
Advocating for the Patient Voice in Cancer Care

Scoti

Workshop
Fall 2023



Opening Message

In the fall of 2023, a workshop was held, which was a collaborative effort between the Canadian Cancer Survivor Network (CCSN) and the Nova Scotia Health Innovation Hub. The purpose of this gathering was to convene stakeholders from patient advocacy organizations and Nova Scotia Health for a conversation on the future of oncology in Nova Scotia. The goal was to determine how to amplify the voices of cancer survivors in shaping the future of cancer care, within an ongoing digital health transformation.

CCSN operates with the mission of taking action to promote the very best standard of care, support, follow-up and quality of life for patients and survivors. The Network's aim is to educate both the public and policy makers about cancer and encourage research on ways to alleviate barriers to optimal cancer care in Canada.

Throughout our discussions, a range of critical topics were explored, including the patient journey, cancer screening, accessibility of care, community engagement, and transparent communication. We are optimistic that the recommendations outlined in this report will contribute to improving the cancer care system, ultimately resulting in a positive and lasting impact in the lives of cancer patients, their families, and caregivers.

With Nova Scotia Health currently undertaking a digital health transformation, the objective was to ensure that the voices of cancer patients were prominently represented within the Oncology Transformation Project (OTP). This will ensure that the systems are designed to work in collaboration with and for the benefit of patients.

At the outset of the day, we were privileged to have the Vice-President of

Research, Innovation & Discovery and Innovation Partnerships at Nova Scotia Health, Dr. Gail Tomblin Murphy, deliver opening remarks. Her message urged us to "Think big. Think differently. Test and try out different solutions."

The Health Innovation Hub served as the perfect location to bring together this group to tackle some of the biggest challenges in cancer care today. It is a first-of-its kind centre of excellence for health research and innovation in Atlantic Canada and is transforming "what is" into "what can be."

We thank the Nova Scotia Health Innovation Hub for hosting us and extend our sincere gratitude to all of those who participated in this first iteration of the workshop. We look forward to continuing to build this partnership to deliver tangible results that will benefit cancer patients.



Signed by the co-moderators:

Jackie Manthorne, President and CEO of the Canadian Cancer Survivor Network

Dr. Jordan Warford, Executive Director, Planning and Performance, Department of Health and Wellness

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Land Acknowledgement

This workshop took place in Mi'kma'ki, the ancestral, traditional and unceded lands of the Mi'kmaq people. The authors and contributors of this report also acknowledge that people of African descent have been in Nova Scotia for over 400 years, and we honour and offer gratitude to those ancestors of African descent who came before us to this land.

Event Details

On October 17th, 2023, the **Canadian Cancer Survivor Network** partnered with the **Nova Scotia Health Innovation Hub** to convene “*Advocating for the Patient Voice in Cancer Care*,” a pivotal oncology workshop featuring patient advocacy organizations, patients, healthcare providers, and Nova Scotia Health officials.

We want to thank the groups that joined us for this initial, critical discussion such as the Canadian Cancer Society, the Canadian Association of Retired Persons (CARP), Colorectal Cancer Canada, Dense Breasts Canada, the Leukemia & Lymphoma Society of Canada, the Lung Association of Nova Scotia and Prince Edward Island, and Myeloma Canada.

This workshop was a first step in what we hope will be an effort to continue to consult and collaborate with a wider array of patient advocacy organizations, stakeholders from equity-deserving groups, and healthcare professionals working on the front lines. This workshop was not all encompassing, and we are excited for the next steps, including further iterations of the workshop with additional stakeholders present.

Throughout the day, patient advocates shared experiences about the patient journey, screening, accessibility, community engagement and communications. Leaders from the Nova Scotia Health Innovation Hub delivered presentations. **Dr. Amanda Caissie**, Medical Lead of the Cancer Care Program's Oncology Transformation Project and Innovator in Residence – Digital Health Solutions provided a comprehensive overview of how the Cancer Care Program is harnessing the power of real-time data and patient engagement through the Oncology Transformation Project (OTP). **Dr. Helmut Hollenhorst**, Senior Medical Director and **Jill Flinn**, Senior Director from the Nova Scotia Cancer Care Program offered high-level perspectives on the current priority areas for Nova Scotia Health.

