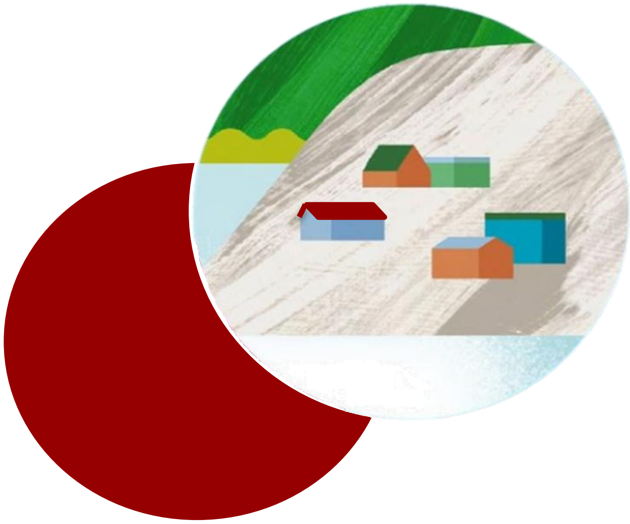
Strategy for Patient-Oriented Research
SPOR
Putting Patients First

Pathways to Impact:
Refreshing Canada’s Strategy for Patient-Oriented Research (SPOR)

March 2025

Land Acknowledgement



This report has been prepared as part of the Strategy for Patient-Oriented Research (SPOR) refresh, an initiative led by the SPOR refresh steering committee, supported by the Canadian Institutes of Health Research (CIHR). The steering committee recognizes that CIHR headquarters is situated on the unceded, unsurrendered Territory of the Algonquin Anishnaabeg Nation, whose presence and stewardship of this land date back to time immemorial.

We pay respect to all Indigenous Peoples (First Nations, Inuit, and Métis) from coast to coast to coast and to the lands they have cared for and continue to care for. We honor the knowledge, traditions, and contributions of Indigenous Peoples who have shaped and guided the development of this strategy, both directly and indirectly.

The SPOR refresh process seeks to respect and integrate Indigenous ways of knowing, doing, and being in research. This work aspires to foster culturally safe, distinctions-based, and inclusive approaches to health research and its mobilization. We aim to advance reconciliation and decolonization through actions that value and center the voices and priorities of Indigenous communities.

Contents

Message From the SPOR Governance and Strategy Refresh Steering Committee Co-Chairs

As Co-Chairs of the SPOR Governance and Strategy Refresh Steering Committee, we are pleased to present this report to CIHR and other SPOR partners. Tasked with developing recommendations to refresh Canada's Strategy for Patient-Oriented Research (SPOR), including a proposing new name, we hope this report will guide the next phase of SPOR's evolution.

This report reflects the insights and collaborative efforts of diverse partners from across Canada, including people and communities with lived experience. Our journey to provide recommendations for a refreshed SPOR has been both inspiring and enlightening, revealing the strength of the commitment to enhancing this type of research among so many partners across the country. With renewed objectives and recommended actions, we aim to ensure the continued relevance of people, communities and partner-oriented research within our evolving health care landscape, offering guidance to all SPOR partners and those interested in research co-production and knowledge uptake.

Reflecting on our engagement process, we are struck by the importance of involving people, communities and other partners in research in order to shape a more inclusive and responsive health system. The insights gathered from the SPOR community highlight the urgency for continued innovation and adaptation to meet the changing needs of our communities and healthcare systems. This includes the current healthcare landscape which is at a critical juncture marked by chronic workforce shortages, persistent challenges in service accessibility, and escalating inequities. As part of this evolution, the proposed renaming of SPOR reflects a commitment to inclusivity, partnership, and a broader focus on people-centred and partnership-oriented research, ensuring the strategy remains relevant and impactful for years to come.

This report not only captures these insights but also sets forward a strategic path to ensure that SPOR remains a vital program for advancing health research. By focusing on what matters most to partners, including people and communities with lived experience, SPOR has the potential to play a pivotal role in addressing these critical challenges while staying true to the original goal of the program: improving care experiences and health outcomes across the country.

The SPOR Governance and Strategy Refresh Steering Committee, which includes 15 dedicated members from various sectors (including patient and community partners, leaders in Indigenous health, research, government, health services, and health charity partners) worked tirelessly to guide this process. The collective expertise and commitment of this group have shaped both the engagement process to hear from the community and the recommendations presented in this report. Integral to the Refresh Steering Committee's work has been the tremendous effort and unwavering support provided by the CIHR-SPOR team. Since the inception of the SPOR refresh process, their dedicated secretarial and operational support has been foundational in enabling this initiative.

Throughout this process, we have emphasized inclusion and open dialogue, engaging a wide range of voices, including people and communities with lived experience, caregivers, researchers, policymakers, funders, and First Nations, Inuit and Métis (Indigenous) scholars and community partners. This collaborative approach has enriched our understanding and ensured that our recommendations are grounded in the diverse experiences and needs of people living in Canada. The collegiality and mutual respect within the Steering Committee have been remarkable, fostering a collaborative environment where every voice was valued and every perspective considered.

We extend our heartfelt thanks to all those who shared their insights and experiences during the engagement process. We acknowledge that channels for ongoing feedback and dialogue with different communities will be needed, recognizing that the journey of people, community and partner-oriented research is continuous and ever-evolving.

In conclusion, we believe that the recommendations in this report are essential to enhancing the impact of people-centred and partnership-oriented research. They are essential for driving the imperative transformation of health research and healthcare systems to become more adaptive, inclusive, and responsive to the immediate and evolving needs of people living in Canada. With the collaboration of all partners, centred on people and communities with lived experience, Canada's SPOR will play a vital role in advancing health research and health care in the coming years.

Diana Ermel, Co-Chair, SPOR Governance and Strategy Refresh Steering Committee, Member, Patient Advisors Network, Co-Chair, Patient Partner Advisory Committee of the Saskatchewan Patient-Oriented Research Centre

Tim Murphy, Co-Chair, SPOR Governance and Strategy Refresh Steering Committee, Vice-President of Health at Alberta Innovates, Member, National Alliance of Provincial Health Research Organizations

Executive Summary

Since its inception in 2011, Canada's Strategy for Patient-Oriented Research (SPOR) has worked to embed the priorities of people and communities into health research, and to embed patient-oriented research evidence into policy and practice, to improve health experiences and outcomes. Recognizing that much has changed in our health systems and health research ecosystem, CIHR and SPOR partners conducted a pan-Canadian engagement in 2023-24 to invite feedback on what is working well and what might need to change to ensure that the SPOR research investment is aligned with evolving health system and health research realities while reflecting the priorities of people and communities with lived experience, researchers, and health system decision makers.

What We Heard

This pan-Canadian conversation affirmed the need for ongoing, targeted investment in research that prioritizes the experiences of people and communities with lived experience, with a view to improving health policy, health services, health experiences and health outcomes. It also highlighted the need for SPOR to evolve, including its name, to better reflect its focus on inclusion, partnerships, and its broader relevance to people-centred and community-driven research. It emphasized the need to deepen SPOR's relevance to current health challenges, including the aftermath of the COVID-19 pandemic, the current health human resources and primary care crises, changing population demographics, the impact of social determinants of health, the need for Indigenous reconciliation, and the health impacts of climate change. It also highlighted the need for focused effort to address ongoing health inequities experienced by people identifying as Black, Indigenous, as having a disability, living rural and remote areas, and other underrepresented groups.

A Note on Terminology:

While this report introduces a proposed new name for the strategy, the term "patient-oriented research" continues to describe a specific and foundational methodology. Its use in the report acknowledges SPOR's historical achievements and the well-established principles of patient-oriented research within the research community.

The Challenge Ahead

SPOR's gains of the last decade are at risk given the persistent challenges and significant new headwinds facing health policy and care. People and communities that continue to face inequities in our current health systems have reason to be skeptical that research will address their needs and help to create change. Increased pressures in health systems often mean that health leaders are focused on solving problems of today, with limited time and resources available to co-develop, test, implement and scale-up patient and community driven-research evidence, innovations and solutions for tomorrow.

A Refreshed SPOR: Four Key Objectives with Actionable Recommendations

As a pan-Canadian research investment strategy focused on people and partner-driven health research, the refreshed Strategy for People-Centred and Partnership-Oriented Research (formerly Strategy for Patient-Oriented Research) can and must be a vector that contributes evidence, innovation, and solutions to the real problems facing people, communities and health systems today.

We believe the way to do this is to focus a refreshed SPOR on four key objectives, each supported by actionable recommendations, that focus people-centred and partnership-oriented health research to tangibly address today's pressing challenges.

