Scoping Decision Makers' Needs for a National Palliative Care Atlas for Ireland

Technical Research Brief

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Executive Summary

Introduction

Palliative care in Ireland has evolved from religious hospice care in the 19th century to an integrated, state-supported service across the acute and community healthcare sectors. Launching its first national policy in 2001, Ireland was one of the first countries in the world to recognise palliative care as a medical specialty. Despite progress, inequities in access persist, with rural areas facing shortages in infrastructure and services. In September 2024, the Minister for Health launched a new National Adult Palliative Care Policy. The new policy aims to ensure universal access to high-quality, needs-based palliative and end-of-life (EoL) care, regardless of geography or ability to pay, in line with the country's broader health reform agenda. As part of the effort to reduce inequalities and strengthen the evidence base for more efficient and effective care planning and delivery, the new policy recommends development of an Atlas of Variation for palliative and EoL care. An Atlas of Variation is a visual mapping tool that uses small area analysis to identify warranted and unwarranted variations in aspects of palliative care geographically and across population groups.

Aims and Methods

This study set out to scope decisionmakers' needs for an atlas of variation for palliative and EoL care in Ireland. A multi-methods study, the research team first carried out a scoping review of the international literature, followed by semi-structured interviews with 17 key informants working across the palliative/EoL care system in Ireland. Key informants were purposively recruited for their expertise in one or more of the following areas: palliative care service model/service delivery, health data infrastructure, and service provision. Interview data was analysed using thematic analysis methodology. Desk research to map data availability within Ireland complemented the review and the qualitative interviews.

Atlases of palliative and end of life care from other jurisdictions: reviewing the literature

The literature review focused on identifying existing atlases of palliative and end-of-life (EoL) care worldwide. The research aimed to understand the diverse methodologies employed in these atlases and the processes involved in their development and implementation. It involved a narrative scoping review of both peer-reviewed articles and grey literature. Key findings from the review include:

1. **Development of International Atlases**: Numerous atlases have emerged globally, with some focusing on cross-national comparisons and others on specific countries. The Dartmouth Atlas Project, initiated in the 1970s, pioneered the use of small area analysis

methodology for analysing variation in healthcare access and outcomes. The ATLANTES Global Observatory of Palliative Care has developed multiple editions of atlases for regions such as Europe, Latin America, and Africa, collaborating with local stakeholders to collect data through surveys and existing databases.

2. **Comparative Analysis**: Atlases like the Global Atlas of Palliative Care and the Atlas of Variation for Palliative and EoL Care in England utilise large datasets to illustrate care provision across regions. However, they differ significantly in methodology. While true Atlases of Variation rely on small area analysis and administrative data, other atlases adopt broader methods that include qualitative and quantitative data. A detailed comparison of seven exemplar atlases highlight diversity in geographic coverage, governance, format, and data collection methods. While some atlases have narrow focuses due to the availability of robust data (e.g., the Dartmouth and England atlases), others with broader aims have included a wider range of domains and indicators.
3. **Facilitators and Barriers**: Limited literature exists on the development processes of these atlases. However, the review identified collaborative approaches as crucial for success, with notable examples being the Eastern Mediterranean Atlas and the Canadian Atlas, which adjusted their methodologies to fit local contexts while maintaining a set of core domains and indicators.
4. **Implications for Ireland**: While few true Atlases of Variation have been developed, the seven exemplar atlases provide a variety of approaches that can serve as a guide for development of an atlas in the Irish context. Decisions regarding the vision for a palliative and EoL care atlas in Ireland will hinge on the defined objectives of the atlas, existing data availability, and available resources.

Interviews with key informants on development of an atlas of palliative/EoL care for Ireland

The interviews with key informants provided valuable insights into the palliative and end-of-life (EoL) care landscape in Ireland, and participants' priorities in terms of the kind of information an atlas for Ireland should capture. Analysis of interview data identified five key thematic areas:

1. **Data Priorities:**

   Mapping Existing Capacity: A consensus exists on the necessity to map data regarding existing palliative care capacity across Ireland's six health regions, including both specialist and generalist care settings.

   Demographics and Needs: An understanding of population demographics and needs is vital for effective long-term planning.

Service Types: The atlas should capture both specialist and non-specialist palliative care, acknowledging that much of the care occurs outside formal settings and may not be recognized as palliative care by providers.
Data Gaps: Many interviewees expressed concerns about the lack of comprehensive data to inform decisions on resource allocation and investment.

2. **Integration and Harmonisation**

Siloed Data Systems: Although substantial data is collected, integration across different datasets remains a significant challenge. Underinvestment in healthcare IT systems has led to fragmented data, hindering the ability to link patient records across care settings.

Unique Identifier: The absence of a unique patient identifier (Individual Health Identifier) poses barriers to data integration.
Health System Alignment: The atlas's geographic units should align with the six HSE Health Regions and other planned sub-national structures to ensure relevant service mapping.

3. **Resources and Capacity**

Necessary Resources: Interviewees acknowledged that while resources could be found, the aims of the atlas need to be clearly defined to determine the necessary resources.
Data Culture: While acknowledging progress has been made, interviewees felt that there is still work to be done to foster a culture of using data to enhance service delivery, particularly among service providers.
Skills Availability: There are sufficient skills available within the public sector and academia to support the development and maintenance of the atlas.

4. **Governance**

Oversight: There was no consensus on which institution should take on governance of an atlas for Ireland, but most agreed that a collaborative approach was called for.
Ensuring Atlas is Actionable: The governing body must not only manage data but also ensure that the information is actionable and integrated into ongoing health system operations.

5. **Stakeholder Engagement**

Collaboration: Engaging stakeholders effectively can foster collaboration across various sectors, bringing together providers, policymakers, advocacy groups, and researchers.
A Community of Practice: Establishing a 'community of practice' around the atlas may enhance its effectiveness and promote shared goals.
Managing Expectations: It is crucial to manage stakeholder expectations to avoid mission creep and ensure focused data collection efforts.

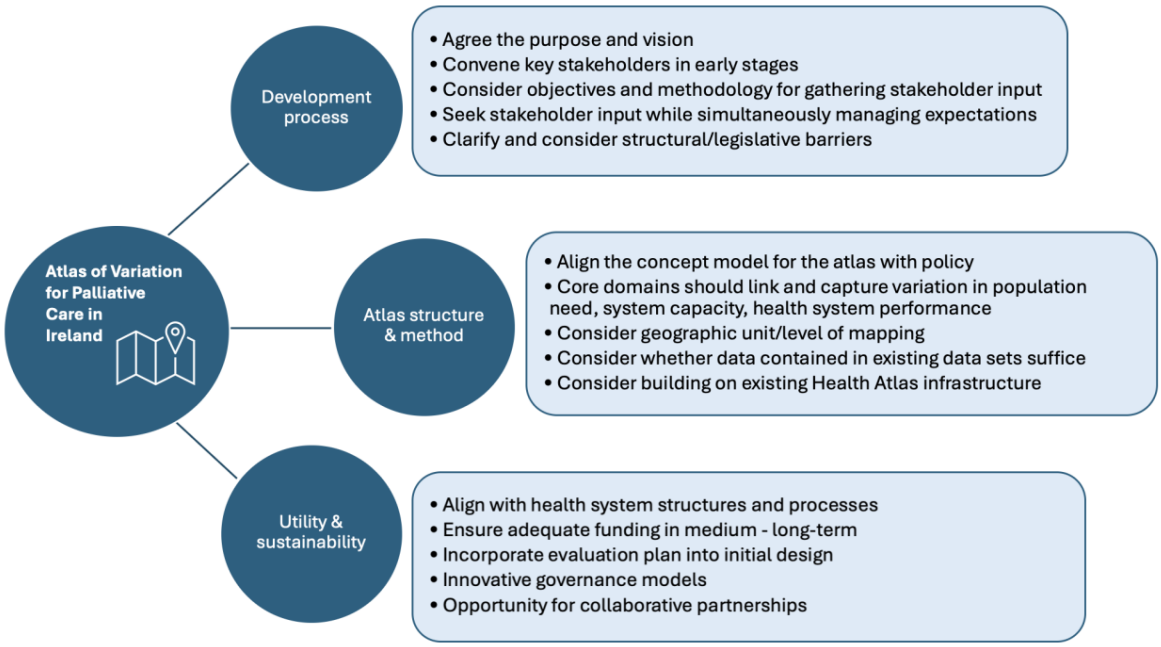
Mapping the data

A series of tables mapping the domains and indicators in each of the seven exemplar atlases to relevant Irish data sources are provided in Appendix B. While the mapping exercise has identified relevant data sets in each of the domain areas, the challenge moving forward will be to formulate a cohesive set of domains and indicators to map variation in palliative and EoL care in the Irish context, and to link the data drawn from the various sources to populate the indicators formulated.

Tying it all together – Emerging learnings for the development of an atlas of palliative and EoL care for Ireland

The findings from the review of the literature, the interviews with key informants, and from the mapping of international and Irish data on palliative/EoL care offer several important learnings to consider in the next stage of developing an Irish atlas of variation for palliative and EoL care. The learnings, presented in Figure 1 below, are grouped into three broad areas intended to facilitate discussions around how to approach: 1) the development process of an atlas, 2) the structure and methodology it will adopt, and 3) the utility or impact and sustainability of the atlas as a tool for decisionmakers.

Figure 1. Emerging learnings for next phase of work



1 Introduction

1.1 Palliative care in international context

Palliative and end of life care is "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (WHO, 2020). Palliative care thus involves an inherently interdisciplinary approach to care for people with life limiting illness and their loved ones, integrating pain and symptom management, goals-of-care conversations with patients, their families, and the attending care professionals and improved communication among same, as well as psychosocial and spiritual support. While historically grounded in care provided to individuals at the end of life, especially to people receiving terminal cancer diagnoses, in recent decades, the value of providing palliative care to people in the early stages of treatment for life limiting illnesses in combination with other treatments and supports has been recognised and the model of care expanded (Pastrana et al., 2008; Seymour, 2012; WHO, 2014).

Access to palliative care is considered an essential component of universal healthcare by the World Health Organization (WHO, 2020): "Palliative care needs to be provided in accordance with the principles of universal health coverage. All people, irrespective of income, disease type or age, should have access to a nationally determined set of basic health services, including palliative care. Financial and social protection systems need to take into account the human right to palliative care for poor and marginalized population groups" (WHO, 2020). As such, ensuring access to palliative care is also integral to the achievement of UN Sustainable Development Goal (SDG) addressing Universal Health Coverage (SDG 3.8). In 2014, a World Health Assembly resolution (Resolution WHA67.19) aimed at strengthening palliative care as a component of comprehensive health and social care delivered across the lifecourse, stated that including equitable access to palliative care is an ethical imperative: "it is the ethical duty of health care professionals to alleviate pain and suffering, whether physical, psychosocial or spiritual, irrespective of whether the disease or condition can be cured" (WHO, 2014).

