



# **Optimizing Equitable Cancer Diagnoses for Structurally Underserved Communities Roundtable: What We Heard**

**Roundtable Report  
January 17, 2024 | Toronto**

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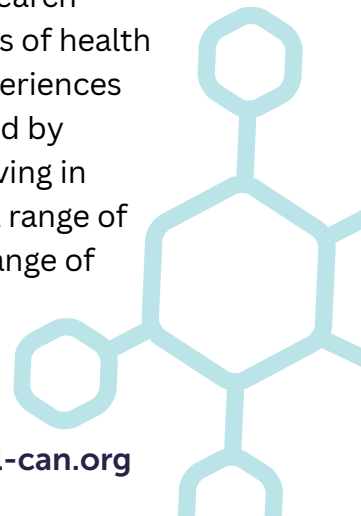
# Introduction

Led by patient groups and people with lived experiences of cancer, [All.Can Canada](#) (ACC) is a national, multi-stakeholder network for cancer care efficiency, with a preliminary aim of optimizing people's entry into cancer care through swift, accurate, and appropriately delivered diagnosis. ACC is a national initiative of [All.Can International](#), a European multi-stakeholder initiative that brings together patient organisations, policymakers, healthcare professionals, industry, and researchers to improve the efficiency of cancer care by focusing on what matters to patients. [Save Your Skin Foundation](#) acts as ACC's Secretariat.

**The primary aim of the Optimizing Equitable Cancer Diagnoses in Canada Roundtable convened on January 17, 2024 in Toronto was to gain insights on the implications, gaps, and opportunities related to ACC's mixed methods research to move towards an optimized, equitable future state of swift, accurate, and appropriately communicated cancer diagnoses for and with structurally underserved communities.**

ACC's Steering Committee is not only producing and sharing this draft report outlining the learnings from the Roundtable for the purposes of obtaining participant input and finalizing the report; we are also asking participants to help us assess priorities on next steps within ACC's mandate and possible new community-led partnerships that would help operationalize prioritized next steps.

All.Can Canada is committed to understanding and working towards addressing barriers built into Canadian healthcare systems, including structural and social determinants of health, in obtaining timely cancer diagnoses. From the outset, when ACC launched their research project in 2020 to better understand the current and desired future state of cancer diagnoses in Canada, the research team aimed to find literature about the implications of the determinants of health during cancer diagnoses and to hear from people with diverse lived experiences of cancer. ACC was successful in hearing from a range of people affected by different types of cancers, including blood and solid tumours; people living in different parts of the country, including rural regions; people living on a range of incomes, including low income households; and people from across a range of ages.



ACC researchers reached out using a variety of methodologies to Community Health Centres (CHCs) across Canada, with particular emphasis on those with specialization in serving structurally underserved communities such as TAIBU, Women's Health in Women's Hands, Access Alliance, Parkdale Queen West, and Centre de santé communautaire de Témiskaming, to help recruit cancer patients who are structurally underserved for patient interviews. However, despite multiple methods of outreach, including personal calls by someone with established professional relationships to leaders in Community Health Centres (CHCs), it was understandably difficult to get their attention during the onset of the COVID-19 pandemic. Being among the few models of care that remained open throughout the pandemic and needing to quickly adapt to serve communities at particular risk, the leaders and providers of CHCs were focused on other priorities at the time of ACC's patient recruitment efforts. Thus, despite extensive outreach to such relevant stakeholders, there were limitations in who ACC's research team was able to interview and what input ACC was able to obtain.

As a result, ACC sees this Roundtable as a foundational next chapter in its work to identify structural barriers in Canadian healthcare, alongside the beginning of establishing new relationships, and identifying opportunities to more equitably improve symptomatic cancer diagnoses. ACC is committed to robustly supporting the leadership of interested structurally underserved community members and community groups in any prioritized next steps coming out of the Roundtable.