1. **Enhance the Relevance and Impact of Research and Advance Health Equity:** Strengthen people, community and partner- oriented research and advance health equity by developing research agendas and research evidence that matter to a greater diversity of people and communities – particularly those that have been historically harmed by or excluded from research. Key recommendations include refocusing the strategy to emphasize partnership and reciprocity, ensuring support and more meaningful involvement of people and communities with lived experience of health inequities to co-lead research.
2. **Integrate Research into Health-System Transformation:** Support health policy and health delivery systems to adapt and evolve, by integrating people, community and partner- oriented research more directly into efforts that improve health care access, safety and quality (including learning health systems), and that drive health-system transformation. Key recommendations include investing in integrated, embedded and applied research teams; supporting rapid-cycle research through capacity-building in agile methods and flexible funding mechanisms; and linking research priorities with policy needs to better integrate research findings into practice and ensure evidence informs decision-making and service delivery.

3. **Mobilize Knowledge for Effective Intervention:** Create better health experiences and outcomes by advancing the use of people-centred and partnership-oriented research findings, insights and effective interventions that address individual and community health priorities, within and across jurisdictions. Key recommendations focus on investing in knowledge mobilization (KM) practices tailored to local contexts and cultures to accelerate evidence uptake in health policy and delivery. This includes co-developing collaborative KM efforts to ensure cultural safety, accessibility and relevance and supporting capacity-building initiatives to enhance the KM skills of researchers, communities, and policymakers. Providing funding for accessible KM platforms and knowledge brokers to bridge gaps between researchers and decision-makers, promoting the continuous use of research findings in policy development and clinical practice. Finally, opportunities for networking, knowledge exchange, and training should also be provided to sustain effective KM practices and ensure the integration of people-centred and partnership-oriented research into health systems.
4. **Sustain and Grow People-Centred and Partnership-Oriented Research** through enhanced governance and other enablers. Recommendations include establishing a governance framework for SPOR that works toward collective impact, promotes shared leadership across partners, including people and communities with lived experience, and working to reduce barriers in the health research ecosystem.

The Path Forward

These recommendations are grounded in promising practices and pathways to impact identified by members of the SPOR community in the pan-Canadian engagement activities. Many of our recommended actions build on work that is already underway across the health research ecosystem. Achieving these goals will require commitment and collaboration across the sector with new partnerships and coalitions, mobilizing multiple levers for change.

In that spirit, we offer this report to all partners involved in the Strategy for discussion and further reflection. As a next step, we invite the Canadian Institutes of Health Research and other health research funding partners to respond to these recommendations, outlining their individual and joint commitments for advancing people-centred and partnership-oriented research across Canada.

Context for the SPOR Refresh

In 2011, Canada's Strategy for Patient-Oriented Research (SPOR) was designed and launched to embed people with lived experience into all stages of the research process, with the goal of increasing the relevance and impact of health research and improving health experiences and outcomes and the quality of health care. Today, SPOR represents a national collaboration of researchers, patients, communities, provinces and territories, health care professionals and health system organizations. Sixty million dollars per year in funding under SPOR through the Canadian Institutes of Health Research (CIHR) is matched overall by many partners across the country.

As part of the SPOR Refresh, we propose renaming the strategy to the Strategy for People-Centred and Partnership-Oriented Research[1] to reflect its broadened commitment to inclusion, equity, and collaboration. This name change represents an evolution of SPOR's objectives while continuing to prioritize foundational principles of research co-creation with people, communities and other partners.

A recent SPOR evaluation emphasized the program's continued relevance and importance in advancing evidence-informed healthcare in Canada. With overall support from partners including people and communities with lived experience, the SPOR program has successfully demonstrated significant benefits including contributions to health policy and improved health services. SPOR has also generated new knowledge, built important research infrastructure, and supported the growth of patient-oriented research capacity among people and communities with lived experience, researchers and partners.

While the evaluation indicated that SPOR has shown success in its immediate outcomes, opportunities remain to strengthen patient-oriented research, address inequities, enhance research impact and strengthen the program's governance. The evaluation underscored the need to increase awareness and shared understanding of patient-oriented research, and other community-driven research methodologies among the health research community and decision-makers. While there are promising examples of SPOR's impact, it is challenging to attribute changes in patient experiences, outcomes, and health system

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[1] **Note on Terminology:**
While this report introduces the new name, the term "patient-oriented research" (POR) is retained in sections that reflect on SPOR's history, achievements, or its specific methodological approach. POR remains a cornerstone methodology within the strategy, and the transition to the broader name emphasizes a commitment to expanding engagement with diverse people, communities, and partners across Canada.

performance directly to SPOR, given the complexity of these factors. As such, more comprehensive evidence is needed to demonstrate SPOR's contribution to widespread improvements.

Following SPOR's evaluation, CIHR, together with SPOR partners, initiated a Refresh of SPOR's strategy and governance in 2023. The SPOR Refresh created an opportunity for the SPOR community to reflect on what has been achieved over the past decade, what is working well, and what might need to change to ensure SPOR is keeping pace with the evolving health care and health research landscape and accurately reflecting the priorities of people and communities with lived experience, researchers, partners, and health system decision makers.

This work was guided by a time limited SPOR Refresh Steering Committee, comprised of people with lived experience and community partners, clinician scientists, and government, organizational and community leaders from across Canada who have significant knowledge of the SPOR program and its objectives (Appendix 1). Co-chaired by Diana Ermel (representing the Patient Advisors Network) and Tim Murphy (representing the National Alliance of Provincial Health Research Organizations (NAPHRO)), the SPOR Refresh Steering Committee worked to define and shape a national conversation on the strengths, challenges and opportunities for refreshing the strategy. CIHR's SPOR team and consultant group Publivate Inc. provided secretariat support to the SPOR Refresh Steering Committee.

Over six months, multiple engagement activities were overseen by the Steering Committee to help inform the future design, governance, and direction of SPOR. These activities included partner-led discussions, virtual engagement roundtables, and an online public engagement platform (see Appendix 2 for further details). Participants also had the option to provide input on SPOR by phone or email, allowing for ease and accessibility.

Hundreds of people from across the country participated in online dialogues and a virtual platform, and hundreds more participated in partner-led meetings and surveys to share their input on the future of SPOR. Collectively, these engagement activities saw significant engagement from a broad and diverse cross-section of the patient-oriented research community that included participation from every province and territory except Nunavut.

The result was a wealth of input about SPOR's strengths, challenges and opportunities to evolve. The CIHR SPOR team provided content analysis of the community's input using NVivo 2020 to code the data. Key themes were subsequently identified, which guided the Steering Committee's development and refinement of recommendations. Summary reports on these themes can be found in Appendix 3. More detailed reports can be found on the NAPHRO website.

SPOR's Successes to Date

> "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."
>
> Engagement participant

SPOR has made significant strides in prioritizing, legitimizing, and valuing patient-oriented research and research co-creation. SPOR has increased awareness and appreciation of patient-oriented research which resulted in a culture shift within the research ecosystem. This shift led to pragmatic, inclusive, real-world research that focuses on priorities and outcomes deemed important by people and communities with lived experience.

SPOR has supported the integration of collaborative, multi-disciplinary environments that include researchers, policymakers, practitioners, people and communities with lived experience and the public. These collaborative environments have enabled researchers to consider issues from various viewpoints, enhancing the relevance of research. The SUPPORT Units and SPOR Networks have particularly been instrumental in establishing a strong infrastructure of local expertise connecting researchers across institutions, providing networking opportunities, methodological support and promoting patient-oriented research.

SPOR's impact on capacity building is evident in its support for researchers, people with lived experience, and organizations, particularly within smaller organizations and those with limited budgets and resources. Participants in the pan-Canadian refresh conversations noted that SPOR has provided valuable tools, training, and mentorship, enhancing the rigor and range of patient oriented-research. This capacity-building infrastructure has not only broadened expertise but also made research more accessible and relevant to people and communities with lived experience. Noteworthy achievements include the partnerships established with First Nations, Inuit and Métis communities, with entities like the CANSOLVE-CKD Network and SUPPORT Units in the Yukon and Northwest Territories leading efforts in Indigenous co-leadership and culturally safe research methodologies.

> "SPOR has supported the integration of collaborative, multi-disciplinary environments that include researchers, policymakers, practitioners, people and communities with lived experience and the public."
> - Engagement participant

Further, the SUPPORT Units have established strong relationships with provincial and territorial governments, aligning community needs with research priorities and influencing policy decisions. For example, since 2015, Alberta's SUPPORT Unit has facilitated close to 2,000 data access requests, reducing the time to access provincial health services data from 3 years to as little as 3-4 weeks. The reduction in turnaround time has remained consistent since 2015, despite the complexity of data access requests increasing over time. The acceleration has enhanced research impact and improved the quality of evidence through more comprehensive data sets. Other notable successes include Newfoundland SUPPORT Unit has contributed to health system transformation activities, and Ontario SUPPORT Unit has hosted policy roundtables that have bridged gaps between researchers and policymakers.

Overall, these achievements reflect SPOR's commitment to advancing patient-oriented research and addressing community health priorities through innovative and inclusive practices.

The Challenge Ahead

Health systems across Canada continue to face significant challenges in delivering needed services to diverse populations spread over vast areas. These challenges are intensified by several factors: the aftermath of the COVID-19 pandemic, the current health human resources and primary care crises, changing population demographics, growing inequities, the need for reconciliation with Indigenous peoples, and the health impacts of climate change. As these pressures mount, social determinants exacerbate existing inequities, making it crucial to address them to close the health gap and achieve health equity.

