



## All.Can Canada 2<sup>nd</sup> Multi-Stakeholder Roundtable Meeting Report Back

November 29, 2021

### Context:

All.Can Canada has recently completed a nation-wide environmental scan assessing the current state of cancer diagnosis and developed a research report with recommendations to improve the state of cancer diagnosis in Canada.

The impetus for this work came from the outcome of the first All.Can Canada roundtable meeting in November 2019 in which participants reached consensus that the priority area of focus for All.Can Canada should be ensuring swift, accurate and appropriately delivered diagnosis as the entry point into the cancer care system.

A second multi-stakeholder roundtable session was held virtually on November 29, 2021, which included review of the *Optimizing Diagnosis in Canadian Cancer Care* research report by participants.

This meeting report outlines the information shared and the themes and ideas for opportunities identified at the second roundtable meeting, plus the next steps agreed upon by the participants with the aim of advancing the recommendations of All.Can Canada's *Optimizing Diagnosis in Canadian Cancer Care* and moving towards an improved future state in cancer diagnosis using the results of All.Can Canada's research.

### Attendees:

- Kathy Barnard, President, Save Your Skin Foundation
- Eva Villalba, Director General, Coalition Priorité Cancer au Québec
- Antonella Scali, Executive Director, Canadian Psoriasis Network
- Martine Elias, Executive Director, Myeloma Canada
- Louise Binder, Health Policy Consultant, Save Your Skin Foundation
- Rachael Manion, Executive Director, Canadian Skin Patient Alliance
- Suzanne Wait, Managing Director, The Health Policy Partnership
- Dr. Martin Dawes, Professor, Department of Family Practice, University of British Columbia
- Dr. Janice Wright, Medical Doctor, Family Practice Oncology Network, BC Cancer
- Dr. Paul Wheatley-Price, Medical Oncologist, Associate Professor of Medicine, University of Ottawa
- Nick Makris, Pharmacist, Global Director, New Product Planning, Theratechnologies
- Fred Horne, former Health Minister of Alberta, Principal, Horne & Associates
- Dr. Jennifer Rayner, Director of Research and Evaluation, Alliance for Healthier Communities
- Stephanie Michaud, Chief Executive Officer, BioCanRX
- Shaneel Pathak, Co-Founder, Zamplo
- Jennifer Chadder, Director of Diagnosis & Clinical Care, Canadian Partnership Against Cancer
- Angela Fowler, Manager of Partner Engagement, Canadian Partnership Against Cancer
- Tina Sahay, Lead Researcher, Health Promotion Consulting Group



- Alex Chambers, Novartis Pharmaceuticals Canada (formerly of Canadian Agency of Drugs and Technology in Health)
- Josee Pelletier, National Patient Advocacy Manager, Bristol-Myers Squibb
- Wendy Morton, Associate Director of National Policy, Merck Canada Inc.
- Christine Meisner, Advocacy Relations Manager, Value, Access & Policy, Amgen
- Lisa Maslanka, Senior Manager Oncology, Value, Access & Policy, Amgen
- Mark Surka, Head of Medical Affairs, Oncology, Sanofi Genzyme
- Bhavanita Patel, Patient Platforms Lead, AI and Digital Health Solutions, Roche
- Brigitte Viel, Director, Patient Advocacy, Pfizer

## Secretariat:

- Leah Stephenson, Leah M. Stephenson Consulting, ACC Strategic Lead
- Amy Rosvold, Amy Jones Marketing & Communications, ACC Project Lead
- Natalie Richardson, Save Your Skin Foundation, Meeting Reporter
- Elizabeth Bono, ACC Hub Coordinator, Meeting Reporter
- Marianne Gagnon, Save Your Skin Foundation, Meeting Reporter
- Chantele Burroughs, Save Your Skin Foundation, Technical Assistant

## Facilitation Consultants:

- Lise Marie Baudry, Meeting Facilitator
- Ron Rosenes, Meeting Facilitator
- Nicola Stein, Meeting Facilitator

## Meeting Objectives:

- To identify opportunities to advance the recommendations of All.Can Canada's *Optimizing Diagnosis in Canadian Cancer Care* report and begin to move towards an improved future state in cancer diagnosis using the results of All.Can Canada's research.

## Next Steps:

The All.Can Canada Secretariat and Interim Steering Committee will:

- prepare a Report Back document from the 2<sup>nd</sup> Roundtable to disseminate to all Roundtable participants;
- create a multi-year, strategic action plan, working with opportunities identified today as a starting point; and
- assess the need to refresh its governance structure to support ACC's strategic action plan.

## Meeting Summary:

### Introduction to All.Can International (Amy Rosvold):

Amy provided an overview of All.Can International. She explained that All.Can is an international multi-stakeholder not-for-profit working to improve the efficiency of cancer care by focusing on what matters



to patients. All.Can connects cancer experts from all sectors to drive better efficiency across the cancer care pathway in four ways:

1. ensuring patient-relevant outcomes are at the heart of everything;
2. investing in data to create a continuous cycle of improvement;
3. installing processes to create accountability across the entire care pathway; and
4. creating political will to focus on better outcomes for patients.