### Why focus on diagnosis?

**Earlier diagnosis means better health outcomes<sup>1</sup> and reduced healthcare costs<sup>2</sup>. Delays are correlated with increased mortality.<sup>3</sup> The cost of cancer care in Canada has risen from \$2.9 billion in 2005 to \$7.5 billion in 2021, largely due to the increased costs in hospital-based care.<sup>4</sup> In Canada, in 2022, sixty-three percent of new cancers were diagnosed through the investigation of symptoms as compared to thirty-seven percent diagnosed by screening.<sup>5</sup> There are also many cancers for which there are no screening programs. As a result, it is crucial to attend to how to improve earlier cancer diagnoses through symptom presentation in order to save lives and reduce health system costs.**

1. Elison L, Saint-Jacques N. Five-year cancer survival by stage at diagnosis in Canada. Statistics Canada. January 18, 2023.
2. Sarma E et al. Achieving Diagnostic Excellence for Cancer: Symptom Detection as a Partner to Screening. JAMA. July 18, 2022
3. Hanna T P, King W D, Thibodeau S, Jalink M, Paulin G A, Harvey-Jones E et al. Mortality due to cancer treatment delay: systematic review and meta-analysis. BMJ 2020;371:m4087
4. Oliveira, D., Weir, S., Rangrek, J., Krahn, M., Mittman, N., Hoch, J., Chan, K., Peacock, S. The economic burden of cancer care in Canada: a population-based cost study. CMAJ 2018, 6(1), E1-E10.
5. Canadian Cancer Society. "Cancer Statistics at a Glance." Updated 2023. <https://cancer.ca/en/research/cancer-statistics/cancer-statistics-at-a-glance>



# Themes from the Roundtable

Seventeen participants with a diversity of expertise related to different structurally underserved communities, including lived expertise, primary care provider expertise, research expertise, community organization expertise, and policymaker expertise, gathered in-person in downtown Toronto. (See Appendix 1 for the participant list.) The day was co-facilitated by Drs. Ambreen Sayani, a member of ACC's Steering Committee, and Paul Wanka.

A pre-meeting package was provided to all participants a month prior to the event, with a summary of ACC's research findings, guiding questions, event agenda, and logistical details. At the event, three facilitated breakout sessions invited participants to respond to the guiding questions, as listed below. Breakout group participants were encouraged to observe commonalities and differences. Groups reported back to each other in plenary sessions. In addition, a post-event networking session was offered. Hopefully, participants were able to network and benefit from establishing new relationships of importance to their communities in service of advancing priorities of mutual interest and addressing common issues.

## Guiding Questions

1

What are your reactions to these research findings on cancer diagnoses? Any surprises? How do they resonate with your experiences? Or don't?

2

What are the implications of these findings on structurally underserved communities? What are the gaps in these findings and recommendations related to these communities?

3

What does a more equitable future in cancer diagnosis look like? What are the opportunities to move towards this more equitable future, including any potential partnerships or areas of mutual support to move towards this more equitable, improved future?

Qualitative analysis of the day's notes, taken by dedicated notetakers, produced the themes outlined below. These themes include analysis of written feedback by participants who were invited but could not attend and were interested in providing their input. They responded to the same guiding questions. Those that provided written feedback are also included in Appendix 1.



## Overarching Themes

**Overarching themes include the foundational importance of healthcare relationships in order to build and sustain trust.** Similarly, at the level of the organizations and providers within and contributing to healthcare and related systems (including community groups), **the connections between providers and organizations are foundational.** As the late complexity researcher, Brenda Zimmerman, has shared: “the most important unit of analysis in a system is not the part (e.g. individual, organization, or institution), it’s the relationship between the parts.”<sup>6</sup> **Approaches grounded in cultural humility/safety/appropriateness and an understanding of trauma are needed at all levels – micro, meso, and macro.**

