

STUDY PROTOCOL

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Developing an evidence base to inform retirement home policy development using an equity and diversity lens: a mixed methods study protocol

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Abstract

Background Retirement homes are an essential support for many older adults as they age. However, retirement homes may not be an option for all, particularly adults with low socioeconomic status or those from linguistic or visible minority groups, in jurisdictions where there are high out-of-pocket costs and limited availability of language- and culturally-concordant home options. Research examining health inequities in facility-based care for older adults has largely focused on the long-term care sector leaving a gap in knowledge and understanding about the care experiences and health outcomes of retirement home residents. The overall aim of this project is to build an evidence base and provide policy recommendations to improve equity in the retirement home sector in Ontario, Canada.

Methods We will conduct a multi-phase sequential mixed methods study involving both quantitative and qualitative data. Phase 1 will involve consulting on social and systemic barriers to equity in RHs with our Community Advisory Committee members and advocacy group collaborators. In phase 2, we will lead retrospective cohort studies using Ontario health administrative data to describe and evaluate differences in rates of RH vs. LTC use and differences in healthcare outcomes. In Phase 3, we will conduct semi-structured interviews with older adults and their family partners preparing to enter or having already entered, facility-based care within the prior 6 months to investigate how individuals' social identity, including language and income, and pragmatic considerations shape decision-making regarding the transition to facility-based care, including choices between retirement homes and long-term care. Findings from Phases 1,2 and 3 will be contextualized in Phase 4 with decision-maker knowledge users, such as from the Retirement Home Regulatory Authority and Ontario Ministries of Health, Long-term Care, and Seniors and Accessibility.

Discussion This project will leverage the existing momentum for long-term care reform where evidence of health inequities is well documented, to engage in research in a neighbouring sector that serves older adults with

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increasingly similar health profiles and complexities. We will disseminate contextualized policy options to both provincial-level decision-makers and community knowledge user partners to help inform future work on equity in retirement homes at different levels of governance.

Keywords Retirement home, Equity, Diversity, Policy, Ontario, Mixed methods

Background

Retirement homes (RHs) respond to key priorities on Canadian provincial health policy agendas, including aging in the right place, addressing health human resource shortages and emergency room overcrowding, and diverting pressure from the long-term care (LTC, also known as nursing homes) sector [1, 2]. Licensed RH capture a wide variety of retirement living in Ontario, from highly independent residents to residents living with very high acute needs [3]. RH are often considered or called assisted living in other provinces, and assisted living in other provinces correlates to a subset of retirement homes in Ontario [4], however they are not the same thing, causing lots of complexity and difficulty around labeling in this sector.

RHs are essential to supporting older adults to age in their preferred place. In the Ontario context, all RHs are regulated, licensed congregate living settings that must provide a minimum of two of the thirteen provincially regulated care services to at least six residents over the age of 65. [5] These care services include “(a) a prescribed health care service provided by a member of a College as defined in the Regulated Health Professions Act, 1991, (b) administration of a drug, as defined in the Drug and Pharmacies Regulation Act, or another substance, (c) assistance with feeding, (d) assistance with bathing, (e) continence care, (f) assistance with dressing, (g) assistance with personal hygiene, (h) assistance with ambulation, (i) provision of a meal, or (j) any other service prescribed as a care service, but does not include any service that is prescribed as not being a care service [6].” Together with a range of care services available for purchase, these homes are meant to support residents seeking independent living with minimum support, according to the legislation which states that RHs are “to be operated so that it is a place where residents live with dignity, respect, privacy and autonomy, in security, safety and comfort and can make informed choices about their care options [6].”

As the Canadian population ages and LTC wait lists grow [7], RHs across the country are increasingly serving as a LTC substitute, as the populations residing in RH compared to LTC have [8, 9] similar sociodemographic characteristics and clinical comorbidities [4]. The demand for RHs in Ontario is at an all-time high [10] particularly given the passage of the *More Beds, Better Care Act* (2022) [11], which enables hospitals to assign and move patients from alternate level of care hospital

beds into LTC without their consent. Alternate level of care (ALC) is used to describe situations where a patient occupies a hospital bed but no longer requires the level of care provided in the hospital setting [12]. To avoid this, individuals with financial means may pre-emptively seek out residence in a RH, rather than risk being admitted to a LTC facility that is not of their choosing.

Unlike LTC homes in Ontario which utilize both government funding and resident contributions, RHs in the province are not publicly subsidized. RHs are operated by private, often for-profit providers. With room, board, and care being paid out-of-pocket by residents, the private costs of RH living in Ontario are substantial, averaging between \$3,800 and \$5,300 CAD per month [4]. Due in part to the high costs and limited availability of language- and culturally-concordant RHs [13, 14], RHs are not an option for all older adults, particularly those with low socio-economic status or from linguistic and/or visible minority groups. Most new residents of RHs are women with cognitive impairments [15]. Historically, many older adults from marginalized groups may choose to stay in their homes or to be cared for by their families, even when their level of care may exceed the support available to them in the community [13]. With this, instead of moving early to retirement homes, while needs are lower, they may end up moving the LTC later, with higher, and more complex health issues. Despite older Canadian's preference to age in their homes [16] and government support for aging at home, there remains a growing need to provide high-quality facility-based care for older adults experiencing worsening health that prevents them from remaining at home. With the promise for health reform to be evidence-based and patient-centered [2], the omission of RH from the political agenda is concerning when the demographics of RH residents are becoming increasingly similar to LTC residents in terms of healthcare needs, yet funding remains focused solely on LTC and not RH. [3, 4].

Research in Canada examining health inequities in facility-based care for older adults has largely focused on the LTC population rather than RHs. In the few European and American studies that focus on RHs, care disparities or inequities in RH use such as among black older adults and individuals living in low socioeconomic status (SES) households, among others have been suggested [13, 14]. In this project we focus on improving health equity, which we define as ensuring that individuals have a fair opportunity to reach their fullest health potential by

reducing avoidable barriers to care, according to Public Health Ontario [17]. Health inequities impose substantial social and economic burdens on both individuals and societies. In the context of health and social care, services that disproportionately benefit individuals with higher socioeconomic status, along with other privileged groups, exacerbate inequities in health outcomes [13, 14, 18, 19]. This gap may be reduced if services are reformed using an “equity lens” to ensure greater access to services for hard-to-reach groups and to avoid service-generated inequalities [20]. Research and policy work on RHs, guided by an equity lens, is essential to ensure that RHs can help meet the needs of the province’s diverse aging population. This project will build an evidence base that can be used to develop equitable policies to improve access to care for older adults in RHs in Ontario.

