



Strategy for Patient-Oriented Research



**Refreshing Canada's Strategy  
for Patient-Oriented Research**



# Refreshing Canada's Strategy for Patient- Oriented Research (SPOR)

## Community Engagement- Summary Reports

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## Context

Since [Canada's Strategy for Patient-Oriented Research \(SPOR\)](#) was first established in 2011, a lot has changed in our health systems and health research ecosystem. In 2023-24 CIHR initiated the SPOR Governance and Strategy Refresh, a widespread engagement process that invited feedback on what is working well and what might need to change. The goal was to ensure that SPOR remains aligned with evolving health care and health research realities, while accurately reflecting the priorities of patients, communities, researchers, partners, and health system decision makers.

The SPOR Refresh engagement process was extensive, involving a wide range of partners and community members from across Canada. Over six months, hundreds of participants contributed their perspectives through multiple engagement activities including partner-led engagement discussions, facilitated virtual engagement roundtables, and an online public engagement platform. A total of 347 people participated in the SPOR Refresh engagement process directly. This included 220 participants across 13 virtual roundtables and 127 individuals who engaged with the online platform, collectively submitting 470 contributions. In addition, 39 partner organizations provided 79 reports that summarized community-led conversations and engagement activities.

Through these activities, a wide range of voices including patients, people with lived experience, caregivers, First Nations, Inuit and Métis community partners, researchers, and policymakers were engaged. Engagement opportunities were promoted widely through CIHR networks, SPOR-funded entities, and national organizations, ensuring broad awareness and inclusion. This collaborative and open process laid the foundation for developing a refreshed strategy that reflects diverse voices and priorities across the country.

This document reflects what we heard through the engagement process to inform a [refresh of SPOR](#) across the following key themes: 1) [Strengths and Challenges for the Program Overall](#); 2) [Important Trends and Emerging Needs of the Future](#); 3) [Delivering on Truth and Reconciliation Commission \(TRC\) Calls to Action and Accelerating First Nations, Métis and Inuit Self-Determination in Health Research through SPOR](#); 4) [Strengthening Equity, Diversity, Inclusion, Anti-Racism, and Accessibility in Patient Engagement and Patient-Oriented Research](#); 5) [Building Capacity for Excellence in Patient-Oriented Research](#); 6) [Strengthening Collaboration with Policymakers and Health Services to Increase Research Impact](#); and 7) [Strengthening Governance for Canada's SPOR](#).

This community input will be used by the [SPOR Refresh Steering Committee](#) to inform recommendations to CIHR and other SPOR partners on future directions for Canada's Strategy for Patient-Oriented Research. A set of recommendations for a refreshed SPOR will be shared back with the community late fall 2024 or early winter 2025.

We are sharing this rich information with the community as a source of patient and community input that can be considered in other related research discussions.

## Theme 1: Strengths and Challenges for the SPOR Program Overall

This summary report includes data from four roundtables (Roundtable 1, 2, 3, and 8), 55 partner engagement reports and 47 interactions (34 comments and 95 votes) from the online public engagement platform.

The roundtables were attended by researchers, PWLEs, Indigenous scholars, policy makers, decision makers, healthcare professionals, funders and representatives from health authorities and health charities. Partners who contributed input on theme 1 include leaders from the community of SPOR-funded Entities (SFEs), SPOR SUPPORT Unit Council, Maritime SUPPORT Unit, Yukon SUPPORT Unit, Manitoba SUPPORT Unit, Saskatchewan SUPPORT Unit, Alberta SUPPORT Unit, Ontario SUPPORT Unit, Québec SUPPORT Unit, Newfoundland and Labrador SUPPORT Unit, British Columbia SUPPORT Unit, Northwest Territories SUPPORT Unit, CAN-SOLVE CKD Network, CHILD-BRIGHT Network, Primary Care Network, Chronic Pain Network, Health Data Research Network, SPOR Evidence Alliance, Passerelle, CIHR- Institute of Health Services and Policy Research (IHSPR), CIHR- Institute of Cancer Research (ICR), Health Charities Coalition of Canada, University of Toronto's Office of the Vice-President, Research and Innovation, Patient Advisors Network and one Canadian Citizen.

### Strengths

1. Mechanisms and infrastructure for patient engagement and co-creation of research.

*"SPOR has been a gamechanger in health research in Canada, it might be still early to understand the full impact at the national, provincial and local levels, but the premise of involving patients as part of the research process is quite innovative and future oriented."*

*"Through SPOR, silos of research and researchers have been broken to create a more collaborative and integrative structure. The SUPPORT Units have brought researchers together and added value to the connectivity. The networking through the SUPPORT Units ha[s] been invaluable to bringing researchers together to outside their institutions and organizations for concrete efforts to network and discuss cross-cutting approaches to patient-oriented and partnered research."*

- SPOR has made impressive progress in prioritizing, legitimizing, and valuing patient and PWLE engagement and research co-creation. This has led to pragmatic, real-world research that focuses on patient priorities and patient-related outcomes.
- SPOR increased the awareness and appreciation of patient-oriented research resulting in a culture shift within the research ecosystem.
- SPOR also facilitated partnerships and connections between academics, patients, and the healthcare community. As such, investigators are more likely to consider issues from different perspectives (i.e., patients, clinicians, broader community etc.) and some policy makers have an appetite for POR which can enable better integration of research and accelerated change.
- SPOR facilitated the development of collaborative, multi-disciplinary environments that includes researchers, policymakers, practitioners, patient partners, and the public. This diversity of research teams brings more perspectives to the research table and ultimately more deliberate research and expansive results.

2. SPOR supports capacity building in patient-oriented research.
  - Researchers and investigators have tools, tips, training modules and mentorship opportunities to support the growth, range, and rigor of patient-oriented research.
  - Participants reflected explicitly on the great progress in capacity building efforts within Indigenous communities. CANSOLVE-CKD Network and Northern SUPPORT Units were specifically cited as entities that have been ensuring Indigenous co-leadership, meaningful Indigenous patient engagement, storytelling and learning pathways to support cultural safety, anti-Indigenous racism, and Indigenous research methodologies.
  - The capacity building infrastructure that SPOR has promoted allows for growth of patient-oriented research and improves expertise over time. It has also allowed for research to “feel less remote and more understandable” for patient and PWLE partners.
3. SPOR Funded Entities Offer Local Expertise, Local Connections and POR Methodological Support.
  - SPOR Funded Entities play an important role of providing POR coordination, POR methodological support, resource sharing and training opportunities. This has been helpful for smaller organizations, organizations with limited capacity and organizations with smaller budgets like health charities.
  - Most SPOR SUPPORT Units have strong relationships with provincial/territorial governments and policy makers which can help link provincial/territorial needs for evidence with patient and community priorities. SPOR SUPPORT Units offer local expertise and are more likely to be in tune with their communities’ needs and priorities.

## Challenges

1. Inadequate evaluation of the impact of POR
  - It has been very challenging to attribute changes in health services or health outcomes to SPOR as the changes tend to be complex with many contributing factors.
  - Further, participants highlighted the lack of incentives for researchers to conduct “ethical, high-quality patient engagement” based on an equal partnership between patients and researchers. Therefore, respondents recommended having a standardized approach for evaluating the effectiveness of patient engagement such as GRIPP2, a reporting checklist for patient and public involvement in health and social care research.
  - More robust and harmonized evaluation strategies are needed to truly measure impact of SPOR. For example, photovoice was recommended for capturing the experiences of patients and people with lived experience “who might be intimidated by traditional interviews, surveys and focus groups.”
2. Time constraints limit adequate relationship building and capacity building.
  - Many SPOR funding opportunities are project based which inherently comes with time constraints. As such, grantees reported limited time to train project coordinators and to engage with community members. Simultaneously, many participants reported that there wasn’t enough time allocated to recruit and build meaningful relationships with patients and community members.
  - Some participants suggested adapting SPOR’s funding model to fund relationship building, particularly with underrepresented communities.

3. Guidance on recognition, reciprocity, and compensation of patients, and community members is lacking.
  - Participants acknowledged that compensation and reciprocity are well established as best practice, however, they stated that more guidance on mechanisms to compensate patient partners (financially and non financially) were needed. For example, guidance on compensating children under 10-years of age are extremely limited. Similarly, non-monetary recognition of patient partners is often overlooked; ensuring patient and community partners understand the impact they've had on research can be very valuable.
  - Compensating patient partners can bring on hardships for certain patient partners. For example, if they are receiving social assistance, financial compensation for their role on research projects, although small, can affect these services. This can greatly impact who can partner with researchers limiting these opportunities to only those that can afford it. Participants suggested that SPOR can play a role in brokering conversations with CRA to make exceptions for income reporting and/or offer other flexible payment methods.
  - Compensating PWLEs can also be challenging for certain organizations including health charities who operate with lower financial resources and often rely on fundraising to support their work.
  - Financial costs were perceived as a barrier to engaging patients from diverse socioeconomic backgrounds. One participant suggested that “offering income tax deductions promotes equity by acknowledging the financial sacrifices that patient partners may incur while participating in research activities.”
4. Engaging underrepresented communities remains a challenge in SPOR\*

*“I am very eager to use my learning in patient partner research but fear it is withering without an opportunity.”*

  - Currently, patient partners are predominantly people who have the time and resources to be involved in research and have an awareness or connection to existing POR opportunities. Participants noted a trend where researchers repeatedly engage the same group of patient partners who do not necessarily represent the typical patient experience, or less privileged, more excluded voices. More intentional efforts are needed to increase awareness of POR and engage underrepresented communities. For example, SPOR can connect with organizations that have pools of PWLEs and patient partners like health charities and Patient Advisory Networks and utilize their existing newsletters to improve awareness and outreach efforts.
  - Participants noted that it has been particularly challenging to engage Indigenous community members, African, Caribbean- and Black (ACB) communities, newcomers, children/youth, folks that reside in rural communities, and those with chronic pain, disabilities, mental health or substance use disorders. Participants attributed this to a lack of awareness of SPOR as well as a lack of trust and/or perception of relevance for underrepresented communities.
  - Participants explained that the required 1:1 funding matching may disadvantage certain community groups, including underrepresented groups and rural communities and smaller research centers/non-profit organizations.

- Participants explained healthcare providers and those working within the health system at all levels are another “underrepresented community” within SPOR partnerships, particularly those working in rural/remote settings or within smaller organizations. They suggested more explicit efforts to engage health service providers to improve coordination of efforts and enhance research uptake.  
\*More details on equity, diversity, inclusion, accessibility, and anti-racism can be found in [Theme 4](#) and Strengthening Indigenous self-determination in health research in [Theme 3](#)
5. SPOR evidence is not “implementation ready” and/or not relevant to policy makers/decision makers\*.
- Participants acknowledged that much of the SPOR Funded Entities’ work has focused on patient engagement and that more concerted and focused efforts are needed to move into healthcare transformation.
  - Further, there is still a gap between research and implementation. Participants attributed this to research reports that are not relevant to policy makers due to length, language, or misaligned priorities with health system priorities, other change efforts in the health system (quality improvement) and health system drivers.
  - Participants also highlighted that awareness of SPOR was not consistent amongst policy makers and suggested building POR into policy and service planning and championing POR at health leadership tables like the Quality forum and Canadian College of Health Leaders.  
\*More details on collaborating with policy and decision makers can be found in [Theme 6](#)
6. Simultaneously, reduced receptor capacity limits SPOR from implementing change. Given the state of the healthcare system, participants explained that SPOR cannot “push” for something when the systems are not ready. Research results may not be taken up by the healthcare systems or clinicians if:
- Results are not modified to fit the circumstances within healthcare.
  - Healthcare organizations and systems do not have processes, policies, or incentives to adapt or apply the research.
  - Healthcare practitioners’ time, resources, and capacity are limited, and their reality doesn’t align with research.
7. POR capacity building efforts are not inclusive of all needs\*
- While generally viewed as a strength of the SPOR program, SPOR’s capacity building efforts were critiqued for being too narrow with some participants suggesting the need for patient and PWLE-specific training and capacity development opportunities. Further, participants suggested that many capacity building materials exist behind a paywall and are not accessible to PWLEs and patient partners.
- \*More details on SPOR’s capacity building efforts can be found in [Theme 5](#).
8. Unclear role delineation and expectations for patient partners
- While having patient and PWLE partners in research was viewed as a strength, some participants noted that more efforts to clarify roles and responsibilities around the table was needed.



- Simultaneously, patient partners reported that they would like to have a larger role in the guidance and governance of SPOR and within health research.

