



Research
Centre

SPRING 2026

Research Project Summaries



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The SE Research Centre is committed to authentic inclusion of end-user experts-by-experience in all stages of the research process, from identifying the topic or problem for study, through development, implementation and evaluation of solutions, guided by its very own **Participatory Research to Action Framework (PR2A)**.



Areas of Focus:



Aging in
Society



Dying,
Death and
Grief



Models
of Care
Delivery



Health
and Care
Experiences



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research studies,
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Development of the Participatory Research to Action Framework (PR2A) to support end-to-end engagement of experts-by-experience

As patients, caregivers, and other knowledge users are increasingly involved in health services research, we identified the need for a framework to guide authentic engagement. The framework needed to be flexible enough to accommodate a wide range of research contexts and methods – but structured enough to address the full continuum of applied health services research including implementation and evaluation. We describe three cases representing the development and application of PR2A.

“PR2A helps researchers to navigate the uncertainties of participatory work with clear steps for iterative project development and relationship-building with end-user experts-by-experience. With its track record of successful application, PR2A is of interest to anyone committed to rigorous, meaningful and action-oriented health services research.”



- Dr. Justine Giosa, Executive Director and Scientific Director, SE Research Centre

Project overview

Participatory approaches in health services research increasingly value the expertise of those with lived experience, such as patients, caregivers and providers.¹ Involving these experts-by-experience improves the relevance and quality of research.²

There are various established approaches to guide participatory work including: community-based participatory research (CBPR),³ experience-based co-design (EBCD),⁴ integrated knowledge translation (IKT)⁵ and participatory action research (PAR).⁶ However, many of these approaches remain specific to a sector, condition, research stage or research design, making them difficult to apply more broadly.⁷

Researchers in the SE Research Centre set out to develop a novel framework that was appropriate to a methodologically and substantively diverse program of community-focused applied health services research, involvement of a wide range of experts-by-experience, and that encompassed the full cycle of research including implementation and evaluation.

What did we do?

The SE Research Centre team developed the **Participatory Research to Action Framework (PR2A)**⁸,

an action-oriented approach designed to authentically engage experts-by-experience across a wide range of projects. The development and application of are described through three cases.

What did we find?

Case 1 - Learning from existing participatory approaches: the SE Research Centre was engaged by a large teaching hospital to help improve a cardiac surgery care pathway. The researchers had previously used EBCD and IKT methods and found them too prescriptive to engage authentically with experts-by-experience. They decided to use a service design approach applying “generative methods,” to explore not only what people say and do, but also what they make when encouraged to participate creatively.

The process led to the successful design of an ecosystem of supports for cardiac surgery patients and their caregivers. However, the team encountered the following challenges: **1) Creative design vs. research structure:** service design approaches are intentionally unstructured at the start, to maximize creativity. This is difficult to balance with the need for transparent, structured, and stepwise research protocols; **2) Implementation limitation:** service design methods offer guidance for ideating and

prototyping interventions or tools, but they do not offer guidance for implementation or evaluation. Thus, the proposed ecosystem of supports was never fully put into practice or evaluated.

Case 2 - Co-designing PR2A: through reflection on experiences including the above described, the SE Research Centre decided to map and describe the steps involved in their applied health services research and evaluation studies. The team identified concepts and strategies from relevant bodies of literature including CBPR, EBCD, IKT, and PAR. These were mapped onto the design cycle from project formation to implementation,⁹ while also expanding this cycle to include essential preparatory, implementation and evaluation stages. This resulted in a framework that addresses how participation can be embedded into six stages of the research cycle (**Figure 1**), offering guidance on who, when, and how to involve participants at each stage. In doing so, the framework balances the generative potential of creativity with the rigor of a structured research process.

Case 3 - Applying PR2A: PR2A has since been applied in several projects. One early example was a project to explore and respond to the experiences of family caregivers and care providers of persons living with

dementia. The project began with the *Readiness* stage, where a group of family caregivers approached the SE Research Centre and raised a need for a focus on person- and family-centred dementia care. The *Discover* stage included literature and environmental scans, as well as diaries and photos produced by caregivers. Qualitative analysis of these materials was used to *Define* the problems faced by caregivers. During the *Develop* stage, co-design workshops with caregivers and care providers were used to create a prototype for a paper-based tool that could help caregivers and care providers to collaboratively navigate their roles along the dementia journey. Finally, the *Deliver* and *Measure* stages led to iteration and expansion into analogue and digital formats. The tool is now available in culturally adapted, multilingual versions. It has been delivered to 7 communities and is undergoing national scale and spread.¹⁰

What are the next steps?

PR2A has become a foundational guiding methodological framework for studies conducted at the SE Research Centre. It has been applied across our diverse research program and aligns with our commitment to inclusive, action-oriented research to drive meaningful system change.

Figure 1. Participatory Research to Action Framework





Aging and mental health: What matters most to Canadians?

The impact of age-related changes on the mental health of Canadians is not widely known or understood. We worked together with the Canadian Mental Health Association (CMHA), older adults, family caregivers and health and social care providers to find out what matters most to Canadians on the topic of aging and mental health to guide future research.

“Identifying priorities for aging-focused mental health research with aging Canadians is an important step but just the beginning. We have a responsibility as scientists to conduct research that meaningfully responds to these priorities and brings funding and policy attention towards inclusive and holistic mental health support, care and treatment.”



- Dr. Justine Giosa, Executive Director and Scientific Director, SE Research Centre

Project overview

Age-related changes (e.g., loss of social roles, retirement, living alone, bereavement, and physical and mental health conditions) can negatively impact our overall mental health¹ — our “*positive sense of well-being, or the capacity to enjoy life and deal with the challenges we face*”.²

While the topic of aging is a globally recognized health research priority, there is a major gap in aging-focused mental health research. To better understand the needs of the diverse growing population of older adults in Canada, we need to learn more about the role and significance of age-related changes on mental health.

This collaboration was originally brainstormed by the SE Research Centre and Canadian Mental Health Association (CMHA) in 2018, with a combined vision to authentically engage older adults, family caregivers and health and social care providers in the identification of an aging-focused mental health research agenda. The project was guided by a steering group composed of older adults, caregivers, and members of aging and mental health organizations from across Canada. Steering group members met monthly to review upcoming project activities and

provide feedback and suggestions on how best to engage and incorporate the perspectives of all Canadians.

Together with Canadians, we identified a top 10 list of unanswered questions related to aging and mental health support, care, and treatment, defined as follows:

- **Support:** focuses on the information, resources, and services meant to communicate to, educate, or connect people on the topic of mental health;
- **Care:** looks at the services focused on protecting and promoting the individual abilities and strengths of anyone experiencing poor mental health;
- **Treatment:** refers to medical and professional interventions used to cure or alleviate symptoms of a diagnosed mental health illness.

Recognizing that significant research is already taking place across Canada on the topic of dementias, including a Canadian Dementia Priority Setting Partnership,³ these topics were excluded from this initiative.

What have we done?

As part of our portfolio investigating Aging in Society, we used a modified James Lind Alliance Approach to

priority setting partnerships⁴ and worked together with older adults, caregivers, and health and social care providers through:

- Monthly steering group meetings
- A national survey to identify Canadians' broad questions and concerns around mental health support, care and treatment
- A rapid review of evidence published in the last 10 years to categorize questions as either answered, or partially/ completely unanswered
- A second national survey to identify a short list of priority questions
- A series of 4 online workshops to prioritize and rank order the final list of 10 unanswered questions and discuss challenges and opportunities for dissemination.

What did we find?

Across two national surveys and four online workshops, over 1,000 survey responses were gathered, and 52 workshop participants were engaged.

- Survey 1 led to the identification of 40+ questions on aging and mental health, 25 of which were unanswered and put forward in Survey 2.
- Survey 2 led to refining the list of 25 questions to a shorter list of 18 questions, prioritizing questions most frequently selected as important by respondents overall and individuals in under-represented groups (e.g., adults 76 years of age and older, men, non-Caucasian individuals, and those who live outside of Ontario).
- Workshops 1-3 involved small groups of older adults, caregivers, and health and social care providers, and Workshop 4 involved a large mixed perspective group. Participants in each workshop worked together to discuss and generate a ranked list of their 10 priority questions. The final list of 10 unanswered questions (scan/click the QR code under **To learn more about this work**) was generated by combining the lists from all 4 workshops.

What are the next steps?

We are sharing the aging-focused mental health research priorities widely. This includes:

1. an open access publication (scan/click the QR code under **To learn more about this work**),⁵
2. formalizing the Canadian Aging Action, Research, and Education (CAARE) for Mental Health Group,⁶
3. an action-oriented project focused on co-designing mental health conversations between aging Canadians and health and social care providers in the community, and
4. pursuing funding opportunities with the CAARE for Mental Health Group to enhance mental health supports for double-duty caregivers and the older adults they care for.

How is this research funded and supported?

This work was funded and supported by SE Health, one of Canada's largest social enterprises, and the Canadian Mental Health Association.

To learn more about this work

Aging and Mental Health: Collaborating on Research Priorities with Older Adults, Caregivers and Health and Social Care Providers across Canada⁵



SE Research Centre's Aging & Mental Health Initiatives

To cite this work

Giosa, J. L., Kalles, E., & Holyoke, P. (2026, April). Aging and mental health: What matters most to Canadians? Markham, Ontario: SE Research Centre.

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Aging and mental health: Co-designing the Mental Health Continuum for Aging Canadians to destigmatize mental health

The mental health of aging Canadians is a growing concern for Canada’s health and social care system. The dual stigmas of ageism and negative attitudes about mental health can make it challenging for older adults to access needed mental health support, care, and treatment. Promoting mental health conversations between older adults, caregivers and health and social care providers in home and community settings is an important step towards expanded system capacity to address unmet needs.

“The Mental Health Continuum for Aging Canadians allows us as older adults and those who care about mental health to view mental health on a continuum. The chart and the supporting materials promote understanding and open dialogue to help remove the stigma surrounding mental health.”

- Mary Hynes, Expert-by-Experience, Working Group Member



Project overview

Mental health of aging Canadians is a longstanding concern for the health and social care system. Older adults disproportionately experience barriers to mental health support, care, and treatment due to systemic ageism and mental health stigma. As a result, older adults’ mental health needs are often unmet in a healthcare system that focuses more on addressing physical health concerns.