Research objectives

There are four phases and four objectives:

PHASE 1.

Objective 1: Identify social and systemic barriers to equity in RHs in Ontario.

PHASE 2.

Objective 2a: Describe and evaluate differences in rates of RH vs. LTC use among older adults who have similar functional and cognitive limitations and are using publicly subsidized homecare services according to their social identity factors, including rates of admission from the community and the rates of exit into LTC facilities from RH. Objective 2b: Describe and evaluate differences in healthcare utilization (e.g., emergency room visits, hospitalizations, primary care visits) for older adults in RHs according to their social identity factors. We will also examine modifiable factors (e.g., home care involvement, primary care access) associated with healthcare utilization.

PHASE 3.

Objective 3: Investigate how social identity factors, including those evaluated in Obj. 2 as well as those not captured in administrative data are perceived by older adults and their family caregivers as intersecting with pragmatic considerations (e.g., health status, cost, moving close to a family member, or waitlist length) to shape their decision-making regarding the transition to facility-based care.

PHASE 4.

Objective 4: Contextualize findings from Phases 1 & 2 through discussions with decision-maker knowledge users and situate findings in existing legislative and regulatory contexts.

Methods

Study design

We will conduct a multi-phase sequential mixed methods design study with qualitative data collection (Phase 1), followed by quantitative data collection (Phase 2), qualitative data collection again (Phase 3), and conclude with a final phase where qualitative data will be collected and all results contextualized (Phase 4). This protocol was submitted as part of the grant application package for a study which has been externally peer-reviewed and funded by a Canadian Institutes of Health Research Project Grant (PJT 191698), 2024–2028. We will start with qualitative data collection to identify social identity factors connecting to social and structural systems of oppression, then based on the prioritized social identity factors identified in phase 1, phase 2 will describe and evaluate differences in RH vs. LTC use and healthcare outcomes. Phase 3 will use qualitative methods again to explore specific aspects or nuances revealed by the initial qualitative and quantitative data with RH residents and families. This work will be informed by people with experience living in and accessing RH, policymakers, hospital and RH partners, and population-based data. See Fig. 1 for the study diagram.

Theoretical framework

This project will be guided by an intersectionality analytical lens. This framework describes how overlapping social identities relate to social structures of racism and oppression [21] to result in the unjust treatment of people. We will apply an equity lens using the social determinants of health framework [22], to identify health equity issues and affected populations to guide the project design; measure and evaluate outcomes and impacts on health disparities; interpret findings in relation to issues of social location, power, and privilege; identify opportunities for policy improvement in partnership with community stakeholders to maximize buy-in and uptake; and advocate for meaningful change by disseminating findings and policy recommendations to relevant audiences and stakeholders, including policymakers. This project will operationalize an intersectional logic to understand how individual social identities (such as gender, race, ethnicity, income status, and language) intersect with contextual variables (such as the location of the home, cost, and proximity to a family caregiver) within existing social

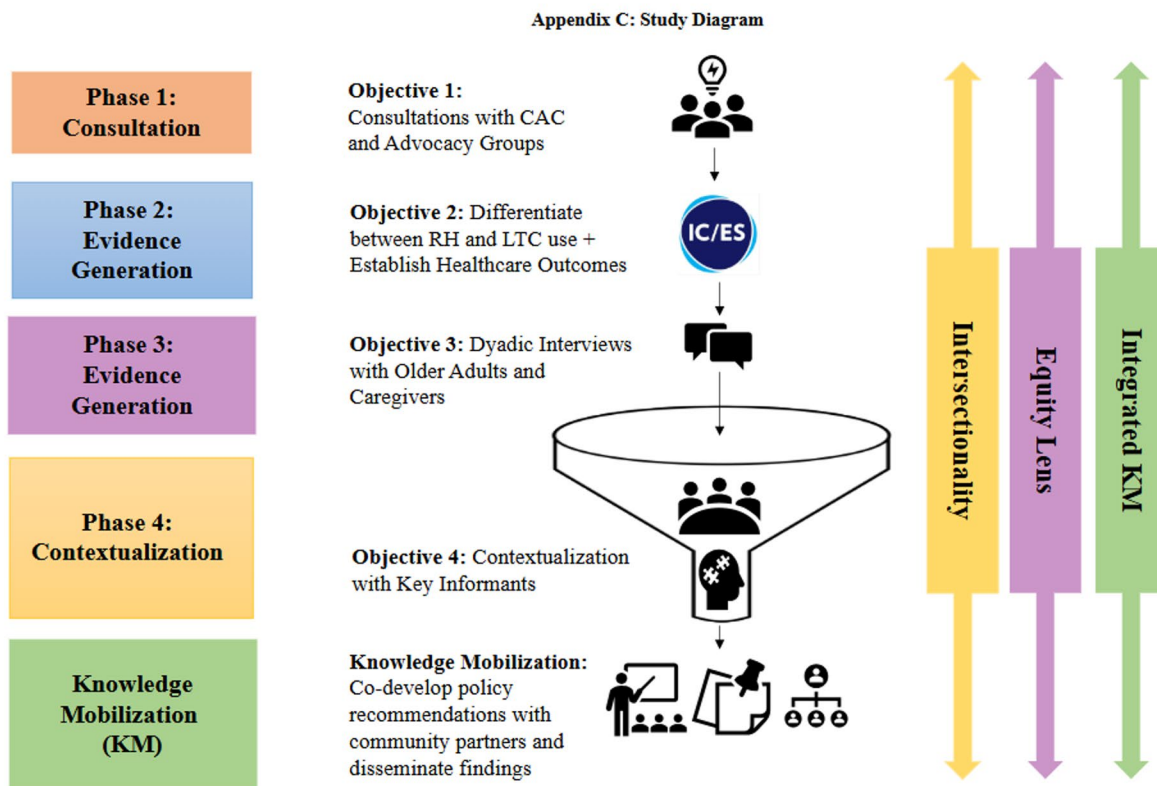


Fig. 1 Study diagram

systems to shape older adults’ access to, and health outcomes in, RHs.

