



# The Pan-Canadian Cancer Data Strategy: Advancing Cancer Data in Canada

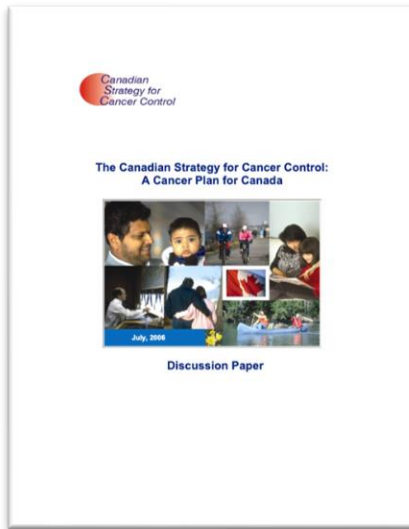
CANADA HEALTH INFOWAY: HEALTH ANALYTICS COMMUNITY – MONTHLY MEETING

MAY 30, 2024

# Objectives

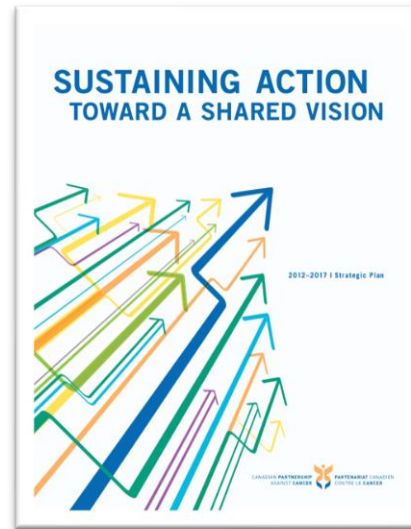
1. Share background information about the Partnership and our role in the cancer system
2. Share an overview of the cancer data strategy and its alignment with federal data strategies
3. Discuss implementation efforts in progress to advance shared priorities from within the cancer data strategy and build analytics capacities in the cancer system
4. Discuss what's next in our efforts to advance cancer data in Canada

# Supporting action on cancer since 2007



**2007–2012**

Advancing  
Canada's first  
cancer strategy



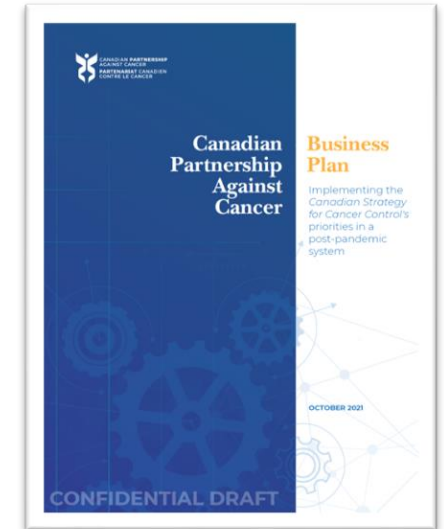
**2012–2017**

Pursuing shared  
priorities



**2017–2022**

Building on  
progress



**2022–2027**

Advancing the  
Strategy in a post-  
pandemic system

# Guiding Canada's health and cancer community

The *Canadian Strategy for Cancer Control* unites the many organizations that make up Canada's health and cancer community under a shared vision — a future where...

- **Fewer people develop cancer**
- **More people survive cancer**
- **Those affected by cancer have a better quality of life**
- **All people in Canada have equitable access to high-quality cancer care**

We worked closely with hundreds of organizations to develop and advance the strategy including F/P/T government departments, agencies and programs, First Nations, Inuit and Métis governments, organizations and communities, cancer organizations, and people living with cancer and their families.