Community-based health and social care providers develop trusting relationships with their clients and have insight into older adults’ home and life circumstances.¹ These providers are well-positioned to talk with their clients about mental health – our *“positive sense of well-being, or our capacity to enjoy life and deal with the challenges we face”*² – but often avoid doing so due to a lack of resources and training available to help build their skills and confidence.

Acting on Research Priorities Identified by Canadians

In 2019, the SE Research Centre and Canadian Mental Health Association National office obtained feedback from health and social care providers, older adults and caregivers to identify priorities for aging and mental health research.³ Two priorities were:

1. Skill-building in community health and social care

providers who are not mental health specialists,
2. Application of user-friendly tools to identify signs of positive and poor mental health.

In response to these priorities, we developed a 3-phase research study guided by the **Participatory Research to Action Framework (PR2A)**⁴ to co-design and test an evidence-informed approach to mental health conversations between health and social care providers and older adults during routine care interactions in rural and urban settings across Canada.⁵ **Phase 1** focused on adapting the Mental Health Continuum Model to be inclusive of older adults as a user-friendly tool to identify signs and signals of positive and poor mental health. In **Phase 2**, we co-designed additional resources with care providers to support them to engage older adults in holistic mental health conversations.⁶ **Phase 3** involved testing the co-designed initiative in practice.⁷ All phases of the work were supported by a Working Group of experts-by-experience (e.g., older adults, caregivers, health and social care providers) from across Canada. This report focuses on Phase 1.

What have we done?

As part of our research portfolio investigating Aging in Society and in alignment with stage 3 ‘Define’ of the PR2A,⁴ we led a series of online workshops and

interviews to adapt an existing resource – the Mental Health Continuum Model⁸ – for use with older adults in home and community care settings. A total of 59 older adults, caregivers, and health and social care providers participated in one of 4 workshops and 2 interviews.

To confirm the acceptability of the adapted resource and gauge its applicability to a wider audience, we then led a pan-Canadian survey. In total, 1,068 individuals participated from all territories and provinces in Canada. Respondents were predominantly older adults (79%) living in urban areas.

What did we find?

The workshops and survey led to the production of the **Mental Health Continuum for Aging Canadians (MHCAC)** (see QR code under **MHCAC Figure**).

Workshop participants appreciated the idea of starting mental health conversations with aging Canadians. To support inclusive and non-judgmental discussions, they identified multiple adaptations to the original Mental Health Continuum Model. Changes incorporated into the MHCAC include:

- Changing the colour scheme to improve visual accessibility
- Renaming the severity levels with action-oriented and non-diagnostic terms
- Emphasizing the dynamic nature of mental health over time
- Re-defining the mental health categories to be inclusive and non-judgmental
- Including signs and signals that are relevant and comprehensive for an aging-focused context.

Almost 90% of survey respondents agreed or strongly agreed that the MHCAC was a valuable resource for mental health conversations. One participant shared,

“[The MHCAC] covers the whole picture in the process of recognizing when things are going well and when things are starting to go amiss”.

Respondents strongly agreed with all of the changes identified, including 84% who felt the 4 levels of the

continuum describe a helpful range of follow-up actions based on the signs and signals, and 89% who felt the MHCAC would be useful overall to start mental health conversations. Free-text responses provided additional support for the MHCAC’s value and potential applications.

What are the next steps?

A peer-reviewed publication reporting on the development of the Mental Health Continuum for Aging Canadians is currently under review.⁹ To build on the MHCAC as an evidence-informed basis, we engaged providers in a series of co-design workshops to create tangible tools and conversation supports (Phase 2).

How is this research funded and supported?

This work was funded by the Canadian Institutes of Health Research (Operating Grant: Addressing the Wider Health Impacts of COVID-19, #478339) and SE Health, one of Canada’s largest social enterprises.

To learn more about this work

Co-designing action-oriented mental health conversations between care providers and ageing Canadians in the community: a participatory mixed-methods study protocol⁵



To cite this work

Giosa, J. L., Kalles, E., Coumoundouros, C., Beresford, T., Peak, A., Oelke, N., Aubrecht, K., Holyoke, P. & McAiney, C. (2026, April). Aging and mental health: Co-designing the Mental Health Continuum for Aging Canadians to destigmatize mental health. Markham, Ontario: SE Research Centre.

References



MHCAC Figure





Co-designing the Mental Health Conversations Initiative to facilitate conversations in home & community care

Promoting mental health conversations between older adults, caregivers and health and social care providers in home and community settings is an important step towards expanded system capacity to address unmet needs. However, due to a historical emphasis on task-based physical health care, capacity-building and evidence-informed resources are needed to support the integration of mental health into providers’ existing practice.

“Evidence-based mental health conversations at the point-of-care are critical to counteracting the dual stigmas of ageism and negative attitudes towards mental health that impede help-seeking behaviours and system integration. The Mental Health Conversations Initiative will expand health system capacity for mental health support, care and treatment in home and community care settings across Canada.”
- Nancy Lefebvre, Senior Vice President and Chief Operating Officer, SE Health



Project overview

The **Mental Health Continuum for Aging Canadians (MHCAC)**¹ is a holistic, visual mental health model illustrating mental health as a spectrum that can change over time, with mental health being influenced by categories that include thoughts, feelings and emotions, daily routine and activities, sleep experience, physical observations, relationships, participation and connection, and habits and coping strategies (see QR code under **MHCAC Figure**).

As an evidence-informed, non-diagnostic, discipline-agnostic resource, the MHCAC can be used by health and social care providers to engage clients and caregivers in conversations about mental health. However, there is a need for additional resources that build providers’ skills and confidence to meaningfully integrate the MHCAC into their daily work.^{2,3} To help ensure resources are usable and applicable, it is important to engage providers in the design process.

What have we done?

In alignment with stage 4 ‘Develop’ and stage 5 ‘Deliver’ of the **Participatory Research to Action Framework (PR2A)**,⁴ this project focused on co-

designing additional resources and processes to support use of the MHCAC during mental health conversations at the point-of-care.

As part of our research portfolio investigating Aging in Society, we conducted a series of workshops in partnership with 15 home and community care organizations across rural and urban communities in British Columbia, Ontario, and Nova Scotia. A Working Group of experts-by-experience provided guidance throughout the project.

First, we conducted 7 workshops in English and French with 84 health and social care providers to generate ideas for what resources and processes are needed to support providers to use the MHCAC to engage clients in mental health conversation.

Next, we developed prototypes based on the ideas generated from the workshops. To support prototype development, we worked with a service design consultancy to conduct 4 additional workshops with 44 health and social care providers and leaders to:

1. Determine which ideas should be prioritized for prototype development, and
2. Get feedback on preliminary prototypes.

These additional workshops supported development of refined prototypes that could be used for pilot testing.

What did we find?

During initial workshops to generate ideas on how providers could use the MHCAC, providers shared they felt the MHCAC was a valuable resource to support mental health conversations between providers, clients, and caregivers, since it could act

“... as a common language for the three different perspectives. And using the key elements of the continuum. So, the categories [of signs and symptoms] and the labels at the top, and the bi-directional arrow ... as things that everybody could understand as a common language to structure their communication about mental health.”

The MHCAC was also thought to provide general education about mental health and serve as a visual reference about the different categories of mental well-being. Providers felt it could be useful to visually track mental health over time, using the action-oriented levels and associated signs and signals (see **MHCAC Figure**). Additionally, the MHCAC could facilitate mental health communication between providers, clients, and caregivers.

Based on the ideas generated from these workshops and additional co-design sessions led by the service design consultancy, the **Mental Health Conversations Initiative (MHCI)** was created. The MHCI is a non-diagnostic and discipline-agnostic initiative that will support more inclusive and holistic attention to mental health needs in home and community care settings. The initiative has 5 components:

1. An **Implementation Framework** with information about the initiative and its development, testimonials to support change leadership, and key implementation learnings to support spread and scale of the MHCI.
2. A **Mental Health Conversations Guide** to support care provider decision-making when engaging clients in tailored, person-centred mental health conversations.

3. **Mental Health Conversations Training** for care providers to equip them with the knowledge and skills needed to facilitate mental health conversations with older adults.
4. A **Mental Health Conversations Toolkit** that includes tangible tools and resources (e.g., a fridge magnet, conversation cards) to support mental health conversations.
5. **Mental Health Conversations** that care providers will facilitate with older adults and caregivers.

What are the next steps?

Peer-reviewed publications reporting on the development of the Mental Health Conversations Initiative are under development. The MHCI is currently being piloted with 11 home and community care organizations across Canada.⁵

How is this research funded and supported?

This work was funded by the Canadian Institutes of Health Research (Operating Grant: Addressing the Wider Health Impacts of COVID-19, #478339) and SE Health, one of Canada’s largest social enterprises.

To learn more about this work

Co-designing action-oriented mental health conversations between care providers and ageing Canadians in the community: a participatory mixed-methods study protocol⁶



To cite this work

Giosa, J. L., Kalles, E., Coumoundouros, C., Beresford, T., Peak, A., Oelke, N., Aubrecht, K., Holyoke, P. & McAiney, C. (2026, April). Co-designing the Mental Health Conversations Initiative to facilitate conversations in home & community care. Markham, Ontario: SE Research Centre.

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MHCAC Figure





Pilot testing of the Mental Health Conversations Initiative: A holistic strategy to support the mental health of aging Canadians

Home and community care providers have opportunities to provide needed mental health support to older adults, given their frequent interactions allow them to build strong relationships with their clients. To leverage these opportunities, home and community care providers need evidence-informed training and tools to build their confidence and skills in engaging older adults in holistic and supportive mental health conversations. The Mental Health Conversations Initiative was co-designed as a strategy to build the mental health capacity of the home and community care workforce to support integration of mental health conversations into routine care. Testing the initiative in real-world settings is essential to ensuring the initiative is acceptable and fits into existing practice.

“One of the things that makes the Mental Health Conversations Initiative so valuable is the training and practical tools it gives providers. These resources build a shared understanding of mental health and strengthen providers’ confidence to talk about mental health with clients. The emphasis on conversations as a way to meet clients’ holistic mental health needs highlights the central role relationships play in providing high quality home and community care.”
- Matthew Minnings, Regional Director, SE Health



Project overview

As part of a national, multi-phase research study,¹ the **Mental Health Conversations Initiative (MHCI)** was co-designed as a **non-diagnostic, discipline-agnostic strategy** to address the mental health needs of aging Canadians.