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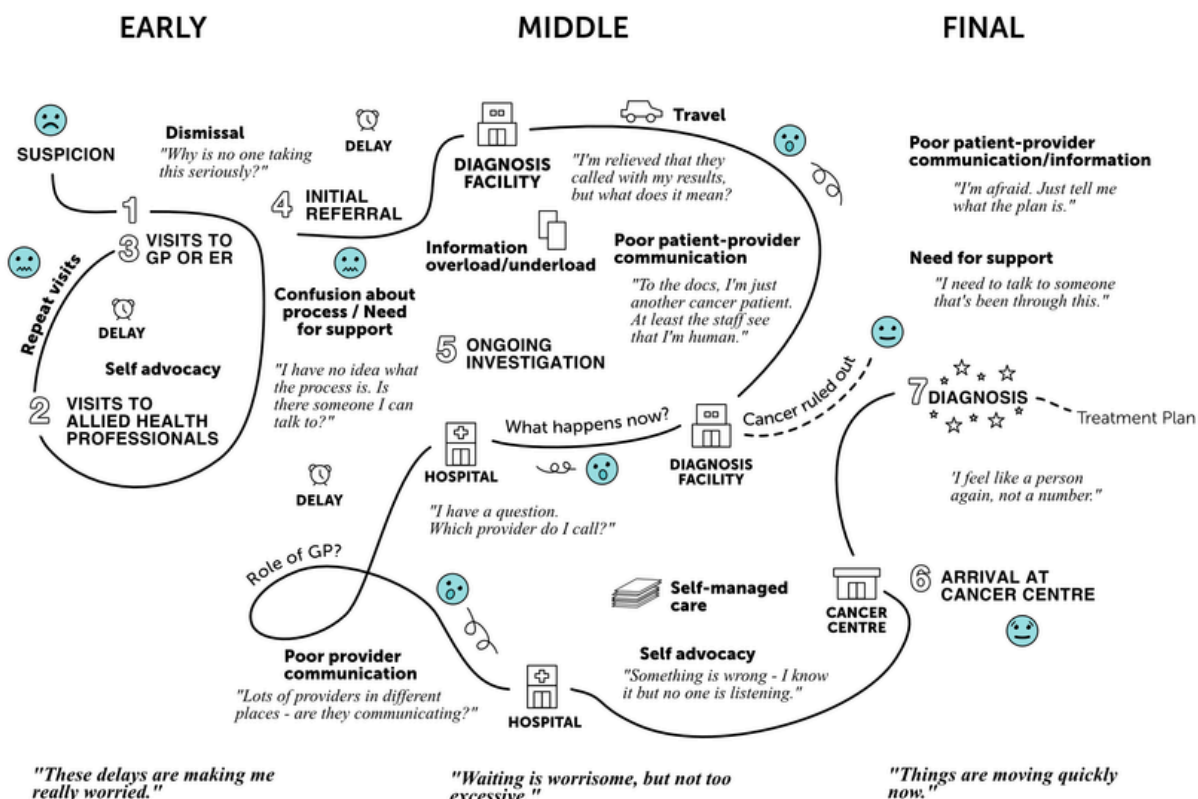
6. For more information: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4891190/>



# Themes - Reactions, Implications, Gaps

A lot of people have been filtered out of the ACC current state infographic (below). They do not even get into the early phase of diagnosis. Intersecting and compounding factors were named that cross all levels of health care from the micro to the meso to the macro. These intersectional factors can stop or drastically slow people from engaging with the healthcare system at all.

## Patient Experience of the Diagnosis Journey - Current State



## These factors include:

- **People's identities not being validated. Intersectionality compounds this**

**"We must be able to talk about racism, homophobia, transphobia, ableism. Also intersecting identities compound discrimination. Recognize there are different levels of privilege."**

- **Racism** including unconscious bias and stereotyping
- **Ableism** including neurodivergent patients who can experience communication, processing and sensory difficulties within healthcare without appropriate supports
- **Lack of money** for testing, time off work, travel to facilities, daycare. For some people, it is a trade off between groceries for the family or getting tested
- **Homeless and housing insecure people** frequently needing to use emergency rooms due to lack of proper healthcare and housing
- **Digital inequities** caused by not having or not being able to use computers, smart phones, internet, or email
- **Newcomers** having experienced very different health care systems and not knowing how to access and navigate care in Canada's systems
- **Refugees** who are uninsured and unable to access health care
- **Cultural and generational factors**

**There are "issues of stigma. Information must be accepted in the community in addition to acceptance by the individual." One participant was outcast from marriageability within her community due to her cancer diagnosis. For many patients, particularly from older generations, there is fear in challenging authority. Therefore, asking questions, seeking a second opinion, any degree of 'self-advocacy' are not possible for many older adults.**

- **Barriers to health literacy**
- **Language barriers**

Structurally underserved communities experience **mistrust of the healthcare system**. Many intersecting and compounding factors were shared that fuel this mistrust. **Racism is a key factor**. Some of the ways racism manifests is through stereotyping, lack of policy change based on existing evidence, and lack of respect, engagement, and relationship. **System fragmentation also fuels mistrust**. As one participant said, “poor care is continuing to fuel intergenerational trauma.” Another stated “harm makes people reticent.”

