

ACCESS

IMPACT REPORT

2023 - 2024

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ABOUT ACCESS

ACCESS is a national research network connecting and empowering diverse people and organizations to conduct research, change policy, and develop new tools to ensure better lives for children and their families who experience cancer in Canada. It is the expert voice of pediatric cancer research and care in Canada.

Despite significant advances in pediatric cancer research globally over the past 30 years, challenges in the treatment and care for hard-to-treat pediatric cancers and the long term late-effects of cancer treatments remain.

Canada's collective capacity for world-leading science and clinical programs can provide high-quality, equitable, efficient, and sustainable systems of care for all children with cancer. But only if we work together.

ACCESS is integrating the voice of Persons With Lived Experience (PWLE) with those of researchers, healthcare providers, industry leaders, and partner organizations who are committed to our mission of ensuring that 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.

By working in this unique collaborative, ACCESS is advancing pediatric cancer experience, science, and survivorship - and transforming lives.

Mission:

To ensure that every child with cancer in Canada has access to the latest scientific advances, diagnostic tools, innovative therapies, and supportive care leading to better health outcomes and quality of life.

Our work is two-fold:

- o Establish and lead a multi-stakeholder pan-Canadian pediatric cancer network.
- o Support research in all phases of the pediatric cancer journey.



ABOUT ACCESS

Establishing ACCESS

In 2021, the federal government committed [\\$30 million to fund pediatric cancer research](#), the largest investment in Canada to date. This funding was a direct result of advocacy by several hundred families directly impacted by pediatric cancer, along with many researchers, clinicians, and partner organizations. The collective goal was for enhanced, coordinated childhood cancer research and care in Canada.

In 2022, the Canadian Institutes of Health Research (CIHR) launched a [\\$23 million team-grant opportunity](#) to support the establishment of a national pediatric cancer consortium that would change the way childhood cancers are researched and treated in Canada.

A successful application led by two physician researchers and a pediatric cancer parent advocate brought together a pan-Canadian team of stakeholders to make real their shared vision to improve the lives of children with cancer and their families in Canada.

Objectives 2023 - 2024

- o Establish a multi-stakeholder Pediatric Cancer Consortium that includes a diverse set of stakeholders, knowledge-users, partners, and national and international research collaborators.
- o Advance pediatric cancer research in high priority areas.
- o Improve the research pipeline for the development and further access to drugs, by engaging with Persons With Lived Experience and influencing system improvements through research and knowledge mobilization.
- o Advance equitable access to new and promising therapies regardless of geography, race, ethnicity, and socioeconomic status.
- o Build capacity for the next generation of pediatric cancer researchers through training and mentorship opportunities, and for Persons With Lived Experience to engage meaningfully in the research ecosystem.
- o Maximize research impact and knowledge mobilization to ensure evidence informs health policy, decision making, and planning.



MESSAGE FROM THE EXECUTIVE TEAM

"If you want to go fast, go alone. If you want to go far, go together." - African Proverb

ACCESS began as a vision about how the difficult and frightening childhood cancer journey could be improved for all families in Canada by working differently, together. This vision was brought to life by the tireless advocacy of patients and families directly affected by pediatric cancer and through a federal government commitment to see that change take place. In the 18 months since funding for our new pediatric cancer consortium was announced, we have come far, and we have done so together.

At ACCESS, we believe our strength lies in our collective expertise and shared passion. Bringing a diverse set of stakeholders together under one umbrella has allowed a new integrated approach to pediatric cancer while fostering a sense of solidarity and shared purpose among patients, families, healthcare professionals, researchers, partner organizations, and advocates. We are immensely proud of this community-building achievement.

We are also proud of having consulted, engaged, and included Persons With Lived Experience (PWLE) in every level of decision-making at ACCESS. Our growing community of PWLEs have made invaluable contributions, from the strategic leadership levels of the network through to individual research projects, ensuring that our efforts and our purpose always remain centred on patients and families. We have developed a PWLE Network as a safe space for PWLE to connect, share their experiences, and support each other, and we have created a new PWLE Advisory Committee to review, and advise on our work from a PWLE perspective.

Lastly, we have been purposeful in building and investing in pan-Canadian research projects and activities across the patient journey that will change what we can achieve together in pediatric cancer research and care. Our initiatives are designed to advance scientific knowledge, provide training opportunities, and translate discoveries into tangible, life-changing outcomes for children affected by cancer in Canada.