Amid this backdrop, SPOR stands at a critical juncture. The input collected through the Refresh engagement activities affirmed that there is a clear and ongoing need for research that prioritizes the experiences of people and communities with lived experience and caregivers, enhancing both policy and decision making as well as health experiences and outcomes for diverse communities across Canada. At the same time, SPOR's gains of the past decade are at risk as health systems are forced to prioritize immediate crises, often leaving little room for people, community and partner-oriented research and innovation. Health leaders have limited capacity and/or support to co-develop, test, and implement innovations that can transform tomorrow's health systems as they grapple with the problems of today.

As a pan-Canadian research investment strategy focused on people-centered and partner-driven health research, SPOR is uniquely positioned to be a vector of change that contributes evidence-based solutions and innovation to the real and urgent problems facing people, communities and health systems. The challenge for a refreshed SPOR is to find ways to systematically ensure that people, community and health system priorities are truly driving health research and knowledge mobilization to improve health experiences and outcomes for all.

This will require the strategy to support sustained relationships with a broader diversity of partners, including people and communities with lived experience to ensure that diverse priorities are driving health research. It will also require the strategy to transition from experimentation and proof of concept to focus on consolidating and scaling up partnerships and integration efforts that will bring tangible benefits to health systems and communities across Canada.

Below, we outline four new objectives that articulate distinct but complementary pathways to enhance SPOR's impact, grounded in the input collected through the SPOR Refresh engagement activities.

Strategic Objectives as Pathways to Impact

1. Enhance the Relevance and Impact of Research and Advance Health Equity

> *"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."*
>
> *- Engagement participant*

A foundational principle of patient-oriented research is that it must be relevant to people and communities with lived experience and focus on their priorities. The engagement process highlighted several barriers that continue to undermine the role of people and communities in driving health research. These include inadequate conceptualization, persistent tokenism, a historic lack of trust and insufficient time to build relationships between researchers and communities experiencing inequities, and various structural barriers.

Throughout the SPOR Refresh engagement sessions, it became evident that the term "patient" did not resonate as intended with many communities. The continued use of "patient" in the SPOR name risks decreased engagement or the perception that SPOR activities are irrelevant to certain groups. As such, a key recommendation for a refreshed SPOR is to rename it Strategy for People-Centred and Partnership-Oriented Research. The new name ensures the strategy remains relevant in addressing contemporary healthcare challenges and inspires a broader, more inclusive range of partners. This requires sharing the vision and engaging with community organizations, people and communities with lived experience, and policy makers.

A significant challenge people with lived experience, including First Nations, Inuit and Métis populations, continue to face in research is persistent tokenism in research relationships. In these cases, patient and community members may be present, but their input does not substantially shape research priorities, agendas and outcomes. Participants stressed the importance of continuing to invest in a culture shift in research towards reciprocal rather than extractive relationships with people and communities. Going forward, SPOR must ensure that collaborative research clearly articulates contributions by and benefits for all partners in the relationship.

Participants in the engagement conversations noted that the people and communities with lived experience who are engaged in SPOR lack representation from diverse segments of the Canadian population. For example, rural and remote communities often have limited access to research and training opportunities, which tend to be concentrated in urban centers. In a refreshed SPOR, it is essential to actively develop strategies to engage underrepresented communities, prioritizing power-sharing and valuing lived experiences. As highlighted by one participant *"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."*

> *"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."*
> - Engagement participant

Researchers highlighted challenges identifying, engaging and supporting involvement of underrepresented communities, as current research processes may not be accessible, framed as welcoming, or meaningful to these groups. They noted that mere representation is only a first step in developing more equitable, inclusive, diverse, anti-discriminatory and anti-ableist research. Superficial inclusion, without addressing deeper systemic issues and power dynamics, can perpetuate harm. While representation is crucial, it must be accompanied by meaningful, equity-based practices throughout the course of research partnerships.

Engagement participants noted opportunities to strengthen guidance on appropriate recognition, reciprocity, and compensation for people and communities with lived experience. Related to compensation, participants noted that financial payments can impact social assistance benefits, potentially limiting opportunities for those unable to afford participation. They suggested that SPOR explore other forms of reciprocity and compensation, while also facilitating discussions with the Canada Revenue Agency to consider exceptions for income reporting or offer flexible payment methods. As one participant recommended "*offering income tax deductions to promote equity by acknowledging the financial sacrifices that patient partners may incur*."

Inadequate definitions, guidelines, training, and supports for effective equity, diversity, inclusion, accessibility and anti-discrimination (EDIAA) work present significant challenges. Participants observed that *"CIHR is lagging behind other countries in terms of guidance to researchers and community partners on EDIA principles in research studies."* Unclear EDIAA definitions and preparation, have perpetuated "checkbox attitudes" and tokenism among some researchers. Furthermore, narrow definitions of underrepresentation do not account for intersectionality, limiting inclusion of various populations, such as rural or remote communities, people with disabilities, those unhoused or experiencing homelessness, immigrants, older adults, youth, linguistic minorities and socially and economically disadvantaged groups.

Structural barriers further complicate inclusion and collaboration efforts. As one participant noted, *"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 communities often face challenges like language barriers, limited time, and limited access to technology, particularly in rural and remote areas and smaller provinces and territories. Inaccessible information and communications, such as documents or platforms not compatible with screen readers and the lack of sign language interpretation, further exacerbate these barriers, making it difficult for many to engage meaningfully. Therefore, to create substantive change, a refreshed SPOR must address historical and structural inequities through intentional, sustained efforts. These efforts must center intersectional approaches, acknowledge ongoing and past harms, establishing safer spaces- including cultural safety, and operationalizing inclusivity beyond mere diversity.

Additionally, project-based funding timelines do not support the relationship-building critical to meaningful EDIAA work, including with First Nations, Inuit and Métis communities. Participants emphasized that forming relationships and building trust takes time, something often not accommodated within fast-paced scientific environments.

Further, they noted that academic environments do not recognize the work that Indigenous researchers are doing within Indigenous communities creating another barrier for Indigenous academics. Participants stressed that *“rigid grant requirements do not account for the dual role some Indigenous researchers/community members need to take."* The current funding model, which necessitates quick solutions and arbitrary timelines, can undermine the community engagement process essential to Indigenous research and people, community and partner-oriented research more broadly.

Input given during the SPOR engagement process underscored the need for a renewed emphasis on meaningful partnerships that incorporate all community voices – particularly those of underrepresented groups, to address community priorities and health system challenges. As such, the following objective was developed:

Strategic Objective 1: Strengthen community, and partner- oriented research and advance health equity by developing research agendas and research evidence that matter to a greater diversity of people and communities – particularly those that have been historically harmed by or excluded from research.

This objective lays the foundation for a transformed SPOR framework, where research priorities genuinely represent and benefit all population segments. This will help close critical gaps in understanding while ensuring that outcomes are directly beneficial to those historically underserved by research efforts.

2. Integrate Research into Health-System Transformation

> *“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 policymakers rather than conferences or papers.”*
>
> *- Engagement participant*

The SPOR engagement process highlighted the importance of ensuring that SPOR continues to be a vector that contributes evidence, innovation, and solutions to real problems facing people, communities and health systems. It also highlighted various challenges that SPOR must address, to contribute positively to health system improvement and change. These include further strengthening awareness, buy-in and system capacity to collaborate and use research and evidence as tools, as well as supporting research teams and partnerships with the agility and nimbleness needed to respond to pressing health policy and system challenges.

Awareness and buy-in from health policy and system decision-makers were identified as basic challenges that SPOR must continue to address. Insufficient information about SPOR's value and impact limits understanding of SPOR's potential to drive system-wide improvements and can undermine the use of SPOR-created evidence and resources. Policymaker turnover and capacity constraints further pose challenges to sustained collaboration. As noted, *"There is a challenge with policymakers around the 'revolving door' i.e., turnover of policymakers. Decision-makers are very busy, really hard to get them on the phone."* High turnover rates and capacity issues among policymakers disrupt ongoing collaborations, and when individuals leave, valuable relationships and individual knowledge about SPOR are often lost. Creating more sustained connections and platforms for bridging health policy organizations and health researchers can mitigate these challenges.

This issue is compounded by reduced receptor capacity within health systems, limiting SPOR's ability to act as a catalyst for change. Receptor capacity refers to how well a person, group, organization or system can take in and use new information, tools, or solutions to improve health services or outcomes. This aligns with the literature, which suggests that the uptake of research evidence, particularly in healthcare, is often constrained when research is not tailored to fit real-world conditions. Healthcare organizations may lack processes, policies, or incentives to integrate research findings, while healthcare practitioners' time, resources, and capacity are limited. These barriers make it difficult for the realities of day-to-day clinical practice to adjust in the face of new evidence. Embedding research within health system operations could mitigate these challenges by ensuring that evidence generation is an integral, ongoing part of healthcare delivery, reducing reliance on specific individuals and creating more robust, system-wide learning.