Rooted in the Mental Health Continuum for Aging Canadians (MHCAC),² a holistic mental health model, the MHCI equips providers with evidence-informed training and tools to engage older adults in mental health conversations.³ The MHCI and MHCAC were co-designed with over 1,000 Canadians representing every province and territory in Canada.^{2,3} However, the initiative has not yet been tested in practice.

What are we doing?

In alignment with stage 6 ‘Measure’ of the **Participatory Research to Action Framework (PR2A)**,⁴

this project focused on testing the MHCI to explore acceptability and feasibility of implementing the initiative in urban and rural settings across Canada.

How are we doing it?

As part of our research portfolio investigating Aging in Society, we pilot tested the MHCI in partnership with 11 home and community care organizations in British Columbia, Ontario and Nova Scotia. A Working Group of experts-by-experience (n=18) was engaged throughout this project to guide recruitment, data collection and knowledge mobilization.

Over 60 home and community care providers working in rural and urban areas completed the MHCI training which included an online education module and a live group training session.

Home and community care providers used the MHCI with over 50 older adults for 8 weeks. Participants

completed surveys and interviews exploring the acceptability of the MHCI based on the Theoretical Framework of Acceptability⁵ and how the MHCI was implemented into routine care interactions.

What did we find?

Who took part

Providers were mainly women (86%), identifying as White (78%) or Black (21%), living in rural (34%) and urban areas (66%), with many having over 5 years experience working in home and community care (47%).

Older adults included women (67%) and men (33%) who identified as White (98%) and lived in rural (43%) and urban (50%) areas. Older adults' self-reported mental well-being ranged from flourishing (37%) to languishing (17%), highlighting that providers sought to use the MHCI with older adults who had diverse mental health support needs.

Acceptability of the MHCI - preliminary findings

Both providers and older adults rated the acceptability of the MHCI as 'good' with an average score of 4 (out of 5).

Interviews with providers highlighted that the MHCI fit well into existing routines and the tangible tools provided to support conversations were a valued resource that differentiated the MHCI from other mental health initiatives. Mental health conversations were valued as a way to build deeper relationships with older adults, with one provider saying:

“Being concerned about their [an older adult’s] mental health shows them you are concerned about them as a person and not just concerned that they are in clean clothes and that their bed is made”.

Interviews with older adults highlighted that strong trust with their provider made them open to talking about mental health. Older adults valued the acknowledgment and empathy they received during mental health conversations, with one older adult saying:

“Well, it [the mental health conversations] just made me feel like I wasn’t alone. [...] It just sort of boosted me up”.

Based on feedback from providers and older adults, strategies to enhance acceptability and use of the MHCI included:

- Enhancing training to provide more examples of how the MHCI tools could be used during a mental health conversation
- Engaging supervisors in MHCI training to ensure they can support and encourage MHCI use
- Ensuring providers are scheduled regularly with the same older adults to provide opportunities for regular, repeated use of the MHCI

What are the next steps?

We are pursuing funding to support spread and scale of the MHCI across multiple care settings (e.g., community care, primary care, hospitals) to ensure the mental health of aging Canadians is supported across our communities and care systems.

How is this research funded and supported?

This work is funded by the Canadian Institutes of Health Research (Operating Grant: Addressing the Wider Health Impacts of COVID-19, #478339) and SE Health, one of Canada’s largest social enterprises.

To learn more about this work

Co-designing action-oriented mental health conversations between care providers and ageing Canadians in the community: a participatory mixed-methods study protocol¹



To cite this work

Coumoundouros, C., Kalles, E., Peak, A., Oelke, N., Aubrecht, K., Holyoke, P., McAiney, C. & Giosa, J. L., (2026, April). Pilot testing of the Mental Health Conversations Initiative: A holistic strategy to support the mental health of aging Canadians. Markham, Ontario: SE Research Centre.



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Mobilizing experts-by-experience for positive change: Canadian Aging Action, Research & Education (CAARE) for Mental Health Group

To support the evolving mental health and social care needs of the growing aging population, initiatives that aim to catalyze positive change require active leadership and inclusion of those that are most affected. The **Canadian Aging Action, Research, and Education (CAARE) for Mental Health Group** is comprised of Canadian experts-by-experience who are committed to mobilizing knowledge and influencing positive change for aging and mental health support, care, and treatment in Canada.

“What I value is the bottom-up approach. But at the same time, that linkage to SE Health... knowing we have SE Health and the research team, the resources and infrastructure to really scale, vocalize and communicate - I find that so valuable.”

- Anne Tran Fazzalari, expert-by-experience CAARE member



Project overview

Mental health is our *“positive sense of well-being, or the capacity to enjoy life and deal with the challenges we face”*.¹ Aging-related changes like declining health, retirement or experiencing the loss of friends/ family can affect overall mental health and well-being. However, there are major gaps in our knowledge regarding the interaction between mental health and aging.

Stemming from our project identifying priority research questions on aging and mental health according to **experts-by-experience** (i.e., older adults, caregivers, and health and social care providers living in Canada),² the **Canadian Aging Action, Research, and Education (CAARE) for Mental Health Group** was formalized in 2021 with support from a Canadian Institutes of Health Research (CIHR) - Institute of Aging Voluntary Sector Knowledge Mobilization Support Grant (2022-2023). The CAARE Group is comprised of members from the original project’s steering group and interested members of the public.

Who is the CAARE Group?

CAARE Group members include 16 older adults, family/ friend caregivers, health and social care providers, and members of organizations across Canada who focus on mental health. Recognizing the importance of authentic partnerships, the CAARE Group aims to challenge existing cultural norms related to ‘expertise’ in mental health research, which often excludes people with lived experience. We strive to be inclusive, non-hierarchical, and representative of diverse perspectives.

What are our goals?

1. **Build and sustain authentic partnerships** between researchers, health and social care providers, older adults, family/ friend caregivers, funders and policymakers interested in working together to advance aging and mental health care, support, and treatment in Canada.
2. **Support the co-design and completion of research and action-oriented projects** on the priority unanswered and answered questions² identified by older adults, family/ friend caregivers, and health

and social care providers.

3. **Advocate and/or apply for funding** to support the priorities and activities of the group.

What have we done?

As a part of our research portfolio investigating Aging in Society, the CAARE Group integrates research evidence with the expertise, experience, and values of our members to champion impact-oriented, equity-driven change related to the priority research questions. The group is grounded in authentic engagement and a collaborative approach to shaping priorities, direction, and a shared vision.

Advancing equitable improvements in mental health support, treatment, and care requires a deep understanding of lived experience. At virtual group meetings, we intentionally engage members through structured, interactive discussions that place their perspectives at the centre. Our approach grounds the development of co-designed initiatives in members' real-world experiences and perspectives.

We have continued to involve group members from across the country in priority-setting and research activities including:

1. Co-design of the **Mental Health Conversations Initiative**³, a non-diagnostic, discipline-agnostic initiative supporting home and community care providers to engage clients and family caregivers in holistic mental health conversations.
2. Co-development of an application for a CIHR Planning and Dissemination Grant to plan more workplace initiatives supporting the mental health of double-duty caregivers and the older adults they care for.

If successful, the grant will bring together the diverse expertise of double-duty caregivers, older adults, and national and provincial home and community care sector partners to understand the current help-seeking experiences of double-duty caregivers and identify opportunities to improve access and availability of mental health supports. By addressing these needs, we can potentially tackle individual

challenges, while protecting the health system's capacity to provide high quality care.

What are the next steps?

The CAARE group continues to play an integral advisory role in multiple research initiatives, offering fresh perspectives that meaningfully help shape the design and direction of research. We will continue to strive to influence positive change by growing the group's reach and representation in ways that better reflect Canada's diverse population, sharing our approach to community-driven research, and seeking opportunities to meaningfully include expert-by-experience perspectives in our aging and mental health initiatives.

The **CAARE in Action Working Group**, established to facilitate deeper discussions and more frequent engagement of a smaller group of CAARE members, will continue to meet monthly to contribute to planning and execution, ensuring that our aging and mental health initiatives lead equity-driven change grounded in living experience.

How is this research funded and supported?

This work is currently funded and supported by SE Health, one of Canada's largest social enterprises.

To cite this work

McLeod, R., Coumoundouros, C., Kalles, E., Hudani, A., Holyoke, P. & Giosa, J. L. (2026, April). Mobilizing experts-by-experience for positive change: Canadian Aging Action, Research & Education (CAARE) for Mental Health Group. Markham, Ontario: SE Research Centre.

References



Evaluating a co-developed palliative approach to care training package to enable social care workers to better support the palliative needs of people experiencing homelessness

Access to palliative and end-of-life care is especially difficult for people who are experiencing homelessness, due to the discrimination they face, and the stigma they encounter in usual health care settings. A **Palliative Approach to Care (PA2Care)** training package was developed for social care workers to build their knowledge and confidence in assisting people experiencing homelessness to gain access to supportive palliative and end-of-life care.

“PA2Care, now offered through the Saint Elizabeth Foundation, gives those supporting people experiencing homelessness practical tools and guidance they can use right away. Participants tell us it strengthens their confidence and helps them approach their work with greater understanding and care. The training’s thoughtful, flexible approach makes a real difference for both the staff and the people they support.”



- Fr. Dr. Matthew Durham, Executive Director, Saint Elizabeth Foundation, SE Health

Project overview

Many people experiencing homelessness have chronic, life-limiting conditions. However, due to social stigma and discrimination, people experiencing homelessness are often unable or unwilling to access health care – including palliative care.^{1,2}

Social care workers (e.g., shelter workers, addiction workers, social workers) work with people experiencing homelessness in a variety of settings, including emergency shelters, transitional housing, and wellness centres. In these roles, workers frequently build trusting relationships that are a crucial foundation for supporting improved access to palliative care. However, previous research has identified that social care workers lack necessary supports and resources to support delivering a palliative approach to care for clients.^{3,4}

In 2018, as part of our research portfolio investigating Dying, Death and Grief, our research team facilitated co-design workshops to co-develop a **Palliative Approach to Care (PA2Care)** training package with social care workers to help them better address the

palliative care needs of people experiencing homelessness.⁵ The 3-part training package includes:

- 1) an online e-learning module** introducing the main concepts of a palliative approach to care and the connections with a harm reduction approach frequently used by social care workers
- 2) materials and facilitator guide** for a one-day, in-person workshop to apply the learned concepts
- 3) an online repository of resources** that continues to be available for learners after completing the training.