This inaugural event, hosted in Nova Scotia, reflects the province's commitment and leadership in oncology innovation with 50% of participants joining from Nova Scotia Health and 50% from patient advocacy organizations. This highlights the prioritization of collaboration and the willingness to include patients throughout the design and implementation process.

The workshop represented an initial step in better understanding the patient journey and the commitment towards continued collaboration. Next steps involve speaking to additional groups to gather more insights on how we can continue to improve cancer care in Nova Scotia.



Participants gathered for the workshop at the Nova Scotia Health Innovation Hub.

Cancer in Nova Scotia

Nova Scotia has among the highest rates of cancer and prevalence of cancer-causing factors in Canada.¹ The cancer prevalence in the province per 100,000 people between 1994 and 2018 was 5,007.8 per 100,000 (46,825 counts)²:

¹ Nova Scotia Health researching cancer risks in hundreds of communities, CBC News: <https://www.cbc.ca/news/canada/nova-scotia/nsh-community-cancer-research-1.6898012>

² Canadian Cancer Statistics, Canadian Cancer Society: <https://cancer.ca/en/research/cancer-statistics/canadian-cancer-statistics>

Summary of projected number of cancer cases and deaths in Nova Scotia (NS) in 2022*

Cancer	Males		Females		Both sexes	
	Cases	Deaths	Cases	Deaths	Cases	Deaths
All cancers	3,600	1,600	3,200	1,400	6,800	3,000
Bladder	280	65	90	20	370	85
Brain/CNS	55	45	40	30	95	75
Breast	10	5	770	180	780	185
Cervical	N/A	N/A	30	10	30	10
Colorectal	420	210	310	170	730	380
Esophagus	85	75	25	20	110	95
Head and neck	160	50	60	20	220	70
Hodgkin lymphoma	15	—	10	—	25	—
Kidney and renal pelvis	190	55	110	30	300	85
Leukemia	100	60	65	40	165	100
Liver	60	40	15	10	75	50
Lung and bronchus (lung)	520	380	560	370	1,080	750
Melanoma	230	40	180	15	410	55
Multiple myeloma	60	25	40	25	100	50
Non-Hodgkin lymphoma	180	55	130	50	310	105
Ovary	N/A	N/A	80	65	80	65
Pancreas	95	90	90	75	185	165
Prostate	770	160	N/A	N/A	770	160
Stomach	60	35	30	20	90	55
Testis	25	—	N/A	N/A	25	—
Thyroid	35	5	90	5	125	10
Uterus (body, NOS)	N/A	N/A	230	50	230	50
Source**	Supplementary Tables 3 (cases) and 5 (deaths)				Males + Females	

CNS=central nervous system; NOS=not otherwise specified; N/A=not applicable
 — fewer than 3 cases or deaths

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Chart depicting the summary of projected number of cancer cases and deaths in Nova Scotia in 2022.

While it isn't yet fully understood why cancer rates are higher in Atlantic Canada, tobacco and alcohol use could be contributing factors, in addition to an aging population.⁴ A report from the Canadian Cancer Society shows that cancer is generally more prevalent in rural settings compared to urban settings, which speaks to many communities in Atlantic Canada.

There are two main cancer centres in Nova Scotia that offer comprehensive care and support for the province, one in Halifax and one in Cape Breton. These two centres are supplemented by various community oncology sites that aim to give patients care closer to home.

The COVID-19 pandemic exacerbated problems within the system that already existed. Backlogs resulting from the pandemic will take several years to address and there will be long-term implications for patients. Further challenges include staffing and hospital bed availability.

³ NS-Specific Stats 2022, Canadian Cancer Society: https://cdn.cancer.ca/-/media/files/research/cancer-statistics/2022-statistics/2022-province-specific/ns-specific-stats-2022.pdf?rev=-1&hash=EA31464A7D5511AFB9C22AF5A11FF679&gl=1*412xzh*_gcl_au*MjA4NDM1NjUxMC4xNjk0NTM0Njg0

⁴ Atlantic Canada has the highest cancer rates in the country, CTV News: <https://atlantic.ctvnews.ca/atlantic-canada-has-the-highest-cancer-rates-in-the-country-25-year-study-shows-1.6149169>

This has led to challenges for cancer patients in timely access to testing, such as biopsies, screening, and diagnostic imaging. In some instances, patients have put off visiting the doctor or hospital out of fear of COVID-19, leading to the late detection of cancers that otherwise might have been caught in the early stages.

