

March 22 Webinar Q & A

We focused on 2 of the 10 requirements today... Engaging: 1) Patients/Public and 2) Policy and Decision Makers. ,

1. **Question:** What are the requirements for documenting the costs for including the patients and public in the research? Is there a need to justify every expense to meet the audit requirements for use of the grant money?

Answer Part 1: On a national level, the Canadian Institute of Health Research (CIHR) has a steering committee that's looking into compensation standards for patients/people with lived experience in health research. The Patient Public Engagement Network in Manitoba, which includes people in mental health as well as all the regional health authorities, are also creating compensation frameworks and have resource tools available. Anyone with questions can contact Carolyn Shimmin Carolyn.Shimmin@umanitoba.ca who is happy to assist you.

Answer Part 2: Expenses around engaging patients, cost of parking, childcare, etc. are expected as part of the budget and there's quite a range of allowable expenses. The only area that is currently in question is when a patient is involved as a co-applicant. Normally co-applicants can't be paid out of the grant, so this is an issue for participatory action research. Some of our CIHR sources claim they are open to paying co-applicants because it is work and everyone else at the table is getting paid. It's important to ask people on your team how they would like to be paid because it could affect their disability payments etc. Other ways to compensate [other than cash] could be to pay tuition for a class, etc.

2. **Question:** What are the opportunities to engage with the Network and how to network within the Network?

Answer: There is no formalized membership process or requirements because the Network isn't meant to be a gate keeper but rather to support and facilitate research which falls under the mandate of Strategy for Patient-Oriented Research (SPOR) and the Manitoba Primary and Integrated Healthcare Innovation Network (MPN). All are welcome to contact Gayle Halas in person or Gayle.Halas@umanitoba.ca. On the MPN webpage, we are creating a fillable form for people interested in being part of the Network to provide information about themselves and enable connections to other teams and projects.

3. **Question:** Three funding opportunities will soon be available: a Knowledge Synthesis Grant, a Comparative Data and Policy Analysis Grant, both somewhat smaller, and then the larger 4-year Grant. How do you see patient engagement working and working well, with 3 different kinds of projects?

Answer: With Knowledge Synthesis there's been a lot of work around involvement with people with lived experience who can contribute to the systematic review - everything from writing the protocols to analyzing the data. Sometimes we think that people with lived experience won't be able to inform on an area because it's too complex but some of the research and studies that have come out in mental health, where people with lived experience have been on research teams, have looked at the data and pointed out things that the researchers wouldn't have considered because they're not coming from that lived experience perspective. I recommend thinking about this at the very beginning, keep it open and feel free to contact Carolyn to meet and talk out possibilities and to find some innovative ways that people with lived experience have and can be involved. Find out where your team is comfortable as far as the involvement strategy, what supports might be needed and what kinds of things you need to think about when you involve patients/public/communities.

4. **Question:** With the 3 funding opportunities, is there a way policy/decision makers might be differently involved in those different kinds of projects?

Answer Part 1: A very important message is early engagement with provincial partners to help them understand your research idea and the best place to gain support for your research idea and where it fits within the government structure. Connect with Gayle Halas first. She will connect you with government to find answers to questions like: *Where does this fit within government, How does it fit i.e., is this an operations or policy issue,*

Who has an interest in it within government, etc. There are a number of policy and decision making levels within government and we will support researchers to connect with the appropriate area to provide policy / decision maker input.

Answer Part 2: Under the PIHCI initiative, and the calls coming forward, we are doing business a different way in that the primary theme of crossing over among researchers, policy/decision makers, clinicians and public really does apply as we are trying to find solutions to complex issues, and trying to bring together different moving parts. There's a great deal of difficulty, not just in Manitoba, in bringing people together from different sectors and having to involve at least one other jurisdiction in Canada. Each provincial jurisdiction or Network has its own deadlines and mechanisms for connecting with people in other provinces.

5. **Question:** What are the mechanisms and requirements for connecting with other Networks?

Answer: Every funding opportunity has the requirement of working with at least one other jurisdiction and most provinces and territories have their own Network. Each Network has a manager or director alongside their 3 tri-partite leads from policy, practice and research. With the requirement to have at least one other jurisdiction we're envisioning the managers and directors as the hub that connects everybody. For example, if you want to connect with Saskatchewan the best way to do that would be through Gayle Halas who would connect with the Saskatchewan manager, who would then communicate with their Network members to ensure that the right kinds of people are engaged, including their policy makers. So again, early and meaningful collaboration is necessary. Other jurisdictions will hopefully also come to the table with partner funding.

If you have your own connections, someone you've been working or collaborating with on a project then it's absolutely fine, of course. But the Network is here to facilitate and support projects that are developing and being conducted in each jurisdiction.