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 improvements against the gold standard Quadruple Aim and Health Equity framework,[1-3] yet current tools are insufficient for emerging and needed models of integrated home and community care.[4,5]

We developed a new PREM called Client Experience Survey for Integrated Home and Community Care (CESI-HCC) with a goal to accurately and meaningfully measure client experiences of integrated home and community care—focusing on domains and concepts that matter most to clients, family caregivers, and providers with lived experience.

Project Overview

The principles of **equity, life care, and continuity** are foundational to integrated home and community care models that aim to better meet client needs and preferences through a combination of home health care (i.e., health care services from health professionals, and needed medical equipment, etc.) with supportive community-based services (i.e., housekeeping, meal preparation, transportation, and socialization).

Equity: Is about measuring if care is accessible and feels safe, respectful, and fair.[3,6]

Life care: Is about measuring if care meets holistic needs such as bodily functions, daily functioning, mental well-being, meaningfulness, participation, and quality of life and is perceived to be collaborative and person-centred.[7,8]

Continuity: Is about measuring if care feels connected, continuous, and coherent–that care providers know what happened to clients before, and what the plan is now.[9]

Patient-reported experience measures (PREMs) 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 for use across a variety of facility-based healthcare settings[10], none exist that were intentionally designed and validated for use in the unique context of integrated home and community care.

Given the critical role of integrated home and community care models to current health system improvement initiatives and the importance of measuring progress towards the Quadruple Aim and Health Equity, there is a need for a valid and reliable PREM tailored to this unique context.

What did we do?

We conducted a 4-phase research study to develop a new PREM for integrated home and community care that included experts-by-experience (healthcare leaders, clients, caregivers, and providers) in the development process.[11]

Phase 1: Item Pool Development

In Summer 2022, we scanned the literature and found 171 existing valid and reliable PREMs with over 3,000+ items. We used the domains of equity, life care and continuity to categorize relevant content from existing PREMs into a literature-based item-pool for a new PREM for integrated home and

community care, consisting of 14 sub-domains and 72 items (e.g., adapted care to lifestyle, having a primary provider, care goals discussion).

Interviews with healthcare leaders (n=6) confirmed the relevance and coverage of these domains, sub-domains, and **72 items** according to their expertise in leading and managing integrated home and community care programs.[11]

Phase 2: Content and Face Validity

In Fall 2022, we engaged home care clients and family/friend caregivers (n=17) in focus groups and health and social care providers (n=15) in interviews. Both groups rated the appropriateness and relevance of the 72 items, commenting on missingness, and how to improve relevance.[11] Recommendations led to:

- Addition of an item measuring the concept of 'kindness', important to individuals
- Exclusion or combination of redundant, vague or non-meaningful items (e.g., "my providers understood my needs").
- Addition of a fourth 'Relational caring' domain with six items–five were moved from life care and equity, and the new 'kindness' item.

The resulting **39 items** (Figure 1) were developed into questions and scaled on a 5-point Likert scale—strongly disagree, disagree, neutral, agree, strongly agree — to produce the CESI-HCC; 'Not Applicable' and 'I Choose not to Answer' options were included, along with participant instructions and demographic questions.

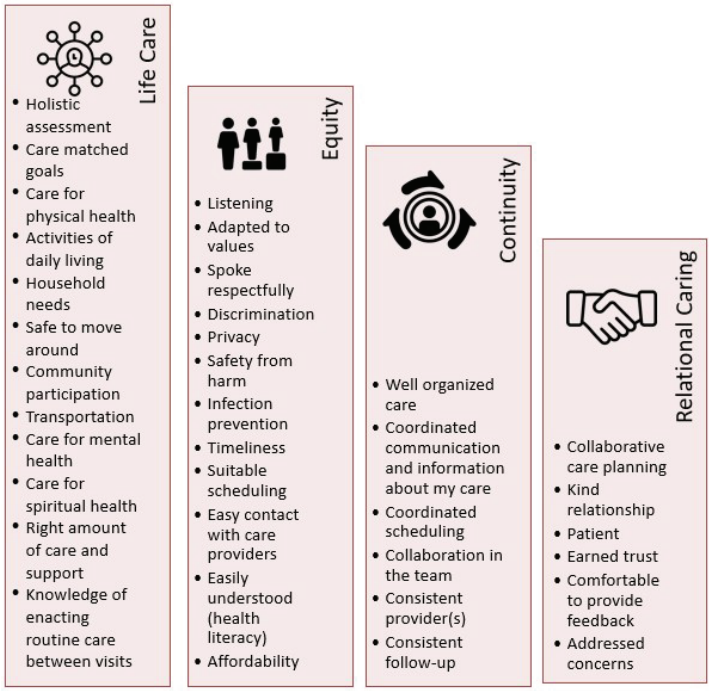
Phase 3: Cognitive Testing

In Winter 2023, we engaged clients and caregivers (n=11) with diverse gender expressions, racial backgrounds, abilities, and socioeconomic status in one-to-one cognitive interviews to identify issues with answering the questions in the CESI-HCC.[11]

Interview participants were engaged in a **"thinking aloud"** process to understand how items were being interpreted, if the items were clear, and if the scale options made sense.[11] From this cognitive testing, several adaptations were made to the PREM:

- Role-specific instructions (client vs. caregiver);
- Clearer definition of "care provider" (anyone who provides paid care in the home);
- Re-ordering of questions to begin with concepts perceived to be easier such as listening vs. holistic assessment;
- Clarity of wording for 19/40 items;
- Collapsing non-response options to 'No answer';
- Amending a question to capture the concept of appropriate care;
- Collapsing two questions about involvement in decision-making.

