

Equitable access to medical assistance in dying: towards patient-centred service and policy design

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ABSTRACT

Background: Access to medical assistance in dying (MAiD) is a critical concern, and understanding the challenges individuals face in accessing this option is essential. This study investigates the complexities surrounding MAiD access in Alberta, aiming to discern potential disparities and areas for improvement in the current system. The central phenomena explored include service delivery mechanisms, social factors, and individual needs and expectations shaping MAiD-seeking journeys. **General Methods:** This research prioritizes patient involvement and collaboration with patients, families, healthcare decision-makers and the general public in Alberta. A combination of survey and interview methods is employed to uncover the relationship between socioeconomic/social determinants of health and MAiD access. Consultative meetings and public engagement initiatives are utilized to gather ongoing partner feedback and co-create meaningful outcomes. Furthermore, survey and interview data will be interpreted critically using equity and intersectionality frameworks to contextualize findings—in relation to EDI and gender-based considerations—about patients' and families' attitudes towards, awareness of, and experiences along their MAiD access routes. **Results:** Socioeconomic status, social determinants of health, health literacy levels, and experiences with health systems significantly influence Albertans' decisions and experiences regarding MAiD. These results emphasize service delivery mechanisms, social structures, and individual needs that impact MAiD experiences, revealing areas of satisfaction and potential improvement within Alberta's current MAiD process. **Conclusions:** The study highlights the multidimensionality of decisions and processes involved in seeking MAiD, varying across different stages of the MAiD journey and types of care settings or providers. Understanding these variations is crucial in shaping equitable and patient-centred MAiD policies and services.

Keywords: medical assistance in dying; health equity; health access; patient experience; social determinants of health

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BACKGROUND

- It remains unknown if Albertans face challenges in accessing medical assistance in dying (MAiD), whether sociodemographic factors signal disparities in MAiD utilization, and broadly, whether the currently devised MAiD system can be improved to better support the needs and preferences of some of the most medically frail and vulnerable patients in the province.
- New evidence is needed to appraise the structures that enable or impede the process of seeking and receiving MAiD in Alberta. Accordingly, this project investigates the central phenomena—service delivery mechanisms, social factors, and individual needs and expectations—that shape people's MAiD-seeking journeys.

RESEARCH QUESTIONS

- How are socioeconomic and social determinants of health related to MAiD access and utilization in Alberta?
- How do individuals seeking MAiD across diverse care settings describe their experiences and what can we learn about barriers & facilitators to appropriate care from their accounts of the process?

METHODS

- Priorities identified and study design developed in close consultation with patient partners, health system decisionmakers, and members of the public in Alberta.
- Survey and interview methods to understand the association between socioeconomic status and MAiD access, and patients' and families' attitudes towards, awareness of, and experiences along their MAiD navigation journeys in Alberta.
- Consultative meetings, public webinars, and project website blogposts for ongoing partner feedback on data collection data analyses and to refine project plan and facilitate co-creation of outcomes.
- Co-design of schematic synthesis maps of patients' journeys through MAiD with partners and shared with stakeholders.