1.2 Palliative care in Ireland

Palliative care has a long history in Ireland, originating in the establishment of hospices by religious orders as places for care of the dying in the late 19th century (HSE, 2009). Voluntary organisations continue to provide most of the specialist palliative care, though their services are increasingly integrated into mainstream health service provision across the acute and community healthcare sectors. In early 2024, the government redesignated the remaining four voluntary

specialist palliative care units with Section 39 designation (contracted by the HSE to provide ancillary or similar services) to Section 38 organisations (directly engaged by the HSE to provide services on its behalf), signaling recognition of the need for more sustainable public sector investment in adult specialist palliative care services (Department of Health, 2023). This decision brought all voluntary specialist palliative care units into alignment as Section 38 organisations. Work to implement this decision by government is ongoing at time of writing.

In 1995, Ireland became only the second country in Europe to recognise palliative medicine as a distinct medical specialty, and in 2001, became one of the first countries in the world to publish a national policy on palliative care (Department of Health and Children, 2001). The report of the National Advisory Committee on Palliative Care (NACPC) outlined what would be needed in terms of public investment and service expansion to develop palliative care and hospice services in the medium term. The report's recommendations were subsequently adopted as government policy (May et al, 2014).

Importantly, the NACPC report calls for universal palliative care access based on need. It distinguishes between three levels of palliative care, structured by level of specialisation:

> **Level one** – palliative care approach: all healthcare professionals should be aware of, and appropriately apply, palliative care principles. Many patients with progressive disease will have their care needs met comprehensively and satisfactorily without referral to specialist palliative care units or personnel.
>
> **Level two** – generalist palliative care: healthcare professionals who are not engaged full time in palliative care but have some relevant training and experience.
>
> **Level three** – specialist palliative care: healthcare professionals whose core activity is providing palliative care.

Specialist palliative care units, commonly referred to as hospices, act as hubs for specialist palliative care delivery in their respective geographic regions (Table 1). A fully developed specialist palliative care unit comprises in-patient unit beds, day hospice, out-patient and bereavement services. It serves as the base for the community palliative care team and for palliative care education and research activities for the region. The specialist palliative care unit coordinates with acute specialist palliative care services provided in hospitals in the same region through the consultants in palliative medicine who are contracted to provide services in both specialist palliative care units and hospital settings. All three levels of palliative care should be accessible to all individuals with palliative care needs. Specialist and generalist services should be offered in all healthcare settings, including inpatient and outpatient services in clinics and acute

general hospitals, palliative day care facilities, and in the community, whether in the patient's home, in local hospitals, or in long-term residential care facilities, such as nursing homes.

Table 1 Specialist palliative care units, by location and type of provider

Specialist Palliative Care Unit (SPCU)	County	Provider type
Donegal Hospice	Donegal	HSE
North West Hospice	Sligo	HSE
Galway Hospice	Galway	Voluntary (Section 38 organisation)
Mayo Hospice	Mayo	Voluntary (Section 38 organisation)
Milford Care Centre	Limerick	Voluntary (Section 38 organisation)
Marymount Hospice	Cork	Voluntary (Section 38 organisation)
Kerry SPC Inpatient Unit	Kerry	HSE
South East Palliative Care Centre	Waterford	HSE
Our Lady's Hospice Blackrock	Dublin	Voluntary (Section 38 organisation)
Our Lady's Hospice Wicklow	Wicklow	Voluntary (Section 38 organisation)
Our Lady's Hospice Harold's Cross	Dublin	Voluntary (Section 38 organisation)
Saint Brigid's Hospice	Kildare	HSE
St. Francis Hospice Blanchardstown	Dublin	Voluntary (Section 38 organisation)
St. Francis Hospice Raheny	Dublin	Voluntary (Section 38 organisation)
LauraLynn Children's Hospice	Dublin	Voluntary (Section 39 organisation)

Sources: Compiled by the authors based on their knowledge of the sector, SPCU websites, and HSE documents.

Since implementation of the 2001 policy, significant advancements have been achieved in terms of the development and delivery of palliative care services. Nonetheless, gaps in service provision persist, leading to inequities in access. Specialist services were historically concentrated in the most populous cities of Dublin, Cork and Limerick, and these urban areas and the regions surrounding them have more advanced infrastructure and provision, while less populated areas continue to have poorer infrastructure, with residents of certain areas lacking a specialist palliative care unit in the vicinity. In the meantime, the need for palliative care services continues to grow as the population ages and needs become more complex (Kane et al., 2015; May et al., 2019). The percentage of the people dying in Ireland that will require palliative care is projected to increase by 68-84% between 2016 to 2046 (May et al., 2019).

The 2020 Programme for Government committed to the development and publication of a new palliative care policy for adults, which would serve as an update to the policy introduced in 2001 (Department of the Taoiseach, 2020; Department of Health and Children, 2001). A Steering Group to develop the new policy, comprised of 17 members including health professionals, patient

representatives, representatives of voluntary organisations, senior HSE management and senior departmental officials was established by the Minister for Health in May 2022 (Department of Health, 2022). In September 2024, the new National Adult Palliative Care Policy was launched by the Minister for Health (Department of Health, 2024).

The aim of the 2024 policy is to ensure that people with a life-limiting illness and their loved ones have access to integrated, high-quality palliative care services, irrespective of ability to pay and place of residence/geographic location. The policy's aim of universal, needs-based, integrated palliative care is aligned with the broader Sláintecare programme of health and social reforms, which has the achievement of universal healthcare in Ireland (Houses of the Oireachtas, 2017; Department of Health, 2021) as its overarching goal.

One of a series of recommendations included in the 2024 policy centers on ensuring equity in access to high-quality palliative care services. An action under this recommendation is development of an Atlas of Variation for palliative and end of life care to support the identification and analysis of inequities in access to and outcomes of palliative care service provision.

1.3 Aims and methods

The aim of this research project was to explore decisionmakers' needs for development and implementation of an Atlas of Variation for Palliative and End of Life Care in Ireland. More specifically, the project objectives were to:

1. Identify and describe excellent examples of Atlases of Palliative and End of Life Care development and implementation across a select range of countries;
2. Establish data availability in Ireland to inform a future atlas development;
3. Examine data relevance and availability issues from the perspective of individuals with insider knowledge of the sector through semi-structured qualitative interviews;
4. Develop high-level recommendations to support development and implementation of the Atlas of Variation for Palliative and End of Life Care in Ireland.

The research employed a multi-method approach. A review of international evidence was first undertaken to identify examples of atlases of variation for palliative care developed in other jurisdictions and to understand the process of designing and implementing atlases in other countries. Based on the review, a mapping of data domains and indicators in international atlases was undertaken, followed by a mapping of the availability of comparable data in Ireland. The review of international evidence and data mapping of Irish data formed the basis for 17 semi-structured interviews with key informants, including individuals involved in palliative care

policy/service delivery model, representatives of palliative care provider organisations, and data specialists with expertise in health information systems/data infrastructure related to palliative care in the Irish context. The interviews were carried out with the aim of gaining participants' views on data priorities, barriers and facilitators, and feasibility of development of an atlas of variation for palliative care for Ireland.

The research project's Advisory Group, co-chaired by Paul Kavanagh, Consultant in Public Health Medicine at the National Health Intelligence Unit, HSE, and the project's Lead Knowledge User, and Maurice Dillon, National Lead for Palliative Care, HSE, and consisting of eight members selected for their expertise as clinicians, researchers, and managers with experience in providing, organising or evaluating palliative care services, provided integral guidance and feedback at three key junctures over the course of the project.

Ethics approval for the interview portion of the research project was sought and granted by the Centre for Health Policy and Management Research Ethics Committee, Trinity College Dublin, in March 2024.

1.4 Structure of the brief

Following the introduction, Section Two of this technical brief gives an overview of atlases of palliative/EoL care developed for other regions and countries. Section Three presents findings from the interviews with key informants, followed by Section Four, which reflects upon the availability of data in Ireland mapped onto the domains and indicators included in the exemplar atlases identified through the literature review. In the fifth and final section, key takeaway messages and learnings from the research project are discussed.

2 Atlases of palliative and end of life care from other jurisdictions: reviewing the literature

2.1 Aims of the review and methods

The research team carried out a literature review to identify atlases of palliative and end of life care developed in other countries and regions. An atlas of palliative/EoL care is defined in this context as a graphical representation, in combination with textual description/explanation, of the landscape of palliative and end of life care provision in a jurisdiction. The aim of the review was to learn about different methodological approaches used in international atlases, and to glean insights about the development and implementation processes themselves. The narrative scoping review included both peer-reviewed academic papers as well as grey literature. The databases PubMed, Medline and Google Scholar were searched using relevant keywords to identify primarily peer reviewed papers. A search of national and regional government and the

websites of palliative care organisations/associations was carried out to identify reports and other outputs relevant to the aims of the review. While atlases have been developed to map different aspects of healthcare provision and utilisation, this review included only those atlases developed to map palliative and EoL care given the research project's objectives of establishing the data domains and indicators of palliative/EoL care used in internationally developed atlases and mapping the availability of comparable data for Ireland.

2.2 Atlases developed in other countries and regions, their objectives and approaches, data domains included

Atlas of variation methodology was pioneered by researchers at the Dartmouth Atlas Project in the US who set out to investigate variations in healthcare service provision, utilisation, and patient outcomes in the 1970s (Wennberg & Gittelsohn, 1973). The key to the Dartmouth Atlas of Health Care, which remains an active study to this day, is the application of small area analysis, i.e. where the unit of analyses are small, specific geographic areas, to identify variations in access to healthcare (Bronner & Goodman, 2022). Explaining the significance of this methodology, Bronner and Goodman state, "When the population of the state is grouped into 13 geographically distinct hospital catchment, or service, areas, variations in health care are often more apparent than they are when the population is divided into fewer, larger areas" (Wennberg & Gittelsohn, 1973: 1102). Wennberg's use of small area analysis was made possible by an innovation in the state of Vermont's (home to Dartmouth College and the Dartmouth Atlas Project) health data infrastructure in 1969, whereby a data system monitoring health care delivery at the local town level was introduced. In subsequent years, the Dartmouth Atlas Project's application of small area analysis would expand beyond the state of Vermont to include all 50 US states, enabled by the research group's access to the claims database of the national health insurance scheme for people 65 years of age and older known as Medicare. The Medicare insurance claims database captures patient-level healthcare utilisation and outcomes data for the majority of Americans over the age of 65. As the Medicare system expanded and changed, the Dartmouth Atlas' units of analysis changed as well, ultimately mapping variation at the state, county, hospital referral region (HRR), and hospital service area (HAS) levels.

