



Public and Patient Engagement Strategy (2018)

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Introduction

Public and patient engagement (PPE) in health care, health policy and research is increasingly identified as a key strategy to drive health system transformation, and ultimately, better health and health system outcomes. MSFHR is relatively new to this area but is keen to take a leadership role in implementing PPE in a funding organization. Given the evolving nature of PPE, this strategy is iterative and adaptive, with strategic opportunities that allow for pilot initiatives that can be systematically evaluated. The strategy also recognizes the importance of working with others in the BC health research ecosystem, including groups like the BC Academic Health Science Network, BC SUPPORT Unit and the Patient Voices Network, to better assess the PPE niche that MSFHR can fill.

Public and patient engagement (PPE)

An inclusive term used to capture a wide range of efforts aimed at actively involving citizens and patients in various domains and stages of health system decision making.¹

In developing the strategy, MSFHR wanted to ensure it was evidence-informed and that it took into account the lessons learned by others working in this field. The process began with an environmental scan focused on identifying knowledge and experience about PPE in health research and in granting agencies and programs. It included a web scan and targeted search of current academic reviews, reports and journal articles as well as interviews with key informants from health research funders/foundations with leading practices in engagement in their work. Several MSFHR staff were also interviewed to better understand their experience with, capacities in and concerns about PPE.

A scan report was prepared and served as a discussion document for two workshops. The first workshop with staff helped determine preliminary options for a PPE strategy for MSFHR. Their deliberations were refined into strategic opportunities. These were tested at the second workshop, where participants were key stakeholders and experts in the field, including patients. Their advice and input was considered and integrated, where possible, into the final PPE strategy. Further testing with staff and stakeholders helped to refine the strategic opportunities.

Both the environmental scan and the workshop participants reinforced for MSFHR that PPE is not going to apply to everything MSFHR does or all the research it funds. But it will be integral in those areas where it is most relevant and strategic.

¹ Abelson, J., et al. (2016). Supporting quality public and patient engagement in health system organizations: development and usability testing of the Public and Patient Engagement Evaluation Tool. *Health Expect*, 19(4).

Defining Public and Patient Engagement

There are a wide range of terms used to describe “public” (e.g. lay person, citizen, community, consumer, patient, partner, and people with lived experience) and to describe “engagement” (e.g. involvement, participation).

Emboldened by participant input at the stakeholder dialogue workshop, the term chosen for MSFHR’s strategy is *public and patient engagement*. It takes into consideration:

- Aligning with terminology currently in use in Canada in the world of health research. “Public and patient engagement” and “patient and public partnership” are being used by various groups.²
- Ensuring inclusion of people who may bring a range of perspectives to different types of engagement activities, for example, perspectives derived from lived experience; that are values-based or are based on different (and overlapping) identities (e.g. tax payer, community member, patient).

Also important to MSFHR is identifying which lenses are the most important ones to engage at a given time depending on the objectives of the engagement. Understanding and defining these lenses is important both for the organization and the individuals it is inviting to engage. People with lived experience (e.g. patients, caregivers) may be most critical in developing a funding opportunity on a particular disease condition or health system issue. A values-based lens (e.g. citizens) may be most relevant in helping to determine organizational or societal priorities. Having all lenses at the table may work best for a public advisory body.

Finally, understanding the spectrum of engagement and what level of engagement is most appropriate for a particular activity is also a critical success factor. An engagement spectrum such as the [IAP2 Public Engagement Spectrum](#) or Vandall-Walker’s levels of patient and researcher engagement framework³ can help determine when and how to engage patients across the spectrum of health research activities.

² While patients are also part of the broader public, in the health field the distinction is made as patients (and their families/informal caregivers) are seen as having a distinct relationship with the health-care system at all levels. The lived experience of patients is seen as critical in the development of improved health outcomes and practices.