While we have achieved much in a short while, we recognize that there is still a long way to go. The groundwork we have laid is just the beginning of the impact we can have by working collectively. Through continuous evaluation and learning embedded within our organizational structure, we will actively assess our impact against our investments and efforts. And as needed, we will make necessary adjustments to drive impactful change for the pediatric cancer community.

Even as we reflect on the early achievements in our journey, we are planning for the growth and sustainability of ACCESS in the future. Having established a multi-stakeholder network, we can now shift our thinking from a start-up to a scale-up. In the year ahead, we will focus on outlining a long-term vision for ACCESS and how we will achieve it. We are developing a sustainability plan to ensure we continue our work and will focus on building meaningful collaborations with national and international partners.

We believe in a collaborative approach to pediatric research and care, so we invite you to join us in our goal to advance childhood cancer experience, science, and survivorship in Canada.



Adrienne Co-Dyre
Co-Chair



David Malkin
Co-Chair



James Whitlock
Co-Chair



Christine Williams
Executive Director



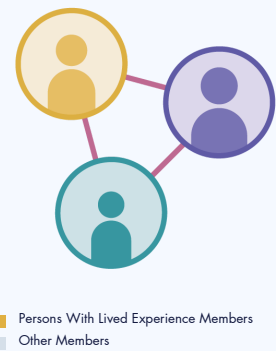
Stephanie Grover
Director

BY THE NUMBERS

We are ACCESS



Persons With Lived Experience Involvement



Community Engagement



1 Annual General Meeting
180 + Attendees



2 Virtual Town Halls
220 + Attendees



7 Monthly e-Updates
750 + Subscribers



12 + Speaking Opportunities



16 Training and Education Activities

*The data presented are as of March 31, 2024

BY THE NUMBERS

Advancing Pediatric Cancer Research

18
Approved Projects

11
Proposals Underway

170 +
Active Participants in
Projects and Initiatives

21
Academic and Research
Institutions Collaborations

25 +
Trainees and Early
Career Researchers



Establishing A Multi-Stakeholder Consortium

1 Driver Project -
PROFYLE (PRrecision Oncology
For Young people)

40 +
Collaborative
Partners

10 +
16

Non-Profits and
Industry
Pediatric Cancer
Centres



Advancing Equitable Access



Formation of the Social Justice, Indigenization & Inclusion Committee to advise on the meaningful inclusion of equity-deserving groups and build expert councils that offer insight on strategic directions.

1 ACCESS Equity Statement

1 Guidance Document on the Collection of Sensitive Data

Building Capacity



Launched a Subsidy Program to support Persons With Lived Experience training and education



Launched the ACCESS Summer Experience Program with 15 trainees from 4 provinces

Maximizing Research Impact and Knowledge Mobilization



Launched a website - a credible source of information on pediatric cancer research and care

*The data presented are as of March 31, 2024

OUR STORIES

Strength in Diversity - A Collaborative Approach to Pediatric Cancer Research and Care

Pediatric cancers are rare diseases that differ significantly from adult cancers. From the biology of their development to long-term survivorship issues for patients, the complexities of pediatric cancers present unique challenges, and gaps in our understanding. Recognizing these complexities, we are approaching pediatric cancer differently, using the power of collaboration. By bringing together the brightest minds and connecting our national resources, we can address these issues from multiple fronts.

Funded through the collective advocacy efforts of patients and families directly impacted by pediatric cancer, we continue to include Persons With Lived Experience (PWLE) at all levels of ACCESS' thinking and planning. To date, we have over 70 PWLE actively involved in ACCESS. This includes 3 out of 13 members on the Senior Leadership Committee; 16 out of 46 Co-Leads spanning our seven research themes and two cross-cutting groups; 4 out of 8 members on the Sustainability Working Group, and numerous members as part of the [PWLE Network](#).

As a pan-Canadian network, our [commitment to inclusion](#) as guided by our Social Justice, Indigenization & Inclusion Committee extends to Indigenous communities and other diverse intersectional identities. At ACCESS, we believe that real change requires centering, engaging, and collaborating with impacted communities - a one-size-fits-all approach to clinical care, research, and policy is insufficient and unjust.

Additionally, to accelerate research and care, our [research themes and cross-cutting groups](#) include

expert teams of PWLE, researchers, healthcare professionals, and community collaborators from across Canada. Together, they are determined to understand cancer biology, evaluate diagnostics and treatments, optimize care, drive policy change, and actively share research evidence on pediatric cancers.