Since development of the Dartmouth Atlas, which includes a series of indicators or 'rates' on end-of life care as part of the larger atlas, a number of other atlases of palliative and EoL care have been published internationally. These include atlases that set out to compare data on palliative and end of life care globally, across multiple countries in a given region, and a more limited number that map aspects of palliative/EoL care within an individual country. In one instance, in Canada, where healthcare—including palliative care—planning and delivery is decentralised to each of the country's ten provinces, separate atlases at province level and national level are planned and are in various stages of completion at time of writing.

Over the past decade, researchers at the ATLANTES Global Observatory of Palliative Care, a group based at the University of Navarra in Spain, and a partner centre of the WHO Collaborating Centre for the Global Monitoring of Palliative Care Development since 2022, have collaborated with regional associations of palliative care and country level stakeholders to develop two editions of the European Atlas of Palliative Care (2013, 2019), two editions of the Latin American Atlas of Palliative Care (2013, 2020), two editions of the Atlas of Palliative Care in the Eastern Mediterranean Region (2017, 2021), and one edition of the Atlas of Palliative Care in Africa (2017). The ATLANTES group's approach includes broad stakeholder consultation and collaboration on the selection of domains and indicators for inclusion in each atlas, and in the data collection process, which involves the deployment of a survey instrument to country experts and officials. Data from existing international and country level databases are also consulted as part of the process. A noted limitation of this approach is the reliance on individual experts and the challenge involved in verifying the information they provide (Tripodoro et al., 2024).

The Worldwide Hospice Palliative Care Association, in collaboration with the WHO, published its second edition of the Global Atlas of Palliative Care in 2020 (WHPCA, 2014; 2020), in which it compares development of palliative and hospice care services across 183 countries worldwide. The Global Atlas relies on existing international and country data sets, as well as published studies for its data.

Atlases of palliative/EoL care have been developed or are in the process of being developed at country level for the US (Dartmouth Atlas Project, 2024, Goodman et al., 2011), Canada[1] (Pallium, 2023), England (Public Health England, 2018), and Scotland (Inbadas et al., 2016). Notably, developers of the Canadian and Scottish atlases use the template developed by the ATLANTES Global Observatory as a starting point for selecting which domains to cover, adapting it to meet their respective atlas' aims and country contexts. The England Atlas most closely follows the approach of the Dartmouth Atlas, using the availability of and access to large scale, administrative population-based healthcare data to guide the selection of its domains/indicators and populate them (PHE, 2018).

In reviewing the literature, an important definitional and methodological distinction emerges between atlases and atlases *of variation*. Both involve the graphic representation of aspects of palliative care in the form of geographical maps in either static (e.g. a published report) or digital, interactive format. The distinction lies in the aim or focus of the atlas, in the information it is

[1] Canada's healthcare system is highly decentralised, with responsibility for care organisation and delivery relegated to the country's ten provinces. As a result, each province has a distinct system of health and social care. For this reason, while a national atlas is in development, Pallium first completed a pilot the atlas for palliative care in the province of Ontario (more precisely, in the Central East region of Ontario), and at time of writing is in the process of finalising atlases for the provinces of Alberta and British Columbia.

intended to capture and convey, and in its selection and formulation of indicators. The atlas of variation methodology was first developed in the US context at a time of increasing policy focus and interest on inequalities in access to health care across different population groups, service providers, and regional/local health care organisations across the country, with the aim of reducing inequities in access, inequalities considered unjust and avoidable. An atlas of variation uses a whole of population approach to identify variations—both warranted and unwarranted—in how (palliative care) resources are distributed, used, and potentially in individual outcomes, using small area analysis (Wennberg & Gittelsohn, 1973). To achieve its aims, atlases of variation tend to employ large administrative data sets to populate quantitative indicators that are regularly updated and fed into an online, interactive atlas. In our review, only the US atlas (Dartmouth Atlas Project, 2024) and the England atlas (Public Health England, 2018) can be considered true atlases of variation. The relative dearth of this type of atlas is likely due to a combination of factors including lack of availability of suitable data, lack of access to available data due to restrictions related to data ownership and privacy, and ultimately, lack of resourcing and political will.

In the absence of individual/population level administrative data, other atlases have adopted a broader interpretation of the term variation, using larger geographical units of analysis, and combining multiple existing data sets and bespoke data collection instruments to compare aspects of palliative/EoL care in their respective jurisdictions. The regional atlases compiled by the ATLANTES research group at the University of Navarra, the global atlas published by the Worldwide Hospice Palliative Care Alliance (WHPCA), as well as the Scottish atlas—using the ATLANTES research group's approach—involve significant additional data collection via a survey instrument, combine quantitative and qualitative data, and are published as static reports rather than in the more dynamic, digital format. The Canadian atlas(es) take a hybrid approach: while they do not incorporate population level service utilization or health data, they map variation across domains and quantitative and qualitative indicators down to the county level, presented in an online, interactive tool.

Considering the advanced level of development of palliative care services in Ireland and the country's status as a High-Income Country (HIC), seven exemplar atlases were selected for their relevance to the Irish context and are analysed in depth in the following sections. An overview of the seven selected 'exemplar' atlases is provided in Table 2. As the table indicates, there is significant diversity across the seven atlases in terms of geographic coverage, developer/governance model, format, and data collection methods.

Table 2 Exemplar atlases of palliative/EoL care at-a-glance

Atlas	Jurisdiction	Developer	Format	Data collection approach
1. Dartmouth Atlas of Health Care: End-of-Life Inpatient Care	US	The Dartmouth Institute for Health Policy and Clinical Practice, Dartmouth College (*Academic*)	Publicly accessible online tool; analyses published in reports and peer-reviewed journal articles regularly since 1994 Online tool (active since 1994): https://data.dartmouthatlas.org/end-of-life-care/	Existing data from the Medicare health insurance claims database (eligible individuals are 65 years of age and older)
2. Atlas of Variation for Palliative and End of Life Care in England	England	The National End of Life Care Intelligence Network (NEoLCIN), Public Health England (*Governmental*)	Publicly accessible online tool; 2018 synthesis report Online tool (active since 2018): http://tools.england.nhs.uk/images/EOLCatlas/atlas.html 2018 Publication: https://fingertips.phe.org.uk/profile/atlas-of-variation/supporting-information/themed-atlases	Existing data collated from multiple datasets
3. Canadian Atlas of Palliative Care: Ontario Edition	Central East Region of the Ontario Province, Canada	Pallium Canada in collaboration with The Dr. Joshua Shadd — Pallium Canada Research Hub, McMaster University (*Non-profit; Academic*)	Publicly accessible online tool (active since 2023): https://storymaps.arcgis.com/stories/005b1ceddda74b4f9193cabe6e6df952	Novel survey instrument
4. Scottish Atlas of Palliative Care	Scotland	The University of Glasgow (*Academic*)	Synthesis report published 2016: https://www.gla.ac.uk/media/Media_486122_smxx.pdf	Novel survey instrument
5. Global Atlas of Palliative Care	183 countries, grouped by WHO region	World Hospice Palliative Care Alliance (WHPCA) in collaboration with WHO (*Non-profit; International Org.)*	Synthesis report published 2020: https://cdn.who.int/media/docs/default-source/integrated-health-services-(ihs)/csy/palliative-care/whpca_global_atlas_p5_digital_final.pdf?sfvrsn=1b54423a_3	Existing data collated from multiple datasets and international research studies
6. EAPC Atlas of Palliative Care in Europe	51 European countries	European Association for Palliative Care in collaboration with International Association for Hospice and Palliative Care and ATLANTES research programme, University of Navarra (*Non-profit; Academic*)	Synthesis reports published 2013, 2019 2013 Publication: https://view.pagetiger.com/crmjfen/1 2019 Publication: https://view.pagetiger.com/gwirld/1	Novel survey instrument; Existing data collated from multiple data sets
7. Atlas of Palliative Care in Latin America [*Atlas de cuidados paliativos en Latinoamérica*]	17 Latin American countries	Latin American Association of Palliative Care [*Asociación Latinoamericana de Cuidados Paliativos*] in collaboration with International Association for Hospice and Palliative Care and ATLANTES research programme, University of Navarra (*Non-profit; Academic*)	Synthesis reports published 2012, 2020 2012 Publication: https://cuidadospaliativos.org/uploads/2013/12/Atlas%20of%20Palliative%20Care%20in%20Latin%20America.pdf 2020 Publication: https://www.iccp-portal.org/system/files/resources/AtlasLatam2020.2Edicion.pdf	Novel survey instrument; Existing data collated from multiple data sets

Source: Authors' own compilation.

There is also considerable diversity in terms of the domains and indicators included in the seven atlases. Table 3 provides a comparison of the domains included in each atlas, while detailed mapping of the domains and indicators included in each atlas are presented in Appendix B. In each instance, the type of information captured by each of the atlases follows on from its stated aims and objectives, which in turn are influenced by matters of feasibility, foremost the availability and accessibility of data, and resourcing. Appendix A provides detailed information on the aims and structures of each of the seven exemplar atlases. While all atlases have an explicit (or implicit) policy aim, i.e. to monitor and improve access to quality palliative and end of life care, in some cases, advocacy is also an explicit aim, such as in the case of the Global Atlas of Palliative Care (see Appendix A, Table A2).

Table 3 Comparison of international atlases, by domains

Domain	Dartmouth Atlas	England Atlas of Variation	Canada Atlas (Ontario)	Scotland Atlas	Global Atlas	Europe Atlas	Latin America Atlas
Demographics	✓	✓	✓	✓		✓	✓
SES context		✓		✓		✓	✓
Policy			✓	✓	✓	✓	✓
Need for care		✓	✓		✓	✓	
Services			✓	✓	✓	✓	✓
Service use	✓	✓	✓		✓	✓	
Training			✓	✓	✓	✓	✓
Workforce					✓	✓	
Resources			✓		✓	✓	✓
Other				✓	✓	✓	

Source: Authors' own compilation.

It is apparent from comparison of domains and indicators across the exemplar atlases that where population level data exists and where the aim of the atlas is to explicitly capture variation at a granular level—as for example in the cases of the Dartmouth Atlas in the US and the England Atlas—the breadth of the domains covered tends to be narrower, more focussed (see Table 3).

Where such population level data is not readily available or accessible, and where the aim of the atlas is broader, extending to advocacy and/or to providing a more holistic view of the palliative care system, the scope of domains included is more expansive.

2.3 Information from other jurisdictions on the development process, facilitators/barriers

A review of the literature revealed limited published material on the atlas development process in terms of facilitators and barriers and beyond documenting the methodological approach and process. A notable exception is a peer-reviewed article published by Sánchez-Cárdenas et al (2022) detailing the process for the atlas for palliative care for the Eastern Mediterranean Region. The process was highly collaborative, involving the WHO and the ATLANTES Global Observatory of Palliative Care. A network of qualified informants was formed to gather reliable data on palliative care across 12 out of 22 countries in the WHO Eastern Mediterranean Region. Experts were selected based on their knowledge of national palliative care and WHO/EMRO endorsement. In countries like Bahrain, Djibouti, and Yemen, no experts were identified.

