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

Building Momentum: Showcasing Progress and Shaping the Future of ACCESS

ACCESS’ 2nd Annual Meeting
January 28 – 29, 2025

“What We Heard” Report

Background and Context

From January 28th to 29th, 2025, the ACCESS Annual Meeting provided its diverse and dedicated community with an opportunity to share updates on the pivotal work happening in pediatric cancer and foster discussions to ensure the future direction of ACCESS is community-informed and community-driven. To achieve this goal, the meeting was centred around two key areas of focus:

1. Reflecting on the priorities and progress made by ACCESS' research themes, cross-cutting groups, and projects; and

2. Shaping the future of ACCESS by identifying areas for optimal impact – including building partnerships, advocating for improved pediatric cancer drug access in Canada and developing a national strategy for pediatric cancer.

Following this event, a post-event survey was sent out to all attendees to provide another opportunity to gather additional feedback on the key areas of focus as well as on the Annual Meeting itself. Although, the response rate was moderate, the **feedback received about the Annual Meeting was overwhelmingly positive, with nearly 90% of respondents expressing strong satisfaction.** Many attendees appreciated the opportunity to meet with a diverse group of like-minded individuals in the pediatric cancer community to discuss how to collectively work towards advancing pediatric care and research in Canada – including discussions about developing a national strategy for pediatric cancer, as well as improving drug access in Canada. **Constructive advice was provided on improving future meetings** with recommendations to provide relevant meeting information earlier, reviewing how ACCESS built on key takeaways from last year's meeting, and offering even more opportunities for persons with lived experience (PWLE) input and involvement. **Beyond feedback on the Annual Meeting itself, there was a strong call for greater transparency** around the long-term sustainability of ACCESS, including ACCESS' current financial status, as well as how projects are being approved and funded and what opportunities are available for new projects.

This report captures the key insights that emerged from the presentations and discussions at the Annual Meeting, enriched with additional feedback from the post-event survey. It also lays out ACCESS' anticipated next steps and the activities it has already identified to build on the momentum of its achievements to date.

Key Themes

Three key overarching themes emerged during ACCESS' 2nd Annual Meeting:

1. ACCESS' research themes and projects have already demonstrated significant progress and impact;

2. The organization has a key role to play in accelerating access to pediatric cancer medicines; and

3. There is a clear opportunity to take the lead on advocating for a national strategy for pediatric cancer.

(1) ACCESS' research themes, cross-cutting groups, and projects have already demonstrated significant progress and impact.

Since its inception, ACCESS has been supporting diverse research themes, cross-cutting groups, and projects. During the Annual Meeting, the progress and impact of these initiatives were showcased through 9 spotlight presentations, demonstrating ACCESS' commitment to:

Supporting research in all phases of the pediatric cancer journey, from tackling system and policy level challenges to enhancing psychosocial support for pediatric cancer patients and their families. The presentations highlighted diverse initiatives, such as policy-driven approaches to improving the implementation of innovative diagnostics in pediatric cancer, research on psychosocial screening measures, as well as the national expansion of the STEP-1 initiative to support travel for patients accessing clinical trials in Canada. Collectively, these initiatives recognize and address the critical need to provide holistic and comprehensive support to patients and families navigating pediatric cancer care.

Centring the unique perspectives and needs of PWLEs in addressing existing inequities in pediatric cancer care and research. At the core of this commitment is a strong emphasis on addressing the unique needs of PWLEs. ACCESS is actively connecting PWLEs to pediatric cancer learning opportunities and creating child-centric pediatric cancer knowledge mobilization resources to help patients and their families better access the education and information required to stay informed about ongoing developments in pediatric cancer research. Complementarily, through research on genetic discrimination and the collection of sensitive sociodemographic information in pediatric cancer care, ACCESS ensures that it strives to address concerns around inequities, data privacy, and inclusivity in pediatric cancer research and care – areas of critical importance to all PWLEs.

Fostering collaborations and partnerships within Canada and internationally. This is demonstrated through initiatives such as the Sarcoma Metastasis Research Taskforce (SMaRT), which brings together expert researchers from across Canada, and the international pilot study of chemotherapy and tyrosine kinase inhibitors in leukemia, a collaborative study with partners in the US and Europe. These efforts highlight ACCESS' dedication to promoting Canadian and international partnerships to accelerate progress in advancing pediatric cancer innovations.

