

“We Need To Be At The Table”: Collaboration with Lived Experts

Sarah L. Canham, PhD, FGSA^{1*} <https://orcid.org/0000-0002-0421-2612>

Rachel Weldrick, PhD² <https://orcid.org/0000-0002-5679-6066>

Anne Cartledge,³

Hilary Chapple,³

Chris Danielsen,³

Dorothy Kestle,³

Michel Gauthier,³

Samantha Teichman, MA, PhD(c) [PhD candidate]⁴ <https://orcid.org/0000-0001-6829-7814>

¹College of Social Work, University of Utah, Salt Lake City, UT

²School of Urban and Regional Planning, Toronto Metropolitan University, Toronto, ON

³Lived Expertise Advisory Committee Member, Aging in the Right Place Partnership

⁴Department of Gerontology, Simon Fraser University, Vancouver, BC

*Corresponding Author: sarah.canham@utah.edu

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ABSTRACT

Background: The recognition of lived experience (LE) as an asset has led to increased involvement of individuals most affected by social or medical conditions in research.

Objectives: This paper presents an example of a LE advisory group that co-conceptualized and executed a knowledge mobilization project on aging and homelessness within three Canadian cities (Vancouver, Calgary, and Montreal). **Methods:** We established the advisory group, determined the group's priorities and objectives, and fostered community engagement through webinars and in-person events. **Lessons Learned:** We learned the importance of digital support to enable inclusion of advisors with experiences of homelessness, providing honoraria to for advisors' time and contributions, scheduling meetings on the same day and time each month, and dedicating meeting time for advisors' personal updates and experiences. **Conclusions:** This model can be replicated by other research teams studying homelessness, aging, or similar marginalized groups, enhancing the impact of research and knowledge mobilization efforts.

KEYWORDS

Lived experiences, Community-Based Participatory Research, Homeless Persons, Health Services for the Aged, Aging, Community health partnerships, Process issues

Background and Objectives

Persons with lived experience (LE) are increasingly recognized by researchers and funding agencies (e.g., the Patient-Centered Outcomes Research Institute)¹ as valued and active members of research teams in ways that extend beyond research participation. Research with LE partners can be found in areas of patient-centered care,² aging,^{3,4} homelessness,⁵⁻¹⁰ mental health,^{11,12} and other disciplines that attend to chronic illnesses and disease states.¹³ Broadly speaking, community-based research has been at the forefront of involving LE partners in research.^{14,15} For over 45 years, extensive community-based participatory research has incorporated persons and communities with LE into research and has informed community-engaged researchers across numerous scholarly disciplines.¹⁶

LE is invaluable to research endeavors as persons most impacted by a social or medical condition are recognized as most knowledgeable of the impact conditions and interventions have on their lives.¹⁷ Persons with LE are advocates for being at the table when research and knowledge is generated that will directly impact their lives. LE partners have been included in research as co-researchers,¹⁸ peer researchers,¹⁹⁻²¹ or advisory board members. Building from these prior examples of collaboration with persons with LE in research, this paper offers an example from one LE group who co-conceptualized a one-year knowledge mobilization (KMb) project, supported the project's funding application, and played an integral role in the project's development and implementation. Key steps and actions taken by the LE team during this process are described, followed by lessons learned from this project that will strengthen future KMb efforts. Lessons presented here can also inform other community-based research partnerships with LE advisors.

