

# DRAFT Death with Dignity

**ADDRESSING BARRIERS  
TO MEDICAL AID IN DYING**

**April 15, 2025**

**Washington State Department of Health**

**Prepared by Uncommon Bridges**



Washington State Department of  
**HEALTH**

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## **FORWARD FROM THE WASHINGTON STATE DEPARTMENT OF HEALTH**

The Washington [Death with Dignity Act](#), [Chapter 70.245 RCW](#), allows some terminally ill adults to request and use prescribed medication from qualified medical providers to end their lives as part of their end-of-life care. RCW 70.245.150 requires the Department of Health (department) to collect information for and publish an annual statistical report. The department is not involved in patient or healthcare provider decisions about participation.

In 2023, the Legislature passed Substitute Senate Bill 5179 (Increasing access to the provisions of the Washington death with dignity act) and a budget proviso directing the department to contract with an equity consultant to evaluate the effect and vulnerabilities of the bill. The evaluation requirements included partnering with community members and gathering feedback on barriers, unintended consequences, challenges, and recommendations for data collection.

The department contracted with Uncommon Bridge's following a competitive solicitation for bids and regularly met with their evaluation team to understand the project design. Enclosed is Uncommon Bridge's report that describes the methodology, findings, and recommendations from the evaluation. The findings and recommendations in the following report do not necessarily reflect the position or recommendations of the department.

In fiscal year 2025, the department made the difficult decision to pause the annual statistical report for the Death with Dignity program. This decision is part of broader budget reductions and reflects the agency's need to prioritize patient safety and other critical public health responsibilities. Healthcare providers are required to continue to submit forms. The department will securely store forms but will not conduct data analysis due to limited staffing capacity. Access to the end-of-life care available under the Death with Dignity Act remains in place and is not affected by the budget reduction.

## DEFINITIONS

**Advance Directive:** Written, legal instructions that state the treatment one wants for medical conditions when they cannot make decisions for themselves. It guides choices for healthcare professionals and caregivers in certain situations.<sup>i</sup>

**Death With Dignity Act:** Washington State law that allows terminally ill adults seeking to end their life to request lethal doses of medication from medical and osteopathic physicians, physician assistants, and advanced practice registered nurses. These terminally ill patients must be Washington residents who have less than six months to live.<sup>ii</sup>

**Do Not Resuscitate/Do Not Intubate (DNR/DNI):** In the event of cardiac arrest, no cardiopulmonary resuscitation (CPR) or electric shock will be performed to restart the heart (DNR). In case of breathing difficulty or respiratory arrest, no breathing tube will be placed in the throat (DNI). These orders may be given separately and are generally prominently noted in the patient's medical chart. The patient can change a DNR and DNI order anytime, and experts urge that such orders be reviewed regularly. In a DNR/DNI situation, a patient is provided comfort care. Emergency medical technicians are legally required to perform CPR without such an order.<sup>iii</sup>

**End-of-Life Planning:** Decisions based on personal values, preferences, and discussions with loved ones about the healthcare one would want to receive if facing a medical crisis. Often documented in a directive.<sup>iv</sup>

**Hospice Care:** A component of palliative care that focuses on the care, comfort, and quality of life of a person with a serious illness approaching the end of life.<sup>v</sup>

**Informed Consent:** A process in which patients are given important information, including possible risks and benefits, about a medical procedure or treatment, genetic testing, or a clinical trial to help in their decision to be treated, tested, or participate in the trial. Patients are also given any new information that might affect their decision to continue.<sup>vi</sup>

**Medical Aid in Dying:** Also known as medical assistance in dying, MAiD is the standard acronym used to describe the implementation of the Death with Dignity Act in this report.

**Palliative Care:** A treatment option that focuses on symptom management, pain relief, and quality of life for patients with severe, advanced illnesses and support for their families.<sup>vii</sup>

**Portable Orders for Life-Sustaining Treatments (POLST):** A portable physician order form that describes the patient's care directions.<sup>viii</sup>

**Self-administration:** A qualified patient's act of ingesting medication to end their life in a humane and dignified manner.

**Terminal Illness:** An illness for which the medical expectation is death within six months.<sup>ix</sup>

**Voluntary stopping of eating and drinking (VSED):** An act by a patient choosing to control their dying by making an intentional decision to stop all nutrition and hydration. VSED is an option for a decision-capable adult who consciously refuses food and fluids to advance the time of their death. Also known as terminal fasting.<sup>x</sup>

## **EXECUTIVE SUMMARY**

In 2024, the Washington State Department of Health (DOH) contracted with Uncommon Bridges to assess recent changes to the Washington State Death with Dignity Act (Death with Dignity). Death with Dignity was passed in 2008 through an initiative supported by 57% of Washington voters, making Washington the second state to legalize medical aid in dying after neighboring Oregon. During the 2023 Legislative Session, the State passed Engrossed Substitute Senate Bill (ESSB) 5179, introducing key changes to expand access and lower barriers to end-of-life services.

The changes expanded definitions and allowances for who can administer end-of-life care and provide counseling services to qualified patients. It shortened the timeframe when a qualified patient must wait to make a second oral request for end-of-life medications and eliminated other required waiting periods to receive and request a prescription. It also permitted the electronic submission of prescriptions to pharmacists and medical records to the DOH. A budget proviso in ESSB 5187 additionally called for gathering feedback from interested parties, vulnerable populations, and communities of color to identify barriers and unintended consequences and to offer suggestions for improving data collection and service measures.

The following report is based on a literature review and an analysis of recent updates to state law and current shifts in healthcare and medical standards. Most importantly, it includes perspectives from various stakeholders across the complex ecosystem that supports individuals accessing medical aid in dying (MAiD). These stakeholders include:

- Medical practitioners: doctors, physician assistants, nurse practitioners, and nurses
- Assisted living and hospice facilities staff and practitioners
- Hospitals administrators
- Nonprofit organizations
- Religious groups, including Hospital Chaplains

The number of patients utilizing medical aid in dying through Death with Dignity has increased from 63 in 2009, when the program was first introduced, to 545 in 2023. Most patients seeking MAiD are enrolled in hospice or palliative care. Over 90% of these patients are White and are more likely to be insured and hold a college degree.

Awareness of Death with Dignity has grown among medical practitioners and hospices, with more hospices integrating MAiD into their end-of-life care services. Washington state has over 50 hospice centers, approximately half providing space to administer MAiD. However, available locations are often limited for those seeking space to administer MAiD in safe, accessible, and culturally relevant settings. Some hospice centers face long wait times for admitting patients for general care, while others struggle with staff shortages of nurses and qualified physicians.

While awareness of the law has increased, there is still a need for more formal training. Healthcare practitioners often lack adequate training or understanding of MAiD policies, with others expressing discomfort in discussing MAiD. One of the most common challenges noted in our engagement was finding a doctor to prescribe MAiD. Complex processes and limited access to participating healthcare practitioners present significant barriers, particularly in rural areas. Recent improvements in telemedicine, pandemic-driven changes, and efforts by End-of-Life Washington to recruit doctors and volunteers are helping to enhance access, especially in underserved areas.

Over the past 15 years, major hospital systems have consolidated. In some instances, this has led to the streamlining of Ethical and Religious Directives, which can impose restrictions on the types of care provided and how patients access services.<sup>xi</sup> Conscience-based refusals by healthcare professionals can impact patient autonomy regarding individual decisions on end-of-life care.

The healthcare system operates within a shifting state and federal landscape. The Trump Administration has introduced funding and healthcare priorities that have altered hospital funding, grant allocations, and medical services. Additionally, political uncertainty at the federal level creates challenges for Washington state hospitals, particularly in prioritizing specific treatments. For instance, a recent National Institute of Health proposal seeks to cap indirect administrative costs for certain research institutions at 15%, many of which focus on cancer research and other terminal, or neurological illnesses commonly diagnosed in patients seeking MAiD.<sup>xii</sup> This proposal prompted a cautionary response from the Washington State Medical Association.

Other proposed federal changes could also influence programs that affect patients' access to medical aid in dying, including Medicare and Medicaid reimbursements, restrictions on drug prices, training standards, and the expansion of value-based care. Additionally, expected cuts to the Washington budget will impact the healthcare system.

### **Engagement Methodology**

To understand the real-world impacts of the updates to the law, Uncommon Bridges engaged with dozens of stakeholders involved with MAiD and end-of-life care. Each brought unique perspectives shaped by their professional roles and personal experiences. Given the individual and complex nature of these discussions, we prioritized thoughtful engagements to foster open dialogue, ensure diverse viewpoints, and capture the range of lived experiences. We received 134 responses to an online survey and conducted 15 in-depth interviews with key stakeholders representing community and senior living and care facilities, medical centers, and others. We held regular check-ins with DOH staff throughout our eight-month engagement.

## Recommendations

Based on this research, analysis, and engagement process, we recommend the following areas for the Washington State Legislature’s action and consideration. They are presented as summary statements, with the full recommendations elaborated in the report's final section. Several recommendations suggest improvements in education and outreach to communities of color and other interested parties. These efforts are not intended to place DOH, the Washington State Legislature, or any government agency in a position to persuade or encourage the use of MAiD. Still, they are meant to enhance awareness of MAiD as an end-of-life option.

## Data Collection and Sharing Agreements

- To enhance transparency and accountability, **the Washington State Legislature should assist the DOH in creating an accessible dashboard that compiles year-over-year data and metrics to understand usage trends and gaps.** Some metrics compiled in the dashboard could include terminal conditions in the event of death, basic demographic data, end-of-life medications dispensed, place of death, insurance status, and the race and ethnicity of patients.

The availability and disaggregation of data by race and ethnicity in Washington State are insufficient. Nationally, Compassion and Choices reports an underreporting and undersourcing of disaggregated data, with Asians representing 3.5%, Latinos representing 2%, and all other races and ethnicities often classified as “Other” in most data sets.<sup>xiii</sup> **The Washington State legislature should continue to fund and advocate for disaggregated data and establish regular evaluations of the participation of vulnerable populations in MAiD.**<sup>xiv</sup>

## End-Of-Life Care

- In Washington State, MAiD dying is closely tied to hospice and palliative care, with nearly seven out of ten patients utilizing it while enrolled in hospice.<sup>xv</sup> Year-over-year data indicate that participants are predominantly White and non-Hispanic. Indeed, communities of color are accessing MAiD at rates lower than their demographic proportions in Washington State. **The DOH should conduct further studies on the disproportionality of patients accessing and enrolling in hospice and palliative care.**

## Advance Directive Practices

- **Advance directives**, including durable power of attorney for healthcare, healthcare directives, and other forms for care decisions such as Do Not Resuscitate (DNR) and Portable Orders for Life-Sustaining Treatment (POLST), serve as voluntary tools for planning and prioritizing end-of-life medical and legal decisions. However, information on MAiD is often missing from these forms, even though most allow for preferences regarding artificial

ventilation, voluntary stopping of eating and drinking, hydration and nutrition, pain management, organ donation, and preferred medications and directives for prolonged life, such as CPR. Including **MAiD information in these forms and discussions is essential to educate and inform patients about their end-of-life options**. This may require further amendments to Chapter 70.245 RCW on Informed Decision (RCW 70.245.070), Written and Oral Requests (RCW 70.245.090), and the Right to Rescind Request (RCW 70.245.100).<sup>xvi</sup>

### Education, Research, and Training

- **Continuing Education (CE)** enhances healthcare professionals' knowledge, skills, and understanding of evolving regulations, ideally improving patient care. In 2020, the passage of the *Protecting Patient Care Act*, Engrossed Substitute House Bill 1608, strengthened protections for staff and practitioners, allowing them to refer interested individuals to MAiD services without fear of termination from restricted healthcare systems. However, confusion remains regarding the scope of these protections and how MAiD can be legally and ethically navigated. Additional education and awareness of MAiD, Washington State law, patient autonomy, and related program provisions are essential. **The DOH and Washington Medical Commission (WMC) should consider funding and hosting voluntary CE training to ensure healthcare professionals have the most accurate and up-to-date information.**

### Equitable Access

- Improved and committed **engagement with communities of color** can foster trust and advance health equity. Both are essential for raising awareness of MAiD in these communities. **The Washington State Legislature should support the DOH by investing time and resources to build more intentional relationships through regular roundtables, webinars, and meetings with community health centers, rural health centers, and health-focused community-based organizations.** These conversations can contribute to qualitative data, inform outreach materials, and enhance culturally competent care.
- Washington State has a variety of **religious, cultural, and spiritual perspectives** that shape how people discuss death and influence their end-of-life decisions. Cultural traditions and stigmas also affect how individuals access end-of-life care and how openly they communicate about MAiD with their healthcare professionals. Our quantitative and qualitative data reveal an underrepresented number of people of color choosing to use MAiD. **The Legislature should allocate additional resources to understand cultural, spiritual, and religious differences and support community-based organizations to engage with affected communities.** This work should focus on understanding cultural norms surrounding death, including the distinction between cultures that emphasize collective grief and those that prioritize individual experience.

## Infrastructure and Operations

- **Create incentives for healthcare facilities, including hospice, palliative, and other care centers, to provide space for MAiD practitioners, especially in rural areas and central and eastern Washington.** Washington state ranks among the top states in offering hospice, palliative, and assisted living facilities; however, geographic isolation, limited availability of practitioners, and space constraints often limit access to MAiD. Most patients who utilize MAiD are enrolled in hospice or palliative care. Existing incentive programs like the Medicaid EHR Incentive Program can offer helpful guidance.