Participants explained that it was unrealistic to expect health research funders alone to transform the healthcare system that is not designed to incorporate research into strategic decision-making nor is it incentivized to do so. However, SPOR has a unique opportunity to invest in mechanisms that help to better integrate research and research evidence into health policy and health care delivery settings, to improve patient experiences and outcomes. This requires a dual focus: supporting health systems to "pull" research toward addressing urgent challenges while also making space for innovation driven by emerging evidence. As one participant noted, *“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 policymakers rather than conferences or papers.”* SPOR has the capacity to integrate both health system priorities and the priorities of people and communities, ensuring research agendas are responsive to real-world needs and patient-centered outcomes. Additionally, supporting mechanisms identified in the engagement sessions, such as investment in implementation science, rapid research methods and embedded researchers, SPOR can ensure the rigour of research is translated into action that transforms and improves care and policy.

Beyond the issue of awareness, buy-in and receptor capacity, the SPOR refresh engagements highlighted that healthcare systems face several pressing challenges that might impede the uptake of research. For example, the current health human resources crisis is exacerbated by increasing demands, leading to provider burnout, staff shortages, and reduced capacity for people and community engagement and involvement in research. Going forward, SPOR must be prepared and responsive to challenges facing health systems across the country to provide timely and relevant evidence. SPOR can also support the use of rapid-cycle implementation science, evaluation and evidence synthesis methods that allow evidence to be continuously generated and applied to pressing health system challenges.

Embedding patient-oriented research within existing quality improvement, learning health systems, and system transformation efforts ensures that research is applied to real-world challenges, making outputs more relevant and impactful. It also facilitates a cohesive approach to health innovation, enabling continuous feedback between research findings and practical implementation. Therefore, a second objective for the refreshed SPOR is:

Strategic Objective 2: Support health policy and health delivery systems to adapt and evolve, by integrating people- and community- oriented research more directly into efforts that improve health care access, safety and quality (including learning health systems), and that drive health-system transformation.

3. Mobilize Knowledge for Effective Intervention

> *"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."*
>
> *- Engagement participant*

The SPOR refresh engagements reinforced that continued investment and capacity building is necessary to bridge the knowledge-to-practice gap in the research process. While SPOR has supported significant growth in people and community engagement in research, participants identified that a more integrated and collaborative approach to mobilizing patient-oriented research evidence is required to ensure research evidence translates into better health experiences and outcomes.

Integrated knowledge mobilization is more than the dissemination of research findings at the end of a study. It is an iterative, participatory process involving the co-production of knowledge with partners, including people and communities with lived experience, clinicians and decision-makers, from the very beginning of the research cycle. This integrated approach ensures that research is not only accessible but also relevant and actionable for diverse knowledge users.

Engagement participants identified that researchers often lack the skills or resources to engage meaningfully with diverse knowledge users, including people and communities with lived experience, clinicians, healthcare administrators, and policy and decision-makers. Research outputs are often misaligned with the needs of these audiences due to issues such as report length, technical language, and a disconnect from broader health system priorities and policy timelines. Furthermore, a single study is rarely the unit of interest for decision-makers seeking to inform policy change. Instead, decision-makers require synthesized evidence that is responsive to the broader health system context and can be integrated with ongoing efforts to improve care. As such, SPOR evidence is not always "implementation ready" or relevant to policymakers, decision-makers, people or communities. To address this, SPOR should facilitate the development of tools, frameworks and mechanisms that aggregate and synthesize evidence across multiple studies, ensuring that knowledge products are timely, actionable and policy relevant.

In addition, people with lived experience and community knowledge users, including First Nations, Inuit and Métis community members spoke of barriers they face in demanding, accessing, understanding, and using high-quality evidence. One participant emphasized *"People have been researching land and medicine, but it is not coming to me... [We need to] 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."* This feedback highlights the importance of enabling communities to access, co-produce, control and apply knowledge locally.

Another participant noted, *"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."* The engagement process revealed that current knowledge mobilization language and efforts may not resonate with the lived realities or epistemologies of Indigenous or underrepresented communities, making intersectional approaches to knowledge mobilization challenging. To address this, future SPOR investments must focus on co-creation and intergenerational approaches and on embedding knowledge users throughout the entire research process to ensure that outputs are more aligned with the real-world needs of people and communities.

To support the development of novel and strategic knowledge mobilization strategies, participants suggested building researchers' capacity to work with different types of knowledge users, including through standardized training and the establishment of a national Community of Practice to support collaborative knowledge mobilization. Collaborative knowledge mobilization is a dynamic process that requires building long-term relationships and leveraging diverse dissemination methods, such as social media, storytelling, and culturally relevant knowledge-sharing strategies. Equally important is the capacity building of people, including youth and communities with lived experience to actively participate in the knowledge mobilization process, ensuring that they are not just passive recipients but co-producers and owners of knowledge.

The feedback that was heard during the engagement consistently emphasized the need for better knowledge mobilization that is not limited to the end of the research process, nor focused solely on dissemination. Instead, it should be a strategic and continuous engagement process that involves diverse knowledge users from research inception through implementation, focusing on effectively addressing community priorities across health sectors. This integrated and participatory approach ensures that interventions move beyond theoretical outcomes to practical use in various health care settings. As such, the following objective was articulated:

Strategic Objective 3: Create better health experiences and outcomes by advancing the use of people-centred and partner-oriented research findings, insights and effective interventions that address individual and community health priorities, within and across jurisdictions.

By fostering a culture of continuous, collaborative knowledge mobilization, SPOR can translate existing patient-oriented research evidence into improved health care interventions, practices and policies, contributing to better health outcomes for individuals and communities across Canada.

4. Sustain and Grow Patient-Oriented Research

Throughout the engagement process, participants consistently emphasized the importance of dedicated, ongoing efforts to sustain and grow patient-oriented research. While considerable progress has been made over the past 10 years in engaging people with lived experience as active partners in research, participants underscored that significant challenges remain. Many people and communities with lived experience continue to face barriers and require sustained support to remain engaged in meaningful ways. It is critical that the needs and priorities of people and communities with lived experience remain the core drivers for improving the quality of research, which can ultimately lead to better health care services, planning and policy.

Input and suggestions focused on a variety of enablers to enhance coordination among many partners supporting patient-oriented research, to improve how decisions are made about SPOR, and to reduce barriers in the research ecosystem. Importantly, SPOR must not only focus on recruiting new lived experience partners but also on sustaining and enhancing the engagement of those who have already contributed to advancing patient-oriented research.

Members of the SPOR community identified the many contributions that diverse actors across the country are making to embed people and community priorities into applied health research, and to mobilize patient-oriented research evidence into health policy and systems. Leaders in advancing patient-oriented research include patient and community-led groups, health charities, academic institutions, health delivery organizations, First Nations, Inuit and Métis governments and research teams, as well as health research funding agencies.

With so many partners contributing to this work, participants identified improved coordination and governance as a key opportunity to strengthen SPOR. They stressed the need for a governance structure that establishes clear program goals and objectives, enhances collaboration among SPOR funding partners and improves accountability for how decisions are made about SPOR. Strong governance should reduce duplication of efforts, improve alignment among partners and increase transparency in reporting and evaluating meaningful engagement of people and communities. One participant emphasized *"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."*

Participants advocated for greater representation of adequately compensated and supported people with lived experience in SPOR's governance structure with one participant asserting, *"We need to ensure there is representation [in governance] of Indigenous peoples and other marginalized/racialized communities in Canada."* Some participants suggested having "*one PWLE to every non-PWLE member of the governance committee"* to balance power. Participants also recommended involving policy makers, health authorities, health charities and other partners in SPOR's governance to promote synergy, better alignment and collaboration.

To promote transparency and accountability, participants suggested clarifying roles and responsibilities, holding regular meetings, and leveraging technology for effective and accessible communication. Participants generally supported the adoption of a collective impact approach, believing it could "deal with fragmentations of the system" and ensure equitable communication and decision-making among governance partners. However, they also noted challenges including the model's resource-intensive nature, the need for long-term staff and corporate memory, and potential jurisdictional differences. As one participant noted, *"Collective impact can get you to go far but is a harder way*."

Beyond governance, members of the SPOR community recognized that barriers in the research ecosystem continue to hinder efforts to grow and sustain patient-oriented research. Time constraints with the project-based funding model were cited as a hinderance to adequate relationship building and capacity building. Participants also noted a lack of incentives for researchers to engage in "ethical, high-quality patient engagement." Participants specifically called for a shift in CIHR's culture, emphasizing that "a shift in culture is required at CIHR, which started by funding basic science and clinical trials." They recommended adapting funding models, amending and better incentivizing peer review processes, and reviewing institutional policies to better accommodate people-centred and partner-oriented research.