Strategy available [here](#)

# Canada's cancer strategy at-a-glance



Decrease the risk of people getting cancer



Diagnose cancer faster, accurately and at an earlier stage



Deliver high-quality care in a sustainable, world-class system



Eliminate barriers to people getting the care they need



Deliver information and supports for people living with cancer, families and caregivers

## Peoples-specific Priorities:



Culturally appropriate care closer to home



Peoples-specific, self-determined cancer care



First Nations-, Inuit-, or Métis-governed research and data systems

## Enablers:



Research



Data



Technology & Innovation



Information Flow

# How we make a difference



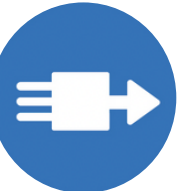
## Convene

- Bring together people and organizations from across the country
- Identify opportunities for collective action



## Share knowledge

- Gather and share evidence to fuel cancer care innovation
- Forge connections that accelerate spread and scale of best practices and innovation



## Enable change

- Provide funding and capacity



## Adapt

- Identify emerging issues
- Tailor funding and implementation efforts to address gaps and support areas of most need



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Canadian  
Cancer  
Society

# Pan-Canadian Cancer Data Strategy (Cancer Data Strategy)

# Modernizing Health Data as a Federal Priority

## Pan-Canadian Health Data Strategy

The **federal government** launched the **pan-Canadian Health Data Strategy** (pCHDS) based on advice from the pan-Canadian Expert Advisory Group, including a pan-Canadian health data charter & interoperability roadmap

- Focuses on establishing a common foundation to modernize the way we use, share and manage health data, including:
  - Enabling clinicians to provide better care
  - Giving people access to their own health data
  - Supporting the use of health data to improve health care, public health and population health
- As part of the Working Together to Improve Health Care for Canadians plan, bilateral agreements with PTs will advance the pCHDS, which will also address long-standing goals of the cancer system

## Pan-Canadian Cancer Data Strategy

While the pCHDS outlines a critical path to:

- interoperability
- an updated approach to privacy
- clarified accountabilities

A cancer-specific strategy can build on these foundational pillars and guide and align investments in specific tactical cancer data improvements.

**The Partnership** and the **Canadian Cancer Society (CCS)** developed the **pan-Canadian Cancer Data Strategy** to respond to these needs.



# Why a cancer-specific data strategy?



## Burden

**2 in 5** people will be diagnosed with cancer. Advances in treatment and life-expectancy mean people are living longer with cancer. This requires **significant resources** from the **health system**.



## Builds on a strong foundation

The cancer system is well-organized as cancer is a reportable disease with **established registries in all 13 provinces and territories** and has an opportunity to be a leader in health data.



## Unique data sets

Cancer registry, screening programs, radiation treatment, and chemotherapy data are often separate from data sources for the rest of the healthcare system.

Based on extensive engagements and consensus-building with partners across the cancer community, **the Partnership** and the **Canadian Cancer Society (CCS)** developed the **pan-Canadian Cancer Data Strategy** (cancer data strategy) to respond to cancer-specific data needs



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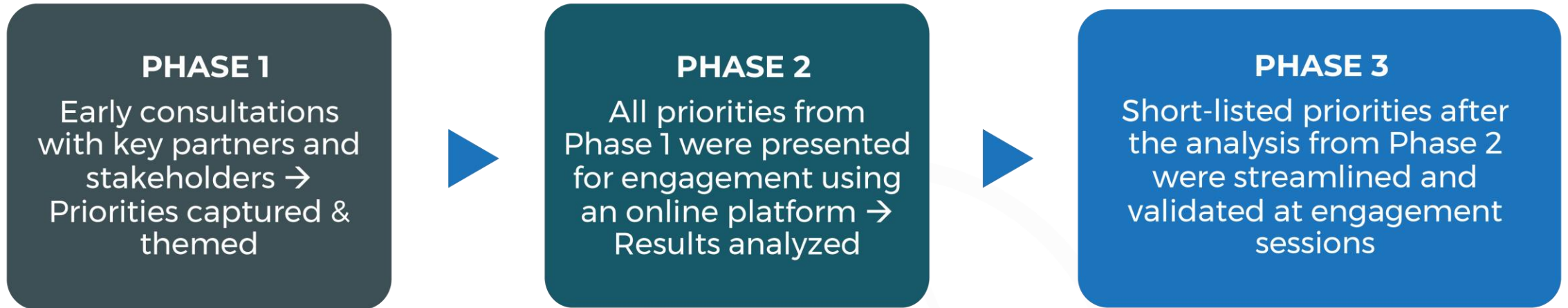
# Goals of the Cancer Data Strategy