### Recommendation Summary

1. **Data Collection and Shared Agreements: Establish Data Dashboard.**
2. **End-of-Life Care: Study Disproportionate Access to Hospice Care.**
3. **Advance Directive Practices: Expand Materials into Advance Directive Practices.**
4. **Education, Research, And Training: Expand Voluntary Continued Education.**
5. **Equitable Access: Increase Engagement with Communities of Color.**
6. **Infrastructure and Operations: Incentivize Providers to Offer Space for MAiD.**

## INTRODUCTION

In 2024, the Washington State Department of Health (DOH) commissioned a study to assess recent changes to the Washington State Death with Dignity Act (Death with Dignity) through a budget proviso in ESSB 5187. Uncommon Bridges was tasked with gathering feedback from affected groups, identifying barriers and unintended consequences, and offering suggestions for improving data collection and service measures. This report organizes our findings by providing an overview of Death with Dignity in Washington, analyzing demographics, sharing stakeholder perspectives, and making recommendations.

### Legislative Context

The Washington State Death with Dignity Act was passed in 2008 after the approval of Initiative 1000. It received support from 57% of Washington voters, making it the second state to legalize medical aid in dying, following neighboring Oregon. During the 2023 Session of the Washington State Legislature, the state passed ESSB 5179, introducing significant changes to expand access and reduce barriers to end-of-life services. A budget proviso in ESSB 5187 directed the DOH to hire

an equity consultant to evaluate the effects of the changes made by ESSB 5179 and to assess any vulnerabilities within it, requiring:

*“...partner[ing] with interested parties, vulnerable populations, and communities of color to solicit feedback on barriers to accessing the provisions of the [DWDA], any unintended consequences, and any challenges and vulnerabilities in the provision of services under the [DWDA], recommendations on ways to improve data collection, and recommendations on additional measures.”*

ESSB 5179 expands the definitions and allowances for those authorized to administer end-of-life care and provide counseling services to eligible patients. It reduces the waiting period for an eligible patient to make a second oral request for end-of-life medications. It removes other mandatory waiting periods related to receiving and requesting a prescription. Additionally, it permits the electronic submission of prescriptions to pharmacists and the Death with Dignity reporting forms to the DOH. The complete changes to the Death with Dignity statute and regulations can be reviewed on the DOH Death with Dignity website.<sup>xvii</sup>

### **Impacts on Healthcare practitioners**

In 2023, updates to the Death with Dignity Act introduced significant changes regarding which healthcare practitioners are authorized to serve as Attending Practitioners and Consulting Practitioners. The revisions also clarified which behavioral health practitioners can conduct psychological consultations for individuals seeking MAiD. As a result, the following professionals can now serve as practitioners:

- Attending and Consulting Practitioners: Advanced Registered Nurse Practitioners (ARNPs) and Physician Assistants (PAs); and
- Psychological Consultants: State-licensed psychiatrists, psychologists, independent clinical social workers (LCSWs), mental health counselors, and Psychiatric APRNs.

These changes increased accessibility to MAiD by broadening the range of practitioners available to support patients during end-of-life care. Many individuals have APRNs or LICSWs as their primary care practitioners or as more accessible behavioral health professionals. With the increase in professionals who can now serve as practitioners, additional education and training on Death with Dignity and MAiD are necessary to ensure that these professionals are equipped to support patients wishing to access these services. The 2023 update also requires all agencies and facilities providing hospice services in Washington to submit their policies regarding access to end-of-life care and MAiD services to the DOH.

Hospital mergers have also impacted access to MAiD. Research commissioned by the Office of Financial Management as part of the Washington State Health Services Research Project highlighted these changes: “In 1986, Washington had three systems and 105 hospitals. Eleven

hospitals, or 10%, were part of a system. By 2017, 10 systems included 45 of 98 hospitals in the state, or almost half.<sup>xviii</sup>

In 2021, CHI Franciscan and Virginia Mason merged to create Virginia Mason Franciscan Health, part of CommonSpirit Health, a religiously affiliated healthcare nonprofit organization. 2012 Swedish Health Services became affiliated with Providence Health & Services, a Catholic healthcare corporation. These mergers raised concerns among some organizations due to the Catholic Health Care Institutions' Ethical and Religious Directives, which are guidelines that can restrict certain medical services, including Death with Dignity options. The Keep Our Care Act – proposed in the 2023 session and reintroduced in 2024 and 2025 – would empower the attorney general to evaluate the impact of hospital mergers on people’s access to care.<sup>xix</sup>

### **Accessing Medical Aid in Dying in Washington State**

Washington state has over 50 hospice centers<sup>xx</sup>, about half offering facilities to administer MAiD.<sup>xxi</sup> Other initiatives, such as A Place to Die, link MAiD patients with locations and community-care centers outside the hospice care system.<sup>xxii</sup> However, for those looking for spaces to administer MAiD in safe, accessible, and culturally relevant ways, options are often limited.

MAiD costs typically range from \$750 to \$800 and are generally not covered by insurance, including Medicare or other federal health insurance programs. These costs can present challenges for lower-income patients and families, particularly when factoring in additional expenses such as travel and other medical-related costs.

### **Ethical & Cultural Viewpoints**

Conscience-based refusals by healthcare professionals can affect patient autonomy in making individual decisions on end-of-life care. In Washington state, conscience-based refusal is addressed in RCW 70.47.160. This is described as the “right of providers, carriers, and facilities to refuse to participate in or pay for services for reasons of conscience or religion.” This practice directly impacts patient access to medical aid in dying.<sup>xxiii</sup> In their report, “Bigger and Bigger: The Growth of Catholic Health Systems,” the authors acknowledge that even in states where Death with Dignity is legal, restrictive religious policies have limited patients’ ability to access services.<sup>xxiv</sup>

Disability rights organizations have offered varying perspectives on MAiD. Some advocate for patient autonomy and the right to choose end-of-life care, while others express concern about the effects on vulnerable individuals who cannot advocate for themselves. These organizations unite in their calls for enhancements to end-of-life care, including improvements to hospice and palliative care, promoting more accessible information and advanced planning, and protecting patient autonomy. Locally, they have also highlighted issues of discrimination in end-of-life care, insufficient training for healthcare professionals, and the necessity for cultural competency.

Varying perspectives on end-of-life care, influenced by religious, ethnic, or social backgrounds, are central to the distribution and accessibility of information about MAiD. Some cultural norms regarding death foster a more open and relational environment, viewing end-of-life care as an ongoing journey rather than a destination. Nevertheless, these perspectives are evolving and dynamic. At a national level, academics and researchers have investigated this issue. *Cain & McCleskey* found that “White participants construed medical aid in dying as more positive than participants in the African American and Latino groups, but participants from all groups expressed a complex set of opinions about what makes a good death.”<sup>xxv</sup> Others have compared religious, ethnic, and cultural perspectives across age groups, revealing variation in generational viewpoints.

## **DEMOGRAPHICS OF PATIENTS ACCESSING DEATH WITH DIGNITY**

Under the Death with Dignity Act, RCW 70.245.150, the DOH is required to generate and make available to the public an annual statistical report of the information collected. The Death with Dignity Act enforces strict privacy protections, exempting information from public records. Consequently, the DOH does not disclose collected information outside the annual statistical report.

The following data is based on official reports from the DOH on Washington Death with Dignity data from 2009-2023.<sup>xxvi</sup> The Department collects this information from healthcare practitioners of patients accessing medical aid in dying, in compliance with RCW 70.245.150 and WAC 246-978-020. The regulations require medical and healthcare practitioners to submit specific documentation about their qualified patients within 30 days after prescribing life-ending medications and within 30 days of the patient’s death. DOH data is also collected from death certificates, the After Death Reporting Form, the Attending Medical Compliance Form, and the Pharmacy Dispensing Form. Sometimes, the data is inconsistent or incomplete, or it factors in multiple complaints, including types of illness and end-of-life concerns.

### **Data Insights**

- Most participants (over 90%) in the Death with Dignity Act are White, non-Hispanic. They are also more likely to be insured and college-educated than other Washington residents. (Table 1)
- People accessing medical aid in dying through Death with Dignity has increased year over year since 2009, when 63 accessed the program, to 545 in 2023. (Figure 1)
- There are no significant differences in accessing medical aid in dying by sex. Male and female participation stays within 40-60% in any given year. (Figure 2)
- Participants in Washington state are generally insured, with anywhere from 87-97% of participants having some form of insurance, whether private or Medicaid/Medicare. (Figure 4)

- Most patients accessing medical aid in dying have some form of cancer diagnosis. Other diagnoses made by participants include those of neurodegenerative, respiratory, or cardiovascular diseases. (Figure 5)

**Table 1: Key Demographics**

Year	Number Participants	Number Deaths	Race	Education	Insurance
2009	63	47 Had Died at Time of Report 36 Died After Ingesting Medication	98% White, Non-Hispanic	61% had some college education or more	89% Had Some Form of Insurance 43% on Medicare or Medicaid Only 29% Private Insurance Only 2% Had End-of-Life Concern of Financial Implications of Treatment
2010	87	72 Had Died at Time of Report 51 Died After Ingesting Medication	95% White, Non-Hispanic	62% had some college education or more	88% Had Some Form of Insurance 43% on Medicare or Medicaid Only 30% Private Insurance Only 4% Financial Implication of Treatment
2011	103	94 Had Died at Time of Report 70 Died After Ingesting Medication	94% White, Non-Hispanic	75% had some college or more	87% Had Some Form of Insurance 40% on Medicare or Medicaid Only 34% Private Insurance Only 4% Financial Implications of Treatment
2012	121	104 Had Died at Time of Report 83 Died After Ingesting Medication	97% White, Non-Hispanic	82% had some college or more	89% Had Some Form of Insurance 55% on Medicare or Medicaid Only 5% Financial Implications of Treatment
2013	173	159 Had Died at Time of Report 119 Died After Ingesting Medication	97% White, Non-Hispanic	76% had some college or more	95% Had Some Form of Insurance 59% on Medicare or Medicaid Only 13% Financial Implication of Treatment
2014	176	170 Had Died at Time of Report 126 Died After Ingesting Medication	92% White, Non-Hispanic	76% had some college or more	93% Had Some Form of Insurance 57% on Medicare or Medicaid Only 8% Financial Implications of Treatment

**Table 1: Key Demographics**

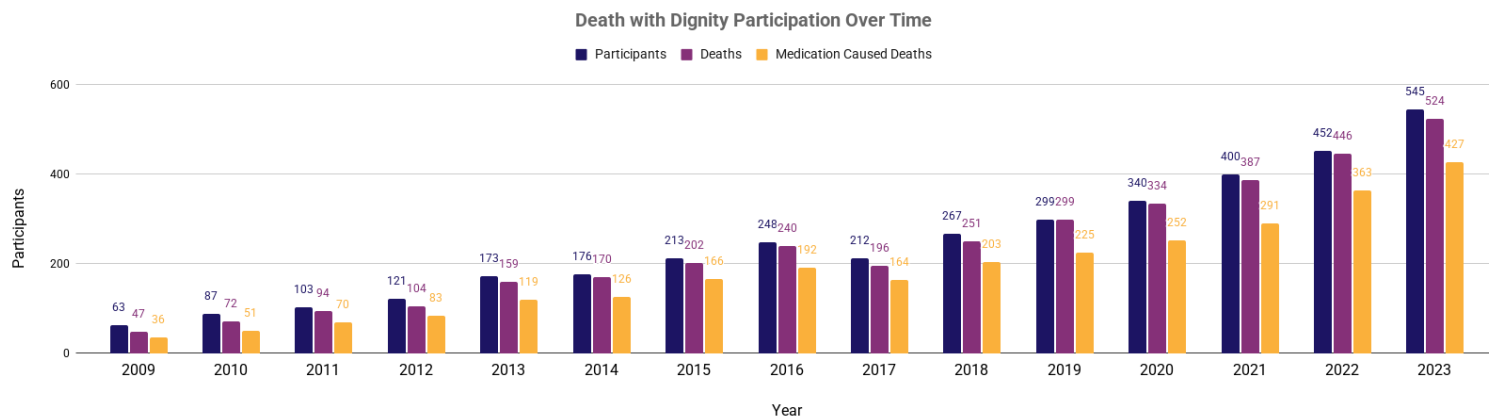
Year	Number	Number	Race	Education	Insurance
	Participants	Deaths			
2015	213	202 Had Died at Time of Report 166 Died After Ingesting Medication	98% White, Non-Hispanic	74% had some college or more	95% Had Some Form of Insurance 50% on Medicare or Medicaid Only 13% Financial Implications of Treatment
2016	248	240 Had Died at Time of Report 192 Died After Ingesting Medication	97% White, Non-Hispanic	67% had some college or more	92% Insured 46% on Medicare or Medicaid Only 8% Financial Implications of Treatment
2017	212	196 Had Died at Time of Report 264 Died After Ingesting Medication	94% White, Non-Hispanic	75% had some college or more	97% Insured 54% on Medicare or Medicaid Only 10% Financial Implications of Treatment
2018	267	251 Had Died at Time of Report 203 Died After Ingesting Medication	96% White, Non-Hispanic	70% had some college or more	94% Insured 66% on Medicare or Medicaid Only 9% Financial Implications of Treatment
2019	299	299 Had Died at Time of Report 225 Died After Ingesting Medication	94.6% White, Non-Hispanic	76% had some college or more	88% Insured -None -None- 8% Financial Implications of Treatment
2020	340	334 Had Died at Time of Report 252 Died After Ingesting Medication	93% White, Non-Hispanic	76% had some college or more	97% Insured 7.8% Financial Implications of Treatment
2021	400	387 Had Died at Time of Report 291 Died After Ingesting Medication	92% White, Non-Hispanic	77.5% had some college or more	95% Insured <5% Had End-of-Life Concerns of Financial Implications of Treatment

