

COMMENT

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Bridging the divide: supporting and mentoring trainees to conceptualize, plan, and integrate engagement of people with lived experience in health research

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Abstract

Health researchers are encouraged by governments, funders, and journals to conduct research in partnership with people with lived experience. However, conducting research with authentic engagement and partnership with those who are experts by experience, but may not have research methods training, requires resources and specialized skills. The McMaster Collaborative for Health and Aging developed a fellowship program for trainees that builds their capacity to conduct research in partnership with older adults with relevant lived experience. We share this case example, with its successes and challenges, to encourage creative reformation of traditional research training.

The Collaborative used an iterative design process, involving researchers, trainees and older adult and caregiver partners, who, together, developed a fellowship program for trainees that provides support and mentorship to plan and conduct health research in partnership with people with lived experience.

Since 2022, the Partnership in Research Fellowship has been offered biannually. The application process was purposefully designed to be both constructive and supportive. Opportunities for one-on-one consultations; key resources, including a guide for developing a plan to involve people with relevant lived experience; and feedback from older adult and researcher reviewers are provided to all applicants. Successful trainees engage with older adult and caregiver partners from the Collaborative to advance and enhance a range of skills from facilitating partner meetings to forming advisory committees. Trainees are awarded \$1500 CAD to foster reciprocal partnerships. Ten graduate students from various disciplines have participated. Trainees reported positive impacts on their knowledge, comfort, and approach to partnered research. However, the time required for undertaking partnered research activities and involving diverse partners remain obstacles to meaningful engagement.

Partnering with people with lived experience in the design of educational programs embeds the principles of partnership and can increase the value and reward for all involved. We share the Partnership in Research Fellowship

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as a case example to inspire new and transformative approaches in research training and mentorship that will move the field forward from engagement theory to meaningful enactment.

Plain English summary

Health researchers are encouraged by governments, funders, and journals to conduct research in partnership with individuals with relevant health conditions or experience. However, conducting research with individuals who are experts by experience, but may not have research training, requires resources and specialized skills. The McMaster Collaborative for Health and Aging developed a fellowship program to support and mentor trainees to conduct their research in partnership with people with lived experience and turn engagement theory into action.

The Collaborative involved researchers, trainees, and older adults in the development of the fellowship program. Since 2022, the Partnership in Research Fellowship has been offered twice a year. The application process was designed to be both supportive and informative. Opportunities for one-on-one consultations; key resources, including guiding questions to consider when planning to involve people with relevant lived experience; and feedback from older adults and researchers, are provided to all applicants. Each trainee receives \$1500 CAD to support building strong, two-way partnerships. Since the fellowship's launch, 10 graduate students from different fields have participated. Trainees reported improvements in their knowledge and comfort to partner with people with lived experience in research. However, challenges, such as the extra time needed for conducting partnered research as well as locating and involving those from diverse backgrounds, were identified.

Involving people with lived experience in the design of research training incorporates partnership principles and may enhance the benefits and satisfaction for everyone involved. We share the Partnership in Research Fellowship, as an example, to inspire new approaches in research training and mentorship.

Keywords Capacity-building, Training, Engagement, Partnership, Patient-oriented research, Mentorship

Background

Health research is increasingly embracing the inclusion of persons with lived experience to advance health and healthcare systems [1, 2]. Governments, research funders, and academic journals [3–6] are increasingly encouraging and mandating that researchers collaborate with individuals and communities whose expertise stems from lived experience rather than formal education or credentials. In Canada, the involvement of *experts by experience* in health research is broadly referred to as patient-oriented research which the Canadian Institutes of Health Research (CIHR) describes as "... a continuum of research that engages patients as partners, focusses on patient-identified priorities and improves patient outcomes. This research, conducted by multidisciplinary teams in partnership with relevant stakeholders, aims to apply the knowledge generated to improve healthcare systems and practices" [3]. With the ultimate goal of improving patient outcomes, CIHR partnered with the provinces, territories, academic institutions, charities and others, to develop and implement a Strategy for Patient-Oriented Research (SPOR) to transform how research is conducted [3]. As part of this strategy, provincial and territorial SUPPORT (Support for People and Patient-Oriented Research and Trials) Units were established to champion and provide infrastructure for patient-oriented research in the provinces and territories [4].