- The [cancer data strategy](#):
  - Supports data stewardship through a **framework** for policymakers, researchers, academic institutions, healthcare systems, and other stakeholders to align with and use, guiding cancer data improvements over the next 5-10 years.
  - Shares **priorities for cancer data improvements** that were identified through broad and extensive stakeholder engagements including cancer programs
  - Emphasizes the **importance of Indigenous data sovereignty** and highlights examples of First Nations, Inuit, and Métis-led initiatives
  - **Guides funding decisions**, using list of priorities

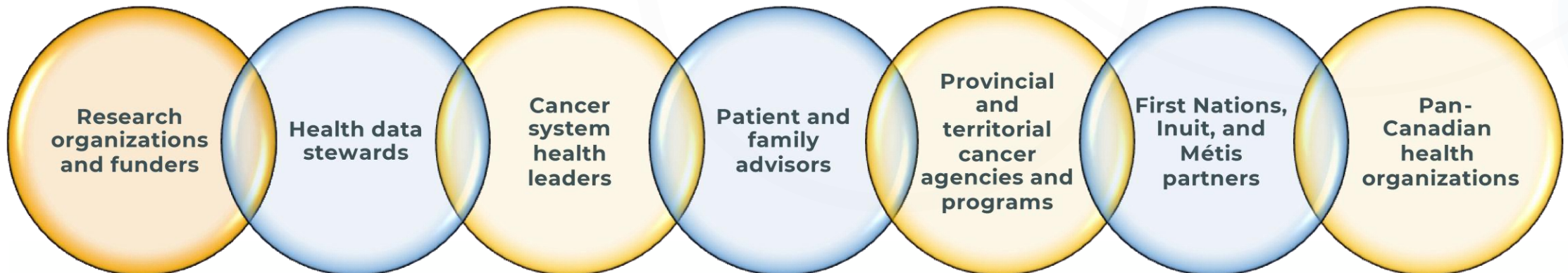
New online content featuring 24 examples of progress in the cancer data system and a framework that more clearly complements the [pan-Canadian Health Data Strategy](#) as an update to the [PDF](#) was released in May 2024.



# Priority Refinement Process



Ongoing parallel process for engaging First Nations, Inuit and Métis partners



# Priority Areas and Facilitators of the Cancer Data Strategy

## 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

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## FACILITATORS

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





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# Implementation of the Cancer Data Strategy