Governance structure

This project is guided by a six-person Community Advisory Committee (CAC) that reflects a diversity of social identities, genders, and perspectives of the many stakeholders and persons with lived experience who are interested in improving equity in the RH sector. The CAC will guide the research team with their perspectives on the social and systemic barriers to equity in RHs in Ontario to ensure the program reflects the experiences of those who live and work in RHs. Working alongside the CAC is a diverse research team including CW and KKM. CW will lead the quantitative portions of the project, under the mentorship of AC, a quantitative methods expert. KKM will lead the qualitative portions of the project, under the supervision of SI, a qualitative and mixed methods expert. CW and KKM will be the primary connections to the CAC, bringing their advice and guidance back to the broader research team and knowledge users. Knowledge users have been involved in the development of the research protocol and will be engaged in the entire research process as we seek their consistent feedback.

PHASE 1: community engagement

Objective 1: Consult with CAC members and advocacy group collaborators to identify social and systemic barriers to equity in RHs in Ontario

Phase 1 will use a Reflexive Thematic Analysis (RTA) study design as developed by Braun and Clarke [23, 24]. We will use interviews as the qualitative data collection method to identify social and systemic barriers, including sex and gender, to equitable access, care, and quality in RHs in Ontario by soliciting the perspectives of our six CAC members and four advocacy group collaborators (AdvantAge Ontario, Care Watch, Carefor Health & Community Services, and Ontario Retirement Communities Association). These key informants ($n = 10$) were selected because of their significant experience in the RH sector (Appendix 1). We will conduct consultations via virtual interviews (duration 1-hr). This study has been approved by the Bruyère Health Research Ethics Board (M16-24-020) and informed consent will be collected before data collection. CAC members will receive a \$1,000 honorarium/year in reciprocity for their time and other interview participants will receive a small honorarium in the form of a \$50 gift card in reciprocity for their time and knowledge.

The interviews aim to engage experts in discussions of priorities for the project given their different perspectives and experiences living/working in RHs and solicit their perspectives on the key social and systemic barriers to equity in the sector. Consistent with best practices in qualitative research methods [25] and to facilitate participant-driven data, a flexible, semi-structured consultation guide using open-ended questions will be used (Appendix 2). The consultations will be audio-recorded and transcribed verbatim. To support rigor, interviewers will engage in reflexive journaling after each consultation [26]. This technique will allow for a log of interview procedures, methodological decision points, evolving perceptions (e.g., of power dynamics among participants and possible implications), and personal introspections as meaning is made from the data [27].

Data from interviews and journals will be analyzed using Braun and Clarke's RTA approach [24]. RTA is used to describe how individuals experience a certain phenomenon through an interpretive approach that facilitates the identification of themes across experiences [28]. RTA is a six-phase recursive and iterative process [27–31] that involves familiarizing ourselves with the data, coding to produce descriptive labels for pieces of information of relevance to the research aim, generating themes by reviewing, analyzing, and combining the coded data to communicate something meaningful to addressing our research aim, reviewing potential themes to assess whether they provide the most apt interpretation of the data in relation to our aim, defining and naming themes, and finally, producing a report describing findings. Coding reliability techniques are inconsistent with the RTA method [32]. The team will leverage multiple coders to sense-check ideas or explore multiple interpretations of the data. In addition, since codes and themes evolve over the course of the analysis, the research team will use memos during coding and analysis to document developing interpretations [33]. Memos will be recorded in the MAXQDA software. The use of techniques such as having multiple coders, memo taking, triangulation of data sources, and reflexivity to identify researcher biases will establish rigor and trustworthiness in this project's qualitative components. The dominant themes identified in these CAC and advocacy group consultations will guide the research team in the selection of social identity factors to study in Phase 2.

PHASE 2: quantitative evidence generation and evaluation

Phase 2 uses an explanatory sequential mixed methods design [34] moving from quantitative to qualitative data collection and analysis.

Objective 2: quantitative analysis of health administrative data

Data sources and linkage Routinely collected health administrative databases from ICES (previously known as the Institute for Clinical Evaluative Sciences) and provided by the Retirement Home Regulatory Authority (RHRA) in Ontario will be used to conduct a series of retrospective cohort studies. ICES data holdings cover a comprehensive set of healthcare sectors in the province, with population-level demographics, healthcare utilization, and clinical data for all Ontario residents. Key ICES data sources include demographic data, RH facility information (e.g., postal codes), home care assessment and service data, long-term care admission and assessment records, census data, hospitalization discharge records, emergency department visit records, and physician claims. Individual records are linked within and across databases using encrypted identifiers.

Study population In Obj. 2(a), we will study transitions into RHs among adults age 65 + who were residing in a private home and receiving publicly-funded home care in Ontario between 2015 and 2021 [35]. Our rationale for restricting the study population to home care clients is that for older adults receiving home care services (vs. those not receiving home care), the decision to enter RH may be driven more by increasing care needs (e.g., increasing frailty) than preferences, and be more time sensitive as they are increasingly unable to live independently at home. Inequities in RH use are expected to be most evident in this group. Those receiving home care would have also received a Resident Assessment Instrument (RAI), an assessment provided to residents at the beginning of receiving care, at least once a year thereafter, and whenever there is a significant change in their condition, to create personalized, restorative care plans [36]. The RAI provides rich information on residents' functional, cognitive, and other impairments which allows us to compare them to LTC residents who also receive RAI assessments. The study population will include new home care clients within the study period, with the admission date being the study index date.

For Obj. 2(b), the study population will include adults age 65 + residing in an Ontario RH between 2015 and 2021. The index date will be January 1, 2015, or the RH admission date, for those who entered after January 1, 2015. We will use an established approach, developed by members of the study team [37], to identify residents of retirement facilities based on one of two criteria: (1) an individual's postal code matches the unique postal code (i.e., 1 address per postal code) of an RH, or (2) an individual's postal code matches the non-unique postal code (i.e., ≥ 1 addresses per postal code) of a RH, and

the individual was receiving home care with the location documented as a RH. Individuals residing in RHs that share a postal code with an LTC facility will be excluded. Cohorts developed using this definition correspond in size to estimates of the Ontario RH population and have similar expected characteristics (e.g., average age) [38].

Study variables

Social identity factors Several social identity factors are captured in the administrative data. We will focus our analyses on the identity factors that are both identified as connecting to social and structural systems of oppression in our Phase 1 consultations and are available as part of the ICES data repository. Some variables are captured only in data from routinely collected home care assessments. Our Obj. 2(a) study population will include RH residents who receive home care and will therefore have data on these variables. Our Obj. 2(b) study population will include all RH residents, of which we expect approximately 50% to receive home care and therefore have data on these variables. Identity factors that are not collected in ICES (e.g., gender, race, ethnicity) but were identified in the Obj 1 consultations will be explored in Obj 3.

