



# THE CHILDHOOD CANCER CARE PLAN:

A ROADMAP FOR ONTARIO 2018-2023



**POGO**  
PEDIATRIC ONCOLOGY GROUP OF ONTARIO

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# OUR PARTNERS IN CANCER CARE



★	MAJOR HOSPITALS WITH PEDIATRIC CANCER PROGRAMS
■	POGO PEDIATRIC INTERLINK COMMUNITY CANCER NURSES
★	COMMUNITY HOSPITALS WITH POGO SATELLITE CLINICS
✱	HOSPITALS WITH POGO AFTERCARE CLINICS

## Working in Partnership to Strengthen the Childhood Cancer Care System for Ontario's Children, Adolescents and Young Adults, and Survivors of Childhood Cancer

On behalf of the Pediatric Oncology Group of Ontario (POGO) and our collaborators, we are pleased to present the Childhood Cancer Care Plan: A Roadmap for Ontario 2018-2023 (the Plan). This is the fifth time POGO, as advisor to the Ministry of Health and Long-Term Care (the Ministry), has led the development of a provincial pediatric oncology plan for Ontario. Building on the strong foundation of previous plans, the vision remains to actively champion an integrated childhood cancer care system that ensures equitable access to the best care for the best possible outcomes for children, adolescents and young adults (AYAs), survivors and their families.

The Plan reflects key priorities identified through in-depth consultation with hundreds of stakeholders. We would like to acknowledge the generous contribution of time, expertise and effort by healthcare providers and administrators, patients, childhood cancer survivors and parents to its development. The Plan illustrates the essential character of POGO as a champion of childhood cancer care committed to maintaining equitable access to high quality, coordinated care for those experiencing cancer in childhood, survivors and their families.

For our pediatric oncology healthcare providers, the Plan continues to encourage the development and delivery of quality education and training programs as well as opportunities to network and share best practice. The Plan will help to ensure that when patients and survivors have different components of their care delivered in different locations by different specialists, it is with confidence and assurance that these programs and services are anchored by a coordinated provincial system. As we look to the future, the Plan will assist Ontario's childhood cancer system to prepare for and adopt advances in childhood cancer care and control as new treatments and technologies evolve from research into clinical practice.

We are confident that the spirit of teamwork and collaboration that infuses the Plan will deepen as we work in partnership to strengthen cancer programs and services for the benefit of Ontario's children, AYAs diagnosed with cancer, and our growing number of childhood cancer survivors.



**Jill Ross, RN, MBA**

Chief Executive Officer  
POGO



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## CHILDHOOD CANCER IN ONTARIO

### THE CONTEXT

Provincial planning for childhood cancer care and control in Ontario began in the late 1980s against a historic backdrop of hospitals producing individual plans for their respective populations. With the formation of POGO came a partnership with these hospitals and the start of a collaborative model of long-range planning. The result—a more integrated provincial system of childhood cancer care. A key challenge in the delivery of childhood cancer programs and services in Ontario is the practical reality that malignancies affect a small number of young people dispersed across a large geographic area. To deliver equitable programs and services that meet appropriate standards of quality, patients and survivors may receive different components of their care in different locations but with confidence that a provincial plan underpins that care.

As advisor to the Ministry, POGO is committed to developing a childhood cancer system that enables Ontario's healthcare providers to deliver the best care for the best possible outcomes, meet current challenges and manage future demands. This five-year system Plan is the fifth such plan for Ontario. Building on the strong foundation of its predecessors, this Plan describes a path for working collaboratively to convert gaps and challenges into opportunities and actions that strengthen Ontario's childhood cancer system. Guided by this Plan, we can create appropriate tools and resources to provide equitable access and optimal experiences for patients, survivors and families, and support pediatric oncology professionals in the delivery of a comprehensive range of quality health programs and services.

### CANCER JOURNEY FOR CHILDREN, ADOLESCENTS AND YOUNG ADULTS, SURVIVORS AND FAMILIES

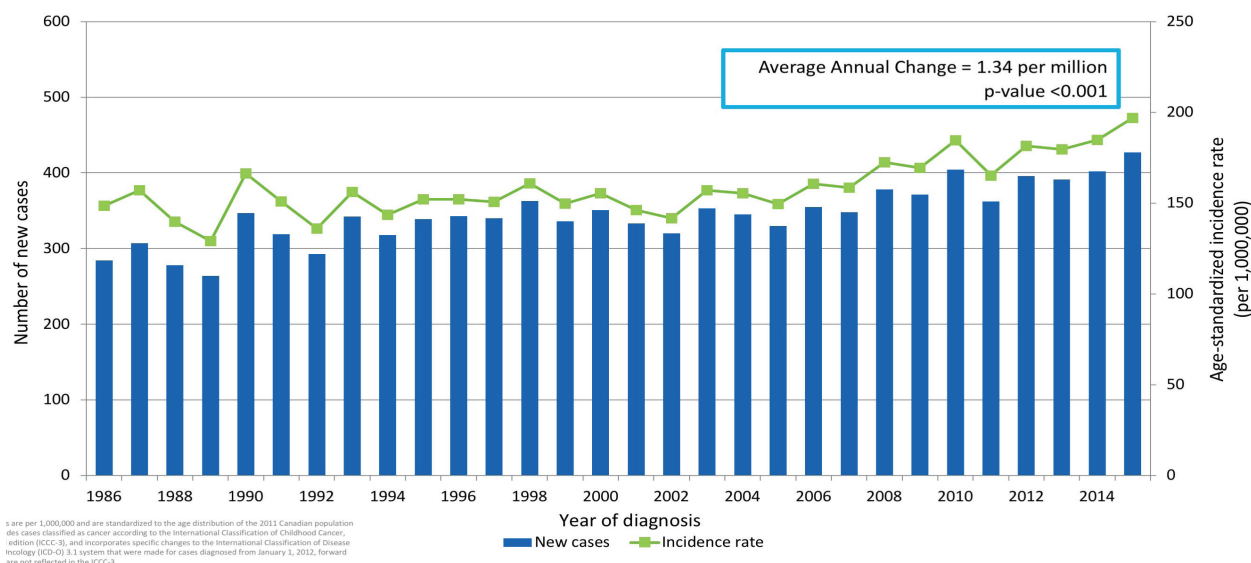
There is no question that a diagnosis of cancer is a life-changing event for the individual and family. Regardless of age at diagnosis, childhood cancer patients come into the system as part of a family. Each member of that family unit is deeply impacted by a cancer diagnosis across all dimensions of life—be it work, school or home. Present advances in childhood cancer care mean that many children will progress through treatment to become long-term survivors. However, a small number of patients and survivors will require palliative and/or end-of-life care. Long-range planning for the childhood cancer system is a necessary first step toward ensuring appropriate health system resources are available and equitably distributed across all disciplines and modalities such that patients, families and survivors are supported as much as possible across the whole of their cancer journey.