³ Amirav, I., Vandall-Walker, V., Rasiah, J., & Saunders, L. (2017). Patient and researcher engagement in health research: a parent’s perspective. *Pediatrics*, 140(3).

Background and Context

The evidence documented in the environmental scan⁴ indicates that there is a strong trend, in Canada and internationally, towards greater involvement of patients and the public in all stages of the research process, from helping set research priorities and determining how research funding is allocated to translating research findings into useable knowledge and practice. This trend has two main drivers:

1. In an environment of limited financial resources, an increased demand for accountability, and the need to address the complex problems faced by society, health research needs to be done in new ways, involving a wide range of stakeholders, including patients and the public.
2. The practice of engaging the public and patients is becoming increasingly embedded in patient care, and in health-system planning, priority-setting and policy-making.

PPE in research builds on a body of research and practice in the field of public engagement in health policy and health system decision-making. It is based on:

- Principles of citizenship, accountability and transparency.
- Empowering people who use health services to influence change and improve issues that concern them.
- The belief that public and patient engagement leads to better quality research (i.e. research that is relevant, accessible and acceptable to participants) and better outcomes for people and the health system.

While the knowledge base for patient engagement in health research is growing, there is still a need for stronger evidence regarding the role and scope of patient engagement in health research activities, and its impact on patient and health system outcomes.⁵ Efforts are underway at the international, national and provincial level to advance the practice of PPE in health research. Health research funding bodies such as the National Institute of Health Research and the Wellcome Trust in the UK, and the Patient-Centered Outcomes Research Institute (PCORI) in the US are all taking major strides in this area.

Here at home, the Canadian Institutes of Health Research (CIHR) is leading the [Strategy for Patient Oriented Research](#), a multi-year, pan-Canadian funding strategy designed to enhance patient-oriented research in Canada.

The interest and growing practice of involving patients and the public in health research is coinciding with similar trends in the grant-making field in general. There is a trend towards “funding and

⁴ A summary of the evidence is provided in the Discussion document developed for the second workshop. An Appendices document provides further detail. Both are available from MSFHR upon request.

⁵ Manafo et al. (2018). Patient engagement in Canada: a scoping review of the ‘how’ and ‘what’ of patient engagement in health research. *Health Research Policy and Systems*, 16(5). doi: [10.1186/s12961-018-0282-4](https://doi.org/10.1186/s12961-018-0282-4)

following,” where funders and funding recipients work together to adapt an initiative as it rolls out in often complex and unpredictable situations. This approach has helped to:

- Foster broader collaboration and engagement to make progress on complex, multi-faceted social problems.
- Engage the public to help inform funding priorities and approaches.
- Increase accountability back to funders – particularly where grant-making is heavily funded by taxpayers and public donors.

The BC Context – Cultivating Collaboration and Mutual Benefit

As a provincial funder of health research recognized for research excellence, MSFHR is well-positioned to influence the health research enterprise in BC. The Foundation can lead by modelling good public engagement within the organization and in MSFHR-funded research and activities. MSFHR has established relationships with many in BC who are involved in public and patient engagement, which has helped to refine the niche it fills to best support this work and further its own mandate and strategic goals. Collaboration will be key to avoid duplication, cultivate the scale of change required, and maximize collective impact of facilitating patient and public engagement in health research.

Notably, MSFHR played a key role in the establishment and ongoing funding of the [BC SUPPORT Unit](#), a multi-partner organization created to support patient-oriented research in BC, established as one of the initiatives under CIHR’s Strategy for Patient-Oriented Research. MSFHR continues to work closely with the Unit’s staff to develop the tools to support research teams interested in conducting patient-oriented research, and to study the best ways to do patient-oriented research. MSFHR is learning from the Unit’s training programs, activities and events with the aim of exploring opportunities to adapt these for the public side of PPE as needed and sharing that experience with others in the BC health research ecosystem.