ACCESS' collaborative and inclusive approach is instrumental in driving forward pediatric cancer research and care. By leveraging the strength of our diverse community, we will make significant strides in understanding and addressing the unique challenges posed by pediatric cancers, ultimately enhancing the quality of life for affected children and their families across Canada.

"Grateful and honoured to be a part of ACCESS, to be able to share my trauma, and channel it into something that's healing, and will help other people..."

- Vinesha Ramasamy, Person With Lived Experience



OUR STORIES

Faster Discoveries through Cross-Disciplinary Collaboration

Scientific research on complex problems often requires years of effort and substantial funding. At ACCESS, we believe in collaboration and bringing experts together to solve problems faster, reduce resource duplication, and utilize funds efficiently - this approach is reflected in the design of our research themes and groups.

ACCESS strategically supports pan-Canadian projects to accelerate discovery and innovation. For example, sarcomas are a rare and diverse group of cancers that occur in the bones and soft tissues. Due to their rarity, high-risk pediatric sarcomas are challenging to study, leading to significant knowledge gaps. The Cancer Biology research themes' national [Sarcoma Metastasis Research Taskforce](#) brings together over 30 experts in sarcoma pathology, biology, model systems, molecular technologies, and drug screening across four provinces. Through a national collaboration, the taskforce will access samples from eight biobanks across Canada, facilitating the sharing of resources and expertise to benefit the Canadian scientific community, and help identify biomarkers for preventing and treating relapse, and metastasis in high-risk pediatric sarcomas.

Similarly, the Clinical Trials research theme's [MIRV Trial](#) demonstrates innovative thinking. Pediatric low-grade gliomas are the most common brain tumours in children, often requiring systemic therapy due to their inoperable locations. In collaboration with clinical centres across Canada, funders, industry, and other community partners in the pediatric cancer ecosystem, ACCESS is supporting a Canadian-led clinical trial focused on low-grade gliomas that will determine the effect of combination therapy on tumour reduction and

evaluate the safety and tolerability of the therapy. In line with ACCESS' mission, the trial will engage at least nine Canadian centres and integrate the use of satellite sites where possible, minimizing travel time for patients and families, and enhancing outreach to communities historically underrepresented in clinical trials. The broad-reaching approach to patient inclusion taken in this trial will serve as a model for future pediatric clinical trials.

Building on the work of the pediatric community, our Clinical Trials and Access to Innovative Therapies & Optimal Care research themes are collaborating on pediatric oncology Drug Access Navigator will act as a national resource to aid clinicians in negotiating access to innovative drugs for their patients, providing treatment and drug information for the development of clinical trials, and supporting other drug access initiatives for patients across Canada. Drug navigation resources will also be shared through an accessible database to improve access to innovative therapies within and across the healthcare systems in Canada.

Through these collaborative efforts, ACCESS is committed to accelerating pediatric cancer research, improving treatment outcomes, and enhancing the quality of life for patients and their families across Canada.



OUR STORIES

Building Capacity Through Innovative Thinking

Capacity building and training requires providing targeted resources at multiple levels - community, institutional, and health systems - and must support a diverse set of people.

With this in mind, the Education & Training research theme recently launched the [Persons With Lived Experience \(PWLE\) Subsidy Program](#) to offset costs for PWLE to attend national and international courses and conferences, both online and in-person, to enhance their knowledge and advocacy efforts in childhood cancer. The subsidy is designed to complement existing opportunities in Canada and expand the pool of resources available for continuous PWLE learning.

Additionally, ACCESS recently led a Summer Experience Program for undergraduate and graduate student trainees involved in ACCESS projects in pediatric cancer across Canada. The first year of this Program connected 15 trainees across four provinces in participatory learning and educational opportunities that expanded their understanding of the breadth of pediatric cancer research in Canada and provided them with a colleague network.

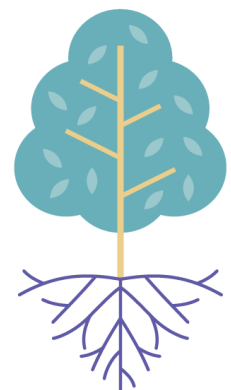
To further develop capacity for community engagement, and empowerment, ACCESS has actively involved PWLE in research projects and planning, including the Knowledge Mobilization Group's [Participatory Action Project](#). This project engaged over 60 teens with lived experience of childhood cancer through workshops in Quebec, in collaboration with [Leucan](#). This initiative intended to equip adolescent cancer patients with the knowledge and resources needed to enhance experience, engagement and ultimately

improve survivorship outcomes.