What have we done?

After developing the training package,⁶ in 2019 we evaluated **a)** changes in self-reported knowledge and confidence, **b)** alignment of the final PA2Care training package with social care workers’ values as well as their expectations and information needs, and **c)** whether the materials supported facilitators to deliver the training. Local facilitators delivered the PA2Care training in 22 workshops across Toronto, Calgary, and Thunder Bay with over 200 learners.

Social care workers who participated in the training were surveyed about self-reported knowledge and confidence at 4 time points (i.e., before, part-way through, immediately after, and three months after). Semi-structured interviews were conducted with course facilitators to obtain feedback on the aspects of the training package that worked well and areas for improvement.

What did we find?

Social care workers (n=243) reported a high level of general knowledge about palliative care prior to participating in the training. However, they reported lacking specific knowledge and practices, including the difference between a palliative approach and what they know as a harm reduction approach in their work. After both the e-learning module and the in-person workshop, social care workers reported significant increases in their knowledge and confidence across all topics. Elements of the training package reported as most helpful include:

- 1) ways to identify available legal and financial resources for the clients as they are dying
- 2) strategies for talking about end-of-life with clients
- 3) a grief and grieving activity, which focused on helping social care workers handle their own emotions and loss when their clients die.

Social care workers reported these strategies helped them to feel better prepared to discuss clients' wishes and priorities for their end-of-life care. The participants also felt that the activity focused on managing grief was helpful for their personal well-being. One participant said,

"I liked the rock exercise best for describing grief - because it gives a concrete metaphor to a very abstract feeling."

Sharing experiences in a positive, interactive, and non-judgmental way during the in-person workshops was highly valued by social care workers. The opportunity to learn strategies and hear stories from colleagues was reported as especially valuable both in learning new techniques and fostering a sense of

connection to the wider community. The incorporation of guest speakers from local palliative outreach programs was also reported as a useful part of the training that provided valuable information on locally available resources.

Feedback from course facilitators was largely positive and they made some suggestions for changes to the training package's format. Specifically, facilitators wanted flexibility to tailor some activities based on their sense of how participants were responding. For example, some groups preferred discussion over role play, and facilitators wanted the opportunity to accommodate these preferences.

What are the next steps?

Based on the feedback from the participants and facilitators, the PA2Care training package was revised, and is available online, free of charge, at <https://pa2care.ca>.⁶ The package and other resources are freely accessible to interested individuals, social care workers, and organizations working with people who are experiencing homelessness.

How is this research funded and supported?

This research was funded and supported by SE Health, one of Canada's largest social enterprises. Partnerships with local organizations included Hospice Toronto, Hospice Northwest, and Calgary Allied Mobile Palliative Program (CAMPP) advocates who work closely with people experiencing homelessness and their social care providers.

To learn more about this work

Palliative Approach to Care for Workers who Support People who are Homeless in Canada⁶



To cite this work

Kalles, E., Hudani, A., & Holyoke, P. (2026, April). Evaluating a co-developed palliative approach to care training package to enable social care workers to better support the palliative needs of people experiencing homelessness. Markham, Ontario: SE Research Centre.



References

Towards more accurate and meaningful measurement of client experience: The Client Experience Survey for Integrated Home and Community Care (CESI-HCC)

Patient-reported experience measures (PREMs) provide critical outcome data for evaluating health system improvement, including progress toward Quadruple Aim and Health Equity.¹⁻³ However, existing PREMs have not kept pace with emerging models of integrated home and community care.^{4,5} In collaboration with experts-by-experience, we co-developed a new PREM to meaningfully measure client experiences of equity, life care, continuity and relational caring in integrated home and community care.

“CESI-HCC gives us meaningful, reliable and valid client experience data – critical to SE Health’s commitment to delivering high quality care that is responsive to individual needs, preferences and goals. The establishment of a learning community dedicated to CESI-HCC use at SE Health is exciting because it is building organizational capacity to meaningfully collect data from practice, transform this data into knowledge, and move this knowledge back into practice.”



- Tricia Swartz, Vice President, Operational Excellence & Professional Practice, SE Health

Project overview

Integrated home and community care models combine home healthcare with community-based services (e.g., housekeeping, transportation, socialization) to better meet client needs and preferences. Equity, life care, continuity and relational caring are foundational principles of these model and central to how clients experience care.



Equity: Care that is accessible and feels safe, respectful, and fair.^{3,6}



Life Care: Care that meets holistic needs and is experienced as collaborative and person-centred.^{7,8}



Continuity: Care that feels connected, coherent, and informed - that providers know what happened before, and what the plan is now.⁹



Relational Caring: Care that feels attentive, collaborative, and supportive of growth and well-being.¹⁰

Patient-reported experience measures are important for identifying, monitoring, and addressing the concerns and priorities that matter most to clients

and their families at the practice, organizational, and system levels.⁵ While PREMs have been developed and validated across a range of facility-based settings,¹¹ none had been intentionally designed and validated for integrated home and community care grounded in equity, life care, continuity and relational caring.

What have we done?

As part of our research portfolio investigating Health and Care Experiences, in collaboration with clients, caregivers, providers and healthcare leaders we co-developed the **Client Experience Survey for Integrated Home and Community Care**, a novel PREM for integrated home and community care¹².

Item pool generation. The research team conducted an environmental scan of academic and grey literature to generate an evidence-based item pool. Items were refined through a consensus process and organized into key topic areas (i.e., domains and sub-domains). Six healthcare leaders were interviewed to assess relevance and coverage.

Item refinement. Focus groups with clients and

caregivers, and interviews with health and social care providers were conducted to assess item and domain relevance and coverage.

User testing. Clients and caregivers were engaged in a “thinking aloud” process to assess how items and response options in the new PREM were interpreted by end-users.¹¹

Field testing. CESI-HCC was administered by telephone to Ontario home and community care clients to assess survey validity (i.e., measures what it is intended to) and reliability (i.e., produces the same results on different occasions).

What did we find?

Item pool generation. We identified 30 PREMs with over 800 items relevant to client experience in integrated home and community care. An initial item pool of 3 domains, 14 sub-domains and 72 items was generated. Interviews with healthcare leaders confirmed the item pool relevance and coverage based on their expertise in leading integrated home and community care programs.

Item refinement. Feedback from clients, caregivers, and providers led to key refinements, including the addition of participant instructions and a 4th domain, **Relational Caring**, and the removal or consolidation of redundant/unclear items. The resulting 39 items were scaled on a 5-point Likert scale with options for ‘not applicable’ and ‘I choose not to answer’, alongside demographic and health service use questions.

User testing. Client and caregiver feedback informed several refinements, including role-specific instructions, re-ordering of items, clearer wording for 19 items, and consolidation of non-response options.

Field testing. Comprehensive psychometric testing

Domain (# of items)	Context	Kaiser-Meyer Olkin MSA	EFA item loadings	Internal consistency (α)	Convergent Validity (r)	ICC 2, A1 (95% CI)
Equity (12)	Field test	.93	.66-.85	.94	.69 (p<.001)	.67 (.52-.81)
	Real-world	.97	.70-.88	.93	.57 (p<.001)	NA
Life Care (12)	Field test	.90	.54-.80	.95	.72 (p<.001)	.67 (.52-.81)
	Real-world	.96	.74-.89	.94	.62 (p<.001)	NA
Continuity (6)	Field test	.88	.67-.90	.90	.75 (p<.001)	.71 (.57-.84)
	Real-world	.91	.69-.90	.89	.64 (p<.001)	NA
Relational Caring (6)	Field test	.87	.84-.90	.91	.75 (p<.001)	.74 (.61-.86)
	Real-world	.91	.80-.92	.91	.62 (p<.001)	NA

demonstrated that CESI-HCC is a valid and reliable measure of client experience in integrated home and community care in Ontario, with four unique scales representing each domain (**Table 1**). An upper bound response bias supported the refinement of response options to better capture variation in experience.

Implementation. In May 2024, SE Health adopted CESI-HCC as its PREM for government-funded home care, reinforcing its commitment to evidence-informed, equity-focused, person-centred care. Subsequent workshops and the establishment of a cross-functional learning community have supported organizational capacity to translate CESI-HCC data into actionable insights to guide decision-making across the organization, supporting SE Health’s progression towards a learning health system.

What are the next steps?

Through SE Health’s CESI-HCC Learning Community and broader cross-sector collaborations, we will continue to refine tools and processes to support CESI-HCC use. Additionally, in November 2025 we received a Canadian Institutes of Health Research Planning and Dissemination Grant to support the pragmatic adaptation of CESI-HCC for electronic and mixed-mode administration and the development of an additional index to support scaling across care contexts. This work is underway, with early activities focused on ethics approvals, an environmental scan of PREMs used in transitional care, and engagement planning with health system partners.

How is this research funded and supported?

This work is funded and supported by SE Health, one of Canada’s largest social enterprises.

CESI-HCC items **To cite this work**



Table 1. CESI-HCC reliability and validity testing results



Research
Centre



COMMUNITY
HEALTH NURSES
OF CANADA



INFIRMIÈRES ET INFIRMIERS
EN SANTÉ COMMUNAUTAIRE
DU CANADA

Updating the Core Competencies for Home Health Nursing in Canada: A modified eDelphi study

The delivery of nursing care in the home requires a unique set of skills, with home health nurses often practicing alone and taking on a range of roles in unpredictable and unstructured physical work settings.^{1,2} Research shows that nurses often face a challenging transition when entering home health practice.³ It is important to support the home health workforce by ensuring home health nurses are well-equipped to handle the demands of nursing in home and community care.⁴

“The updated home health nursing competencies highlight the skills and expertise needed to provide high-quality, effective care in the home setting. They are a valuable tool for organizations to assess staff strengths, identify areas for growth, and design training that reflects the evolving nature of the work. I am proud that SE Health is taking the next step towards implementation by exploring how the competencies can be used to strengthen nurse capacity and confidence to support high-quality care at home.”



