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## CONFERENCE ABSTRACT

# Designing meaningful surveys: Engaging experts-by-lived experience in the development of a patient-reported experience measure (PREM) of integrated home and community care.

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**Background:** People want to live well in their homes and communities for as long as possible. To support this, some home care services in Ontario, Canada are restructuring to integrate medical and personal care, with community-based social care and services (e.g., friendly visiting, meals, and transportation). Measures of client experience, referred to as 'patient-reported experience measures' (PREMs) are important for guiding health system improvements in a way that is meaningful to clients. A current challenge is that existing PREMs are insufficient for measuring client experience of new models of home and community care.

**Aims:** This study engaged clients, family/friend caregivers, and health and social care providers in a participatory process to develop relevant items for a PREM for integrated home and community care. This engagement process aimed to provide opportunities for client feedback to support integrated care and ensure the new PREM will collect data that can inform health system improvements in ways that are most meaningful to clients and caregivers.

**Methods:** Guided by Streiner et al.'s (2015) approach, we engaged experts-by-lived experience in content and face validity testing of an item pool matrix to determine relevance and coverage of domains and items. The matrix consisting of 3 domains, 14 categories, and 72 items was based on a literature review of home and community PREMs (32 PREMs with 550+ items) and interviews with healthcare leader experts (n=6). To conduct content and face validity testing we held three focus groups with home care recipients and family/friend caregivers (n=17) as well as individual interviews with health and social care providers working in home care (n=15). We analyzed transcripts line-by-line to generate themes related to face and content validity of each item.

**Results:** Participants agreed that client experience of innovative home and community care is well captured by three domains: equity, continuity, and life care. They also agreed the corresponding 72 proposed items had face validity. Suggestions to improve content validity included that items be adapted to recognize the role of caregivers; the role of primary providers and/or coordinators in delivering well organized care; and shifting from a focus on self-management to having needed supports to stay in the home, and collaboratively developing care plans. Participants excluded several items due to being vague or not meaningful, such as asking, "my providers understood my needs". Based on feedback, 22 items were removed from the matrix.

**Learnings:** Engaging experts-by-lived experience in development of PREMs helps ensure the data generated from PREMs will be meaningful and useful for guiding health system improvements that matter to clients. Relying on existing literature and traditional expert opinion alone did not guarantee relevance or coverage of items.

**Next steps:** The feedback from participants will be used to further refine and scale the PREM items. Clients of home care and family/friend caregivers will then be re-engaged in cognitive testing to identify issues related to answering the questions on the scale. Once complete, the PREM will undergo psychometric testing.