Identify factor	Where the data will be ascertained from
Income	Measured using Canadian census data. Quintiles of median household income for census dissemination areas (roughly 400–700 individuals) will be assigned to individuals based on their home postal code at index (Obj. 2(a)) or prior to RH entry (Obj. 2(b)).
Language	Recorded in home care assessment data and categorized as Anglophone, Francophone, or Allophone (i.e., individuals whose mother tongue is not English or French). We will explore specific linguistic subgroups within the Allophone group, as the sample size allows.
Age and Sex	Via the Registered Persons Database (gender is not currently captured).
Marginalization	Based on the Ontario Marginalization Index (ON-MARG). This index uses Canadian census data to capture four domains of marginalization, including (1) Households and Dwellings (2) Material Resources (3) Age and Labour Force, and (4) Racialized and Newcomer Populations. Quintiles for each dimension will be assigned based on home postal code at index (Obj. 2(a)) or prior to retirement entry (Obj. 2(b)).
Immigration status	From the Immigration, Refugees and Citizenship Canada (IRCC) database, and categorized as < 5, 5–10, or > 10 years since immigration, or Canadian-born/long-standing residents.
Rurality [39]	Measured using a definition that classifies areas into four categories across the urban/rural continuum according to population size, population density, and integration of rural and urban areas. The categories include (1) Large urban population center.

Identify factor	Where the data will be ascertained from
	(2) Medium/small population center within a census metropolitan area or census agglomeration, (3) Rural area within a census metropolitan area or census agglomeration with strong metropolitan influence, and (4) Area with moderate, weak or no metropolitan influence and rural and remote areas. Rurality will be assigned to individuals based on home postal codes at index (Obj. 2(a)) or prior to RH entry (Obj. 2(b)).
Education and Marital status	As recorded in home care assessments. Education (no schooling, 8th grade or less, 9th–11th grade, high school, technical or trade school, some college/university, diploma/bachelor's degree, graduate degree or unknown) and marital status (married, separated/divorced, widowed, and never married).

Outcomes

- RH admission: The outcome in Obj. 2(a) will be entry into a RH in 5 years from index. As a competing event, we will also capture LTC admission, as we expect that individuals from equity-deserving groups may be more likely to enter LTC vs. RH, given barriers to RHs (e.g., costs).
- Healthcare outcomes: The outcomes in Obj. 2(b) will be rates of emergency department visits, hospitalizations, and primary care visits. We will describe reasons for healthcare utilization (e.g., hospitalizations for ambulatory care sensitive conditions [40] or medication-related adverse events) to contextualize our findings.

Additional covariates

These variables will be measured at index date and analyzed as confounders of associations between social identity factors and study outcomes (Obj. 2(a) and (b)), and as predictors of health outcomes (Obj. 2b). This is important in being able to compare ‘like’ residents in RH and LTC.

- Chronic conditions and multimorbidity, including the presence and count of specific conditions [41–49].
- Health instability from home care assessments, measured using the Changes in Health, End-Stage Disease, and Signs and Symptoms (CHESS) scale [50], scored from 0 (stable) to 5 (high degree of instability).
- Cognition from home care assessments, measured using the Cognitive Performance Scale [51] and scored from 0 (intact) to 6 (very severe impairment).
- Functional independence in activities of daily living (ADLs) and instrumental ADLs (IADLs), scored from 0 (independent) to 6 (dependent) and measured using home care assessment data.

- Communication and vision, including whether the individual can make themselves understood, understand others, and has difficulty hearing or seeing, as documented on home care assessments.
- Mobility is based on whether individuals walk with or without assistive devices (e.g., walker), use a wheelchair, or are bedbound, as documented on home care assessments.
- Caregiver support, as documented in home care assessments. We will measure the presence of informal caregivers, their relationship to the individual, whether they live with the individual, whether caregivers have expressed feelings of distress or are unable to continue providing care, and their caregiving burden.
- Family physician rostering. We will identify whether individuals are rostered to a family physician, are unrostered but with a usual provider of primary care or have no usual provider of primary care.
- Home care support, based on the types (e.g., nursing, personal support worker) and intensity (e.g., hours of care per week) of home care services received.

Statistical analysis

We will describe the study populations using descriptive statistics and standardized differences. For Obj. 2(a), we will describe the proportion of individuals who entered RHs during follow-up and the distribution of the time to entry and length of stay, overall and by prioritized social identity factor(s). We will use descriptive statistics, bivariate tests (e.g., log-rank test), and multivariable cause-specific Cox proportional hazards regression to describe and evaluate associations of social identity factor(s) with time to RH entry. We will treat LTC admission and death as competing events. For Obj. 2(b), we will describe the distribution of health outcomes, including rates of hospitalizations, emergency department visits, and primary care visits, overall and by prioritizing social identity factor(s). As previously described, the analyses for Obj. 2(b) will focus on those social identity factor(s) prioritized by our CAC in Obj. 1. If the social identity factors of interest require home care data for measurement, we will restrict our cohort to the 50% subset of RH residents who receive home care; otherwise, the entire study population will be analyzed. We will use descriptive statistics, bivariate tests, and multivariable Poisson regression to examine associations of social identity factors with health outcomes, as well as to examine other predictors of health outcomes. For all regression analyses, confounders will be included in fully adjusted models based on prior evidence of their association with the exposures and outcome. We will use e-values to quantify the minimum strength of an unmeasured confounder required to nullify any observed

associations [52]. If the CAC identifies social identity factors that are not available in ICES data, those factors will be explored to a greater extent in phase 3, during interviews with residents and their families.

We will use interaction analysis to explore whether outcomes differ across unique intersectional identities (e.g., income and immigrant status, education, and language). We will identify interactions of interest a priori based on consultation with our CAC and use established approaches [53, 54] to evaluate and report on intersectional effects.

PHASE 3: qualitative evidence generation

Objective 3: qualitative analysis of interviews with older adults and family caregivers

This qualitative objective will use an RTA study design and semi-structured virtual individual or dyadic interviews ($n = 9-17$). We will undertake an in-depth investigation asking how older adults and their family caregivers perceive how (a) the social identity factor(s) evaluated in Obj 2 intersect with (b) social identities not available in the health administrative data (e.g., gender, race, ethnicity) and (c) pragmatic considerations (e.g., cost, moving close to a family member, or waitlist length) to shape their decision-making process regarding their transition to facility-based care. The study population will be older adults (65+) who have moved from home or ALC into facility-based care within the past 6 months. The CAC will help determine a sampling strategy based on their prioritization of the social identity factors evaluated in Obj. 2. For example, if the CAC determines minority linguistic status is a factor of key importance, we will focus on recruiting older adults for whom English is not their primary language.

