

Engagement of people with lived experience in primary care research

Living with HIV Innovation Team Community Scholar Program

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There is a growing imperative to involve patients, their caregivers, and their family members in the planning and conduct of health research projects if our goal is to have a substantial effect on the people our research is intended to serve.¹ Despite this growing trend toward patient engagement in research, finding and collaborating with patient partners is uncharted territory for many Canadian primary health care researchers. This paper describes how a primary care research team created a program to support and promote the inclusion of people with lived experience of HIV within a national program of research.

The Living with HIV (LHIV) Innovation Team is a community-based primary health care team that received grant funding in 2013 from the Canadian Institutes of Health Research. The LHIV team's research aim is to evaluate and apply evidence-based models of primary care and chronic disease management to improve the health outcomes of people living with HIV in Canada. The team comprises an interdisciplinary group of researchers, decision makers, people with lived experience, and clinicians from Manitoba, Ontario, and Newfoundland and Labrador.

Recognizing the value of lived experience

During the early stages of the grant and in consultation with people with lived experience, the team created a formal program of patient engagement called the Community Scholar Program.² Collaboratively, the team chose the term *community scholars* to refer to team members with lived experience in order to explicitly recognize the value they bring to the program of research. The community scholars were invited at the outset to become full members of the LHIV team steering committee and thereby participate actively in the oversight of research priorities, protocol development, and program activities of substudies.

The Community Scholar Program is grounded in the global principles of GIPA (Greater Involvement of People Living with HIV and/or AIDS) and MEPA (Meaningful Engagement of People Living with HIV and/or AIDS), which recall the early days of the epidemic when people with HIV became "citizen scientists" through necessity.³ The LHIV team created terms of reference based

on these principles to guide both community members and researchers and to delineate mutual expectations in terms of roles and responsibilities, time commitments, and remuneration. The mutually-agreed-upon guidelines specify an annual stipend that includes an overall anticipated commitment rather than tracking a number of specific outputs or assigning a precise number of hours that community scholars are obliged to meet. In addition to the annual stipend received by community scholars, the research budget was also adjusted to cover expenses related to travel for in-person meetings for all team members. Community scholars are further funded to attend conferences, such as the Canadian Association for HIV Research and the Canadian Association for Health Services and Policy Research conferences, in order to learn about related research, to have an opportunity to meet other community scholars, and to further their own capacity to participate on research teams.

Value of contributions from community scholars

Three community scholars, representing each of our partner provinces, have been enthusiastic members of the LHIV team and provide perspectives from a variety of experiences in terms of age, sex, health status, and previous involvement in research. The community scholars have actively contributed to the research processes, including the development of protocols, revision of research tools, and interpretation of research findings. Their input has been particularly constructive to help other team members understand the perceived gaps identified in primary care delivery and chronic disease management, to determine best practices, and to find opportunities for the recruitment of research participants. Community scholars are attuned to the concerns of their communities with respect to bioethical issues and informed consent. They are essential to building an integrated program of knowledge translation and exchange to inform their communities of research findings and implications of public health policy.


As equal members on the LHIV steering committee, community scholars are included as co-authors on presentations and manuscripts arising from research outputs. The research program has greatly benefited from their involvement and, currently, the community

scholars are helping to develop and design future research grant submissions.

Overcoming challenges to inclusion

We recognize that engaging people with lived experience in research can be time-consuming. For example, efforts might be required to build the research literacy of community members. Further, communication styles and processes need to be attended to in order to optimize the inclusion of all members. The LHIV team found it helpful to hold annual face-to-face meetings to facilitate communication among members. Another challenge relates to questions about whether community scholars are engaged to represent their own individual perspectives or the views of larger communities of people with lived experience. One way to facilitate representativeness and legitimation of community voices was to invite more than one community scholar to project meetings.

Conclusion

The LHIV team recommends the adoption of a community scholar approach by other research teams. It provides a formal structure to enhance the participation of people with lived experience and to support meaningful engagement by providing a clear understanding of roles and expectations throughout the entire research process. 

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Competing interests

None declared

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