**Table 1: Key Demographics**

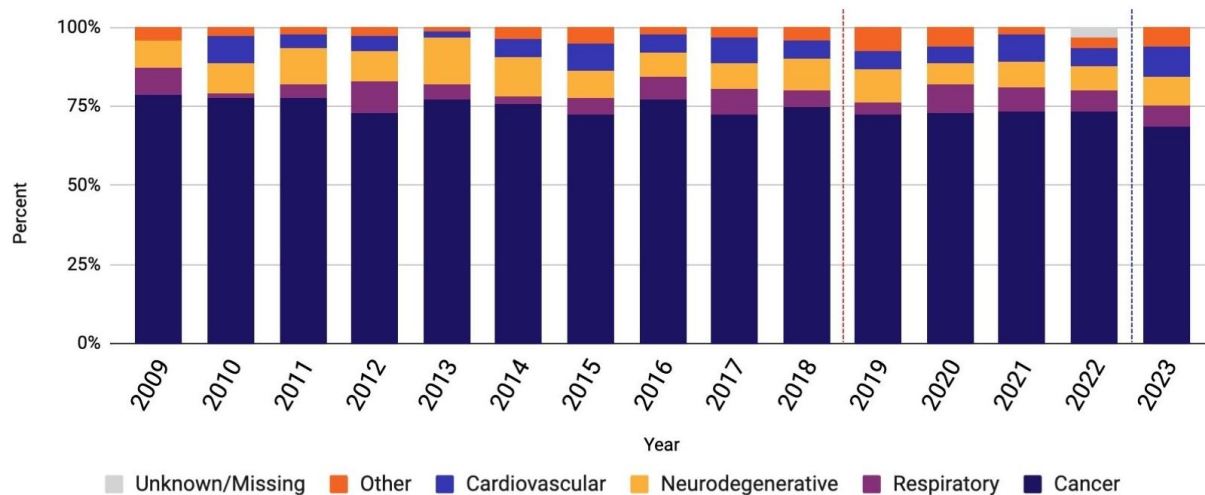
Year	Number		Race	Education	Insurance
	Participants	Deaths			
2022	452	446 Had Died at Time of Report 363 Died After Ingesting Medication	93% White, Non-Hispanic	74% had some college or more	91% Insured 9% Uninsured or Unknown 10% Financial Implications of Treatment
2023	545	524 Had Died at Time of Report 427 Died After Ingesting Medication	95% White, Non-Hispanic 2% Asian	74% had some college or more	89% had some form of Insurance 11% Uninsured/Unknown 10% Financial Implications of Treatment

**Figure 1: Participation Over Time**

The red line and blue line indicate when shifts in the law occurred to expand access.

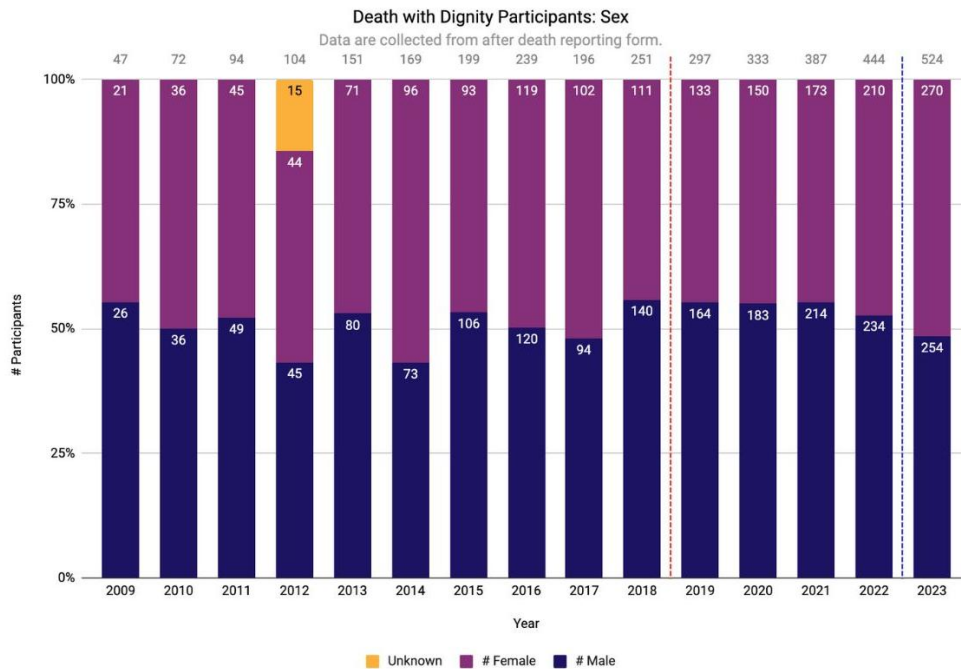


**Figure 2: Underlying Illnesses**

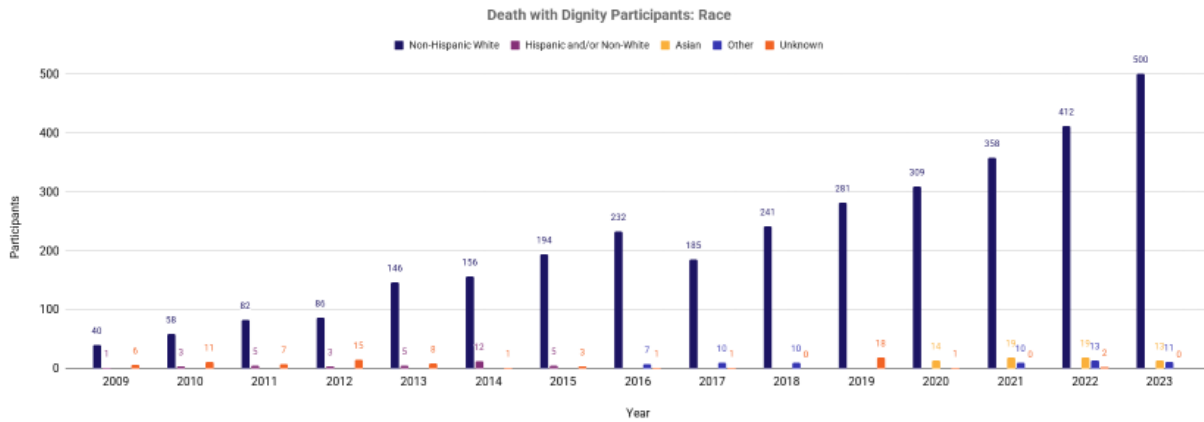


**Figure 3: Participants by Sex**

Data is collected from the Death Certificate.



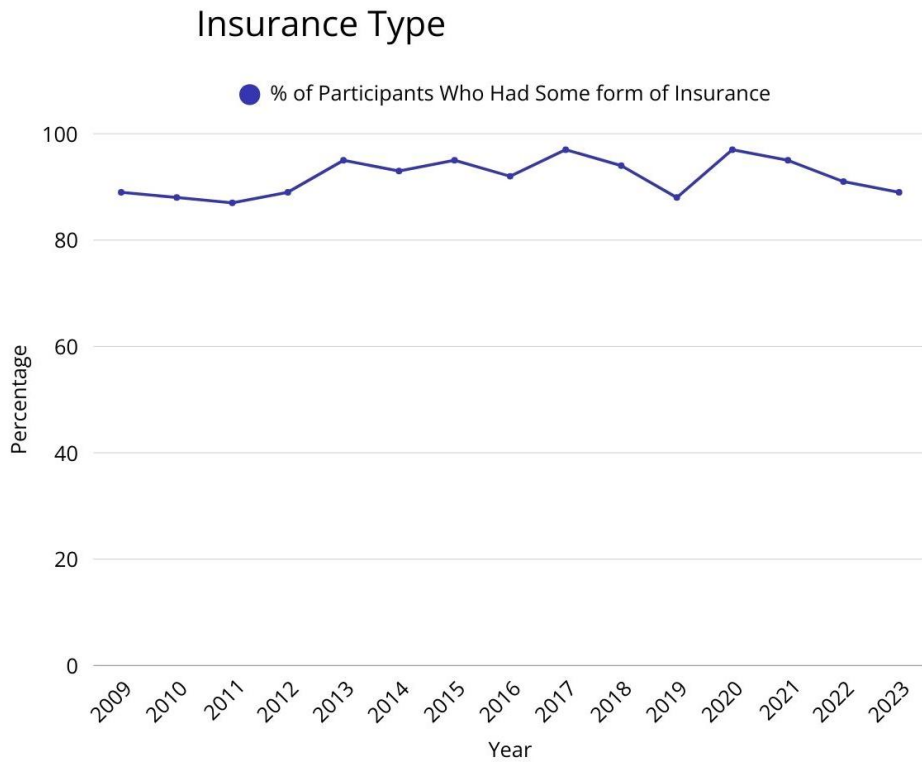
**Figure 4: Participants by Race**



**Figure 5: Participants by Level of Insurance**

The method of collecting insurance has changed since the law passed in 2009.

Year	% of Participants Who Had Some form of Insurance
2009	89
2010	88
2011	87
2012	89
2013	95
2014	93
2015	95
2016	92
2017	97
2018	94
2019	88
2020	97
2021	95
2022	91
2023	89



## ENGAGEMENT METHODOLOGY

As part of our research process, we engaged stakeholders involved in medical aid in dying and end-of-life care through online surveys and one-on-one interviews. Given the deeply personal and complex nature of these discussions, our team prioritized thoughtful engagements to foster open dialogue, ensure diverse viewpoints, and capture the range of lived experiences. While we initially planned to host focus groups with various stakeholders, the sensitive nature of the topics led us to determine that one-on-one interviews were a more effective method for qualitative data collection.

### Surveys

Research for this report was generated from a survey sent to volunteers for End of Life Washington, which included client advisors, phone volunteers, medical care practitioner volunteers, and ambassadors. The survey was open for six weeks and received 134 responses. Compensation was provided to participants.<sup>xxvii</sup> The common questions across all four surveys included barriers to access, observed changes since ESSB 5179, unintended consequences, equity in accessing Death with Dignity, and additional comments.

#### Who took the survey?

- 49 Medical Practitioners
- 13 Ambassadors
- 6 Phone Volunteers
- 66 Client Advisors
- 21 Counties Represented

### One-on-One Interviews

Uncommon Bridges hosted 15 interviews with key stakeholders from various organizations representing community and senior living care facilities, medical centers, and more. We conducted online video interviews, focusing on barriers to accessing MAiD, equity concerns, awareness of ESSB 5179 changes, and ideal scenarios for equitable access.

#### Who we interviewed:

- 4 Palliative Care Practitioners
- 1 Cancer Care Practitioners
- 1 Death Midwife and Educator
- 1 Bioethics Registered Nurse
- 1 State Representative
- 3 Hospice/Palliative Spiritual and/or Chaplaincy Practitioners
- 3 Individuals from the WA Medical Commission
- 1 Hospice Volunteer

#### Where interviewees are from:

- 4 from Seattle
- 2 from Yakima
- 1 from Tacoma
- 1 from Walla Walla
- 2 from Wenatchee
- 4 Washington State

## KEY ENGAGEMENT FINDINGS

### Survey Results

#### Positive Changes Observed since ESSB 5179

- 90 respondents have seen a positive change in their client's experience since SB 5179.
- There is an appreciation for reduced wait times, having more medical professionals that can serve, and easier access to medication.

"Less wait time (7 days as opposed to 15) and additional medical staff who can participate as Attending and Consulting medical practitioners has made the experience with MaiD faster and easier."

#### Negative Changes Observed since ESSB 5179

- 10 Respondents have seen a negative change in their client's experience since SB 5179
- The shorter waiting period still isn't fast enough, and there is increased strain on current medical practitioners and delayed updates to policies.

"Unclear and overly broad language prohibiting supervising practitioners to participate on the same case as their supervisees is confusing and creates barriers to practitioners' participation for"

The survey asked, "Have there been any unintended consequences (good, bad, or neutral) as a result of the passage of SB 5179?"

- 12 respondents said Yes, and 87 respondents said No.

### Medical Care Practitioners

- 79% of medical practitioner respondents have never been trained on Death with Dignity or MAiD, but still, many are aware of the law.
- 71% of respondents said that Death with Dignity or MAiD is discussed in the workplace.
- 76% of respondents feel the behavioral health professionals completing psychiatric evaluations for MAiD patients have adequate training.
- 69% of respondents have not participated in a case where a formal psychiatric evaluation was needed.
- For the process of obtaining a psychiatric evaluation:
  - 9% of respondents said the process is working
  - 9% said the process is not working
  - 81% said unsure

"Being unable to have two mid-level practitioners for a patient can impact the timing of response to requests. For myself, an ARNP, I have many years of experience with end-of-life care and think I have more to offer than some of the MDs who I volunteer beside."

"Some residential hospices and many living communities don't permit ingestion onsite. Some families don't want their loved ones dying in the home, for a variety of reasons."

### Client Advisors

- 26% of respondents have frequently spent two or more hours problem-solving barriers that clients face when seeking MAiD.
- 66% of respondents have encountered clients who don't have a place to administer MAiD.

### Ambassadors

Ambassadors to End of Life Washington raise awareness about Death with Dignity. They most often present to seniors, the public, veterans, and those self-selecting to receive MAiD.