**“Poor care is continuing to fuel intergenerational trauma.”**

Numerous participants shared that the ACC findings seemed “very accurate and resonate...The system is fragmented, even in the Greater Toronto Area. Systems don’t talk to each other, still using fax machines. Once patients get to us [healthcare providers], we need to build trust again as they have been frustrated by the system.”

Different parts of the system are fragmented, such that, even during the investigation phase, it can take months between tests and people are lost in the waiting periods. As one family physician working with structurally underserved communities said “silos cause harm and death.” **The structural expectation of self-advocacy is a symptom of a broken health care system**. Self-advocacy requires agency, confidence, and power, which can be challenging for members of communities facing discrimination and oppression. This fragmentation also results in **‘barriers to personhood.’** People do not feel that their whole selves and the complex reality of their lives are being adequately addressed in the fragmented system. As one participant shared, **“you don’t leave your other issues behind when cancer comes to town.”** For example, some autistic patients are unable to express, recognize, and articulate their symptoms, which creates additional barriers throughout the cancer diagnosis trajectory. For some communities, there is stigma associated with cancer. For some, language barriers create unsafe and inequitable care. **Patient Reported Outcome Measures (PROMs)** that incorporate relevant dimensions of people’s lives (e.g. psychological wellbeing, sexual health) can help mitigate this tendency to reduce people’s experience and include dimensions of their lives that are important to them and others like them.

**“You don’t leave your other issues behind when cancer comes to town.”**



- **To increase connections and reduce fragmentation, effective teams are needed everywhere throughout the system including during the diagnostic trajectory. Navigation and psychosocial supports are needed as part of teams. These teams must be truly integrated in how they work together with a clear point of contact for patients. Care needs to be hyper-local, culturally appropriate, and trauma-informed to better serve structurally underserved communities. Supports addressing the social determinants of health need to be integrated into medical care, including disability funding, housing, support for income loss, support for costs associated with accessing required health care services for those that cannot afford to pay out-of-pocket (e.g. test costs, travel, daycare).**
- **“Communitarian knowledge”, knowledge shared through community networks and community groups, is powerful. Community supports and sources of community knowledge need to be proactively connected with medical care.** As a start, given the proliferation of solo practitioners, it can be as basic as all primary care providers knowing about and proactively sharing with patients and caregivers the [Community Resource Locator](#) so people can search for needed community-based supports as soon as the word “cancer” is mentioned and investigation begins.



- **Primary care can be a barrier to equitable cancer diagnoses. Team-based, equity focused models of primary health care like Community Health Centres (CHCs) are solutions.** ACC's recommendations' emphasis should not be on the education of primary care providers. It should be on the health care system supporting primary care providers to work as they are trained to work, in teams. Many primary care providers want to provide better care but the system works against them. There should be no more fee-for-service or solo practitioner models. Existing models of team-based, equity focused primary health care (such as CHCs in Ontario) face systemic barriers such as an inadequate, illogical funding formula to provide primary health care services to uninsured people (i.e. the amount of non-insured funding is based on when the organization was established not how many non-insured clients it serves). CHCs are simultaneously charged out-of-country rates (rather than much lower provincial rates) by other providers when delivering services to non-insured clients including refugees, thereby reducing the number of uninsured people who can be served. **Outcomes should drive funding and models of care.**
- Finally, **data disaggregation** is urgently needed, with comprehensive efforts to govern and work with structurally underserved communities in such a way that consistently demonstrates reasons for them to trust that their data are being used to help, not harm, their community; data returning to communities; and PROMs and PREMs (patient reported experience measures) co-designed with communities in the lead.



## Themes - Equitable Future State & Opportunities

An equitable future state of cancer diagnoses in Canada consists of...