Academic environments also continue to operate in a culture that can disincentivize people-centred and partner-oriented research. Competing priorities for early career researchers and misaligned goals make it difficult for them to meaningfully operationalize their patient, community and partner-oriented research training. As noted by one participant, “*early career researchers [doing patient-oriented research] face challenges in how they are evaluated for tenure and promotion.”* SPOR’s emphasis on research co-production and relationship building often conflicts with the traditional metrics of academic success, such as publishing in high-impact journals. Engagement participants also identified how current research ethics review processes are not designed to assess community engaged, co-produced research, or applied research where findings may be applied in real time to care.

Recognizing the importance and impact of governance and ecosystem on people-centred and partner-oriented, a refreshed SPOR must address these key areas in order to support this type of research to grow, as outlined in the following objective:

Strategic Objective 4: Sustain and grow people-centred and partner-oriented research through enhanced governance and by evolving other enablers beyond governance such as funding models, capacity-building mechanisms, and institutional policies, to ensure long-term sustainability and meaningful partnership with people and communities with lived experience.

The Recommendations: Charting the Course Forward for SPOR

Based on the insights gained during the SPOR refresh engagements and the strategic objectives outlined above, eight recommendations have been developed. These recommendations are accompanied by some specific sub-recommendations focusing on actions to move the objectives forward. The recommendations are meant to be led and actioned collectively by SPOR partners and are meant to ensure that the needs and priorities of people and communities with lived experience remain the core drivers of the strategy.

To support the implementation of the recommendations outlined in this report, examples of potential investments and efforts shared by the SPOR community can be found in Appendix 4. These examples are intended to illustrate the diverse pathways for advancing each recommendation. By showcasing community-shared initiatives, the report aims to inspire both existing and new partners, to consider these as actionable starting points for their involvement in SPOR initiatives.

Strategic Objective 1: Strengthen community, and partner- oriented research and advance health equity by developing research agendas and research evidence that matter to a greater diversity of people and communities – particularly those that have been historically harmed by or excluded from research.

1. **Rename Canada's Strategy for Patient-Oriented Research to Strategy for People-Centred and Partnership Oriented Research.**
   This renaming reflects the evolution of SPOR's objectives and its commitment to inclusion, partnership, and shared ownership.

2. **Ensure people and communities with lived experience are supported to meaningfully partner in research design, leadership, and decision making.**
   a. Co-design and implement protocols and guidelines outlining the roles and responsibilities of partners in people-centred and partner-oriented research while strengthening guidance on appropriate recognition, reciprocity and compensation for people with lived experience.
   b. Co-develop and implement initiatives to raise awareness of people-centred and partner-oriented research among people and communities with lived experience and policy/decision makers. This should include regular social media outreach, and partnerships with healthcare and patient advocacy organizations to utilize existing communication channels.
   c. Co-develop tools and resources to address power imbalances and promote equitable, meaningful partnerships including diverse recruitment and engagement strategies rooted in trust and reciprocity.
   d. Establish a national platform led by people with lived experience from diverse populations to facilitate communication, mentorship, and the exchange of knowledge between people with lived experience and community members engaged in research.
   e. Broaden allowable costs to cover wellness and accessibility needs, plain-language adaptations of research outputs and by advocating for tax exemption for people with lived experience in research.
   f. Expand partnerships across sectors such as education, justice, social services, and those responsible for the physical environment (e.g., urban planning, housing, transportation, parks, and environmental conservation) and climate action (e.g., energy, environmental protection, and agriculture) to ensure health research addresses broader determinants of health and root causes of inequities contributing to health disparities. Recognize that many of these sectors operate across multiple levels of government and require coordinated approaches.

3. **Support and build capacity in underrepresented communities[2] to conduct and co-lead health research in safe, respectful, and reciprocal ways.**
    a. Partner to co-develop and apply national guidance on conducting respectful, high-quality research that advances reciprocity and advances reconciliation.
    b. Enhance capacity within the health research community to meaningfully and reciprocally partner with members of underrepresented communities and people with lived experience.
    c. Provide research funding, capacity, and support directly to communities experiencing health inequities (especially northern, rural, and remote communities) to address community health research priorities.
    d. Promote partnerships across sectors, such as social services, education, and justice, to build a cross-sectoral response to health inequities, recognizing that health disparities often stem from intersecting social systems.

4. **Support First Nations, Inuit, and Métis (Indigenous) communities' self-determination in health research to address the unique priorities of their communities while acknowledging differences in capacity, operations, and needs.**

    a. Provide research funding to community-based organizations to better address the health priorities of Indigenous communities.
    b. Invest in education, training, and capacity-building for health research within Indigenous communities to accelerate Indigenous self-determination, leadership, and autonomy.
    c. Continue building and deepening reciprocal partnerships and relationships among First Nations, Inuit, and Métis community leaders and non-Indigenous community members, health services and health care professionals, health research funders, and researchers at national, provincial, territorial, and local levels.
    d. Invest in and support non-Indigenous health researchers to strengthen understanding and respect for distinction-based Indigenous epistemologies, culturally safe engagement and partnership, and Indigenous ways of knowing.

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[2] Communities that are underrepresented in health research include Indigenous community members, African, Caribbean- and Black (ACB) communities, immigrants and newcomers, children/youth, older adults, people that reside in rural and remote communities, members of the 2SLGBTQ+ community, people with disabilities, linguistic minorities including Anglophones in Quebec and Francophones outside Quebec and other visible and non-visible minorities.

Strategic Objective 2: Support health policy and health delivery systems to adapt and evolve, by integrating people and community- oriented research more directly into efforts that improve health care access, safety and quality (including learning health systems), and that drive health-system transformation.

5. **Fund patient-oriented research as an integrated component of learning health systems and broader efforts to improve health care access, safety and quality, and drive health system transformation**.
    a. Invest in integrated, applied research partnerships and embed research teams and researchers in local health systems, regional health authorities, F/P/T policy/decision makers, universities, people with lived experience, and health charities.
    b. Invest in rapid-cycle research, including building researcher and health system partners' capacity in agile research methodologies, and establishing flexible funding opportunities that support fast-tracked projects.
    c. Create responsive mechanisms that link research agendas with current policy priorities, to address pressing health issues.
    d. Support health system and policy partners in approaches that integrate patient-oriented research evidence into policy, service delivery and clinical practice.

Strategic Objective 3: Create better health experiences and outcomes by advancing the use of people-centred and partner-oriented research findings, insights and effective interventions that address individual and community health priorities, within and across jurisdictions.

6. **Invest in knowledge mobilization (KM) best practices that account for local contexts, cultures, and jurisdictions, that facilitate ongoing exchange and learning, and that accelerate the uptake of evidence in health policy and delivery.**
    a. Invest in the co-development and implementation of effective, culturally safe and accessible KM efforts that facilitate knowledge exchange and shares best practices with communities and practitioners.
    b. Develop and enhance the capacity of researchers, people and communities with lived experience, First Nations, Inuit and Métis and underrepresented communities to build KM capacity, foster KM culture, engage policy and decision makers and effectively present evidence in a way that meets their needs.
    c. Fund accessible KM platforms and knowledge broker positions to bridge the gap between researchers, health decision-makers, and care practitioners. Enhance and leverage these positions and existing KM platforms to ensure continuous use, adaptation, and the practical application of findings to inform health policy, innovation, clinical guidelines and standards.

d. Invest in spread and scale initiatives to expand the reach and impact of patient-oriented research findings, insights, and effective interventions, ensuring accessible and collaborative approaches that enhance relevance and broaden access to validated practices.
e. Create targeted opportunities for researchers, people with lived experience, healthcare practitioners, and policymakers involved in patient-oriented research KM to network, exchange knowledge, access tools and training, and collaborate to support the sustained application of effective KM.

Strategic Objective 4: Sustain and grow people-centred and partner-oriented research through enhanced governance and by evolving other enablers beyond governance such as funding models, capacity-building mechanisms, and institutional policies, to ensure long-term sustainability and meaningful partnership with people and communities with lived experience.

7. **Establish a governance framework for SPOR that includes a diversity of people with lived experience and other SPOR partners, and promotes collective impact, shared leadership, and accountability.**

    a. Create a coordinating governance body that represents multiple perspectives involved in SPOR, builds consensus on shared priorities and advises CIHR and other SPOR partners on major research investments for the strategy.
    b. Develop structured working groups and mechanisms to empower people with lived experience and other partners in shaping SPOR priorities and governance decisions.
    c. Launch a National Coordinating Centre (NCC) as the operational and strategic hub, facilitating collaboration, knowledge mobilization, and synergy across SPOR-funded entities and broader initiatives. As a part of its mandate, the NCC will maintain this report as a living document, incorporating ongoing feedback to adapt SPOR activities to evolving needs and priorities.
    d. Establish clear reporting and evaluation criteria to ensure accountability to the strategic objectives and collective impact principles, with regular progress monitoring and outcomes reporting. These criteria should include indicators and evaluation approaches that are meaningful and relevant to all partners, including First Nations, Inuit, and Métis partners.
    e. Progress towards a collective impact approach by enhancing cross-sector partnerships, reducing redundancies, and strengthening coordination.