The ATLANTES Global Observatory of Palliative Care collaborated with regional experts to establish baseline indicators for monitoring palliative care progress. This involved a two-round Delphi consensus process where experts rated indicators based on relevance and feasibility, with a few new indicators being proposed. A regional survey using the agreed indicators was conducted, with experts consulting national authorities for accurate data. Feedback was gathered from experts and WHO units to ensure alignment with the monitoring objectives. One of the main challenges identified by Sánchez-Cárdenas et al (2022) is establishing a sustainable monitoring system using the indicators. Despite this, the process has demonstrated significant efforts by stakeholders to coordinate and improve access to palliative care. Leveraging regional and international resources and involving various stakeholders proved to be important facilitators.

The research team supplemented the literature review by reaching out to the developers of the England Atlas and the Canadian Atlas to ask if they would be willing to share their experiences and reflect on facilitators and barriers encountered during the respective development processes. A senior team member of the Canadian research group responded positively and shared their experience in a virtual meeting with the research team. Given the size of Canada and the highly decentralised structure of its healthcare system, the team is taking a province-by-province approach, starting with Ontario, British Columbia, and Alberta, with a countrywide atlas to follow. The Canadian atlas(es) have aligned their methodology with the approach developed by the ATLANTES Global Palliative Care Observatory, however, for planning at national and sub-national levels, the atlases for the Canadian provinces needed to be more detailed than international (regional) atlases, such as the Europe Atlas, but not overly detailed. The team retained domains and indicators developed by the ATLANTES Observatory, adding additional

ones to fit the local Canadian provincial contexts and meet specific local needs and aims, which included both advocacy and service improvement goals. The team member highlighted that governance of the atlas sits with Pallium Canada, a non-governmental, social enterprise organisation, which allows for independence while embracing collaborations with the provincial government agencies, provider organisations, and other local, provincial, and national stakeholders and funders.

2.4 Key messages

The review of the literature reveals that a limited number of atlases of variation for palliative and EoL care have been developed internationally to date. Seven exemplar atlases were identified in the course of the review, and of these, three are regional atlases comparing select domains/indicators of palliative/EoL care across countries, while four are country atlases mapping domains/indicators at sub-national level. The regional atlases, together with the Scotland atlas and the Canadian atlas, are not technically speaking atlases of variation in that they do not employ small area analysis methodology to analyse variation at population level using large, linked administrative data sets. Instead, the latter atlases provide a more holistic comparative overview of the state of palliative/EoL care across the respective jurisdictions, covering domains such as existence of palliative care policies and programmes, workforce training, voluntary and community resources, among others. Data availability and accessibility in a given jurisdiction, as well as differences in the aims, vision, and ultimately in the need or purpose the various exemplar atlases have been developed to fulfill, are key factors in determining each atlas's approach. There is an apparent trade-off between the depth and breadth of data an atlas includes. Ultimately, the approach chosen for a future atlas for Ireland will depend on decisions around what precisely the atlas is intended to accomplish, and influenced by data availability and accessibility, and available capacity and resources. The exemplar atlases speak to the different approaches possible to developing an atlas for palliative and EoL care and the importance of context specific considerations.

3 Interviews with key informants on development of an atlas of palliative/EoL care for Ireland

Building on learnings from the international atlases identified in the course of the literature review, interviews with key informants with insider knowledge of the palliative/EoL care landscape in Ireland were conducted to explore what the development of an atlas for Ireland might involve. Interview participants were asked for their views on the type of data and indicators they would want to see captured in an atlas, the availability of and gaps in existing data, and the feasibility of developing such a tool.

3.1 Methodology

Semi-structured interviews with a diverse group of 17 key informants (see Table 4 below) were carried out between May and July 2024. Key informants were purposively recruited for their expertise variably in palliative/EoL care service model/service delivery, health data infrastructure, and service provision. Particular attention was paid to ensuring disciplinary and geographic diversity among participants recruited in the service provider category. Key informants in this category were drawn from nursing, medical and social care disciplines and from five counties across the country, encompassing both urban and rural areas. Members of the project's Advisory Group suggested individuals with the desired expertise to participate, and the Group's co-chairs, including the project's Lead Knowledge User, acted as gatekeepers, making the initial contact to potential interview participants on behalf of the research team in most cases.

Table 4 Key informants, by area of expertise and personnel type

Interview No.	Type of expertise	Organisation
01	Service model/delivery	Health Service Executive (HSE)
02	Data infrastructure	Department of Health (DoH)
03	Data infrastructure	DoH
04	Data infrastructure	Health Information and Quality Authority (HIQA)
05	Data infrastructure	HIQA
06	Service model/delivery	All-Ireland Institute of Hospice and Palliative Care (AIIHPC)
07	Data infrastructure	HSE
08	Service model/delivery	DoH
09	Service model/delivery	HSE
10	Service provider; Service model/delivery	HSE
11	Data infrastructure	HSE
12	International expert in integrated care; Service model/delivery	World Health Organization, formerly HSE
13	Data infrastructure	HSE
14	Service provider	Voluntary Hospice Group
15	Service provider	Nursing Homes Ireland
16	Service provider	RCSI Hospital Group
17	Service model/delivery; Service provider	Ireland East Hospital Group

The interview topic guide included questions on interview participants' priorities in terms of data to include in an Irish atlas, perceived gaps in national data, the feasibility of developing and implementing an atlas of palliative/EoL care for Ireland, and the resources and capacity that such an initiative would require (see Appendix C, Document C4 for a copy of the interview topic guide).

With the participants' consent, interviews were audio recorded and transcribed using Otter.ai software. The interview transcripts were cleaned and uploaded into NVivo data management software for analysis. The research team applied thematic analysis methodology to analyse the interview data, using a combination of inductive and deductive codes (Braun & Clarke, 2006). The following section presents the findings emerging from the interviews with key informants, by thematic area.

3.2 Findings by thematic area

The interviews with key informants provide rich insight into the palliative and EoL care landscape in Ireland and its attendant data infrastructure, and what, from their diverse vantage points, would be important information to capture in an atlas. Five key thematic areas emerged from the analysis of the interview data addressing: general consensus on broad **data priorities** with a need for systematic process(es) to agree and define atlas domains and indicators going forward; the **integration and harmonisation** of palliative care data, and relatedly and by extension, the integration of palliative/EoL care services; the **resources and capacity** needed and available; **governance** of a future atlas; and the role of **stakeholder engagement** in the atlas development process. The following sections provide a more detailed summary of the main points raised by key informants under each thematic area.

3.2.1 Data priorities

There was consensus among interview participants that, broadly speaking, mapping data on existing capacity within the system across the HSE's six health regions should be a core element of an atlas. More specifically, data on specialist palliative care service capacity (provided by specialist palliative care in-patient units, community specialist palliative care teams, and specialist palliative care teams in acute hospital settings); and generalist palliative care (provided across primary, acute, and long-term care settings). One interviewee emphasised the importance of clearly delineating the different care settings where specialist and general palliative/EoL care is provided across the country, information that is not necessarily available even to those working within the system:

> *[…] at times you wouldn't know whether, if somebody said that their loved one may have passed away in a certain place, whether they had actually died in an acute hospital or whether they had died in a step-down facility that was related to it."* [05, Data infrastructure expert, HIQA]

Asked how, in the absence of comprehensive data on existing capacity within the system, decisions are taken regarding where additional investment and resources are needed, another interviewee stated that decisions are still in part being made on the basis of local lobbying, rather than being wholly driven by evidence grounded in data.

Beyond providing information on the 'the state of play' in terms of service capacity and service availability, several key informants imagined an atlas having what one interviewee referred to as discrete 'buckets of data', consisting of: population demographics, population needs data for palliative care, which could be juxtaposed with service capacity/availability, system performance, and care recipient outcomes. The same interviewee highlighted the vital link between understanding population demographics and need, and effective long-term care planning:

> *"…really understanding the population, the numbers, the age profile, the deprivation profile, […] the blend of ethnicities, different things like that are hugely powerful in terms of health service planning. So, for example, the scale of the population, their age profile, their deprivation profile, could be useful in terms of then determining how much palliative care resource is required in an area."* [7, Data infrastructure, HSE]

While the focus of the atlas was acknowledged to be on mapping variation in specialist palliative care, several interviewees stressed the importance of ensuring that an atlas capture data on both specialist and general palliative care provision; and on the specialist as well as non-specialist palliative care workforce. Interviewees stressed that failing to capture non-specialist palliative care provided by nursing home care professionals, general practitioners (GPs), and public health nurses (PHNs) results in a significant underestimation of palliative care capacity, utilisation, and ultimately access. It is also a missed opportunity to integrate non-specialist providers into the palliative/EoL care eco-system and acknowledge the important palliative care they provide as part of their wider care work. One interviewee noted that nursing home care professionals and other general palliative care providers often do not recognise that they are in fact providing palliative care because they are "just not able to label it", to record and report it [15, Service provider, NHI]. At the same time, interviewees noted the difficulty in meaningfully measuring, quantifying non-specialist provision of general palliative care.

Interviewees expressed that in an ideal world, an Irish atlas would include data that capture the transition between different types and levels of health care services - crucially, between community-based services and acute hospital services. A significant barrier to achieving this is the absence of population level data linked across care settings. An interviewee working at regions level said:

> *"Well, ideally, I would like something that would focus on patients and not episodes of care. There's a big difference between two people having 20 admissions and one person having 40 and you can't currently pull that out with a lot of the datasets that we have. So having proper linked records would be a great idea so that you can see what's happening at an individual level."* (11, Data infrastructure expert, HSE)

Other categories of data prioritised by key informants interviewed include:

- Indicators of **health system performance** that **capture the patient experience of care**, such as timely access to palliative care across different care settings;
- Data on geographic variations and variations across care settings in **patients living with chronic and progressive fatal illnesses** who are **seen by a specialist palliative care provider**;
- Data on palliative **care provided by *private* hospitals, community, and residential care providers** as, at present, little to no information is available concerning patients with palliative/EoL care who seek care outside the public system;
- Inclusion of **palliative/EoL care for children** as one aspect or domain, while recognising that within the current model of care, services for children and related data collection is distinct from specialist palliative care for adults.

Some key informants expressed uncertainty about the type of data that an atlas of palliative/EoL care for Ireland should include. Others held strong views on the categories or domains of data an atlas should include, with a few interviewees providing specific indicators they would want captured. While there was substantial overlap among the key informants in terms of the high-level categories of data to include, presented in the section above, additional consensus-building activities would need to be undertaken in order to agree the aim(s) of the atlas, and following from that, the domains and the formulation of indicators.