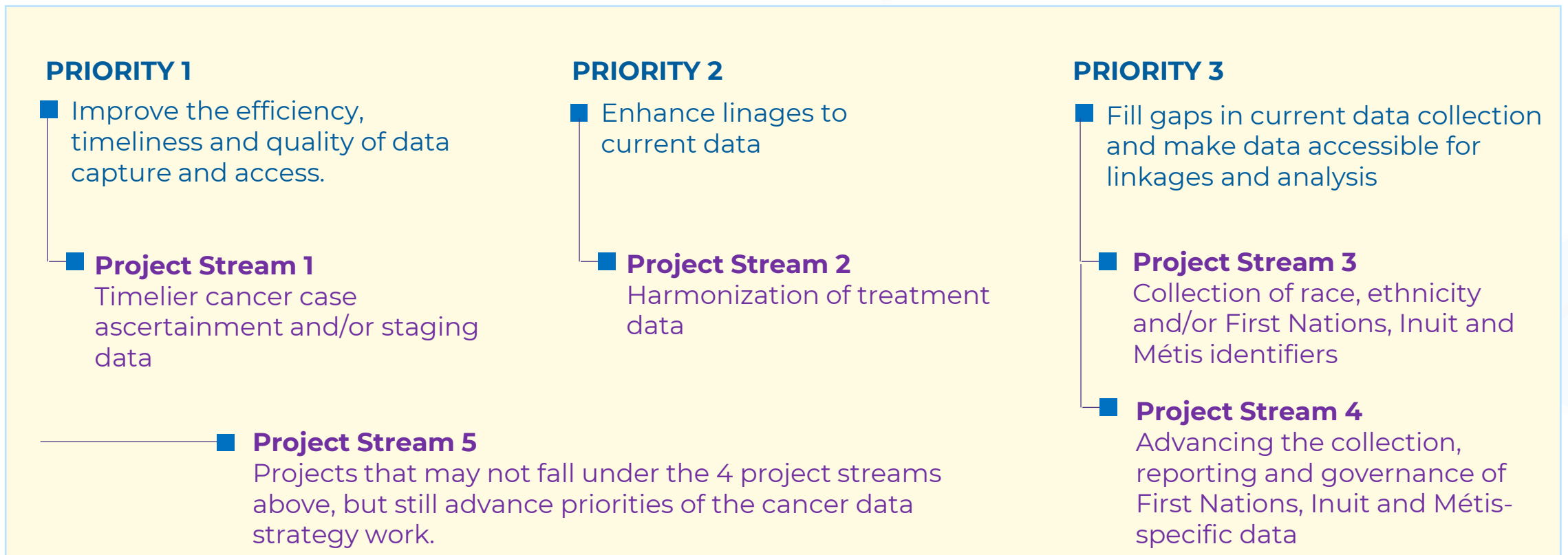
# Implementing the Cancer Data Strategy

- **The Partnership has \$6M in funds available to support partners in pursuing initiatives under project streams over the next three years (with some flexibility to cross over into FY 2027/28):**
  - Based on numerous engagements with partners, five project streams were identified from within the cancer data strategy as key areas of focus for initial investment (see next slide).
  - Jurisdictions can choose to pursue more than one project stream.
  - Partner project proposals will be co-developed with the Partnership and used to inform funding agreements (i.e., a non-competitive process).
  - Will utilize an inclusive and equitable approach to funding.
  - Implementation will began on a rolling basis based on partner readiness, starting on **April 1<sup>st</sup>, 2024.**
- The Canadian Cancer Society (CCS) has funds available to support researchers through the [Data Transformation Grant Program](#) on novel approaches to address concerns related to accessibility, completeness, quality and/or timeliness of cancer data in Canada



# Partnership Funded Project Streams

The cancer data strategy is vast and profiles **three priorities for action and investment over the long-term**, CPAC has identified **five funded project streams** aligned to the priorities to create **impact over the short to medium term**.



The Canadian Cancer Society is also providing funding aligned with the priorities through the [CCS Data Transformation Grants](#).

# Timelier Case Ascertainment and Staging

Currently cancer case registries across Canada experience delays for entering data of ~ two years. As a result, the health system is unable to identify how cancer case identification or stage at diagnosis was impacted by health system closures due to the COVID-19 pandemic and whether/when to anticipate a surge in cancer diagnoses.

## Initiative

- Improve the efficiency, timeliness and quality of data capture using technologies such as artificial intelligence (AI) and machine learning to reduce manual labor
- In collaboration with StatCan, process maps were developed to identify how cancer data flows through the system and identified the gaps that must be addressed
- Conducted an environment scan of the evidence
- A few jurisdictions are collaborating to test and validate AI models
- 8/10 provinces are participating in the implementation of this initiative
- Knowledge exchange and collaboration opportunities available to support partners

## Potential Outcomes

- Reduce the time needed to register a new case into jurisdictional cancer registries
- Expedite the staging of cancer cases (for the four most common cancers)
- Advance use of innovative tools, such as AI and natural language processing, that may impact health system data more broadly

## Stream 2: Harmonization of Radiation Data

Approximately 50% of cancer patients will receive radiation treatment. There is significant variation in how radiation treatment data is captured and organized, both inter- and intra-provincially. International standards have been established for the coding of radiation treatment; however, they have not been widely adopted in Canada.