Some have referred to the involvement of people with lived experience as a paradigm shift in health research; reflecting an increasing commitment to foster more

equitable and inclusive research practices that amplify the voices of those who have direct experience and personal knowledge of the health-related issues under investigation [7]. The justification behind this shift in health research can be categorized into three distinct yet complementary rationales, namely: (1) a moral duty of researchers and a right of "patients" to be involved in research related to their medical condition; (2) to improve the relevance, feasibility, value, and impact of health research; and (3) to increase the transparency and accountability across the research process to improve public trust in science and research [8, 9]. This paradigm shift has the potential to enhance the relevance and applicability of research findings [10] and may empower individuals and communities whose voices have been historically marginalized [11].

Setting and context

The McMaster Collaborative for Health and Aging is a part of the Ontario SPOR SUPPORT Unit (OSSU) network of research centers that champions patient-oriented research in the province [4]. OSSU is jointly funded by the Canadian Institutes of Health Research, the Government of Ontario and partner Ontario hospital foundations and institutes. As one of the 11 SPOR SUPPORT Units across the country, and as part of the Strategy for Patient Oriented Research, capacity development is one of OSSU's four pillars for providing infrastructure, expertise and support to people engaged in patient-oriented research. The McMaster Collaborative for Health

and Aging (herein, 'the Collaborative') is a coalition of researchers, trainees, older adults, and caregivers working together to improve the health equity and well-being of older Canadians by advancing patient-oriented health research on aging.

Rationale

Conducting research in partnership with individuals and/or communities who are experts by experience, but may not have formal education in research methods, necessitates a nuanced set of skills, ethical considerations, and methodological approaches that extend beyond conventional research paradigms and training [12–14]. While the potential benefits of this approach are strong, the risks of engagement gone wrong should not be ignored [7, 15–17].

In this paper, we introduce a training fellowship that has been co-developed by the Collaborative's researchers, trainees, and older adult and caregiver partners. This fellowship aims to provide trainees with the support and mentorship to gain experiential knowledge in meaningful and ethical engagement of experts by experience in research on aging. We share this program as a case example, with its successes and challenges, to encourage the development of creative training and mentorship programs. Our goal is to go beyond acknowledging the value of inclusion and contribute to structures that bridge the divide between theory and action.

McMaster Collaborative for Health and Aging Partnership in Research Fellowship

Planning and objectives

The Collaborative identified a critical gap for specialized training to foster authentic partnerships and facilitate patient-oriented research on aging. Supported by a mandate and funding for capacity development, the Collaborative involved researchers, trainees and older adult and caregiver partners in an iterative design process to bridge this training gap. The first step was brainstorming sessions where priorities and existing barriers for trainees to conduct their research in partnership with older adults were identified. Trainees were interested in formal training related to patient-oriented research and opportunities to interact and learn from researchers with experience engaging people with lived experience in their research. Specific questions they identified, related to gaps in their training, included how to engage marginalized groups of older people and how to communicate with partners with lived experience to keep them engaged as meaningful research contributors throughout the research process. From these sessions and corresponding discussions with Collaborative leadership members and the team of older adult and caregiver partners, the Managing Director drafted a training and mentorship proposal, including

potential goals, eligibility, and program components, for further rounds of review, feedback, and refinement. This proposal was presented to the team of older adult and caregiver partners for discussion and feedback, with specific questions about their interest and comfort with potential roles and activities (e.g., as members of the application review committee). Collaborative leadership members and trainees who had expressed an interest in initiatives that addressed their identified needs were also sent documents at two stages and invited to provide feedback electronically or through individual discussions. From this process, a training fellowship that facilitates health research conducted in partnership with older adults with relevant lived experience was developed.