3.2.2 Integration and harmonisation

Interviewees mostly agreed that while important gaps exist, substantial data are being collected on palliative care. The challenge lies in the integration of existing data sets, and in pulling specific variables from different data sets, which are often under the ownership of different governmental agencies.

GDPR and other data sharing legislation can add significantly to timelines and resources. Following on from the GDPR, in 2019 the government introduced the Data Sharing and Governance Act, which brings in extra stipulations for government bodies sharing sensitive personal data. And for government bodies that do not explicitly identify health research

(conducting surveys) as part of their mandate or remit, a further requirement is that a public consultation lasting six weeks be organised to ensure that the public is informed of the purpose of the proposed data sharing. The public consultations are organised centrally through the Office of the Government Chief Information Officer (OGCIO).

> *"… if you have to comply with the data sharing and governance Act, which is this additional piece of legislation, you have to not only use a very extensive data sharing agreement templates, but it has to go into public consultation, so that the public are aware of us and that they know and they can comment on this as well."* [04, Data infrastructure expert, HIQA]

While the personal health data of every living individual is covered by GDPR, it does not cover the health data of deceased individuals. Processing the data of deceased individuals falls under the Data Sharing and Governance Act. While not necessarily a barrier, in developing an atlas, consideration should be given to the different types of data being processed and shared across governmental and non-governmental institutions, what the regulatory requirements for data sharing and protection are at each stage, and how these will impact on timelines, if at all.

According to the majority of key informants, a significant barrier is the lack of investment historically in the country's healthcare IT systems, resulting in the siloed, un-linked nature of the many IT systems operating within the healthcare sector, and the continued use of paper-based records in some care settings. One interviewee spoke of the challenge in accessing WTE data for the palliative/EoL care workforce for monitoring and planning purposes, sharing that they had to chase down accurate figures over the phone for one service area in particular because they were not being inputted into the system. Another interviewee pointed out the difficulty in linking data across care settings in which palliative/EoL care is provided, stating:

> *"…the fact of the matter is…each of the different components of the service are counted in silos, whether that can be community inpatient unit or outpatients because we don't have that unique identifier going across. We're essentially double counting [the] number of people accessing hospital-based palliative care, probably a good few of them are the same number accessing community palliative care, but we absolutely have no way of knowing."* [17, Service model/delivery expert, Ireland East Hospital Group]

The lack of implementation or use of a unique patient identifier—known as the Individual Health Identifier (IHI) number[2] in Ireland—was seen by more than one interviewee as a major barrier to integrating data.

Data quality was another key issue raised related to the integration/harmonisation of data for the purposes of an atlas. In the reporting of Hospital In-Patient Enquiry (HIPE) data, where two new data quality fields for each indicator were introduced as part of the 2024 HIPE Data Dictionary, some of the newer indicators added, of great relevance to palliative/EoL care (e.g. when a specialist palliative care team attended a patient during their episode of care), are in the development phase and the data reported are likely to be incomplete and of unknown quality. Data quality issues were also reported related to data on place and cause of death.

A critical point raised by several interviewees is that the geographic unit(s) of analysis used in an atlas for Ireland must be aligned with the new HSE Health Regions, and if possible, with the sub-national structures planned, specifically, the Integrated Health Areas (IHAs), Community Health Networks (CHNs), and Community Specialist Teams (CSTs). One interviewee, a service provider and expert in service model/delivery was of the view that the integrated health areas (IHAs), which are intended to bring together the different service types and care settings within the HSE Health Regions, could prove to be the most useful level to disaggregate data to map variation:

> "*A Community Health Network is probably the lowest level you'd go to that actually would be useful, and obviously our integrated health areas still haven't been announced, but that's probably a more functional organisational level as well because that's really where we're going to pull together all the different components of the health services as such, so certainly have them at integrated health area level."* [10, Service provider & Service model/delivery expert, HSE]

Multiple interviewees highlighted that the fragmented nature of palliative care data is indicative of the fragmentation of the palliative care and wider health and social care system, where until recently, acute hospital groups were not necessarily aligned geographically or administratively with outpatient care services. The new HSE health regions are working to address this issue, but some interviewees maintained that many of the details are still being worked out at the sub-

[2] Following enactment of the 2014 Health Identifiers Act, residents in Ireland with a Personal Public Services Number (PPSN) were assigned an Individual Health Identifier (IHI) number. While it is not currently being used to do so, in future, the aim is for the IHI to be used to link individual patients' health records together. (source: https://www.hse.ie/eng/about/who/national-services/individual-health-identifier/)

regional level. For example, a key informant working within one of the six regions said that work to identify exactly who falls within the region's catchment area is still underway:

> *"…some areas that should be within my region are pulled back westward, and it doesn't cover them and probably will need to in the future. But it's very hard to work up what your populations need when you don't actually know what your population is composed of." [11, Data infrastructure expert, HSE]*

Relatedly, the omission of Eircodes or postal codes as part of all health data collection generally and palliative care/EoL care data specifically was also raised by a key informant with data infrastructure expertise as a current gap. They noted that, "we're trying to encourage it because if we have the Eircode, then it's a single point and we can then find the data at whatever level" [03, Data infrastructure expert, DOH].

Interviewees were hopeful that ongoing developments related to the introduction of the Health Information Bill and the national shared patient record would bring about better integrated healthcare data, including palliative care data in future. For the time being, however, there was consensus that the collection and sharing of patient level data across settings and services is limited and would pose an obstacle to the development of an atlas *of variation* for palliative and EoL care.

3.2.3 Resources and Capacity

A key consideration in developing an atlas of variation for palliative/EoL care for Ireland is identifying the level of resourcing and capacity required, and the extent to which the latter are available within the system. All interviewees were of the view that the resources could be found, but that the aims and design of the atlas would need to be clearly defined before the level of resourcing necessary could be determined and that resource constraints could impact on the ambitiousness of the exercise. A strong emphasis was placed on the need to clearly articulate the potential value and utility of the atlas early on, i.e. its potential to improve the efficiency of resource allocation for palliative and EoL care.

Interviewees noted that a 'data culture'—a culture of using data to improve service delivery and quality and recognising its value for same—has not penetrated the healthcare system in Ireland and that this can result in reluctance on the part of care providers to comply with new data requests, particularly if the data compares services across the different provider organisations and makes them identifiable in the public domain. One key informant noted that it had been their experience that service providers became concerned about how their services were being represented after data they had submitted had been analysed and (re-)shared with them:

"[…] *people submit things and then next minute, they're like, 'oh no,' they see it presented and then they're like, 'well, that's not accurate.'* [06, Service model/delivery expert, AIIHPC]

It was therefore suggested that resources should be invested in raising awareness among and training providers in any new data reporting requirements or data collection instrument associated with an atlas.

Some interviewees indicated that developing, interpreting, and maintaining an atlas would require considerable human resources over an extended period, in particular if the atlas were to involve the deployment of a new data collection instrument. While potentially resource intensive, most interviewees were of the view that the necessary skills could be found from both within and external to the public sector.

> *"…the resources required to develop something like this are very easily found in Ireland. So, between academia, the Department of Health and the HSE there are so many analysts, administrative, clinical and GIS staff that this—it would not be easy to do—but the skills required to do this are everywhere*." [11, Data infrastructure expert, HSE]

3.2.4 Governance

To a certain extent, the governance of the atlas relates to the issue of resourcing and capacity discussed above and was raised by several interviewees in that context. Governance here refers to responsibility and accountability for the atlas. While there was no consensus among the key informants interviewed as to which institution or institutions should have governance oversight of an atlas, some felt strongly that whichever institution(s) ends up responsible should already have—or legally be able to gain—access to and be able to process and integrate relevant data sets.

Just as if not even more important for some interviewees was the perceived need for an atlas' governing body to have the capacity to interpret and make appropriate use of the information provided by the atlas, to ensure that it is both actionable and dynamic:

> *"…the more a data set is used and live and considered [a] core part of business, the better it will be, but if it sits again in a silo somewhere off at the side of a sector, it will die over time."* [17, Service model/delivery expert, Ireland East Hospital Group

Interviewees suggested both the National Clinical Programme for Palliative Care and the National Health Intelligence Unit within the HSE as possible governing bodies, respectively. A few interviewees were of the view that an atlas of palliative/EoL care could simply be an extension of or incorporated into the existing Health Atlas currently maintained by the Health Intelligence

Unit. Others felt that while the Health Atlas could be a vital resource, an atlas of palliative/EoL care should be a separate, distinct tool, with an emphasis on being public facing and on visually mapping variation across a range of domains and indicators.

While a public, government institution such as the HSE was most frequently suggested as the governing body for an atlas, key informants inside and outside the public sector stressed the importance not only of competence but also of a degree of independence for the group or body ultimately responsible:

> "*It has to be somebody that's, not independent, but is at least, that people are confident that there's independence and there's no influencing of it and that's capable of analyzing, gathering and you know, making sure it's accurate.*" [14, Service provider, Voluntary Hospice Group]

3.2.5 Stakeholder engagement

Dovetailing with the last point under the previous thematic area, several interviewees expressed the view that engaging relevant stakeholders in the development and operation of an atlas is about more than just getting input and being able to say that broad participation was achieved. Instead, most interviewees agreed that engaging stakeholders can serve the dual purpose of integration work, bringing providers, health care system operators, policymakers, researchers together around a common cause:

> "*I think it would be great if from the start, there was a partnership kind of an approach. So for example, they were partnered with patient care offices…or you know, we have the Service Providers Network whereby the organisations and they all work together, and obviously the regions, the RHAs [HSE Health Regions] and the lead so, I think, ownership perhaps, or responsibility in a place like the health intelligence unit, but I suppose with very active links externally so that there it isn't seen as a resource that it is hard to gain access to, which can happen sometimes with the datasets.*" *[17, Service model/delivery expert*, Ireland East Hospital Group]

One interviewee took the idea of stakeholder engagement with the atlas a step further, highlighting its value in bringing people together beyond its value as a technical tool or platform and suggesting the creation of a 'community of practice' around it centred on the 'people element' [07, Data infrastructure expert, HSE].

Other interviewees raised certain challenges or considerations in taking a participatory approach. One key informant, working in a service provider capacity, said that some providers may need to be convinced of the strategic value of collecting and analysing data on the services they provide

and that any requests for participation should be framed as an enabler, not simply as a reporting requirement, and that the emotional aspect of palliative/EoL care providers' work must be taken into account in terms of messaging.