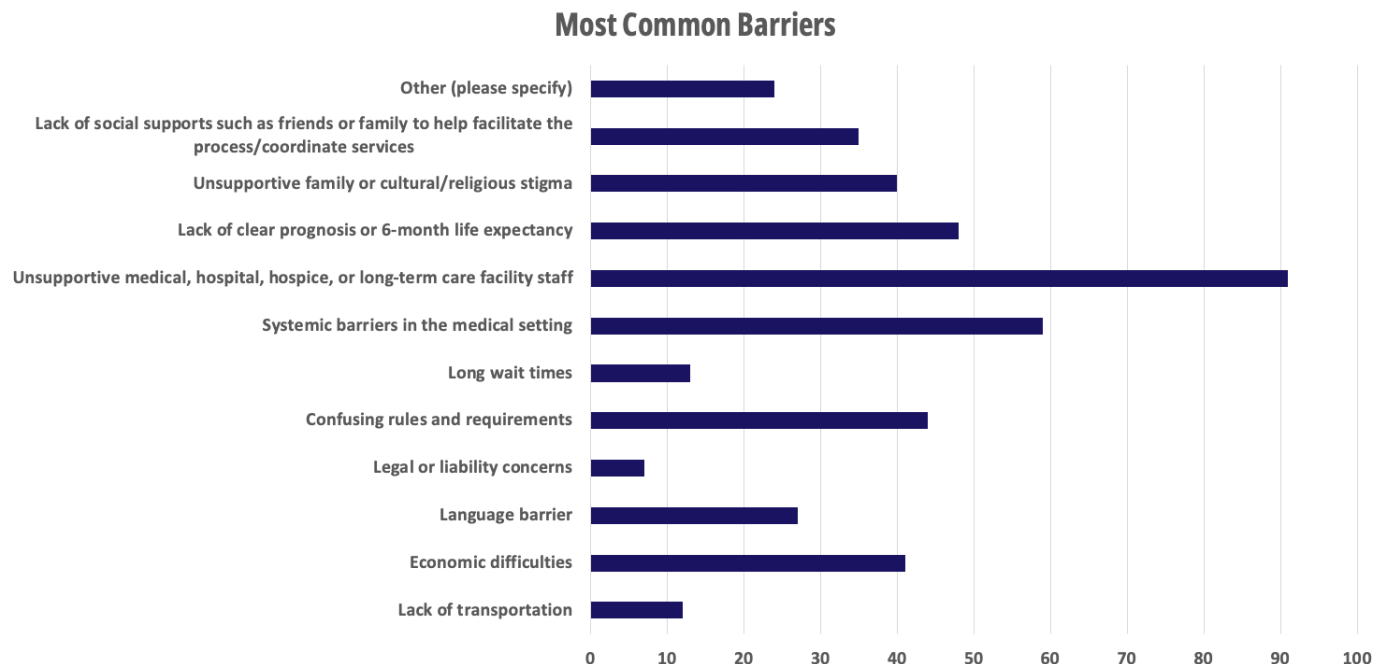
- The most frequent questions the Ambassadors get about Death with Dignity or MAiD include:
- How does it work?
- How to access it?
- Details about the limitations on who can receive it?

### Phone Volunteers

- Most people reaching out about receiving MAiD are late in life, in hospice, or after receiving a six-month prognosis.
- Finding a doctor to prescribe MAiD is the most frequent challenge cited on calls.

"...the changes to the Death with Dignity act have increased access but has not decreased the financial impact that low-income populations face, they still struggle with finding the means to pay for their Death with Dignity meds."

"The vast majority want to know how to get started on the process. Many are overwhelmed by the complexity. Most do not have supportive practitioners or have not specifically made overtures to the practitioners."



*The survey received 134 responses. Not every respondent answered every question.*

## Survey Themes

These themes are compiled from conversations with the engaged interested parties as part of this outreach process. Some observations captured in the quotes below speak to the need for further education and information about MAiD and highlight the significant barrier of a lack of up-to-date information about the law and its impacts.

**Public and practitioners' awareness is increasing.** Telemedicine, pandemic-driven changes, and End of Life Washington's efforts to recruit doctors and volunteers are helping to improve access, especially in underserved areas. More training opportunities for healthcare practitioners and hospice nurses are being created, and more hospices are integrating MAiD into their end-of-life care services.

**Patients face long wait times.** There is a growing demand for the law's services. The current 7-day waiting period is often extended due to appointment availability due to limited practitioners prescribing MAiD.

**Some requests are very urgent.** Many individuals seeking assistance with end-of-life options tend to reach out too late, often when they are in the final stages of their illness or crisis. While some patients contact practitioners well in advance of their expected death, many wait until they are experiencing unbearable pain or have been given a terminal diagnosis, which leads to frustration and a sense of urgency in processing their requests.

**Some patients lose eligibility too soon.** Progressive illnesses like Alzheimer's and certain cancers may cause individuals to lose decision-making capacity before completing the MAiD process, raising concerns among stakeholders for those who had previously expressed clear intent.

**Families need support.** The rapid sequence of actions required in the process may overwhelm families, especially without adequate anticipatory grief support.

**Many practitioners still feel unsafe.** The waiting period for Death with Dignity has alleviated anxiety for some families, and hospice organizations are increasingly supportive. However, many healthcare practitioners still feel unsafe discussing Death with Dignity, especially within religiously affiliated systems.

**Educate patients before it's too late.** The timing of when patients seek help varies widely, from those who plan on receiving a diagnosis to those who wait until they are actively dying. There is a call for better education and support to ensure individuals are aware of their rights and options before they reach a crisis point.

A very big barrier is that so many of our health facilities have religious based policies that don't allow their team members to provide MAID services. I find myself intentionally choosing to support clients with Kaiser because they have a dedicated MAID department and support qualifying patients. Additionally, clients who are at poverty level and are on Medicaid typically are being cared for in a federally funded clinic. These clinics, in my experience, have overworked medical staff who, while they may be willing to provide MAID services, in particular helping clients access the two required practitioners, the organization isn't set up to provide this support. As a volunteer, it is a huge barrier to overcome in supporting a client who, in a most recent instance, was so sick that having the energy to advocate for herself was just not there. I did a lot of advocating and phone calling on her behalf. I was happy to do this and unhappy that it was necessary.

- Volunteer

No, not really. People with a high level of autonomy and personal empowerment (mostly educated s) use Death with Dignity in my county. It is not being accessed equitably.

- Ambassador

There will be more and more people requesting aid in dying. We do not have enough practitioners to accommodate what is coming soon.

- Medical Practitioner

I'd like to see the wait period go away completely. I'd also like to see the state residency requirement go away (like Oregon and Vermont).

- Medical Practitioner

Large parts of the state are served by religious health care organizations, who do not allow their practitioners to participate in the law. This adds burdensome extra effort for patients who want to access the law as is their right.

- Medical Practitioner

Lower-income people of all backgrounds have difficulty accessing the law. I've never yet been assigned to help an ESL client. Only one of my clients has been in a lower economic level. No black and no [Hispanic] clients.

- Client Advisors

Not all practitioners talk about it with patients, because distrust in the health care system and previous negative experiences make some patients wary of the proposal, particularly from practitioners who don't look like them or come from their communities.

- Medical Practitioner

## INTERVIEW RESULTS

Uncommon Bridges conducted 15 online video interviews with key stakeholders from various organizations representing the community, senior living and care facilities, medical centers, and more. The key themes from the interviews include:

### Barriers to Access

- **Legal & Logistical Issues:** Complex paperwork, medication delivery, and uncertainty around billing add additional barriers to accessing MAiD.
- **Lack of Practitioners' Education:** Healthcare practitioners often lack the training or understanding of MAiD policies, leading to discomfort in discussing or administering them.
- **Facilities' Reluctance:** Many healthcare facilities, particularly in conservative areas, do not want to participate in MAiD, which limits patients' options.
- **Rural Access:** Rural communities face challenges due to limited healthcare practitioners, a lack of hospice services, and fewer training opportunities for healthcare professionals.
- **Cultural & Religious Resistance:** Cultural, religious, and political beliefs, especially in conservative areas, create resistance to MAiD. Specific faith-based institutions, namely Catholic hospitals, can have a significant impact on access.

### Equity Concerns

- **Disparities in Access:** Marginalized groups (i.e., people with disabilities, low-income individuals, and racial minorities) experience greater difficulty accessing MAiD due to financial, educational, and systemic inequalities.
- **Geographic Inequities:** Access to MAiD is particularly limited in rural and underserved areas, where healthcare infrastructure is weak or absent.
- **Cultural Barriers:** Cultural stigma and a lack of normalized discussions around MAiD contribute to uneven access, particularly for certain communities (i.e., Latino, Black, or religiously conservative populations).

### Policy and Legislative Impact

- **ESSB 5179:** The changes brought by the new law, such as a shorter wait time and broader prescribing access, are seen as steps forward. However, there is still confusion and resistance around its implementation, particularly concerning hospice roles.

### Solutions and Vision for Equitable Access

- **Normalizing Medical Aid in Dying:** MAiD should be integrated into standard healthcare practices, with more regular conversations about it among practitioners. It should be included in medical care to ensure consistent access across different populations.

- **Hospice Houses:** More hospice services, including hospice houses, are needed to provide a comfortable environment for MAiD administration.
- **Education and Outreach:** A widespread, culturally sensitive education campaign is necessary to inform both patients and practitioners. This includes promoting MAiD in medical schools, providing information in healthcare settings, and increasing awareness in underserved communities.
- **Support for Families and Practitioners:** It is critical to increase support for families and healthcare practitioners through education and training and ensure clear guidance on ethical and legal considerations.

### Focus Areas for Stakeholder Engagement

- **Terminally Ill Patients:** Focus on the needs of individuals facing terminal illnesses, particularly those who are not aware of or able to access MAiD.
- **Medical Practitioners and Chaplains:** Engage both participating and non-participating practitioners, along with chaplains and rural healthcare professionals, to foster greater understanding and involvement in MAiD.
- **Policy Makers:** More advocacy and policy changes are needed to lower barriers and enhance support for MAiD at the state level.

I believe that people in **news deserts** do not know about Death with Dignity and are at a disadvantage. I also believe that some medical professionals do not provide accurate or complete information about Death with Dignity (particularly religious groups). Once people contact End of Life WA, I strongly believe everyone gets the best assistance available.  
– Ambassador

The vast majority of people who call want to know how to get started on the process. Many are **overwhelmed by the complexity**. Most do not have supportive practitioners or have not specifically made overtures to the practitioners.  
– Volunteer

## ENGAGEMENT SUMMARY BY IDENTIFIED BARRIERS

### Barriers to Access

Community input reveals various structural and cultural barriers that restrict access to MAiD, particularly for marginalized and rural populations

- **Legal & Logistical Complexity:** Paperwork, medication delivery, billing confusion, and administrative burdens are consistent access barriers.
- **Workforce & Institutional Resistance:** Many healthcare providers lack training, feel unsafe discussing MAiD, or work in faith-based facilities that prohibit participation.
- **Geographic Disparities:** Rural areas lack practitioners, hospice services, and training opportunities, compounding access issues.
- **Cultural & Religious Tensions:** Conservative and faith-based community values can create stigma or outright resistance, deterring both patients and providers.

I want to mention the absolute necessity of **expanding the law to include people who** are clear on their intent to use MAiD but **lose their cognitive ability and are thusly excluded.** This can easily happen and is so troubling. We are not serving large numbers of people. Cancer is a common cause of someone losing cognitive ability as tumors spread to the brain, and of course, dementia and Alzheimer's patients are excluded under their diagnoses. We must extend rights to these people. We must also expand options for self-administration. It is tragic for someone with ALS, for instance, to lose the ability to self-administer and thereby lose their right to MAiD. We can do better.

– Client Advisor

### Unintended Consequences

While MAiD legislation seeks to expand end-of-life options, several unintended consequences have emerged

- **Late Requests & Crisis Situations:** Many patients seek MAiD too late, during active dying or severe pain, causing logistical strain and emotional distress.
- **Delays in Care:** A shortage of trained providers and facility constraints often extend the already-shortened 7-day waiting period.
- **Inconsistent Support for Families:** Families' emotional and logistical demands, especially during rapid MAiD timelines, are often unaddressed.
- **Vulnerability of Patients Losing Cognitive Ability:** Those with progressive diseases like Alzheimer's who previously expressed intent may be excluded once cognitive decline sets in.

### Challenges & Vulnerabilities in Service Provision

Fragmented data, limited resources, poor inter-agency coordination, and ongoing inequities that reduce access and quality for vulnerable populations challenge service provision.

- **Practitioner Risk & Silence:** Healthcare workers, especially in religiously affiliated institutions, feel unsafe or unclear about discussing or providing MAiD.
- **Uneven Integration Across Hospices:** While some hospice organizations have integrated MAiD, others have not, resulting in confusion and limited options.
- **Marginalized Groups Left Behind:** People with disabilities, BIPOC communities, and low-income individuals face greater difficulty navigating and accessing MAiD.

## RECOMMENDATIONS FOR LEGISLATIVE CONSIDERATION

The following represents a mix of seven programmatic, administrative, and legislative actions for DOH and the legislature to consider because of our landscape analysis and engagement of stakeholders. They are organized by:

<b>Purpose and Objective</b>	Defines the policy's purpose and intended objectives.
<b>Context</b>	Identifies applicable history and context to consider.
<b>Key Components</b>	Discusses primary points of the recommendation.
<b>Implementation Considerations</b>	Explores how this recommendation can be implemented, by whom, and the timeline for implementation.
<b>Community Stakeholder Feedback Summary</b>	Summarizes how this recommendation connects to qualitative and quantitative research.
<b>Intended Outcomes</b>	Expected results based on successful implementation of the recommendation
<b>Addressing Barriers</b>	How recommendations address stated barriers listed in the proviso.
<b>Legislative References</b>	Cites the applicable RCW or WAC.

## 1. DATA COLLECTION AND SHARED AGREEMENTS

### Recommendation – Establish Data Dashboard

#### **Purpose & Objectives**

To enhance MAiD data collection and reporting practices to improve transparency and enable clearer communication of trends and gaps over time. Special emphasis will be placed on disaggregating data for vulnerable and overburdened communities to better identify disparities and inform targeted interventions

#### **Context**

DOH is mandated to publish annual MAiD reports, currently available online, and follows strict Small Numbers Publishing Guidelines to protect privacy. These guidelines require suppression of any data counts below 10, which limits the granularity of demographic analyses. Practitioners and pharmacists must submit multiple forms within 30 days of prescribing or dispensing MAiD medication. However, the existing system's reliance on death certificates for race and ethnicity data restricts accurate tracking of MAiD participation across diverse populations. Nationally, non-white groups remain underrepresented in the data, hampering equity efforts.