We have partners in place to assist with the recruitment of participants, either by providing access to their RHs, facilitating partnerships with other RHs in their networks, facilitating connections with hospital staff responsible for ALC discharge, and with minority populations. Obj 3 will use purposive sampling to collect a gender-diverse sample and will prioritize the voices of women and ethnic minorities as groups more likely to have experienced gender- or race-based oppression. We will aim for an a priori sample size of 9–17 interviews [55] in recognition that saturation is “the gold standard by which purposive sample sizes are determined in health science research” [56], to seek theoretical saturation when sampling in Obj 3. Theoretical saturation occurs when the complete range of constructs that make up the theory is fully represented by the data. In our project, we will determine that saturation has been reached when we have sufficient data to illustrate intersectionality theory [21]. Interviewers will conduct 1-hour virtual individual

or dyadic interviews with older adults and their family caregiver (when possible) using the same RTA data analysis techniques outlined in Obj 1.[57].

PHASE 4: contextualization of findings

Objective 4: Contextualize findings with knowledge users and situate findings in Ontario's RH legislative and regulatory context

This qualitative objective will use an RTA study design with 1-hour semi-structured virtual focus groups with policymaker knowledge users ($n=8$). We will contextualize our findings from Phase 2 by inviting 2 knowledge users from each of the Retirement Homes Regulatory Authority, and the Ontario Ministries of Health, Long-term Care, and Seniors and Accessibility to participate in focus groups by organization to discuss results and interpretation and see if they resonate with their professional experience. The focus groups aim to situate our findings within the current legislative and regulatory context of the RH sector in Ontario and illuminate opportunities for evidence-based, equity-focused RH reform. Obj 4 will provide the context needed to ensure that our policy recommendations align with, and/or address gaps in, government or institutions' strategic priorities with regard to equity in RHs. This will increase the likelihood that they will influence change.

Data integration across all phases Will be accomplished by: Firstly, linking the themes from Objective 1 (Obj 1) to the quantitative variables that will be analyzed in Objective 2 (Obj 2). Then, designing a joint display to visually show how the themes from Obj 1 connect to the specific elements of the quantitative data in Obj 2. Next, analyzing the results from Obj 2 and interpreting how they support or challenge the themes from Obj 1, highlighting any statistical findings that need further explanation. In Objective 3 (Obj 3), designing qualitative research to explore questions that require deeper analysis. Creating another joint display that shows how the qualitative results from Obj 3 enhance the quantitative findings from Obj 2. For Objective 4 (Obj 4), designing qualitative research to help contextualize the findings from Obj 1–3. Interpreting how the qualitative results in Obj 4 add value to the overall understanding. Finally, bringing the results from all four objectives to the CAC to help shape our knowledge-sharing strategy at the end of the grant. This process will involve the co-development of policy options for improving equitable access, use, choice, and care quality in the RH sector with our community partners. See Fig. 1 study diagram.

Knowledge Mobilization Our knowledge mobilization plan will ensure that our work benefits our community partners and is disseminated to various levels of government policymakers. The research team will engage with

our CAC ($n=6$), RH staff ($n=3-5$), and hospital staff ($n=3-5$) to co-develop policy recommendations for reform at both the provincial and community levels. At the end of the grant, the research team will hold a half-day in-person workshop with the leadership team and staff members at each of our project partner sites - Carefor Health and Community Services and the Montfort Hospital. These workshops will be used to discuss the applicability of our project findings to their organizational context and to co-develop policy and practice recommendations relevant to their organization, which would then be transferable to other similar organizations within Ontario and potentially other provinces. The materials will be tailored to the specific context and scope of each of our partner organizations. We will also hold a half-day in-person workshop with our CAC members focused on co-developing policy recommendations targeted at key decision-makers.

Discussion

Impact

This project will leverage the existing momentum for equity-focused reform in LTC to meet the needs of an aging society. While evidence of health inequities is well documented and existing health administrative data in Ontario is of high quality, there continue to be limitations for understanding the nuances of the many intersecting variables impacting the health of RH residents. Using a multiphase, mixed methods study design, this project will leverage a variety of methods to address a complex problem that can only be understood through a multitude of approaches and data types. We will disseminate key learnings and recommendations and contextualized policy options to both provincial-level decision-makers and community knowledge user partners to help inform future work on equity in RHs at different levels of governance in Ontario. We will also disseminate our findings directly to RHs and hospitals to inform their plans for dealing with mandatory ALC transfers through the *More Beds, Better Care Act*. [6] By meaningfully involving equity-deserving groups throughout the research process (e.g., through membership in our CAC, in co-developing policy recommendations) this project will connect and empower these communities so that the impact may go beyond the scope of the study. Finally, this project provides an opportunity for researchers to work collaboratively with community and policymaker partners to develop effective working relationships that will form the basis for continued collaboration and advocacy for equity in RH care.

Anticipated challenges and mitigation strategies

Identity factors in administrative data

Ontario has the most developed linked population-based health administrative data in Canada. However, we are still unable to capture many identified factors including

but not limited to gender, race, and ethnicity. We are also only able to measure certain identity factors among individuals receiving home care (100% of the Obj. 2(a) study population, approximately 50% of RH residents in Obj. 2(b) study population). This is a limitation of the Obj 2(b) quantitative analysis that we will offset in two ways. First, for the Obj. 2(b) analyses that are restricted to the subgroup of RH residents receiving home care, we will examine differences in that group compared to RH residents not receiving home care. We will consider how any differences in these groups may impact our results and contextualize our findings accordingly. Second, we have included several qualitative streams/objectives in this project, which will allow us to examine factors that are currently unmeasurable in the population-level administrative data among a purposive subset of our target population.

Identifying RH residents

We will be unable to identify RH residents who reside in homes with non-unique postal codes and who were not receiving home care. This group is estimated to represent approximately 10% of the RH population.

Recruitment of RH residents

This population can be hard-to-reach, and thus difficult to recruit for qualitative analyses. To mitigate this, we have partnered with Carefor and the Montfort Hospital to assist with recruitment and building partnerships with other RHs who can help recruit. We have also allocated a long recruitment window of 12 months.