9. Research priorities not driven by patient and PWLE partners.

While SPOR has made great strides in patient engagement, some participants noted that research priorities are still set by investigators and institutions. More efforts are needed to ensure research priorities are driven by patients and communities. For example, participants suggested the following:

- SPOR can play a role in synthesising community priorities, patient-reported experience measures (PREMs), patient-reported outcome measures (PROMS) and establishing a common research agenda.
- SPOR can design funding opportunities that are led by patient partners who can recruit academics to support their work. However, participants commented on the institutional barriers for patient engagement as research activities need to be connected to an academic institution.
- More involvement of patient, and communities in decisions about data, and in the analyses and interpretation of data.
- Early involvement of patient and PWLE partners in the research process, including youth and young adults, to ensure that research priorities are relevant and ultimately beneficial to the community.

10. Privacy Legislation, Jurisdictional Issues and Complex Relationships Hinder Data Access\*, Management, Linking and Sharing

- Participants stressed that national variation in privacy laws and outdated approaches or interpretation of privacy, delays or complicates data sharing between regions, governments, researchers, and healthcare organizations. Simultaneously, participants suggested that “data holding organizations that have a culture of custodianship instead of a stewardship” which further complicates data management.
- Participants cited a lack of diversity in health data and explained that work surrounding the collection of race/ethnicity-based data from health systems has been siloed and stagnant and as such, has not adequately yielded effective culturally safe, anti-racist health interventions.
- Participants suggested that funding for data infrastructure has been insufficient and advocated for more governmental support to co-establish and update robust data collection, management and sharing processes and policies with PWLEs and researchers.

\*Participants noted that challenges pertaining to data access were acute in Northern regions of the country due to “a notable deficits in the expertise needed to facilitate access, particularly in comprehending the principles of OCAP.”

11. Siloed SPOR efforts and Inadequate Governance Structures\*

Participants explained that governance has been a real challenge for SPOR. They suggested that a stronger governance structure can promote better collaboration and connection between

SPOR funded entities and reduce duplication of efforts. Additionally, they suggested increasing requirements for reporting and evaluating meaningful engagement of patient partners.

\*More details on Strengthening SPOR's Governance structures can be found in [Theme 7](#)

12. Some research disciplines still don't prioritize/are underutilizing POR.

While participants acknowledged that there has been a culture shift that emphasizes the pervasiveness of POR in the research community, some research disciplines, like basic sciences are still underutilizing POR.

## Theme 2: Important Trends and Emerging Needs of the Future

This summary report includes data from four roundtables (Roundtable 1, 2, 3, and 8), 36 partner engagement reports, and 39 interactions (41 comments and 84 votes) from the online public engagement platform.

The roundtables were attended by researchers, PWLEs, Indigenous scholars, policy makers, decision makers, healthcare professionals, funders and representatives from health authorities and health charities. The partners who contributed input on theme 2 include SPOR SUPPORT Unit Council, Maritime SUPPORT Unit, Yukon SUPPORT Unit, Manitoba SUPPORT Unit, Saskatchewan SUPPORT Unit, Alberta SUPPORT Unit, Ontario SUPPORT Unit, Québec SUPPORT Unit, Newfoundland and Labrador SUPPORT Unit, British Columbia SUPPORT Unit, CAN-SOLVE CKD Network, CHILD-BRIGHT Network, Primary Care Network, Chronic Pain Network, Health Data Research Network, SPOR Evidence Alliance, Passerelle, CIHR- Institute of Health Services and Policy Research (IHSPR), CIHR- Institute of Nutrition, Metabolism and Diabetes's (INMD), Health Charities Coalition of Canada, University of Toronto's Office of the Vice-President, Research and Innovation, and Centre of Excellence in Youth Mental Health and one Patient Partner.

Participants acknowledged that they identified many emerging trends health research could focus on, and that it was not possible for SPOR to adequately address them all. Instead, they suggested that SPOR should hone in on one to two trends using the Delphi method to ensure focus and effectiveness of efforts.

### Changes in How Healthcare is Being Delivered

- **Health Human Resources Crisis**

*“Health human resources are a huge problem, there is a shortage but there are also challenges with training.”*

Participants explained that demands\* on the healthcare system have been mounting and will continue to increase in the coming years. This will contribute to healthcare provider burnout, staff shortages and turnover, impacting the quality of health services. As such, clinicians will have little to no time to dedicate to research and meaningful engagement, limiting opportunities for patient partners. Participants explained that training will be key to improving the performance of our healthcare systems and to developing an alternative workforce (i.e. peer support) that will be critical to delivering more quality, equitable, care. Finally, some participants suggested that the Canadian health system was inevitably going to fall apart and warned that SPOR needed to be ready to pivot to deal with it when it happens.

\* While demands on the healthcare system and health care providers are universal, participants noted that they are more pronounced and more acute in northern regions in the country.

- **Technology**

Participants commented on the strengths and challenges of technological advancements. They explained that some show potential promise in health research and practice if they're “designed well” and are “easy to navigate.”

- **Artificial Intelligence (AI)**

Participants reflected on the proliferation of AI within research and healthcare and highlighted that it can be an important diagnostic tool and can help support decision making. AI can conduct systematic reviews, analyze large amounts of data, and translate research into plain language in a cost effective and efficient way. However, despite its potential, many participants voiced ethical dilemmas that need to be considered. For example, AI can reproduce stereotypes, biases and assumptions that exist in our healthcare system that can translate into inappropriate care and worsen outcomes for populations that already experience inequity. Combining large amounts of data may lead to care that is largely based on an algorithm and may not provide the individualized care our current system delivers. Participants also doubted that AI can replace a “human touch”, empathy and nuances of social determinants of health.

- **Virtual Care**

*“We have to accept that virtual health is here, and we have a good opportunity to ensure... ‘the patient is not meeting the model, the model is meeting the patient.’”*

Participants acknowledged that virtual care has been a growing trend since the pandemic. Many patients are interested in receiving healthcare virtually as it is efficient, cost-effective, and convenient. Participants explained that virtual care can also address some of the challenges in healthcare including the health human resource crisis and gaps in services as well as providing more choice, control, and flexibility for patients.

Participants stressed that technological advancements including AI and virtual care are often exclusionary to communities that have limited infrastructure, and to those that cannot afford fast speed internet and technological devices such as laptops and smart phones. Therefore, suggested that equity needs to be considered to ensure access across the country.

Finally, to ensure technology such as AI and virtual care are being used to improve the delivery of health services and quality of life, participants suggested the need for more patient-oriented research to assess their risks and impact, and standards to guide their development across Canada. They also advocated for more capacity building and training efforts that would allow the healthcare system to take advantage of this new technology.

- **Health Data**

- Participants described an increase in the amount of data generated through health applications, medical devices, electronic medical records, and social media. Much of this data is generated and held within the private sector, however, there is a lack of legislation that governs their role within healthcare. They suggested that SPOR can play an important role in centralizing and linking this data, sharing it with Canadian communities and applying it to support policy development. Further, the concepts of data access, data control, privacy, and the impact of these data in medicine should be explored.
- Participants explained that requests to access and control personal health information were going to increase. They suggested that SPOR can take a role in

better understanding what kinds of supports patients need to understand their health information.

- Data on race/ethnicity from health systems have been collected to support the development of culturally safe, anti-racist services. However, this work is siloed and stagnant. As such, SPOR can support the centralization and integration of this data and promote collaboration across the country.
- Similarly, genomic data is also being collected and compiled internationally. However, despite being at a competitive advantage due to Canadian diversity, Canada does not have large integrated genomic biobanks that would help accelerate diagnosis, treatment, and screening.
- Participants advocated for more funding and support for data infrastructure, the development of interoperable data systems and cross-jurisdictional access of Patient Reported Experience Measures (PREMs) and Patient Reported Outcome Measures (PROMs). They also suggested updating policies and processes related to privacy, data collection, data management and data sharing while advocating for more tools, resources and training for researchers that include cybersecurity.

- **Aging Healthcare Infrastructure**

*“A lot of aging infrastructure, traditional hospital settings can be older, and we are regularly adding blocks onto them. But is this the right model for the health system that we need in 5-10 years from now? How we’re setting up the health system to meet future needs.”*

Participants reflected on the aging infrastructure of traditional hospital settings across the country and suggested the need for updates that can mitigate overcrowding, support energy efficiency, and align with community needs and priorities.

## Changes in Patient and Community Needs

### Community Needs are not Met by the Current Healthcare System

*“Healthcare has fundamentally changed over the years. The needs and expectations of patients and clinicians are no longer being met.”*

Participants explained that the current healthcare system is not set up to support overall wellness nor is it aligning with patient and community needs. Health professionals are attempting to do more with less and are struggling to do their jobs while the system fails to meet patients’ needs leading to frustration on both ends. Further, primary care is currently the main access point for patients into the healthcare system. However, as it is a clinical discipline, issues tied to fundamental needs like housing, food and water are not adequately addressed. This is contributing to scope creep and high turnover within primary care providers, exacerbating shortages in a system that requires patients to go through this sector to access specialized healthcare services. As such, participants advocated for a radically reimagined healthcare model that utilizes a multi-disciplinary, team-based approach to holistic patient-centered care that addresses a broad range of health and social needs.

- **Changing Demographics**

Participants suggested that SPOR should focus future research funding on engaging diverse and underrepresented communities that reflect Canada's changing demographics. They stressed that these engagements should include youth, the aging population, and new immigrants to assess how the healthcare system can prepare and adapt to meet their unique needs. Further, participants reflected that knowledge and principles of Equity, Diversity, Inclusion, Accessibility, and Anti-Racism (EDIAA) haven't adequately been integrated within the healthcare system.

- **Social Determinants of Health**

*"SPOR is not paying enough attention to social determinants of health, it's more so participating at the clinical level, i.e. how their experience is going through the health system, however we know health overall is more impacted by social determinants of health rather than interaction with the health system on its own."*

Participants recommended having a broader view of the trends impacting health to inform research priorities. For example, participants explained that SPOR hasn't adequately explored the impacts and root causes of inequities and social determinants of health, nor has it emphasized upstream solutions to health inequities. Participants also noted that SPOR hasn't adequately engaged harder to reach populations like precariously housed and homeless communities and people who use substances. Despite the housing crises and substance use crises across the country, not much attention has been given to support the longer-term goals or the root causes of these crises and their impacts on health.

- **Focus on Prevention and Personalized Medicine**

Participants stressed that more effort and attention should be paid to optimizing prevention strategies that preclude people from needing the healthcare system and becoming patients. When they do become patients, an emerging trend involves tailoring their treatment to their individual characteristics, known as personalized medicine. Participants explained that patients and PWLE can play an important role supporting personalized medicine by sharing their health data and experience.

- **Climate Change**

*"It's important to understand how climate change is affecting different populations in different regions and not ignore this issue if it's not impacting everyone the same way."*

Participants reflected that climate change has impacted food supply, water, housing, overall cost of living, and vector-borne diseases. They acknowledged that climate change may have a bigger impact on Indigenous and rural communities and communities with socio-economic inequality. As such, they suggested that more research is needed to investigate how climate change is affecting health and what mitigation strategies need to be put in place to cope with these changes.

- **Misinformation**

*"[I think] misinformation is the biggest health threat to [the] health of Canadians, more than climate change."*

Participants highlighted that misinformation and mistrust in healthcare was growing in Canada. They explained that this was in part due to the politicization of science and social media.

Participants suggested that SPOR can help build public trust through transparency and dedicated efforts to manage misinformation.

## Changes to Policy and Practice

- **Urgency in Implementing and Evaluating New Ideas in Healthcare**
  - Participants stressed that healthcare systems cannot wait for research cycles to implement changes. As such they suggested funding short-term initiatives and rapid research approaches to support the urgent need for evidence.
  - Participants reflected on changes to healthcare financing, e.g. private healthcare and suggested that SPOR can comment on such policies and practices while studying the impacts of these changes on healthcare and patient outcomes.
  
- **Bridging the Evidence-Practice Gap**

Participants highlighted that more work needs to be done to understand the requirements to consistently enable successful bridging of the research to practice gap. Some of the strategies that were suggested to achieve this include:

  - Expanding partnership in patient-oriented research beyond patients to include others like policy makers, decision makers, healthcare providers, provincial and regional health authorities and offering embedded training opportunities.
  - Aligning SPOR patient engagement opportunities with those in the health system to better involve patients in strategic planning for health service delivery.
  - Increase focus on Learning Health Systems to support continuous learning and improvement by embedding research into the healthcare delivery process. These Learning Health Systems need to be co-designed in a multi-disciplinary, multi-jurisdictional way with patients and families.
  