The Foundation is also fostering collaboration with the [BC Academic Health Science Network](#), a provincial network uniting a number of key resources, services and supports, including the BC SUPPORT Unit, Clinical Trials BC, and Research Ethics BC, to deliver high-priority, high-impact innovations into the health system.

PPE in health research is also being explored as part of the development of MSFHR’s next strategic plan, which will guide the Foundation’s funding programs and activities for the next several years. This strategy will be reviewed once the new organizational strategic plan is in place to ensure alignment and coherence.

Vision

We integrate public and patient perspectives into our work in a meaningful way to enable relevant, accessible and useable research that improves health outcomes and the health system in BC.

As a publicly-funded foundation, we believe that PPE is the right thing to do. But it is more than that. There is growing recognition among research funding agencies that engaging the public and patients can strengthen the relevance and impact of health research, but in the absence of an established evidence base, funders are interpreting and operationalizing PPE in very different ways.⁶ Bringing different perspectives and experience both to our own work and to the research we fund has the potential to uncover research areas and/or priorities that might otherwise be overlooked. These areas might make a significant difference to a patient's health care experience or the health of a community and the knowledge, support and behaviors that shape health outcomes for populations.

To be an effective leader in PPE as a health research funder requires that MSFHR build its own experiential capacity and understanding of what it takes for PPE to be meaningful and have an impact. This will require "walking the talk" (i.e. ensuring that patients and the public inform MSFHR's own work, strategic thinking and decisions as to what research we fund).

In turn, funding research that is relevant to and valued by the public and patients will increase the likelihood that the results of research are being used, accelerating decision-making, dissemination and the uptake of new practices. In part, this occurs as patients/public become partners with researchers in the actual research process, grounding it in their concrete experience and values and catalyzing new approaches and perspectives through the collaboration. It also occurs as patients and the public themselves use and promote research findings that are useful to them in making evidence-informed decisions about their own health and health care. In this way, PPE in health research is a critical lever in the overall improvement of health outcomes and the health system.

Strategic Opportunities

Integrating PPE into the work of MSFHR as appropriate will improve the relevance of the research we fund and enable its translation into policy and practice, contribute to more effective health services and products, and ultimately lead to better health outcomes and an enhanced health system in British Columbia. Based on evidence collected during the development of this strategy, opportunities for MSFHR fall into the following categories:

⁶ van Bekkum, J.E., Fergie, G.M., & Hilton, S. (2016). Health and medical research funding agencies' promotion of public engagement within research: a qualitative interview study exploring the United Kingdom context. *Health Research Policy and Systems*, 14(23).

1. **Integrating PPE into MSFHR as an organization that supports health research**, e.g. helping set the organization’s strategic direction, setting research priorities, informing funding program development, participating in grant review processes, and raising awareness about research and knowledge translation.
2. Strengthening PPE in the **research MSFHR funds and supports**, e.g. structuring engagement into research funding requirements, and building the capacity of researchers/teams to integrate engagement into their work.

Area 1: Integrating PPE into MSFHR as an organization

Strategic opportunity #1: Ensure the strategic thinking and decisions of MSFHR are informed by PPE

Evidence indicates that developing and selecting research priorities that have been informed through PPE improves the relevancy of research. This aligns with the experience of innovative funding organizations and foundations that engage their communities and the public in determining strategic and funding priorities. Ensuring that patients and the public inform MSFHR’s own work and strategic thinking will help build the experiential capacity of MSFHR itself, enabling it to be a more responsive role model for effective PPE in the research funding ecosystem.

In the early days of PPE, it will be important for MSFHR to build its own capacity to conduct PPE that lives up to its guiding principles (see page 7). Thus the initial steps are focused on implementing a small number of PPE processes that are time-limited, carefully monitoring and learning from those experiences. This approach will help MSFHR determine if an ongoing PPE mechanism would be useful and appropriate.