At ACCESS, community also includes researchers and academics at an institutional level. The ACCESS-supported [Pediatric Cancer Models & Mechanisms Network](#) in collaboration with the [Rare Diseases: Models & Mechanisms Network](#), helps streamline the research pipeline for pediatric cancers by connecting pre-clinical and clinical researchers and establishing a pathway for developing collaborations to prioritize and answer research questions across Canada.

Identifying gaps and bottlenecks within the health system is crucial for the efficient use of resources, funding, and the workforce. Our Regulation, Policy & Economics research theme is evaluating data for robust analysis regarding regulation, policy, and [access to precision diagnostics](#) in pediatric cancer across Canada and internationally. By connecting data and lessons learned from various institutions and jurisdictions, they aim to better understand the inefficiencies, barriers, and gaps in the pediatric cancer space. This understanding will help design and build stronger, more efficient health systems, use evidence to inform and shape policy, and adopt or adapt effective models from other countries to improve the quality of life for patients and families in Canada.

These initiatives are designed to support capacity building and connections between people and institutions which will ultimately support more efficient and sustained progress in pediatric cancer research, education, and care.



OUR STORIES

Empowering the Pediatric Cancer Community

In the absence of intentional and planned knowledge translation activities, research findings often remain in databases, never reaching the communities that need the findings the most. This is especially true for patients and families affected by pediatric cancer, many of whom struggle to find trustworthy information amidst a sea of online content.

At ACCESS, we believe that evidence-based resources and information, tailored to meet all relevant stakeholder needs, not only empower individuals to take control of their health and wellness but also equip them to engage in productive, well-informed conversations with their healthcare providers.

ACCESS is spearheading key initiatives to maximize research impact and planned knowledge mobilization activities for the benefit of the broader pediatric cancer community. One such initiative is the creation of a comprehensive [Resources](#) page on the ACCESS website. This page will serve as a one-stop-shop for information on pediatric cancer, including research papers, videos, courses, and other evidence-based materials for the public. It will also include links to important information and resources offered by partner organizations.

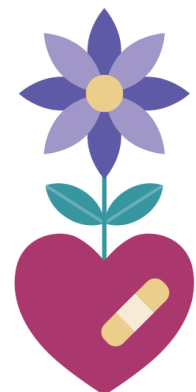
To support the well-being and quality of life of patients, survivors, and their families, the Psychosocial & Survivorship research theme is working on two important projects. They are developing an interactive, evidence-informed [platform](#) for cancer patients and survivors. This platform will include a repository of resources for symptom reporting and management, survivorship education, and tools for ongoing survivorship care.

The content, based on the Children's Oncology Group (COG) Long-Term Follow-Up Guidelines, will be tailored for Canadian children in close collaboration with patients and survivors. Concurrently, they are conducting a [needs assessment](#) to identify tools for psychosocial distress screening to increase awareness of psychosocial screening in pediatric cancer and mobilize efforts to implement such screening into standard practice across Canada.

On a systems level, the Education & Training research theme has formed and is leading the Patient and Family Education Community of Practice, which connects pediatric oncology nurses and other healthcare professionals across the country. With the participation of 15 nurses from various provinces and work underway to include PWLE, this initiative will foster active knowledge sharing and collaboration and ongoing education on pediatric cancer care.

Moreover, on a pan-Canadian level, the Ethical, Legal and Societal Issues & Implementation Science research theme is exploring ways to improve [data-sharing processes](#) and enhance access to comprehensive medical information for patients, caregivers, and healthcare professionals.

These initiatives aim to empower patients and families to manage their physical, emotional and psychological well-being throughout their cancer journey.





Advancing Childhood Cancer
Experience, Science & Survivorship
Agir Contre le Cancer
des Enfants avec Succès



Connect with us:

ACCESS is a pan-Canadian pediatric cancer network advancing childhood cancer experience, science and survivorship. Our network of researchers, healthcare providers, industry leaders and Persons With Lived Experience believe in equitable access to scientific advances, diagnostic tools, innovative therapies, and supportive care to better health outcomes and quality of life for children with cancer and their families. Visit accessforkidscancer.ca for more information. ACCESS is supported by the Canadian Institutes of Health Research (CIHR).

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[Instagram](#)

[X](#)

[YouTube](#)