- **Indigenous Community Engagement and Research**

Participants explained that given that complexity of Indigenous health research, meaningful community engagement has not been consistent or adequate within SPOR. While some researchers do good work, others still tokenize Indigenous health researchers and community partners. Participants stressed that research priorities need to come from Indigenous communities and encompass land-based healing, traditional practices, and culturally safe care. Further, SPOR needs to advocate for Indigenous data sovereignty and ensure the provision of Indigenous-specific research opportunities as well as budget adequate time within these opportunities to build relationships. Finally, cultural safety training opportunities need to be mandated for researchers who want to partner with Indigenous communities.
  
- **Election Cycles and Changes in Government**

Participants reflected on the upcoming Federal election in Canada and acknowledged the chance of changing leadership and priorities. Trust in research varies between political parties and as such, budgets dedicated to research and healthcare may be impacted depending on which political party is in control. Participants suggested that SPOR can and should build and strengthen their relationship with all political parties and play an advocacy role where they raise awareness of the issues.

## **Theme 3: Delivering on TRC’s Calls to Action and Accelerating First Nations, Inuit, and Métis (Indigenous) Self-Determination in Health Research through SPOR**

This summary report includes data from two roundtables (Roundtable 12 and 13), 21 partner engagement reports, and 9 interactions (7 comments and four votes) from the online public engagement platform.

The roundtables were attended by First Nations, Inuit and Métis scholars, researchers, community members, healthcare professionals, youth, and representatives from health authorities. Partners who contributed input on theme 3 include leaders from the community of SPOR-funded Entities (SFEs), SPOR SUPPORT Unit Council, Indigenous CoP, Hotìì ts'eeda (NWT SUPPORT Unit), Maritime SUPPORT Unit, Yukon SUPPORT Unit, Manitoba SUPPORT Unit, Saskatchewan SUPPORT Unit, Alberta SUPPORT Unit, Ontario SUPPORT Unit, Québec SUPPORT Unit, British Columbia SUPPORT Unit, CAN-SOLVE CKD Network, CHILD-BRIGHT Network, Health Data Research Network and University of Toronto’s Office of the Vice-President, Research and Innovation.

### **Barriers around Research Methodologies, Protocols and Support.**

- **Rigid Grant Requirements, Lack of Transparency and Administrative Barriers**
  - Participants explained that current grant structures and timelines make recruitment, and training of staff difficult. Grant timelines don’t account for the time needed to hire and train staff.
  - Project-based funding makes retention challenging as community organizations can only keep staff as long as the project is funded. Further, with project-based funding models, researchers can only put forward projects with one community working on one research topic with clear boundaries. While participants agreed that project-based funding can be useful, the scope of such projects can be small. Participants explained that community priorities are usually aligned with research that is based around system-wide changes. For example, communities have shown interest in research that supports the development of training around cultural safety and responsiveness and research methodology that address systemic issues. In the current funding model, researchers are driven to apply with narrow research questions “sneak” broader system-wide explorations into a project.
  - Participants reflected on the differences in recognition and opportunities for publication within Indigenous health research compared to other research disciplines. Academics working within Indigenous health research don’t get the same standing as their counterparts within their institutions as there are fewer opportunities to publish. As such, some Indigenous communities have difficulty recruiting academics to support Indigenous research.
  - Rigid grant requirements do not account for the dual role some Indigenous researchers/community members need to take nor do they account for the realities of some Indigenous communities (i.e., need for more flexible funding).
  - In some instances, grant funding that was held by a research institution was not allocated to the community as originally proposed, and decisions about allocation of



funding lacked transparency. Participants proposed sharing the funding equitably between researchers and community organizations/partners.

○ **Challenges related to Peer Review**

*"I think a component of a lack of involvement in peer review is: what is the incentive to do it? I don't think that's clear to most folk or properly incentivized."*

*"I believe in reciprocity, but I have so many demands on my time because of the lack of Indigenous health researchers. If I have to choose, do I sit on CIHR peer review or do I answer the call from tribal council for what they need to do. I will always pick community; my reciprocity is there."*

Participants described several issues within the existing peer review process at CIHR including:

- Blind/closed peer review processes are colonial and do not align with Indigenous methodologies or ways of knowing. Further, blind processes tend to favour certain researchers who repeatedly receive funding and are often the people who abuse and misuse patient involvement. One participant suggested that they would be much more interested in participating in peer review if it was an open, iterative process.
- Incentives to participate in peer review are inadequate or do not align with the priorities of Indigenous scholars and community members. Further, due to the lack of Indigenous health researchers, many scholars have competing priorities for their time and the peer review process, as it stands, does not take precedence.
- Indigenous measures of success are not embedded in the peer review process, instead, current indicators are largely quantitative.
- Existing peer reviewers are not adequately trained to review Indigenous research proposals. Reviewers have historically suggested harmful recommendations that fall outside the scope of the proposed project. For example, a peer reviewer suggested dissolving the Federation of Sovereign Indigenous Nations in Saskatchewan.

○ **Continuation of Tokenism**

*"They [researchers] use Elders because they need an Elder and ask you to be on the research committee, but they don't ever get back to you afterwards, this is inappropriate."*

*"Patient Partners aren't true partners if we don't have all the details we require, they gather information about us and don't share it, this is not ethical. They need to be more responsible and respectful to us when they are doing research on us, about us, and for us".*

- Participants stressed that tokenistic attitudes were pervasive in the research ecosystem. Some researchers engage Elders and community members at the time of grant proposals, but once funding is granted or the data gathering process is complete, they do not follow up with the community, update them on the findings or outcomes. Participants explained that this was abusive, eroded trust and was harmful to Indigenous communities.
- Participants reflected that tokenism can be amplified when evaluation and reporting guidelines define success by the number of community members engaged or the

number of people from the community who participate in activities. Instead, participant suggested asking researchers to report on “how they are working in the community and for the community in a meaningful and inclusive way.”

- Participants also reflected on the lack of First Nations, Inuit, and Métis diversity in some SPOR-funded entities and advocated for more Indigenous representation and leadership within SPOR.

○ **Inadequate Follow-up with Community on Research Findings**

*“People have been researching land and medicine, but it is not coming to me... We can learn about our medicines and what can heal my children in my backyard around the lake, collect this knowledge and create our own database here in my community so that it is not stuck over there in the university that I don’t even know how to access it.”*

*“The information that we’ve researched is not alive or have a spirit, right now in the way it is.”*

The way researchers are disseminating research findings do not align with Indigenous ways of knowing and being. Participants indicated that ample energy and funding has gone into research, but the knowledge doesn’t go anywhere or get used; it may get published but beyond that, it has no life in the community. Findings from the research are not communicated to Indigenous community members and as such, they are unable to apply this new knowledge. Research must be used meaningfully to inform actions and interventions that address community priorities and needs.

Further, participants reflected that current knowledge translation efforts are outdated and suggested modernizing them while staying true to Indigenous roots to ensure information reaches the community. Participants suggested the possibility of training communities to be involved in research result dissemination. In addition, using methods that are appropriate for different groups, including social media platforms like Instagram, and TikTok for the younger generations and opting for storytelling for Elders and community members.

○ **Research Priorities are Still Driven by Researchers and Academic Institutions**

*“Research is driven by institutions or a student that wants to learn more... Who is prioritizing research? It certainly is not me at the grassroots level, I don’t get that information.”*

*“We feel empowered and connected because we see what is meaningful to us in action. This is the true meaning of reconciliation.”*

- Participants explained that research priorities are still driven by researchers and academic institutions and largely motivated by advancing their careers and quenching their curiosity. As such, research doesn’t align with Indigenous communities’ priorities and interests.
- Participants stressed that research was lacking in rural areas, concentrated in urban areas, and typically focused on diabetes, and HIV/AIDS.
- Some of the research priorities identified by participants included investigating:
  - Higher rates of rheumatoid arthritis, lupus, and autoimmune disorders in the north
  - Impact of mercury mines in northern British Columbia
  - Chronic pain and pain management

- Mental health and substance use
- **Compensation and Reciprocity**
  - Participants noted the existing disparity in compensation between patient partners and researchers and suggested equitable parity regarding patient-partner remuneration.
  - After \$500, compensation for patient participation in research is currently classified as taxable income, this can be a barrier to some community members, specifically those on parental leave, retired, receiving disability and/or social assistance. Therefore, participation in research for some community members becomes cost prohibitive.
  - Participants advocated for the development of equitable and transparent compensation structures for all partners in the research process.
- **Pan-Indigenous Approaches**

Participants underscored the importance of taking a distinction-based approach advocating for the removal of the “Indigenous” umbrella. They stressed that research is only for the people in the studied region and should not be generalized to other communities.
- **Delays in Research Projects caused by Ethics Board Approvals**

Participants noted that Ethics Board approvals often lead to delays in research projects. Researchers are unable to start relationship building or access funding until they get ethics approval.

## Future Directions

### 1. Invest in Education, Training and Capacity Building

*“In the territories, there is FN 101 course that researchers are asked to take. It’s a very good idea because it gives researchers who aren’t familiar an idea on the context in the territories, how to build relationships and how to go about it.”*

*“Some are still tied into the idea that academic process is still the most imp [sic] thing. The best process for engagement is to get into community but academics still want to sit in their office for 3 weeks developing a communication strategy.”*

- Participants suggested that CIHR can take on a role of collating training modules that were developed in partnership with Indigenous community members, Indigenous researchers, Elders and Knowledge Keepers and design a national Indigenous Research and Engagement Training Package. This package should include training on, OCAP, relationship building, respect, reciprocity, Indigenous research methodologies, sovereignty, budget considerations, power imbalance, two-eyed seeing, hierarchy of expertise/evidence/methodology and best practices for engaging Indigenous community members. Participants stressed that CIHR should take a distinction-based approach that represents the vast array of Indigenous cultures, geographic diversity and lived experience to this synthesis. This package can be disseminated to SPOR-Funded entities that can adapt it to their local context to ensure respectful and culturally safe engagement approaches and use of data, without having to reinvent the wheel.

- Participants also suggested mandating the training package to the following:
  - Any applicants applying for SPOR funding that involves Indigenous communities.
  - Those that currently hold SPOR funding including SPOR-Funded Entities
  - Those working within the healthcare, education, and legal systems before they start working with Indigenous communities.
  - Students at the university level regardless of the degree they are pursuing.
  - People at every level of the research ecosystem including the adjudication level to ensure a good understanding of Indigenous philosophy and methodologies ultimately leading to fair, equitable funding allocation and research practice.
- Participants proposed using a train the trainer model to build better capacity around anti-racism and cultural safety training, protocols, and methodologies.
- While participants acknowledged the value, flexibility, and benefits of online trainings, they stressed that in person conversations, story telling, and field trips are far more influential and impactful. One participant suggested a mixed approach where folks attend an online training session followed by a separate debrief session that has an in-person component with conversational methods.
- While participants generally agreed that non-Indigenous scholars should be trained up in Indigenous epistemologies, culturally safe engagement, and Indigenous ways of knowing, they cautioned that it must be done with the spirit and intent of proper allyship, understanding of self-positionality, and appropriate roles in Indigenous-engaged research. These trainings should help researchers understand their role within Indigenous communities, what would be appropriate and the limits of their scope.
- In addition to cultural safety training for non-Indigenous people, participants highlighted the importance of providing training on research processes to Indigenous community members. This would help build their capacity and orient them with the processes and timelines.
- Participants suggested investments and training into data sovereignty and establishing data agreements with Indigenous communities.

**2. Ensure the provision of longer-term, sustainable inclusive, transparent, flexible, and equitable funding models.**

*“With Indigenous ways of knowing, it takes seven years of teaching to be prepared for anything. Do we have capacity to fund projects for seven years?”*

- Participants proposed longer term investments suggesting at least seven years per project to align with Indigenous ways of knowing. They explained that current funding timelines are too tight and don’t allow for relationships building or full exploration of issues that are important to the community.
- Participants advocated for more sustainable, flexible funding for Indigenous health research as existing funding models are not flexible and do not have carryover funds that allow the community to continue the good work they are doing, without interruption.

- Participants suggested decolonizing the funding process by developing a unique program for Indigenous applicants that includes an iterative review approach and offers mentorship to those that do not receive funding. They also advocated for more accessible language and supports during applications to research grants and reporting.
- Given the small size of the Indigenous health research community, funding rules should be adapted to support project participants who wear multiple hats – for example as researchers, community members and also playing a leadership role in a network.

### **3. Ensure Funding is Coupled with Capacity Building Efforts**

*“We give communities funding without capacity building; funding needs to be coupled with capacity building otherwise it won’t work.”*

- Participants noted that some funding models currently do not address the underlying issue of limited capacity that exists in some Indigenous communities. They stressed that any future funding that involves Indigenous community partners should be coupled with capacity building funding that gives community full autonomy to lead and own research, data collection and sharing and knowledge mobilization.
- Participants also noted a decrease in support for Indigenous health graduate students and new investigators and suggested that robust funding and support mechanisms are needed to continue to build capacity.
- Participants suggested that SPOR can support the drafting and development of Indigenous Ethics Protocols with interested Indigenous communities. This can promote meaningful and respectful boundaries.