Methods

Setting

The Aging in the Right Place (AIRP) Partnership initiated in 2020 as three-city research project on aging and homelessness situated in three major Canadian cities: Calgary, Montreal, and Vancouver.²² All three cities, while unique in their cultural make-up, serve as economic hubs in their respective provinces of Alberta (Calgary), Quebec (Montreal), and British Columbia (Vancouver). As with the United States,²³ policy and program responses to homelessness in Canada are largely uncoordinated and fragmented across jurisdictions, with individual provinces and municipalities responding independently, and with varied effectiveness.²⁴ Vancouver, the largest city on Canada's West coast and second most expensive city in Canada in terms of the cost of living,²⁵ is home to a network of housing and homelessness organizations working in the downtown core and peripheral communities. In Montreal, home to Canada's largest French-speaking community, homelessness is addressed by a patchwork of agencies and community sector organizations, and a longstanding emphasis on social housing.²⁴ Montreal and Vancouver share a similarity in this sense; Quebec and British Columbia were the only two provinces to continue developing new social housing units following the termination of social housing programs by the Federal government in the 1990s.^{26,27} In Calgary, a city whose economic and social health is closely tied to that of the oil and gas industry, homelessness is addressed via a collection of agencies, many of which are affiliated with a single non-profit organization that receives and administers both provincial and federal homelessness funds.^{24,28}

With five-year funding from the Canadian Mortgage and Housing Corporation (CMHC) and the Social Sciences and Humanities Research Council (SSHRC), the AIRP Partnership includes a project director [first author], three City Lead co-applicants in Montreal, Calgary, and Vancouver, 12 other co-applicants, 40 partner organizations that include and governmental and

non-governmental agency representatives working in the homelessness, housing, and aging sectors, and eight LE advisors. These diverse entities include individuals and organizations who were part of the funding proposal, following the project director and co-applicants' prior community-engagement work that developed and sustained relationships. To date, the research team has also included over 50 students and trainees.

Figure 1 depicts the AIRP Partnership's governance structure. The project is supported by an Executive Committee (EC) and informed by three Local Advisory Committees (LACs), which are chaired by the City Leads who direct research, training, and KMb activities in Montreal, Calgary, and Vancouver. While LE representatives collaborate at the local level and serve on the LACs alongside academics and community partner organization representatives from their respective cities, LE advisors have also formed an independent committee (the Lived Experience Advisory [LEA] Committee), which we describe below. Based on peer payment guidance,²⁹ AIRP project funds provide a \$25/hour honoraria for the time and contributions of LE advisors. LE advisors have brought their experiences of housing insecurity and homelessness to these committees, providing input into the research³⁰ and conceptual development³¹ of the AIRP Partnership project.

Participants: LE Advisors

During the application stage for the AIRP Partnership project, the project director and co-applicants (with academic positions) engaged individuals with LE whom they knew from prior research endeavors in Montreal, Calgary, and Vancouver and invited them to advise the AIRP project, pending a successful award. These LE advisors included two men and six women aged 50+ with diverse experiences of homelessness and housing insecurity. Since the initiation of the project, three additional men have been recruited to the committee, one from each city, to include

additional perspectives. Advisors' past experiences of homelessness range from living unsheltered, to couch surfing and sleeping in one's car, to staying in emergency shelters. Presently, all advisors are living in either market rental housing, low-income affordable rental units, permanent supportive housing, or temporary housing sites. Advisors are primarily English-speaking, though several advisors are primary French-speakers.

Lived Expertise Advisory (LEA) Committee Meetings

Given the geographical distances between LE advisors, LEA committee meetings are hosted on Zoom. To support meeting attendance for two advisors who did not have a personal digital device, the project coordinator worked with the advisors' support workers who loaned a digital device and provided trainings on using this video technology. In addition to the advisors and project director, the Partnership's project coordinator and a minimum of one research assistant (RA) from each city attend each meeting to support advisors however needed (e.g., live-time English-to-French translation, ensuring honoraria are paid). Meetings are also conducted such that all members are given the opportunity to speak on all agenda items, identify specific agenda items, and contribute to decision-making. Conducting meetings in this way allows for equitable and lateral communication across all members, regardless of status, role, or position. At the first meeting, the advisors resolved to hold standing one-hour meetings at the same time each month. With support from the project coordinator, the project director assumes responsibilities for sending calendar invites, agendas, and documents prior to each meeting, and follow-up with minutes and action items. At the conclusion of each meeting, the project director and advisors discuss action items and decide on agenda items for the next meeting. Meeting minutes are prepared by the project coordinator in English, translated by a RA into French, and circulated by

email. Local city teams coordinate honoraria payment to advisors, either through electronic transfers or taking cash to advisors in person.