### Initiative

- Prepare all jurisdictions to have organized, interoperable radiation treatment data that is collected in a harmonized way across the country
- Modernize how radiation data is stored to enable linkages with cancer registry data, and is accessible for secondary use
- 6/10 provinces are ready to initiate work this year, with an expectation that additional jurisdictions will join later

### Potential Outcomes

- Establish a data standard/minimum dataset for radiation treatment data
- Advance standardization and pan-Canadian benchmarking
- Enhance capability for system-level decision-making

# Knowledge Exchange Opportunities

- **KTE Webinars for Cancer Data Strategy Partners**
  - Focused on partner-driven topics that advance projects under the cancer data strategy
    - **Feb 1<sup>st</sup>:** [Canadian Artificial Intelligence & Data in Radiotherapy Alliance \(CADRA\)](#) presented on an interprofessional and collaborative approach to standardizing radiotherapy standards
    - **Mar 27<sup>th</sup>:** NL and ON co-presented on overcoming data privacy barriers
- **Cancer Data Strategy Knowledge Products**
  - **Digital solutions environmental scan (available upon request)**
    - Includes a set of 26 recommendations to achieving timelier cancer case ascertainment and staging
- **Project Stream-Specific Workshops (in development)**
  - Developing workshops for each project stream to continue knowledge collaboration efforts in advancing project stream-specific work