...**health care systems** that:

- Are **flexible and adaptive** so that providers and organizations can work together better to meet people's actual needs using hyper-local responses
- Are taking a **trickle up social justice**<sup>7</sup> approach, a commitment to understanding that social justice efforts need to centre the experiences of the most vulnerable in order to benefit everyone
- Support swift **integration of foreign-trained health care providers**

...**health care services** that:

- Are **trauma-informed, trans-informed, and culturally safe**
- **Non-judgmentally meet people where they actually are** without bias and stereotyping, including bringing care to where people are in community settings if they cannot come to a healthcare setting
- Are **publicly funded**, including all the necessary enablers for healthcare access to be possible such as supportive housing, travel for care, resources in rural and remote regions, funded and accessible services for people who are uninsured
- Are **team-based**, including **peer and community navigators**, case managers, social workers. Equity-focused, culturally safe, and trauma-informed primary health care teams like CHCs need to be accessible and able to serve structurally underserved communities across Canada
- Are **connected** so that different parts of the system can easily communicate (e.g. primary care, oncology, trans care, mental health services, disability services) and so community resources / communitarian knowledge and networks are better integrated with medical care. Constellations of different community supports are able to collaborate and raise awareness of each other
- Are provided, led, and governed by a **diverse workforce and volunteer governors**
- Are supported by **cancer diagnosis protocols and pathways** inclusive of primary care providers
- Proactively provide **interpretation and translation** when needed
- Are **digitally equitable**

7. Concept by Dean Spade

...all of which is supported by **data and research** that...

- Are **disaggregated by socio-demographic factors, such as gender, race/ethnicity and First Nation, Inuit, Métis status, ability, and sexuality**
- Build **social trust** through **community governance, co-design, uses that identify and assess the effectiveness of tailored, hyper-local responses to improve outcomes, and rapid knowledge translation of information back to communities**
  - A precondition for this work is **readiness capacity building** by any participants in the work who are not part of the community such that they are able to provide support effectively
- Co-design and use, with communities in the lead, **PROMs and PREMs as well as relevant system-level outcomes (e.g. Quintuple Aim<sup>8</sup>)** for funding and service delivery decision-making
- Are **publicly accessible** for more accountability with respect to the use of collected data for the equitable improvement of care, services, and systems

In order to achieve long-term change, the opportunity is to form “a unified front. We need cross-stakeholder advocacy on common issues so no stakeholder can be dismissed alone.”

**“We need cross-stakeholder advocacy on common issues so no stakeholder can be dismissed alone.”**

8. Nundy S, Cooper LA, Mate KS. The quintuple aim for health care improvement: A new imperative to advance health equity. JAMA. 2022;327(6):521-522.  
<https://www.ihl.org/resources/publications/quintuple-aim-health-care-improvement-new-imperative-advance-health-equity>

# Proposed Next Steps

ACC members are deeply grateful to all participants who took invaluable time to offer their expertise. Many individual stories were generously shared during breakout sessions that clearly demonstrate the individual and community harms caused by systemic issues. Systemic solutions were equally shared. Despite the variety of identities, experiences, and sectors, there were many cross-cutting themes. Specific equity dynamics critical to improving earlier cancer diagnoses are being brought into the spotlight.

For next steps, internally, ACC will implement an ongoing cultural humility plan (see Appendix 2) for all existing members, which will also be offered to all new members as part of their onboarding to ACC.

Below are three possible next steps to be undertaken with interested community members and community groups in the lead with ACC providing robust support:

## Possible Next Steps

1

Revise All.Can Canada's Current State Infographic, Future State, and Recommendations to reflect what was learned at the Roundtable for use in co-designed knowledge mobilization efforts with relevant decision-makers, provider associations, and other stakeholders across Canada;

2

Create 'Equity Spotlights' that feature stories shared by Roundtable participants of harm within Canada's healthcare systems; unpack the systemic issues; and present solutions, also for use in co-designed knowledge mobilization efforts with relevant decision-makers, provider associations, and other stakeholders across Canada; and

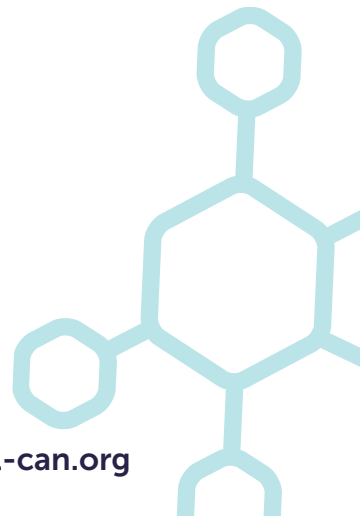
3

Feature the voices of interested family physicians and other primary care providers serving structurally underserved communities in discussing the challenges and opportunities to improving cancer diagnoses as part of ACC's planned communications strategy focussed on reaching primary care providers across Canada.