As done by other LEA groups,¹⁷ the advisors reached consensus that the committee's name should reflect "lived expertise" which implies more than "lived experience." During the initial team meetings, discussions centered on goal and expectation setting. Facilitated by the project director, LE advisors were asked to discuss a set of guiding questions and identify: 1) How would you like to be involved in the Partnership? 2) What additional ways would you be interested in contributing to the Partnership? 3) In what ways should the LEA committee work together? 4) What roles should the LE advisors have? (See Table 1). Captured in meeting minutes, advisors discussed how the voices of LE often go unheard by changemakers and elected officials—though there is some groundwork underway by the Canadian Association to End Homelessness that prioritizes and advances the voices of LE. Advisors described their motivation to educate the public about the reality of homelessness for older adults and share findings/resources from the partnership via social media. Advisors expressed interest in developing op-eds and social media campaigns, speaking to media, and sharing best practices and lessons learned across the cities. A key idea expressed by advisors was that "education equals power" and that people with LE and those working on the frontlines are most knowledgeable about supporting older persons experiencing homelessness. This led the advisors to identify educational activities they wanted to develop in each of the three cities: 1) talks to educate the public about homelessness; 2) disseminating resources for people experiencing homelessness; and 3) opportunities to pair people experiencing homelessness with a community member to exchange stories over a meal. To initiate these activities, however, which were

beyond the scope of what was proposed in the AIRP Partnership project, the project director identified the need for additional funding.

Development of Community-Engaged Knowledge Mobilization Project

While the project director and coordinator sought potential funding sources, monthly LEA meetings continued to design ways to engage with and educate the community. In discussions of what they wanted the public to know about the experience of homelessness in later life, one advisor wanted the public to understand the “complete sense of hopelessness” that homelessness causes individuals. Another advisor wanted the public to know “that we’re all human” and not the stereotypes of drug users who don’t want to work. Addressing stigma and negative stereotypes toward persons experiencing homelessness⁶ alongside the unique intersections of age and homelessness³² was of particular interest to advisors who discussed that community education is one mechanism for addressing stigma.^{33,34} Advisors had a wealth of ideas on possible formats for community education events, including webinars and panel discussions composed of LE speakers and art displays created by persons with LE.

In March 2022, the project director and coordinator identified a university-based funding source for a small grant to support community-engaged initiatives. Concurrently, the advisors decided to name their events: *Community Conversations to Disrupt Discrimination Toward Older Persons Experiencing Homelessness*. It was agreed that the project director and coordinator would draft the funding proposal, including project description and objectives, but shared drafts at LEA meeting, and revised as needed to ensure advisor’s perspectives were captured. The project aimed to engage communities to dismantle discrimination towards older people experiencing homelessness, with specific objectives to 1) shift perspectives and disrupt stereotypes about late-life homelessness through community events and a webinar; and 2) co-

develop and disseminate KMb outputs that can be disseminated beyond the conclusion of the project. We proposed to host three free and publicly accessible community-based stereotype card exhibits and panel discussion events in Vancouver, Calgary, and Montreal, as well as a webinar to enable conversations nationally. The stereotype cards were designed to showcase myths (and corresponding counter-narratives) about homelessness in later life as a mechanism to disrupt stereotypical images of homelessness and aging, while panel discussions of lived experts sharing experiences, stories, and thoughts on disrupting discrimination against older people experiencing homelessness sparked dialogue among attendees.