Figure 1: Overview of integrated home and community care PREM



Phase 4: Field Testing

In Fall 2023, we conducted field testing of the CESI-HC, which was administered via telephone to diverse home and community care providers in Ontario, Canada (T1 n=184; T2 n=20). Preliminary reliability testing to determine if the PREM produces the same results on different occasions (i.e., test-retest) indicated moderate reliability[12] for domains with excellent internal consistency[13] (Table 1). These results are a good indication this tool performs consistently well with Ontario home care clients.

Field testing data was skewed to the upper bounds (4 and 5) of the scale, leading to a modification of the scaling options to discriminate more on the

agreement side (i.e., removing the neutral point) for future implementation and testing. The CESI-HCC is currently being implemented in Ontario as part of a quality improvement initiative by a large home care provider organization.

Table 1: reliability and validity testing results

PREM Domain	# of Items	Internal Consistency (α) (n=184)	ICC 2, A1 (95% Confidence Interval) (n=20)
Life Care	12	0.95	0.65 (0.51-0.80)
Equity	12	0.94	0.67 (0.52-0.81)
Continuity	6	0.90	0.71 (0.57-0.84)
Relational Caring	6	0.91	0.74 (0.61-0.86)

What will we do next?

We will continue reliability and validity testing (e.g., Exploratory Factor Analysis), using field testing and quality improvement data, and continue to iterate on the CESI-HCC to ensure it measures what it is meant to and that it produces consistent results.[11] We are also exploring funding opportunities to explore adaptations to other community care contexts (i.e., facility-based settings).

What will be the impact?

Adoption of the CESI-HCC will result in data that is more meaningful, reliable, and valid for evaluating client experience of integrated home and community care models in Ontario and beyond. These data will inform ongoing health system improvement initiatives and optimization of integrated home and community care models for meeting clients' expectations, preferences and needs.

How was the research funded and supported?

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

Researchers from the SE Research Centre

Celina Carter RN PhD Research Scientist, SE Research Centre
Valentina Cardozo MSc Research Associate
Paul Holyoke LLB MSc(Econ) PhD
Vice President, Research & Innovation, SE Health
Margaret Saari RN PhD Clinical Scientist
Justine Giosa PhD Scientific Director

References

1. Bodenheimer, T., & Sinsky, C. (2014). From triple to quadruple aim: care of the patient requires care of the provider. *Ann Fam Med*, *12*(6), 573-576.
2. Canadian Institutes of Health Research. (2021). *Institute of Health Services and Policy Research Strategic Plan 2021-2026: Accelerate Health System Transformation through Research to Achieve the Quadruple Aim and Health Equity for All*. https://cihr-irsc.gc.ca/e/53008.html
3. Nundy, S., Cooper, L. A., & Mate, K. S. (2022). The quintuple aim for health care improvement: a new imperative to advance health equity. *JAMA*, *327*(6), 521-522.
4. Marchildon, G., & Allin, S. (2021). *Health systems in transition: Canada* (3rd ed). Toronto, ON: University of Toronto Press.
5. Schick-Makaroff, K., Karimi-Dehkordi, M., Cuthbertson, L., … & Sawatzky, R. (2021). Using Patient-and Family-Reported outcome and experience measures across transitions of care for frail older adults living at home: a Meta-Narrative synthesis. *Gerontol*, *61*(3), e23-e38.
6. Ford-Gilboe, M., Wathen, C. N., Varcoe, C., … & Browne, A. J. (2018). How equity-oriented health care affects health: Key mechanisms and implications for primary health care practice and policy. *Milbank Q*, *96*(4), 635-671.
7. Giosa, J. L. (2018). *Developing an integrated geriatric care planning approach in home care*. Waterloo: UWSpace. http://hdl.handle.net/10012/13673
8. Giosa, J. L., Saari, M., Holyoke, P., Hirdes, J., & Heckman, G. (2022). Developing an evidence-informed model of long-term life care at home for older adults with medical, functional and/or social care needs: a mixed-methods study protocol. *BMJ Open*, *12*, e060339.
9. Haggerty, J. L., Reid, R. J., Freeman, G. K., … & McKendry, R. (2003). Continuity of Care: a multidisciplinary review. *BMJ*, *327*(7425), 1219-1221.
10. Bull, C., Byrnes, J., Hettiarachchi, R., & Downes, M. (2019). A systematic review of the validity and reliability of patient-reported experience measures. *Health Serv Res*, *54*(5), 1023-1035.
11. Streiner, D. L., Norman, G. R., & Cairney, J. (2015). *Health measurement scales: A practical guide to their development and use* (5th ed). New York, NY: Oxford University Press.
12. Fleiss, J. L. (1986). *Design and analysis of clinical experiments*. New York, NY: Willey.
13. Kline, P. (2000). *Handbook of psychological testing* (2nd ed). New York, NY: Routledge.