inuit and Métis communities and non-Indigenous communities.[20] First Nations, Inuit and Métis-specific data can reveal inequities in access to care, experiences and outcomes that result from racism and discrimination. It is equally important to align the collection and use of this data with First Nations, Inuit and Métis principles of data governance. Currently, most cancer data about First Nations, Inuit and Métis in Canada is held by other data stewards and partners (e.g., government, pan-Canadian health organizations, hospitals, cancer centres). It is therefore critical that these data stewards build trusting relationships with First Nations, Inuit and Métis organizations and governments; support First Nations, Inuit and Métis data systems; work to facilitate collaborative partnership for linkages to broader health system data; and implement approaches to protect the privacy of First Nations, Inuit and Métis individuals and communities.

There are numerous examples of First Nations, Inuit and Métis-led data efforts:

- The Mik'maw of Nova Scotia have developed the Mi'kmaw Client Linkage Registry, which can be linked to administrative health data sets and used to develop population health reports for their communities.[21]

- The Métis Nation-Saskatchewan and Saskatchewan Cancer Agency have signed a memorandum of understanding and are working together to use health data to understand Métis experiences with cancer.[22]

- The Kenora Chiefs Advisory led work to link their First Nations Client Registry with the Ontario Cancer Registry and Cancer Care Ontario's cancer screening data set, equipping them with cancer-related information for their community.[23]

- Chiefs of Ontario, Cancer Care Ontario and the Institute for Clinical Evaluative Sciences collaborated on a report on risk factors and cancer rates between First Nations and other people living in Ontario.[24]

Support First Nations, Inuit and Métis data governance and self-determination

The pCHDS recommends that "jurisdictions demonstrate support for First Nations, Inuit and Métis Nation data sovereignty across geographies with a distinctions-based approach" that recognizes the rights of First Nations, Inuit and Métis to self-determination and self-governance.

First Nations, Inuit and Métis organizations have developed or are in the process of developing data governance strategies and principles, describing the stewardship and processes needed to retain control over their data and advance data sovereignty.[15] Examples include:

- The First Nations Information Governance Centre (FNIGC) released the First Nations Data Governance Strategy[8] in 2020. This strategy includes information (e.g., strategic framework, guiding principles, pillars for action) to advance First Nations-led data governance and stewardship. FNIGC also coordinates activities and is the data steward for the First Nations Regional Health Survey, a First Nations-led national health survey that aligns with the principles of OCAP®.[13]

- Inuit Tapiriit Kanatami (ITK) is developing a national Inuit data strategy.[10] ITK also works collaboratively with the four Inuit land claim organizations (Inuvialuit Regional Corporation, Nunavut Tunngavik Incorporated, Makivik Corporation and Nunatsiavut Government) to co-design and implement the Qanuippitaa? National Inuit Health Survey,[25] a permanent and ongoing Inuit-determined and Inuit-owned survey on health and wellbeing.

- The National Association of Friendship Centres is developing a national data strategy, which will include recommendations and actions to "bring us from where we are now to becoming Indigenous information leaders, who honour our traditions by using stories to provide an understanding of urban realities and the Indigenous context." Other data initiatives include the Bridging Across Canada database to support the collection of disaggregated data about the services offered by Friendship Centres and community-led data collection to build data capacity and expertise.[26]

- The First Nations, Inuit and Métis data governance and research guidelines and principles include the CARE Principles for Indigenous Data Governance;[15] Guidelines for Research Involving Inuit (2021);[27] Inuit Qaujimajatuqangit Principles;[28] Principles of Ethical Métis Research (2011);[29] Manitoba Métis principles of ownership, control, access and stewardship; and First Nations Principles of OCAP®.[13]

- The CARE Principles for Indigenous Data Governance state that the "use of Indigenous data invokes a reciprocal responsibility to enhance data literacy within Indigenous communities and to support the development of an Indigenous data workforce and digital infrastructure to enable the creation, collection, management, security, governance and application of data." In implementing this strategy, cancer data players should enter into partnerships based on reciprocity.[30]

Establish relationships based on reciprocity, trust and respect

There are many First Nations, Inuit and Métis-led efforts to improve self-determined data and advance data sovereignty, but there is more work to be done in partnership. It is important that efforts to improve First Nations, Inuit or Métis-specific cancer data are co-developed with, by and for First Nations, Inuit and Métis. First Nations, Inuit or Métis must have a seat at the table where decisions are being made about their data and its use. First Nations, Inuit or Métis principles of data governance must be respected and adhered to, and findings must be shared back with and be used to benefit First Nations, Inuit and Métis communities. By working together and respecting First Nations, Inuit and Métis rights to their own data, knowledge and worldviews, progress can be made to collect high-quality, distinctions-based data. This data can inform efforts to close the health equity gaps that exist between First Nations, Inuit and Métis communities and non-Indigenous communities.