The Partnership in Research Fellowship was designed as an activity to contribute to the Collaborative's goal to build capacity in patient-oriented research specific to health and aging, including building awareness of resources that support the implementation of Canada's Strategy for Patient Oriented Research (SPOR). More specifically, the fellowship aims to provide trainees with the support and mentorship to conduct meaningful and ethical engagement of experts by experience in their graduate or post-doctoral aging research. The secondary objective, informed by the interests and positive experiences of our members, is to provide opportunities for trainees and the Collaborative's older adult and caregiver partners to exchange knowledge and expertise.

The Collaborative's core principles for partnership (clear communication; information exchange; empowerment; transparency; mutual respect; and responsiveness) [18] and our commitment to improving health equity and fairness in research [19] provide the foundation for this trainee fellowship and informed the design process.

Program design and structure

This training opportunity was designed to be informative and constructive for trainees regardless of their eligibility or the success of their application (see Table 1 for key components of the fellowship). For example, before they apply, interested trainees must participate in a one-on-one consultation meeting to help develop their partnership plan. These consultations provide applicants with the opportunity to brainstorm various ways they can involve experts by experience in their research. Approaches discussed vary based on the stage of the project, the research question and methods, and the population most affected. Recommended partnership activities may include, but are not limited to, partners being involved in data collection (e.g., peer interviewers), the creation of an advisory committee, a community consultation event to inform the research question, and/or the recruitment of co-investigators with lived experience. Strategic advice offered to applicants can include frank

Table 1 Partnership in Research Fellowship program components

Fellowship Outreach & Application Process

- **Building awareness:** Information about the fellowship is shared during conversations with trainees doing aging-related research (e.g., at conferences, workshops) and broadly through patient-oriented research and aging research communities and organizations.
- **One-on-one consultations:** Trainees interested in applying for the fellowship are directed to contact the Collaborative to schedule a one-on-one consultation for individualized feedback and broad discussion of partnership opportunities and strategies.
- **Providing fellowship materials with links and references to resources:** Guidelines are publicly available (online) all year, with references to support current and future grant applications [20].
- **Step-by-step application process:** The application form is designed to guide trainees in the development of an engagement plan and associated budget, with questions to consider and references for self-directed learning.

Fellowship Application Review Process

- **Recruitment of a diverse review team:** The review team is comprised of diverse perspectives including researchers ($n=3$), older adult and caregiver partners ($n=2$) and trainee(s) ($n=1-2$).
- **Orientation for reviewers:** The review team meets before the submission deadline to foster a common understanding of the initiative's purpose and to empower all reviewers while encouraging a collective understanding and a consistent approach to reviewing and evaluating applications.
- **Submission of individual reviews:** Before the review team meets, each reviewer independently reads and evaluates each application, submitting their feedback online using a combination of numeric and open-ended responses.
- **Reviewer team discussion:** The review team meets to discuss a summary of the individual reviews and come to consensus on individualized and general feedback for applicants – identifying strengths and limitations and suggestions for next steps for the fellowship program.
- **Written feedback for applicants:** Constructive written feedback is provided to all applicants.
- **One-on-one feedback sessions:** All applicants are invited to schedule a one-on-one meeting to ask questions and discuss resources and potential next steps. Trainees' faculty supervisors are invited to participate in the meetings. All applicants are encouraged to become Collaborative members, attend Collaborative events, and access resources and tools to support their learning and research activities.