### CHILDHOOD CANCER: A UNIQUE DISEASE

Understanding the unique aspects of childhood cancer is essential for effective planning. It is a relatively rare event with an age-standardized incidence rate of 196.8 per million population ages 0 to 14 years in 2015 (Figure 1). This incidence rate is comparable to other jurisdictions including the US as well as some European nations, such as Norway, Finland and Portugal. There were 427 cases of childhood cancer diagnosed in Ontario in 2015 compared with 330 cases in 2005, a decade earlier. Childhood cancer incidence is increasing in Ontario and cannot be explained by population increases alone (*POGO Surveillance Report, 2018*). Assuming past trends will continue, our planning for childhood cancer services must take into account an average annual increase of about 1% in childhood cancer incidence.

FIGURE 1

Incidence counts and age-standardized incidence rates of cancer in children, all cancers combined, aged 0-14 years, Ontario, 1986-2015



Data Source: Pediatric Oncology Group of Ontario Networked Information System (POGONIS), December 2017 Extract, POGO. POGONIS was created and began capturing data in 1985.

Childhood cancers strike during a critical phase of developmental vulnerability—when physical, emotional, cognitive and sexual growth are occurring. The types of cancers experienced by children are very different from adult cancers. Children do not get breast, prostate or lung cancer. Instead, their cancers are largely of the blood, brain and rapidly developing soft tissues and organs, often requiring intensive treatment modalities that require the subspecialty expertise available in the pediatric cancer programs at five tertiary centres.

Childhood cancer does not follow a predictable pattern of healthcare utilization, but rather, a resource consumption pattern that is intense, punctuated by episodes of acute illness, stretching over long periods of active treatment. Therapy is usually delivered over several months, and in many cases, years. In the most common childhood cancer, acute lymphoblastic leukemia, primary cancer therapy continues for up to three years after diagnosis. Completion of therapy reduces but does not eliminate healthcare utilization.

The success of childhood cancer treatment is demonstrated by the tremendous improvement in five-year overall survival rates, rising from 72% in 1986 to current rates above 85% (*POGO Surveillance Report, 2018*). As of January 1, 2014, there are an estimated 17,750 survivors of childhood cancer in Ontario. However, many survivors carry with them substantial risk of developing serious health conditions as a result of the treatments that cured them, and so require lifetime monitoring. Responsibility for preventive and supportive health services, and for the care of childhood cancer survivors does not end when treatment ends.

## POGO'S ROLES AND RESPONSIBILITIES IN ONTARIO'S CHILDHOOD CANCER SYSTEM

POGO champions childhood cancer care in collaboration with a network of childhood cancer specialists, allied health professionals and hospital leadership. In partnership with these clinical experts, POGO establishes clinical and operational standards and funds:

- Seven POGO Pediatric Oncology Satellite Clinics in community hospitals managing more than 7,000 ambulatory care visits per year, bringing care closer to home for patients and families;
- Seven POGO AfterCare Clinics providing preventive health care and services to 2,800 childhood cancer survivors annually; and,
- Eleven POGO Interlink Nurses managing nearly 8,000 visits annually to coordinate care for children and their families as they rotate between hospital and home; and who work in partnership with Cancer Care Ontario's Aboriginal Nurse Navigators to ensure the cancer journey for Indigenous children and families is culturally safe and medically secure.





## DEVELOPING THE PLAN

The planning process started with 50 childhood cancer professionals attending a Thought Leaders' Day to provide first-hand insight and to identify and validate areas of focus. To develop the Plan, POGO engaged with over 200 individuals in the childhood cancer community to further explore and articulate those areas of focus. Planning was guided by a broad vision for the childhood cancer system in Ontario to:

- Optimize equitable access to care, technology and psychosocial support across the cancer journey;
- Employ advances in the understandings of biology, diagnosis, staging, treatment and psychosocial impacts of childhood cancer;
- Engage pediatric oncology healthcare professionals in regular multi-disciplinary programs of education, knowledge exchange and skills development;
- Provide a coherent, culturally-sensitive child- and family-friendly environment; and,
- Function as an integrated system of care.

The planning process acknowledged the context of significant fiscal challenges related to increasing incidence, prevalence and costly emerging therapies; and increasing public knowledge and expectations with respect to healthcare access and equity.

The consultations resulted in five major goals for Ontario's childhood cancer system, each with a set of strategic objectives to be accomplished 2018-2023. Action steps serve as starting points for development of implementation strategies and are not intended to represent a comprehensive work plan.

## PLAN GOALS



**Right Care in the Right Place:** Equitable access to care in the most appropriate setting balancing specialized needs and care closer to home



**Integrated Psychosocial Care:** Integrated psychosocial care at all stages of the cancer journey



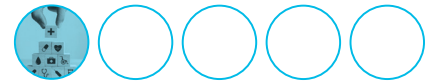
**Survivorship and AfterCare:** Physical health and emotional well-being of childhood cancer survivors are optimized



**Access to Drugs and Technologies:** Equitable, appropriate and timely access to emerging and evolving oncology drugs, diagnostics and technologies



**Data-Driven Quality Improvement:** The right data are available and being used to drive an effective childhood cancer system



## GOAL

# RIGHT CARE IN THE RIGHT PLACE

## Equitable access to care in the most appropriate setting balancing specialized needs and care closer to home

### POGO Satellite Clinics

The location of where childhood cancer treatment and care can be delivered is shifting rapidly from inpatient to outpatient settings and, in the near future, into a patient's home with appropriate supports. Parents describe the burden of travelling to tertiary centres for their child's treatment and unexpected out-of-pocket costs associated with time away from home as a tremendous source of distress. Locating care closer to home may reduce family burdens while supporting community healthcare partners with tools and information to care for children with cancer in the community.

#### Strategic Objective I

- Continue to grow and enhance the POGO Satellite Clinic Program to promote care as close to home as possible.

