

# Patient- and community-oriented research

## How is authentic engagement identified in grant applications?

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*Coming together is a beginning; keeping together is progress; working together is success.*

Henry Ford

Engagement in research has been shown to enhance the ability of individuals and communities to address their own health needs and health disparity issues while ensuring that researchers understand the priorities of individuals and communities.<sup>1,2</sup> However, everyday researchers with limited understanding of and experience with effective methods and tools of engagement write and submit proposals that would benefit from engaging patients and communities. Furthermore, guidance that is available for peer-review panels on evaluating research proposals that engage patients and communities has not been systematically applied.<sup>3</sup>

Patients and communities do not necessarily need to be involved in all aspects of the research process; however, their involvement affords academic researchers more specific and relevant research questions, contextual interpretation, and knowledge translation in and with the community. We have had experience cocreating various elements of the research process with patients and communities.<sup>2,4-9</sup> The Canadian Institutes of Health Research has been supporting full engagement with the inclusion of knowledge users who are patients or community members as co-investigators (equal partners) on implementation and translational research endeavours.<sup>10</sup>

In Canada, the framework for engaging patients and communities is clearly outlined in the 2014 Tri-Council policy statement, which includes a chapter that focuses on working with aboriginal communities.<sup>11</sup> The approach outlined in this policy statement can and should be adapted more broadly when considering patient and community engagement. As identified by Jagosh and colleagues,<sup>2</sup> engagement leads to improved community well-being; therefore, services and systems need to support the investment necessary to make this a reality.

This article aims to provide some practical tips and guidance for the peer-review process and the evaluation of grant proposals in which patients and communities are engaged. These tips have been designed to assist patients and communities, community-academic research teams, and reviewers of grant proposals to clarify the extent to which the process of engagement has been authentic and robust.

### Considerations for the peer-review process

Butler and Greenhalgh<sup>12</sup> indicate that contemporary approaches to patient and community engagement involve codesign, coproduction, coleadership, and mutual learning, frequently within a systems model.<sup>12,13</sup> The principles espoused are found within the constructs of participatory health research.<sup>14</sup> As part of community engagement, the experiences and knowledge of patients and communities are important, as they provide learning for researchers and health care providers, as well as help policy makers to make decisions about treatment or management.<sup>12</sup> Relationships are key in codesign, coproduction, coleadership, and mutual learning. Individuals and communities need to be engaged in the process over time in order to develop sustainable, mutually respectful, and trusting relationships before asking or systematically answering relevant questions.<sup>12,15-19</sup>

Peer review is a thoughtful critique by peers—1 or more people with competencies similar to those of the authors of the work being reviewed. When reviewing proposals that purport to engage patients and communities, we suggest that reviewers consider the following questions.

- Are patients and communities equitably involved in all appropriate aspects of designing the proposal?
- Is there coproduction of the processes to be used during and throughout the research proposed?
- Are patients and community members named as *investigators* (and is there a description of past collaborations with the patients or community) or are they considered members of the leadership team?
- How are patients or communities involved in analysis and interpretation of results, in dissemination of findings through presentations, and as co-authors?
- How is mutual learning to be fostered?<sup>12,15-19</sup>

Letters of support from the patients or communities being engaged should clearly describe the following: the relationship with the research team; the origin of the research questions or study topic; the role of the patient or community in defining the goals, objectives, and research questions; and plans for interpretation of findings and ongoing participation including dissemination, which includes the importance of the research from the perspective of patients or the community. In addition to this, the research team should describe meetings and other events convened to engage patients or communities in the planning of the research project.<sup>20</sup> **Figure 1**

presents an example of a letter of support that evolved from authentic community engagement. This letter is by no means a template, but it serves as an example of a letter of support that was developed with a community in response to clarifying its authentic engagement. In contrast, a letter that only states, for example, "...

support for the research proposal of Drs [insert names] is a priority in our community" might be considered token involvement and not authentic engagement.

The peer-review system is designed to ensure accountability not only to the funding sources, but also to the patients and communities. Therefore, patients

**Figure 1. An example of a letter of support that evolved from authentic community engagement**

To whom it may concern:

As a community, [insert name] is constantly striving to develop partnerships to enable us to move forward to effectively address the diabetes epidemic in our community and with our community.

Education is knowledge. By providing current up-to-date information to the community on disease prevention and management, we hope to reduce the effect that diabetes has on and in the community.

We find no value in having things done for us, but we have adopted a cooperative approach wherein we work together and learn from each other. We have worked with Dr [insert name] for the past 10 years cocreating and engaging in the research process from the conception of an idea to systematically answering the research questions that we (the community and the university) have put forward using processes that are meaningful to the community. Over a number of face-to-face meetings both in the community and at the university, we have engaged in cocreating the questionnaire, collecting the data, and reviewing the results, which evolved from the data before they were shared with the wider community through presentations or publications that were cocreated and copresented.

We fully support the program of research being put forward collaboratively by Dr [insert name] and our community. This is a proactive approach designed to develop evidence-informed, chronic disease prevention and management programs in and with the community.

Thank you for your consideration of this proposal.

Sincerely,

[Insert name and title]

cc. [Insert those who are appropriate]

and community members should be complementing the scientific expertise of researchers and be reviewing grant applications for patient or community relevance. In many communities, there are people who are familiar with research methods and who are knowledgeable in reviewing grant applications from their own perspective. To increase patient or community capacity to participate in reviewing project submissions, training and educational opportunities are essential, and might include engagement strategies such as boot camp translation, which was developed and tested by patients in the High Plains Research Network<sup>9</sup> in Colorado. During boot camp translation, community members and researchers work together to devise appropriate communication strategies for intervention-related messages that fit the community's needs.

## Conclusion

As we move toward authentic engagement within the research process, grant applications should describe the elements that have been or will be undertaken collaboratively. Letters of support should clearly describe the relationship between the patients or communities and the research team. Thus, grant applications should be reviewed by patients or communities and researchers. 🌱

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### Competing interests

All authors are members of the Participatory Research in Primary Care Working Group of the North American Primary Care Research Group.

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