All participants are now being asked: **Which next steps, if any, do you consider to be a priority? Would you be interested in possibly participating in helping lead the work, with robust support from All.Can Canada?**

ACC's Steering Committee will listen to this feedback to finalize ACC's prioritization of next steps with interested structurally underserved community members and/or groups in the lead and will ensure the needed resources are dedicated to supporting these efforts.

Finally, participants interested in potentially becoming a new member of the Steering Committee, any of the Working Groups, or to be engaged in other ways (see Appendix 4 for ACC's current governance structure) are asked to email Taylor Tomko at [all.can@saveyourskin.ca](mailto:all.can@saveyourskin.ca). Deepest thanks to those who have already expressed interest. We look forward to connecting with you soon.



# Appendix 1: Participants

Cliff Ledwos	Access Alliance
Dr Gayathri Naganathan	University of Toronto
Dr Robin Urquhart	CanPath, Dalhousie University
Dr Evan Taylor	Queering Cancer
Dr Paula Holmes-Rodman	Independent Researcher, Caregiver, Cancer/Disabilities Advocate
Dr Aisha Lofters	University of Toronto, St. Michael's, Dalla Lana School of Public Health
Michelle Audoin	Patient Advocate and Collaborator
Cate Ahrens	Parkdale Queen West Community Health Centre
Bee Lee Soh	Anti-Poverty and Housing Advocate
Ken Noel	Executive Director, Walnut Foundation
Anthony Henry	President, Walnut Foundation
Vinesha Ramasamy	Lived Experience, Advocate
Cheryl Louzado	Canadian Partnership Against Cancer
Dr Xixi (Zhuxi) Gong	London Intercommunity Health Centre
Atiqa Mohammad	Movember
Tara Bond	Alberta Health Services' Cancer Strategic Clinical Network
Nila "Amy" Devi	Lived Experience, Advocate

Unable to attend in-person but able to provide answers to guiding questions in writing:

Tomilola John	Women's Health in Women's Hands
Tameika Shaw	TAIBU Community Health Centre

# Appendix 2: All.Can Canada Cultural Humility Plan

As an outcome from the All.Can Canada Optimizing Equitable Cancer Diagnoses in Canada Roundtable, members of the All.Can Canada Steering Committee and Working Groups will be undergoing cultural humility training to provide our members with the tools and praxis to more effectively and respectfully engage with structurally underserved populations. This training is voluntary, not mandatory, though we will be prioritizing ACC members who have received this training in our equity-oriented projects. Fees for this training will be covered by All.Can Canada. These trainings and resources will be offered to all new members of ACC on an ongoing basis. Our hope is that ACC members will bring learnings from these sessions not only to their work with us, but back to their teams, partners, and healthcare practices.

Our intentions for 2024 are to run three separate courses of training in group sessions through the programs Whiteness at Work, Trauma Informed Victim Advocacy (by Justice Clearinghouse), and Working Effectively with Indigenous Peoples (by Indigenous Corporate Training).

We have also been compiling an ongoing list of free online resources and book suggestions for our members. Any suggestions for this list, or comments on this programming, are always welcome.

# Appendix 3: Evaluation Results

Unfortunately, we were unable to get a robust response to the evaluation survey. Below is the response received.

**1. What is resonating most for you at the end of this event (i.e. a question, a new idea, a feeling)?**

It was a very energizing event. I felt honoured to be included in these very important discussions with such passionate and awesome people.

**2. What part of the event worked best for you? Why?**

Small group discussions were great. I also really liked how people were able to take the time to share their stories during the introductions. Kudos to the organizers and facilitators!