Cancer care has benefited from being forced to find different ways to work during the pandemic. Telephone and virtual appointments, when appropriate, can save patients hours of driving to get to a doctor. Some treatment protocols have begun to be modified in keeping with evidence and research. Some radiation treatment, for example, is being done in shorter courses, but at higher doses using high-precision imaging and other technology. The approach, which was only beginning to emerge before the pandemic, means patients getting treatment delivered in shorter time periods, being away from home for less time, and reducing the amount of time they're exposed to radiation. The Nova Scotia Cancer Care Program is embarking on a project to facilitate and support cancer care at home – a transition from inpatient care to ambulatory care to care in community oncology, and eventually, for those where it is safe, to care at home. Cancer care delivery is evolving to meet the needs of patients and Nova Scotia has been at the forefront of this change.

Nova Scotia's Leadership

Nova Scotia is investing to improve cancer care for Nova Scotians. The province has demonstrated significant momentum, with ongoing initiatives unfolding in real-time. Their leadership has garnered the attention from other provinces and has also attracted global interest.

- ❖ Nova Scotia is the first in the world to launch ARIA Core with software enabling real time communication between cancer centres, community oncology clinics, and their patients through the Oncology Transformation Project.
- ❖ Nova Scotia invested \$18 million in 2021 towards funding for cancer therapy and support for travel and accommodation for patients needing it.⁵
- ❖ Nova Scotia invested \$500 million to expand the Cape Breton Regional Hospital with a two-and-a-half storey new cancer centre.⁶
- ❖ Nova Scotia is the first Atlantic province to undertake an in-depth, localized research project that analyzes the risk of 22 types of cancer in 301 communities across the province.⁷
- ❖ Cancer care patients in Nova Scotia will start receiving care on the first-in-the-world Ethos radiotherapy system with HyperSight imaging solution in January 2024. Powered

⁵ Government Invests in Improved Cancer Care for Nova Scotians, Nova Scotia:

<https://novascotia.ca/news/release/?id=20210705010#:~:text=The%20Rankin%20government%20is%20providing,accommodation%20for%20patients%20needing%20it.>

⁶ Cape Breton Regional Hospital expanding with \$500 million and 400,000 square feet, Daily Commercial News:

<https://canada.constructconnect.com/dcn/news/infrastructure/2022/08/cape-breton-regional-hospital-expanding-with-500-million-and-400000-square-feet>

⁷ Nova Scotia Health researching cancer risks in hundreds of communities, CBC News:

<https://www.cbc.ca/news/canada/nova-scotia/nsh-community-cancer-research-1.6898012>

by artificial intelligence, Ethos allows care teams to target tumour sites while protecting surrounding organs from potential damage.⁸

- ❖ Nova Scotia has made significant investments in stabilizing and optimizing care in community oncology and cancer centers.
- ❖ Nova Scotia Health supported the co-development of the Mi'kmaq Cancer Care Strategy.⁹
- ❖ Nova Scotia has begun developing a lung cancer screening program.
- ❖ Nova Scotia is the first province to co-develop an event of this kind to find solutions working alongside patient associations and industry.

Background

Oncology Transformation Project

Nova Scotia Health is well underway in planning and delivering the Oncology Transformation Project (OTP). The OTP's goal is to change the way that cancer care is delivered in Nova Scotia by bringing oncology systems together, in real time. OTP includes an oncology-specific clinical information system, ARIA®, and a patient engagement platform, Noona®.

ARIA software serves to enable clinical and patient systems to be interoperable aiming to create one process for referring, triaging (prioritizing patients by clinical need), and scheduling patients across the province. The new system will improve patient safety and reduce wait times through standardized electronic processes. When fully implemented, OTP has the aim of providing evidence-based clinical and operational decision making through use of the data analytic component of OTP, Gen 2 Insightive®.