#### **Key Policy Components**

Washington State law protects patient privacy and allows for disclosure only through an annual statistical report. Yet, DOH can improve transparency by implementing key revisions to existing policies. DOH should consider a new policy that would allow the agency to compile all annual report information into one, easy-to-read dashboard that can show year-over-year trends, address gaps, and ensure compliance with state law. In particular:

##### *Improve Data Collection Quality and Completeness*

Conduct a comprehensive audit of race, ethnicity, and geographic data capture points throughout the MAiD process, from prescription to dispensing to reporting, to identify gaps and inconsistencies. This will inform refinements in data collection protocols that reduce missing or aggregated small-number data.

##### *Enhance Disaggregation and Representation*

Strengthen the collection of demographic variables to enable finer disaggregation by race, ethnicity, geography, underlying conditions, and other relevant factors. Embed regular evaluations of underrepresented populations' participation to monitor equity in access and service delivery.

### *Develop a Dynamic, Interactive Dashboard*

Move beyond merely digitizing the annual report by developing a centralized dashboard that visualizes year-over-year trends and demographic breakdowns while ensuring compliance with privacy laws. This dashboard will offer stakeholders accessible, real-time insights into MAiD usage, aiding in the identification of service gaps and inequities.

### *Increase Community Engagement and Outreach*

Support funding for community-based organizations and health centers to enhance outreach among marginalized groups. Improved engagement will encourage broader participation, helping to “reduce the small numbers” by increasing the dataset’s representativeness and completeness.

## **Implementation Considerations**

### *Short-Term Implementation Considerations*

- The Legislature should allocate resources for DOH to create and maintain the dashboard, either internally or through a trusted third party, while ensuring that privacy safeguards are upheld. A target rollout by the upcoming annual report update is recommended.
- Grants for community organizations should be expanded to enhance outreach efforts that improve data quality and build trust among vulnerable populations.
- DOH should meet regularly with community partners to assess data gaps and explore ways to enhance quantitative data with qualitative insights.

### *Long-Term Implementation Considerations*

Below are additional long-term implementation considerations that could create the foundation for a more robust and equity-centered data dashboard by enhancing the quality, consistency, and completeness of MAiD data. Standardized collection protocols and improved data fields ensure reliable inputs across the system; training and audits boost accuracy and accountability; community partnerships and innovative tools address demographic and experiential gaps; and supplemental sources enrich mandated reports. Together, these efforts empower the Department of Health to build a transparent, actionable dashboard that reflects real-world use, identifies disparities, and informs policy improvements.

### *Standardize Data Collection Procedures Across All Points of Care*

Develop and enforce consistent protocols for collecting demographic information—including race, ethnicity, language, geographic location, and underlying health conditions—at every stage of the MAiD process (e.g., initial request, prescription, dispensing, and follow-up reporting).

### *Integrate enhanced data fields into existing forms and electronic systems.*

Consider updates to practitioner and pharmacist reporting forms, electronic health records (EHR), and pharmacy systems to include mandatory standardized fields for detailed demographic data, reducing the number of missing or incomplete entries.

*Inform healthcare providers and pharmacists on the importance of data collection.*

Provide regular training and resources to practitioners and pharmacists to enhance their understanding of the significance of accurate demographic data, boost their comfort in collecting sensitive information, and minimize reporting errors.

*Implement Routine Data Quality Audits and Feedback Loops*

Establish regular audits to evaluate the completeness and accuracy of data submissions, identify systemic gaps, and offer feedback and technical assistance to reporting entities to foster continuous improvement.

*Leverage Community Partnerships to Supplement Quantitative Data*

Collaborate with community health centers and advocacy groups to gather qualitative insights and promote patient participation, particularly among marginalized groups, enhancing the dataset's richness and representativeness.

*Pilot Innovative Data Collection Approaches*

Consider using tools like patient self-reporting portals, mobile data apps, and integration with state health information exchanges to collect more comprehensive demographic data. These sources can improve mandated annual reports by addressing gaps in race, ethnicity, geography, and access trends. When utilized alongside required reporting, they provide a more complete picture of MAiD use, support equity analysis, and guide targeted outreach, all while ensuring strong privacy protections.

## **Community & Stakeholder Feedback Summary**

Stakeholders consistently requested more timely, accessible, and disaggregated data, with specific interest in trends by underlying illness, geography, and ethnicity. They also emphasized the importance of linking data on MAiD use with hospice and end-of-life care availability to understand access disparities better.

## **Intended Outcomes**

- **Stakeholders and the public actively monitor MAiD trends and disparities** by using transparent and accessible data, which enables targeted interventions that close service gaps and promote equity.
- **Providers and community organizations enhance trust-based partnerships with vulnerable populations**, providing more equitable access to MAiD and culturally responsive care delivery.

## **Addressing Barriers**

### *Enhancing Transparency and Reporting*

Developing a centralized, user-friendly dashboard that consolidates annual MAiD report data enables precise year-over-year tracking of trends, gaps, and key metrics (number of deaths, underlying conditions, medication dispensed, place of death, insurance status). This approach simplifies complex reporting requirements and enhances public accountability while ensuring compliance with privacy laws, including Washington State's Small Numbers Publishing Guidelines.

### *Improving Data Disaggregation and Equity Focus*

Strengthening the collection and regular evaluation of race, ethnicity, and other demographic data throughout the MAiD prescription, dispensing, and reporting process. This addresses known limitations in current data sources (reliance on death certificates), enabling the identification of disparities impacting vulnerable and underrepresented populations.

### *Supporting Targeted Resource Allocation*

Utilizing enhanced data insights to identify geographic and demographic service gaps, which inform a more equitable distribution of resources and focused training efforts to reduce legal, logistical, and institutional barriers.

### *Enhancing Community Engagement and Trust*

Advocating for increased funding for community-based organizations to improve outreach, particularly among marginalized groups who face cultural, linguistic, or institutional barriers. This fosters trust and enhances awareness and navigation of MAiD services.

### *Mitigating Service Delays and Provider Challenges*

Facilitating better coordination and provider support through timely, high-quality data to address issues such as delayed MAiD requests, inconsistent family support, and workforce reluctance can ultimately enhance patient outcomes and experiences.

### *Encouraging Legislative and Operational Support*

Recommending legislative funding for the DOH to develop and maintain the dashboard, whether in-house or through a third party, along with a feasible implementation timeline that aligns with the upcoming annual report cycle. This approach promotes collaboration with key partners, such as community health centers, to integrate qualitative data and address ongoing data gaps.

## **References & Supporting Documents**

RCW 70.245.150 – Reporting of information to the Department of Health

Draft Death with Dignity: Addressing Barriers to Medical Aid in Dying

DOH Standards for Reporting Data with Small Numbers

Request for Medication to End My Life in a Humane and Dignified Manner form (DOH 422-063)

Attending Qualified Medical Provider Compliance form (DOH 422-064)

Consulting Qualified Medical Provider Compliance form (DOH 422-065)

Psychiatric/Psychological Provider Compliance form (DOH 422-066), if an evaluation was performed.

Attending Qualified Medical Provider After Death Reporting form (DOH 422-068)

Pharmacy Dispensing Record Form (DOH 422-067)

## 2. END-OF-LIFE CARE

### Recommendation – Study Disproportionate Access to Hospice Care

#### Purpose & Objectives

To examine the disproportionality of illness, race, and ethnicity among patients in hospice and palliative care centers, identifying barriers that impact equitable access to MAiD under Death with Dignity. The aim is to reveal systemic disparities that may hinder awareness of or the ability to seek MAiD among marginalized populations and to develop strategies for reducing those barriers.

#### Context

In Washington State, nearly 70% of patients who access MAiD are also enrolled in hospice care, making hospice a crucial entry point to Death with Dignity. However, current annual data shows that MAiD participants are disproportionately White and non-Hispanic, with communities of color significantly underrepresented compared to their share of the state population. This pattern suggests that unequal access to hospice and palliative care may directly impact who can meaningfully consider and pursue MAiD.

Existing state-level quantitative data frequently lack completeness and may be duplicative, with disaggregated data on race, ethnicity, sexual orientation, and gender identity being notably limited. Additionally, qualitative input indicates that non-white and LGBTQIA+ patients tend to avoid discussions about end-of-life care or enrolling in hospice services, likely due to cultural stigma, mistrust, or insufficient culturally competent services. These factors present indirect yet significant barriers to accessing the provisions of Death with Dignity, especially for patients from underserved communities and those with terminal illnesses that are not typically associated with MAiD participation (i.e., neurodegenerative diseases).

#### Key Policy Components

DOH should study and collaborate with community health centers, hospice, and palliative care practitioners to research disparities in hospice and palliative access, particularly among vulnerable and underserved populations in Washington state. Other components included:

*Advance equity in hospice access to enhance MAiD participation.*

Concentrate research and data collection on how disparities in hospice and palliative care enrollment affect equitable access to MAiD. Examine differential access by race, illness type, geography, language, sexual orientation, and gender identity to identify which populations are disproportionately excluded from pathways leading to MAiD.

*Partner with Community-Based Organizations to Inform Outreach*

Collaborate with trusted community-based organizations, hospice providers, and palliative care teams to jointly develop culturally relevant outreach, education, and navigation supports that enhance awareness of end-of-life care options, including MAiD, among underserved communities.

**Short-Term Implementation Considerations**

Building lasting and authentic relationships can take time and focus. The DOH and the Legislature should bring together internal stakeholders, including those responsible for licensing and regulating hospice centers, to examine how current systems contribute to enrollment disparities and impact equitable access to MAiD.

Implementation must be rooted in building community trust and require sufficient time, funding, and support for ongoing engagement. The DOH should host regular webinars with hospice administrators to share data, discuss strategies for equitable enrollment, and create pathways to enhance culturally responsive care practices that connect more eligible patients to information about Death with Dignity.

**Long-Term Implementation Considerations**

Here are long-term implementation strategies to ensure equity is integrated in data inputs and reporting and in the institutional practices and relationships that determine who receives care, when, and how. Together, they can establish a more comprehensive, transparent, and equitable Death with Dignity data infrastructure.

*Facilitate Cross-Agency Coordination to Identify System-Level Barriers*

Bring together internal stakeholders—including those responsible for licensing and regulating hospice centers—to examine how current operational systems and enrollment processes may contribute to racial, geographic, or diagnostic disparities in hospice access. This cross-agency collaboration can help identify how existing practices unintentionally affect patients' ability to access MAiD and clarify where policy or procedural changes are needed to reduce structural barriers.

*Strengthen Institutional Accountability through Recurring Forums*

Establish a series of recurring webinars, roundtables, or listening sessions hosted by DOH with hospice and palliative care administrators to discuss disparities, share disaggregated enrollment data, and identify solutions that align with culturally responsive care principles. These sessions should include data presentations, case studies, and strategies to improve eligible patients' access to end-of-life care information, including their rights under Death with Dignity.

### *Ensure Community Trust Through Sustained Engagement and Investment*

Recognize that building relationships with disproportionately impacted communities requires a long-term commitment. Allocate time, staff, and funding to nurture authentic partnerships with community-based organizations and care providers dedicated to underserved populations. These relationships can inform data interpretation, enhance patient trust, and collaboratively develop pathways for improving awareness and decision-making related to MAiD, without promoting any specific outcome.

### **Community & Stakeholder Feedback Summary**

Interviews revealed staffing shortages, inadequate training, and the necessity for more culturally competent services as significant challenges in hospice care. Stakeholders emphasized that the lack of equitable access to end-of-life care, including MAiD, undermines the intent of Death with Dignity and perpetuates disparities in how patients experience death and dying in Washington State.

### **Intended Outcomes**

- **Underserved and marginalized populations access hospice and palliative care at higher rates**, which improves equity in end-of-life care, including access to MAiD.
- **Community-based organizations conduct ongoing, trust-centered outreach**, resulting in more effective and culturally relevant engagement with historically excluded populations.
- **Patients and caregivers make earlier, better-informed decisions about hospice and MAiD** because they understand the available end-of-life options more clearly.

### **Addressing Barriers**

#### *Studying Disproportionality in Access to End-of-Life Care*

Collaborating with hospice and palliative care providers, community health centers, and academic partners to analyze disparities in enrollment based on race, ethnicity, diagnosis, geography, and LGBTQIA+ identity. This research will highlight where and why underrepresented populations are less likely to access hospice care, informing strategies to reduce barriers to equitable end-of-life options.

#### *Enhancing Community Partnerships and Cultural Relevance*

Building long-term, trusted relationships with community-based organizations and culturally specific providers to co-design outreach and education campaigns. These partnerships encourage early discussions about palliative care, reduce stigma, and ensure that information about end-of-life care is accurate, culturally relevant, and accessible.

*Aligning statewide hospice licensing and policy discussions*

Engage internal stakeholders—including those overseeing hospice licensing—to assess how existing regulatory frameworks may contribute to patient disproportionality. Convening hospice administrators through regular webinars can foster a shared understanding, highlight best practices, and support ongoing quality improvement across the system.

*Increasing Equity-Focused Training and Capacity Development*

Encouraging hospice centers to implement culturally competent care practices and improve staff training to engage underserved populations fosters more inclusive care environments, enhances patient-provider communication, and addresses institutional resistance that may hinder diverse participation in hospice services.