Impacts of COVID-19

Our study population in Obj. 2 will include individuals who entered RHs and/or received care in RHs during the COVID-19 pandemic. The pandemic had substantial impacts on transitions into congregate settings. Older adults may have avoided RHs given the increased risk of infection in congregate settings. LTC homes were also less accessible as new admissions were paused at times of outbreaks. Staffing shortages may also have impacted care quality in RHs. We will explore the impacts of COVID-19 in Obj. 2 via sensitivity analyses where we look at care transitions, quality, and outcomes separately before and during the COVID-19 pandemic. If we observe differences between the time periods, we will report on them separately.

Conclusion

This study will help us to better understand the differences that exist in access, choice, and care quality when Ontarians move from a private home to either a RH or a LTC home. This evidence base is novel and will be instrumental in informing the work of the policymakers in areas such as aging in the right place, addressing health human

resource shortages and emergency room overcrowding, and diverting pressure from the LTC sector [1, 2]. A better understanding of how issues of equity and diversity impact people’s experiences accessing and receiving care in RHs will shed light on what kinds of reforms could help to make RHs a more desirable place to age for the increasing number of older adults from diverse groups.

Appendix 1

Objective 1 key informants

Role	Individual or organization
CAC	Retirement home resident partner
CAC	Older adult caregiver partner
CAC	Sunnybrook, geriatrician
CAC	Health and wellness manager at the Carp Commons Retirement Home
CAC	Perley Health, lead of senior living portfolio
CAC	Carefor is Eastern Ontario’s largest not-for-profit charitable organization that provides home-, community-, institution-, and clinic-level health services and programs to older adults. They offer a vast range of services and programs that includes, but is not limited to, personal support services, in-home care, social and exercise activities, rehabilitation, respite care, palliative care, and retirement homes.
Key informant	AdvantAge Ontario is a not-for-profit organization that advocates for not-for-profit care and housing of older adults by voicing their opinion on policies, building community relationships, and ensuring a thriving business practice. They are proponents of not-for-profit care and aim to educate stakeholders/partners about its merits and positive impacts on seniors.
Key informant	Care Watch is a not-for-profit advocacy organization that advocates for equitable, accessible, home- and community-level services for all older adults. Home and community services are provided to older adults that allows them to stay in the community easily and avoid expensive formal care institutions. Care Watch voices their concern on privatization and advocates for publicly funded services that are delivered by not-for-profit providers.
Key informant	Ontario Retirement Communities Association represents and advocates for licensed retirement communities of Ontario by collaborating with the province and stakeholders to share the needs of the retirement communities. They provide guidance to retirement homes, share and inform RH regulation, and promote the growth of the RH sector. The organization works closely with health system stakeholders and advocates for publicly funded home- and community-care for older adults.
Key informant	Retirement Homes Regulatory Authority is an independent, self-funded, not-for-profit regulator mandated by the government to protect and ensure the safety and well-being of seniors living in Ontario’s retirement homes under the Retirement Homes Act, 2010. They put residents first by ensuring retirement homes follow the rules and by sharing unbiased, transparent safety information with seniors and their loved ones.

Appendix 2

Consultation guide

Objective 1: individual consultations with CAC members and advocacy groups

Q1. Given our interest in gaining a better understanding of the retirement homes sector in Ontario, what perspective do you bring to this project?

Q2. By equity, we mean that individuals have a fair opportunity to reach their fullest health potential through the reduction of unnecessary and avoidable barriers to care. How do you understand equity in the context of the retirement home sector?

Q3: Someone's social identity is comprised of their gender, race, ethnicity, income level, and many other factors. In your experience, what aspects of social identity have the most significant impact on access to, and quality of, care in retirement homes? Explain.

Q4: What are the key influences in decision making when older adults and their families must consider moving from home to facility-based care? Is this different for retirement homes versus nursing homes?

Q5: We are very interested in understanding the social and structural barriers that cause inequities in access to, and quality of, care in retirement homes. In your experience, what are the biggest barriers to equitable care in the retirement home sector? Do these change over time?

Abbreviations

ALC	Alternate level of care
CAC	Community advisory committee
LTC	Long-term care
RH	Retirement home
RTA	Reflexive thematic analysis

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Authors' contributions

KKM, CW, and SI conceptualized and designed the study. KKM and CW will lead project management, data collection and analyses. KKM and VW drafted the manuscript based on the grant application prepared by KKM, CW, and SI. CW, SI, CB, IB, CJM, SF, SJ, CEK, DM, MM, MN, WL, KP, AS, KS, PT, and PY have reviewed and revised the manuscript for important intellectual content. All authors read and approved the final manuscript.

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Data availability

No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate

Objectives 1, 3, and 4 were approved by the Bruyère Health Research Ethics Board (M16-24-020). Objective 2 will use ICES data. ICES is a prescribed entity under Ontario's Personal Health Information Protection Act (PHIPA). Section 45 of PHIPA authorizes ICES to collect personal health information, without consent, for the purpose of analysis or compiling statistical information with respect to the management of, evaluation or monitoring of, the allocation of resources to or planning for all or part of the health system. Projects that use data collected by ICES under Sect. 45 of PHIPA, and use no other data, are exempt from REB review. The use of the data in this project is authorized under Sect. 45 and approved by ICES' Privacy and Legal Office.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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References

- Dix A, Whiteside J. Provincial Health Services Authority 2023-24 Mandate Letter. 2023. Available from: <http://www.phsa.ca/about-site/Documents/PHS-A-2023-24-Mandate-Letter.pdf>. Cited 2024 Nov 7.
- Office of the Premier. Together, Let's Build Ontario. Ontario Newsroom. Available from: <https://news.ontario.ca/en/speech/1002230/together-lets-build-ontario>. Cited 2024 Nov 7.
- Roblin B. Ontario's retirement home residents need health-care funding too. Ottawa Citizen. 2018. Available from: <https://ottawacitizen.com/opinion/columnists/roblin-retirement-homes-and-long-term-care>. Cited 2024 Nov 7.
- Manis DR, Bronskill SE, Rochon PA, Sinha SK, Boscart V, Tanuseputro P, et al. Defining the assisted living sector in Canada: an environmental scan. *J Am Med Dir Assoc*. 2022;23(11):1871–e18771. <https://doi.org/10.1016/j.jamda.2022.07.018>.
- Manis DR, Rahim A, Poss JW, et al. Do assisted living facilities that offer a dementia care program differ from those that do not? A population-level cross-sectional study in Ontario, Canada. *BMC Geriatr*. 2021;21:463. <https://doi.org/10.1186/s12877-021-02400-w>.
- Retirement Homes, Act. 2010. e-Laws | Ontario.ca. 2024. <https://www.ontario.ca/laws/statute/10r11>.
- Health Quality Ontario. Wait Times for Long-Term Care Homes. Available from: <https://www.hqontario.ca/system-performance/Long-Term-Care-Home-performance/wait-times>. Cited 2024 Nov 7.