Amy indicated that the All.Can coalition is made up of 28 partners consisting of patients, researchers, clinician associations, policymakers, and funders. It is active in 18 countries and takes a holistic approach to cancer care. The objective is to focus energy on what matters most to cancer patients and improving efficiency with that end in mind.

She gave an overview of All.Can's governance structure to guarantee independence, transparency and multi-stakeholder engagement in the decision-making processes.

Amy provided a summary of All.Can's major projects and publications, including:

- All.Can international's first policy report published in January 2017, which looks at improving efficiency in cancer care as a means of achieving better health outcomes for patients, and making better use of available resources.
- The All.Can patient survey conducted in 10 countries, including Canada, and completed by nearly 4,000 current or former patients and caregivers. From the findings, the report, 'Patient Insights on Cancer Care' was published in which four main opportunities were identified to improve efficiency from the patients' perspective to drive change for everyone affected by cancer. In both the international survey, and the Canadian survey results, diagnosis was the top area where patients reported the greatest inefficiency throughout their cancer care trajectory.
- All.Can's Efficiency Hub, which provides dozens of examples of best practices across the entire cancer pathway, from prevention and screening to treatment and follow-up care, end-of-life care and survivorship – for all cancer types. The aim of this hub is to create a learning community around efficient practices and help others find and implement potential solutions to common issues.
- All.Can's 2021 policy report, *Harnessing data for better cancer care*, assesses the essential role of data in cancer care to improve outcomes for all people with cancer, offering policymakers, care providers, patients, and decision-makers a forward-looking view of how to ensure high-quality health data are systematically collected and used to improve outcomes.

Amy shared All.Can's draft roadmap for the next three years which includes:

- A patient survey,
- Expanding the Efficiency Hub,
- Policy and data reports,
- Multi-stakeholder knowledge exchange and collaboration,



- National initiative information exchanges, and
- Hosting another global summit.

## Optimizing Diagnosis in Canadian Cancer Care: Summary of Key Findings & Recommendations (Leah Stephenson):

Leah provided an overview of the genesis and governance of All.Can Canada, explaining that Save Your Skin Foundation has been serving as All.Can Canada's Secretariat since bringing All.Can to Canada in 2018. She described the early convening of a working group to complete a discovery phase to identify the top areas of waste and inefficiency in Canadian cancer care. Using the findings from this discovery phase, SYSF hosted the inaugural multi-stakeholder roundtable meeting in November 2019 to find consensus on priorities and next steps. Participants at the first roundtable were patients, healthcare professionals, patient group representatives, former health technology assessment professionals, industry representatives, and researchers. The group achieved consensus on a preliminary area of focus to be on *“ensuring swift, accurate, and appropriately delivered diagnosis as the entry point into the cancer care system”*.

She indicated that the first roundtable meeting also agreed to a preliminary governance approach for All.Can Canada through the establishment of a patient-led, multi-stakeholder Interim Steering Committee, supported by the Secretariat. The roundtable participants asked that the Interim Steering Committee provide strategic guidance and oversight of research to assess the current state related to achieving “swift, accurate, and appropriately delivered diagnosis” of cancers in Canada.

The objectives of the research included identifying outcomes that matter most to patients, reviewing promising practices in cancer diagnosis, and exploring areas of inefficiency that represent opportunities for improvement. The research was conducted from June 2020 to March 2021 by an independent third-party consultant and was approved by an independent research ethics board. The methods included a literature review, 30 qualitative interviews with cancer survivors across Canada who had been diagnosed in the last 18 months, and a survey of relevant healthcare providers across Canada.

She then gave an overview of the findings, describing how, irrespective of cancer type, stage of disease or social determinants of health, patients described the diagnosis process as taking place in three distinct phases:

- Early: the period from when a person first tries to contact or interact with a health care provider over a suspicion of cancer until the first referral to a diagnostic facility for testing
- Middle: the period during which a person undergoes diagnostic testing to investigate a suspicion of cancer
- Final: the period from when a person arrives at a dedicated cancer facility to the time they receive their cancer diagnosis.

Leah then described the seven outcomes that were voiced by people as being critical to the diagnosis experience and provided an overview of the issues, opportunities, and spotlight practices for each outcome:

1. Swiftness of the diagnosis process
2. Validation of concerns by primary care providers



3. Excellent patient-provider communication
4. Effective provider-provider communication
5. Better information
6. Integrated psychosocial support
7. Coordinated and managed care

She emphasized that an improved future state of cancer diagnosis doesn't mean starting from scratch. Through ACC's research, numerous opportunities and existing practices were identified that, if adapted and scaled for jurisdictional and regional needs, can be an excellent place to begin the realization of an improved future state of cancer diagnosis.

Leah then presented the beginnings of a quality framework aligned with the seven desired outcomes, including proposed metrics that can be used to measure the seven outcomes identified in the diagnosis phase.

