

# ACCESS: Accelerating Childhood Cancer Experience, Science & Survivorship

ICRP Meeting  
May 15, 2024

Christine Williams, PhD  
Executive Director



# Why does Canada need ACCESS?

Cancer is the **leading cause** of disease-related death in children and adolescents, beyond the newborn period.

In Canada, approximately **1,500** children and adolescents are diagnosed with pediatric cancer each year.

There is an overall survival rate of less than **15%** in children with refractory, relapsed or metastatic cancer.

Childhood cancer rates are increasing about **0.8%/year**.

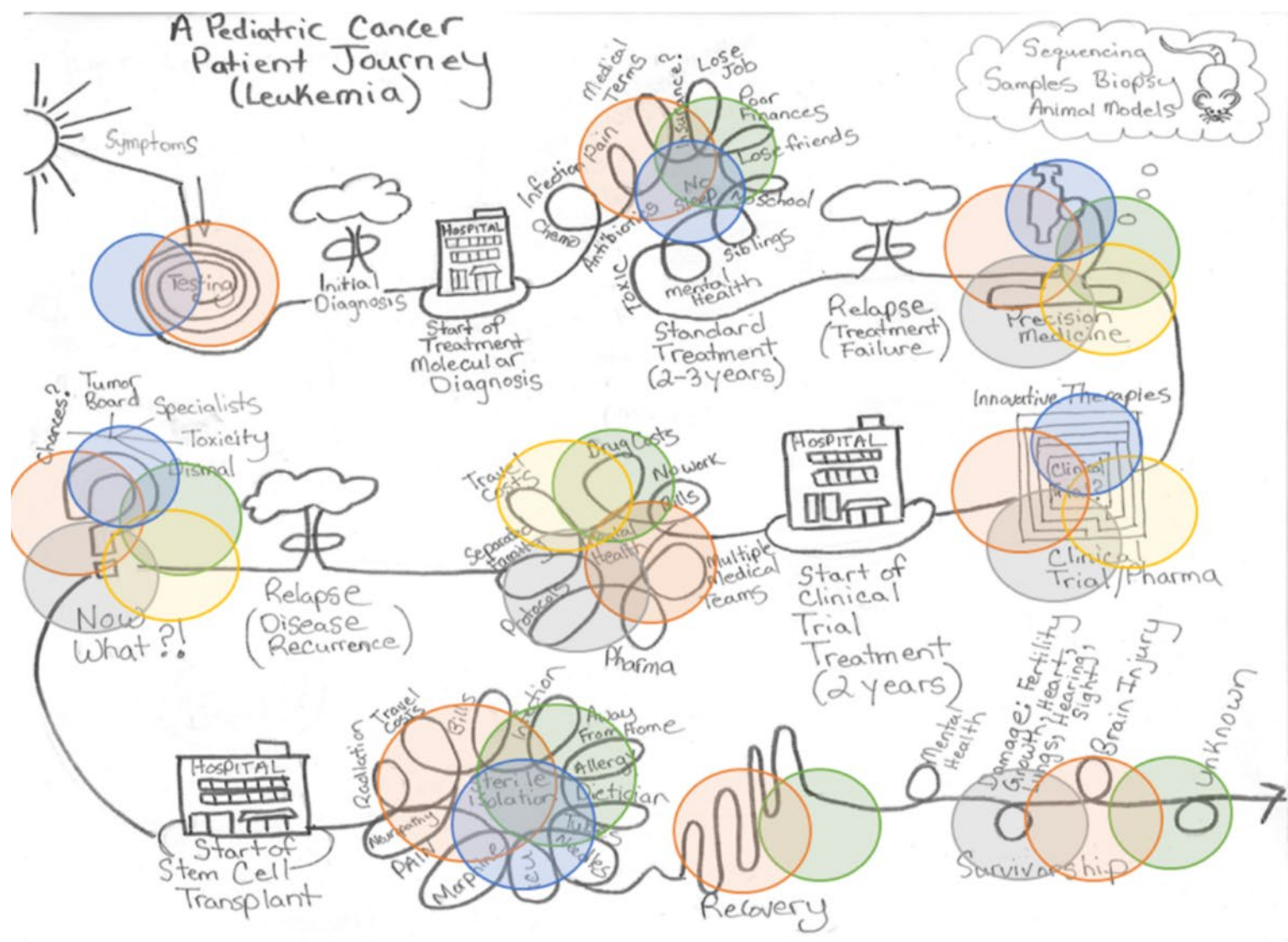
More than **80%** of adult survivors of childhood cancer experience long-term side effects.