Fellowship Activities

- **\$1500 CAD award:** Funding is provided to support reciprocal partnerships and can be used for partner honorariums, training, partner travel and/or hospitality for meetings that engage partners.
- **Presentation & consultation with older adult and caregiver partners:** Trainees present their research and consult Collaborative older adult and caregiver partners on their plan to engage people with lived experience in their work. Trainees are responsible for preparing and facilitating their individual (90 min) meetings with the Collaborative partners, including pre-meeting and follow-up communication. Trainees' (faculty) supervisors are invited to attend.
- **Trainees receive written feedback from older adult and caregiver partners:** Collaborative partners anonymously provide (a) feedback to trainees on the clarity of their communication and the strengths and opportunities from the meeting, and (b) strategic advice on their research and proposed engagement plan.
- **Trainee network and meetings:** Fellowship trainees are connected and meet 3 times/year to share experiences, reflections, and helpful resources related to their engagement of people with lived experience in their respective projects.
- **Ongoing support available for trainees:** Trainees are encouraged to reach out to the Collaborative for support and/or to brainstorm about challenges implementing their engagement plan, at any time.

Fellowship Trainee Reporting

- **6-month reports:** Trainees reflect on their engagement activities, challenges and successes, and self-report the impact of the fellowship on their knowledge, comfort, actions, and future plans related to partnered research.

discussions of potential challenges and the feasibility of various timelines. In addition, all trainees (whether their application is successful or not) receive written feedback on their applications, including constructive feedback from older adult and caregiver partners. All applicants are offered the opportunity to have a one-on-one meeting with the Managing Director of the Collaborative to discuss their feedback, potential next steps, and ask general questions about partnering in research.

Successful trainees are awarded \$1500 CAD to support their work in engaging people with relevant lived experience in their research. After meeting with the Managing Director to discuss the reviewer feedback, trainees are provided with materials to support their planning, execution, and follow-up of meetings or activities with people with lived experience. For each fellowship trainee, we organize a meeting with the Collaborative older adult and caregiver partner team for the trainees to present

their research and revised engagement plan (based on the reviewer feedback) for discussion and further guidance. Trainees identify goals for the meeting and relevant questions for the older adult and caregiver partner team, which vary according to the trainee's project and timeline. For example, one trainee sought feedback on their community advisory committee recruitment materials, another had questions about her plan for onboarding new partners (with lived experience). In addition to providing trainees with further feedback and advice on their engagement plans, these meetings offer a supported opportunity to facilitate a meeting with older adults and practice communicating about their research in accessible ways. After the meetings, Collaborative partners anonymously submit feedback and suggestions for the trainees specific to their communication and facilitation of the meeting.

Over the remaining six to 18 months of their fellowship, trainees implement their engagement plans, identifying and working with people with relevant lived experience to advise on their ongoing research. Fellowship trainees meet as a group three times per year to discuss their successes and challenges and share relevant information and resources. Every six months they are required to submit an activity report. We created these reports to encourage reflection, support the advancement of trainees' engagement efforts, and assess the program's effectiveness. They also provide important information to refine and enhance the program. In addition to reporting on the engagement activities conducted, trainees are asked their greatest challenges and most valuable learning, to reflect on their successes and challenges related to the equity, diversity and inclusion of their engagement activities, the impact of the fellowship, and their recommendations for improvement. Fellowship trainees are also encouraged to engage in other Collaborative activities (e.g., Journal Club, seminar series) and to reach out for advice, mentorship, or support related to their partnered research, at any time.

The removal of financial barriers was not a primary goal of this initiative. However, we included financial support to increase the diversity of applicants and to ensure that the partnerships that are supported were reciprocal, ethical, and aligned with our values. We wanted this training opportunity to be accessible to trainees, regardless of their research funding, research environment, and level of patient-oriented research experience of their supervisor(s). Financial support ensured trainees could recognize the value of lived expertise through honorariums and co-production and provides the opportunity for trainees to develop, and receive feedback on, a budget to support their engagement plans. Applicants are required to submit a budget (maximum \$1500 CAD) with at least 25% allocated to directly support people with lived experience (e.g., honourariums, travel reimbursement, training).