Implementation of Knowledge Mobilization Project

In June 2022, the *Community Conversations* funding proposal was successful, enabling the hire of a new RA (last author) to support the implementation of this sub-project. Advisors continued brainstorming the design and content of the stereotype cards during monthly meetings. Using Google's Jamboard, a free online note-taking platform which allows for collaborative idea-sharing, advisors worked in small groups to develop an initial list of stereotypes and myths about homelessness in later life. When asked to assist, RAs typed advisors' ideas on the Jamboard. In total, advisors developed a list of 23 statements about: 1) people experiencing homelessness; 2) how people become homeless; 3) experiences of homelessness; and 4) support available to people experiencing homelessness. Through conversation, advisors prioritized nine of the myth statements to develop into stereotype cards (Table 2) and decided to make the cards bilingual to maximize reach. The iterative stereotype card development involved advisors providing feedback to the subproject-RA at monthly meetings on the design and wording, and the RA making revisions prior to the next meeting until all myth statements and images were agreed upon. Feedback about card design included having text in black/dark color, making font

consistent and easy-to-read, using dramatic colors, including images that grab the attention of the audience to evoke feeling, using images that do not reproduce stereotypes of homelessness but highlight the humanness and resilience of older persons experiencing homelessness, identifying research evidence to support each of the counternarratives, and adding an acknowledgement to each card.

Planning for the webinar simultaneously continued and four advisors (one from Vancouver, one from Montreal, and two from Calgary) volunteered to serve as panelists who would share personal stories of discrimination and offer insight into supports that would have been good to know about while homeless. Advisors decided to use the stereotype cards to depict personal stories and to dispel myths of homelessness. Using the webinar as a template for in-person community events, additional planning involved discussions about the need to recruit LE panelists with diverse perspectives who were not advisors, and to provide panelists with honoraria and transportation funds to support their attendance. As a result, 1-2 additional LE panelists were recruited for each event.

Event sites in each city were brainstormed until accessible and affordable sites were identified: a community space, city hall, and a mobile van. These three events were developed and hosted based on feedback from each respective city, taking shape as contributors and participants were identified. During the planning stages, brainstorming and problem-solving was critical and occurred at LEA meetings. Fostering an open dialogue about budgetary constraints, varying capacities of different city teams, and challenges that might arise during events led to pragmatic adjustments that could accommodate the unique needs of each city and their team. While each event was designed with slight variation in execution and structure, the primary goals of the events were the same—to engage with community members in conversation to disrupt the

discriminatory ideas held about older persons experiencing homelessness. Advisors developed city-specific lists of community members to invite, including political figures, decisionmakers, community organizations, media outlets, advocates, and others with experiences with homelessness. For each event, advocacy letters calling for political action to address homelessness were drafted to the respective Minister of Housing in the host province and were made available for all event attendees to sign. Letters were mailed to these Ministers of Housing as a call to action—a priority identified by the LE committee. Each event was well-received by the community and resulted in increased awareness of issues of homelessness among older persons and discrimination towards people experiencing homelessness. Attendees who completed the optional survey at each event reported learning about the shortage of affordable housing in Canada, ageism and stigma towards people experiencing homelessness, hidden homelessness, and the prevalence of homelessness among older persons in Canada. Event details, including attendees and activities, are in Table 3.

Lessons Learned

The goal of this paper was to describe an example of a collaborative lived expertise-academic team that developed and implemented a KMB project to disrupt discrimination towards older persons experiencing homelessness. This work required that the team overcome several challenges. First, to host our three-city team, monthly meeting attendance required access to video-enabled devices and the Internet. Second, team members had to have the time to commit to the project amidst competing interests (e.g., employment, appointments). Third, team members included individuals whose first languages were both French and English, which required a translator and/or the technical support from Google translate, though the latter does not always provide accurate translation. Finally, despite significant attempts to connect with local

government leaders and media outlets to invite them to the events, these efforts were unsuccessful, with none in attendance at any of the events.