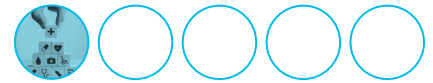
POGO operates seven Satellite Clinics across the province, each linked to a tertiary centre. The POGO Provincial Pediatric Oncology Satellite Program has been successful in diverting thousands of outpatient visits each year and saving hundreds of inpatient days in tertiary centres. For families, care closer to home means less travel, and disruption in family life and family income loss due to missed work days. Establishing POGO Satellite Clinics, supported by training, tools and knowledge, enables community hospital professionals to meet the needs of pediatric cancer patients and families in their home communities. POGO regularly monitors the number of newly diagnosed childhood cancer cases within areas served by tertiary and community hospital partners. Planning for new POGO Satellite Clinics or enhancements to existing Clinics is informed by evaluating service demand, the clinical requirements of individual patients and associated family needs, and the clinical and program support needs of hospital healthcare teams.

### Adolescents and Young Adults

Cancer is among the leading causes of death in AYAs in the US and Canada. However, progress in clinical outcomes and research in AYA cancer lag behind that focused on children and older adults. Inferior AYA survival as compared to younger children has been demonstrated across several malignancies such as leukemia, lymphoma and sarcoma, and across multiple jurisdictions. Although many mechanisms play an explanatory role, healthcare system-level factors may also contribute to inferior AYA outcomes.

#### Strategic Objective II

- Promote effective and appropriate care for adolescents and young adults treated in all settings.
- Developing strategies for how to best organize our current healthcare system to optimize care and



outcomes for AYAs begins with a good understanding of their particular health needs. This extends beyond survival to encompass issues of fertility, psychosocial well-being, education and employment. AYA patients and providers identified a current lack of designated programs and resources to address their most important issues, such as treatment consequences for fertility or help to manage psychosocial problems.

Recognizing the unique and varied phases of physical growth and social development that characterize this age group, current best practice recommends that AYA cancer therapy be administered by oncology professionals with AYA-specific expertise. However, most jurisdictions, including Ontario, lack policies organizing AYA cancer care in this manner. In Ontario, AYAs aged 15-21 years receive some or all of their care in pediatric or adult cancer systems, neither designed for the specific needs of this vulnerable age group. Organizing a provincial program of AYA treatment and care is a large task requiring coordinated efforts across both pediatric and adult cancer systems. Through consultations, a five-year, three-phase approach was outlined with each phase requiring increased engagement with stakeholders, including Cancer Care Ontario and its network of Regional Cancer Centres, and POGO tertiary hospitals as well as participation by government to secure necessary system resources.

## Education and Information Needs

A diagnosis of childhood cancer can be overwhelming for the child and family. Pediatric oncology professionals advise that parents of newly diagnosed children need specialized education in order to manage symptoms and provide needed medications at home. Parents confirm their educational needs and also request that key information be routinely provided, such as who to call for information both during treatment and when at home between their child's treatment cycles.

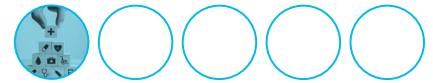
### Strategic Objective III

- Improve availability of education and information provided to patients and families in formats that meet their needs and preferences.

Parents confirm a need for targeted information in proper administration of home medications, recognition of when to bring their child to the hospital for emergent treatment, and knowledge regarding how to access appropriate care both from the treatment team and in the community in a timely fashion. Parents also report difficulty retaining important pieces of information and stress a need for repetition.

Both parents and professionals identify POGO Interlink Nurses as valuable sources of education and information for patients and families, for example, helping to maintain their child at home and avoid unnecessary hospitalizations. Working closely with Cancer Care Ontario's Aboriginal Nurse Navigators, POGO Interlink Nurses also support Indigenous children with cancer and their families by providing education and information and by sharing expertise about childhood cancer care.

While a wide range of educational and informational materials are currently available to patients and families, updating existing materials was identified as an important first step toward providing information in formats that better meet needs and preferences. Over the longer term, meeting patient and family education needs will require multi-disciplinary input into the development of tools and materials.



## Clinical Practice Guidelines

Clinical practice guidelines provide a way to translate scientific evidence into clinical practice. Across many clinical domains, treatment provided according to clinical practice guidelines has been shown to optimize outcomes and improve patient quality of life.

### Strategic Objective IV

- Promote enhanced supportive care through clinical practice guideline development and uptake.

While most children in Ontario receive their cancer therapy according to a clinical trial protocol or institutional adaptation of a protocol, delivery of supportive care is more variable. Supportive care encompasses the prevention and management of adverse effects of cancer and its treatment, including management of physical and psychological symptoms, and treatment-related side effects across the continuum of the cancer experience. There are very few current, evidence-based supportive care guidelines available to healthcare providers caring for children and AYAs with cancer. Ensuring the goal of right care is achieved means developing a comprehensive set of evidence-based supportive care guidelines and evaluating implementation.

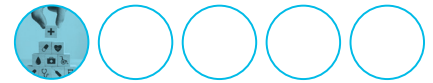
## Diagnostic Imaging Information

Childhood cancer is a complex disease involving different clinical specialties in diagnosing the type of cancer, determining treatment, and monitoring treatment efficacy and patient outcome. Capturing diagnostic information, particularly diagnostic images, in a standardized format that can be accessed regardless of geographic location improves timely decision-making while reducing the burden on patients from repeated testing.

### Strategic Objective V

- Improve the availability of clinical information in appropriate formats across care settings.

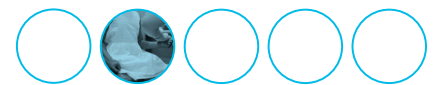
Delivering the right care in the right place is enabled by diagnostic imaging technologies with capacity to deliver a digital image across different platforms. Access to diagnostic images, regardless of location, benefits patients and families by making important clinical information quickly available for consultation with families and informing treatment decisions. In this regard, eHealth Ontario is working on the integration of diagnostic images and reports under its Diagnostic Imaging Common Service initiative that will enable sharing and viewing of images across Ontario's hospitals. POGO tertiary and community hospitals are also working to make diagnostic images readily available to the treating team wherever patients are receiving care.