8. **Address barriers and support enablers to people-centred and partner-oriented research within the research ecosystem**.

a. Establish robust and harmonized evaluation strategies co-designed with people with lived experience, including First Nations, Inuit and Métis community members and members of underrepresented communities. These strategies should include measurable objectives, timelines, metrics, and evaluation criteria to monitor progress and ensure accountability.
b. Fund and support cross-jurisdictional, patient-oriented research through improved data linkages, data sharing, analytics, and data management, ensuring that these processes respect Indigenous data sovereignty, working in partnership with Indigenous communities to develop culturally appropriate data governance frameworks.
c. Address institutional barriers within funding agencies that impede patient-oriented research, including administrative barriers and peer review processes.
d. Revise institutional eligibility criteria and establish flexible funding streams to allow community-based organizations and Indigenous organizations to directly apply for and administer research funding.
e. Develop partnerships to identify and address barriers to advancing patient-oriented research within the research ecosystem, including evolving tenure policies and research ethics processes to better support POR.

Conclusion and Next Steps

While more work is required to promote the co-creation of research and its mobilization, the future looks bright as we build on the important investments that SPOR has made to date, establishing further pathways to increase the impact of patient-oriented research on health policy, health systems, health experiences and health outcomes. Our goal is to break down silos and position research not as a standalone effort, but as an integral part of the larger ecosystem dedicated to improving health and healthcare for all.

Importantly, these recommended actions are directed at multiple actors within the health research ecosystem. Throughout the SPOR Refresh engagement process, we heard about the many contributions that diverse actors across the country are already making to embed patient and community priorities in applied health research, and to mobilize patient-oriented research evidence into health policy and systems. We also heard that barriers and facilitators for patient-oriented research exist across many different parts of the ecosystem. To truly advance this work, new partnerships and coalitions, leveraging diverse expertise and mobilizing multiple levers for change, will be necessary.

Taking to heart the vision that this is ***Canada's*** *SPOR,* we believe that the strategy will only succeed if many actors continue to actively contribute to advancing these refreshed objectives. As numerous members of the SPOR community have pointed out, a collective impact approach holds promise as a more open, transparent and collaborative way to govern the strategy moving forward.

As a starting point, collective impact requires a common agenda, shared by many partners. We believe this report, grounded as it is in the input of hundreds of SPOR participants from across the country, could form the basis of that common agenda around which many partners may coordinate their people-centered and partnership-oriented research activities. We see this report as a living document, with the potential to frame the work ahead while being adaptable in response to evolving circumstances and needs of the patient-oriented research community.

In that spirit, we offer this report to all partners in the Strategy for Patient-Oriented Research for discussion and further reflection. We invite the Canadian Institutes of Health Research and other health research funding partners to respond to these recommendations, outlining their individual and joint commitments for advancing patient-oriented research across Canada. As leaders in patient-oriented research and individual members of this vibrant community, we look forward to working together with everyone in the patient-oriented research community to continue to strengthen co-created health research that ultimately improves health systems, health experiences and health outcomes for Canadians.

Acknowledgements

The SPOR refresh process was made possible through the collaboration and support of many organizations and individuals. We gratefully acknowledge the Canadian Institutes of Health Research (CIHR) for providing funding for the SPOR strategy and governance refresh process.

We extend our heartfelt thanks to the CIHR-SPOR team, whose dedicated secretarial support was integral to the success of this initiative. We also sincerely appreciate Publivate for their expertise and efforts in facilitating the Pan-Canadian engagement process. Additionally, we acknowledge the National Alliance of Provincial Health Research Organizations (NAPHRO), a valued SPOR partner, for hosting the “What We Heard” report and ensuring this critical document was accessible to all partners.

Finally, we express our profound gratitude to all who participated in the SPOR refresh engagement conversations, generously sharing their insights, experiences, and perspectives. We are especially thankful to those who took on leadership roles in facilitating these discussions, ensuring diverse voices were heard and included. Your contributions have profoundly shaped our recommendations for a refreshed SPOR and will continue to guide its implementation as it evolves.

Appendix 1- SPOR Governance and Strategy Refresh Steering Committee (RSC) Members

Table 2: SPOR Governance and Strategy Refresh Steering Committee (RSC) Members

RSC Member Name	RSC Member Bio
Diana Ermel, Co-Chair	Diana Ermel is the past chair of the Canadian Breast Cancer Network and co-chair of Patient Partner Advisory Council of the Saskatchewan Centre for Patient-Oriented Research. She is a volunteer advocate who is passionate about patient-oriented research and equal access for patients at all health-related decision-making tables.
Tim Murphy, Co-Chair	Tim Murphy is Vice-President of Health at Alberta Innovates, and formerly Vice-President of Provincial Platforms and SPOR. Tim was the inaugural Executive Director of Alberta's SPOR SUPPORT Unit and as Vice President of Provincial Platforms, he led the Secondary Use of Health Data Project and built and mobilized capacity for patient-oriented research by securing the necessary governance and partnership relationships amongst Alberta's academic, policy, and health service delivery organizations.
Math'ieya Alatini	Math'ieya Alatini, a member of the Kluane First Nation, puts her experience and energy to work for Canada's Indigenous governments and northern communities as the chief strategist for GSD Strategies, where she leads successful partnerships.
Laura Commanda	Laura Commanda is the Associate Scientific Director of the Institute of Indigenous Peoples Health (IIPH). She is Anishinaabe and a member of the Serpent River First Nation in Ontario. She has a keen interest in strengthening health information and research at the community level.
Julie Couture	Julie Couture is Director of Research and Internal Coordination at the Quebec Ministry of Health and Social Services. She is a manager with rich and

	varied experiences in the field of health and social services research.
Vincent Dumez	Vincent Dumez, MSc., C.Q., patient partner, Director of Community Partnerships at the Faculty of Medicine, holds a finance degree and a master's degree in management science from HEC Montréal. Mr. Dumez is actively involved in developing the "patient partner" concept.
Richard Glazier	Dr. Richard Glazier, Scientific Director of CIHR's Institute of Health Services and Policy Research is a professor at the University of Toronto in the Department of Family and Community Medicine, Faculty of Medicine, and Dalla Lana School of Public Health. His research focuses on the evaluation of health system transformations to improve health equity.
Fiona Jeffries	Fiona Jeffries has been Executive Director of Standards and Policy in the Health Policy and Planning Division of the Ministry of Health, Seniors, and Long-Term Care since 2021. Prior to joining the government, she led community health assessment, community development, and health education in regional health authorities.
Maria Judd	Maria Judd is the Vice-President of Strategic Initiatives and Programs at Health Excellence Canada. A physiotherapist and epidemiologist by training, and a fellow of the NHS Quality and Safety Programme, her portfolio includes priority and cross-cutting areas.
Carol Fancott	Dr. Carol Fancott is Director, Patient Safety, Equity, and Engagement at Healthcare Excellence Canada and leads work to integrate safety, equity, and engagement as core elements for system transformation.
Amy Lang	Dr. Amy Lang is the Executive Director of CIHR Patient-Oriented Research. She provides leadership and expertise for the Canadian Strategy for Patient-Oriented Research (SPOR), and other patient-oriented research initiatives within CIHR.
Shana Menkis	Currently serving as the Executive Director of the Quality and Citizen Experience (QCE) Branch with Manitoba Health, Seniors and Long-Term Care (MHSLTC), Shana and her team oversee health system quality, including patient safety people-

	centred care, patient and public engagement and patient experience. Shana came to the branch from MHSLTC Infrastructure, where the team oversaw the capital program for the health system. In her previous roles, Shana led operations for service delivery with central government services as well as in the social service sector. She holds a Master's in Business Administration, with a particular interest in resource management and leadership development. Shana has certification in psychological safety in the workplace and trains non-profit professionals on designing safe and respectful work environments. She currently sits on the Community Advisory Board for Reaching Home with Service Canada as well as maintaining participant-facing volunteer roles with West Central Women's Resource Centre, Jewish Child and Family Service, and 1JustCity. She loves working with high-energy teams and building systematized supports for all staff.
David Phipps	David Phipps, Network Director of Research Impact Canada and Assistant Vice-President of Research Strategy and Impact, sits on knowledge mobilization committees around the world and has been awarded the Queen Elizabeth Diamond Jubilee Medal for his influential work.
Victoria Schuckel	Victoria is Executive Director, Research and Technology at the British Columbia Ministry of Health. She has been active in commissioning and mobilizing research knowledge and actively engaging people with lived experience through many initiatives and processes. She remains active with the BC SPOR Support Unit, Chronic Disease Networks, the Health Data Research Network, and other SPOR initiatives.
Lehana Thabane	Dr. Lehana Thabane is Vice-President of Research at St. Joseph's Healthcare in Hamilton; Scientific Director of the Joseph's Healthcare Research Institute; Professor of Biostatistics; Associate Member of several Departments of Medicine; an elected member of the International Statistical Institute; and Editor-in-Chief of the journal *Pilot and Feasibility Studies*. He has served on several CIHR review committees.