> "*I think you have to do it as an enabler […] it's having the conversations of saying to people, 'okay, well, you know, in terms of your role and your strategy and what's important to you, what are the key things, what are you trying to achieve?' So, you know, the emotional piece is very strong…but it's then having something that's data, is completely independent, accurate, this is reality, these are the facts and then you have the other softer pieces that go with it.*" [14, Service provider, Voluntary Hospice Group]

Another key informant cautioned that bringing all stakeholders to the table, so to speak, can lead to long lists of wishes and preferences in terms of data to include and 'mission creep'. It was suggested that if a participatory approach was desirable, that stakeholders' expectations were carefully managed and stakeholder engagement activities carefully planned and facilitated by skilled moderators.

3.3 Key messages

The interviews with key informants offered detailed insights into Ireland's palliative and end-of-life (EoL) care system, emphasizing five critical areas for a data atlas. There was consensus on the need to prioritize data that maps service capacity across specialist palliative care units, community care, hospitals, and residential settings. Importantly, they stressed capturing both specialist and non-specialist palliative care to avoid underestimating service availability. Data integration across care settings emerged as a priority, but the fragmented nature of IT systems, lack of a unique patient identifier, and regulatory hurdles such as GDPR pose significant challenges. Interviewees noted the importance of aligning data collection with new HSE Health Regions and sub-national structures for better service planning. In terms of resources and capacity, the scope of the atlas must be well-defined to ensure targeted investment and support. Governance was a point of discussion, with some recommending the HSE or National Health Intelligence Unit to oversee the project, ensuring the atlas is used effectively. Finally, stakeholder engagement was seen as crucial not just for gathering input but also for fostering collaboration across the healthcare sector, though care must be taken to manage stakeholder expectations.

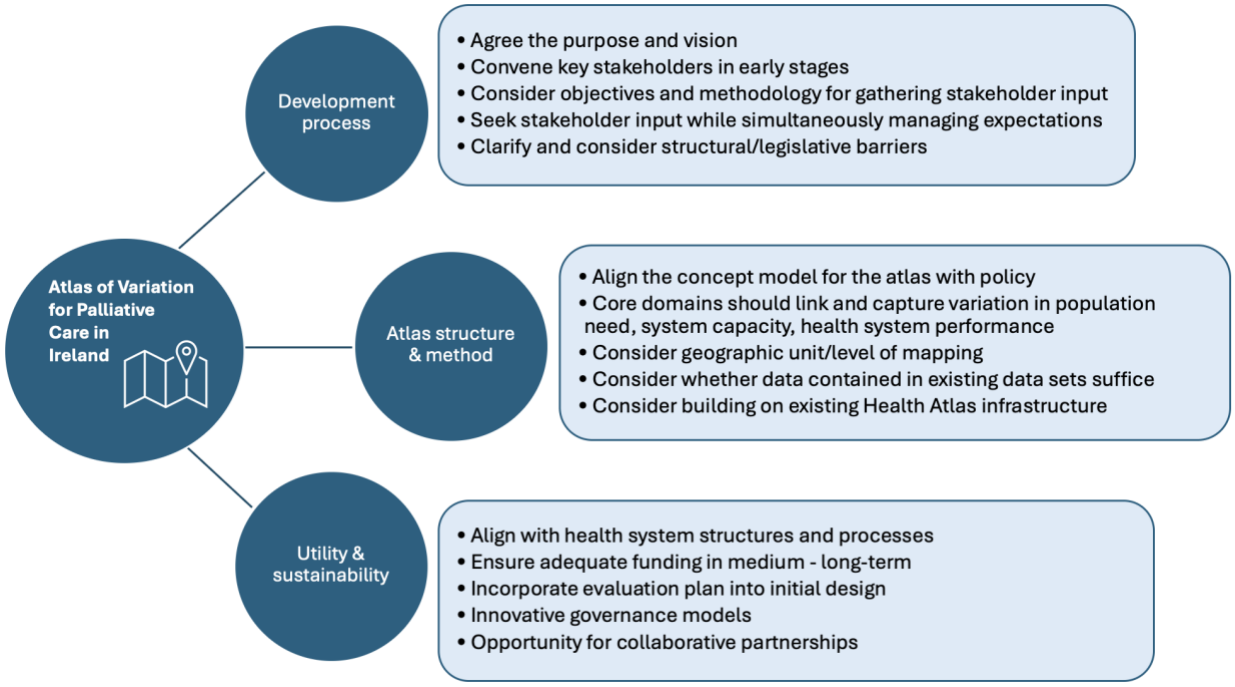
4 Mapping the data

A series of tables mapping the domains and indicators in each of the seven exemplar atlases to relevant Irish data sources are provided in Appendix B. While the mapping exercise has identified relevant data sets in each of the domain areas, the challenge moving forward will be to formulate a cohesive set of domains and indicators to map variation in palliative and EoL care in the Irish context, and to link the data drawn from the various sources to populate the indicators formulated.

5 Tying it all together – Emerging learnings for the development of an atlas of palliative and EoL care for Ireland

The findings from the review of the literature, from interviews with key informants, and from the mapping of international and Irish data on palliative/EoL care offer several important learnings to consider in the next stage of developing an Irish atlas of variation for palliative and EoL care. The learnings, presented in Figure 1, are grouped into three broad areas intended to facilitate discussions around how to approach: 1) the **development process** of an atlas, 2) the **structure and methodology** it will adopt, and 3) the **utility** or impact **and sustainability** of the atlas as a tool for decisionmakers. Further detail on the learnings derived from the research in each of these three areas is provided in the subsequent sections.

Figure 1 Emerging learnings for next phase of work



5.1 Development process

- Begin by agreeing on the purpose and vision of the atlas. Determine what the atlas should achieve and identify its intended users or audience. Decisions on domains and indicators will be made based on these determinations.
- Convene key stakeholders from the early stages of the development process to ensure their buy-in, obtain expert input, and avoid the perception that the atlas is merely another reporting requirement or burden.

- Consider the objectives and methodology for gathering stakeholder input, including applying consensus-building techniques to focus groups, workshops, interviews, or surveys. Identify who the key stakeholders should be.
- Seek stakeholder input while simultaneously managing expectations. Engage an individual or team with the appropriate skills and authority to facilitate or moderate consensus-building workshops with stakeholders on the development of the atlas.
- Clarify and consider legislative barriers to data sharing and integration across institutions and government departments or agencies.

5.2 Atlas structure and method of data collection

- Align the conceptual model for the atlas with the national policy for palliative care and with the broader aims of Sláintecare. This includes ensuring universal provision, equity in access to all three levels of palliative care, and integration of care across different settings and types.
- Core domains should capture and link variations in population need, system capacity (availability of services and workforce), and health system performance (structure, process, and outcomes). Data should be mapped at the highest level to HSE Health Regions, and ideally to Integrated Health Areas and Community Health Networks.
- Assess whether the data contained in existing datasets are sufficient or if an additional survey instrument is needed. This decision will depend partly on available resources and capacity, though the task of harmonizing and processing existing data should not be underestimated in terms of the required resources.
- Consider building on existing Health Atlas infrastructure as the technical platform for the new atlas.
- Prioritise domains and indicators that capture the following information identified by key informants:
    - Data on the current state of the system, including existing capacity and variation in the system;
    - Data that capture transitions between different types and levels of health care services, particularly between community-based and acute hospital services;
    - Data on specialist and non-specialist palliative care provided in residential care facilities, GP practices, and other community-based care settings;
    - Data on the specialist and non-specialist palliative care workforce.

5.3 Utility and sustainability

- Ensure alignment with broader health system structures and processes by establishing formal links with relevant officials and stakeholders in each Health Region, and ideally

also in the Integrated Health Areas, Community Health Networks, and Community Specialist Teams, and in the national office located within the HSE Centre.

- Secure adequate funding for a specified number of years to ensure that the atlas can contribute to health service improvement mechanisms.
- Incorporate an evaluation plan into the initial design to periodically assess the impact and added value of the atlas tool.
- Allow for adaptability and periodic revision of the design to accommodate new data resulting from changes in legislation or policy, such as the national shared record, unique patient identifier, or population-based needs data.
- Consider innovative governance models, such as partnerships between government, NGOs, and academia.
- View the atlas as an opportunity to build on and formalise existing collaborative partnerships, for example, through the creation of an Observatory on Palliative and EoL Care.

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Appendix A. Stated aims and structures of international exemplar atlases

Table A1. Atlas of Palliative Care in Latin America

Aims	
"The main objective of the Atlas is to provide guidance and to report on the degree of progress and development of palliative care in Latin America. The secondary objectives are: Understand and disseminate the current situation of palliative care in the region through maps, graphs and infographics; Provide updated data that serves policymakers, planners and professional associations in decision making and policy setting for integration of palliative care; Facilitate access to information and communication between institutions and associations dedicated to palliative care in the region; Enable comparison between countries in the region to stimulate exchange and promote the development of palliative care" (p.12).	
Chapter/Section	**Domain**
Introduction	Geopolitical maps
	Economic and social context
Thematic maps (regional)	Timeline of recent developments in palliative care
	Palliative care teams
	Service provision in hospital setting
	Service provision in the community
	Paediatric palliative care provision
	Legislation and public health policy
	Training in palliative care
	Opioids distribution
	National associations of palliative care
Infographics by country (national)	*'Thematic maps' from previous section presented for each of the 17 countries in the Latin Americas region*

Table A2. Global Atlas of Palliative Care

Aims	
"The purpose of this Atlas is to continue to **shine a light on the need for palliative care globally and to provide useful information for those wishing to increase access.** This document addresses the following questions: What is palliative care? How many people are in need of palliative care worldwide? What are the main diseases requiring palliative care? What are the main barriers to palliative care? Where are the existing gaps? How well is palliative care developed in each country? Where is palliative care currently available? What are the models of palliative care worldwide? What resources are devoted to palliative care? What is the way forward?" (p.12)	
Chapter/Section	**Domain**
Introduction	
How many adults and children are in need of palliative care worldwide?	Worldwide need for palliative care
	Worldwide need for palliative care for adults
	Worldwide need for palliative care for children
What are the main barriers to palliative care?	Policy
	Education
	Medication availability
	Health workforce need
	Psychological, social, cultural, and financial barriers
	Palliative Care for Special Populations
How are palliative care services developing worldwide to address the unmet need for care? Where are the main existing gaps?	Results of palliative care findings from the WHO Country Capacity Survey (2019)
	Maps showing levels of palliative care development by country from "Mapping Levels of Palliative Care Development" (2017)
	Maps showing numbers of palliative care-specific providers to base population
	Map showing the availability of children's palliative care services
	Estimate of total number of patients receiving palliative care by region
What are existing models of palliative care (including financial mechanisms) in different resource settings?	Country case studies
	Stories from Direct Stakeholders needing palliative care

What are the available resources at global/regional levels to support palliative care policies, programmes and research in low–middle income countries?	Financial resources devoted to palliative care and models for resource distribution
What is the way forward to advance palliative care in the health and human rights agendas at global/regional/country levels? And conclusions	Research support including leading institutions
	WHO Resources for Planning and Implementing Palliative Care
	WHPCA Resources Other Organizational Resources