Given these challenges, there were several lessons learned. First, to ensure digital inclusion of older adults³⁵ and persons with LE of homelessness³⁶ on research teams that span multiple cities, the provision of additional support accessing a digital device or training advisors on the use of video technology may be required. Second, the necessity of paying LE participants for their time and contributions cannot be overemphasized. Just as student RAs are offered hourly payment for their efforts, so too should LE advisors. Holding meetings on the same day and at the same time each month allowed team members to save-the-date on their calendar in advance and, when possible, schedule around these meetings. Third, creating a welcoming and inclusive virtual space that acknowledged and celebrated team members' various stories and unique positionalities contributed to LE advisors feeling safe to share and have their experiences validated. Finally, when planning future community events, direct engagement with municipal leaders or media during the planning stage (e.g., having representatives from these sectors on the committee) could increase event attendance and participation and potentially policy change. We hope our example offers a model that can be replicated by other teams engaged in research and KMB efforts, whether on topics of older adults experiencing homelessness or similar other groups.

Conclusions

As the *Community Conversations* funding term concludes, the team remains energized to continue outreach and education efforts. With the community events, there were opportunities to connect with new LE advisors who have now joined the team and will help direct the next group-generated project. The idea to write this academic article was generated by our group to educate

others on the mechanics of how to develop partnerships and have meaningful community-engaged research. Following multiple meetings, the manuscript's goals and lessons learned were agreed up on by all co-authors, including those with LE. To disseminate these findings, the lead author developed a draft manuscript summarizing key processes and lessons learned. All authors reviewed the draft collectively and shared feedback with the lead author who revised the draft accordingly (e.g., one advisor suggested that our title include "we need to be at the table"). Once finalized, the manuscript was submitted by the first author. Future goals include presenting these ideas at conferences, developing a best practices document, op-eds, a children's book, webinars, zines, and local resource lists to help persons experiencing homelessness identify resources. The lessons learned thus far will strengthen our team's future LE KMB efforts, as well as inform other community-based research partnerships with LE advisors.

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Table 1. Lived Expertise Advisor Responses to Guiding Questions

Question	Response
How would you like to be involved in the Partnership?	Advisors described their motivation to educate the public about the experiences and challenges of homelessness for older adults and share findings/resources from the partnership with the public through social media.
What additional ways would you be interested in contributing to the Partnership?	Advisors expressed interests in writing op-eds, contributing to social media campaigns, speaking to media, and sharing best practices and lessons learned across the cities.
In what ways should the LEA committee work together?	Advisors identified educational activities that they wanted to prioritize: 1) talks to educate the public about homelessness; 2) the sharing of available resources for people experiencing homelessness; and 3) opportunities to pair people experiencing homelessness with a community member to exchange stories over a meal.
What roles should the LE advisors have?	Advisors felt that people with LE and those working on the frontlines are most knowledgeable about what does and does not work when aiming to support older persons experiencing homelessness.