- Tricia Swartz, Vice President, Operational Excellence & Professional Practice, SE Health

Project overview

Competence of care providers directly impacts client health outcomes and patient safety.⁵ Home health is a specialty area of nursing practice involving the autonomous and asynchronous coordination and delivery of multi-disciplinary care in an unstructured and unpredictable environment. In 2010, the **Community Health Nurses of Canada (CHNC)** completed a project to articulate a set of nursing competencies specifically focused on the knowledge, skills, attitudes, and personal attributes required to support the safe and ethical delivery of home health nursing care.⁶ Since then, several important changes to the home health environment have occurred including: rising use of digital health and telemedicine⁷; growing ethnocultural diversity in Canada^{8,9}; and increasing client acuity.¹⁰ These changes have prompted calls for review and updating of the competencies.

What was the goal?

The aim of this participatory project was to update Canada’s home health nursing competencies to reflect

available evidence and the specific skills and expertise needed to provide care in the current home health practice environment.

What have we done?

As part of our research portfolio investigating Health and Care Experiences, we partnered with CHNC to conduct an environmental scan and a modified eDelphi study engaging home health nurses and interdisciplinary home care team members from across the country to revise the 2010 Home Health Nursing Competencies.⁶ An Advisory Working Group of 24 experts-by-experience (e.g., home health nursing leaders working in point-of-care, management, academic or research roles) guided project decision-making and provided direct feedback on the competency generation process.

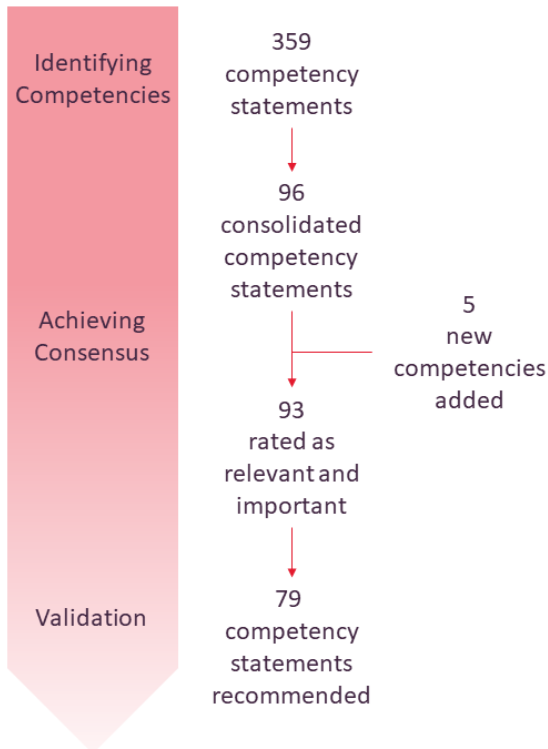
What did we find?

Identifying existing competencies

In January 2024 we completed an environmental scan of pre-existing competency statements, domains, and standards found in peer-reviewed and grey literature

published by nursing organizations. Over 300 pre-existing competency statements were reviewed across 5 sources and consolidated into 96 unique competency statements (Figure 1).^{6,11-14} Identified competency statements were organized using the 2019 Standards of Practice developed by CHNC¹² as a framework.

Figure 1. Competency selection process



Engaging home health nurses to achieve consensus

A panel of 43 home health nurses representing point-of-care, operations/ management, and academic research/ education perspectives from 10 provinces participated in the eDelphi process. Across 3 rounds of surveys, nursing panel members were asked to rate the relevance and importance of each pre-existing competency identified in the environmental scan. Panel members also generated 5 additional competencies for consideration.

A total of 93 competency statements were identified as relevant to present-day home health nursing by 75% or more of the panel AND rated as either “important” or “essential” to practice. These 93 competencies were used to obtain feedback during

additional consultations.

Consultations and validation

To validate and refine the draft competencies generated from the nursing panel, further feedback was obtained from 12 interdisciplinary home care team members and 41 attendees at a pre-conference workshop focused on home health nursing competencies at the CHNC Conference 2024. Based on these consultations and guidance from the Advisory Working Group, a final set of 79 competencies was generated.

The final set of recommended competencies were shared with CHNC and used to inform the **2024 Home Health Nursing Competencies in Canada** published by CHNC.¹⁵



What are the next steps?

As part of Healthcare Excellence Canada’s 2025 EXTRA™: Executive Training Program, a cross-functional team from SE Health will be identifying and designing strategies to support implementation of the 2024 Home Health Nursing Competencies.

How is this research funded and supported?

This work was funded and supported by SE Health, one of Canada’s largest social enterprises.

To learn more about this work

Advancing home health nursing competencies in Canada to reflect a dynamic care environment and complex population health needs: a modified eDelphi study¹⁶



To cite this work

Saari, M., Coumoundouros, C., Tadeo, J., Northwood, M., Chyzy, B., Holyoke, P. & Giosa, J. L. (2026, April). Updating the Core Competencies for Home Health Nursing in Canada: A modified eDelphi study. Markham, Ontario: SE Research Centre.



References

Co-designing practice resources to support meaningful inclusion of personal support providers in home and community care teams

The **Observe, Coach, Assist and Report (OCAR) framework** provides a formal structure to support intentional integration of personal support (PS) providers and their care contributions in home care teams. Recent research has shown a need for practice resources to facilitate use of OCAR by PS providers in the home. This project will co-design, implement, and test an evidence-based toolkit, to optimize PS practices at the point-of-care and organizational level in two Canadian home care organizations.

“OCAR provides a practical, evidence-based way to structure personal support provider practice, strengthening their role in team-based and person-centred home care. Intentional uptake and integration of OCAR to guide practice at the point-of-care and organizational levels offers a pathway to support personal support provider job satisfaction and workforce stabilization in the home and community care sector.”

- Nancy Lefebvre, Senior Vice President and Chief Operating Officer, SE Health

Project overview

Canadians prefer to live and receive care at home and in their communities as they age.¹ Most paid home care services are delivered by personal support (PS) providers, who have frequent, sustained contact with clients and are well positioned to notice changes in client care needs. Despite this, PS providers are often excluded from formal care planning and communication processes, which can result in reduced care consistency and efficiency.²⁻⁴

Strengthening the intentional integration of PS providers into home care teams is critical for improving person-centred care, care consistency and provider experience – key factors in workforce stabilization and sustainability.⁵⁻⁷

In collaboration with point-of-care providers and clinical leaders, the **Observe, Coach, Assist and Report (OCAR) framework**⁸ was developed to describe the essential role PS providers play in delivering person-centred, team-based home care. In the OCAR framework, four activity types describing the daily work of PS providers are defined⁸:

- **Observe:** pay careful attention to, and make pointed inquiries about, client health and social care needs
- **Coach:** encourage, explain, and/or demonstrate how to complete a given care activity
- **Assist:** provide verbal and/or physical support to complete care-related tasks
- **Report:** notify care team members about important observations related to client care needs.

Together, these activities describe how PS providers contribute to the follow of timely, relevant information within care teams and support safe, coordinated and person-centred care.

In a 2023 survey, PS provider staff working at a large home care organization in Ontario reported on current uses and discussed future opportunities for OCAR to structure PS provider work.⁹ Survey respondents reported that OCAR was relevant to their daily practice, and identified many opportunities for expanded use including improving knowledge about the PS provider role; establishing clear care

expectations; and supporting client care consistency and intra-/inter-professional communication. Participants also identified a need for consistent and ongoing education about how to use OCAR, and better integration of OCAR with existing processes.

What are we doing?

As part of our research portfolio investigating Health and Care Experiences, we partnered with two Ontario home care organizations in a multi-year project to co-design and test an **OCAR Toolkit** with pragmatic resources to help structure PS practice in home care. We will also develop and test implementation processes to support spread and scale of the Toolkit.

Guided by the **Participatory Research to Action Framework**¹⁰ and an advisory committee of experts-by-experience (e.g., point-of-care providers, home care leadership), this study addresses four objectives:

1. To explore, synthesize, and compare evidence of, and opportunities for, alignment of current PS home care practice and OCAR type activities
2. To co-design an OCAR Toolkit and supporting processes with experts-by-experience in PS practice
3. To develop tailored organization-level action plans to implement the Toolkit and supporting processes
4. To implement and test the Toolkit and supporting processes to assess feasibility and provider experience in real-world home care settings.

This project is now underway with Phase 2 focusing on addressing Objective 1.

What did we find?

We examined how current PS provider practice aligns with OCAR type activities, and where there are opportunities to better support consistent, team-based care.

Interviews with clients, caregivers and staff including PS providers, managers and practice leaders across two home care organizations highlighted variation in how OCAR type activities are supported in practice. Review of existing practice documents (e.g., policies, education and orientation modules, charting tools)

helped identify where OCAR could be more intentionally embedded.

Opportunities for strengthening alignment with OCAR type activities were identified across four key practice components:

- **Communication** (e.g., emails, meetings)
- **Documentation** (e.g., progress notes, care plans)
- **Education** (e.g., orientation with new staff)
- **Governance** (e.g., policies and procedures)

Preliminary findings suggest that embedding OCAR into on-going education opportunities and documentation processes offers a practical starting point for strengthening PS provider integration and improving communication in team-based care.

What are the next steps?

Findings from Phase 2 will inform design of a series of workshops with PS providers, managers and practice leaders to co-create the OCAR Toolkit components. Subsequently, prototype toolkits will be shared and implementation processes will be developed with cross-functional leaders to support integration of the Toolkit into organizational education, documentation and governance structures.

How is this research funded and supported? This work is funded and supported by the Canadian Institutes of Health Research (Project Grant Spring 2024, #519352) and SE Health, one of Canada's largest social enterprises.

To learn more about the OCAR framework

Observe, Coach, Assist, and Report: An Emerging Framework for Integrating Unregulated Healthcare Providers into Interdisciplinary Healthcare Teams⁸



To cite this work / References

Saari, M., Kalles, E., King, E., Lefebvre, N., Holyoke, P., McKay, S., Mitchell, L., Prentice, D., Zagrodney, K., McLeod, R., & Giosa, J. L. (2026, April). Co-designing practice resources to support meaningful inclusion of personal support providers in home and community care teams. Markham, Ontario: SE Research Centre.