Strategic opportunity #2: Embed public and patient perspectives and advice into the grant review process

Ensuring that research is relevant to the public and patients requires that their perspectives are considered determining what research is funded. The phrase “Nothing about us, without us” applies as much to the decisions taken of what research applications to fund, as it does to the development of those applications and the eventual research roll-out. This does not need to happen in all areas of research funding, or at least not initially. A good starting point would be to look at grant review processes for research areas where PPE is a criteria for funding.

Area 2: Integrating PPE in the research MSFHR supports

Strategic opportunity #3: Fund research that appropriately integrates PPE, including patient-oriented research

The trend towards greater involvement of patients and the public in all stages of the research process is underway in BC. As a leader in that BC research ecosystem, the Foundation can make a significant contribution to enhancing health research by fostering the inclusion of PPE into the design and evaluation of the programs it funds or by collaborating with partners like the BC SUPPORT Unit to fund PPE. This can act as a key driver of change – encouraging and enabling researchers to integrate PPE into their research processes when appropriate.

Strategic opportunity #4: Fund research on public/patient engagement in health research to inform the practice and science of PPE

The practice of PPE in health research is evolving and growing. Evaluation is needed to drive good engagement practices and develop a more nuanced understanding of the contribution of PPE as well as the effectiveness of various methods of engagement. As a funder committed to the success of the people and projects we fund as well as the broader health research enterprise, we are uniquely placed to advance the science of health research funding, including funding focused on PPE.⁷

Guiding Principles

Collectively, the principles guiding our strategy provide consistent direction to staff. They ensure that the engagement MSFHR undertakes with the public and patients is meaningful and relevant and helps individuals and groups know what they can expect when we invite their participation.

1. **Inclusiveness:** We will invite a diversity of views, cultures and experiences to ensure our work and the research we fund are reflective of a wide range of perspectives.
2. **Collaboration:** We will structure processes to encourage all participants to work together, providing flexibility to the extent they wish to be engaged and maximizing the contributions of all.
3. **Respect:** We will acknowledge and value the expertise and experiential knowledge of all those involved in PPE processes. We will be respectful of people's time, conducting PPE when it is a worthwhile investment of patient/public time and can make a meaningful contribution to our work.

⁷ MSFHR Forward Thinking blog, Feb 2018: <https://www.msfhr.org/news/blog-posts/fund-and-forget-to-help-it-happen>

4. Openness and Transparency: We will strive for open and honest communications and practices, which are integral to building trust and credibility. This includes being clear about the aim, scope and outcomes of engagement.
5. Commitment to Learning and Improvement: We will aim for continuous improvement of our PPE practices through shared learning, measurement and evaluation. This also implies sharing our learnings with those involved and the broader research community as appropriate.
6. Support: We will provide adequate support and flexibility to all involved to ensure that they can contribute fully to discussions and decisions. This implies creating safe environments that promote honest interactions, cultural competence, training, and education. Support also implies financial considerations.
7. Accountability: We will ensure that the results of the PPE processes we conduct are used and have impact (e.g. influencing and informing planning and decision-making). We will share these impacts with the patients and public involved in this work. This implies implementing PPE processes when we have the means, skills and capacity to do so responsibly and with integrity.

MSFHR will develop criteria/indicators to help it assess how well it is incorporating these principles, as part of our overall evaluation framework to measure and evaluate the implementation of the PPE strategy.

Conclusion

Undertaking this new push into PPE will require MSFHR to be a learning organization, reflecting on the PPE activities and processes it undertakes within the spirit of continually improving the quality and contribution of those activities. We recognize that an evaluation framework and process for our PPE work will need to be developed in alignment with our overall organizational evaluation and impact analysis strategy. Having some common success criteria and performance measurement indicators will help to integrate PPE into key areas of our work.

Our PPE strategy is the result of an evidence-based review and the insights and contributions of staff, key informants and other experts in PPE, as well as many stakeholders, including patients. We hope to continue to benefit from and build on this collaboration as the strategy is implemented.