The prognosis for most pediatric cancers has stagnated over the past **30 years**.

There is **no national strategy** for pediatric cancer research and care.

# Background

- The creation of ACCESS is the result of dedicated patient and parent advocacy for **change**.
- Allocation in the 2021 Federal Budget for “strategic research on pediatric cancer, and more specifically, the creation of the Canadian Pediatric Cancer Consortium”



- Theme 1: Cancer Biology
- Theme 2: Clinical Trials
- Theme 3: Access to Innovative Therapies and Optimal Care
- Theme 4: Regulation and Policy, ELSI, and Implementation
- Theme 5: Training and Education

# Background

- The creation of ACCESS is the result of dedicated patient and parent advocacy for **change**.
- Allocation in the 2021 budget for “strategic research on pediatric cancer, and more specifically, the creation of the Canadian Pediatric Cancer Consortium”
- CPCC received \$23 million to be spent over two years (June 2022 – May 2024), from the Government of Canada through a CIHR team grant; a no cost extension is available to 2026.
- Led by three Co-Chairs: Drs. David Malkin and Jim Whitlock, who are clinician-scientists from SickKids, and parent advocate Adrienne Co-Dyre.
- Supported by a secretariat of 7 staff members.
- Rebranded as ACCESS-ACCES in 2023

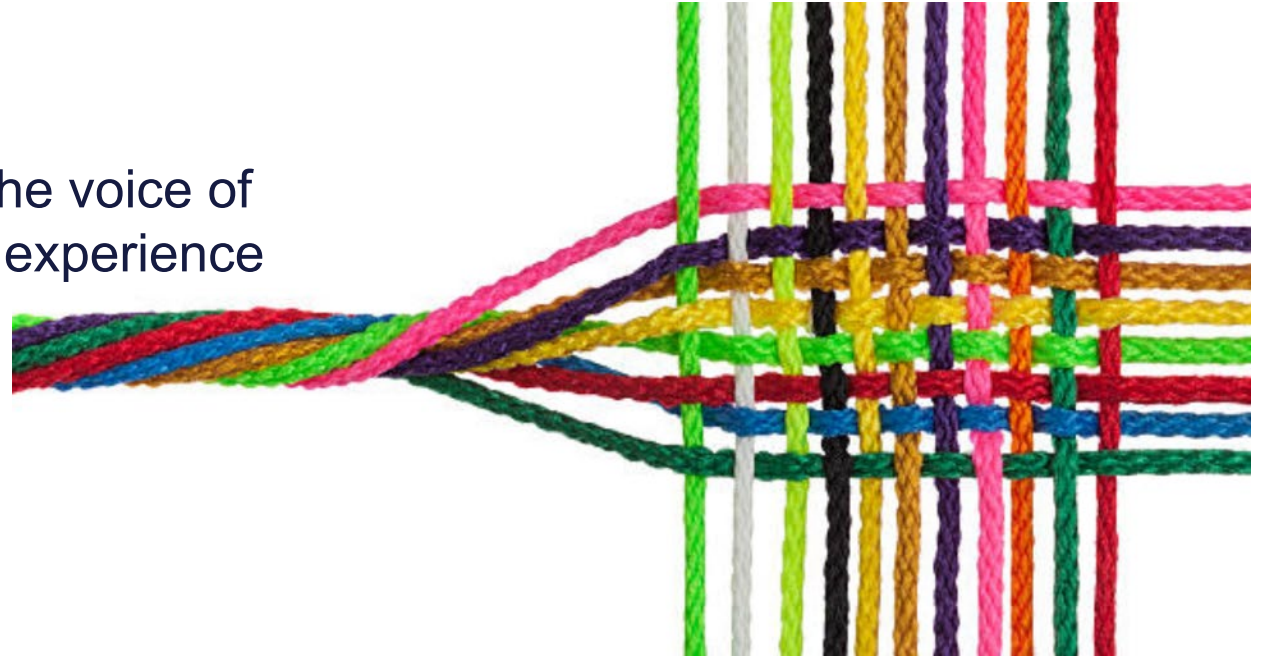
# We are building a new kind of organization



Interdisciplinary

Inclusive

Interwoven with the voice of  
people with lived experience  
(PWLE)



We are driven by asking:

***What will be transformative for children and their families  
experiencing cancer in Canada?***

# Our 'why'

## Mission

Every child with cancer in Canada will have access to the latest scientific advances, diagnostic tools, innovative therapies and supportive care leading to better outcomes and quality of life.