Long-term LIFE Care at Home: The future of aging-focused care in Canada

Although 96% of Canadians want to live, age, and receive care at home long-term,¹ policy and debate continues to focus on building more hospital and long-term care facility beds.²⁻⁴ To prioritize aging Canadians' quality of life, we need to expand system capacity for meeting their 'life care' needs long-term. Using routinely collected health assessment data and consultation with experts-by-experience, we developed an innovative model of integrated home and community care called **Long-term Life Care at Home** which attends to the broad range of health and social care needs of aging Canadians.

"Long-term Life Care at Home is a new model of integrated, data-informed, holistic, people-centred care. It aims to preserve aging Canadian's autonomy and choice around where to live, age and receive care; and help shift our long-term care system to focus less on bricks and buildings and more on people and communities."



- Dr. Justine Giosa, Executive Director and Scientific Director, SE Research Centre

Project overview

Canadian home care is underfunded, often resulting in inadequate service availability.⁵ Frequently, care is task-focused and only provided for short periods after a hospital stay.⁶ Existing home care models are not designed to support social or mental health needs,^{7,8} relying heavily on unpaid caregivers.⁹ With the population of Canadians aged 85+ set to triple in the next 30 years,¹⁰ we must look beyond building long-term care (LTC) facilities to meet the demand for care.

As part of our research portfolio investigating Models of Care Delivery, we aimed to develop a solution focused on meeting the long-term needs of people in their own homes. This approach aligns with Canadians' care preferences and reserves hospital and LTC facility capacity for those whose needs that are best met in those settings.¹¹

What have we done? ¹¹

1. Reviewed ~205,000 home care assessments to group Ontario's home care population based on known risk factors of LTC facility admission;
2. Analyzed each group to describe their dominant medical, functional and social 'life care' needs¹²;

3. Conducted a survey-based consensus process with 42 home care providers to identify packages of care/ services to meet life care needs;
4. Compared life care needs and average daily costs of care between the *Long-term Life Care at Home* model and existing types of LTC "beds";
5. Facilitated six workshops engaging 67 older adults, family caregivers, and health and social care providers to validate and refine the model;
6. Conducted interviews with 10 health and social care decision-makers to explore their perspectives on positioning the model and mapping a referral process for *Long-term Life Care at Home* in Ontario.

What did we find?

Ontario's home care population can be divided into six groups based on known risk factors for LTC admission (**Figure 1**).¹² Their medical, functional, cognitive, and social 'life care' needs can be described using the six dimensions of the Pillars for Positive Health¹³: Bodily Functions, Mental Wellbeing, Meaningfulness, Quality of Life, Social & Societal Participation, and Daily Functioning.

There are 61 different types of care and support services needed in a variety of combinations to support the range of life care needs of older adults in their homes. Base care packages designed to meet life care needs range from 3 - 8 hours per day, inclusive of direct care and coordination (Figure 1).¹²

Overlap in the life care needs of older adults in home care and LTC in Ontario suggests the potential to shift the setting of care for more older adults to their homes. *Long-term Life Care at Home* care packages are lower in cost than hospital Alternate Level of Care (ALC) rates; and many are lower in cost than a private room in a LTC home.

Feedback from older adults, caregivers, and care providers suggest opportunities for model refinement (e.g., optimizing the number of providers in the home) and support for design principles (e.g., caring for the person and caregiver as a dyad). Feedback from health and social care decision-makers highlighted potential for the model to supplement existing services and the importance of taking a person-centred, integrated care approach.

How is this research funded and supported?

This work was funded and supported by SE Health, one of Canada’s largest social enterprises.

What are the next steps?

We are developing new tools to support the future implementation of *Long-Term Life Care at Home*, including a case-based learning programme to build interprofessional competencies for care providers by leveraging the profiles of the six groups.

To learn more about this work



Developing an evidence-informed model of Long-term Life Care at Home for older adults with medical, functional and/or social care needs in Ontario, Canada: a mixed methods study protocol.¹⁴



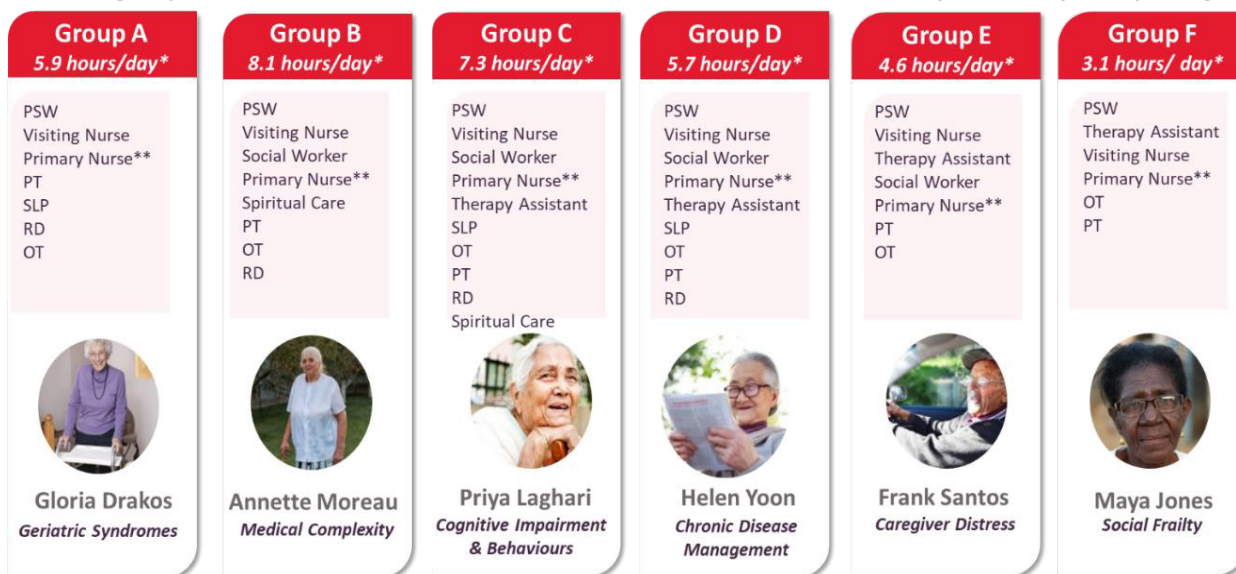
Profiling the medical, functional, cognitive, and psychosocial care needs of adults assessed for home care in Ontario, Canada: The case for Long-term ‘Life Care’ at Home.¹⁵

To cite this work / References

Giosa, J. L., Saari, M., Holyoke, P., Cardozo, V., Hirdes, J. P., & Heckman, G. A. (2026, April). Long-term LIFE Care at Home: The future of aging-focused care in Canada. Markham, Ontario: SE Research Centre.



Figure 1. Six groups of older adults based on Ontario home care assessment data & preliminary care packages



*Average daily total **care and coordination** hours across home care team; **Primary nurse responsibilities include care integration as well as the delivery of direct nursing care; ***Hours for caregiver supports included in the total hours of care.



Understanding the care needs of adults assessed for home care in Ontario: The case for long-term LIFE Care at Home

Traditional models of home care are not optimally structured to support clients’ holistic health needs. In turn, clients may struggle with unmet needs, reduced quality of life,¹ caregiver burden,² and adverse events.²⁻⁴ It is time to shift towards more holistic, equitable, and person-centred home care. This research describes the ‘life care’ needs of adults assessed for home care services, providing important evidence to guide system transformation.

“Home care today is about much more than basic support—it’s about recognizing and responding to the complex, multidimensional needs of every client. This research demonstrates how we can apply routinely collected data to enable person-centred care planning and integrated service delivery, essential to help our clients thrive at home, not just survive.”



- Madonna Gallo, Senior Vice President and Chief Strategy Officer, SE Health

Project overview

With an aging population, demand for home and community care is growing substantially, with clients facing increasingly complex medical, functional, cognitive, and psychosocial needs.⁵ Traditional home care models, which are task-focused and designed around discrete services, are not well equipped to support this type of complexity over time. This work contributes to a broader program of research aimed at advancing a feasible alternative model to facility-based long-term care that supports older adults to receive needs-based ‘life care’ at home, long term.

By leveraging routinely collected health assessment data to understand clients’ multidimensional needs across six **Positive Health** domains^{6,7} – bodily functions, mental wellbeing, meaningfulness, quality of life, social participation, and daily functioning – this work provides actionable evidence to inform care model design, workforce development and planning and system transformation.

What have we done?

As part of our research portfolio investigating Models of Care Delivery, we analyzed routinely collected **interRAI Home Care (interRAI HC)**⁸ assessments from

over 205,000 older adults assessed for home care in Ontario. We identified **six distinct groups of clients with shared patterns of medical, functional, cognitive, and psychosocial care needs.**

These groups were intentionally developed to support engagement of experts-by-experience in co-designing a new model of home-based long-term care. Each group was named to reflect the characteristics that placed them at elevated risk of admission to facility-based long-term care.

What did we find?

Older adults assessed for home care demonstrated substantial needs across multiple Positive Health domains, underscoring that effective support at home must extend beyond medical and functional care alone. More than half of clients presented with dependence on at least one instrumental activity of daily living (IADL), unsteady gait, or mental health concerns, such as depression and anxiety.

While these common needs represent the foundation of effective home care, the six client groups with distinct patterns of complexity highlight opportunities to more precisely target care approaches, workforce competencies and service intensity.

The six client groups and their care needs are:

Geriatric Syndromes (Group A): Extensive medical and social complexity due to the convergence of multiple geriatric syndromes such as functional limitations, falls, depression and complex medication needs.

Medical Complexity (Group B): High medical instability, requiring frequent monitoring and coordinated management of both acute and chronic health issues.

Cognitive Impairment and Behaviours (Group C): Cognitive and behavioural health needs, combined with high functional dependency and substantial caregiver distress.

Chronic Disease Management (Group D): On-going chronic disease management alongside mild cognitive impairments affecting daily functioning.

Caregiver Distress (Group E): Clients supported by co-resident spousal caregivers experiencing sustained and intensive caregiving demands.

Social Frailty (Group F): Reduced social resources and participation, often compounded by living alone with limited informal supports.