ACCESS' Next Steps: Access will finalize the portfolio of projects that defined ACCESS' "launch" phase; work with co-leads to foster more effective cross-consortium linkages; evolve our communication strategy to better capture and convey the impact of our work through a new set of KPIs and other metrics, and launch a Partnership Forum to support and strengthen our work with priority partners.

(2) The organization has a key role to play in accelerating access to pediatric cancer medicines.

The drug access landscape in Canada is complex, involving multiple steps and system partners who all play important roles in evaluating and delivering innovative medicines to the patients who need them.

The current pediatric cancer drug access landscape in Canada is complicated. The drug review system in Canada consists of several key organizations: Health Canada, which is responsible for regulatory review; the Canada Drug Agency (CDA) and the Institut national d'excellence en santé et services sociaux (INESSS) (in Quebec), which oversee health technology assessments; the pan-Canadian Pharmaceutical Alliance (pCPA), which handles reimbursement negotiations; and provincial drug plans, which have the final authority on whether a drug is listed in individual provinces and territories.

Although the drug review system is designed to ensure that reimbursed drugs deliver value to the health system, too many barriers leave too many patients and clinicians struggling to access the therapies they need. Additional complications include manufacturers with insufficient incentives to sponsor pediatric cancer drug reviews and health technology assessment (HTA) bodies with far less experience reviewing cancer drugs with pediatric indications. Together, these factors reinforce the difficulties patients face in accessing pediatric cancer drugs in Canada.

However, there are important system developments that represent tangible signs of progress. In recent years, there have been significantly more opportunities for meaningful input and engagement between the health system and PWLEs. One notable example is Health Canada's consultation on the draft National Priority List of Pediatric Drugs, which gave patients, family members, advocacy organizations, and others the opportunity to share their perspectives on how effectively the draft priority list addresses the unmet needs in pediatric cancer care in Canada. Additionally, HTA bodies globally are trending towards widening the value lens by considering outcome measures beyond traditional assessments on safety, efficacy, and cost-effectiveness. HTA bodies are beginning to incorporate insights from PWLEs and experts, such as clinicians and payers, to better understand the broader value of medicines.

Although there are promising shifts in the system towards greater PWLE engagements and broadening the value lens, more work is needed grow these initiatives to truly accelerate access to pediatric cancer medicines.

External voices – including ACCESS – have key roles to play in strengthening pediatric cancer drug access in Canada. Centring PWLE and clinician perspectives in regulatory, HTA, and reimbursement evaluation processes is fundamental to driving equitable improvements to patient access to pediatric cancer drugs across Canada. ACCESS brings together a passionate and diverse community committed to driving positive change in the pediatric cancer space, making it uniquely positioned to advocate for and drive efforts to improve access to pediatric cancer medicines. Furthermore, the ACCESS community could serve as a crucial source of pediatric-specific expertise and input in drug review processes, especially as the system continues to broaden its engagement.

ACCESS' Next Steps: Following the Annual Meeting, ACCESS issued a Call to Action to assemble individuals interested in participating in further discussions on potential next steps to address challenges in pediatric cancer drug access in Canada. Once a Study/Working Group is assembled, ACCESS will aid in the facilitation of meetings to continue these conversations and drive ongoing action.

(3) There is a clear opportunity to take the lead on advocating for a national strategy for pediatric cancer.

Anchoring the second day of the Annual Meeting was a “carousel” session designed to allow participants to share their views on the pivotal need for a national pediatric cancer strategy, its essential components, the elements of an inclusive and effective development process, and the key partners who should be involved.

A National Strategy for Pediatric Cancer would embed pediatric cancer as an ongoing national priority and help establish standards that improve equitable access to care across Canada. Having a unified national approach to pediatric cancer care and research will enable Canada to ensure that every child with cancer, regardless of their location, has access to the same standards of care, including clinical trials and innovative treatments.

Existing cancer strategies focus on adult cancers, but pediatric cancer care differs significantly from adult cancer care, particularly when considering the long-term needs of survivors. A national pediatric cancer strategy is critical to addressing the unique needs of pediatric cancer patients and their families, including ensuring comprehensive survivorship care and providing psychosocial support to help families navigate emotional and financial challenges.