8. Manis DR, Kirkwood D, Fisher S, Li W, Webber C, Tanuseputro P, Stall NM, Watt JA, Hsu AT, Savage RD, Bronskill SE, Costa AP. Transitions to nursing homes among residents of assisted living and Community-Dwelling home care recipients. *J Am Med Dir Assoc*. 2025;26(2):105429. Epub 2025 Jan 16. PMID: 39709180.
9. Manis DR, Katz P, Lane NE, Rochon PA, Sinha SK, Andel R, Heckman GA, Kirkwood D, Costa AP. Clinical comorbidities and transitions between care settings among residents of assisted living facilities: A repeated Cross-Sectional study. *J Am Med Dir Assoc*. 2023;24(9):1356–60. Epub 2023 Jul 26. PMID: 37507099.
10. Ontario population projections. ontario.ca. 2021. <https://www.ontario.ca/page/ontario-population-projections#chart2>.
11. Calandra P, Bill M, Beds BC. Act. 2022. Available from: <https://www.ola.org/en/legislative-business/bills/parliament-43/session-1/bill-7>.
12. Canadian Institute for Health Information. Definitions and guidelines to support ALC designation in acute inpatient care. Ottawa, ON: CIHI; 2016.
13. Jenkins Morales M, Robert SA. Black-White disparities in moves to assisted living and nursing homes among older medicare beneficiaries. *The Journals of Gerontology: Series B*. 2020;75(9):1972–82. <https://doi.org/10.1093/geronb/gbz141>.
14. Lera J, Pascual-Sáez M, Cantarero-Prieto D. Socioeconomic inequality in the use of long-term care among European older adults: an empirical approach using the SHARE survey. *Int J Environ Res Public Health*. 2020;18(1):20. <https://doi.org/10.3390/ijerph18010020>.
15. Manis DR, Kirkwood D, Li W, Webber C, Fisher S, Tanuseputro P, Watt JA, Backman C, Stall NM, Costa AP. Clinical and sociodemographic characteristics of new residents of assisted living: A nested Case-Control study. *J Am Med Dir Assoc*. 2024;25(11):105270. Epub 2024 Sep 20. PMID: 39313036.
16. National Institute on Ageing (NIA). Ageing in the Right Place: Supporting Older Canadians to Live Where They Want. 2022. Retrieved from <https://static1.squarespace.com/static/5c2fa7b03917eed9b5a436d8/t/638e0857c959d1546d9f6f3a/1670252637242/AIRP+Report+Final2022-.pdf>.
17. Public Health Ontario. Health Equity. Available from: <https://www.publichealthontario.ca/en/Health-Topics/Health-Equity>. Cited 2024 Nov 7.
18. Yarnell CJ, Fu L, Bonares MJ, Nayfeh A, Fowler RA. Association between Chinese or South Asian ethnicity and end-of-life care in Ontario, Canada. *Can Med Assoc J*. 2020;192(11):E266–74. <https://doi.org/10.1503/cmaj.190655>.
19. Victora CG, Vaughan JP, Barros FC, Silva AC, Tomasi E. Explaining trends in inequities: evidence from Brazilian child health studies. *Lancet*. 2000;356(9235):1093–8.
20. Lorenz T, Petticrew M, Welch V, Tugwell P. What types of interventions generate inequalities? Evidence from systematic reviews. *J Epidemiol Community Health*. 2013;67(2):190–3. <https://doi.org/10.1136/jech-2012-201257>.
21. Crenshaw KW. On intersectionality: essential writings. New York: New; 2017.
22. Social Determinants of Health Framework and Resource Guide. Ontario Health. 2024. <https://www.ontariohealth.ca/system-planning/social-determinants-of-health-framework-and-resource-guide#:~:text=Social%20determinants%20of%20health%20are,economic%2C%20political%20and%20social%20context>.
23. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3(2):77–101.
24. Braun V, Clarke V. *Thematic Analysis: A Practical Guide*. SAGE Publications; 2021.
25. Milne J, Oberle K. Enhancing rigor in qualitative description. *J Wound Ostomy Continence Nurs*. 2005;32(6):413–20.
26. Lincoln YS, Guba EG. But is it rigorous? Trustworthiness and authenticity in naturalistic evaluation. *New Dir Program Evaluation*. 1986;1986(30):73–84. <https://doi.org/10.1002/ev.1427>.
27. Lincoln YS, Guba EG. Establishing Dependability and Confirmability in Naturalistic Inquiry Through an Audit. 1982. Available from: <https://files.eric.ed.gov/fulltext/ED216019.pdf>. Cited 2024 Nov 7.
28. Braun V, Clarke V. *Thematic analysis*. In: APA handbook of research methods in psychology, vol 2: research designs: Quantitative, qualitative, neuropsychological, and biological. Washington: American Psychological Association; 2012. p. 57–71.
29. Braun V, Clarke V. *Successful Qualitative Research: A Practical Guide for Beginners*. 1st ed. SAGE Publications; 2013.
30. Clarke V, Braun V. Thematic analysis. In: *Encyclopedia of critical psychology*. New York, NY: Springer New York; 2014. p. 1947–52.
31. Braun V, Clarke V. One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qual Res Psychol*. 2021;18(3):328–52. <https://doi.org/10.1080/14780887.2020.1769238>.
32. Braun V, Clarke V. Reflecting on reflexive thematic analysis. *Qual Res Sport Exerc Health*. 2019;11(4):589–97. <https://doi.org/10.1080/2159676X.2019.1628806>.
33. Maher C, Hadfield M, Hutchings M, de Eyto A. Ensuring rigor in qualitative data analysis. *Int J Qual Methods*. 2018;17(1). <https://doi.org/10.1177/1609406918786362>.
34. Creswell JW, Plano Clark VL. *Designing and Conducting Mixed Methods Research*. 2nd ed. SAGE Publications; 2011.
35. Hébert PC, Morinville A, Costa A, Heckman G, Hirdes J. Regional variations of care in home care and long-term care: a retrospective cohort study. *CMAJ Open*. 2019;7(2):E341–50. <https://doi.org/10.9778/cmajo.20180086>.
36. Hawes C, Morris JN, Phillips CD, Fries BE, Murphy K, Mor V. Development of the nursing home resident assessment instrument in the USA. *Age Ageing*. 1997;26(Suppl 2):19–25. https://doi.org/10.1093/ageing/26.suppl_2.19.
37. Manis DR, Poss JW, Jones A, Rochon PA, Bronskill SE, Campitelli MA, et al. Rates of health services use among residents of retirement homes in Ontario: a population-based cohort study. *Can Med Assoc J*. 2022;194(21):E730–8. <https://doi.org/10.1503/cmaj.211883>.
38. Costa AP, Manis DR, Jones A, Stall NM, Brown KA, Boscart V, et al. Risk factors for outbreaks of SARS-CoV-2 infection at retirement homes in Ontario, Canada: a population-level cohort study. *Can Med Assoc J*. 2021;193(19):E672–80. <https://doi.org/10.1503/cmaj.202756>.
39. Mondor L, Maxwell CJ, Hogan DB, Bronskill SE, Gruneir A, Lane NE, et al. Multimorbidity and healthcare utilization among home care clients with dementia in Ontario, Canada: a retrospective analysis of a population-based cohort. *PLoS Med*. 2017;14(3):e1002249. <https://doi.org/10.1371/journal.pmed.1002249>.
40. Health Quality Ontario. Health Quality Ontario. Indicator Library. Available from: <https://www.hqontario.ca/System-Performance/Measuring-System-Performance/Indicator-Library>. Cited 2024 Nov 7.
41. Gruneir A, Bronskill SE, Maxwell CJ, Bai YQ, Kone AJ, Thavorn K, et al. The association between multimorbidity and hospitalization is modified by individual demographics and physician continuity of care: a retrospective cohort study. *BMC Health Serv Res*. 2016;16(1):154. <https://doi.org/10.1186/s12913-016-1415-5>.
42. Jaakkimainen RL, Bronskill SE, Tierney MC, Herrmann N, Green D, Young J, et al. Identification of physician-diagnosed Alzheimer's disease and related dementias in population-based administrative data: a validation study using family physicians' electronic medical records. *J Alzheimers Dis*. 2016;54(1):337–49. <https://doi.org/10.3233/JAD-160105>.
43. Koné Pefoyo AJ, Bronskill SE, Gruneir A, Calzavara A, Thavorn K, Petrosyan Y, et al. The increasing burden and complexity of multimorbidity. *BMC Public Health*. 2015;15(1):415. <https://doi.org/10.1186/s12889-015-1733-2>.
44. Lane NE, Maxwell CJ, Gruneir A, Bronskill SE, Wodchis WP. Absence of a socioeconomic gradient in older adults' survival with multiple chronic conditions. *EBioMedicine*. 2015;2(12):2094–100. <https://doi.org/10.1016/j.ebiom.2015.11.018>.
45. Mondor L, Cohen D, Khan AI, Wodchis WP. Income inequalities in multimorbidity prevalence in Ontario, Canada: a decomposition analysis of linked survey and health administrative data. *Int J Equity Health*. 2018;17(1):90. <https://doi.org/10.1186/s12939-018-0800-6>.
46. Mondor L, Maxwell CJ, Bronskill SE, Gruneir A, Wodchis WP. The relative impact of chronic conditions and multimorbidity on health-related quality of life in Ontario long-stay home care clients. *Qual Life Res*. 2016;25(10):2619–32. <https://doi.org/10.1007/s11136-016-1281-y>.
47. Muggah E, Graves E, Bennett C, Manuel DG. The impact of multiple chronic diseases on ambulatory care use: a population based study in Ontario, Canada. *BMC Health Serv Res*. 2012;12(1):452. <https://doi.org/10.1186/1472-6963-12-452>.
48. Petrosyan Y, Bai YQ, Koné Pefoyo AJ, Gruneir A, Thavorn K, Maxwell CJ, et al. The relationship between diabetes care quality and diabetes-related hospitalizations and the modifying role of comorbidity. *Can J Diabetes*. 2017;41(1):17–25. <https://doi.org/10.1016/j.cjcd.2016.06.006>.
49. Thavorn K, Maxwell CJ, Gruneir A, Bronskill SE, Bai Y, Koné Pefoyo AJ, et al. Effect of socio-demographic factors on the association between multimorbidity and healthcare costs: a population-based, retrospective cohort study. *BMJ Open*. 2017;7(10):e017264. <https://doi.org/10.1136/bmjopen-2017-017264>.
50. Canadian Institute for Health Information. *Changes in Health, End-Stage disease and signs and symptoms (CHES)* scale. Ottawa, ON: CIHI; 2021.
51. Morris JN, Fries BF, et al. MDS performance scale. *J Gerontol*. 1994;49:m174–82.