Table A3. EAPC Atlas of Palliative Care in Europe

Aims	
"The objectives of the project are to: 1. Create a network of palliative care professionals across Europe interested in the palliative care global development and to promote, with them, the access to information and to improve communication and cooperation. 2. Develop a set of consensus-based indicators that will be openly available, capable of measuring palliative care development in the WHO-European region and that could be applied to other regions for use in future research. 3. Develop a set of specific indicators to assess integration of palliative care into paediatrics, primary care, long-term care facilities, volunteering, cardiology and oncology. 4. Conduct the first assessment of national-level paediatric palliative care development. 5. Provide open access data on palliative care development of each European country to facilitate discussion and measure progress in a comparative way" (p.25).	
Chapter/Section	**Domain**
Introduction	
Aims and objectives	
Population and methods	
Development and Integration of Palliative Care across Europe	Specialised Palliative Care Services for Adults
	Integration of Palliative Care and Paediatrics
	Palliative Care integration in national health systems in Europe
	Palliative Care education across Europe
	Use of medicines for Palliative Care
	Palliative Care vitality and professional activity
	Integration of Palliative Care in Long-Term Care Facilities in 18 European countries
	Development of Volunteering in Hospice and Palliative Care in 15 European Countries
	Integration of Palliative Care at the Primary Care level
	Integration of Palliative Care into Cardiology
	Integration of Oncology and Palliative Care
Development of Palliative Care at the Country-Level	*Data from above sections presented for 51 member countries considered part of the European region by EAPC*

Table A4. Scottish Atlas of Palliative Care

Aims	
"During 2015, as work proceeded on the Scottish Parliament inquiry into palliative care and the Scottish Government's Strategic Framework for Action on Palliative and End of Life Care, the idea was proposed that, using the EAPC template as a guide, we might produce an extended 'atlas entry' for Scotland. This document is the result. It is a contribution to Commitment 9 in the Strategic Framework, which refers to supporting improvements in the collection, analysis, interpretation and dissemination of data and evidence relating to needs, provision, activity, indicators and outcomes in respect of palliative and end of life care in Scotland" (p.9).	
Chapter/Section	**Domain**
Introduction	Socioeconomic data
	Health boards in Scotland and population
Definitions	
	Specialist palliative care services in Scotland
	Specialist palliative care services per health board
	Palliative care inpatient beds in Scotland
Palliative care development indices	Key data on palliative care development
	Hospice and palliative care milestones up to 2006
	Developments in hospice and palliative care since 2006
Policy	Development of palliative care policy since 2006
	Perceived barriers to the development of hospice and palliative care
	Perceived opportunities for the development of hospice and palliative care
Education	Developments in palliative care education and training since 2006
	Opioids
	Published national documents relating to palliative care standards and norms
Sociocultural	Changes in socio-cultural, ethical, moral attitudes since 2006

Table A5. Atlas of Variation for Palliative and End of Life Care in England

Aims	
"One of the key aims of the Atlas of variation series is to highlight geographical variation and to try to differentiate between warranted and unwarranted variation. [...] Due the complexity of assessing unwarranted variation in health care services for palliative and end of life care it is recommended that providers and commissioners use the indicators shown in this Atlas alongside the End of life care profiles and local data, to create a picture of need, provision and outcomes. This can help to identify whether local variation is unwarranted or responding to local need appropriately" (p.9).	
Chapter/Section	**Domain**
Introduction	
Introduction to the data	
Magnitude of variation summary	
Maps	Section 1: Need for palliative and end of life care Section 2: The role of hospitals in palliative and end of life care Section 3: Palliative and end of life care in the community
Palliative and end of life care resources	

Table A6. Canadian Atlas of Palliative Care – Ontario Edition

Aims	
"[…] aims to map out the current state of palliative care service availability in Ontario, including existing strengths, areas of excellence, and gaps. This research will then be translated into powerful and visual user-friendly tools that will help to improve the availability of palliative care in Ontario."	
Chapter/Section	**Domain**
Introduction	
Demographics	
Policy	
Services	Palliative Care Units
	Hospitals: Integration of the palliative care approach across services (inpatient units and outpatient clinics)
	Access to specialist-level palliative care in the community
	Availability of 24/7 Palliative Home Care Services
	Primary Palliative Care provided by Family Physicians and Primary Care Clinics
	Hospice residences
	Community hospice services
	Integration of palliative care approach into long term care (LTC)
	Provision of palliative care by paramedic emergency medical services (EMS)
	Availability of Advance Care Planning (ACP) resources
System performance	
Education	Undergraduate
	Postgraduate
Additional domains	Focused Populations
	Programs to support Informal Caregivers
	Community Engagement: Volunteer opportunities and Compassionate Communities
	Hospice Grief & Bereavement Services
	Palliative Care Professional Activities

Table A7. Dartmouth Atlas Project – End of Life Care (US)

Aims	
"The intensity of care in the last six months of life is an indicator of the propensity to use life-saving technology. The question of whether more medical intervention is better must be framed in terms of the potential gain in life expectancy for populations living in regions with greater intensity of intervention. Our research has provided evidence that populations living in regions with lower intensity of care in the last six months of life did not have higher mortality rates than those living in regions with higher care intensity. More than 80% of patients say that they wish to avoid hospitalization and intensive care during the terminal phase of illness, but those wishes are often overridden by other factors. If more intense intervention does not improve life expectancy, and if most patients prefer less care when more intensive care is likely to be futile, the fundamental question is whether the quality of care in regions with fewer resources and more conservative practice styles is better than in regions where more aggressive treatment is the norm."	
Chapter/Section	**Domain**
Inpatient End of Life Care mapped by: Hospital Referral Region; Hospital Service Area; State; County	*Hospital Admissions per Decedent During the Last Six Months of Life* *ICU/CCU Admissions* *ICU/CCU Allowed Charges (*Number of patients spending 7 or more days in ICU within six months of the death date) *Inpatient Days* *Inpatient Spending (*Inpatient reimbursements ($) within six months of the death date) *Percent of Deaths* *Percent of Hospital Hospitalizations (*Number of enrollees with one or more hospital admissions within six months of the death date)

Appendix B. Data variables included in international atlases, by domain

Table B1. Demographic data

Demographic					
Atlas of Variation for palliative and EOL care in England (2018)	***Canadian Atlas of Palliative Care - Ontario Edition (2023)***	***Scottish Atlas of Palliative Care (2016)***	***Atlas of Palliative Care in Europe (2019)***	***Atlas of Palliative Care in Latin America (2020)[1]***	**Available Irish data source(s)**
Actual and projected number of deaths, 1995 to 2040	Population density per km^2 (region and sub-regions)	Population (N)	Population density (INH/Km^2)	Total population (N)	♦ CSO - Vital statistics ♦ Census data ♦ Ordnance Survey Ireland ♦ TILDA
Number of deaths by age at death, 2006-2016	Total Population (N)	Population density (N per (km^2)	Population total (N)	Area (km^2)	
Current and projected number of deaths by age and sex, 2016, 2030 and 2040	Population size (N, by Age Range)	Surface (km^2)	Surface area (Km^2)	Population density (inh per km^2)	
Number of deaths by selected cause of death by age at death, 2007-2016	Share of population by Age Range (%)		Life expectancy at birth, total (years)		
Variation in crude death rate (%) by CCG[2]					
The number and percentage of deaths by place of death, 2007 and 2016					
Distribution of deaths by place of death and age at death, 2016					
Distribution of deaths by place of death and cause of death, 2016					
Percentage of deaths in each place of death by selected cause of death, 2007-2016					

Table B2. Socioeconomic data

Socioeconomic				
Atlas of Variation for palliative and EOL care in England (2018)	***Scottish Atlas of Palliative Care (2016)***	***Atlas of Palliative Care in Europe (2019)***	***Atlas of Palliative Care in Latin America (2020)***	**Available Irish data source(s)**
Index of multiple deprivation average LSOA score CCG quintiles[3]	GDP per capita (GBP)	GDP per capita (USD)	World Bank country classification by income group (low; lower-middle; upper-middle; high)	♦ CSO ♦ Census ♦ Pobal HP Deprivation Index ♦ System of Health Accounts (SHA) ♦ Doctors Integrated Management E-System (DIME) ♦ *United Nations - Human Development Index* ♦ *World Bank - World Development Indicators*
Pensioner poverty	Physicians per 1,000 inhabitants	Health expenditure total (% GDP)	Gross Domestic Product (GDP)	
Percentage of the population with Black, Asian and Minority Ethnic groups by CCG	Health expenditure per capita	Health expenditure per capita (PPP)	Human Development Index (HDI)	
	Health expenditure, Total (% of Gross)	Physicians per 1,000 inhabitants (N)	Poverty rate (%)	
	Human Development Index 2014	Human Development Index (HDI) ranking	Expenditure on health (% of GDP)	
	Human Development Index Ranking Position		Per capita expenditure on health (N)	
			Public expenditure on health (%)	
			Physicians per 10,000 inhabitants (N)	

Table B3. Policy data

Policy					
Canadian Atlas of Palliative Care - Ontario Edition (2023)	***Scottish Atlas of Palliative Care (2016)***	***Global Atlas of Palliative Care (2020)***	***Atlas of Palliative Care in Europe (2019)***	***Atlas of Palliative Care in Latin America (2020)***	**Available Irish data source(s)**
Existence of Palliative Care Policy (Y/N)	Most important legal or policy changes affecting the development of hospice and palliative care (*descriptive*)	Laws that acknowledge and define that palliative care is part of the health-care system (Y/N)	National standards and norms for Paediatric Palliative Care	National legislation on palliative care (Y; Y for cancer patients)	♦ Public-facing government websites ♦ Key informants: public sector agencies/ units
Designated unit responsible for palliative care	Development of a national palliative care consensus (*descriptive*)	National standards defining how palliative care programs must operate (Y/N)	Palliative care legislation (Specific law/Other laws-decrees/Both)	National strategy on palliative care (Y; Y for cancer patients; N; No data)	
An active palliative care strategic plan	Development of an advocacy framework for integrating palliative care into the health care system (*descriptive*)	Clinical guidelines for the delivery of palliative care services (Y/N)	Reference to palliative care in the national health law (Y/N)	Existence of standards, norms or guidelines on palliative care (Y/N)	
Law to ensure palliative care access	Strategies to improve political awareness and government recognition of palliative care (*descriptive*)	Establishment of palliative care as a recognized medical specialty/sub-specialty (Y/N)	Designated person at the Ministry for Health (Y/N)		
Law related to ACP	Perceived barriers to the development of hospice and palliative care (*descriptive*)	Regulations that establish palliative care as a recognized type of health-care provider with accompanying licensing provisions (Y/N)	Database specific to palliative care provision (Y//N)		
Standards and norms for palliative care	Perceived opportunities for the development of hospice and palliative care (*descriptive*)	National strategy on palliative care implementation (Y/N)	National palliative care plan/strategy (Y/N)		
Compassionate care benefits	Legislation on PC (Y/N)	Percentage of Member States with a national NCD policy, strategy or action plan that includes palliative care, by income group (%)	Official documents regulating palliative care provision in LTC facilities (National strategy/standards/protocols/guidelines (Y/N)		