Finally, she shared the set of six recommendations All.Can Canada has developed to improve the swiftness, accuracy and appropriateness of communication of cancer diagnoses in Canada. Opportunities to advance these recommendations were then discussed and explored in detailed by all meeting participants in four breakout groups.

The participants then broke into four rooms to discuss the six recommendations in smaller groups. The discussions focused on identifying opportunities to advance the recommendations and determining where All.Can Canada should lead the work, and where we should partner with other organizations already active in that area. Following the discussion, the breakout groups reported back to all participants in the plenary session.

### Themes from Breakout Room Discussions:

Main themes and ideas from breakout room discussions included the following. These will be used as a starting point for a multi-year, strategic action plan for All.Can Canada.

#### A) Enhance Primary Care Provider Knowledge:

- Identify trusted, high quality primary care education bodies/networks across Canada, (overtime consider identifying allied health bodies such as pharmacists' associations) (i.e. BC's Family Physicians Oncology Network and other P/T primary care provider groups, Medscape, OncologyEducation, DeSouza Institute, Medical Schools)
- Coordinate the creation and delivery of content/curriculum additions relevant to ACC's findings with patient subject matter experts via education bodies/networks
- Advocate for access to accountable primary care providers, in particular integrated, interprofessional primary care teams
- Explore and establish partnerships with groups such as CPAC, cancer control agencies, Canada Health Infoway, panCanadian Health Data Strategy, Health Excellence Canada on diagnostic pathways and guides, electronic decision supports

#### B) Ensure available and accessible Patient Navigation, Multidisciplinary Teams (MDTs), Diagnostic Assessment Programs (DAPs):



- Clarify/define patient navigation (including do any standards exist? recommended competencies? training/certification programs?)
- Identify inspiring exemplars of patient navigation and effective DAPs that include MDTs & patient navigation from our research (and CPAC's scan) and share best practices
- Explore and establish partnerships (i.e. CANO, CAPO, drug access navigators) for advocacy & coordination
- Support CPAC's development and roll out related to Innovative Models of Care to improve cancer diagnosis
- Coordinate the creation and delivery of content/curriculum additions on these topics to primary care and oncology educational bodies plus policymaker associations/conferences

## C) Ensure available and accessible Psychosocial Support:

- Clarify definition of psychosocial support
- Explore and establish partnerships (i.e. CAPO, MHCC, CANO, Collaborative Mental Health, CANAge)
- Continue and expand ACC's Psychosocial Support Hub that was created during the pandemic and is transitioning to the longer-term (possible resource additions - 411 in Ontario, CCS resources, Home & Community Care Support Services)
- Coordinate educational opportunities/resources for primary care providers and oncologists to enhance their compassionate communication skills and ability to proactively offer psychosocial supports to people early in the diagnosis process

## D) Share Best Practices:

- Explore the feasibility of creating an online portal, such as an All.Can Canada Efficiency Hub using and/or adapting the infrastructure and lessons learned from All.Can International, including inclusion/exclusion criteria
- Develop a framework for diagnosis information resources for different types of cancers based on best practices identified in our report and encourage its uptake by patient groups, industry, and others already creating such resources
- Potentially create and maintain an All.Can Canada Efficiency Hub to share best practices that advance our recommendations
- Identify, vet, organize, and share via the Efficiency Hub existing diagnosis information resources that meet the framework/best practices ACC's report identified
- Identify, vet, organize, and share via the Efficiency Hub existing care pathways developed with patient partnership

## E) Recommendations related to Data & Technology:

- Undertake advocacy and explore/establish partnerships related to data & technology needs associated with improved cancer diagnosis (i.e. panCanadian Health Data Strategy, CPAC's Cancer Data Strategy), including connectivity (federal Minister of Innovation) and digital equity (Healthcare Excellence Canada)

## F) Establish a Quality Framework for cancer diagnoses:

- Explore and establish partnerships and coordinate with groups like CIHR's international cancer benchmarking partnership, CIHI, Canadian Centre for Applied Research and Cancer Control



## G) Establish an Indigenous Stream:

- Secure funding and identify Indigenous leaders and researchers to develop and implement a self-governing research stream (CCO's Aboriginal Cancer Strategy led by Alethea Kayawash could be a good starting place)

## H) Establish a Racialized Stream:

- Secure funding and identify racialized leaders and researchers to develop and implement this research stream (TAIBU's Dr. Onye Nnorom could be a good starting place)

## I) Travel Funding:

- Consider adding existing, limited travel supports (e.g. funding, air travel, patient groups providing such support) as a section in the ACC Psychosocial Support Hub as it transitions from a Pandemic Oncology Hub
- Collect data from SYSF and other patient groups currently filling the oncology travel gaps to show the need. Undertake advocacy about this issue.

## Meeting Close:

Leah thanked the participants for their time and contributions and outlined next steps.

Kathy closed the meeting with her thanks to everybody who helped make it possible.