52. VanderWeele TJ, Ding P. Sensitivity analysis in observational research: introducing the E-value. *Ann Intern Med*. 2017;167(4):268–74. <https://doi.org/10.7326/M16-2607>.
53. Bauer GR. Incorporating intersectionality theory into population health research methodology: challenges and the potential to advance health equity. *Soc Sci Med*. 2014;110:10–7. <https://doi.org/10.1016/j.socscimed.2014.03.022>.
54. Knol MJ, VanderWeele TJ. Recommendations for presenting analyses of effect modification and interaction. *Int J Epidemiol*. 2012;41(2):514–20. <https://doi.org/10.1093/ije/dyr218>.
55. Hennink M, Kaiser BN. Sample sizes for saturation in qualitative research: a systematic review of empirical tests. *Soc Sci Med*. 2022;292:114523. <https://doi.org/10.1016/j.socscimed.2021.114523>.
56. Guest G, Bunce A, Johnson L. How many interviews are enough? *Field Methods*. 2006;18(1):59–82. <https://doi.org/10.1177/1525822X05279903>.
57. SPOR Networks in Chronic Diseases, PICHI Network. Recommendations on Patient Engagement Compensation. 2018. Available from: https://diabetesaction.ca/wp-content/uploads/2018/07/TASK-FORCE-IN-PATIENT-ENGAGEMENT-COMPENSATION-REPORT_FINAL-1.pdf

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