*Addressing Geographic and Diagnostic Disparities*

Studying how different types of diagnoses, their locations, and the local availability of hospice services affect patient access to MAiD and palliative care. The findings can inform targeted resource allocation and workforce support in rural or under-resourced communities and broaden care options for patients beyond cancer and cardiovascular disease.

**References & Supporting Documents**

Hospice Death with Dignity Form

Chapter 246-335 WAC

Chapter 70.127 RCW

### 3. ADVANCE DIRECTIVE PRACTICES

#### Recommendation – Expand Materials into Advance Directive Practices

##### **Purpose & Objectives**

To raise awareness and support informed decision-making, provide clear, educational information about Washington’s Death with Dignity Act in commonly used end-of-life materials, such as brochures, forms, and patient guides. This recommendation **does not aim to amend the Natural Death Act**, which includes provisions for advance directives. Instead, it seeks to include Death with Dignity information in related materials that patients typically encounter during end-of-life planning.

##### **Context**

Advance care planning tools, such as advance directives, POLST forms, and informational brochures, are vital resources that patients and providers use to document and communicate preferences regarding end-of-life care. These tools usually cover interventions like artificial hydration, ventilation, pain management, and voluntary stopping of eating and drinking (VSED). However, they often neglect to mention MAiD. This omission is significant, given that nearly 70% of individuals who access MAiD are enrolled in hospice, where advance care planning is a standard part of patient intake and care coordination.

The absence of standardized MAiD information in these planning materials restricts patients’ ability to understand and thoroughly evaluate all legally available end-of-life options fully. It may also lead to delays, last-minute decisions, and inequities in access, especially for those who depend on these tools to navigate care in complex or rapidly evolving medical situations.

##### **Key Policy Components**

MAiD information should be incorporated into advance directive forms and discussions to educate and inform patients about their end-of-life options. Specific components should include:

###### *Standardize Educational Content on MAiD in Advance Care Planning Materials*

Develop and incorporate clear, standardized educational language about MAiD—covering eligibility criteria, the process, and patient rights—into end-of-life planning materials used in clinical and community settings to enhance patient awareness and informed decision-making.

*Clarify Educational Purpose and Legal Distinctions*

Ensure all MAiD-related content is identified as educational information only, not part of legally binding advance directives, to avoid confusion and maintain compliance with existing legal frameworks.

*Promote Consistent Messaging Across Care Settings.*

Coordinate communication strategies among healthcare providers and care settings to align messaging on MAiD, supporting consistent and legally appropriate information dissemination throughout the patient care continuum.

**Short-Term Implementation Considerations**

- The DOH should lead or collaborate with partners to create culturally inclusive and accessible materials.
- Distribution should occur through healthcare providers, hospices, community health centers, public health channels, and community-based partners.
- Staff training should accompany the rollout to ensure respectful and accurate communication about MAiD in relevant end-of-life conversations.

**Long-Term Implementation Considerations**

Long-term implementation considerations could further embed equity not only in the content of end-of-life education but also in the systems, practices, and partnerships that influence who receives information about MAiD and under what conditions. Together, they promote a more consistent, inclusive, and transparent approach to educating patients about their rights under the Death with Dignity Act.

*Implementation Strategies to Identify and Reduce Disparities in Access*

To examine the disproportionality of illness, race, and ethnicity among patients in hospice and palliative care centers, these implementation strategies seek to uncover the systemic conditions that determine who receives end-of-life information and who is excluded. By embedding equity in the information provided and how and by whom it is delivered, these steps aim to dismantle structural barriers to MAiD awareness and access for historically marginalized communities. Collectively, they establish a stronger, more inclusive foundation for equitable participation under Death with Dignity.

*Facilitate Cross-Agency Coordination to Identify Structural Barriers*

Convene DOH staff, hospice regulators, and licensing entities to assess how current systems, such as enrollment procedures or facility policies, may create disparities in access to MAiD based on race, geography, or medical conditions. These collaborative assessments can inform

improvements to operational practices that unintentionally restrict equitable end-of-life care planning.

#### *Build Institutional Accountability Through Recurring Learning Forums*

Hold webinars or roundtables hosted by the DOH with hospice and palliative care leaders to review disaggregated data, highlight community case studies, and share actionable practices for integrating MAiD education into routine patient care. These sessions can foster shared responsibility for improving outreach and access.

#### *Invest in Sustained Community Partnerships for Long-Term Impact*

Allocate funding, time, and resources to build strong relationships with BIPOC-led organizations, LGBTQIA+ advocates, rural health providers, and disability justice groups. These partners are vital in co-developing messaging, reviewing materials, and ensuring respectful integration of MAiD education into broader end-of-life care systems, without promoting MAiD as a preferred outcome.

### **Community & Stakeholder Feedback Summary**

Stakeholders noted that patients often receive incomplete or inconsistent information about MAiD, particularly in hospice settings. Many emphasized the importance of early, culturally respectful discussions that treat MAiD as one of several legal options, rather than as a taboo or prohibited topic. Including MAiD in educational end-of-life materials was seen as a low-barrier, high-impact solution to promote awareness without advocacy.

### **Intended Outcomes**

- **Patients make earlier decisions about end-of-life care** due to a better understanding of options under Death with Dignity.
- **Practitioners adhere to Death with Dignity protocols more consistently and appropriately**, supported by transparent and standardized educational materials that outline legal rights and responsibilities.
- **Patients from various communities receive culturally relevant and consistent information** about end-of-life options, which reduces disparities in awareness and access to Death with Dignity services.

### **Addressing Barriers**

#### *Including MAiD in Advance Directive Materials*

Incorporating educational information about MAiD into advance directive forms and brochures ensures that patients understand all legal end-of-life options. This addition aligns MAiD with other common directives like DNR, POLST, VSED, and organ donation, promoting informed decision-making without positioning MAiD as an alternative outcome.

*Normalizing Conversations About End-of-Life Options*

Standardizing materials and procedures that include MAiD helps normalize the topic across healthcare settings. By incorporating this information early in the planning process, patients, especially those in hospice care, are better prepared to discuss their options with providers and family members before reaching a crisis point.

*Reducing Logistical and Informational Barriers*

Clear, accessible language and consistent formats in all end-of-life documentation help reduce legal and procedural confusion. Including key elements of Death with Dignity (i.e., informed consent, the ability to rescind, and required requests) makes the process more understandable and manageable for patients and caregivers.

*Expanding Equity Through Inclusive Communication*

Developing culturally sensitive, multilingual, and community-informed versions of advance directive materials enhances broader public understanding. This is particularly crucial for BIPOC, rural, LGBTQIA+, and disabled communities that encounter disproportionate barriers to MAiD access and information.

*Strengthening Provider Engagement and Consistency*

Partnering with the DOH or third-party organizations to implement these changes improves consistency across institutions. Regular webinars and training sessions for hospice administrators and providers can promote standardization, clarify legal responsibilities, and reduce institutional silence around MAiD.

**References & Supporting Documents**

Informed Decision (RCW 70.245)

Written and Oral Requests (RCW 70.245.090)

Right to Rescind Request (RCW 70.245.100)

## 4. EDUCATION, RESEARCH, AND TRAINING

### Recommendation – Expand Voluntary Continued Education

#### **Purpose & Objectives**

To ensure authorized healthcare professionals are informed, trained, and up-to-date on MAiD practices, including their rights and responsibilities under Death with Dignity, while addressing RCW 70.245.190 regarding practitioner participation and referral obligations.

#### **Context**

The 2020 Protecting Patient Care Act (ESHB 1608) protects healthcare staff and practitioners from termination for referring patients to MAiD services, including in faith-based or restricted healthcare systems. The Washington Medical Commission (WMC) requires 200 hours of Continuing Medical Education (CME) for MDs and 150 hours for DOs per licensure cycle.

#### **Key Policy Components**

Providing comprehensive, up-to-date education on Death with Dignity equips healthcare providers with the knowledge and confidence to navigate legal requirements and patient rights effectively. This helps reduce confusion, ensure informed patient care, support practitioner compliance, and lower barriers to access for those seeking MAiD services.

##### *Develop voluntary continuing medical education on Death with Dignity*

Partner with the WMC to fund and deliver voluntary CE courses focused on the legal framework, clinical duties, and patient rights under the Death with Dignity Act, enhancing provider knowledge and confidence in MAiD services.

##### *Emphasize Legal Protections and Provider Responsibilities*

Include education on referral protections under ESHB 1608 and clarify practitioner obligations under RCW 70.245.190 to ensure that providers understand their rights and responsibilities when discussing or participating in MAiD.

##### *Expand Access to Training in Underserved and Rural Areas*

Provide remote and accessible CE opportunities to reach clinicians in rural and under-resourced communities, addressing workforce shortages and reducing geographic disparities in MAiD access.

### *Integrate Culturally Responsive and Equity-Focused Training*

Incorporate cultural competency and equity principles into CE content to prepare providers for sensitive, respectful patient communication that acknowledges diverse values and helps reduce stigma surrounding MAiD.

### *Support Early and Informed End-of-Life Discussions*

Equip clinicians with tools and knowledge to initiate timely conversations about MAiD and other end-of-life options. This will help prevent crisis-driven requests and ensure patients can make informed decisions before their decision-making capacities decline.

## **Short-Term Implementation Considerations**

- The WMC, in collaboration with the DOH, should begin a public rulemaking process to develop voluntary CE focused on Death with Dignity. This could involve holding open workshops, stakeholder meetings, and public hearings, as required under RCW 18.71.017, standard WMC procedures, and other applicable provisions under the WAC.
- Funding mechanisms should be identified early, possibly through legislative appropriation or grants, to support third-party CE development and delivery. Resource allocation should prioritize access for rural, under-resourced, and culturally diverse provider populations.
- Stakeholder engagement should include professional medical associations, hospice administrators, primary care providers, legal experts, and community-based advocates to ensure that course content is clinically relevant, legally accurate, and addresses practitioners' concerns about institutional resistance or liability.
- CE providers should be evaluated for their capability to deliver culturally responsive, equity-informed content that transcends mere legal compliance, ultimately enhancing the quality of patient-provider communication at the end of life.

## **Long-Term Implementation Considerations**

Long-term implementation should aim to incorporate legal literacy, culturally responsive practices, and system-wide equity into Washington's clinician education framework. Ongoing training must assist practitioners in navigating the complexities of MAiD law while remaining responsive to evolving regulations, patient diversity, and ethical considerations.

### *Ensure Regulatory Adaptability and Evaluation Frameworks*

Given that rulemaking can be complex and subject to legal challenges, political shifts, or other changes, implementation should include mechanisms for regularly reviewing and revising CE content based on legal updates, the evolution of clinical practices, and feedback from frontline providers. Evaluation frameworks should be integrated from the outset, utilizing provider surveys, participation metrics, and relevant indicators to measure impact and guide improvements.

*Achieve Statewide Consistency Through Coordinated Rollout*

To prevent fragmented implementation, participating agencies should collaborate with major healthcare systems, continuing education accrediting organizations, and county public health agencies to ensure consistent messaging and participation. Special attention must be given to integration within faith-based, rural, and underserved clinical settings, where barriers to participation may be more significant.

*Strengthen Equity Through Targeted Outreach and Provider Support*

Sustained equity and the removal of barriers must extend beyond content and into practice. The rollout of CE should include support for providers working with patients historically excluded from MAiD conversations, such as individuals with disabilities, Black and Indigenous communities, and those with limited English proficiency. This includes funding for translation, interpretation, and co-design with culturally specific organizations.

*Build Long-Term Institutional Capacity and Trust*

Implementation should involve continuous learning opportunities, such as regional webinars, case-based learning groups, and mentoring networks, to reinforce legal updates, encourage peer learning, and foster institutional trust. These frameworks will help normalize informed MAiD discussions across diverse clinical environments and reduce stigma and fear among providers.

**Community & Stakeholder Feedback Summary**

Clinicians report a lack of knowledge about Death with Dignity, end-of-life options, and their legal responsibilities, with hospitals often not providing sufficient information. Voluntary continuing education can enhance provider confidence, improve understanding of evolving laws, and elevate patient care quality.

**Intended Outcomes**

- **Practitioners accurately inform patients of their end-of-life options** under Death with Dignity, leading to more timely and informed decision-making.
- **Providers demonstrate increased compliance with referral protections and legal responsibilities**, resulting in reduced institutional barriers and more consistent access to MAiD.
- **Healthcare systems implement and maintain MAiD-related education as part of continuing professional development**, ensuring sustained legal and ethical alignment across care settings.
- **Patients receive clearer, earlier, and more culturally responsive guidance** from trained clinicians, improving equity and reducing disparities in MAiD awareness and access

## **Addressing Barriers**

### *Improving Clinician Knowledge and Legal Clarity Around MAiD*

Partnering with the WMC to fund and deliver voluntary Continuing Education (CE) focused on Death with Dignity. This education will address legal responsibilities, patient rights, and clinical duties, helping providers navigate the MAiD process with greater clarity and confidence. Emphasizing referral protections under ESHB 1608 also reduces institutional barriers and enhances legal literacy among practitioners.

### *Expanding Provider Capacity in Underserved and Rural Regions*

Offering accessible, remote CE training ensures that clinicians in rural or under-resourced communities can enhance their capacity to support MAiD discussions and care. Expanding the geographic reach of trained providers helps reduce disparities in access caused by workforce shortages and uneven hospice service distribution.

### *Reducing Institutional Resistance Among Providers*

Voluntary education allows healthcare professionals to explore MAiD-related questions in a safe, non-punitive environment. Providers gain clarity about what they can and cannot do under current state law—especially in institutions with religious or philosophical objections—ultimately reducing fear, misinformation, and referral delays.