Noona, when fully implemented, aims to enable patients to take a more active role in their treatment and journey. Currently, patients who choose to download and use the Noona application have access to their cancer appointment schedules and reminders, all from their mobile device or home computer.

Full rollout is expected in 2024 and has the goal of allowing cancer patients to be able to report their symptoms from home and access patient education materials as they want or need them. Noona is also aiming to accelerate cancer research in Nova Scotia and connect patients to cutting edge treatments via clinical trials.

The status of the project is as follows:

- OTP planning was launched in February 2023.

⁸ Nova Scotia Health and Varian continue to advance cancer care in Nova Scotia, Nova Scotia Health: <https://www.nshealth.ca/news-and-notice/nova-scotia-health-and-varian-continue-advance-cancer-care-nova-scotia>

⁹ Mi'kmaq Cancer Care Strategy, Union of Nova Scotia Mi'kmaq: <https://www.unsm.org/dept/mikmaq-cancer-care-strategy>

- Phase 1 went live in June 2023. Since then, all patient scheduling across the province is occurring through a single system – ARIA.
- Patients who choose to download Noona now have access to their cancer appointment schedules and reminders.
- Phase 2 began in July. It includes the clinical roll-out of ARIA across provincial Systemic Therapy (medical oncology, hematology, and gynecological oncology). Nine design workshops were held throughout September with subject matter experts from cancer care teams across the province. They provided input on the design of ARIA and Noona to ensure both meet the needs of Nova Scotia’s patients and providers.
- The full clinical ARIA system will be implemented first at the community cancer clinic in Truro in December 2023. Teams will monitor what works well and what needs to be improved, and then the phased roll-out will continue to the remaining cancer centres and community cancer clinics across the province.
- Noona features and functions will be phased in over the course of implementation.

OTP is a collaborative project with the Cancer Care Program, Nova Scotia Health Innovation Hub, industry (Varian Medical Systems, a Siemen’s Healthineers Company), and the Province of Nova Scotia.

Atlantic Clinical Trials Network (ACTN)

Nova Scotia Health is the lead member of the Atlantic Clinical Trials Network (ACTN), a partnership of health system leaders for the co-development of an Atlantic Canadian clinical trial ecosystem capable of contributing on the world stage by serving public and private stakeholders through research and innovation. The Network’s mission is to increase capacity and access to clinical trials, while increasing economic investment in Atlantic Canada. Including:

- **Improving access** to clinical trials for the health, social, and economic benefit of Atlantic Canadians.
- **Integrate research** into the continuum of care.
- **Drive efficiency and innovation** to deliver high quality clinical trials.
- **Grow the research portfolio** with industry sponsors and granting agencies.

The Network aims to provide a seamless point of entry to Atlantic Canada for partners who want to innovate, explore opportunities, and create impact in clinical trial research. Now, a population pool of 1 million has grown to 2.5 million. There has already been demonstrated impact through early-stage partnerships with industry and a shared focus on increasing capacity and access to clinical trials while bolstering the economic health investment in the Atlantic region for the benefit of our populations.

Nova Scotia is an optimal place for research and can leverage this strength towards having the best access to innovation. There is a lack of awareness and understanding among patients of where they are situated in their cancer journey, what innovations may be available to them, what clinical trails look like in Nova Scotia, and of what work is being done to expand clinical research to give them further options. There are pathways that may exist in a patient’s future journey and each patient deserves to understand all their options.

Cancer Care Control Strategy

In 2020, Nova Scotia Health developed a five-year internal Cancer Care Control Strategy that is now in the optimization phase. The strategy contains five strategic priorities, including:

- Access and Flow
- IT/IMIT/Digital Health Care Solutions
- Quality and Patient Safety
- Our people and our facilities
- Research, Innovation and Discovery

Transparency is vital in ensuring the success of this strategy over the next five to ten years. Sharing this strategy with the public including its vision, strategic pillars, and associated funding support, will not only benefit patients but also foster a deeper understanding of the plan's objectives. This open approach will promote accountability and inclusivity, ultimately contributing to the strategy's long-term success.

Case Study – British Columbia's Cancer Action Plan

British Columbia has unveiled a 10-year cancer care action plan. The 10-year plan aims to:

- Expand cancer care teams and service hours,
- Improve cancer screening programs,
- Support cancer research,
- Increase Indigenous patient support positions,
- Increase funding to support expenses related to travelling for cancer care, and
- Add more cancer centres throughout the province to bring treatment closer to home.