PRELIMINARY RESULTS

ENGAGEMENT MECHANISMS AND CO-DESIGNED TOOLS

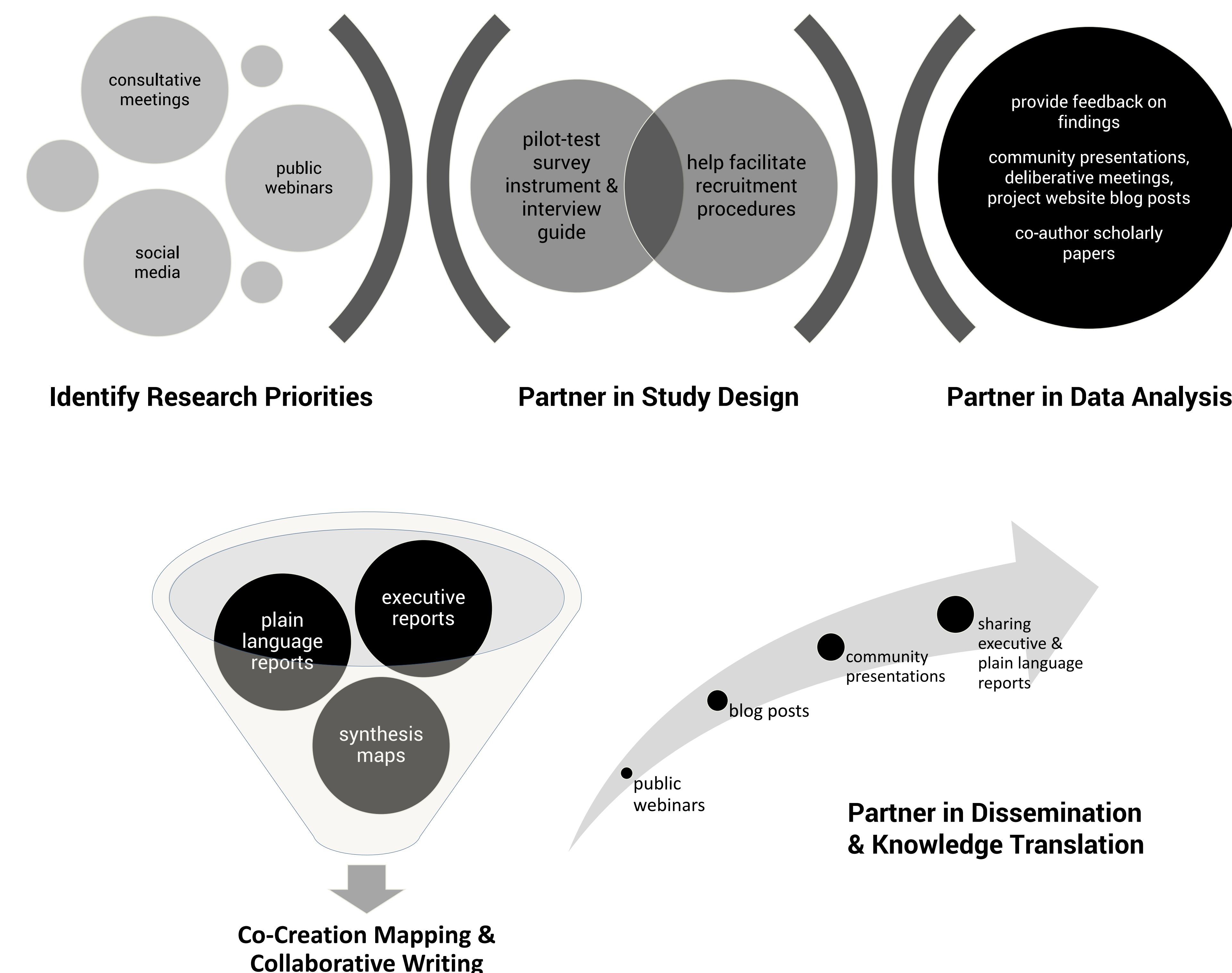


Figure 1 Phases of Engagement Process and Collaborative Development of Research Plan, Tools, & Outcomes

CONCLUSIONS (BASED ON CURRENT PROGRESS, ONGOING ANALYSES, AND ANTICIPATED FINDINGS)

- Socioeconomic status (SES), social determinants of health, health literacy levels, and experiences with health systems influence health-seeking behaviours, and correspondingly, end-of-life decisions. By extension, these factors may be linked to unknown MAiD utilization inequalities and imbalances.
- The decisions and processes involved in seeking MAiD are complex, sensitive, and multi-dimensional. These vary based on stages in an individual's MAiD journey and the type of care settings/providers they interact with (e.g., non-participating sites; healthcare professionals with conscientious objections; hospices versus large general hospitals; rural versus urban areas). These differences may alter realities and perceptions of service accessibility, and the experiences of navigating various alternatives along diverse MAiD service pathways.

EQUITY, DIVERSITY, & INCLUSION (EDI) AND SEX & GENDER-BASED ANALYSIS (SGBA+) CONSIDERATIONS

- Survey data will be interpreted critically using equity and intersectionality frameworks to contextualize the association between SES and patients' and families' attitudes towards, awareness of, and experiences along their MAiD access routes.
- Interview data will be interpreted using equity, intersectionality, and patient-centred synthesis mapping frameworks and contextualized based on EDI, gender-based considerations, and type of care settings/providers to discern variations in patient experiences across the health system.

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