## Action Steps for Right Care in the Right Place

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- Expand services at existing POGO Satellite Clinics based on safety and effectiveness criteria.
- Monitor need, plan for and establish POGO Satellite Clinics in underserved areas.
- Develop and implement a program that focuses on improving and integrating care for adolescents and young adults across care settings.
- Strengthen the POGO Interlink Nurses program to enable patients and families to receive education and information to safely manage their child's care and avoid unnecessary hospitalizations.
- Assess implementation of evidence-based supportive care practice guidelines.
- Champion efforts to make diagnostic images readily available to the treating team, regardless of location.



## GOAL

# INTEGRATED PSYCHOSOCIAL CARE

## Integrated psychosocial care at all stages of the cancer journey

The entire family unit can be emotionally impacted by a child's cancer diagnosis and treatment. Access to quality psychosocial care is critical in promoting emotional well-being and optimal functioning for both patient and family during and beyond treatment. As well, there is growing recognition that psychosocial assessments yield important information that can improve cancer planning, monitoring, and management of patients and families over the illness course.

Screening patients and families enables access to appropriate psychosocial services. However, screening processes and tools are not standardized across centres. Emerging research supports routine and systematic assessment of psychosocial healthcare needs as best practice.

### Strategic Objectives I & II

- Promote the use of evidence-based screening and assessment tools and guidance statements to improve appropriateness of psychosocial care.
- Ensure integration of psychosocial care into standardized care planning to improve quality of life for patients, families and survivors.

For most families, their child's cancer diagnosis is extremely stressful, and 40% of families are at moderate to high risk for developing greater than expected psychosocial difficulties and may require a multi-system approach to treatment for their mental health condition and/or family complexities. Research has demonstrated that dependence on clinician identification of psychosocial distress results in both over and under detection of psychosocial issues, leading to disparities and/or suboptimal care.

Following a literature review and discussions with field experts carried out as part of the Plan process, the Psychosocial Assessment Tool (PAT) was identified as a valuable, validated tool to screen for psychosocial distress. This tool evaluates parent responses to a brief set of questions. It discriminates areas of patient and family risk with implications for referral to treatment or interventions to support family adaptation and address problems. Originally developed at Children's Hospital of Philadelphia for use with childhood cancer patients and families, it has been adapted for use in Canada by researchers at The Hospital for Sick Children in Toronto. However, tools alone are not sufficient to ensure all patients are provided with and benefit from a psychosocial care plan.

Although documentation of medical issues and creation of medical care plans occur reliably, consistent documentation of patient and family psychosocial problems and creation of a psychosocial care plan could be improved, to the benefit of both families and healthcare professionals. Pivotal to psychosocial care plan development and integrated delivery of psychosocial care is the designation of a pediatric oncology team member responsible for oversight of the care plan to ensure patients and families receive appropriate interventions. Designation of a team member is essential not only for ensuring appropriate referrals but for tracking and documenting patient and family outcomes.



### Strategic Objective III

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- Provide tools and training for healthcare providers to support delivery of medically-safe, culturally-sensitive care.

An essential component of psychosocial care is understanding and integrating patient and family perspectives into treatment and care decision-making, allowing them to draw information and emotional support from their healthcare team to better manage their cancer journey. The initial conversation that takes place between members of the healthcare team and family when a child is diagnosed with cancer sets the tone for the entire trajectory of care. It is critical that healthcare practitioners have a good understanding of the unique history and culture of individuals when engaging with immediate and extended family members.

Efforts are underway to better support childhood cancer care for Indigenous people. POGO has worked closely with Cancer Care Ontario's Aboriginal Cancer Control Unit and with childhood cancer professionals to create a new pediatric oncology education module in the refreshed Aboriginal Relationship and Cultural Competency courses. These courses are designed to equip healthcare professionals and others working with Indigenous patients and families with knowledge and training to provide culturally-appropriate, person- and family-centred care.

#### Action Steps for Integrated Psychosocial Care

- Develop a plan to endorse and promote evidence-based screening tools and guidance statements to streamline patient and family referrals to appropriate psychosocial care, and initiate implementation.
- Develop training, tools and materials to assist healthcare providers in meeting psychosocial needs of patients and families.
- Improve the availability of culturally-appropriate education and information for Indigenous children with cancer and their families.
- Establish an advisory table of Indigenous healers and elders with an interest in childhood cancer, and pediatric oncology care providers, and create a prioritized action plan.



## GOAL

# SURVIVORSHIP AND AFTERCARE

## Physical health and emotional well-being of survivors are optimized

In response to an increasing number of childhood cancer survivors experiencing adverse physical and mental health events related to treatments received, POGO implemented a network of survivorship clinics in the late 1990s—The POGO Provincial AfterCare Program. Risk-adapted surveillance, the objective of POGO AfterCare programs, targets early detection of adverse health events (e.g., second cancers, heart disease), collectively referred to as late and longer-term effects. Surveillance allows for interventions which can mitigate treatment sequelae and improve overall quality of life for survivors. POGO AfterCare Clinics are staffed by multi-disciplinary oncology professionals and are located in the five tertiary centres and two affiliated adult cancer centres. In Ontario, survivors of a childhood cancer are eligible to receive risk-based, longer-term survivorship follow-up care in POGO AfterCare Clinics.

### Strategic Objective I

- Ensure survivor perspectives and priorities inform POGO AfterCare program enhancements to improve quality of care.

The term “childhood cancer survivor” refers to an individual diagnosed with a childhood cancer when they were less than 19 years old and for which they are no longer in active treatment. Over the past three decades, five-year survival rates for children with cancer, aged less than 15 years in Ontario, have improved from 72% to over 85%. As a result of the increasing incidence of childhood cancer, combined with the marked improvements in survival, the absolute number of childhood cancer survivors is growing rapidly. At present, there are an estimated 17,750 survivors of childhood cancer in Ontario.

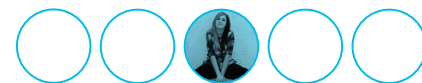
Survivors confirm the value they place on AfterCare programs in managing their longer-term health and well-being. However, many also report experiencing a daily burden through debilitating effects of treatment sequelae and/or worries about potential serious late effects, including new cancers. Survivors encourage pediatric oncology professionals and healthcare planners to undertake consultations across various survivor groups to ensure that planning for AfterCare program enhancements is informed by the many unique perspectives and experiences. Working with diverse survivor populations will be critical to ensure program and service improvements reflect needs and preferences across various survivor communities.