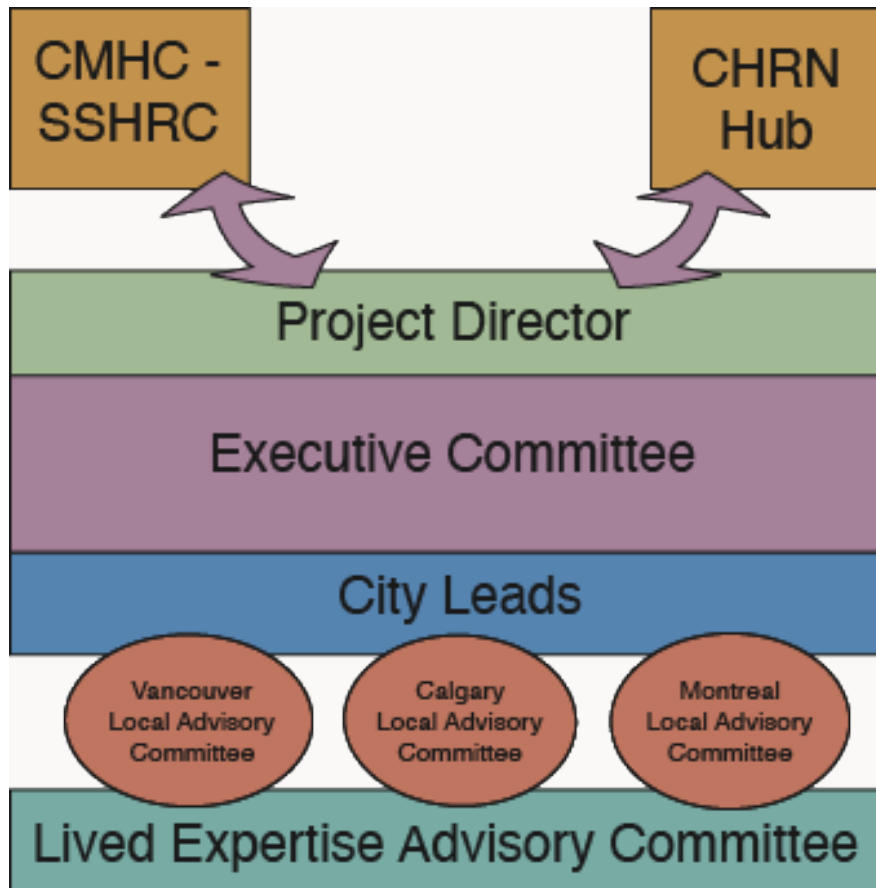
Table 2. Stereotype card myths and counternarratives

Myth	Counternarrative
“Homelessness does not happen to older adults.”	People can become homeless at any age, including ages 65+.
“All people experiencing homelessness are sleeping on the street or in shelters.”	There are varying degrees of homelessness – such as unsheltered, sheltered, fleeing abuse, hidden homeless.
“Housing is accessible and affordable for seniors.”	‘Affordable housing’ is not always affordable or sustainable for seniors living on fixed income.
“People who are homeless don't have any life skills.”	People who are homeless are diverse in terms of life skills, occupations, education, and social roles.
“People become homeless because of their poor choices”	Many factors beyond a person’s control can lead to homelessness and housing insecurity, including a lack of affordable housing or inadequate health services.
“Every person who is homeless is homeless for the same reason.”	There are many diverse reasons for homelessness, such as job loss, trauma, domestic abuse, discrimination, eviction, and unmet health and social needs.
“People who are homeless are lazy and don’t want to work.”	It’s not always easy to re-enter the workforce. People with experiences of homelessness can face discrimination from employers.

Table 3. Summary of three local events

City	Event Format	Event Activities	Location	# of Participants
Vancouver	In-person community event with panel	-Lived expertise (LE) panel discussion -Social/networking hour -Light catering and refreshments -Open letter to the Minister responsible for housing -Stereotype cards as discussion prompts and take-home materials (French and English)	Accessible community space	50 attendees
Calgary	In-person community event with panel and art exhibit	-Four-day exhibit featuring art and photographs taken by older veterans with LE of homelessness -LE panel discussion -Open letter to the Minister responsible for housing -Stereotype cards as discussion prompts and take-home materials (French and English)	City Hall	25 attendees at panel event
Montreal	Mobile photo exhibit	-Mobile photo exhibit inside a cube van featuring photos taken by older adults with LE of homelessness -Light refreshments -Informal discussions at each location -Open letter to the Minister responsible for housing -Stereotype cards as discussion prompts and take-home materials (French and English)	Rental van (i.e., mobile event) parked in three locations	~80 across three locations

Figure 1. Aging in the Right Place (AIRP) Partnership Governance Structure



Note: The arrows indicate the Project Director 1) has reporting responsibilities with CMHC (the Canadian Mortgage and Housing Corporation) and SSHRC (the Social Sciences and Humanities Research Council); and 2) supports project knowledge mobilization through the Collaborative Housing Research Network (CHRN), a pan-Canadian, cross-sectoral network dedicated to providing the evidence to meet the goals of Canada's National Housing Strategy.