# What we do

Our Name = Our Purpose.

ACCESS: Advance Childhood Cancer Experience Science and Survivorship  
*for all children and their families experiencing cancer in Canada.*

## **Our work is two-fold:**

1. To establish and lead a multi-stakeholder, pan-Canadian pediatric cancer network.
2. To support research in all phases of the pediatric cancer journey.



# How we work together

## 7 Research Themes

**Cancer Biology** – Better understand the biology of pediatric cancers by connecting research efforts, removing barriers and leveraging knowledge and expertise.

**Clinical Trials** – Develop a national trials infrastructure, improve cross-country trial availability, and build remote access pathways to Canadian studies.

**Access to Innovative Therapies & Optimal Care** – Improve access to novel therapies, sustainable solutions and better system navigation for pediatric cancer patients.

**Regulation, Policy & Economics** – Assess health policy and systems to improve on health equity and disparities by promoting evidence-informed policies and programs.

**Education & Training** – Improve patient involvement in cancer care and research and enhance career development and training opportunities of clinicians and researchers.

**Ethical, Legal and Societal Issues & Implementation Science** – Improve system processes including ethics reviews, data governance and data sharing.

**Psychosocial & Survivorship** – Advance the wellbeing and life quality for patients, survivors and families through prevention and management of cancer treatment side effects.

## 2 Enabling Groups

**Knowledge Mobilization Group** – Advance information sharing with the research and patient communities to improve uptake of evidence-based knowledge.

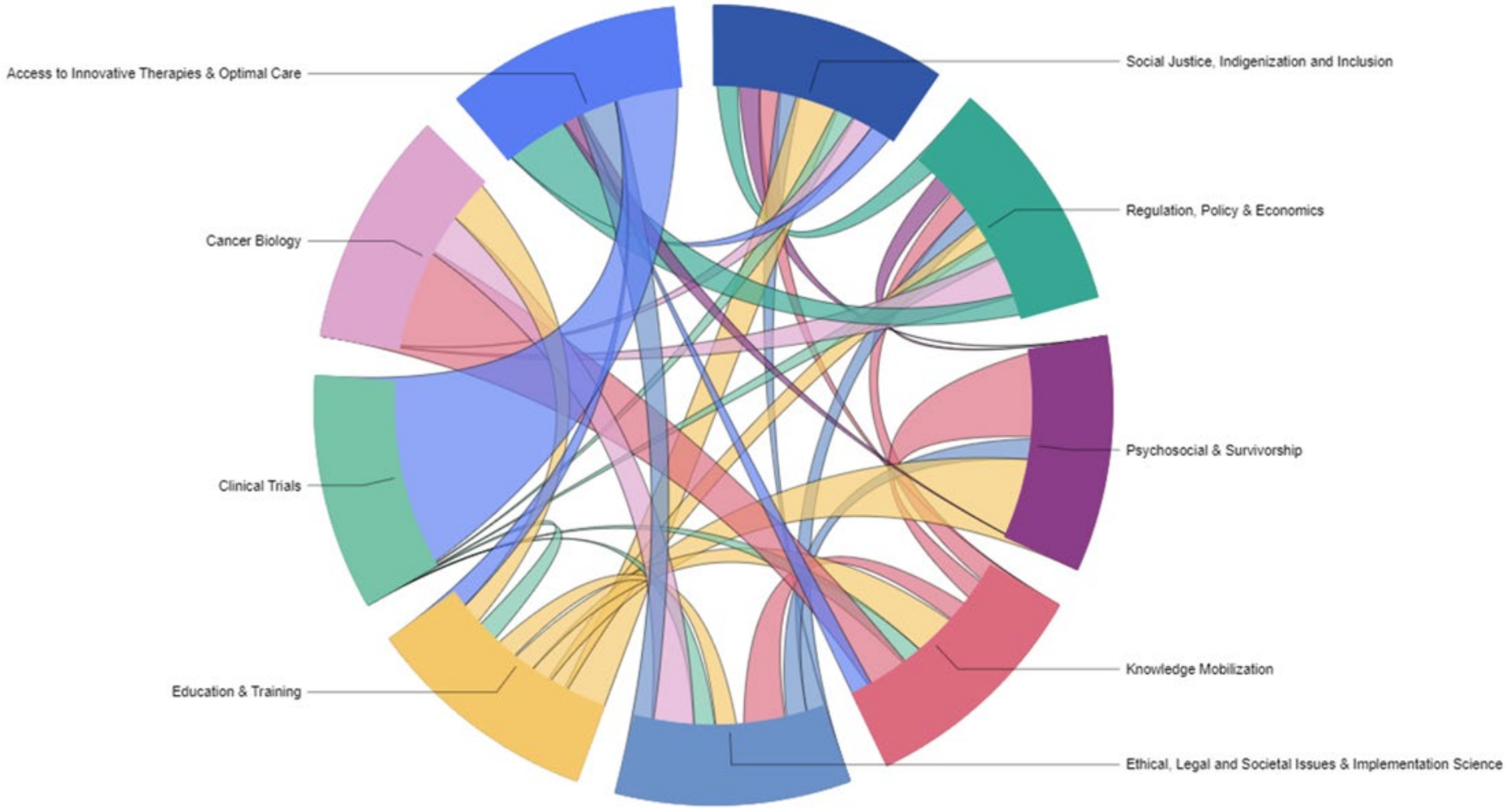
**Social Justice, Indigenization & Inclusion (SJII) Committee** – Develop guidelines for the inclusion of equity-deserving groups and build expert councils that offer insight on strategic and project direction.