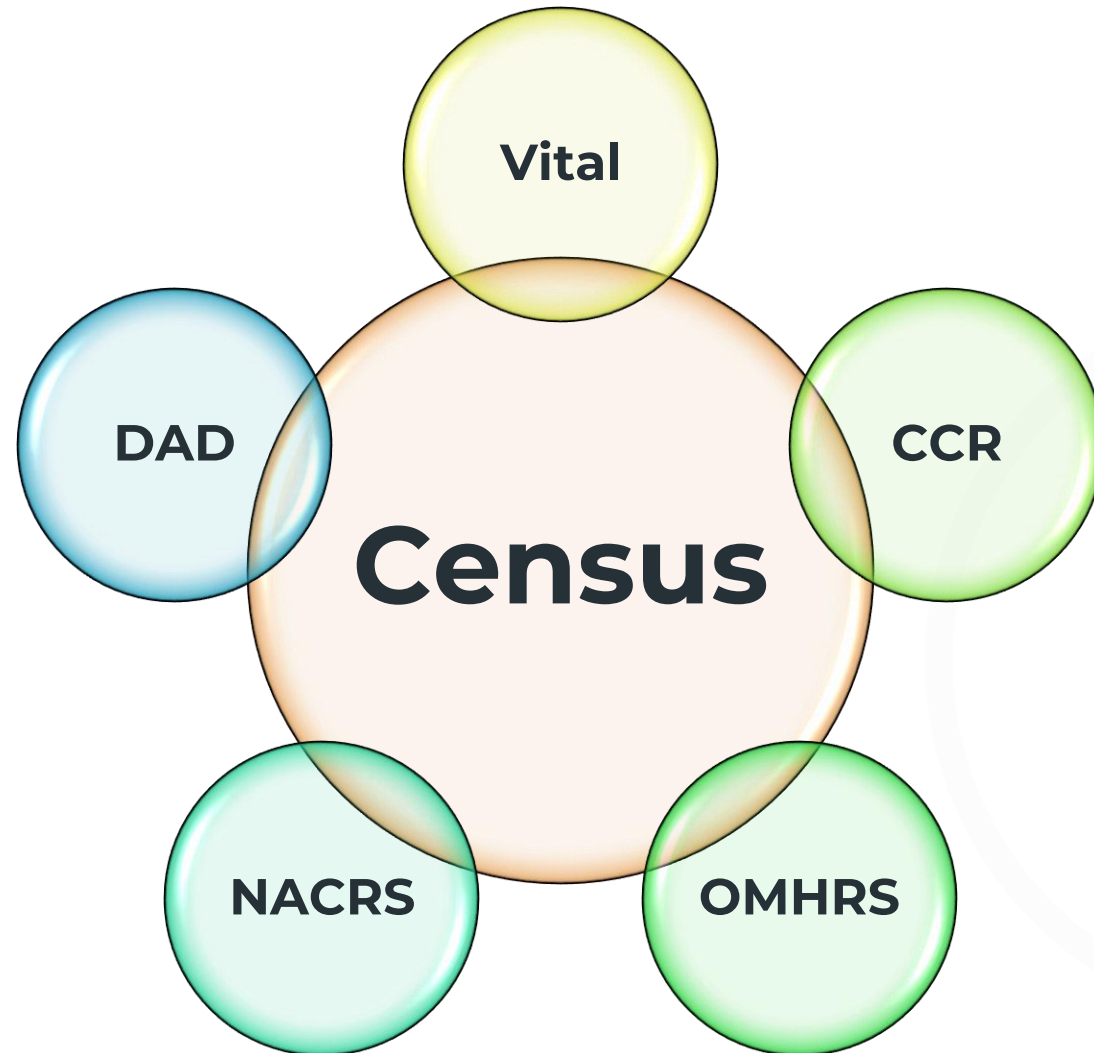
# Knowledge Exchange Opportunities

- **Canadian Council for Cancer Registries (CCCR) Annual General Meeting  
May: 7 – 8**
  - The **CCCR AGM** enabled networking and roundtable discussions/breakout sessions on Stream 1 projects
- **North American Association of Central Cancer Registries (NAACCR)  
Annual Conference: June 25 – 27**
  - Invited to **NAACCR AGM** to do a 20 min presentation on “Using Innovative Solutions to Advance Cancer Data in Canada” – focused on the e-scan findings
- **Ongoing cancer program engagements**
  - The Partnership in their role as convenor holds regularly scheduled engagement opportunities for leaders in the cancer system across Canada to come together to share knowledge and collectively drive change in the cancer care system

# Digital Solutions Environmental Scan

- **Purpose:** conduct an environmental scan to identify digital solutions and innovations to facilitate timelier cancer case ascertainment and/or staging
- **Methods:** Risk Sciences International (RSI) conducted a thorough scan of available data maps, review and analysis of implementation planning survey responses from partners, and market analysis of available products
  - Reviewed the challenges and solutions and data metrics documents
  - Gained useful insight from selected interviews from informants and Advisory Group meetings with provincial/territorial representatives
- **Deliverable:** A list of usable recommendations, by jurisdictions, on “practical and tactical” ways in which they can achieve timelier cancer case ascertainment and staging. The full report was shared with partners in Feb 2024 to guide proposal development
- A prioritization of the 26 e-scan recommendations was conducted to guide partners in considering recommendations to apply in their short- and long-term goals of implementing their Stream 1 projects

# Data Linkage – CanCHEC and CCR



- Canadian Cancer Registry (1992-2021) is linked to CanCHEC (2016)!
- Enables the examination of cancer data linked to sociodemographic information to better understand disparities among equity-deserving populations
- Support pan-Canadian equity-focused analyses to advance cancer equity measurement and reporting
- Data linkage is accessible through the Research Data Centers (RDCs) this summer.

# Cancer Data Strategy – Where We Are Going

**By 2027 the cancer data strategy has the potential to have a tangible impact on the cancer system that could have a ripple effect throughout the rest of the health system:**

- Jurisdictional cancer data registries will be modernized allowing for faster case ascertainment and staging and some jurisdictions will be able to link treatment data with cancer registry data.
- We will identify partners ready to collaborate on better integrated and harmonized cancer treatment data, enabling pan-Canadian system performance measurement and reporting and a better understanding of the cancer treatment landscape.
- There will be improved collection of race/ethnicity and First Nations, Inuit and Métis identifiers, so that we can identify equity gaps and work to reduce them.
- Jurisdictions will advance the collection, reporting, and governance of First Nations, Inuit and Métis data.

# Questions

Any comments, questions, or feedback you would like to share with the team?



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