Pamela Valentine	A neuroscientist by training, Dr. Pamela Valentine believes in achieving impact in the health domain, a passion she developed as a basic scientist with a strong desire to facilitate translation between research and clinical care. Passionate about community involvement, she sits on numerous boards and committees, including the Health Charities Coalition of Canada and the International Progressive MS Alliance.
Connie Côté	Connie Côté has been involved in the not-for-profit, regulatory and charitable health sector for over twenty-five years and is currently the Chief Executive Officer of the Health Charities Coalition of Canada (HCCC) and a Director with the Brockville Hospital Board of Directors. Her priorities at HCCC include advocating on issues related to health research and health policy and working with members to bring forward the interests of people with lived experience and communities served by health charities.

Appendix 2: The SPOR Refresh Engagement Process

This section describes the methodology that guided the refresh engagement process. Throughout the process, the shared commitment to inclusivity, open dialogue, and respect helped ensure productive and insightful discussions. The SPOR Refresh Steering Committee worked for a year to define and shape a national conversation on the strengths, challenges and opportunities for refreshing the strategy. Hundreds of people from across the country participated over six months in community meetings, online dialogues and a virtual platform, to share their input on the future of SPOR.

Engagement Design

Over six months, multiple engagement activities were overseen by the Steering Committee[3] to help inform the future design, governance, and direction of SPOR. Committee members were selected for their lived experience, leadership, and knowledge of patient-oriented research and related systems of SPOR. The engagement activities consisted of partner-led discussions, facilitated virtual engagement roundtables, and an online public engagement platform as described in Table 1. Participants also had the option to provide input on SPOR by phone or email, allowing for ease and accessibility.

Table 1: Summary of Partner Engagement Activities

Engagement Activity	Description	Participants/ Reports
Partner-led Discussions	▪ A toolkit was developed by CIHR to equip leaders and other interested partners to facilitate conversations with their communities across the seven engagement themes (or other topics of interest) related to SPOR. ▪ Virtual meetings with partners, including CIHR Institutes and their advisory boards, SPOR-funded entities, University Delegates, and national organizations relevant to POR. ▪ Focus groups and surveys have been conducted with people with lived experience across various partner organizations.	79 reports from 39 partner organizations

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[3] Appendix 1 lists the SPOR Governance and Strategy Refresh Steering Committee members.

Engagement Roundtables	▪ Purposeful selection was used to ensure that a variety of perspectives were represented through 13 virtual roundtables, including geographical representation, Indigenous representation, gender diversity, and diversity of background and experiences including those of youth and older adults. ▪ Two Indigenous-focused roundtables were led by an Indigenous facilitator and were opened and closed by an Indigenous Elder.	220 participants at 13 engagement roundtables
Public Engagement Platform	▪ Online platform in English and French open to anyone interested in SPOR/POR.	127 participants

Insights and Analysis

The data gathered through the engagement process was analysed using descriptive statistics to understand the participants' demographics. NVivo 2020 was employed to conduct content analysis, allowing the identification of key themes that guided the Steering Committee's development and refinement of recommendations.

Who We Heard From

The engagement process brought together a wide array of partners and collected valuable insights through diverse methods. The online platform and roundtables collectively saw significant engagement from a broad and diverse demographic that included participation from every province and territory except Nunavut. Out of the 347 participants:

- 38.3% (133) self-identified as a person with lived/living experience.
- 24.5% (85) self-identified as a researcher.
- 9.5% (32) self-identified as Indigenous (7), First Nations (18), Métis (5), or Inuit (2).
- 17.3% (22/127) self-identified as a member of a racialized community (this data was only available for the online platform).
- 7.1% (24) self-identified as francophone or bilingual.
- 6.9% (23) self-identified as policy/decision maker.
- 5.5% (19) self-identified as a funder.

- 73% (153/220) self-identified as female, 23% (47) male, 1% (2) two-spirit, 1% (2) non-binary and >1% (1) genderqueer (this data was only available for the roundtables).

While efforts were made to be as inclusive as possible, certain groups remained underrepresented, including those from the northern territories and Atlantic provinces; males; francophones; members of the 2SLGBTQ+ community; and Indigenous groups (particularly Métis and Inuit). Recognizing these gaps is crucial and highlights a need to develop strategies for building trust and better connections with underrepresented communities to ensure inclusive engagement in the future.

Appendix 3: Findings and Emerging Themes

This section summarizes the findings from partner engagements. The feedback is organized under seven themes, each of which includes the key insights from the engagement process, including strengths and challenges. These findings, in turn, provide the basis for the four strategic objectives and our recommendations. Longer summaries can be found here.

Theme 1: Strengths and Challenges

Participants identified several strengths and achievements of the SPOR program. For example, they cited SPOR's success in incorporating people with lived experience perspectives, which led to increased community awareness of research, and encouraged a shift toward more collaborative and inclusive practices within the research community. Further, with the help of resources, training, and mentorship, participants explained that SPOR has enhanced the capacity of people and communities with lived experience, researchers and organizations – particularly smaller organizations and those with limited resources – to contribute to patient-oriented research (POR). They also outlined that SPOR-funded initiatives are more likely to be in tune with local community needs, providing coordination, methodological support, and responsiveness to specific health priorities, thereby improving health outcomes.

Simultaneously, participants highlighted challenges and limitations that a renewed program can address. For instance, the short timelines around SPOR's project-based funding make effective relationship- and capacity-building very difficult. Additionally, despite efforts to be inclusive, geographic, linguistic, and cultural barriers make it difficult to engage certain underrepresented groups, such as First Nations, Inuit and Métis communities, newcomers, and people residing in rural and remote areas. Participants also noted how the evidence produced through SPOR does not consistently influence policymaking. This may be due to misaligned research and health system priorities, the formats in which findings are presented, or reduced capacity within the system to use these insights (receptor capacity). Further, inadequate governance structures and strict privacy laws complicate effective data management and sharing, leading to duplicated efforts and isolated initiatives. It has also been difficult to demonstrate the program's overall impact due, in part, to the complex range of factors that contribute to health outcomes.

Finally, adapting the operational culture of research funding processes to better support patient-oriented research – including changes in funding timelines, peer review processes, and policies that impact participant engagement – is vital for aligning with SPOR's objectives.

Theme 2: Important Trends and Emerging Needs

Since SPOR was created in 2011, much has changed in our health systems and the health research ecosystem. Participants outlined some of the emerging trends while reflecting on evolving health, partner, including people and community with lived experience priorities that a renewed SPOR strategy can prepare to address. The health human resources crisis that has been affecting health care providers' ability to engage in research was also raised. Participants suggested better training and alternative workforce models (such as peer support) to address these challenges. Innovations like artificial intelligence and virtual care are further changing the health care landscape. Participants explained that while these technologies bring benefits, they also pose challenges, such as new ethical dilemmas and issues of access, which require further research to ensure that new tools are both safe and effective. As demographics shift, the needs of communities change and health care systems must be reevaluated and adopt new approaches, ranging from research partnerships with diverse groups to more holistic models focused on wellness and prevention. Similarly, the health effects of climate change are becoming more apparent. Research is needed to develop strategies to address these effects and understand their broader impacts. Finally, participants flagged the erosion of public trust and rise of misinformation. They suggested building trust through transparency and combating misinformation to strengthen public confidence and ensure community support for SPOR initiatives.

Theme 3: First Nations, Inuit and Métis (Indigenous) Self-Determination and Health Research

Participants stressed that Indigenous communities should have the authority to lead research agendas that impact them. This includes controlling research priorities, design, implementation, and dissemination to ensure alignment with their needs and values. However, challenges in effective engagement and participation often stem from administrative and funding barriers that do not reflect the realities of these communities. Other issues include tokenistic practices that disrespect Indigenous knowledge and delays caused by exchanges and responses to ethics board suggestions. Participants recommended ensuring research capacities are built within Indigenous communities. This requires investments in education to support cultural competency and combat anti-Indigenous racism, alongside flexible, long-term funding to support sustainable efforts and relationship building. They also recommended developing research frameworks that respect and incorporate Indigenous knowledge systems for meaningful knowledge mobilization and the production of outcomes that are truly beneficial to Indigenous communities.

Theme 4: Strengthening Equity, Diversity, Inclusion, Accessibility, and Anti-Discrimination (EDIAA) in Patient Engagement and POR

Participants explained that current patient-oriented research activities do not involve the diversity of the Canadian population or address the full range of the population's health research needs. This is in part due to inadequate Equity, Diversity, Inclusion, Accessibility, and Anti-Discrimination (EDIAA) definitions, guidelines, and frameworks, leading to tokenistic practices and insufficient guidance on how to effectively implement and measure EDIAA strategies. Further, various structural barriers, such as language issues, poverty, and limited Internet access, hinder full participation from underrepresented groups. Systemic issues in health care and research also prevent equitable participation. To support EDIAA effectively, participants suggested comprehensive reforms in funding and policy. These include restructuring funding to prioritize relationship building and incorporating support for accessibility aids and community-led initiatives. Enhancing the representation and involvement of diverse groups in patient-oriented research requires the creation of dedicated positions and training programs. This will increase leadership from underrepresented communities and assist in developing community partnerships for genuine engagement.