**All Themes and Groups are working with their communities to prioritize and submit research projects for funding.**

# Project examples from Themes and Groups

- Federated research platforms for biospecimens, proteomics, liquid biopsies, cancer models, and data sharing
- National network to identify therapeutic targets to prevent/treat metastasis and relapse in high-risk sarcomas
- National team to study 3D/4D DNA structure to identify novel therapeutic targets for brain tumours
- Cross-Canada pediatric network to manufacture and deliver novel CAR T-cell therapies
- Clinical trials incubator and support for new Canadian-led investigator-initiated trials
- Canadian patient participation in an international pediatric proton/photon consortium registry
- Remote access model for clinical trials
- National data governance framework
- 'Innovation sandbox' to test changes to systems, processes and/or regulatory structures to improve access to pediatric clinical trials
- National drug access navigator
- Identify disparities in access and equity by mapping the current Canadian health policy landscape
- Education hub and learning management system
- Subsidize PWLE to further their knowledge of childhood cancer and/or build advocacy skills
- Expand capacity for youth engagement in pediatric cancer research
- Standardize national psychosocial health measures
- Assess implementation of a digital 'passport for care' for personalized survivorship care plans for survivors
- Inventory of knowledge mobilization products, events and networks
- Best practice guidelines for collection of socio-demographic data in research projects

# The work of the research themes and groups is interconnected



# Governance



# Blueprint for impact: ACCESS' path forward

## Strategic

1. Achieving organizational sustainability
2. Supporting connectivity and inclusivity
3. Building strategic partnerships
4. Enhancing data connectivity and sharing

## Operational

1. Launching a website and communications plan
2. Improving information sharing and collaboration
3. Ramping up stakeholder engagement and support

# Next Steps: important actions & tactics

## 1. Sustainability and Strategic Planning

- Developing a strategic sustainability and growth plan under the guidance of a working group
- Starting an early draft of ACCESS' strategic plan

## 2. Digital Infrastructure and Communications

- Developing and launching a robust ACCESS website (July)
- Finalizing and actioning a communications strategy

