

# Summary of Stakeholder Interviews RESULTS

## A Mixed-Methods Policy Research Study of Dying at Home: A SSHRC-Funded Project



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### BACKGROUND

This summary highlights interviews with 24 grassroots stakeholders, including advocates, volunteers and workers with knowledge of the experiences of diverse communities. It explores the complexity of social meanings and conditions around dying at home in Canada. Participants shared diverse perspectives on their preferences for location of dying and their understandings of the meanings of dying at home and care responsibilities at the end of life.

Recruitment targeted ‘compassionate community’ advocates, palliative care professionals and volunteers, bereaved family carers, Francophones, members of 2SLGBTQ+ and immigrant communities, rural and remote residents, and advocates for/workers with ‘structurally vulnerable’ (i.e., precariously housed, in poverty) populations. Some participants also identified as Indigenous, and many participants identified with more than one of the above categories.

### SUMMARY RESULTS

- Participants often define their preferences for location of dying against **where one does *not* want to die** (usually institutional care such as hospital or nursing homes).
  - However, some participants distinguish between a period of ‘dying at home’ prior to the actual death which could occur in institutional care (without being seen as a failure).
- **The meaning of home itself is fluid**, shifting depending on circumstances, yet is often about our relation to others. For some, home is not based on a ‘place’, but is defined as a ‘feeling’ or as connected to the presence of familiar things and people.
- Stakeholders **do not straightforwardly accept idealized visions of dying at home**.
  - Many emphasize that dying at home is not always a positive experience, especially for family and in certain circumstances (e.g., having complex care needs, severe symptoms, or poor housing).
- **Social backgrounds, life histories, and previous experiences shape meanings of dying at home**.
  - For instance, one participant, who had supported her mother to die in a nursing home, included death in this setting as part of what ‘dying at home’ means to her.
- **Choice over physical location *per se* is less important overall** than sustaining connection to people (especially family and friends), to familiar things, to nature and to pets. Participants highlighted the importance of the quality of interactions and experiences at the end of life.
- **Structural barriers shape preferences around location of dying, and for many, preclude the very idea of ‘choice.’**
  - Participants emphasize that dying well at home is not attainable for many, including those with certain illnesses or conditions, and those with poor access to publicly funded services, stable housing, financial resources, or capable family caregivers.

- When speaking of the meaning of dying at home, participants typically characterize **home as facilitating the following outcomes for dying persons and their communities:**
  - **Social Integration:** Dying at home reflects but also reinforces our relational connection to family, friends, and communities. Being at home is believed to generally make it easier to sustain connection and social integration.
  - **Reclamation:** Dying at home can reflect and reinforce a return to (or reclaiming of) social integration, interdependence and mutual aid, and an approach to death that is less formalized, less medicalized, and wherein funerals are less commodified.
  - **Preserving Selfhood:** For some participants, being around the familiar is about protecting self from harms of institutional care (e.g., stigma, discrimination). More broadly, home helps facilitate ongoing relations and connection not only to people but to material things, physical spaces, and to our identities.
  - **Control and Autonomy:** Being at home could facilitate control over aspects of everyday life and routine, and freedom from unwanted intrusion (even as participants acknowledge that some people do not have access to this control in their lives). For some people, the choice over location of death is more important than for others.
    - For instance, one member of the 2SLGBTQ+ community states:

*“...older adults in that community who have had so much choice revoked from them or not allowed until more recently in history, just having the choice to do that part of your life the way that you want I think is really valuable.”*
- There are **strong desires to continue to care for and protect family members**, and concern about impacts on family and friends.
  - The meaning of dying at home here is linked to ideas of **burden** – of care, of decision-making, of witnessing suffering or death, and of difficult memories of home spaces. Because of this, participants spoke of how being open to dying in an institutional setting (especially hospice) can be thought of as protecting family and friends (that is, as a form of caring for them).

## WHAT THIS MEANS

Research and policy around end-of-life need to move beyond questions of ‘preferences’ and ‘locations’ and account for the contingent and relational nature of dying experiences and interpretations. In addition, it is important to address the inequities shaping experiences of dying at home and whether or not we even have a choice. Our findings can help:

- a) direct attention to social justice across the life course and address structural barriers to end-of-life care;
- b) nuance public policy and health system quality indicators to better reflect structural barriers and impacts on family caregivers.
- c) shift how dying at home (and other locations) are portrayed in public arenas; and
- d) improve communication between patients, families, and health care providers at the end of life.

**Note:** The research team would like to thank all participants for their time and interest. If you have further questions, please contact Dr. Laura Funk, lead researcher, at [Laura.Funk@umanitoba.ca](mailto:Laura.Funk@umanitoba.ca). Stay tuned for future reports from this and other aspects of our project: <http://www.dyingathome.ca/> (a French language version of this summary is also available at this website).