For more information regarding the plan: <http://www.bccancer.bc.ca/about/news-stories/stories/bc-cancer-care-action-plan>

Comprehensive cancer strategies in provinces such as British Columbia, [Ontario](#), and [Prince Edward Island](#) encompass the following elements:

1. A well-defined vision that aspires to ensure a cancer-free future for more Nova Scotians while delivering modern, evidence-based care.
2. Thoroughly elaborated rationales for each pillar of the strategy, including clear roadmaps outlining the steps and milestones necessary to achieve its goals.
3. Adequate investments and funding allocation to support the effective implementation of the strategy, ensuring its success

4. Established Key Performance Indicators (KPIs) and governance structures to promote accountability.

Nova Scotia is committed to prioritizing patient perspectives by actively engaging a diverse range of stakeholders including patients, their families, caregivers, equity-deserving groups, and patient advocacy organizations on its own Cancer Care Control Strategy. Nova Scotia has already implemented an interactive data dashboard that provides information on health services Nova Scotians use such as service volumes, hospital inpatient occupancy levels, surgery volumes and wait times. A comparable oncology dashboard would be effective in helping patients to access important, regularly updated healthcare data to better understand the cancer care system.

Key Findings

Throughout the day, five key themes emerged:

1. The Patient Journey
2. Cancer Screening
3. Accessibility of Care
4. Community Engagement
5. Transparent Communication

The Patient Journey

A patient's journey is a profoundly personal and often daunting odyssey. The cancer care environment and the healthcare system are intricately complex, involving various healthcare professionals, including surgeons, nurses, pharmacists, medical oncologists, navigators, general practitioners, and other specialists. Within this multifaceted landscape, it is imperative to establish a transparent and seamless system that prioritizes the patient's journey, ensuring the best possible outcome with the right diagnosis and timely treatment. This complexity can be overwhelming for patients and their caregivers, emphasizing the need for enhanced continuity of care.

New technologies, like Noona®, have the potential to significantly improve the patient journey, offering a roadmap for each patient's specific tumor type treatment process. This roadmap can answer critical questions about the next phase of treatment, waiting times, activities to engage in while waiting, and how to address any adverse reactions to treatment. By supporting this new communication technology with an operational structure that can not only connect with patients but act upon needs in real time and through working with communities and patient advocacy organizations, the system can provide a comprehensive and empowering guide through the cancer care journey.

Cancer Screening

The importance of timely and appropriate cancer screening cannot be understated, as it plays a crucial role in early detection. Getting the right test at the right time is not always an easy task. A report from Statistics Canada released in May 2023, highlighted a concerning trend. It revealed that in 2020, there was a 12.3 percent drop over the previous five-year period in new cancer diagnoses in Canada.¹⁰ This decline in diagnoses can be attributed to several factors which include screening service disruptions, difficulties accessing primary care services, and fewer in-person appointments due to lockdowns and travel restrictions.

The unfortunate consequence of these trends is that patients are being diagnosed with more advanced cancers, which can have a profound impact on their prognosis and treatment options.

As diagnostic technology advances, there is an increasing need for a greater number of diagnostic services. Initiatives that promote screening taking place closer to home can significantly enhance accessibility and early detection. Studies have demonstrated the potential of mobile health as an emerging technology that can be highly effective in cancer screening.¹¹ Mobile health offers numerous advantages, including the potential to improve health outcomes, reduce costs, enhance efficiency, and minimize the number of patient visits to healthcare facilities. Furthermore, it provides on-demand, localized, and personalized interventions, making it a promising tool in the effort to improve cancer screening and early detection.¹²

The significance of receiving the most appropriate cancer screening test is underscored by the ongoing changes to cervical cancer screening for women across Canada. Many provinces such as Quebec and Prince Edward Island have replaced the old Pap test and have moved to the human papillomavirus (HPV) test as the primary screening method for cervical cancer. Nova Scotia is planning a transition to primary HPV screening, though implementation could take at least 3 years.¹³ Ontario has also recently lowered the age of eligibility to receive publicly funded regular breast cancer screening for those aged 40-49 to promote health equity and support early detection.¹⁴

¹⁰ Drop in cancer diagnoses in 2020, CBC News: <https://www.cbc.ca/news/health/canada-cancer-diagnosis-2020-covid-19-statistics-canada-1.6846564>

¹¹ The Impact of Mobile Health on Cancer Screening: A Systemic Review: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7573752/>

¹² Ibid.