### *Embedding Equity in Training Content and Patient Communication*

Integrating culturally responsive approaches into continuing education curricula fosters more inclusive and respectful patient-provider interactions. Training aids providers in understanding how cultural and religious values may influence patients' end-of-life preferences and equips them with the skills to engage in nuanced conversations without judgment or coercion.

### *Supporting Earlier and More Informed End-of-Life Decision-Making*

CE prepares providers to initiate timely, informed discussions with patients and families about MAiD. This approach helps prevent crisis-driven decisions and late-stage requests, especially among individuals at risk of losing decision-making capacity due to progressive illness. Early conversations allow patients to consider all end-of-life options with dignity and clarity.

## **References & Supporting Documents**

CME requirements (WAC 246-919-430)

WMC authority to change, update, and add to Chapter 246-918 WAC– Physician Assistants and Chapter 246-919 WAC– Washington Medical Commission (RCW 18.71.017)

## 5. EQUITABLE ACCESS

### Recommendation – Increase Engagement with Historically Disadvantaged Communities

#### Purpose & Objectives

To address disparities in end-of-life care engagement and ensure equitable access to accurate, culturally relevant information, the Department of Health should support meaningful community engagement, outreach, and education efforts with historically disadvantaged communities. This initiative aims to empower patients with information, not to influence their end-of-life decisions, and to tackle systemic barriers to understanding the options available under Death with Dignity.

#### Context

National and local data indicate that communities of color, LGBTQIA+ individuals, people with disabilities, and other vulnerable populations are less likely to engage in advance care planning, hospice, or MAiD compared to their White counterparts. These disparities can stem from longstanding and well-documented mistrust in healthcare systems, rooted in histories of medical neglect, unethical experimentation, and systemic racism. This mistrust is further compounded by ongoing experiences of bias, unequal treatment, and a lack of providers who reflect or understand the cultural values of these communities.

In Washington, various religious, cultural, and spiritual traditions influence how individuals approach death and dying. Stigma, fear, and a lack of information also prevent many from discussing end-of-life options with their healthcare providers. Without culturally responsive education and community-based dialogue, these groups face systemic barriers to informed decision-making.

This recommendation directly addresses concerns raised by interested parties and vulnerable populations during the engagement process. It highlights the need for respectful, accessible, and community-led education on all end-of-life options, not just MAiD.

#### Key Policy Components

Engaging equitably with historically underserved and marginalized communities is crucial for building trust and raising awareness of end-of-life options. Partnering with trusted community organizations and messengers, addressing cultural misconceptions, and fostering open, respectful conversations about sensitive topics like grief and dignity help to break down deep-rooted barriers such as mistrust, stigma, and communication challenges. This foundation of equitable

engagement ensures fair access to information about Death with Dignity and empowers individuals to make informed decisions that reflect their values and cultural contexts.

*Plan and Fund Community Engagement with Health and Cultural Organizations.*

Coordinate with community health centers, culturally specific nonprofits, and public health partners to regularly engage communities about the legal end-of-life options available under Death with Dignity. These efforts aim to address cultural misconceptions and overcome communication barriers that hinder access.

*Co-Host Inclusive Community Dialogues on End-of-Life Topics*

Organize and support community-based events—including town halls, listening sessions, small group conversations, and educational webinars—that promote open dialogue about grief, spirituality, dignity, and patient rights, creating safe spaces for impactful discussions.

*Partner with Trusted Messengers to Develop Culturally Relevant Materials*

Collaborate with community leaders and trusted messengers to co-create educational resources in multiple languages and culturally appropriate formats, ensuring that outreach is community-centered, respectful, and non-directive to honor diverse values and perspectives.

## **Implementation Considerations**

Despite a history of medical harm and justified mistrust, equitable engagement with communities of color and other underserved groups remains essential. Government agencies must engage in active listening, build relationships based on respect, and work with trusted messengers to co-create culturally relevant materials. This ensures that all individuals, regardless of background, have access to clear and respectful information about their legal end-of-life options, including MAiD, and can make informed decisions that reflect their values.

## **Short-Term Implementation Considerations**

- Identify and establish partnerships with Federally Qualified Community Health Centers, culturally specific nonprofits, and public health agencies to enhance engagement efforts.
- Collaborate with trusted community messengers and cultural advisors to co-create multilingual, culturally appropriate educational materials that explain Death with Dignity.
- Organize initial community dialogues, including town halls, listening sessions, small group conversations, and webinars, in partnership with community organizations.
- Offer foundational training on culturally responsive communication to healthcare providers and community-based organizations.
- Secure dedicated funding to support outreach activities, develop materials, provide translation services, and enhance staffing capacity.

- Establish initial metrics and feedback processes to monitor engagement and collect community input.

## **Long-Term Implementation Considerations**

### *Deepen and Sustain Community Partnerships*

To ensure lasting impact, formal partnerships with community organizations should be continually nurtured and expanded. Regular collaboration will keep outreach efforts and educational materials culturally relevant and responsive to the evolving needs and perspectives of the community regarding end-of-life care.

### *Enhance Provider Capacity Through Ongoing Training*

Ongoing training programs must evolve to meet emerging challenges and equip healthcare providers and community organizations with the skills necessary for culturally responsive communication. This continuous capacity building fosters trust and enhances patient-provider dialogue in diverse settings.

### *Maintain Funding and Resource Commitment*

Sustained funding is essential for supporting translation, interpretation, outreach expansion, and staffing capacity, particularly in rural and underserved communities. Dedicated resources ensure that engagement activities and material updates can be delivered consistently over time.

### *Implement Robust Monitoring and Evaluation Frameworks*

Evaluation efforts should be refined to capture detailed data on community participation, barriers, and shifting needs. Continuous feedback mechanisms will guide ongoing improvements and help tailor outreach strategies to better serve marginalized populations.

### *Institutionalize Equity-Focused Engagement Practices*

Embedding culturally relevant engagement within the DOH and partner organizations' standard practices will build long-term trust and normalize open, informed discussions about end-of-life options. This institutionalization is essential for closing gaps in awareness and access among historically underserved communities.

DOH should consider partnering and expanding relationships with the **28 Federally Qualified Community Health Clinics (FQHCs)**, which are nonprofit public entities that serve medically underserved populations:

1. Columbia Basin Health Association
2. Columbia Valley Community Health
3. Community Health Association of Spokane
4. Community Health Care
5. Community Health Center of Snohomish County
6. Community Health of Central Washington
7. Cowlitz Family Health Center
8. Family Health Centers
9. HealthPoint
10. International Community Health Services
11. Lake Roosevelt Community Health Centers
12. Mattawa Community Medical Clinic
13. Moses Lake Community Health Center
14. The NATIVE Project
15. Neighborcare Health
16. NEW Health
17. North Olympic Healthcare Network
18. One Community Health
19. Peninsula Community Health Services
20. Public Health - Seattle & King County
21. Sea Mar Community Health Centers
22. Seattle Indian Health Board
23. Seattle Roots Community Health
24. Tri-Cities Community Health
25. Unity Care NW
26. Valley View Health Center
27. Yakima Neighborhood Health Services
28. Yakima Valley Farm Workers Clinic

### **Community & Stakeholder Feedback Summary**

Community members and stakeholders emphasized that a lack of trust in the healthcare system, compounded by institutional racism and cultural stigma, continues to hinder participation in hospice care, advance directives, and end-of-life planning. Many expressed the need for more trustworthy, community-based education in their own languages, not to promote any option, but to clarify the available choices and how to access them. The state's FQHCs were specifically mentioned as potential allies in this effort, given their history of serving these populations with cultural responsiveness and care.

### **Intended Outcomes**

- **A better understanding of all available care options**, including MAiD, enables individuals to make earlier, values-aligned end-of-life decisions.
- **Equitable health outcomes improve** as trust and collaboration strengthen between community-based organizations and government agencies.
- **Communities utilize culturally relevant materials and communication strategies** that reflect their spiritual, religious, and cultural values without bias towards any specific end-of-life option.
- **Underserved populations actively engage in advance care planning**, supported by clear, legally precise, and accessible information.

## **Addressing Barriers**

### *Strengthening Engagement with Historically Marginalized Communities*

Conducting regular outreach and engagement with community health centers, culturally specific organizations, and public health partners to foster early, values-based conversations about end-of-life care. These efforts address cultural stigma, clarify misconceptions, and create space for diverse perspectives on grief, spirituality, and MAiD, ensuring that the information is relevant and trusted.

### *Partnering with Federally Qualified Health Centers to Expand Access*

Collaborating with Washington's 28 Federally Qualified Health Centers to co-develop and distribute end-of-life education and MAiD information. These partnerships tap into trusted networks already serving medically underserved populations, especially in rural areas, enhancing access to linguistically and culturally responsive materials and discussions.

### *Reducing Cultural and Religious Stigma Around MAiD*

Hosting quarterly roundtables, webinars, and town halls to explore the intersection of cultural beliefs, spiritual values, and end-of-life care. These spaces normalize conversations about death, foster culturally rooted dialogue, and reduce the stigma that prevents patients and providers from openly discussing MAiD as part of informed care planning.

### *Improving Representation in Public Health Communications*

Collaborating with BIPOC, LGBTQIA+, and disability-led organizations to review and refine end-of-life materials. This ensures that the content reflects community values, is presented in preferred languages, and is delivered through trusted messengers, resulting in greater awareness and more equitable access to MAiD education.

### *Building Sustainable, Trust-Based Infrastructure for Outreach*

Investing in long-term relationships with community-based partners supports ongoing engagement beyond one-time events. This approach ensures that education efforts are not only responsive to current needs but also embedded in broader systems of care, promoting continuous dialogue and co-learning across institutions and communities.

## **References & Supporting Documents**

Washington Community Health Centers

## 6. INFRASTRUCTURE AND OPERATIONS

### Recommendation – Incentivize Practitioners to Offer Space for MAiD

#### **Purpose & Objectives**

To reduce structural barriers that limit access to MAiD by incentivizing the increase and availability of physical spaces where services can be safely and legally accessed, especially in rural and lower-income areas, through voluntary, community-centered approaches.

#### **Context**

Although Washington has a well-established end-of-life care infrastructure, access to MAiD remains uneven. Rural and underserved areas often face compounded challenges, including limited hospice capacity, provider shortages, and a lack of suitable spaces to support individuals choosing MAiD outside the home. While many patients still prefer to die at home, feedback from the community and providers shows that some patients, particularly those who are housing insecure, socially isolated, or navigating complex family dynamics, may seek alternative, non-hospital settings for end-of-life care.

Currently, very few spaces exist where MAiD can be safely administered outside of private homes. Practitioners often must coordinate care off-site or across multiple facilities, leading to delays, confusion, and logistical burdens for patients and families. This situation can be particularly challenging for communities already facing disparities in access to care. This recommendation is not intended to promote any individual end-of-life decision but to explore whether voluntary participation by healthcare entities can help reduce geographic and logistical inequities that currently limit meaningful access to a full range of legal end-of-life options.

#### **Key Policy Components**

##### *Explore Voluntary Incentive Models for MAiD Facility Participation*

Identify and evaluate voluntary incentive strategies to assist healthcare providers, especially in rural and underserved areas, who decide to establish or retrofit facilities for MAiD services. These models should build upon existing best practices from statewide programs and ensure that they do not influence provider or patient decisions regarding participation.

##### *Offset Costs Through Targeted Administrative and Facility Support*

Design incentives to help healthcare organizations tackle cost barriers, such as staffing, administrative overhead, or improvements to physical space, that currently limit their ability to

enhance MAiD access. Support must remain voluntary and aligned with legal requirements that protect provider choice and autonomy.

#### *Adapt Grant and Technical Assistance Programs to Support Equitable Access*

Utilize and modify established state-level funding mechanisms, such as Medicaid Quality Incentives and Health IT incentives, to provide grants, technical assistance, or expedited licensing pathways for eligible providers. These supports should enhance infrastructure in a way that promotes geographic equity without dictating clinical or personal decisions concerning end-of-life care.

#### **Short-Term Implementation Considerations**

- Launch targeted pilot programs in rural, isolated, and low-income communities, partnering with FQHCs, community clinics, and end-of-life providers.
- Coordinate across state agencies (Health Care Authority, Department of Health, Office of Rural Health) to align incentives and streamline implementation while protecting provider autonomy.
- Engage healthcare providers and community members early and continuously to ensure ethical, culturally aware, and relevant pilots.
- Provide technical assistance, administrative support, and startup funding to pilot sites, including help with facility upgrades and staff training.
- Define clear evaluation criteria and equity metrics, disaggregated by geography, race/ethnicity, and income, to measure pilot success and progress in reducing disparities.

#### **Long-Term Implementation Considerations**

Addressing physical access barriers to MAiD services, particularly in rural and underserved communities, necessitates a thoughtful, phased approach based on collaboration, cultural awareness, and respect for provider and patient autonomy. These implementation considerations are crucial to ensure that incentives effectively reduce logistical and structural obstacles without imposing pressure on care decisions.

By piloting initiatives with community-based partners, coordinating across agencies, and embedding continuous feedback along with equity-focused evaluation, we can establish a sustainable and accessible MAiD infrastructure that respects diverse values and expands end-of-life options for all Washingtonians. This approach balances innovation with ethical responsibility and helps close persistent gaps in service availability, fostering greater health equity across geographic and demographic lines.

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#### *Scale Equitably Based on Community Readiness and Demand*

After conducting a pilot evaluation, expand the voluntary incentive program to additional sites based on demonstrated need, interest, and capacity. Geographic equity should guide the scaling process, ensuring that communities with a history of underinvestment are prioritized.

#### *Sustain Interagency Collaboration for Effective Governance*

Maintain long-term coordination among state agencies to align funding, regulatory guidance, and support systems. This ongoing collaboration ensures consistent messaging, prevents duplication, and strengthens the overall infrastructure for MAiD service delivery.