### Strategic Objective II

- Improve the quality, continuity and sustainability of AfterCare by integrating primary care providers and family health teams into the management of survivor care.

A sustainable system of AfterCare requires better integration of survivors’ primary care providers than currently exists. Following a survivor’s initial AfterCare assessment, it may be determined,





in consultation with that survivor, that regular monitoring through the annual AfterCare Clinic visit is not required. Instead, continuing care may be provided by their family health team or family physician closer to home.

Planning is underway to develop a framework to identify those survivors who would benefit from this type of ongoing care. All survivors receive AfterCare plans which contain information about their earlier diagnosis and treatment history as well as recommendations for relevant screening programs. To ensure quality care for survivors, this information may be shared by survivors with their family physician and others in their circle of care.

A recent review of attendance by survivors at POGO AfterCare Clinics revealed that individuals living at a distance were less likely to travel for scheduled visits. For survivors who can be safely managed in their home community, creation of tools and educational materials to support family health teams will enable quality follow-up care, where travel or other factors present a barrier.

### Strategic Objective III

- Improve availability of clinical information for survivors and their care team over time and across care settings.

Survivors express a desire to have their medical history, health information, medical appointments and healthcare resources provided in a format that is easily accessible both for their personal use and to share with their primary care physician or family health team. Both parents and survivors advise that personal health information provided in a dynamic and meaningful format (e.g., electronic-based communications tools and technologies) would contribute to greater engagement of survivors in follow-up care and, ultimately, to better physical and psychosocial outcomes.

### Strategic Objective IV

- Enhance survivor care to improve access to psychosocial, neuropsychological and mental health services.

When planning AfterCare program enhancements, subgroups of survivors identified for particular focus include survivors of brain tumours who are at elevated risk for neurocognitive problems from the cancer and treatments received, and individuals who may under-report symptoms of mental distress due to perceived stigma. There is broad appreciation that several allied health disciplines within AfterCare programs are equipped to offer psychological and emotional support. However, participants reported difficulties in accessing mental health services in their home communities. Planning to meet the needs of survivors must include developing pathways that help survivors connect with appropriate community-based psychosocial and mental health service providers in their local community.

### Strategic Objective V

- Engage with survivors to determine educational needs and how best to meet these needs across diverse survivor populations.

Survivors express concern about a lack of survivor education. Many feel that not all survivors have relevant information about or are aware of possible consequences for their longer-term physical and



emotional well-being related to their treatments. This is particularly so for survivors who completed treatment before 1998 when the POGO AfterCare program was introduced. Consequently, many older survivors may lack important information about longer-term health consequences. Engagement with survivors is necessary to better understand their information needs, enhance existing programs and provide new educational opportunities to meet those needs across survivor communities.

### Action Steps for Survivorship and AfterCare

- Assess POGO AfterCare programs and work closely with survivors and providers to implement enhancements.
- Explore development of a risk stratification framework to facilitate survivor access to appropriate levels of care.
- Develop a strategy for engagement of primary care providers and family health teams in the management of survivor care.
- Update survivor care plan software to reflect current practice guidance recommendations for care of survivors of childhood cancer.
- Explore and test options for making treatment information and survivor care plans available electronically to survivors and their care team.
- Develop evidence-based clinical practice guidelines for neurocognitive care.
- Engage with survivors to increase understanding of their information needs, enhance existing and provide new educational opportunities to meet those needs.
- Develop a mental health strategy for survivors.



## MY STORY

### Monitored for life: It doesn't end with cancer-free

By Myles Davis

MD

At four, I was diagnosed with stage 4 rhabdomyosarcoma, in my case a tumour the size of a baseball in the lower abdominal area near my bladder. At 20, I have lived almost my entire lifetime in cancer care. And alongside my parents, POGO, through its many programs and services, has been with me every step of the way. POGO teams have supported me through treatment, which included eight rounds of chemotherapy and a series of surgeries at the age of four. And now, 16 years later, as I manage the late effects that have developed as a result of my treatment, POGO AfterCare Clinics continue to support me.

**Most people know that cancer treatment can be fairly aggressive, but what many don't realize is that it can have serious side effects many years later.**

I continue to be monitored by oncology for second cancers. I need to see a cardiologist every six months because the toxic mix of drugs I was given has the potential to seriously lower my Ejection Fraction Index, which is the fraction of blood pumped out with every heartbeat. And I visit my internist annually because the surgeries that removed my tumour also left a lot of scar tissue.

Until a few years ago, all of my follow-up care took place at SickKids where I was diagnosed and treated. When I turned 18, I graduated from the all-encompassing children's hospital system, with its seamless management and coordination between departments, to the adult system (in most situations I am by far the youngest person in the waiting room!). While I have three new doctors spread across the city, luckily for me, and every childhood cancer survivor in Ontario, all of my follow-up care is still coordinated through a POGO AfterCare Clinic. So when my cardiologist wanted to change my medication, POGO teams were able to determine that it wouldn't do any damage based on the treatment I had as a child. And when my internist wanted to do an exploratory procedure, POGO teams again intervened noting it could do more damage than good with the scar tissue that was built up over many surgeries.



*As you can see from my personal story, childhood cancer requires a lifetime of follow-up care.*

Myles Davis





## GOAL

# ACCESS TO DRUGS AND TECHNOLOGIES

## Equitable, appropriate and timely access to emerging and evolving oncology drugs, diagnostics and technologies

### Drug Access

#### Strategic Objectives I, II & III

- Facilitate inclusion of pediatric oncology expertise into oncology drug submissions for regulatory/funding review.
- Provide advice to government and other healthcare partners to improve access to childhood cancer drugs.
- Support utilization of all relevant pediatric oncology drug funding sources.

Childhood cancer has shown near continuous improvement in survival outcome over the past 30 years. These gains have resulted from a combination of biologic discoveries opening up new therapeutic options, traditional chemotherapies used more intensively and improved supportive care agents.

Drugs have been identified as the fastest growing healthcare expenditure with new and more expensive agents rapidly entering the market. A small portion of these agents are developed specifically to treat childhood cancers. Many other agents, however, are developed and approved for use in adult cancers and may be re-purposed to treat pediatric cancers due to their mechanism of action or molecular target. However, re-purposed adult cancer drugs are not often approved by Health Canada for these rarer pediatric indications. Furthermore, there is often little incentive for pharmaceutical companies to submit resource intensive applications to a body such as the pan-Canadian Oncology Drug Review (pCODR) for these indications due to the small number of potential patients. This creates a substantial barrier to evidence-based drug funding. In cases such as these, clinician-led submissions are possible. While pediatric oncology clinical expertise can be rallied to support these, a mechanism for the economic analysis required for such a submission does not currently exist.