¹³ Cervical cancer screening for Canadians is changing, Global News: <https://globalnews.ca/news/9821466/hpv-test-pap-smear-cervical-cancer-canada/>

¹⁴ Ontario Connecting More Women to Breast Cancer Screening Earlier, Ontario Health: <https://news.ontario.ca/en/release/1003714/ontario-connecting-more-women-to-breast-cancer-screening-earlier>

Case Study: Nova Scotia Health Brings Breast Screening on the Road



The Nova Scotia Breast Screening Mobile Clinic travels to 30 remote geographical locations to make it as convenient and accessible as possible for individuals to get screened.

The Nova Scotia Breast Screening Program began in 1991 as a single fixed screening site in Halifax. In 1994, the program expanded to include mobile mammography, with a transition to a province-wide service in 2013. The Mobile has the capability of performing more than 11,000 exams per year.

Screening mammograms are the key to early cancer detection, which increases the odds of less invasive treatment and better outcomes.

“The mobile clinic is really important because the whole purpose of it is to reach communities that are further away from fixed sites,” says Nova Scotia Breast Screening program manager, Trena Metcalfe. “Any mobile stop is generally 50-kilometres from a fixed site, so it’s meant to make it more accessible for people to be able to go into their community and access it. It’s also meant to be more accessible for some of our priority populations like First Nation communities and African Canadian communities.”

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¹⁵ Mammograms go mobile: Nova Scotia Health brings breast screening on the road, Saltwire: <https://www.saltwire.com/atlantic-canada/more/mammograms-go-mobile-nova-scotia-health-brings-breast-screening-on-the-road-100840913/>

Accessibility of Care

During the workshop, two prominent barriers to accessibility which can significantly impact the provision of care were identified. These were barriers of **jurisdiction** and **inertia**.

Barriers of Jurisdiction: The concept of jurisdiction centers around the allocation of responsibilities and decision-making.

As previously mentioned, delays in diagnosing and treating cancers have led to patients presenting with more advanced cancers. Although there is a shortage of healthcare professionals across the world, Nova Scotia has made commendable strides in recent years by expanding and broadening the scope of practice of various healthcare professionals, such as allowing pharmacists to administer vaccines. We can continue to broaden pharmacist and other healthcare professionals' scope of practice, for example, expanding their ability to order diagnostic tests. Other priority areas include encouraging additional training in oncology for General Practitioners (GPs) and supporting General Practitioners in Oncology (GPOs) within cancer centres and in primary care settings to alleviate pressures on oncology specialists, investments for acquiring diagnostic equipment and trained personnel, and further education for patients on the importance of early diagnosis and screening.

Clearly defined jurisdictional responsibilities are required to ensure the sustainable provision of these diverse healthcare resources over the long term, spanning five, ten, or fifteen years into the future.

Barriers of Inertia: Inertia relates to the tendency of systems to continue their current practices, often based on historical norms, without adequately considering how they can be adapted to better serve the evolving needs of Nova Scotians, advancements in technology, and changing circumstances.

“THERE’S A BETTER WAY TO DELIVER QUALITY HEALTH CARE IN NOVA SCOTIA. BUT THE ONLY WAY WE’LL GET THERE IS WITH A CONCERTED, FORWARD-FOCUSED EFFORT OF BOLD THINKING AND A WILLINGNESS TO LET GO OF OUTDATED IDEAS.” – NOVA SCOTIA HEALTH INNOVATION HUB

Some areas where inertia is evident include a lack of access to Health Human Resources, as well as geographical challenges. Access to cancer care facilities, especially specialized centres, is constrained in rural and remote areas. Patients in rural regions may need to travel long distances for treatment, which can be particularly challenging for seniors. Many treatments and appointments currently conducted in hospitals,

such as diagnostic procedures and tests for cancers, could potentially be relocated to facilities closer to patients' homes. Given that oncologists can analyze scans remotely, there is less need for patients to undertake extensive and expensive travel for such services.