Implementing this strategy

Achieving the goals of this cancer data strategy requires concerted, collaborative efforts and investment from partners throughout Canada's health system. Through extensive engagement with partners, the strategy outlines the most critical priorities for cancer data improvements and a set of facilitators that must be put in place to deliver on them. In the next five to ten years, it will be necessary for health system partners to:

- **Work together to drive collective action:**

  - Identify the health system partners who will be responsible for implementing solutions to improve cancer data, in alignment with the priorities identified in this strategy.

  - Continue to seek alignment with federal and provincial/territorial priorities for health data to better coordinate initiatives that will improve access to data as well as the timeliness and completeness of data, such as the pan-Canadian Health Data Strategy, the Health Data Charter, and Shared Interoperability Roadmap.

  - Maintain ongoing engagement of diverse voices at decision-making tables, including those with lived experience of inequities in the healthcare system, to meet their data needs and expectations and support the use of this data to advance health equity.

  - Engage First Nations, Inuit and Métis organizations and governments to understand self-determined priorities for health data and data governance. Seek out opportunities to form trusting reciprocal partnerships to support the development of culturally safe policies, programs and services that benefit First Nations, Inuit and Métis in Canada.

- **Invest in cancer data improvements** to support the realization of the collective vision of enhanced data collection, integration and use to improve cancer control and outcomes for all people in Canada.

- **Establish and convene a community of practice** to share data initiatives and related knowledge among all health system partners. This knowledge exchange may generate new ideas to advance data quality and promote increased collaboration among partners to solve common data challenges.

- **Monitor and evaluate** progress made toward the priorities of the cancer data strategy and put mechanisms in place to enable adaption and innovation as required as advancements in technology and data continue to evolve.

CCS's Data Transformation Grant program supports projects that use novel approaches to address concerns related to accessibility, completeness, quality and timeliness of cancer data in Canada. The projects funded through this program align with the cancer data strategy priorities, demonstrating specific actions that can be scaled and sustained to improve the cancer data ecosystem in Canada.

The Partnership's analytic capacity-building initiative will enhance the use of cancer system data to inform clinical practice and policy decision-making. As part of the initiative, the Partnership will collaborate with partners to implement data improvement initiatives to address aspects of the cancer data strategy. These include improving the timeliness of cancer data; supporting more comprehensive data collection across the cancer experience; improving the ability to conduct equity analyses; and supporting First Nations, Inuit and Métis-led data initiatives. As stewards of the Canadian Strategy for Cancer Control, the Partnership will continue to monitor and report on cancer system performance measures, including health equity.

We all have a role to play

Data has the power to transform the cancer care ecosystem in Canada and improve health outcomes for all people in Canada. But to realize the full potential of cancer data, a coordinated effort guided by a dedicated strategy is required with contributions from a wide range of partners. Patients, healthcare providers, administrators, researchers and policy makers all have a role to play in making sure cancer data is collected consistently and linked appropriately so it can be used most effectively. As we work to make data accessible and promote its widespread use, we must also keep the privacy, security and governance needs and rights of all people and communities involved with cancer care—including First Nations, Inuit and Métis—front and centre in all considerations.

This strategy outlines clear priorities specific to the data-related needs of the cancer system and concrete actions that can be taken to advance those priorities. It was developed based on extensive community and partner engagement and reflects common aspirations that will help advance Canada's cancer care data ecosystem. However, there are likely perspectives and considerations not adequately represented in this version of the strategy. Engagement is ongoing and this strategy will continue to evolve as new insights are gained.

On behalf of our partners involved in the development of this strategy, the Canadian Partnership Against Cancer and the Canadian Cancer Society invite all members of the cancer data community to engage with this strategy and implement its priorities—and help build a more cohesive cancer data ecosystem that benefits all people in Canada and is positioned to respond to future priorities.

Appendix 1: Glossary

Canadian Cancer Registry (CCR): An administrative database managed by the Canadian Research Data Centre Network that collects information on cancer incidence from all provincial and territorial registries in Canada.

Canadian Institute for Health Information (CIHI): An independent, not-for-profit organization that provides essential information on Canada's health system and the health of people in Canada.

Cancer data: All data and information that is relevant to the cancer continuum, including provincial/territorial and federal administrative data sets, data sets from major research studies and programs, relevant digital health data sets, and more.