At present, there is a complex and challenging path to funding high-cost pediatric cancer medications. While the recent addition of asparaginase products to the New Drug Funding Program managed by Cancer Care Ontario for the treatment of childhood leukemia is an important step forward, high-cost cancer therapies remain a barrier to equitable access and to care closer to home across the province.

In Ontario, pediatric oncology drug funding comes from a variety of sources including hospital global budgets; government programs such as the Ontario Drug Benefit and Exceptional Access Programs; compassionate access programs sponsored by pharmaceutical companies; and a variety of employee and consumer-purchased health benefit plans. Some care teams are aware of and regularly access different funding sources more effectively than others. In some centres, a facilitator provides important and timely access to drug funding sources. Rapid introduction of new drugs and evolving new uses



for adult cancer drugs that are emerging as standard care in childhood cancer therapy require flexible funding models to maintain equitable access for patients, across all care settings.

### Action Steps for Access to Drugs

- Integrate pediatric oncology expertise into clinician-led submissions for regulatory review/approval.
- Work with Cancer Care Ontario and the Ministry to develop a framework to fund and manage a pediatric-specific formulary within the New Drug Funding Program.
- Advise Ontario Public Drugs Program on current agents and new requests to facilitate rapid approvals for oncology drugs and therapies.
- Explore creation of a centralized drug access resource to advise POGO's tertiary and satellite centres on sources of funds for oncology drugs.

## Emerging and Evolving Technologies in Pediatric Cancer Care

Scientific advancements are accelerating the introduction of new therapies and technologies into standard care, and are establishing new applications for existing technologies. These advances come with substantial human resource implications and at material cost to the healthcare system. Several technologies are identified for focused attention over the next five years. Pediatric oncology expertise and evidence-informed evaluations will be required to manage integration of relevant therapies and technologies into clinical practice and to incorporate new uses for existing technologies.

### Strategic Objective I

- Advise government in the development of provincial policies, processes and funding to ensure timely access for patients to emerging therapies and technologies in childhood cancer.

The volume and pace of new drugs, therapies and technologies coming to clinical attention make it a challenge for government and healthcare providers to determine the right investments for optimal patient outcomes. Developing policies and processes to support timely uptake and appropriate utilization requires clinical knowledge and health planning expertise. Through its networks, POGO is able to coordinate pediatric oncology advice to inform decision-making and support planning for the childhood cancer system.



## **SOME EMERGING TECHNOLOGIES AND TRENDS THAT WILL IMPACT HOW CHILDHOOD CANCER CARE WILL BE PROVIDED**

### **Hematopoietic Stem Cell Transplant (HSCT)**

Hematopoietic stem cell transplantation is the therapy of choice for multiple medical conditions. The objective of stem cell transplant is to replace the patient's own stem cells damaged by intense chemotherapies designed to destroy the cancer. Several illnesses and conditions for which stem cell transplantation produces good health outcomes will require incremental resources to support expanding treatment options and growing patient volumes.

### **Chimeric Antigen Receptor T-Cell (CAR T) Therapy**

CAR T-Cell therapy is a promising new way to get the body's own immune cells, called T cells (a type of white blood cell), to fight cancer cells. The first commercial product available for CAR T therapy will come to market in the near future, at significant cost, with similar products to follow quickly. Much work has been accomplished by Cancer Care Ontario in planning for CAR T therapy involving government and POGO.

### **Proton Beam Therapy**

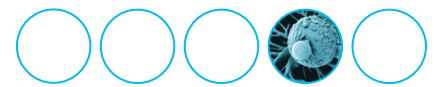
Proton beam therapy represents a significant advance in radiation treatment through more precise delivery of a radiation beam to the tumour site while sparing surrounding healthy structures. This is particularly relevant to young children who will benefit from reduced late and longer-term effects closely associated with radiotherapy. Working through the pediatric oncology networks and with Cancer Care Ontario, POGO can identify pediatric oncology clinical experts to advise on appropriate indications for out-of-country referral for proton therapy and to assist in the development of a provincial feasibility/planning evaluation of an Ontario-based facility.

### **Computed Tomography-Positron Emission Tomography (CT-PET) Scans**

CT-PET is a specialized diagnostic imaging technology that is valuable in staging some cancers and identifying possible disease recurrence. Through the Ontario Pediatric PET Registry managed by Cancer Care Ontario, CT-PET imaging is provided for patients under the age of 18 for eligible conditions. An objective of the PET Registry is the collection of data about how this technology is being applied in childhood cancer treatment. This data will contribute to a better understanding of standard indications in childhood cancer and clinical utility of imaging results in circumstances where indications are uncertain.

### **Application of Genomics to Pediatric Cancer Care**

There has been an explosion of knowledge in human genetics creating opportunities for more personalized care through use of genomic information to tailor treatments to an individual cancer patient. For many, this will mean both improved survival and fewer longer-term adverse health events. Growing knowledge and emerging genetic technologies will impact all spheres of cancer care including early identification of those predisposed to a childhood cancer. Genomics is an evolving area that requires ongoing monitoring to ensure availability of appropriately trained and skilled professionals.

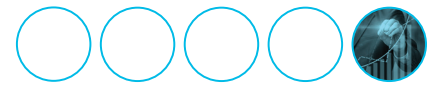


## Action Steps for Emerging and Evolving Technologies in Pediatric Cancer Care

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- Formalize the approach for collaborating with Ministry and Cancer Care Ontario to plan and implement a provincial program for CAR T-Cell therapy.
- Work with Cancer Care Ontario, the Ministry and institutional stakeholders to facilitate appropriate access to proton therapy.
- Work with tertiary hospitals to develop a strategy to evaluate CT-PET utilization.
- Identify opportunities to inject pediatric oncology expertise into relevant provincial pediatric genomics initiatives.





## GOAL

# DATA-DRIVEN QUALITY IMPROVEMENT

## The right data are available and being used to drive an effective childhood cancer system

Enhancing pediatric cancer data holdings and expanding data-sharing opportunities through new partnerships are priorities that support healthcare professionals, researchers, planners and policy makers in planning, monitoring and evaluating childhood cancer related programs and initiatives.