To address these challenges, a shift away from maintaining the status quo is imperative. It is essential that all Nova Scotians receive equitable cancer care, regardless of their postal code.

Community Engagement

The exploration of under screened and under treated populations in Nova Scotia has revealed a critical need to establish and maintain strong partnerships with patient communities and community organizations to combat health inequities.

Communities that are underserved in the context of health services are populations that face inadequate and disadvantaged access to healthcare due to various factors such as race, age, language, geography, gender identity, sexual orientation, and socio-economic status. A person who is part of an underserved community may:

- Be more likely to be exposed to cancer risks,
- Have problems getting care or services they need,
- Receive less care or a lower standard of care,
- Get services or treatments that do not meet their need,
- Be less satisfied with services than the general population, and/or
- Have poorer outcomes during their cancer experience.¹⁶

Further work must be undertaken, and attention must be paid to these communities to begin to address these inequities.

Building trust with communities is essential for fostering effective, collaborative relationships between healthcare providers and the community. By leveraging community leaders to educate and disseminate information that is tailored to their respective communities, it can be ensured that programs are not one size fits all. Actively involving diverse community members in the planning process of a program can ensure that a community's unique needs are met.

Cancer patient navigators play a pivotal role in providing support to patients throughout their cancer journey. They connect patients with health professionals, support groups, and other resources in the community. They also aid in enrolling patients in assistance programs such as pharmacare, disability benefits, and transportation programs. With deep ties to the community, we can harness the power of the navigator to address health inequities. Nova Scotia Health has hired eight additional navigators with plans to hire more in 2024 and has redefined the role, resulting in hiring additional drug access navigators, a function that was in the past covered by the navigators. To fully address patients needs, there can be further investments into sub specializations for providers that will navigate patients such as in social work or psychology.

Nova Scotia Health has a project underway to build a new framework of psychosocial oncology care delivery for Nova Scotia. This is key, as a community-centered approach is imperative to address the healthcare needs of underserved populations in Nova Scotia and to ensure a more inclusive and equitable provision of care.

¹⁶ Health Equity, Canadian Cancer Society: <https://cancer.ca/en/about-us/our-health-equity-work>

Transparent Communication

A pervasive theme throughout the discussions held during the workshop was the importance of effective communication. While the Cancer Care Program and the Innovation Hub are spearheading numerous critical projects and programs, their full potential will only be realized when they are communicated effectively to the individuals who stand to benefit the most. Any initiative, especially a Cancer Care Control Strategy, must involve patient perspectives in the early development phase and throughout implementation. This is a fundamental practice that can have a transformative impact on the outcomes. Patients are the primary users of healthcare services and through involving them from the outset, it ensures that the design and development of initiatives are tailored to their needs. Patients can continue to provide valuable insights into unmet needs and gaps in services as their lived experience can shed light on aspects of care that may be overlooked.

Another challenge is how to ensure that any essential information cascades down to the frontline staff, and most importantly, reaches those in need of these programs and resources. There should be an alignment among service providers in where to guide a patient to at every point in their journey. Patients facing financial hardships pertaining to traveling to receive care, often lack awareness of Nova Scotia's available boarding and travel subsidies tailored to specific demographics. Increasing awareness and expanding services to those in need is crucial in alleviating additional stress and burden on patients.

The opportunities for collaboration with patient advocacy organizations to improve communication are abundant. The introduction of the Oncology Transformation Project and specifically Noona, will help improve enhanced communication with patients before and during their cancer journey. Patient advocacy organizations offer countless resources for patients that can be seamlessly integrated within the existing platform and can highlight real patient experiences. Communities and patients should be empowered to engage with government and health care programs, confident that their inquiries will be addressed promptly and will contain accurate information.

By prioritizing robust, patient-centred, and community-focused communication strategies, Nova Scotia can better ensure that healthcare resources and initiatives are made accessible and relevant to those who need them most, ultimately contributing to improved patient experiences and health outcomes.