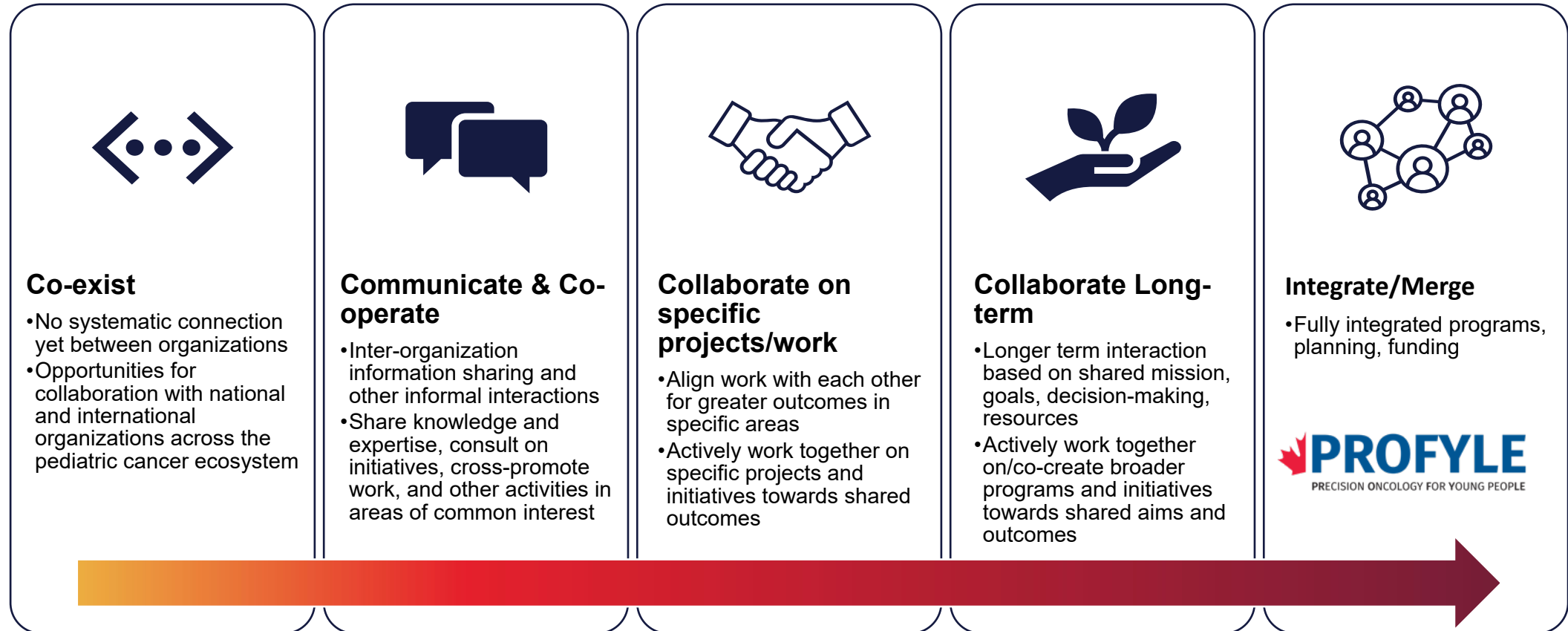
## 3. Partnership and Collaboration

- Developing a partnership strategy
- Establishing a PWLE Advisory Committee and Network

## 4. Operational Excellence and Execution

- Reporting on metrics/deliverables to communicate our impact and support partnerships
- Establishing cross-ACCESS priorities along with how to action and resource them
- Appropriately supporting themes/groups to achieve their research goals

# ACCESS is building a spectrum of collaborations to enhance our collective impact in pediatric cancer



*\*Figure adapted by ACCESS from the Tamarack Institute - Collaboration Spectrum Tool  
<https://www.tamarackcommunity.ca/interactive-tools/collaboration-spectrum-tool>*

# PRrecision Oncology For Young people

## Pan-Canadian precision medicine platform



- The PROFYLE Program was launched in 2017
- A national collaborative program for children, adolescents and young adults (0-29) with refractory, relapsed and metastatic ('hard-to-cure') cancers
- Goals:
  - developing and implementing a pipeline to provide equitable access to tumour molecular profiling (using next-generation molecular tools, cancer model systems and proteomics)
  - identifying disease- and patient-specific biomarkers
  - uncovering novel targeted treatment options in a clinically relevant timeframe
- ***Ultimately, to positively impact the lives of and improve outcomes for CAYA across Canada (no matter where they live) with 'hard-to-cure' cancer.***





# PROFYLE as a 'driver project' within ACCESS

## Driver project

A “driver project” is an initiative that is undertaken by ACCESS to address the broader needs of the pediatric cancer community in Canada.

It must have the potential to significantly improve the childhood cancer journey.

It must be relevant to at least three of the ACCESS Themes, reflect SJI best practices and include planned Knowledge Mobilization activities.

**PROFYLE is the first Driver Project within ACCESS**

# Final Thoughts



*"Like the Northern Lights, we are tiny independent particles coordinated by a magnetic field into something wondrous."*

*-Dr. Michel Duval,  
CHU Sainte-Justine, Montreal QC*

ACCESS is early in its journey!

“Start up” phase of building community, collaborations, culture.

Now focused on sustainability and growth to ensure collective long-term impact.

Thank you  
Merci



[accessforkidscancer.ca](https://accessforkidscancer.ca)



[/company/access-acces/](https://www.linkedin.com/company/access-acces/)



[/access\\_acces](https://www.instagram.com/access_acces)