Implementation

To date, the program has been coordinated online. Meetings with the fellowship review team and the trainees' meetings with Collaborative staff and older adult and caregiver partners have occurred via Zoom. However, funded trainees are encouraged to choose their location and means of partner engagement based on the preferences of the experts by experience they plan to engage and the feasibility for their project. Virtual meetings have both advantages (e.g., flexibility, reduced transportation burden) and disadvantages (e.g., digital literacy and access requirements, reduced non-verbal communication) when compared to in-person meetings.

All 10 of the Collaborative older adult and caregiver partners have been actively engaged in the implementation of this program. Partner team meetings with fellowship trainees have had a minimum of five partners. Seven of the 10 partners have served at least once as a member of the application review committee (with two partners per round).

We have integrated a quality improvement framework into the program and encourage informal feedback and suggestions throughout the year. We also collect information from all stakeholder groups: through the fellowship trainee 6-month reports; through supervisor support forms at the application phase; and after partner team meetings with fellowship trainees. At the end of review committee meetings, we reflect on the latest round of applications and discuss potential improvements for the next program offering based on our individual and collective experiences with the program operations.

Fellowship outcomes

At the time of writing, the fellowship has been offered a total of four times in two years (every six months). We have supported and mentored 10 graduate students, from various disciplines, in conceptualizing, planning, and implementing engagement of people with lived experience, as experts, in their research. Examples of trainee projects include a systematic review, a qualitative case study, and analysis of secondary data. From evaluations, the Collaborative's older adult and caregiver partners have unanimously rated the value of this training opportunity as "excellent" in terms of supporting meaningful engagement of older adults and caregivers in aging-focused research. Funded trainees have similarly reported being appreciative of the personalized support and mentorship by the Managing Director and the Collaborative's older adult and caregiver partners. Trainees have shared their perspectives on the value of the program and a range of "a-ha" moments they have experienced – from valuing the peer component (as a means to share challenges and successes with other fellowship trainees) to learning from the Collaborative's older adult partners that their research may not be of interest to all audiences. All trainees agreed or strongly agreed that their knowledge about patient-oriented research had increased because of the fellowship program. The impact on other outcomes, such as their comfort with engaging people with lived experience in research, planned or completed engagement activities, and future research plans, were less consistent although such outcomes were identified to be strongly impacted by at least one trainee. Notably, one trainee indicated that the fellowship had highlighted potential risks of engaging people with lived experience, if not done well, which initially affected their

comfort of involving those with lived experience in their research project.

Time constraints were the most prevalent challenge identified by trainees: time pressures of competing activities (with their program of study more broadly); difficulty finding mutually agreeable times for meetings with partners with lived experience; and research and engagement steps (e.g., research ethics board approval, connecting with community-based organizations, recruitment of partners with lived experience) taking longer than anticipated. Another challenge identified by trainees was connecting and engaging people within their target population and ensuring that a range of perspectives were represented. Based on conversations, this often resulted in research partners who were less diverse, in terms of important characteristics such as ethnicity, gender, and education, than the study's target population and what was desired. When asked to reflect on these challenges, trainees noted the need to tailor approaches to specific partner organizations and the importance of reflecting on "who was not at the table." These challenges are not unique to trainees but may be accentuated in their context where many have limited power and control over external requirements and may also have fewer existing relationships (with community organizations and individuals with relevant lived experience) on which to build and may lack stability for fostering ongoing relationships.