Recommendations

Prioritize the Cancer Patient Journey

- Ensure that patients have a **clear understanding** of their position in the treatment continuum, offering education and information about their progress and treatment schedule. Ensure the aggregate data gathered from patients is measured against standards of care (time to first treatment, time to pathology test, time to diagnosis, etc.).
- Maximize the full power of Noona to **empower patients** to take an active role in their screening and treatment journey, providing them with tools and information to make informed decisions.
- Increase awareness among Nova Scotians on the importance of **clinical trial participation**.
- Provide **timely access** to approved cancer therapies to provide best outcomes for Nova Scotians.

Increase Cancer Screening

- Provide **enhanced training** to health care providers on the value of cancer screening and prevention, equipping them with the knowledge and tools to better serve their patients.
- Increase the **availability of screening sites** and mobile screening programs, especially in rural areas, to improve accessibility of screening.
- Use **innovative communications** strategies to increase awareness about the importance of prevention and screening, using personal narratives to inspire action.
- Implement a **lung cancer screening** program in Nova Scotia.

Deliver Accessible Care Closer to Home

- Utilize **local community health care providers** to help ensure the 5 Rs for cancer patients: Right Information, Right Care, Right Place, Right Time, and Right Provider and reduce burden on medical oncologists.
- Expand **virtual care** options for medical appointments to make healthcare more accessible and timelier, particularly for those in rural areas. Identify innovative and non-traditional uses of community gathering spaces to lower dependence of cancer specific sites.
- Continue to facilitate the delivery of treatment **closer to patients' homes** or at home whenever feasible, reducing the burden of hospital-based care.
- Provide increased **financial support** when in-person treatment is necessary and incurs additional travel, accommodation, and parking costs.

Engage Communities and Stop Working in Silos

- Continue establishing a **Patient and Community Advisory Council** to engage patients and communities in the design and implementation phases of healthcare innovations through a new **6th pillar** in the Cancer Care Control Strategy.
- **Leverage existing relationships** between communities and patient advocacy organizations to eliminate redundancy and create synergies in efforts to support cancer patients and their families.
- All patients entering the cancer system should be offered, when appropriate, the support of a **cancer patient navigator**. Expand the number of BIPOC patient support positions in the province and use them to assist in community building.

Consistent and Transparent Communication

- Expand and communicate the **5-year cancer control strategy** to meet the needs of today and prepare for future needs. Develop and communicate the vision, goals, actions, funding plan, monitoring and evaluation regime including benchmarks, Key Performance Indicators, and governance structures to ensure accountability.
- Utilize the OTP as a means to **communicate with patients** both during and after their treatment, ensuring they are well-informed and supported throughout their health care journey.
- Collaborate with **patient advocacy organizations** to effectively disseminate information through their established networks, reaching a broader audience and enhancing public awareness of available resources and programs.
- Work with patient organizations to roll out a **public education campaign** to understand cancer, services, screening, and importance of early diagnosis.

Conclusion

By implementing these recommendations and tracking progress, Nova Scotia has the ability to strengthen its approach to cancer care and address the critical issues that we've identified around the patient journey, cancer screening, accessibility of care, community engagement and transparent communication. We recognize Nova Scotia's role in caring for patients from neighboring provinces and aim to expand our initiative to other regions, fostering cross-province discussions to enhance cancer care standards.

We want to thank all the groups that joined us for this critical discussion such as the Canadian Cancer Society, the Canadian Association of Retired Persons (CARP), Colorectal Cancer Canada, Dense Breasts Canada, the Leukemia & Lymphoma Society of Canada, the Lung Association of Nova Scotia and Prince Edward Island, and Myeloma Canada.

The participation from these patient advocacy organizations and Nova Scotia Health showed the importance of these discussions and the willingness of all to collaborate.

Without all of you, and without our partnership with the Nova Scotia Health Innovation Hub, the workshop would not have been possible. CCSN and all participants look forward to continuing to work together to improve cancer care in Nova Scotia for patients and their families in the years to come and towards the next phase of the Oncology Transformation Project.

We would also like to thank our industry sponsor, Merck Canada Inc. for their support in this oncology workshop.

Next Steps

This workshop was a first step in what we hope will result in an effort to further consult and collaborate with a diverse set of stakeholders.