**3. What part of the event worked least for you? Why?**

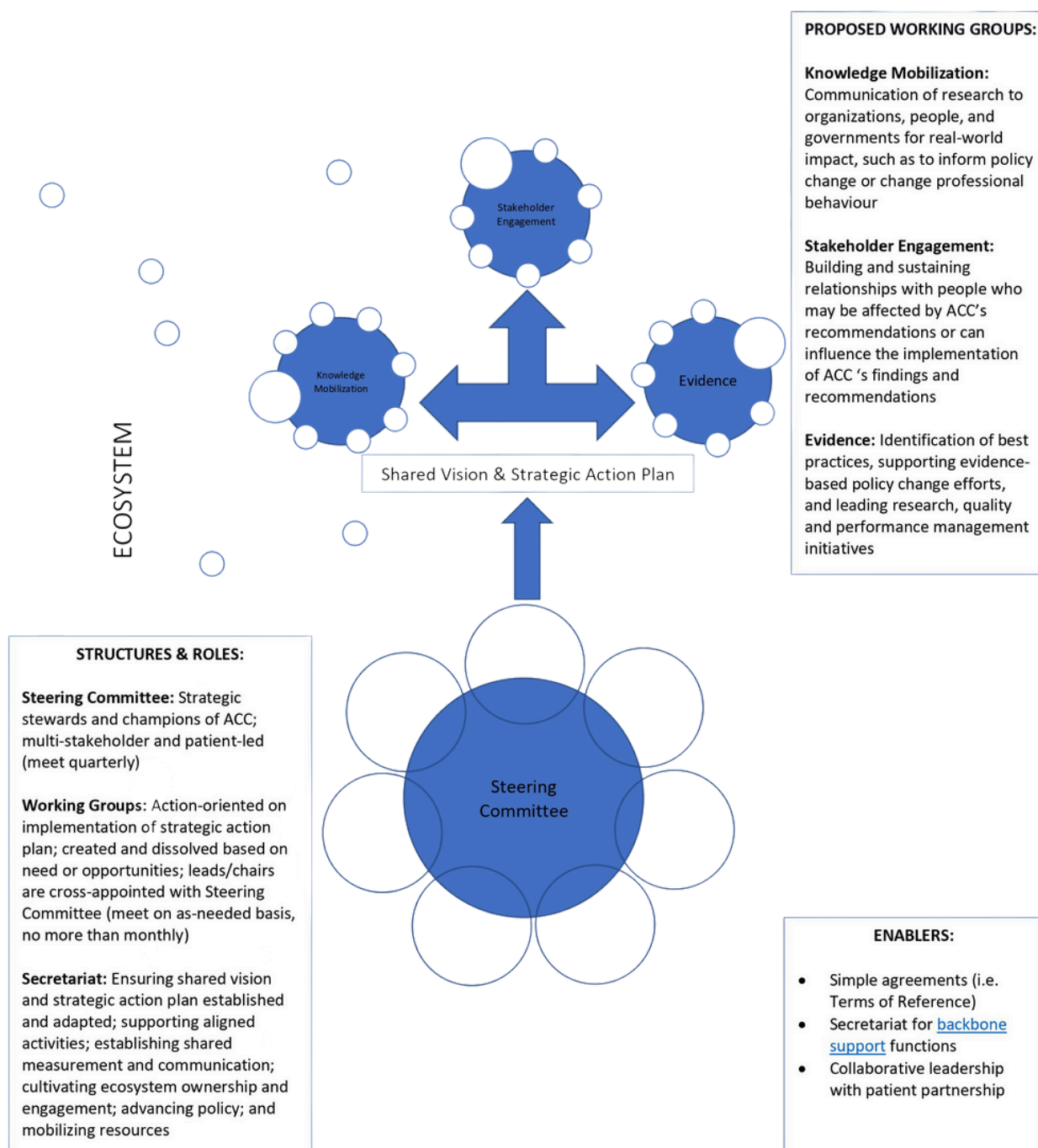
Umm... not sure. I really enjoyed the day. You did a great job organizing it.

**4. Please rate the various elements of the event:**

	Dissatisfied	Satisfied	Very Satisfied
Facilitation (plenary)			x
Facilitation (breakout)			x
Agenda			x
Venue			x
Catering			x
Pre-Meeting Communications			x
Pre-Meeting Material			x

**5. Any last comments?**

# Appendix 4: ACC Governance Structure



## Appendix 5: Sponsors

Thank you to all of the sponsors of the All.Can Canada Optimizing Equitable Diagnoses in Canada Roundtable. Your generous, unrestricted grants enabled this successful event.

Thank you to AstraZeneca for the in-kind support of the meeting venue.



Our warmest thanks to the remaining All.Can Canada Sponsors, who make our efforts throughout the year possible.