Data linkage: The act of bringing together data from different sources to create a richer data set.

Data steward: An entity or individual responsible for overseeing the quality, integrity and security of data. The steward also makes sure data is managed in accordance with applicable laws, policies and individual permissions.

Diagnostic and treatment data: Includes screening, diagnostic, ambulatory and treatment data. It could also include research data from clinical trials.

Facilitators: Foundational efforts that are required to improve data within the cancer system but are also applicable in the broader healthcare system and aligned to the Pan-Canadian Health Data Strategy.

First Nations, Inuit and Métis data sovereignty:[8] The right of First Nations, Inuit and Métis Peoples to determine the means of collection, access, analysis, interpretation, management, dissemination and reuse of data pertaining to Indigenous people from whom it has been derived, or to whom it relates.

Health data: Data related to an individual's mental or physical health, health system performance, or population characteristics.

Interoperability: The ability for health data and information to be seamlessly shared and used between health system partners. It includes technological, policy, governance and other elements.

Pan-Canadian Cancer Data Strategy: A cancer-specific strategy for collecting, integrating and using data to improve health outcomes. It was developed by the Canadian Partnership Against Cancer and the Canadian Cancer Society, through engagement with cancer system partners.

Pan-Canadian Health Data Strategy (pCHDS): A foundational strategy for improving health data collection, standardization and use across Canada's healthcare system. It was developed by the Public Health Agency of Canada, in consultation with healthcare system partners.

Portable data: Data that can be accessed and reused for another purpose.

Social determinants of health: Non-medical factors that influence individual and population health outcomes, including personal, social, economic and environmental factors.

Appendix 2: How the strategic framework was developed

Before work started on creating the pan-Canadian Cancer Data Strategy, the Partnership and the CCS launched an engagement process to develop a strategic framework to serve as the foundation of the strategy. This engagement process consisted of five stages:

Stage 1: Set strategy focus
Two working sessions were conducted to identify the appropriate scope for the strategy, gain alignment on its focus and refine any considerations.

Stage 2: Define strategy core elements
Two sessions, led by an external facilitator, brought together key representatives and partners in the Canadian cancer data community. During these sessions, the initial mission, vision, values and success factors for the strategy were drafted.

Stage 3: Engage external partners
Individual engagement sessions were held with pan-Canadian organizations and partners with expertise in health data; key patient and family advisors; and First Nations, Inuit and Métis advisors and partners. In these sessions, the draft framework elements developed in Stage 2 were presented to gather feedback and make required changes.

Stage 4: Refine and finalize framework elements
Using collected partner input, the core framework elements were refined to ensure alignment with partner goals.

Stage 5: Present framework online for comment
The framework was presented online to solicit feedback from the broader cancer data community to confirm that it correctly represents the community and its needs.

Appendix 3: Recommendations of the Pan-Canadian Health Data Strategy

Published in May 2022, the third report of the Expert Advisory Group on the Pan-Canadian Health Data Strategy defines the foundational elements for improving data quality and access throughout the health system. Specifically, it calls on federal, provincial, territorial and other health data partners to work together to implement the following 10 recommendations:

1. Endorse a vision that "by 2030, all people living in Canada will benefit from a fully integrated and continuously optimized learning health system" and that the implementation will be guided by common principles in a Canadian Health Data Charter.

2. Demonstrate support for First Nations, Inuit and Métis data sovereignty across geographies with a distinctions-based approach.

3. Establish an independent and competency-based Health Information Stewardship Council to design and drive stewardship of the health data foundation and provide advice on health data investments to jurisdictions and First Nations, Inuit and Métis representative bodies.

4. Establish one or several government-led learning health system table(s), with First Nations, Inuit and Métis representative bodies, to create and drive work on an integrated learning health system roadmap, supported by substantial new funding.

5. Establish meaningful and ongoing engagement with the public and stakeholders to understand their health data needs and expectations.

6. Develop communications plans with the public and other stakeholders to demonstrate how their health data needs and expectations are being addressed.

7. Establish a policy framework for data stewardship that mandates appropriate data exchange, reuse and collaboration across critical health data supply chains, balanced with security, confidentiality and respect for privacy.

8. Establish a harmonized pan-Canadian health data policy framework that supports person-centric data, open-by-design and the stewardship model of health data management.

9. Establish common integrated health data standards and data architecture and drive and monitor their roll-out.

10. Establish a common approach to digital and health data literacy that is grounded in common language and content to increase data capability among all health data users and expand professional standards for critical health data roles.

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