Theme 5: Building Capacity and Partnering for Excellence in Patient-Oriented Research

Building capacity for patient-oriented research among all relevant partners including people and communities with lived experience, practitioners, organizational leaders, policymakers, researchers, and research funders has always been a core goal of SPOR. However, participants outlined several challenges related to this goal. For instance, participants noted that many SPOR-funded entities (SFEs) work in silos leading to duplicative efforts and misuse of resources. Further, low awareness and limited access to SPOR resources have had a negative impact on uptake within the research ecosystem. Participants stressed that early career researchers' tenure and promotions rely heavily on publications, while establishing relationships can take considerable time. This makes it difficult to conduct and sustain patient-oriented research work in a meaningful way and may lead to tokenistic engagement despite adequate capacity building efforts and training. Participants suggested co-drafting a "POR Foundations Curriculum" with people with lived experience that harmonizes existing training opportunities and utilizes experiential, collaboration-based learning that aligns with the needs of people and communities with lived experiences and underrepresented communities, knowledge users (such as health care professionals, academics, and PhDs), trainees, students, and youth to support their understanding, awareness participation, and uptake of POR.

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

Communicating and integrating research findings into the policy making process has been an ongoing challenge in health research broadly and within SPOR. Participants explained that this is due to a gap between the priorities, objectives, evidence needs, and timelines of researchers, on one hand, and policymakers, on the other. Additionally, policymakers' awareness of SPOR's role and full potential is lacking, leading to underuse of available research resources and a lack of engagement. Finally, challenges like high turnover among policymakers and capacity constraints, along with a health care system not optimized for integrating research into decision-making, limit effective collaboration.

Participants suggested several strategies to address these challenges. For example, building networks and reciprocal relationships can foster trust and test ideas among researchers, people with lived experience, and policymakers. Further, engaging directly with decision-makers and health authorities from the start to co-create research can help align research priorities and results. Participants also suggested placing scholars within government organizations such as health ministries, health authorities and publicly funded health advocacy organizations who can serve as bridges between research and policy sectors, enhancing mutual accountability. SPOR can also support the creation of concise communication tools like infographics and one-page briefs which can make research findings more accessible and actionable. Finally, adjusting evaluation metrics for research success to include impacts on policy and practice can encourage deeper engagement with policy processes.

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

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. To do so, they suggested establishing clear, achievable goals for cohesive efforts and measurable outcomes within the SPOR framework. Participants recommended enhancing the governance inclusivity by involving a broad spectrum of partners – including people with lived experience, SPOR-funded entities, policymakers, health authorities, the National Alliance of Provincial Health Research Organizations (NAPHRO), health charities, universities, and health care providers at all levels – to ensure that diverse perspectives drive SPOR's strategies. Participants stressed the importance of clearly defining the roles and responsibilities of all governance participants to improve accountability and effectiveness. A collective impact framework with well-defined terms of reference, robust accountability mechanisms, and clear communication channels was suggested by participants.

Appendix 4: Examples of the Kinds of Investments and Efforts Needed to Operationalize the Recommendations

The following examples represent a cross-section of specific investments and strategic efforts identified by the SPOR community throughout the refresh engagement process. These community-driven ideas serve as practical illustrations of how SPOR recommendations can be implemented and adapted across diverse contexts and jurisdictions. In sharing these examples, we hope to ignite momentum toward action and encourage the SPOR community to take active ownership of these examples, adapting and expanding upon them to address their own unique contexts. This collaborative approach will be essential to the long-term success of SPOR's mission and the realization of our shared vision for a healthier, more inclusive future.

Equity, Diversity, Inclusion, Accessibility, and Anti-Discrimination (EDIAA) Initiatives

- Funding to co-design and synthesize trauma-informed engagement, EDIAA definitions, and training modules developed in partnership with underrepresented community members and researchers, with clear guidelines on incorporating EDIAA practices in POR.
- Funding that connects researchers with accessibility professionals to support and improve accessibility while fostering a learning environment.
- Funding for equitable access to existing training modules and resources currently behind paywalls.
- Funding to establish an EDIAA Community of Practice to guide and support EDIAA initiatives across SPOR-funded entities, reduce redundancies, and promote collaboration.
- Funding to build capacity and create opportunities for underrepresented community members to be trained and hired in EDIAA and research leadership roles.
- Funding and support for communities to create their own accreditation systems based on their EDIAA needs and priorities.

Indigenous Self-Determination and Community-Led Research

- Funding to co-develop research agendas reflecting the needs, priorities, and aspirations of First Nations, Inuit, and Métis partners.
- Co-designed funding opportunities for community- and people-led research based on First Nations, Inuit, and Métis priorities and needs.

- Funding to support Indigenous students (undergraduate, graduate, clinical trainees, and early career researchers) through access to research training, scholarships, and mentorship.
- Investments in capacity-building efforts promoting full autonomy for First Nations, Inuit, and Métis communities to lead and own research, data, and information sharing.
- Funding to develop and curate distinction-based Indigenous training modules in partnership with Indigenous community members, researchers, Elders, and Knowledge Keepers.
- Modification of SPOR grant requirements to include Indigenous cultural safety training before application submission.
- Investments in embedded research fellows and knowledge mobilization experts within Indigenous communities.

Capacity Building for Researchers and Community Partners

- Funding to develop scholar positions for people from underrepresented communities with existing relationships and connections within their communities.
- Funding for patient-oriented research capacity building and partnerships with national and local non-governmental and nonprofit organizations.
- Academic and non-academic training programs for students, community members, and leaders to build research capacity, including proposal writing.
- Funding for co-designed funding opportunities supporting community-led relationship development, networking, and research agenda setting.
- Funding to support community-led accreditation systems, creating a "stamp of approval" based on local needs and priorities.

Strengthen Long-Term Relationships with Communities and People with Lived Experience

- Funding to foster and strengthen respectful, authentic, and trusting long-term relationships with underrepresented communities and PWLE.
- Investment in PWLE Engagement/EDIAA Specialists to provide “along-siding support”, a structural and relationship-based, liaison-type support for community members and people with lived experience.
- Funding to support community-led relationship development, networking, and research agenda co-development.
- Funding to support mutual respect and trust-building with Indigenous Peoples, with a focus on co-developing research agendas that reflect Indigenous needs and priorities.
- Funding to foster long-term, mutually respectful relationships with First Nations, Inuit, and Métis communities.

Support Health System Change and Policy Engagement

- Investments in embedded research fellows and knowledge mobilization experts within health authorities, health systems, and governments.
- Funding to support research within provincial and territorial health systems to better align research agendas.
- Funding to identify gaps, opportunities, and drivers of current behaviors within the health system and suggest implementation strategies to support change.
- Investment in a cross-jurisdictional national Community of Practice, enabling learning networks where researchers, policymakers, and health authorities can share best practices.
- Funding to create a matching platform for researchers, health system representatives, policymakers, and PWLE to publish and match research priorities with skilled researchers.

Knowledge Mobilization and Communication

- Invest in early-stage co-design workshops where researchers, people with lived experience, community partners, and policymakers collaboratively identify knowledge mobilization priorities and strategies before research begins.
- Funding to co-design culturally safe knowledge mobilization strategies with PWLE and underrepresented communities.
- Funding for evidence synthesis, rapid reviews, plain language briefs, and infographics to ensure research findings are accessible and actionable.
- Funding to build researchers' and PWLE capacity to engage policy and decision-makers, including training in best practices, storytelling, and message synthesis.
- Investment in a centralized Knowledge Mobilization Hub for sharing POR findings, resources, reports, and policy briefs.
- Funding to raise awareness of patient-oriented research, share PWLE stories, and communicate SPOR successes within academia, health sectors, and policy spaces.

Governance and Structural Supports for Sustainable Research and Community Engagement

- Establishment of a Collective Impact Approach to governance, ensuring clarity of roles, accountability, and partner responsibilities.
- Establish a National Coordinating Centre that would serve as a "backbone" for SPOR. This centre would coordinate activities across SPOR, support working groups, and enhance collaboration and knowledge mobilization across CIHR initiatives as well as support a shared framework for tracking progress and evaluating the impact of patient-oriented research.
- Funding for human resources within a "backbone institution" to support Collective Impact governance, coordination, and oversight.

  - Funding for the development of workshops and educational materials to ensure that all governance members and stakeholders understand Collective Impact principles and can apply them effectively. This includes building capacity for relational rather than hierarchical governance structures.
  - Investments in training programs and mentorship to support PWLE capacity for meaningful governance partnership.
  - Funding to co-design and scale interoperable data systems and infrastructure to facilitate rapid learning in healthcare and research.
  - Amendments to peer review processes, including iterative, open review and training for reviewers to assess engagement and people and community partnerships meaningfully.