### **4. Ensure Funded Research is Driven by Indigenous Community Priorities**

*“We need more research led by grassroots people and people who want to know more about Indigenous knowledge. It is not a priority to academia or folks in university... We need to gather the stories, language, song and all the pieces of “me” that are missing.”*

- Participants explained that there is still a mismatch in the research that is being funded and the research that matters most to Indigenous communities. For example, many community members are interested in the knowledge that was lost due to colonization including Indigenous knowledge, ceremonial knowledge, and traditional knowledge. Participants suggested that researchers should provide evidence that the research priorities and/or research questions are coming from the community at the time of grant application.
- Participants stressed that SPOR and CIHR must continue to engage Indigenous scholars, researchers, Elders, and community members to identify their research needs and priorities, barriers and facilitators to their work, best practices, and engagement preferences. Participants suggested prioritizing and building trust and reciprocity, attending community events when invited with cultural humility, and creating time and space for relationships to flourish. Participants explained that time is needed to develop these relationships, and this time should be built into the research process and funding opportunities.

- Participants expressed an interest in exploring how fiscal funding models impact Indigenous health outcomes.

#### **5. Mandate Robust Knowledge Mobilization grounded in Indigenous Ways of Knowing**

*“Anyone doing research with the community needs to consider what they are leaving behind – you need to be able to implement real policy change, employ and train people in the community or leave a product behind.”*

*“Researchers need to do follow up, as well as share results.”*

- Participants underscored the importance of having clear and robust knowledge mobilization plans that hinge on sharing the results and outcomes of research with community members in culturally safe and meaningful ways.
- Participants explained that often, researchers, academics, and governments focus on community challenges without acknowledging, beauty, resilience, and strength. As such, they advocated for strength-based communications when referencing Indigenous communities or groups.

#### **6. Draft Culturally Responsive Evaluation Approaches**

*“Indigenous measures of success are distinctly different than western societies. Has SPOR looked into Indigenous measures for success?”*

Participants stressed that CIHR should partner with First Nations, Inuit and Métis communities and researchers to draft Indigenous, culturally responsive evaluation frameworks and measurable goals that focus on Indigenous measures of success, deliverables, and outcomes.

#### **7. Decolonize Systems by Ensuring the Recognition of Traditional Knowledge, Interconnectedness and Knowledge Sharing.**

*“There are so many teachings that have been taken away from me. When they opened the first doors of residential schools we had to eat in a certain way and disconnect from our languages. I want to know more about who I am, what is my role and what are our songs...”*

- Participants highlighted that many community members are seeking knowledge that was lost due to colonization including Indigenous knowledge, ceremonial knowledge, and traditional knowledge to improve their wellbeing.
- Future grants and researchers should acknowledge and incorporate holistic, traditional knowledge and practices and land-based healing, weave Indigenous ways of knowing with Western medicine and offer support for Indigenous traditional healers.
- Future grants should focus on de-siloing work, focusing on developing solutions and responses to community-identified questions and needs, promote knowledge sharing and interconnectedness between communities.

#### **8. Provide Support for Community Embedded Faculty Positions**

*“Faculty members are in the ivory tower and need to be embedded in the community.”*

Indigenous academics are often asked to work out of an office within their university. Participants explained that allowing Indigenous scholars to work out of an office in an Indigenous community organization would be more beneficial. This would allow them to interact more freely and frequently with community members and as such are more likely to develop strong reciprocal relationships.

#### **9. Promote Language and Terminology to Build Trust**

*"I don't use the word researcher in my community, instead I translate it to learning things to bring home."*

Participants emphasized that research has harmed and is continuing to harm Indigenous communities. As such, communities mistrust research and are wary to partner with academics. One suggestion to foster trust with community members was to be mindful of language and terminology. Participants explained that speaking Indigenous languages builds credibility and trust with grassroots organizations and Indigenous communities. Some suggested replacing the word 'research' with 'knowledge gathering' or 'grassroot learner'.

#### **10. Expand Allowable Costs to Support the Wellness of PWLE and Community Partners**

Participants suggested expanding allowable costs within a grant to support PWLEs and community partners around potentially triggering topics. These supports may include wellness care, before, during or after-care with an Elder or therapist, treatment, respite care etc.

#### **11. Increase Collaborations with NEIHRs and Indigenous Community-Based Organization**

- Participants suggested more explicit collaboration between SPOR and the NEIHRs. This can help de-silo work, avoid duplication, complement efforts, and support research efforts.
- Participants proposed moving research into Indigenous community-based organizations which can hold and control funds and make them more accessible to Indigenous communities.

#### **12. Establish an Indigenous SPOR Network**

Some participants advocated for an Indigenous SPOR Network that is led by Indigenous Elders, PWLE, community members and researchers. They suggested that this Network can promote Indigenous leadership and autonomy in research while acknowledging the differences in priorities, capacity, operations and distinct needs of First Nations, Inuit, and Métis communities.

### **Promising Practices**

- [CANSOLVE's Cultural Competency Learning Pathway](#) is a learning pathway that is composed of existing resources that aim to enhance knowledge and awareness of racial biases, Indigenous stories, the affects of colonization on Indigenous health, and culturally safety in health research.
- [San'yas Anti-Racism and Indigenous Cultural Safety Training Program](#) that focuses on uprooting anti-Indigenous racism and promoting cultural safety for Indigenous people. The training is unique because it accounts for local contexts (British Columbia, Manitoba, and Ontario), includes different speakers from different regions in Canada, and has discussion groups.

- Hotì ts'eeda, Northwest Territories SUPPORT Unit established collaborative and successful governance, modeled on Indigenous practices of accountability, trust and knowledge sharing. Hotì ts'eeda is accountable to Indigenous governments, the Government of the Northwest Territories, and the University of Alberta Faculty of Medicine representatives which is hosted by a self-governing Indigenous government.
- The Yukon SPOR SUPPORT Unit hold regular research knowledge mobilization events where researchers share their findings with the community. These events ensure findings are directly communicated to the community, provides opportunities for networking and relationship building.
- First Nations University of Canada (FNUC) is currently developing a model on how REBs should be processing Indigenous engaged research ethics applications and make them more accessible. CIHR to follow up to learn more and promote the tool.
- [Building Research Relationships with Indigenous Communities](#) was referenced by participants as a promising training course on engaging in Indigenous research utilizing best practices and methods.
- Participants signaled that while the seven SPOR Networks have been valuable, CANSOLVE CKD have become true allies for Indigenous Peoples. They have instituted deliberate efforts to support Indigenous communities and have recognized and improved health outcomes for Indigenous Peoples.



## **Theme 4: Strengthening Equity, Diversity, Inclusion, Accessibility and Anti-Racism (EDIAA) in Patient Engagement and Patient-Oriented Research (POR)**

This summary report includes data from Roundtables 4 and 5, 30 partner engagement reports, and 18 interactions (15 comments and 21 votes) from the online public engagement platform.

The roundtables were attended by researchers, PWLEs, healthcare professionals, knowledge brokers, policy and decision makers, funders and representatives from health authorities and health charities. Partners who contributed input on theme 4 include leaders from the community of SPOR-funded Entities (SFEs), SPOR SUPPORT Unit Council, Maritime SUPPORT Unit, Yukon SUPPORT Unit, Manitoba SUPPORT Unit, Saskatchewan SUPPORT Unit, Alberta SUPPORT Unit, Ontario SUPPORT Unit, Québec SUPPORT Unit, Newfoundland and Labrador SUPPORT Unit, British Columbia SUPPORT Unit, CAN-SOLVE CKD Network, CHILD-BRIGHT Network, Primary Care Network, Chronic Pain Network, Diabetes Action Canada, Health Data Research Network, SPOR Evidence Alliance, CIHR- Institute of Aging (IA), CIHR- Institute of Aging Older Adult Advisory Council, University of Toronto's Office of the Vice-President, Research and Innovation, Centre of Excellence in Youth Mental Health, and Patient Advisors Network.

### **Challenges and Barriers Impacting EDIAA Work**

#### **1. Inadequate Definitions, Guidelines, Training and Supports for Good EDIAA Work**

*"CIHR is lagging behind other countries in terms of guidance to researchers and community partners on EDIA principles in research studies."*

##### **a. Unclear EDIAA Definitions and Preparation**

- Participants explained that unclear EDIAA definitions have allowed the continuation of "checkbox attitudes" and tokenism amongst some researchers. Simultaneously, definitions of underrepresentation are too narrow and don't account for intersectionality. As a result, outreach to certain populations has been limited. For example, rural/remote populations, people with disabilities, immigrants and newcomers, older adults, youth, linguistic minorities including Anglophones in Quebec, Francophones outside Quebec etc.
- Preparation for EDIAA work is ineffective as EDIAA conversation for different sociocultural and distinct groups usually become conflated under a single pan-EDIAA conceptualization. This is problematic as nuance of the barriers and potential solutions are stripped under a hypothetical centre which consequently does not represent anyone.
- Participants cited a mismatch in how SPOR is set up to do patient-oriented research. Currently, SPOR is taking a clinical approach and trying to embed EDIA research considerations on top. In reality, these are very different approaches, methodologies, and positionalities. Instead, participants suggested centering a trans-disciplinary approach that takes community based and participatory action methodologies and then building clinical research on top of that. This aligns with the kind of methodology that those working with Indigenous communities and structurally disadvantaged communities do.

##### **b. Training Opportunities are not Practical or Pragmatic**

- While there are many learning modules on academic/theoretical approaches to EDIAA, participants explained that training opportunities and guidance on the practical application of EDIAA for researchers are lacking.
    - While new training modules were suggested by many participants, one participant noted that *“EDI training is not an evidence-based strategy, it is not successful and should not be proposed as a solution.”*
  - Despite its importance, there has been a lack of understanding of trauma and trauma informed approaches which has led to a lack of psychological safety in research. Participants cited an acute need for more nuanced and tailored trauma informed practices, training, and tools for both researchers and patient partners.
  - Participants highlighted a lack of understanding of Indigenous ways and respectful relationship-building practices of different communities. Despite this, they explained that training on how to properly engage with Indigenous communities has been insufficient, specifically training on the rights, responsibilities, and accountabilities.
- c. Lack of Guidance on Compensation, Reciprocity, and Recognition
- “In the ideal world, this pyramid would be turned upside down so that those people that do really carry the work and effort will be recognized and compensated fairly on par with those of us that sit on the other side of the table with privilege.”*
- Participants explained that guidelines on compensation, reciprocity, and recognition need to mirror those that are set up for researchers and academics and go beyond remuneration. For example, offering patient partners support navigating the healthcare system, language support, co-authorship, presenting at conferences, career advancement etc.
  - Monetary compensation for patient participation in research is currently classified as taxable income, this can be a barrier to some PWLEs, specifically those on parental leave, retired, receiving disability and/or social assistance as compensation payments can interrupt income. Simultaneously, compensation comes with paperwork that poses challenges to certain populations as well. For example, some organizations need social insurance numbers and/or addresses and this can be challenging for precariously housed or homeless populations.

## **2. Identifying, Engaging, and Supporting Patient Partners from Underrepresented Communities can be Challenging.**

- a. Participants shared the importance of having diverse patient partners and participants in research, including people from rural settings.
- b. Making Connections with Underrepresented Communities can be Challenging.
 

*“It can be very challenging to make connections and work with underrepresented community members because they don’t feel that it is relevant to them, they don’t understand what POR is and they don’t understand that they have lived experience that is very, very important.”*

  - Members of underrepresented communities may not be aware of patient-oriented research, its benefits, or the impact their lived experience can have on research.