### Strategic Objective I

- Enhance data holdings to reflect advancing sciences and support childhood cancer investigation and research.

Over the past 30 years, the POGO Networked Information System, POGONIS, has grown into a substantial data repository on childhood cancer in Ontario. POGONIS has increased in value because of data it holds and its ability to link with other data repositories, such as the Ontario Cancer Registry and the Institute for Clinical Evaluative Sciences (ICES) data repository, among others.

New data sources are emerging and will expand the utility of POGONIS in driving an effective childhood cancer system. For example, advancing research in areas such as genomics will create new data to evaluate risk factors, contribute new insights into patterns and trends in the occurrence of childhood cancer and better predict system resource needs. Increasing standardization of existing data is also creating new data sources. For example, the utility of diagnostic information generated by pathologists in different care settings is enhanced by adoption of standardized reporting of specific diagnostic features. Synoptic reporting in childhood cancer pathology uses systematic checklists which ensure standardized data can be collected across pathology reports, no matter where a report is generated.

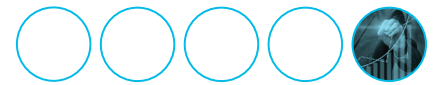
New partners in data collection are emerging as well and include organizations such as Cancer in Young People in Canada (CYP-C), a national surveillance system gathering information on children and youth with cancer, including treatments, complications and outcomes. These developments are creating new opportunities to add to current data holdings in POGONIS and to generate new partnerships for data sharing. Expanded investigations and new research initiatives in childhood cancer care and control will be encouraged and supported by augmented data holdings and facilitated by increased opportunities for linkages with provincial and national data repositories.

### Strategic Objectives II & III

- Support local program planning by making POGONIS data more accessible.
- Enhance quality and timeliness of data and collection processes to enable health system planning, surveillance and public reporting.

Accessible data collected in a reliable and timely manner are foundational to health system planning and service delivery. POGO and the tertiary centres will examine ways to provide timely access to





institutional data in formats that meet each centre’s analytic and program planning needs.

Plans are underway to publicly report childhood cancer surveillance information. Public reporting of this information is important in providing comprehensive, accurate and timely information on childhood cancer incidence, mortality, survival and prevalence in Ontario. Accessible surveillance data benefits health system planners, service providers, and provincial and national researchers by contributing to the generation of new areas of investigation and development of new research questions in childhood cancer. Making this data publicly available is also helpful for patients, families, survivors and the general public with an interest in childhood cancer, in order to facilitate education and knowledge translation regarding impacts of childhood cancer.

### Action Steps for Data-Driven Quality Improvement

- Explore opportunities for new data-sharing agreements to enhance the utility of POGONIS, including addition of diagnostic and genomic data.
- Increase availability of childhood cancer incidence, prevalence and survival information.
- Work with national bodies to align data elements to enable comparisons across jurisdictions.
- Promote synoptic reporting to enhance capture of standardized data.
- Create a mechanism to allow tertiary centres to access their POGONIS data.
- Enhance routine data quality reviews and remediation processes.

## **PLAN CHAMPIONS & DRIVERS**

# **HOW THE CHILDHOOD CANCER CARE PLAN WILL BE IMPLEMENTED**

The Childhood Cancer Care Plan identifies opportunities for a wide group of stakeholders to champion childhood cancer care and drive Ontario's childhood cancer system to deliver the best possible care for the best possible outcomes, and to meet current and future challenges. Critical to effective implementation of the five-year Plan are the champions—people, partnerships—and the drivers—system resources, capacities.

## **PLAN CHAMPIONS**

### **Partnerships, Collaborations and Clinical Engagement**

Effective implementation of this Plan over the next five years will depend on the ongoing engagement and collaboration of the childhood cancer community and other provincial and national cancer care partners. Building new and supporting current partnerships is an essential next step. This means working closely with pediatric oncology networks, government, Cancer Care Ontario, and national organizations, such as CYP-C—combining efforts and forging alliances to articulate mutual responsibilities, share data and resources, engage in creative thinking and evidence-informed discussion, and move forward with manageable steps for execution by relevant partners.

### **Patients, Families and Survivors**

Integrating diverse experiences and perspectives of patients, families and survivors is essential to ensure the evolving childhood cancer system meets their needs and expectations for culturally-sensitive, safe and respectful care at all stages of the cancer journey. Moving to implementation, patients, families and survivors will be partners in design and execution of action plans, reviewing data and information, and providing advice and guidance for an effective patient- and family-centred system of cancer care.

## **PLAN DRIVERS**

### **Education and Training**

The best possible outcomes for patients and families can only happen when both they and their providers have opportunities to participate in education, skills development, and training and networking activities. Forums for presentation of new research and information are essential for sharing insights and developing new knowledge in the rapidly evolving arena of childhood cancer care and control.

POGO has been proactive in creating skills development and educational opportunities such as the Annual POGO Multi-Disciplinary Symposium, and AfterCare and Satellite Education Days where experts present topical insights into clinical practice and leading-edge research. Presenting opportunities for survivor involvement in educational forums is an objective of POGO Survivor

Conferences, where individuals are able to network, exchange information about current issues and participate in problem-solving activities. Families and survivors play an equally important role as presenters and on planning teams, sharing their experiences first-hand. POGO will continue to coordinate and ensure pediatric oncology expertise leads the development and delivery of relevant training and education programs.

## Data and Information

An effective childhood cancer system requires that data be collected, evaluated and translated into effective and sustainable policies and initiatives. Working with the pediatric oncology networks and other healthcare partners, POGO will continue to collect and use data to evaluate impacts of programs and services on patient outcomes and experiences to better meet needs and improve quality of life for patients, families and survivors.

## Specialized, Donor-Funded Support for Families, Survivors and Research

POGO and its partners will continue community fundraising efforts to provide important services consistent with the goals of this Plan.

**Financial assistance** is available for families of children with cancer who face tremendous and unexpected out-of-pocket costs associated with the disease. Through the POGO Financial Assistance Program, funding is provided to families for accommodation, for food and child care for siblings under the age of twelve when treatment takes place away from home.

**Personalized educational and vocational counselling** is provided for childhood cancer survivors experiencing difficulty in areas of employment and education related to neurocognitive changes as a result of their disease or its treatment.