Now is an optimal time to advocate for the development of a national pediatric cancer strategy. The momentum generated by ACCESS presents an unprecedented opportunity to leverage existing networks and expertise to advocate for a national strategy. As recognition of the unique needs of pediatric cancer patients grows across Canada and internationally, there is an emerging push for coordinated action to enhance pediatric cancer care. Recent technological advancements – such as improved data sharing and coordination platforms – further enable pan-Canadian and global collaborations, making it increasingly feasible to develop and implement a national strategy across Canada. The upcoming Canadian federal election also provides an opportunity to engage policymakers on the importance of a national strategy with clear objectives and accountability measures. The current attention Canadian politicians and policy-makers are focusing on improving Canada’s self-reliance and overcoming interprovincial barriers also provide an opportunity to position pediatric cancer as an ‘innovation sandbox’ to new coordinated national approaches to research and care.

A comprehensive national strategy for pediatric cancer must address concerns around equity and consider the entire patient journey. First and foremost, the PWLE community has clearly expressed that a national strategy must establish minimum standards for diagnosis, treatment and follow-up care that are accessible to children and their families in all communities across Canada. This emphasis on equitable access to care and treatment options, including clinical trials and innovative therapies, reflects the desire that no child is left behind in their cancer care journey. Moreover, these standards must extend beyond treatment to address the long-term needs of survivors, a fundamental and distinguishing aspect of pediatric cancer care.

In this context, acknowledging the importance of survivorship and long-term care support is essential. This includes addressing fertility concerns, supporting the transition from pediatric to adult care, and providing continuous psychosocial support throughout treatment and into survivorship. To ensure a comprehensive and integrated approach to care, it is equally important to train healthcare providers at all levels – from general practitioners to specialists and allied professionals – so that every aspect of a patient’s journey is effectively supported. Finally, the sustainability of funding is crucial for maintaining the strategy’s long-term success, and a clear plan for stewardship and securing ongoing financial support should be integrated into the strategy.

Incorporating input from diverse partners and using creative approaches to engage underrepresented groups is central to an inclusive and effective strategy development process. Key partners include advocates (i.e., PWLEs and patient organizations), champions, government, policymakers, health system leaders, healthcare providers, researchers, industry partners, and regulators. It is especially important to involve partners across the entire continuum of care – including adult cancer organizations, psychosocial services providers, and adolescents and young adult (AYA) groups, among others – to ensure a holistic and comprehensive approach. Special attention should be given to involving underrepresented groups, such as Indigenous, equity-deserving and rural communities, to ensure the strategy is equitable and inclusive.

Leveraging existing collaborations and relationships and employing creative and targeted outreach methods are key to effectively reaching underrepresented communities. This may include any combination of grassroots channels, surveys, emails, social media outreach, and the circulation of accessible documents. Outreach efforts should be intentional and targeted to maximize reach to diverse partners in the pediatric cancer community. To further encourage active participation and input, appropriate incentives, such as emotional and/or financial support to facilitate and enable involvement, could be offered. It will also be important to develop a robust communication plan to maximize the strategy's reach and impact, as well as strengthening and sustaining collaborations and partnerships.

ACCESS' Next Steps: ACCESS will continue to advocate for a national strategy for pediatric cancer and explore what an effective strategy and development process would involve. However, its role in the potential development of the strategy will be shaped by future funding. ACCESS is dedicated to advancing the development of the national strategy in any feasible and necessary capacity to ensure its success.

Final Thoughts

The 2025 Annual Meeting was defined by the dynamic engagement and passionate participation of the entire ACCESS community, resulting in an incredibly insightful and impactful event. By building on its achievements to date and continuing to integrate the voices of PWLEs in meaningful ways, ACCESS is well-positioned to continue making a positive impact across Canada's pediatric cancer ecosystem.

In addition to the specific next steps outlined for each theme, ACCESS will continue to identify and engage a wide range of diverse partners – from PWLEs and industry to clinicians and researchers – to achieve three overarching priorities over the coming months:

(1) **Support the long-term viability of ACCESS by** implementing our Sustainability Action Plan and looking for opportunities to engage the new Federal government following the upcoming election, building on previous positive engagements with the office of the former Minister of Health.
(2) **Report and measure the impact of ACCESS by better** tracking and communicating the tangible outcomes and impacts of our projects.
(3) **Improve support for clinical trials by** working with a priority set of foundational partners – including C17, 3CTN, CCTG, ACT and N2 – to continue strengthening Canada's clinical trials ecosystem.

Over the coming weeks and months, ACCESS will be engaging with the pediatric cancer community as it finalizes its plans for 2025. The next ACCESS Annual General Meeting is already being planned for **March 2026** and we look forward to reconvening to share key successes and learnings after another year of progress in driving meaningful change to the pediatric cancer community across Canada.