- Community members may not feel research is relevant to them, some communities may have bigger priorities like paying rent, getting food on the table, and meeting their basic needs over participating in research.
  - Rural and remote communities often only have access to local research which can be very limited. Researchers from urban settings tend to engage and offer training opportunities to patient partners from urban centres as this can be cost effective (less travel) and convenient but ultimately leads to low awareness of POR in these communities.
  - Therefore, participants recommended building strategies for engaging patient partners and participants from underrepresented communities, as reflected in the following quote: “Take an interest in people from communities so that they in turn take an interest in research, we must recognize the values, beliefs, perspectives of communities.”
- c. **Structural Barriers to Inclusion**  
*“We can’t speak about inclusion without ensuring the means and awareness of POR, internet connection, cell signal, device to connect with, and time to connect, learn and work with the POR team.”*  
 Marginalized and underrepresented communities often experience structural barriers including language barriers, digital poverty, digital literacy challenges, and challenges with internet bandwidth. Participants emphasized that these barriers are more pronounced for patient partners in rural/remote settings and in the Maritimes. To support participation and engagement, participants suggested purchasing or loaning technological devices such as laptops, phones, Wi-Fi etc. However, in the current grant system, these materials are not an allowable cost.
- d. **Challenges with Engagement Are Not Limited to Patient Partners in POR but Extend to Representation at Various Leadership Tables Responsible for EDIAA Decisions.**  
 Participants reflected on a trend where a small group of wealthy, privileged, mainly white people, are at various tables representing marginalized and underrepresented groups. While they are advocating for professionalization of underrepresented groups, compensation and other issues related to equity at these tables, this mismatch in representation can be dangerous and inherently lead to biases and widening inequities.

### **3. Tokenism Persists in POR**

*“I have also witnessed “professional” patients who are selected / self-select within a patient role on studies despite not representing many less privileged and more excluded lived experience voices.”*

- Participants reflected that patients and PWLE are not meaningfully engaged or embedded within the research team. Instead, many researchers are involving them as a box to check rather than an ongoing partnership.
- Participants also noted a trend where the same group of patient representatives (“professional patients”) are engaged repeatedly. They suggested that this contributes to tokenism as “professional patients” often do not represent many less privileged and more excluded lived experience voices.

### **4. Lack of Trust in Some Underrepresented Communities**

*“From my work with underprivileged, underrepresented, underserved, stigmatized and vulnerable communities like LGBTQ+ and Indigenous communities, a challenge is trouble establishing trust and connection especially since these communities typically have been hurt by research.”*

Some participants cited difficulty establishing trust with some underrepresented communities, particularly those who have been harmed by research in the past including Indigenous and 2SLGBTQ+ communities. This can be further complicated by a general lack of understanding of authentic patient and community engagement, or its benefits, throughout the continuum of research by mainstream researchers.

## **5. Project-Based Funding Timelines Don’t Support Meaningful EDIAA Work**

*“Forming relationships, trust and effective partnerships takes time. In a fast-paced scientific environment, how can we do this?”*

*“Funding timelines currently do not accommodate these time-consuming practices and often researchers must use the quickest solution instead of the best solution because they have to report back to the funding body.”*

*“Something I learned with humility from working with Indigenous communities is that we can only work at the pace of trust.”*

- Participants stressed that the project-based funding paradigm of SPOR does not provide adequate time to build relationships, trust, effective partnerships and conduct community engagement in a meaningful way.
- With project-based funding, participants explained that researchers arbitrarily set timelines that they believe they will complete work within. However, when community engagement is involved, these timelines can shift dramatically as relationships and trust are built. As a result, researchers don’t meet these timelines and their work is seen as incomplete.
- Community engagement is not the only cause of delays within a project, multi-university, multi-REB processes often do not align and can take up considerable time (from 1 year to 18 months) to complete. This sometimes means that funding timelines are done without the completion of any activities. This erodes trust within the community.

## **6. Ableism and Challenges with Accessibility and Inclusion**

*“A lot of accessibility barriers in health research exist due to a lack of knowledge and awareness. Disability in the health space is viewed as a condition that should be treated or rehabilitated as opposed to a lived experience. The notion of somebody with a disability engaging in a conversation other than being a research participant under a certain power dynamic, is a bit of an alien thought to a lot of researchers. Therefore, they don’t think about whether they need accessible formats or tools in place.”*

- Participants cited challenges with accessibility and inclusion in health research. Some attributed it to a lack of awareness while others cited challenges with costs, time, and available infrastructure.
  - Participants noted that accessibility challenges are more pronounced in rural and remote settings and in the Maritimes.
- Ableism impacts accessibility and inclusion, many researchers don't think about ensuring the use of accessible tools and formats in their communication, materials, and meetings. Furthermore, they may use language that inadvertently excludes certain groups. For example, if the study inclusion/exclusion criteria are phrased in a way that asks participants to independently complete a task and a participant needs interpretive support or communication support (i.e. not doing it independently), they will be excluded.

## 7. Inherent Power Imbalances

*“Accountability is not a stand-alone thing; it cannot be separated from the systems of power that lead to the harms that we have observed in research. How do you hold someone who holds power over a community accountable? To address accountability, we need to shift structure on who holds power in these relationships, and this is a much more difficult and deeper and more important thing to focus on”.*

*“One thing I’ve experienced in being the patient and caregiver partner is the expectation to be super open and vulnerable about my experiences — an expectation that is not extended to the researchers or clinicians. That power dynamic is not appropriate or conducive to good research.”*

- Participants reflected on the power imbalances that still exist in the research community stressing that expectations, compensation, and standards are very different for each group. They also stated that research is still driven by researchers, clinicians, universities, and those sitting on funding review boards.
- Institutional barriers do not allow patients to hold grant funding unless they are affiliated with an organization or university. As such, patients can't lead or own their research.

## EDIAA Strategies

### 1. Co-design and Co-develop National Training/Guidance on:

- a. EDIAA metrics, implementation and reporting tools, EDIAA, power-sharing and intersectionality training, and clear guidelines for researchers on how to incorporate EDIAA concepts and practices in POR.
  - Support community engagement to outline EDIAA needs and expectations as opposed to abiding by generic standards that take a pan-EDIAA approach.
  - EDIAA training should be ongoing effort rather than a one and done program.
  - Showcase effective EDIAA approaches, strategies, and successful models.
  - Some participants suggested an EDIAA Community of Practice or a dedicated CIHR coordinator who would guide EDIAA work and initiatives across SPOR-Funded Entities, reduce redundancies and promote collaboration.

- b. Compensation, reciprocity, and recognition: these guidelines should be equitable and based on community needs while ensuring compensation is a requirement in funding applications.
- c. Engagement best practices including culturally safe practices, delineation of roles and responsibilities, power imbalances etc.
- d. Tailored, specific trauma informed training tools to support trauma-informed engagement, avoid re-traumatization, support self-care for participants and partners, adequately respond to trauma shared during engagement.
- e. Support the creation of safer spaces, reflection, introspection and learning within the research ecosystem as a lot of feedback is currently met with defensiveness.

## **2. Support Capacity Building and Representation of Underrepresented Community Members**

- a. Funding scholar positions for people from underrepresented communities who have existing connections and relationships with their community.
- b. Improve representation at leadership tables by creating opportunities for underrepresented community members to be trained and hired for this work.
- c. Create research ambassadors by building capacity of people who are rooted and trusted in communities who can act as a liaison between researchers and communities.
- d. Support the development of community data governance to ensure data is interpreted and reported in the correct socio-cultural context.
- e. SPOR can develop or support the development of a national matching tool or infrastructure that can facilitate strategic collaborations and match interested people with lived experience with suitable research opportunities across the country. This tool can also include mentorship and capacity building components.
- f. Support partnerships with national and local Non-Governmental and Non-Profit Organizations that work at the grassroots level and have established relationships with underrepresented communities. SPOR can provide capacity building, mentorship and infrastructure support to these organizations so that they can participate in POR.
- g. Implement diverse recruitment, engagement and awareness building strategies that are based in trust and reciprocity including targeting places where patients will likely congregate including hair salons, barber shops, grocery stores, community centres and libraries. Regular social media campaigns were also proposed by participants as an ideal strategy to engage underrepresented communities.

## **3. Shift and Restructure Funding**

- a. Invest in:
  - Pre-Grant Relationship building: This funding will allow groups to work together and build strong, authentic, and trusting relationships between researchers and communities. Participants stressed that the only outcome that should be expected from this funding is the establishment of a relationship between researchers and the community.
  - Codesign of research: This funding will provide an opportunity for PWLEs and patient partners to co-develop and co-write funding proposals.
  - Applied research proposals that focus on implementation and evaluation.

- Building infrastructure to solve structural challenges rather than one-offs.
  - Projects that lead to systemic change and directly address experiences of inequity in the health system and social determinants of health that require interdisciplinary, and community engagement embedded into design.
  - Along Siding Support: This is a structural and relationship-based, liaison type support for PWLEs, a dedicated person buddies with PWLEs and helps translate the context of the researcher or research into something meaningful. Building this into grants/making it a SPOR requirement can be helpful.
  - Cultural safety officers or EDIAA coaches that support research teams.
- b. Restructure Grants to:
- Redefine success from deliverables to relationships. This will help promote listening, trust and mutual respect, the deliverables will follow. Simultaneously, indicators for success and evaluation frameworks should be co-developed by underrepresented communities.
  - Address institutional barriers and allow patient partners, community led organizations and communities to hold funds (including administrative support and overhead) and lead their own research, conduct engagement, and immerse researchers in those engagements.
  - Offer more flexible, long-term funding. For example, five years, instead of one or two years to build meaningful relationships based on trust.
  - Expand allowable costs to include devices (laptop, phone, Wi-Fi, pocket-talkers, video conferencing technology), translation in multilingual environments (including sign language, French, English, and Indigenous languages), respite and childcare expenses, training and adapting outputs into plain language.
- c. Ensure Research is Driven by Communities by
- Asking researchers to provide evidence that the research priorities and/or research questions are coming from the community at the time of grant application.
  - Asking researchers to demonstrate a good understanding of meaningful patient engagement by providing evidence of attending certain learning modules or evidence of conducting meaningful patient engagement in the past, before applying to SPOR funding opportunities.
  - Asking researchers to provide evidence of established, trusting relationships with communities they are working with before applying for SPOR funding opportunities.
  - Offer incentives or recognition, for example, awards, to research teams that engage diverse patient partners with additional opportunities as an example for teams that may be more resistant.
    - \* While incentives were recommended by some participants, others reflected that they are likely more effective for some groups compared to others. For example, a full tenured professor will less likely be moved by an award compared to an early career researcher.

#### 4. Remove Administrative Barriers

- a. Train peer reviewers to assess meaningful engagement and criteria to look for in research proposals, i.e. budget, meaningful codesign etc.
  - b. Ensure the implementation of feedback mechanisms where patient partners, PWLEs and researchers can reflect on patient engagement, methods, tools, and applications of EDIAA in every step of the research. Participants suggested doing this via focus groups or interviews compared to written communication.
  - c. Review institutional policies that impede PWLE participation including CCV requirements, and institutional eligibility.
  - d. Work with the research ethics community to adapt ethics requirements to support equitable community-engaged research. This includes allowing community members to be part of the research team, in addition to participants in the research. It also involves removing requirements that are ableist for example (i.e. not allowing research participants to have a helper support them to participate).
  - e. Champion conversations with CRA to make compensation for research involvement tax exempt.
- 5. Address Accessibility and Anti-Ableism in Research**
- a. Funding to support accessibility, and flexibility to support non-traditional researchers and learners.
  - b. Connect researchers with the accessibility professionals that can support accessibility and mitigate challenges to it while creating a learning environment for researchers.
  - c. Invest in accessibility and anti-ableism training for research teams and those in the research ecosystem.
- 6. Universities can Support Multi-Disciplinary, Community-Engaged Research**
- a. Universities can Support researchers from underrepresented communities in their institutions who are willing and have the skills to engage their communities, learn with humility, and apply it to their research.
  - b. Reduce administrative barriers including payment rules and multiple REBs that impact community engaged research.
  - c. Allow researchers the flexibility and time to engage in relationship building with communities.

## Strategies that Support Accountability

### 1. Structural changes

*“If we want to hold people accountable for doing EDIA work, we need to make sure the barriers are removed, and ensure they have the time to do this work well”.*

Accountability cannot be separated from the systems of power that they are connected to. Therefore, more focus on structural changes and who holds power in these relationships is vital. Participants reflected that holding researchers accountable individualizes responsibility and bypasses the root of the problem, while reproducing inequity for researchers with fewer resources.

### 2. Incorporate EDIA feedback in research processes.

- Ensure the implementation of feedback mechanisms where patient partners, PWLEs and researchers can reflect on patient engagement, methods, tools, and applications of



EDIAA in every step of the research. Participants suggested doing this via focus groups or interviews compared to written communication.

- Support the creation of safer spaces, reflection, introspection and learning about good practices that support EDIAA within the research ecosystem as a lot of feedback is currently met with defensiveness.
- Empower communities to create their own accreditation systems and provide researchers with a stamp of approval. This may lead to better performance and understanding on the researcher' side.

### **3. Provide EDIAA Guidelines and Metric for Researchers to Report on**

- Participants suggested providing researchers with guidelines and metrics through which they can report their EDIAA performance. One example that was given was CANSOLVE CKD's six R's of culturally relevant engagement including respect, relevance, reciprocity, relationships, reflection, and reconciliation. While these were designed for engagement with Indigenous communities, participants agreed that they can likely be applied to all communities.