These groups (**Figure 1**) illustrate how shared needs form the baseline for all home care, while distinct group patterns create clear opportunities to focus and tailor care models and supports.

What are the next steps?

Ongoing work is applying the described Life Care grouping methodology to routinely collected interRAI HC assessment data across care settings, including

transitional care and direct-to-consumer home care, to support a **learning health system approach** to home and community care. By examining how care needs vary across the long-term care continuum, this work will inform intersectoral integrated care workforce planning and education that enables person-centred, goal-oriented Life Care at home.

How is this research funded and supported?

This work was funded and supported by SE Health, one of Canada’s largest social enterprises.

To learn more about this work

Profiling the medical, functional, cognitive, and psychosocial care needs of adults assessed for home care in Ontario, Canada: The case for long-term ‘life care’ at home⁹



To cite this work

Saari, M. E., Robibaro, F., Nova, A., Cardozo, V., Holyoke, P., Heckman, G. A., Hirdes, J., & Giosa, J. L. (2026, April). Understanding the care needs of adults assessed for home care in Ontario: The case for long-term LIFE Care at Home. Markham, Ontario: SE Research Centre.

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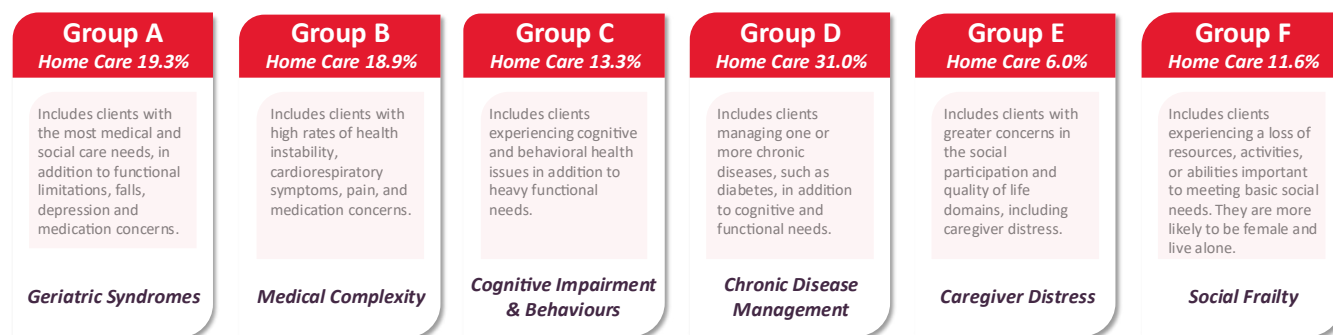


Figure 1. Six home care client groups with dominant care needs

The influence of integrated home and community care programmes on Quadruple Aim and Health Equity outcomes across the health care system

Health system transformation requires an understanding of how each sector interacts and influences other settings and the broader system. As Canada looks to transform health care to better meet the needs and preferences of its aging population, it is crucial to understand the influence of integrated home and community care programmes on the health system.

“The prioritization of ‘value’ in the evidence reveals how heavily cost-reduction weighs in health system planning and decision-making. By grounding our work in the Quadruple Aim and Health Equity, we endorse a shift toward a more balanced approach to health system research and reform, an approach that generates a thorough understanding of the evidence needed to scale and spread high-quality, integrated care.”

- Dr. Justine Giosa, Executive Director and Scientific Director, SE Research Centre



Project overview

As Canada’s population continues to age, care needs are changing. Systems designed to address short-term, acute care needs are challenged with supporting an increasing number of people requiring continuing care for chronic and medically complex conditions.¹

Expansion of home and community care services has been identified as a promising mechanism to attend to the population’s growing medical, functional, cognitive, and psychosocial care needs while simultaneously supporting widespread preferences to live, age, and receive care at home.² Further, integration of care and services has been endorsed as a potential solution to the coordination and prioritization challenges of caring for an aging population,³ however the influence of integrated home and community care programmes on the broader health system, is not well understood.

The **Quadruple Aim⁴ and Health Equity** provides a lens to better understand the influence of integrated care on the health system.

What have we done?

As a part of our research portfolio investigating Models of Care Delivery, we conducted a scoping review of published research literature to better understand what the evidence tells us about the influence of integrated home and community care programmes across health service settings.

We searched three research databases to gather relevant literature examining the influence of integrated home and community care programmes on Quadruple Aim and Health Equity outcomes in five health service settings of interest. Major integrated care journals were hand searched to identify articles not identified through database searching.

We assessed 5,087 titles and abstracts and 567 full-text articles. Data was extracted from 47 peer-reviewed articles that met our inclusion criteria. Details of the identified programmes and their influence on Quadruple Aim and Health Equity outcomes across five health system settings were extracted and analyzed. Consultations with health system leaders were conducted to validate findings,

leveraging their knowledge and expertise in the design, delivery and positioning of integrated home and community care to support the interpretation of results.

What did we find?

Figure 1 provides a simple summary of the identified literature, visualizing areas of focus and direction of influence. Across the published evidence, five integrated home and community care programme types were represented: integrated palliative care, transitional care, comprehensive coordinated care, preventative care, and restorative care.

Most studies examined influence on hospitals and emergency departments, reflecting prioritization of the acute care sector over other areas of the system. When examining the literature through the lens of the Quadruple Aim and Health Equity framework, evaluations most often prioritized outcomes in the ‘value’ domain, including reductions in hospital admissions, readmissions and length of stay. In contrast, there was limited evidence available on patient and caregiver experience, and very little on provider experience, and health equity; population health outcomes were not examined.

Findings highlight the need for future research and evaluation that generates a more comprehensive understanding of the influence of integrated home and community care, enabling a more balanced,

evidence-informed approach to planning and decision-making at the system level. A learning health system model that links data, knowledge, and practice is recommended to bring together the necessary resources and expertise to facilitate continuous, applied learning.

What are the next steps?

Now published in the *International Journal of Integrated Care*, this review can serve as an important resource to guide evidence-informed planning and evaluation of integrated home and community care programmes.

How is this research funded and supported?

This work was funded and supported by SE Health, one of Canada’s largest social enterprises.

To learn more about this work

Examining the Influence of Integrated Home and Community Care Programs on Quadruple Aim and Health Equity Outcomes Across the Health Care System: A Scoping Review.⁵



To cite this work

Saari, M., McLeod, R., Cardozo, V., Holyoke, P., & Giosa, J. L. (2026, April). The influence of integrated home and community care programmes on Quadruple Aim and Health Equity outcomes across

the health care system. Markham, Ontario: SE Research Centre.

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	Hospitals	Emergency Medical Services	Primary Care Clinics	Informal	Facility-Based Long Term
Value	+	+	⊗	-	⊗
Patient & Caregiver Experience	+	+	+	+	+
Population Health					
Provider Experience	⊗				
Health Equity	+	+			

Positive influence

Negative influence

Mixed results

No studies identified

Figure 1. Influence of home and community care programmes on Quadruple Aim and Health Equity outcomes across the health system



Identifying leading practices in the development and delivery of case-based learning programmes for health and social care providers

To meet the needs of aging populations, care systems are shifting towards integrated, people-centred models which require interdisciplinary teamwork. Yet, current education offers limited opportunities for collaborative learning and interprofessional skill development. Case-based learning (CBL) shows promise for building analytic, communicative and collaborative skills alongside content knowledge. However, there is little synthesized evidence to guide effective design and delivery of CBL programmes for health and social care education.

“To enable integrated care, we must start by transforming how we train our health and social care providers. The summary of leading practices for case-based learning generated by this project will serve as a critical foundation for evidence-informed design of education that produces collaborative, practice-ready teams equipped for person-centred, real-world care delivery.”



- Matt Snyder, Senior Vice President & Chief Human Resources Officer, SE Health

Project overview

Case-based learning (CBL) is a teaching approach that engages participants through authentic clinical cases with the goal of bridging theory and practice. This method is learner-centred, collaborative, and guided by specific learning objectives. CBL presents a unique opportunity for health and social care providers to engage in context-specific education and training.^{1,2}

What have we done?

As part of our research portfolio investigating Models of Care Delivery, we are conducting a scoping review to summarize leading practices and gaps in the design and delivery of CBL programmes for health and social care providers. With guidance from a health sciences librarian, we developed a robust search strategy which was executed across six major research databases to gather relevant published literature on CBL programmes.

We will also be conducting supplementary searches of unpublished and grey literature, as well as targeted searches of key journals and authors specializing in this topic.

What do we hope to find?

By critically analyzing existing evidence, we will be able to highlight leading practices that inform the design of future workforce development initiatives.

We expect to:

1. **Identify enablers and barriers** to CBL education, training, and competency development,
2. **Uncover gaps** in current education and training approaches,
3. **Establish foundational evidence** for the development of CBL education programmes,
4. **Generate actionable insights** to guide healthcare organizations and educators in future workforce planning and integration strategies.

What are the next steps?

To date, we have reviewed 4,970 titles and abstracts and carefully examined 1,382 full-text articles to determine whether they meet study eligibility criteria.

The next step is to finish extracting key information from each source, focusing on the ideas and approaches that guide CBL programmes, their key design features, and details about how they are delivered. We will then complete a search of grey literature to identify any relevant unpublished sources.

All extracted information will then be synthesized to describe the types of CBL programmes identified, highlight common leading practices and identify where evidence is limited.

Preliminary results will first be shared with a group of point-of-care clinicians, health and social care educators, and home and community care leaders. The goals of these consultations will be to validate findings, support interpretation, and discuss real-world applications to ensure results are relevant to real-world training and workforce development needs for integrated, people-centred care.

How is this research funded and supported?

This work is currently funded and supported by SE Health, one of Canada's largest social enterprises.

To learn more about this work

Leading practices in the development and delivery of case-based learning programmes for health and social care provider education: a scoping review protocol.³



To cite this work

Cardozo, V., McLeod, R., Nova, A., Hudani, A., Maynard, R., Giosa, J., & Saari, M. (2026, April). Identifying leading practices in the development and delivery of case-based learning programmes for health and social care providers. Markham, Ontario: SE Research Centre.