**The POGO Research Unit (PRU)** reflects POGO's commitment to qualitative and quantitative research. Funding is provided by the PRU for research priorities across the spectrum of childhood cancer control within four key areas: epidemiological studies, health services research, health economics and survivor outcomes/quality of life. Through its Research Fellowship and Seed Funding Grant programs, providing access to its extensive POGONIS database, and by sharing and enhancing tools and methodologies, POGO and the PRU contribute to building a multi-disciplinary, multi-institutional community of childhood cancer researchers who are a resource to other investigators.

## ACKNOWLEDGEMENTS

POGO gratefully acknowledges funding support from the Ontario Ministry of Health and Long-Term Care. As advisor to the Ministry on childhood cancer, POGO is responsible for long-range plans for the childhood system. With deep gratitude, we acknowledge the important contributions of the many pediatric oncology healthcare professionals, patients, parents and survivors of childhood cancer who generously gave their time and expertise to the development of this Plan. We are deeply grateful to POGO staff for their unwavering commitment to excellence throughout the planning process. Their professional contributions in support of the many working groups was instrumental in guiding planning to its final stage and to assembling the Plan. POGO offers a special thank you to Dr. Corin Greenberg who served as POGO's Chief Executive Officer for 30 years. Corin developed the first plan in 1988, with subsequent successful long-range plans strengthening programs and services for patients and families. Corin's many contributions continue to be made as, together, we begin implementation of the Childhood Cancer Care Plan: A Roadmap for Ontario 2018-2023.

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## Participating Institutions

Children's Hospital, London Health Sciences Centre

Children's Hospital of Eastern Ontario

Grand River Hospital

Kingston Health Sciences Centre

McMaster Children's Hospital, Hamilton Health Sciences

Northeast Cancer Centre, Health Sciences North

Southlake Regional Health Centre

The Hospital for Sick Children

The Ottawa Hospital Regional Cancer Centre

Princess Margaret Cancer Centre

# THE MAKING OF THE CHILDHOOD CANCER CARE PLAN:

A ROADMAP FOR ONTARIO 2018-2023

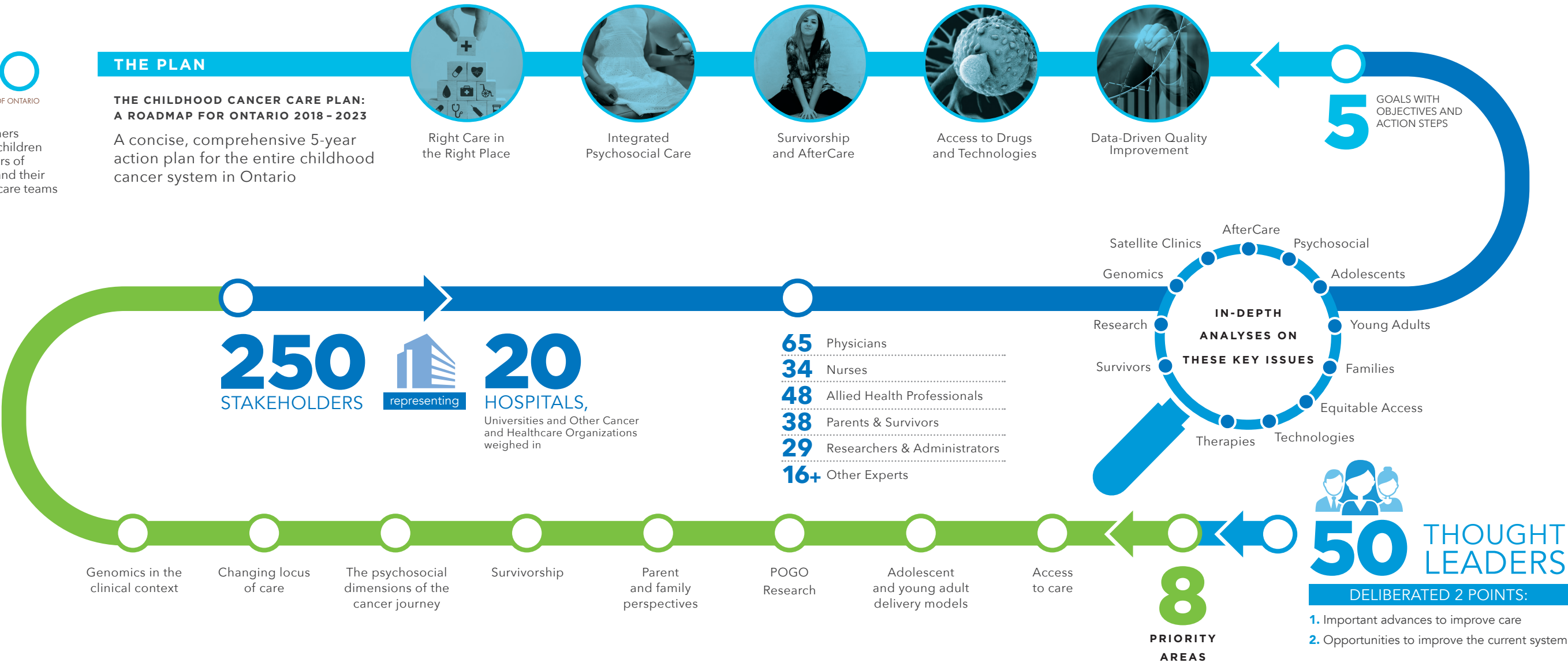
## Converting gaps and challenges into opportunities and actions that strengthen Ontario’s childhood cancer system

This is the fifth time POGO, as advisor to Ontario’s Ministry of Health and Long-Term Care, has led the development of a provincial pediatric oncology plan for Ontario. Building on the strong foundation of previous plans, the vision remains to actively champion an integrated childhood cancer care system that ensures equitable access to the best care for the best possible outcomes for children, adolescents and young adults (AYAs), survivors and their families. The Plan will help

to ensure that when patients and survivors have different components of their care delivered in different locations by different specialists, it is with confidence and assurance that these programs and services are anchored by a coordinated provincial system. The Plan will assist Ontario’s childhood cancer system to prepare for and adopt advances in childhood cancer care and control as new treatments and technologies evolve from research into clinical practice.



POGO and its partners champion care for children with cancer, survivors of childhood cancer, and their families and healthcare teams across Ontario





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