### **4. Accountability in Leadership**

*"Another component of accountability is leadership; we need to walk the walk and not just talk the talk. CIHR doesn't have a good track record of diverse transformative leadership, it is hard to care about being accountable if you are not seeing it from CIHR leaders themselves."*

Participants stressed that leadership teams must represent all Canadians. These leaders must have an understanding of what tools to hold folks accountable and which measures would be appropriate.

## Theme 5: Building Capacity and Partnering for Excellence in Patient-Oriented Research (POR)

This summary report includes data from one roundtable, Roundtable 6, 33 partner engagement reports, and 22 interactions (19 comments and 17 votes) from the online public engagement platform.

The roundtable was attended by researchers, PWLEs, and healthcare professionals. Partners who contributed input on theme 5 include leaders from the community of SPOR-funded Entities (SFEs), SPOR SUPPORT Unit Council, Maritime SUPPORT Unit, Yukon SUPPORT Unit, Manitoba SUPPORT Unit, Saskatchewan SUPPORT Unit, Alberta SUPPORT Unit, Ontario SUPPORT Unit, Québec SUPPORT Unit, Newfoundland and Labrador SUPPORT Unit, British Columbia SUPPORT Unit, CAN-SOLVE CKD Network, CHILD-BRIGHT Network, Primary Care Network, Chronic Pain Network, Health Data Research Network, SPOR Evidence Alliance, Passerelle, Health Charities Coalition of Canada, University of Toronto's Office of the Vice-President, Research and Innovation, Patient Advisors Network, Centre of Excellence in Youth Mental Health and HealthcareCAN VPR.

### Capacity Building Challenges

#### 1. Duplication of Tools and Resources Across SPOR Funded Entities

*"There's a lot of duplication [in capacity building efforts] across SUPPORT Units. A lot of wheels are being recreated. Many tools can be borrowed and customized from other regions."*

Participants noted that many SPOR-funded entities worked in silos and were creating similar tools and resources which has resulted in a lot of duplication of efforts.

#### 2. Low Awareness of Existing SPOR Capacity Building Initiatives

*"We have a robust collection of learnings with few people aware of them. SPOR could improve marketing of initiatives to the public to increase engagement..."*

Participants reflected on SPOR's vast array of capacity building initiatives and explained that despite that, awareness of these initiatives is low among the general public and the research community. Participants suggested the development and mobilization of awareness building efforts to increase awareness and uptake.

#### 3. Diversity in Capacity Building Needs and Priorities

*"We are trying to design training based on needs, but needs are so diverse. Finding a definition of patient involvement that is a one size fits all is difficult because lived experiences vary and therefore, contributions vary as well. We don't want to see certain lived experiences marginalized."*

*"Prioritizing patient training as the way that patient partners can get involved is not ideal. We need to avoid being exclusive. Training can be a huge barrier."*

Participants explained that while some patient partners and PWLE would like to be involved in capacity building efforts and training, they stressed that this may not be the case for everyone. Participants cautioned mandating training modules for PWLEs as this can become a barrier and limit participation in research to those who have the time and financial means. It may also imply that lived experience is not enough. Further, given the diversity in the roles of PWLEs in research and their experiences and needs, designing training modules that align with this diversity can be challenging.

#### **4. Engaging with Underrepresented Patient Partners**

*“There are patient partners who experience discrimination and racism on daily basis. There is a great need to gather their voices and inputs into research. ....There is a large group of people that we are not building capacity within these communities, whether its training on how to do stats or simply how to work together. We need greater diversity in patient partners, and to be more inclusive.”*

Participants noted that tokenism is a challenge that persists in POR. They reflected that not enough is being done to creatively engage PWLEs from underrepresented communities\* in health research, build capacity within these communities and ensure environments are welcoming and safe. As such, POR hasn’t adequately heard from a diversity of voices and cannot effectively address distinct social experiences as well as intersectionality. Participants stressed that for capacity building efforts to be successful, they must be based on the needs and priorities of those they are designed for.

\*Underrepresented communities were referenced broadly by participants and used to represent the following communities: rural/remote populations, immigrants and newcomers, older adults, youth, linguistic minorities, people with disabilities and communities that have experienced racism, particularly Black and Indigenous communities.

#### **5. Competing Priorities for Early Career Researchers**

*“Early career researchers face challenges in how they are evaluated for tenure and promotion and compete with the aim of SPOR...”*

Participants explained that the values of SPOR do not align with how early career researchers are evaluated for promotions. For example, SPOR focuses on PWLE partnership and relationship building which can be time consuming while early career researchers are expected to publish numerous articles in high impact journals. As such, these competing priorities make it difficult for early career researchers to conduct and sustain POR work in a meaningful way and may lead to tokenistic engagement despite adequate capacity building efforts and training. Participants suggested that SPOR can work with academic institutions to raise awareness of the values and importance of POR while highlighting the tensions and competing priorities researchers may be experiencing. SPOR can also advocate for new performance indicators and impact measure for researchers.

#### **6. Evaluating Capacity Building Efforts**

*“We just track how many patients are involved early on, but once things get busy or complicated or projects run out of money, the rest of the [evaluation] plan is not followed through.”*

Participants cited challenges with evaluating capacity building efforts beyond tracking attendance. They stressed the importance of robust evaluation metrics to assess the effectiveness of existing and planned capacity building efforts.

## Strategies for Effective Capacity Building/Ideas for the Future

### 1. Invest in Development of Specific Types of Capacity to Strengthen POR.

Participants suggested drafting a “POR Foundations Curriculum” that offered core competencies like relationship building, principles of EDIAA and cultural safety, and research designs and methods for the optimization of POR. They suggested utilizing experiential, collaboration-based learning as opposed to passive transmission of information through self-paced or in-person training. Participants stressed that this training must be pragmatic and focus on “how rather than why.”

- For PWLEs, community members and patients

*“We need to ensure that patient partners have the best knowledge and be the best partners that they can be. We need more courses on every aspect of research so that they can be valuable assets.”*

*“If CIHR will prescribe that principle of EDI and Decolonization and Indigenization, [it] should provide budget money for training or create mandatory training modules to have everyone have base level knowledge before the grants get going.”*

- Participants suggested that the next phase of SPOR should focus on co-developing capacity building training specifically for and with PWLEs and underrepresented communities. This training should include all aspects of research (including peer review), emphasize safety and inclusion and be adaptable enough that it can align with PWLEs diverse needs and builds on their existing strengths and expertise.
  - Participants proposed building the capacity of trusted members and leaders of underrepresented communities. That way, they can take on a liaison or research ambassador role within their community.
  - Participants explained that often, training is not only about skill development, but it also helps PWLEs feel more comfortable and confident partnering in research. Participants stressed that training must be coupled with opportunities to apply and advance skills and experiences and not just didactic instruction.
- For Academics, Knowledge Users and PhDs
- “80% of people with PHDs don't become professors, we need to populate health systems with people who understand patient engagement and can facilitate research uptake.”*

While a lot of the existing capacity building efforts in SPOR have been focused on building researchers' capacity in POR, participants suggested expanding the audience for these efforts to include knowledge users such as healthcare professionals, academics, and PhDs to support their understanding, participation, and uptake of POR.

- For Trainees and students

*“Fund into high school programs, expose youth to research and its goals, fund the research that leads students from high school into college and universities that perform the research on the same community. In a couple of generations, the research leads would come out from the same communities that would benefit from the research. It would be a self-fulfilling model of patient and community first research.”*

*“Most such activities to date have been focused on bringing youth to the table, but not bringing research training and skills to them i.e., not comprehensive.”*

Participants recommended building the capacity of youth in POR starting in high-school to better meet the future demands of the community.

*“[Embedding POR early in curricula] would embed the concept of patient engagement as part of the research culture early on and it’s clearer what the differences are between patient partner and patient participant.”*

Participants also suggested embedding POR capacity building efforts early in curricula during the research training process in schools and within existing research training programs and institutions. This would embed POR into research culture, improve awareness and uptake.

## **2. Continue to Invest in National Capacity Building Platform**

- Participants explained that a National Capacity Building Platform would help co-create a national training strategy and coordinate training and reduce duplication of capacity building efforts. This can be done by:
  - Harmonizing existing training opportunities and showcase successful efforts in one place.
  - Funding collaboration and knowledge exchange between the SPOR Funded Entities.
  - Providing synchronous and asynchronous capacity building training opportunities.
  - Engaging patient partners who are part of condition-focused support groups and charities, to broaden the number of people with capacity to engage in research.
  - Incentivizing mentorship opportunities by offering specific grants and/or awards.
  - Ensuring the platform could be searched by condition, or location to support opportunities for partnership.
- Develop a national matching tool that matches researchers with PWLEs and community partners and connect patient groups with training and research opportunities.
- Improve evaluation, understand impact, and strengthen accountability for POR and capacity building efforts by standardizing evaluation metrics, outcome measurement and follow up on research after publication, to understand impact.

## **3. Future Funding**

*“CIHR should invest in programmatic funding models that bring people together. We need to have a good look at funding pathways that maximize engagement and impact and reflect diversity. Funding often goes to the same places time after time.”*

- Funding to build better relationships and support planning.  
This funding can support relationship development, offer training around relationships and partnership, and support the true co-design of projects. Participants cited the SPOR Summit as a good example of a networking event that supports capacity building. However, this summit should not be exclusive to senior executives and researchers and needs to include representation from across the SPOR community.
- Funding that promotes inclusion, impact, and innovation:
  - Participants advocated for the development of funding models that support diverse meaningful engagement, reflect diversity, and mitigate barriers to underrepresented populations as opposed to funding open competitions that tend to go to the same researchers.
  - Participants suggested funding that promotes the understanding of new, innovative, and exciting treatments that improve patient’s lives, are showing promise or can accelerate testing and access.
  - Participants highlighted the importance of offering awards and bursaries to cover travel, accommodation, and conference fees for PWLEs who are interested in attending.
- Funding to Hire Patient Engagement Specialists  
Participants suggested investing in several Patient Engagement Specialists that work within healthcare and research organizations across the country whose goal is to build capacity for health research. These specialists can connect on a regular basis to share knowledge and exchange information and best practices.

#### **4. Support the Development of a National Forum or Platform for PWLEs**

Participants suggested the development of a national platform or community of practice that is led by PWLEs and would promote communication, mentorship, and exchange knowledge and experiences between PWLEs, community members and patients involved in research.

### **Capacity Building Promising Practices**

**These practices and tools were specifically recommended by participants in the SPOR Refresh**

- [Methods Clusters](#) were created by the BC SUPPORT Unit during Phase 1 of SPOR. Clusters thought through different methods required for patient-oriented research, and identified six areas where more methods research was most important. These method clusters supported the training of entire research cohorts on patient engagement and on how POR could be applied to their work.
- [Patient-Led Research Scorecards](#) this tool has been used for both evaluation and training and assesses how effective patient-researcher collaborations will be at conducting patient-led work.

It focuses on patient governance, patient integration in the research process, patient burden and research organization readiness.

- [Patient Centered approach to Clinical Trials \(PACT\)](#) is a pan-Canadian initiative that has interesting training modules and has had some success in ensuring patients and patient groups are equal partners in Clinical Trials and throughout the Clinical Trial Continuum.
- [Family Engagement in Research \(FER\) Course](#) was suggested as a course every PWLE working in research should take.
- [Faster Cures](#) is a US based organization that has great examples of capacity building for Patient-Reported Outcomes and patient engagement.
- Becoming a member of CIHR's College of Reviewers was suggested as a great way to indirectly build capacity in research for PWLEs. Participants noted that the College of Reviewers can expose PWLEs to a great variety of research, methodologies and potentially provide insights on contributions they can make in the future.
- [Reach BC](#): "In BC we have established a common resource on research as well as a method for patients to become involved in the research as partners, facilitators, or clinical trials. This has been developed jointly between researchers and a patient network."
- [Centre of Excellence in Youth Mental Health](#): "CEYMH persons with lived experience write web blogs regularly that are accessible to the public."

## **Theme 6: Strengthening Collaboration with Policymakers and Health System Decision Makers to Increase Research Impact**

This summary report includes data from one roundtable, roundtable 7, 35 partner engagement reports, and 14 interactions (10 comments and 8 votes) from the online public engagement platform.