Promising practices for sustainability and scale-up

Reflecting on our experience to date, we believe the co-development of this training opportunity was critical to its success. We continue to both revise the program and celebrate its achievement in supporting our mandate through various knowledge translation activities (e.g., conference presentations, newsletters). The commitment and enthusiasm of the older adult and caregiver partners in reviewing applications, meeting with successful trainees, and offering their guidance on and across their projects, creates a sense of connection and energy for the initiative. The lived experiences of the Collaborative's older adult and caregiver partners are diverse and extensive in many areas – including culture, education, and health. This broad range of lived experiences benefits the trainees when planning who and how to engage experts by experience in *their* research and enriches the training for all involved, including trainee (faculty) supervisors. The one-on-one discussions and mentorship components of our fellowship are fundamental to the spirit and goals of the program but could limit scalability of the initiative. However, as more experts by experience, trainees, and researchers develop expertise with research done in partnership, there will be opportunities for additional mentors, peer mentorship, and train-the-trainer models. There are also knowledge syntheses, reflective papers,

and resources that are being developed and disseminated, which can support the creation and implementation of training opportunities similar to this training fellowship. Building on existing relationships and structures, we created this program to help us strengthen our institutional mandate. Our approach was largely informed by our collective experiences (as educators, trainees, research partners with lived experience, and researchers with extensive experience working with community), our principles of partnership, and a quality improvement approach (of plan-do-study-act). However, other teams may find resources such as Engage for Equity's Tools and Resources for Evaluation and Collective-Reflection of Community Based Participatory Research (CBPR) and Community Engaged Research (CErR) [21] useful as a framework for planning, reflecting on, and improving their own training programs created in partnership.

As previously mentioned, one trainee in the program shared their increased concern for causing unintentional harm while working in partnership (e.g., through choice of language). The Collaborative promotes reflection and awareness of potential risks of engagement, which have the potential for ripple effects on community trust and relationships between others from the same academic institution. This fellowship program creates an environment for trainees to explore and discuss such risks, allowing them to plan ahead and try to mitigate potential sources of harm. Understanding these risks is a critical part of their learning. Trainees (vs. established researchers) may face additional barriers if conducting their research in partnership and also operate under conditions that may increase the risk of what Richards and colleagues [15] refer to as "how it can go wrong." Research conducted by trainees plays a crucial role in the advancement of knowledge. However, mentorship is critical for trainees to develop complex research skills, such as those necessary for conducting research through authentic partnerships, and to conduct ethical and impactful research [22–24]. As such, mentorship programs may be critical to mitigating these risks and can facilitate trust and reciprocal relationships with community organizations and people with lived experience. Risks that may be especially relevant in trainees' research are tokenism and the sense of loss at the end of the engagement. A trainee may move on with their career, possibly shifting research focus and changing institutions, without continuing to pursue the broader objectives and subsequent phases of their research project. This situation can leave partners and advisors without the chance to apply their knowledge and insights in activities that build upon the research project. To mitigate this risk, we encourage fellowship trainees to embed reciprocity in their engagement plans throughout their project and to consider the post-project transition for people who have partnered with them:

what were their partners' goals for engaging in the project and are there opportunities or people the trainees can connect them to that may help them achieve their goals? As an organization, we can also help to bridge this gap, by acting, in part, as a central hub for researchers and partnership opportunities.

Conclusion

We share the Partnership in Research Fellowship as a case example with the aim of inspiring other innovations in research training and mentorship that support moving from engagement theory to meaningful enactment. To support a paradigm shift in what and how research is conducted and how it is used to improve health, health care, and equity – we must support the researchers of tomorrow to engage with people and communities with relevant lived experience from the outset, not as an afterthought. Mentorship programs can provide the opportunity for learning, experiencing, and conducting research in partnership with the values foundational to its success. Partnering with people with lived experience in the design of educational opportunities for trainees embeds the principles of partnership and can increase the value for all involved.

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Author contributions

SCC, CD'A, SD, LD, ATF, MK, JL, MM, KN, PP, DW, RG and BV contributed to the design of the fellowship program and analytical discussions of the program and lessons learned. SCC led the writing of the manuscript. All authors contributed to the writing and revising of the manuscript and read and approved the final manuscript.

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Data availability

No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate

The engagement of older adult and caregiver partners in the McMaster Collaborative for Health and Aging has been reviewed and approved by the Hamilton Integrated Research Ethics Board (#7640).

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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