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Evaluating Nurse-led Care Management and Navigation: A Focus on Program Outcomes and Sustainable Implementation

The **Nurse-led Care Management and Navigation Program** is a client-directed home care model designed to enhance the health and wellbeing of home care clients receiving personal support services in a private insurance model. As part of a 2025 process and outcome evaluation, the SE Research Centre has evaluated this new and innovative program, including its strengths and opportunities for improvements, to support refinement, scale, and spread opportunities.

“This evaluation of the Nurse-led Care Management and Navigation Program highlights the value of linking research with care delivery. It is an example of how SE Health is a learning health system that puts clients and care providers at the centre.”



- Zulf Kassam, Managing Director, Elizz by SE Health

Project overview

Health inequities, workforce pressures and fragmented services continue to limit access to care. Short-term, task-based home care often fails to meet the holistic care needs of clients.¹ To facilitate access to person-centred care, researchers and healthcare decision makers have advocated for a more flexible approach which combines client choice, coordination, and navigation support.^{2,3}

The **Nurse-led Care Management and Navigation Program** is designed to offer resources to support client decision-making, needs-based care management, and continuity – all while ensuring positive patient and provider experience – but designing and implementing home care interventions is a challenging process. Implementation of novel approaches to care elicits a need for comprehensive programme evaluation that considers client and provider experience, equity, and ‘real-world’ contexts.

What have we done?

As part of our research portfolio investigating Models of Care Delivery, the SE Research Centre conducted a mixed-methods evaluation of the Nurse-led Care Management and Navigation Program. We examined

five programme elements, guided by the RE-AIM framework⁴:

1. **Reach** – we analyzed data collected through routine care delivery to describe who receives care within the programme. We also grouped clients into eight unique needs-based groups to capture differences in their care and support needs.⁵
2. **Effectiveness** – we linked operational, assessment, and survey data to examine if and how the programme influences Quadruple Aim and Health Equity⁶⁻⁸ outcomes.
3. **Adoption** – we conducted interviews to explore how care managers, care coordinators, and leaders describe their experiences working within the programme.
4. **Implementation** – we examined data collected through routine care and programme operations to determine whether the programme was implemented according to plan.
5. **Maintenance** – we synthesized our findings to evaluate sustainability, including opportunities for future programme development.

What did we find?

In 2025, 1,006 individuals had at least one interaction with the programme. Of these, 887 had a care

planning, care review, or care navigation support session.

Using initial assessments from 839 clients, we have highlighted medical, functional, cognitive, and social ‘life care’ needs of elevated concern. Clinical profiles of the eight Life Care Needs Groups, illustrated in **Figure 1**, suggest that a proactive, person-centred, and goal-oriented model of health and social care would benefit this population. Personal support hour recommendations aligned closely with client need, with the influence of non-need factors (e.g., living arrangement) highlighting the importance of equity-focused monitoring.

Out of 110 clients who completed an experience survey, 81.8% (n = 90) agreed or strongly agreed that they would recommend SE Health to friends or family. Eight interviewed providers identified satisfaction with teamwork, safety, and leadership responsiveness as programme strengths. Feedback identified opportunities to strengthen continuity of care, mitigate provider stress and workload, and enhance documentation processes, workflow, and information sharing for future programme development.

What are the next steps?

Programme evaluation results have been shared with programme leaders to support ongoing development and quality improvement. We also plan to share our findings on programme reach at the 2026 International Conference on Integrated Care (ICIC26), Canadian Association for Health Services and Policy Research (CAHSPR) Conference 2026, and within an open access peer-reviewed journal article.

How is this research funded and supported?

This work was funded and supported by SE Health, one of Canada’s largest social enterprises.

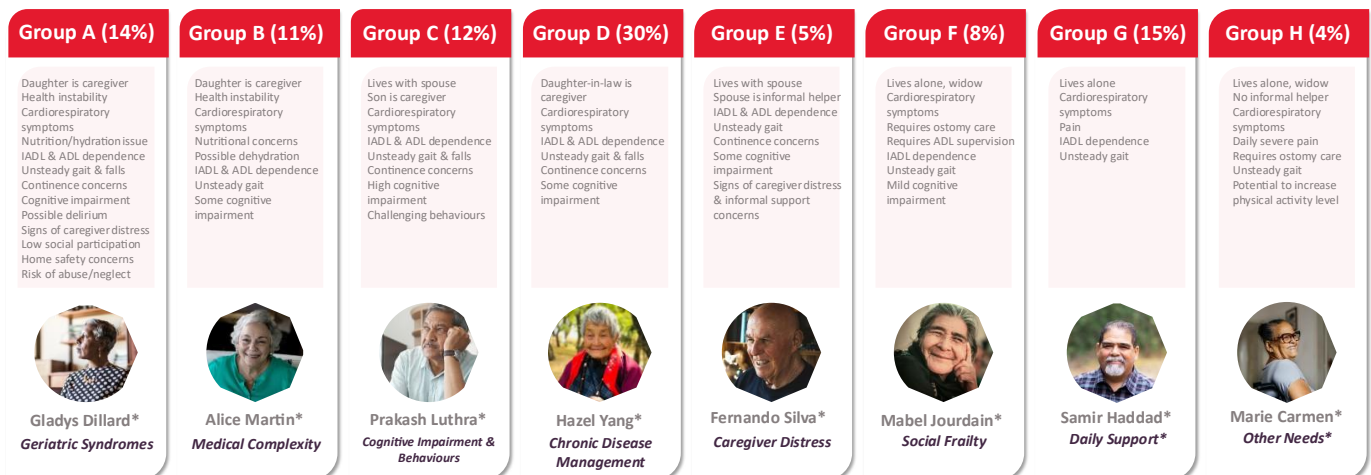
To cite this work

Saari, M., Nova, A., & Giosa, J. L. (2026, April). Evaluating Nurse-led Care Management and Navigation: A Focus on Program Outcomes and Sustainable Implementation. Markham, Ontario: SE Research Centre.

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Figure 1. Client profiles within the Nurse-led Care Management and Navigation Program with dominant life care needs



* Tentative names subject to change based on future consultations

* Group and persona names are tentative and subject to change based on future analyses and consultations

ADL, Activities of Daily Living; IADL, Instrumental Activities of Daily Living

Understanding patterns of care needs and service use in community-based transitional care

Transitional care programmes are designed to support patients to safely return home after a hospital stay; clients transitioning from hospital can be highly diverse in their medical, functional, cognitive and social care needs. Despite this complexity, transitional care programmes are often designed using standardized models with limited opportunities to use data to support targeting to local contexts. This project addresses this gap by using routinely collected operational and clinical assessment data to identify distinct transitional care client needs profiles, supporting more needs-aligned programme design.

“Transitional care is not one-size-fits-all. Understanding and responding to diverse client care needs is crucial to delivering the right support, at the right time. By leveraging standardized assessment data to identify distinct needs profiles, this project will inform more targeted transitional care programmes, supporting recovery at home and easing pressure on the health system.”



- Shelby Fisch, Vice President, Acute Care Operations and Rehabilitation Strategy, SE Health

Project overview

Transitional care programmes support people as they move from hospital to home, aiming to enable safe discharge, reduce avoidable readmissions, and support recovery at home.^{1,2} Clients receiving transitional care often have complex and varying medical, functional, cognitive, and social support needs, yet programmes are frequently designed without systematic use of data to understand this heterogeneity.¹⁻³

The **interRAI Home Care (interRAI HC)** is a reliable and valid, widely used assessment instrument that captures comprehensive information across medical, functional, cognitive, psychosocial, and environmental domains.³ Despite its strengths, interRAI data are under-utilized beyond care planning at the point-of-care; however, when systematically analyzed at the programme- and population-level, these data can reveal patterns of need – supporting more evidence-informed programme design, workforce planning, and resource allocation.⁴

This project leverages data from over 12,000 clients receiving community-based transitional care through SE Health’s **Acute Care Transitions programs** to generate holistic profiles of transitional client care needs. Applying a needs-based grouping algorithm and using a **Life Care**⁴⁻⁶ lens to describe multidimensional client needs, this study moves beyond diagnosis-driven approaches to generate programme- and population-level insights that support transitional care planning and system-level decision-making.

What are we doing?

As part of our research portfolio investigating Models of Care Delivery, we are conducting a retrospective cohort study using routinely collected interRAI HC assessments linked to programme-level service utilization data.

Using a **Life Care** lens, we have grouped clients into eight distinct care needs profiles using a validated needs-based algorithm that captures multidimensional care needs across physical,

functional, cognitive, and psychosocial domains.⁵ Each group has been characterized using standardized clinical indicators to develop a deeper understanding of the Life Care needs across the transitional care population.

Building on previously established methods, our next step will be to examine patterns of service utilization within and across profiles, including the type, intensity, and duration of care, to assess alignment between identified care needs and services provided.⁴

All analyses will also be stratified by programme model to examine differences in service use driven by local population needs, referral patterns and programme design.

Throughout the project, emerging findings are regularly being shared with an advisory group to leverage their expertise across clinical, operational, and system levels, supporting interpretation and alignment with programme delivery and broader health system planning.

What are we finding?

Preliminary analyses suggest that the transitional care population represents a heterogeneous population that clusters into distinct care needs profiles with differing levels of clinical and social complexity. This aligns with published evidence demonstrating substantial heterogeneity in both clinical and social care needs among individuals transitioning from hospital to home.^{1,7} Further analyses will build on these early insights to examine how patterns of service use align with differing Life Care needs.

What are the next steps?

Next steps include:

- Deeper analysis of care needs within each **Life Care** profile,
- Examination of patterns of service utilization across profiles, and
- Subgroup analyses by transitional care programme type.

Transitional care profiles will also be compared with profiles generated in other settings, including government funded home care, direct-to-consumer models and facility-based long-term care, to situate transitional care needs within the broader care continuum.

Ongoing consultation with cross-functional clinical, operational, and system leaders will support interpretation of emerging findings and ensure relevance for future-facing transitional care planning and programme design.

How is this research funded and supported?

This work was funded and supported by SE Health, one of Canada's largest social enterprises and the Consortium on Analytics and Data-Driven Decision Making (CAnD3) program hosted at McGill University.

To cite this work

Saari, M., Robibaro, F., & Giosa, J. L. (2026, April). Understanding patterns of care needs and service use in community-based transitional care. Markham, Ontario: SE Research Centre.

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