The roundtable was attended by researchers, policy and decision makers, healthcare professionals and representatives from health authorities and health charities. Partners who contributed input on theme 6 include leaders from the community of SPOR-funded Entities (SFEs), SPOR SUPPORT Unit Council, Maritime SUPPORT Unit, Yukon SUPPORT Unit, Manitoba SUPPORT Unit, Saskatchewan SUPPORT Unit, Alberta SUPPORT Unit, Ontario SUPPORT Unit, Québec SUPPORT Unit, Newfoundland and Labrador SUPPORT Unit, British Columbia SUPPORT Unit, CAN-SOLVE CKD Network, CHILD-BRIGHT Network, Primary Care Network, Diabetes Action Canada, SPOR Evidence Alliance, Passerelle, CIHR- Institute of Health Services and Policy Research (IHSPR), CIHR- Institute of Cancer Research (ICR), CIHR- Institute of Nutrition, Metabolism and Diabetes's (INMD), CIHR- Institute of Aging, CIHR- Institute of Human Development, Child and Youth Health (IHDCYH) Youth Advisory Council, University of Toronto's Office of the Vice-President, Research and Innovation, Centre of Excellence in Youth Mental Health, Health Charities Coalition of Canada, The National Alliance of Provincial Health Research Organizations, Research Impact Network, Patient Advisors Network and CIHR's engagement with policy makers to inform the KM framework and action plan.

### **Challenges and Barriers to Effective Collaboration with Policy Makers**

- **Researchers and Policymakers May Have Misaligned Priorities, Evidence Needs and Timelines**

*"We need more opportunities for the health systems to put forward the research priorities based on system needs and require alternative ways that research gets to the policy makers rather than conferences or papers."*

*"We need to find a match between what is keeping our policymakers up at night and what our researchers can support and the way that we're connecting them."*

Participants explained that researchers typically work within incremental projects that have clearly defined and narrow research questions and methods while policy makers often operate in environments where decisions need to be more nimble, adaptive, and responsive to political pressures. Further, researchers often communicate the findings of their research via conferences and journal publications, however, these knowledge products are not always useful for policy makers nor are they ready for "real-world integration". As such, policy development and decision-making processes often have different evidence needs and priorities compared to those that guide research. Participants also highlighted that collaboration is further complicated by the fact that evidence generation takes longer than policy timelines permit.

- **Lack of Awareness and Buy in from Policy and Decision Makers**

*"Lack of buy-in is because of fundamental lack of awareness of value of [patient-oriented] research."*



Participants described a lack of consistency in the awareness of SPOR, its activities and utility amongst senior government officials, policy makers and decision makers. They attributed this, in part, to the lack of information about the SPOR program's value and impact on SPOR's website. This lack of awareness may mean that health decision-makers don't value, understand, or use SPOR evidence or resources. Further, participants explained that there is no clear expectation or "push" for policy and decision makers to participate or engage in research.

- **Policymaker Turnover and Capacity Challenge Meaningful Collaboration**

*"There is a challenge with policy makers around the "revolving door" i.e. turnover of policy makers. Decision makers are very busy, really hard to get them on the phone."*

Participants noted that high turnover rates and capacity constraints amongst policy and decision makers are significant challenges to consistent, collaborative efforts. Further, SPOR-Funded Entities tend to collaborate exclusively with "top-level officials" and senior government representatives. When turnover inevitably happens, these relationships, awareness of SPOR and associated corporate memory leave with the individual. Participants suggested that SPOR should broaden the definition of decision and policy maker and consider a framework of distributed leadership where SPOR funded groups invest in building connections at different levels throughout an organization or community. For example, some participants suggested more collaborative efforts with civil service, who may not be policy makers directly but often offer policy advice.

- **Receptor Capacity**

*"We don't need to improve our messaging and make research more appealing. The problem is the system can't or won't do what it doesn't want to do."*

Participants explain that it was unreasonable to suggest that a funding agency alone can change the healthcare system. The system is not designed to incorporate research into strategic decision making nor is this process adequately incentivized. As such, it is not "ready" to support the implementation of evidence-based change. Despite this, participants stressed that it is important to continue funding research and change advocacy initiatives like SPOR.

## **Strategies to Strengthen Collaboration with Policymakers and Health System Decision Makers/Future Directions**

### **1. Invest in Relationship Building, Networking Opportunities and Reciprocal Relationships**

- Invest in Relationship Building

*"The most actionable research starts and ends with relationships. Help us build those."*

- Participants stressed the importance of building relationships with policy and decision makers at all levels. These relationships can be fostered through dedicated funding that promotes facilitated linkages, test ideas, and build trust between researchers, PWLEs and policy makers. This funding can also provide an opportunity to demonstrate initial success that may motivate continued collaboration and build the foundations of infrastructure that will support the required growth and desired outcomes. Further, to foster these relationships, they must be incentivized. For

example, PWLEs, clinicians and researchers must all be remunerated when attending partnership tables.

- Participants also suggested collaborating with non-profit organizations and health charities who may already have established connections with policy makers.

- Expand Relationships to Diversify Collaborations Within the Policy and Health System Decision Making Systems

Participants recommended that SPOR-Funded Entities should expand relationships to include mid-level policy makers, policy advisors and policy makers at the municipal and/or organizational level. They also suggested that the SPOR program should foster connections with federal entities such as Health Canada. These collaborations may improve impact and promote multi-level, multi-jurisdictional buy-in and leadership. That said, participants stressed that these relationships need to be “reciprocal” where governments support and invest in these connections.

- Support Networking Opportunities

*“It would be interesting if there were speed networking events where government officials or other policy makers agreed to attend to learn about what people are doing or make connections.”*

Participants suggested the development of networking opportunities to connect universities, researchers, policy, and decision makers and PWLEs. These opportunities may also be a platform where researchers or policymakers can pitch ideas and research priorities to explore. Participants stressed that attendance to these events must be incentivized to ensure turnout and impact.

## 2. Encourage Priority Setting and Codesign

*“It’s important to identify research priorities and questions early on with policy and decisionmakers, so that the research findings are meaningful to them which would facilitate the uptake of the recommendations.”*

- Participants stressed the importance of cocreating research with policy and decision makers, health authorities, and healthcare providers and identifying collective research priorities as early as possible. They explained that this ensures research is meaningful to all parties involved, would help bridge the research-practice gap and promote evidence uptake and implementation. Conversely, policy makers will need to become more comfortable taking risks and making decisions based on “imperfect knowledge as research will rarely answer all of their potential questions.”
- Embedded positions were also suggested by participants who noted that they “are key to moving ahead in a collaborative way.” Scholar positions embedded within governmental organizations and health authorities can help bridge the “research and policy worlds” and promote accountability on both sides.
- Participants advocated for a matching platform where health systems, and policy and decision makers can publish their research priorities based on their needs. They can then be “matched” with researchers who possess the skills and interest to pursue these priorities. [Areas of Research Interest Database](#) in the United Kingdom was suggested as an example of such work.

- Regular touchpoints with SPOR-Funded Entities and ministers, deputy ministers and decision makers were also proposed by participants. They explained that these touchpoints may prompt discussions on research priorities and validate research that is underway.

### **3. Support the Development of Novel and Strategic Knowledge Mobilization Strategies**

*“Getting research to inform decision-making involves a lot more than just summarizing results in more understandable aggregate forms and finding the most persuasive ways in which to communicate them.”*

- Dedicated Funding for Knowledge Mobilization
  - Participants suggested dedicated funding grants that focus on knowledge mobilization or ensuring explicit and robust knowledge mobilization phases for all SPOR-funded projects.
  - Participants explained that SPOR can support knowledge mobilization by providing funding and training to support evidence synthesis and curation, rapid reviews, one-page briefs and infographics that ensure that research findings are effectively distilled and communicated to inform policy decisions.
  - Some participants found that integrating librarians on research teams was very helpful in customizing searches, creating file systems and databases. As such, they advocated for funding to embed librarians within research teams.
- Invest in the Creation of a National Knowledge Mobilization Hub
  - Participants advocated for a national, centralized platform where researchers, PWLEs and policy makers can share and explore findings, resources, reports, and policy briefs related to POR.
  - Participants suggested that policy and decision makers can also use this platform to pose a question or inquiry and receive the best available answer to support decision making. If the answer is not readily available through existing research, interested researchers can receive funding to conduct research that answers the policy question.
- Improve Awareness of SPOR and POR
  - Participants stressed that awareness of POR was impacting the uptake of SPOR evidence in health policies and decisions. As such, they suggested that SPOR dedicate efforts to improve awareness, share patients’ stories and leverage their voices and communicate SPOR successes within academia and among policy makers.
  - Participants noted that patients and PWLEs are viewed as electors by policy makers. Therefore, they are more likely to consider their opinions and direction. Some participants suggested training social media influencers who have a large audience to help spread and amplify the message of SPOR.

#### 4. Build Researchers' Capacity to Work with Policy and Decision Makers and Vice Versa

- Participants explained that working with policy and decision makers requires certain skillsets including storytelling, marketing strategies and message synthesis. Participants suggested that SPOR can offer standardized training based on best practices to researchers to build their capacity and effectively present evidence and engage policy makers.
- Participants suggested the establishment of a cross-jurisdictional, national Community of Practice where researchers can share successes, best practices, and learn from one another.
- Simultaneously, participants advocated for capacity building efforts for policy and decision makers to support their understanding of the value, role, and mechanisms of research and how they can benefit health policy and service delivery.
- Participants stressed that training modules must ensure roles and responsibilities of researchers, PWLEs and policy and decision makers are clearly outlined and communicated.
- Participants also recommended revisiting language and terminology. For example, what many refer to as “research” is in fact quality assurance or quality improvement from a policy perspective. As such, participants recommended using terminology that policymakers can relate to and avoids misinterpretation while keeping them engaged.

#### 5. Incentivize Policy Work for Researchers

Participants explained that policy work is currently not a priority for researchers whose focus is typically tied to the number of publications their work yields and the impact of their research. As such, participants suggested revising success indicators for research by reducing the emphasis on publications and instead, assessing whether research outputs are “policy-ready”, calculating the number citations within policy documents, considering whether research informs decision-making and evaluating the rigor of engagements and relationships. Participants also suggested working with universities to broaden the requirements for tenure to include contributions to health policy and practice. The University of Toronto Faculty of Medicine [Creative Professional Activity](#) promotion criteria were cited as one positive example.

### Promising Practices

- [Ontario General Medicine Quality Improvement Network \(GeMQIN\)](#) was a promising practice cited by participants that brings researchers, clinicians, policymakers, and patients together to improve patient care. Participants explained the key factors to the Network's success was flexibility in funding timelines, aligned incentives, and that research findings generated by the Network have driven policy work, simultaneously, policy questions have driven the Network's research priorities.

- [Health Accord for Newfoundland & Labrador](#) is another successful collaboration cited by participants. The Health Accord aims to use evidence and public engagement to improve the health in Newfoundland and Labrador. Research conducted by Newfoundland and Labrador SUPPORT Unit has successfully been incorporated into the Health Accord and is directing health transformation in the province.
- General Evidence Contractor Model was also suggested by participants as a promising practice that has been successfully utilized in the United Kingdom (UK) and United States. In this model, policy and decision makers pose a complex question that requires and different research teams (i.e. implementation, qualitative, evidence synthesis and evaluation teams) to solve. These researchers report back to the main coordinator or “general contractor”. [EPPI Centre for Policy and Practice in the UK](#) was suggested as an example.
- Participants explained that the [Ministry of Health Research Seed Grant Program](#) from BC was a great example of successfully matching the Ministry of Health’s policy questions with researchers whose area of study aligned with question. These grants are small pots of funding under \$50,000 that were meant to be completed in 1-2 years.
- [Ontario COVID-19 Science Advisory Table](#) was cited by participants as a successful collaboration where the government connected researchers to relevant policymakers to address research questions.
- Ontario SPOR SUPPORT Unit has had success coordinating policy roundtables and regular conversations with Assistant Deputy Ministers and Deputy Ministers. This has led to a broad understanding of Ministry prioritization and in turn allowed them to connect PWLEs with decision makers, influence policy and impact health services.
- BC SPOR SUPPORT Unit operates via a distributed team model, with staff housed within Michael Smith Health Research BC and across regional health authorities. They attributed this model to a lot of their success in brokering relationships and connect research and evidence to the right people

## Theme 7: Strengthening Governance for Canada’s Strategy for Patient-Oriented Research

*“It is essential that CIHR establish strong governance as part of the SPOR refresh, because the effects of good governance cascade down and affect all aspects of SPOR.”*

Throughout the engagements, participants stressed the importance of establishing strategically focused, appropriately funded management and governance of the SPOR program to build on the Strategy’s achievements and impacts.

This summary report includes data from three roundtables, Roundtable 9,10 and 11, 22 partner engagement reports, and 14 interactions (13 comments and 13 votes) from the online public engagement platform.