#### *Ensure Incentives Do Not Influence Clinical or Personal Decisions*

As the program scales, it is important to maintain a clear distinction between incentivizing infrastructure and preserving individual autonomy. Safeguards should be integrated into all communications and program designs to emphasize that participation remains voluntary for both providers and patients.

#### *Normalize Facility-Based MAiD Options Without Mandate*

Over time, the availability of neutral, community-based spaces can become a normalized part of end-of-life care, especially for patients who lack safe or preferred options at home. However, this availability must be presented as one of many choices, rather than a preferred or promoted outcome.

#### *Embed Community Voice and Oversight*

Long-term implementation should involve a standing advisory group composed of healthcare professionals, community leaders, and equity advocates to guide program refinement. Continued community involvement ensures the initiative remains rooted in ethical practices and real-world experience.

### **Community & Stakeholder Feedback Summary**

Stakeholders emphasized the lack of appropriate spaces to administer MAiD, often requiring providers to travel significant distances or coordinate care outside their regular sites of practice. This adds strain for both patients and clinicians, particularly in regions with limited hospice availability. Community advocates noted that expanding access to physical space could alleviate these barriers, without pressuring individuals or providers, and may provide culturally appropriate options for those unable or unwilling to die at home.

### **Intended Outcomes**

- **Expanded geographic access to MAiD-related services**, particularly for individuals in rural, low-income, or underserved areas who currently face limited physical options.

- **Reduced logistical delays and burdens** in coordinating end-of-life care, resulting in smoother, more timely access to legal options for eligible patients.
- **Improved equity in end-of-life care** through support for facilities that choose to participate voluntarily, without overriding conscience protections or legal limitations.
- **Strengthened partnerships with trusted, community-based care organizations**, ensuring that space availability is rooted in local need and respectful of cultural context.

## **Addressing Barriers**

### *Expanding Physical Access to MAiD Services*

Providing incentives for healthcare facilities, particularly in rural and lower-income areas, to establish dedicated MAiD spaces directly enhances physical access for patients who prefer or need a non-home setting. This addresses a critical gap for families lacking suitable home environments or seeking alternative sites due to cultural or logistical reasons.

### *Reducing Geographic and Institutional Inequities*

Piloting MAiD incentives in under-resourced areas addresses structural access barriers, including provider shortages, geographic isolation, and institutional prohibitions. This promotes more equitable service availability and aligns with Washington's broader health equity goals.

### *Respecting Provider Autonomy While Encouraging Participation*

Incentives are designed to be voluntary and significant enough to offset administrative burdens, respecting the legal rights of providers under RCW 70.245.190 while encouraging participation among willing facilities. This approach alleviates provider hesitation without infringing on conscience-based refusals.

### *Strengthening Community-Based Partnerships*

This strategy bolsters capacity in trusted, accessible environments by emphasizing incentives for community health centers and other local care providers. It fosters relationships with underserved communities and enhances continuity of care for patients exploring end-of-life options.

### *Improving Care Coordination and Patient Experience*

Designated MAiD facilities can streamline complex processes, such as medication administration, paperwork, and family support, thereby reducing delays, emotional strain, and last-minute crisis planning. Enhanced infrastructure facilitates smoother, more dignified end-of-life experiences.

### *Informing Future Statewide Policy Through Pilots*

Launching incentive pilots in selected regions allows the state to assess operational feasibility, uptake, and patient/provider outcomes. These insights can inform future legislation and funding strategies, ensuring that any broader rollout is guided by data and focused on equity.

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**References & Supporting Documents**

Hospice Death with Dignity Act Form

Basis for prohibiting health care providers from participation (RCW 70.245.190)

Health Care Authority – Hospital Reimbursements

## **APPENDIX**

### **Survey Questions**

#### **Intro/Background (Who we are, purpose of survey)**

- Who We Are: (Uncommon Bridges, contracted with DoH)
- Our role: addressing “barriers for more equitable access to the Death with Dignity end-of-life care option available to Washingtonians with terminal conditions.”
- We are soliciting feedback on barriers to accessing MAiD, discovering any unintended consequences and any challenges and vulnerabilities in the provision of services under the Death with Dignity since the passage of SB 5179. We are also instructed to focus on vulnerable populations’ experiences, such as people at risk of adverse or undesired public health outcomes because of factors like socioeconomic status, household characteristics, literacy, language, disability, identity, racial and ethnic minority status, location, housing type, or transportation access.

#### **What is SB 5179?**

This law went into effect on 7/23/2023.

- SB 5179 made some changes to the old Death With Dignity Act (Initiative 1000, passed 2008) with the express intent to make it MORE equitable and easy to access, including:
- EXPANDED types of medical practitioners who can legally administer the medication.
- REDUCED waiting period burdens.
- MINIMIZED barriers and red-tape on medical practitioners.
- INCREASED transparency required from hospitals and hospice care regarding internal policies.

#### **Questions for ALL volunteer groups**

- County of residence
- Type of volunteer
- Years of volunteer service at End of Life WA
- Name and Email are optional and will only be used for follow-up questions and invitations to participate in a focus group.
- In your opinion, is the Death with Dignity Act being accessed equitably? Please explain why or why not. [LONG ANSWER]
- What are the most common barriers to access that your clients experience? Check all that apply, and write in others if they do not appear on this list. [MULTIPLE CHOICE + ADDITIONAL FIELDS]
- Lack of transportation

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- Economic difficulties
- Language barrier
- Legal or liability concerns
- Confusing rules and requirements
- Long wait times
- Systemic barriers in the medical setting
- Unsupportive medical, hospital, hospice, or long-term care facility staff
- Lack of clear prognosis or 6-month life expectancy
- Unsupportive family or cultural/religious stigma
- Lack of social supports such as friends or family to help facilitate the process/coordinate services
- Other
- Have you observed any POSITIVE changes in clients' experiences since SB 5179 went into effect last August? [Y/N]
- If you answered yes, please explain. [LONG ANSWER]
- Have you observed any NEGATIVE changes since SB 5179 went into effect? [Y/N]
- If you answered yes, please explain. [LONG ANSWER]
- Have there been any "unintended consequences" (good, bad, or neutral) as a result of the passage of SB 5179? [Y/N]
- If you answered yes, please explain. [LONG ANSWER]
- Please provide any additional thoughts or comments that you think would be helpful. [LONG ANSWER]

### Questions for specific volunteer categories

- Ambassadors
- When you are out in the community sharing information about MAiD, who are the most common groups of people that you present to? [SHORT ANSWER]
- What are the most frequent questions you get about Death with Dignity or MAiD? [SHORT ANSWER]
- Client Advisors
- At what stage in their end-of-life planning do people usually contact End of Life WA? [SHORT ANSWER]
- Have you encountered clients who don't have a place to administer their MAiD? [YES/NO]
- If so, please share more. [SHORT ANSWER]

- How often do you have to spend a significant amount of time troubleshooting and problem-solving around barriers that clients face when seeking MAiD? [MULTIPLE CHOICE: NOT OFTEN, SOMETIMES, FREQUENTLY, EVERY TIME]
- Phone Volunteers
- Please describe the types of calls you most typically receive (note: we have not defined the “type” of call for you - please answer in whatever way feels most descriptive and honest based on your unique volunteer experience). [LONG ANSWER]
- At what stage in their end-of-life planning do people typically first reach out to End of Life WA? [SHORT ANSWER]
- What are the most frequent challenges that you hear about on calls? [LONG ANSWER]
- What are the most frequent questions you get from those who call? [LONG ANSWER]
- Medical Care Practitioners
- Have you ever participated in a case where a formal psychiatric evaluation was needed? [Y/N]
- When a formal psychiatric evaluation process is indicated, are there any barriers to obtaining this evaluation? If so, please describe. [SHORT ANSWER]
- How do you feel the process of obtaining a psychiatric evaluation is working? [MULTIPLE CHOICE: WORKING EFFECTIVELY, UNSURE, NOT WORKING EFFECTIVELY]
- Please elaborate on your answer [LONG ANSWER]
- Do you feel that the mental health professionals completing psychiatric evaluations for MAiD patients have adequate training and systems in place? [Y/N]
- In your medical training, were you ever trained on Death with Dignity or MAiD? [Y/N]
- If yes, please share more [LONG ANSWER]
- In your medical career, is Death with Dignity or MAiD ever discussed in the workplace or is continuing education or professional development offered on the subject? [Y/N]
- If yes, please share more [LONG ANSWER]
- Have you ever engaged with someone at any stage of the MAiD process (whether they completed the process or not) who has an intellectual or developmental disability or cognitive impairment? [Y/N]
- Have you ever engaged with someone at any stage of the MAiD process (whether they completed the process or not) who has a mental health condition that might impact their decision-making on this subject? [Y/N]
- What are your thoughts on people with mental health, developmental/intellectual disabilities, or cognitive impairment accessing this service? [LONG ANSWER]

### Interview Questions

- In your opinion, are there any barriers to accessing MAiD?
- If so, what are those barriers?
- Are there any barriers that pose a specific equity concern (ex, for people with disabilities, rural communities, low-income people, or communities of color)?
- Are you aware of the changes made by SB 5179 that broaden accessibility and reduce barriers to accessing MAiD?
- Since SB 5179 went into effect in July of 2023, have you observed any instances of these changes having either a positive or negative impact on a patient's experience?
- In a perfect world, what would fair, just, and equitable access to Death with Dignity look like to you?
- Who are the other stakeholders in this space that we should talk to?
- We have focus groups drafted from input from other stakeholders, but we can't host all these focus groups – which would you prioritize?
  - People with Terminal Illness
  - Medical Care Practitioners
  - Practitioners who don't participate in MAiD
  - Chaplains who do not participate in MAiD
  - Chaplains who do participate in MAiD
  - Rural via end-of-life care
  - Hospice, Social Workers, Palliative Care

## End Notes

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- i Mayo Clinic: Living wills and advance directives for medical decisions: <https://www.mayoclinic.org/healthy-lifestyle/consumer-health/in-depth/living-wills/art-20046303>
- ii Washington State Department of Health, "Frequently Asked Questions About Death with Dignity," accessed March 13, 2025, <https://doh.wa.gov/data-and-statistical-reports/health-statistics/death-dignity-act/frequently-asked-questions-about-death-dignity> .
- iii Death with Dignity, "Death with Dignity: A Glossary of Terms for Discussion." <https://deathwithdignity.org/resources/assisted-dying-glossary/>
- iv *ibid.*
- v National Institute of Aging
- vi "Definition of Informed Consent - NCI Dictionary of Cancer Terms," Cancer.gov, n.d., <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/informed-consent>.
- vii Compassion and Choices, "My End-of-Life Decisions: An Advance Planning Guide and Toolkit."
- viii Washington State Department of Health: <https://doh.wa.gov/you-and-your-family/illness-and-disease-z/portable-orders-life-sustaining-treatment-polst>
- ix Compassion and Choices, "My End-of-Life Decisions: An Advance Planning Guide and Toolkit," Compassion and Choices, September 26, 2024, <https://compassionandchoices.org/wp-content/uploads/2024/09/compassion-choices-my-end-of-life-decisions-guide-fillable-final-9-26-24.pdf>.
- x *Ibid*
- xi *Ibid.*
- xii National Institutes of Health, "Changes Coming to NIH Applications and Peer Review in 2025 | Grants & Funding," National Institutes of Health: Grants and Funding, September 25, 2024, accessed March 11, 2025. <https://grants.nih.gov/policy-and-compliance/changes-coming-2025>.
- xiii Compassion & Choices, "Medical Aid in Dying Utilization Report," Compassion & Choices, March 2025.
- xiv DOH adheres to the small numbers related to data collection, analysis, and use to promote good professional practice among staff involved in assessment activities within the department and in local jurisdictions in Washington. See full standards: Guidelines for Working Small Numbers
- xv Luai Al Rabadi et al., "Trends in Medical Aid in Dying in Oregon and Washington," JAMA Network Open 2, no. 8 (August 9, 2019): e198648.
- xvi The Washington Death with Dignity Act, Chapter 70.245 RCW, Washington State Legislature (2024)
- xvii See: <https://doh.wa.gov/data-and-statistical-reports/health-statistics/death-dignity-act>

xviii Washington State Health Services Research Project. See:

<https://ofm.wa.gov/sites/default/files/public/dataresearch/researchbriefs/brief105.pdf>

xix Nina Shapiro, "Your health care may be limited by Catholic directives. Now WA lawmakers are stepping in," *The Seattle Times*, February 8, 2023.

xx 2024 estimate per DOH Website, <http://doh.wa.gov/licenses-permits-and-certificates/facilities-z/hospice-agencies/policies>

xxi End of Life Washington, Hospice Center Map, <http://endoflifewa.org/hospice-map/>

xxii For example, A Sacred Passing, <http://www.asacredpassing.org>

xxiii White and Wicclair, "Navigating Clinicians' Conscience-Based Refusals to Provide Lawful Medical Care." p. 1465

xxiv Tess Solomon et al., "Bigger and Bigger: The Growth of Catholic Health Systems," *Community Catalyst* (Community Catalyst, February 8, 2020).

xxv Cain, C. L., & McCleskey, S. (2019). Expanded definitions of the 'good death'? Race, ethnicity and medical aid in dying. *Sociology of health & illness*, 41(6), 1175–1191. <https://doi.org/10.1111/1467-9566.12903>

xxvi Washington Death with Dignity Data (2009-2023). Available from:

<https://www.doh.wa.gov/YouandYourFamily/IllnessandDisease/DeathwithDignityAct/DeathwithDignityData>

xxvii Uncommon Bridges worked with DOH to compensate participants who completed surveys, participated in interviews, or engaged in virtual interviews. Compensation rates were \$25 for a completed survey and \$150 for a one-hour interview.