The roundtables were attended by researchers, PWLEs, funders, representatives from health authorities and health charities. Partners who contributed input on theme 7 include leaders from the community of SPOR-funded Entities (SFEs), the SPOR SUPPORT Unit Council, Maritime SUPPORT Unit, Manitoba SUPPORT Unit, Saskatchewan SUPPORT Unit, Alberta SUPPORT Unit, Ontario SUPPORT Unit, Québec SUPPORT Unit, Newfoundland and Labrador SUPPORT Unit, British Columbia SUPPORT Unit, CAN-SOLVE CKD Network, CHILD-BRIGHT Network, Diabetes Action Canada, Health Data Research Network (HDRN), The National Alliance of Provincial Health Research Organizations (NAPHRO), Health Charities Coalition of Canada (HCCC), University of Toronto’s Office of the Vice-President, Research and Innovation, Patient Advisors Network (PAN) and Centre of Excellence in Youth Mental Health.

### Considerations for Successful SPOR Governance

- **Clearly Articulated Program Goals and Objectives**

*“Function before form, strategy before governance structure.”*

Participants stressed that regardless of the governance model SPOR adopts, it is vital that clear goals and objectives as well as measures to track progress are established for the program. This will allow cohesion in the work conducted by the SPOR-Funded Entities. An effective governance model can then provide oversight, coordinate efforts, and ensure that these goals are met.

- **Greater Representation of PWLEs in Governance**

*“We need to ensure there is representation [in governance] of Indigenous peoples and other marginalized/racialized communities in Canada.”*

Participants advocated for greater representation within SPOR’s next governance structure at all levels of the health system (i.e., provincial/territorial, and federal). Specifically, they suggested embedding patient partners, PWLEs and members of underrepresented and Indigenous communities. Participants stressed that SPOR must consider investing time and resources, including mentorship opportunities, to support building PWLEs capacity so that they can meaningfully partner in governance. Participants also underscored the importance of including more than one PWLE in governance committees to avoid tokenism. In fact, some participants recommended having one PWLE to every non-PWLE member of the governance committee to help balance power and give authority to PWLE. Regardless of the governance structure,

participants strongly suggested that SPOR ensures PWLEs are adequately compensated and recognized for their time and contributions.

- **Better Alignment and Collaboration with Health and Social Services Systems**

*“If the vision for SPOR is to improve health outcomes and healthcare for the public, then we really need to be aligning with what the health priorities are in each region and each province and in each territory.”*

*“CIHR came up with this program in a vacuum without considering with what was already out there. And health charities were already doing many things.”*

Participants recommended including policy makers, decision makers, health authorities, health charities, NAPHRO, universities (large and small), rural healthcare providers, and primary care providers within SPOR’s governance. This would allow alignment of SPOR’s efforts with those led by these partners and as such, reduce duplication, de-silo work and promote collaboration towards common goals. They stressed that the roles of these partners should align with their capability, and expectations. For example, some SPOR funding partners explained that they are often brought to the table as funding partners, however, they see themselves more as implementation partners and suggested clarity of roles early in partnerships helps improve effectiveness.

- **Representation of SPOR-Funded Entities**

*“If networks and SUPPORT Units are to work together in post-Refresh SPOR, then the governance model will need to reflect that.”*

Some participants advocated for the inclusion of representatives from SPOR-Funded entities within SPOR’s overall governance to operationalize collaboration and help tailor funding opportunities to reflect health system and regional needs. However, others proposed having SPOR-Funded Entities represented within Regional Governance Hubs that report to a central, National Coordinating Oversight Committee. Participants referred to this model as “Tiered Governance”. CIHR would sit within the Oversight Committee along with patient partners and other partners. Reporting to this committee, would be Regional Governance Hubs that are dedicated to the oversight of specific areas within POR.

- **A Shift in CIHR Culture, Policies and Processes**

*“A shift in culture is required at CIHR which started by funding basic science and clinical trials. This type of research is very different from POR, which involves health systems and community organizations.”*

Participants suggested that there needs to be a shift in CIHR culture for SPOR and its governance to be successful. Participants explained that a lot of CIHR’s policies are based on what was needed and worked for basic sciences and typical research. However, given that POR is person-centred, certain processes must be adapted to accommodate this new way of working. For example, participants recommended the following:

- Adapting and allowing more flexibility of funding timelines to support relationship building with communities and research partners. Shifting funding models from project-based funding to longer-term funding that allows systemic changes.

- Amending peer review processes to make them more iterative and open when appropriate and training peer reviewers to assess meaningful engagement and criteria to look for in research proposals to gauge appropriate patient-partnership.
  - Review institutional policies that impede PWLE participation including CCV requirements, and institutional eligibility.
- **Ensure Adequate Human Resource Capacity**  
Regardless of the Governance structure, participants highlighted the importance of ensuring adequate human resource capacity to support ongoing governance engagement, oversight, and coordination.

### Considerations to Promote Transparency and Accountability in Governance

- Participants emphasized the importance of clarifying roles and responsibilities of each partner involved in governance to formalize accountability, reduce confusion, and maximize success and effectiveness.
- Participants recommended holding regular meetings and leveraging technological tools such as project management software and/or online communication portals to facilitate communication and information sharing, streamline governance processes and enhance collaboration.
- To support accountability, participants advised having more than one representative from an organization or group if possible.
- Lastly, participants suggested enhancing communication and awareness of the roles and responsibilities of the SPOR program vs. SPOR-Funded Entities and partners.
- Another example of a governance model from the Ontario Asthma Plan of Action, Primary Care Asthma Program (PCAP) to strengthen transparency and accountability to partners: *“PCAC was guided by an advisory panel including a policymaker, researchers, patients, and primary care providers. SPOR can ensure transparency and accountability within its governance structure through regular reporting and presentations of results to stakeholders.”* In this same perspective, another respondent suggested sharing and reviewing these results openly with patients, people with lived experience, researchers, and policy makers *“to devise plans forward that all can agree on and whose foundation is built on the ability to evolve and change accordingly to natural societal changes.”*

### Governance Model for Consideration: Collective Impact Approach

*“Collective impact approach is one that perhaps could be drawn from in considering an adapted model of governance for SPOR.”*

*“Working together towards something makes everyone stronger than everyone working apart. No one organization has the full ability/capacity to do all this and deliver on SPOR strategy.”*

*“I cannot imagine any other way to make SPOR successful.”*



*“I feel that this kind of collective impact approach could be a really big breakthrough for patient-oriented research in Canada.”*

As demonstrated by the quotes above, participants generally supported the adoption of a Collective Impact Approach. Participants indicated that this approach can “deal with fragmentations of the system” and ensures equitable communication and decision making among governance partners.

### **Considerations for Success**

To successfully adopt the Collective Impact Approach, participants recommended ensuring the following:

- Clear, comprehensible, and concise terms of reference and accountability mechanisms
- Strong, open, and transparent communication channels
- Strong leadership from the backbone organization, CIHR
- Leverage lessons learned from organizations who have adopted a Collective Impact Approach within SPOR like Health Data Research Network (HDRN) and Integrated Youth Services Network (IYS-Net) and adapt the model to align with SPOR’s needs.

### **Challenges to Adopting a Collective Impact Approach**

While many participants saw the potential of this governance model, there were a number of challenges they highlighted as well.

- Time and Resource Intensive  
*“Collective Impact can get you to go far but is a harder way. It requires resources and persistence and should not be taken lightly.”*

*“It is a good model, but we will all have to learn how to work together differently. All partners will have to learn what this model means and how to do it.”*

Since this approach is newer to many partners, operationalizing it requires considerable communication, time and resources to ensure buy-in and commitment from everyone involved.

- Collective Impact Requires Long-Term Staff and Corporate Memory  
Staff turnover within health systems and policy making spaces across the country is common. This makes creating momentum challenging as new staff would require onboarding and orientation before work can continue.
- Jurisdictional Priorities May Differ  
Participants reflected on the diverse mandates and priorities of regional, provincial/territorial, and national partners and suggested that it may be challenging to have such diversity at one “table” and reach a place of mutual agreement when it comes to operationalizing efforts to achieve common goals.

# Ideas for Renaming the Strategy for Patient Oriented Research (SPOR)

*Input from SPOR Roundtables, Online Platform and partner engagement activities*

## Participant Suggested Names

### 1. New Name, Same Acronym

Some participants suggested that the SPOR acronym is a brand within the research community in Canada and internationally. They explained that time and money spent on rebranding can be better spent developing reciprocal relationships. As such, they advocated to keep the acronym the same, but change what the letters stand for. Examples include Strategy for Person Oriented Research or Strategy for Partnership Oriented Research.

- Strategy for Person Oriented Research or Strategy for Person Centric Research

Participants explained that many folks do not identify with the term “Patient”. Using it in the SPOR name may lead to low engagement or a perception that SPOR work is not relevant to them. Some examples of individuals who the term patient is inappropriate include individuals from 2SLGBTQI+ communities, people who are homeless, underrepresented communities who have been harmed by the healthcare system etc. Therefore, the term “person” was suggested as a replacement for “patient”.

- Strategy for Partner Oriented Research

Replacing the term “patient” with “partner or partnership” was also suggested by participants. “Partner” stresses the importance of the culture shift SPOR is aiming for. I.e., changing how research has traditionally been done in the past by creating meaningful partnerships with people in a way that is more accessible and meaningful.

### 2. New Name, New Acronym

Some participants suggested names that created new acronyms. One participant commented that the name change would depend on the scope of the SPOR refresh: “If the focus is on truly patient-oriented research (i.e. research that is focused on the impact of care or wellbeing of patients - so a clinical focus) then the name as is may be appropriate. However, if the scope of the program extends beyond that then it seems a name change is needed.”

- Strategy for Patient and Population Driven Impact Research (SPPDIR), Strategy for Patient and Public Involvement in Research (SPPIR) or Citizen Led Evolving Action Research Initiative (CLEAR)

These names were suggested by participants as a way of remarketing SPOR. Participants explained that leaving patient in the name and adding population/public would make the name more relevant to a larger group of people (i.e., those that identify as patients and those that don’t). These names also allow flexibility of interpretation. For example, research surrounding a rare disease would involve patient engagements while broader healthcare implications and knowledge mobilization would involve the public or citizens.

Further the term “driven” in the first name was added to stress that research would be led by PWLEs.

- Strategy for Community Oriented Research Engagement (SCORE), Community Access and Research Expertise (CARE), or Community Partner-Oriented Research (CPOR)

Participants who suggested this name explained that conceptually, patient-oriented research is community-oriented research. It involved research that is embedded in culture, land, language and promotes, sustains, and shares traditional knowledge. As such, they suggested replacing the word “patient” with “community”. Participants also stated that administratively, it is easier to remunerate community members compared to patients.

- People with Lived Experience (PLEX), Patient and Public Involvement and Engagement (PPIE) or Patient Engagement Knowledge Network (PEKN)

These names were suggested as participants explained that many people are turned away from the term research. These names may be helpful as researchers are working on building relationships with communities. Another suggestion was to use the terms Alliance, Engage, or Embark instead of an acronym.

- Collaborative Health Research Initiative (CHRI)

The term “collaborative” was recommended as an inclusive term that emphasizes working together and implies power sharing, while maintaining the term “research” in the acronym.

- One commenter cautioned that this acronym was too close to CIHR.

- Canada Health Participatory Research Initiative (CHPRI), Canadian Research for Community Collaboration (CRCC), Canadians Allied in Research Engagements (CARE), or Canadian Initiative for Patient and Community Oriented Research (CIPCOR)

These names were suggested by participants who suggested explicitly including the term “Canada/Canadian” in the acronym to emphasize the engagement of people in Canada in patient-oriented research.

### **3. Some Were Hesitant to Move Away from the Term “Patient”**

Some participants expressed that they did not think SPOR should replace the term patient in its name. They explained that this may lead to confusion, especially among those that are just starting to understand POR. Others worried that removing the term patient might lead to engagement and partnerships with people who do not have lived experience or relevant experience within the healthcare system. They suggested that any change to the name must be made with intention and awareness among everyone involved. For example, one participant commented: “I feel we still need to make it explicit that patients, caregivers and the community

are included in research. When the word 'partnership' is used it is unclear to those who are naive to the research system that they are included.”

### **General Feedback Received on the SPOR Name**

Some participants had feedback on the SPOR name but did not have explicit recommendations on a new/different name. Participant feedback includes:

- The name SPOR raises a lot of issues and is not being properly conveyed in French.
- Using the term knowledge user or service user instead of patient.
- The term strategy may not be needed anymore as the focus is now on execution.
- The term engagement is not a correct term to use in POR. It implies that the researcher or academic is “reaching-out and inviting-in”. This risks amplifying power imbalances and inequities and suggests patients or PWLE are not full partners.