Policy (cont'd)					
Canadian Atlas of Palliative Care - Ontario Edition (2023)	***Scottish Atlas of Palliative Care (2016)***	***Global Atlas of Palliative Care (2020)***	***Atlas of Palliative Care in Europe (2019)***	***Atlas of Palliative Care in Latin America (2020)***	**Available Irish data source(s)**
Formal and active strategy to integrate palliative care into: Home and community care; In-patient and outpatient hospital services (cancer and non-cancer); LTC facilities; Paramedic/emergency services	Official National Strategy (Y/N)		Funding for palliative care provision in LTRC facilities (Y/N)		♦ Public-facing government websites ♦ Key informants: public sect or agencies/units
Public funding for: Palliative Care Home Services; Hospices Residences; Community Hospice Services; Medications (palliative care); Supplies and equipment; Continuing palliative care education	Worldwide Palliative Care Alliance level of development		Incentives for early identification of palliative care patients at primary care level (work; academic/curricular; time; money; none)		
Formal strategy for paediatric palliative care (Y/N)	Published national documents relating to palliative care standards and norms: National HIV/AIDS Strategy; National Primary Health Care Strategy; Systems of auditing, evaluation or quality assurance that monitor the standard of palliative care; Opioid legislation / Pain guidelines; Funding of palliative care services (*descriptive*)		Mention of palliative care provision at the primary care level in official documents (law; plan/strategy) (Y/N)		
Formal strategy for 'Focused population groups – others': LGBTQ2SIA+; Homeless and Marginally Housed; Prisoners; Recent Immigrants and Refugees (Y/N)					
Formal strategy to support Informal Caregivers (Y/N)					

Table B4. Care needs data

Care need				
Atlas of Variation for palliative and EOL care in England (2018)	***Canadian Atlas of Palliative Care - Ontario Edition (2023)***	***Global Atlas of Palliative Care (2020)***	***Atlas of Palliative Care in Europe (2019)***	**Available Irish data source(s)**
Variation in the proportion of all people who died who were aged 75 years and older by CCG	Number of deaths per year & cause of deaths	Distribution of major causes of death worldwide for all ages, males and females[4] (%)	People who died in Europe needing Palliative Care, by disease category[5](%)	♦ Census ♦ CSO - Vital Statistics ♦ TILDA
Variation in the proportion of adults who are aged 65 years or older and who are living alone by lower tier local authority		Need for palliative care for decedents and non-decedents, (all ages all sexes) (%)		
Variation in the proportion of the population aged 16 years or older who are unpaid carers by CCG		Worldwide need for palliative care by age group (%)		
Variation in the proportion of all people who died with an underlying cause of cancer by CCG		Worldwide need for palliative care for adults, by major diagnostic group (20+ years) (%)		
Variation in the proportion of all people who died with an underlying or contributory cause of dementia by CCG		Worldwide need for palliative care for adults by disease group (20+ years) (%)		
Variation in the proportion of all people who died with an underlying cause of chronic heart disease by CCG		Worldwide need for palliative care for adults by age and disease group (20+ years) (%)		
Variation in the proportion of all people who died with an underlying or contributory cause of chronic obstructive pulmonary disease (COPD) by CCG		Worldwide need for palliative care for adults, by WHO region (20+ years) (%)		
Variation in the proportion of people who died with an underlying cause of stroke by CCG		Worldwide need for palliative care for adults, by WHO region and per 100,000 population (20+ years; 183 countries) (N)		
Variation in the proportion of all people who died with an underlying cause of liver disease by CCG		Worldwide need for palliative care for adults, by WHO region and disease categories (20 + years; 183 countries) (%)		

Care need (Cont'd)				
Atlas of Variation for palliative and EOL care in England (2018)	***Canadian Atlas of Palliative Care - Ontario Edition (2023)***	***Global Atlas of Palliative Care (2020)***	***Atlas of Palliative Care in Europe (2019)***	**Available Irish data source(s)**
Variation in the percentage change in the annual number of people dying between 2014 and 2030 by lower-tier local authority		Worldwide need for palliative care for adults by World Bank income category (20+ years) (%)		♦ Census ♦ CSO - Vital Statistics ♦ TILDA
		Worldwide need for palliative care for adults per 100,000 population by World Bank income category (20+ years) (N)		
		Worldwide need for palliative care for adult decedents and non-decedents by major disease categories in LMICs. (20+ years) (N)		
		Worldwide need for palliative care for adult decedents and non-decedents by major disease categories in HICs (20+ years) (N)		
		Percentage of days that adults worldwide experience serious health related suffering for 20 health conditions for 16 symptoms by decedents (20+ years) (%)		
		Percentage of days that adults worldwide experience serious health related suffering due to 20 illness conditions for 16 symptoms, non-decedents (20+ years) (%)		
		Worldwide need for palliative care for children by WHO region (0-19 years) (%)		
		Worldwide need for palliative care for children per 100,000 population by WHO Region (0-19 years) (N)		
		Worldwide need for palliative care for children by disease groups (0-19 years) (%)		
		Worldwide need for palliative care for children (0-19) by WHO regions and disease categories (183 countries) (%)		
		Worldwide need for palliative care for children (0-19) by income group (183 countries) (%)		

Care need (Cont'd)				
Atlas of Variation for palliative and EOL care in England (2018)	***Canadian Atlas of Palliative Care - Ontario Edition (2023)***	***Global Atlas of Palliative Care (2020)***	***Atlas of Palliative Care in Europe (2019)***	**Available Irish data source(s)**
		Worldwide need for palliative care for children per 100,000 population by World Bank income category (0-19 years) (N)		♦ Census ♦ CSO - Vital Statistics ♦ TILDA
		Worldwide need for palliative care for children (0-19), decedents and non-decedents, by major disease categories in LMICs (N)		
		Worldwide need for palliative care for children (0-19), decedents and non-decedents, by major disease categories in HICs (N)		
		Percentage of days that children (0-19) worldwide experience serious health-related suffering for 20 health conditions for 16 symptoms by decedents (%)		
		Percentage of days that children (0-19) worldwide experience serious health related suffering by 20 illness conditions for 16 symptoms by non-decedents (%)		

Table B5. Service availability data

Service availability					
Canadian Atlas of Palliative Care - Ontario Edition (2023)	***Scottish Atlas of Palliative Care (2016)***	***Global Atlas of Palliative Care (2020)***	***Atlas of Palliative Care in Europe (2019)***	***Atlas of Palliative Care in Latin America (2020)[2]***	**Available Irish data source(s)**
Location of Palliative Care Units (PCUs)	Inpatient units (N and %)	Percentage of Member States reporting general availability of palliative care (reaching at least 50% of patients in need) in primary health care, by integrated NCD policy and funding availability	Number of total Specialised Palliative Care services for adults per population (N)	Number of residential hospices (N)	♦ Public-facing websites ♦ Key informants: public sector agencies/units; care providers ♦ HSE workforce data - NDTP
Number of beds in each PCU	Out-patient clinics (N and %)	Levels of palliative care development, all countries[9]	Home Palliative Care Specialised Services in Central and Eastern Europe (ratio per 100,000 inh)	Number of palliative home care teams for adults (N)	
Type of hospital the PCU is located in	Hospital support teams (N and %)	Services/providers to base population (Rates of number of services delivering Palliative Care, N services per 1M population)	Home Palliative Care Specialised Services in Western Europe (ratio per 100,000 inh)	Number of paediatric palliative home care teams (N)	
Adequacy of the N of PCU beds in region[6]	Home care teams (N and %)	Estimated number of patients receiving palliative care (Rates of number of services receiving Palliative Care, N patients per 1M population)	Total Specialised Palliative Care Services for adults (N)	Number of palliative care services in community centres (N)	
Integration of Palliative Care Approach[7] in hospital inpatient units and outpatient services across whole region (Y/N/P)	Day care centres (N and %)		Total Inpatient Hospices (N)	Number of palliative care services/units operating in secondary hospitals (N)	
Formal strategy in place to integrate palliative care in all services across hospitals in region (Y/N)	Palliative care services per 10,000 inhabitants		Palliative Care inpatient units in hospitals (N)	Number of palliative care services/units operating in tertiary hospitals (N)	
Access to specialist-level palliative care in the community (Full/Partial/Hardly any)[8]	N of different types of services in each health board (Inpatient, Out-patient, Hospital support teams, Home care teams, Day care centres)		Hospital Palliative Care Support Teams (N)	Number of multi-level/multi-professional palliative care services/teams (N)	

Service availability (Cont'd)					
Canadian Atlas of Palliative Care - Ontario Edition (2023)	***Scottish Atlas of Palliative Care (2016)***	***Global Atlas of Palliative Care (2020)***	***Atlas of Palliative Care in Europe (2019)***	***Atlas of Palliative Care in Latin America (2020)[2]***	**Available Irish data source(s)**
Availability of 24/7 Palliative Home Care Services	Palliative care inpatient beds per 10,000 inhabitants (N)		Home Palliative Care Teams (N)	Number of hospital support services/teams (paediatric; adult; mixed) (N)	♦ Public-facing websites ♦ Key informants: public s ector agencies/units; care providers ♦ HSE workforce data – NDTP
Primary Palliative Care provided by Family Physicians and Primary Care Clinics	Distribution of Inpatient beds by type of provider (N) (Children's hospices, Charitable hospices, NHS inpatient hospices)		Mixed Palliative Care Teams (N)	Number of day centres for palliative care (paediatric; adult; mixed) (N)	
Total number of hospices in region	Palliative care beds (ratio per million inhabitants)		Palliative care programs specific for children – Hospice inpatients (N)		
Total number of hospice residence beds in region	Palliative care for children (N & *descriptive*)		Palliative care programs specific for children – Home care services (N)		
Are number of hospice residence beds in region adequate?[10]			Palliative care programs specific for children – Hospital services(N)		
Total N of Community Hospice Programs[11]			Paediatric Palliative Care Consultants (Y/N)		
Integration of palliative care approach into long term care (LTC) (Y/N/P)			Perinatal Palliative Care Reference Centres (Y/N)		
Provision of palliative care by paramedic emergency medical services (EMS) (Y/N/P)			Day Care Programmes (N)		

Service availability (Cont'd)					
Canadian Atlas of Palliative Care - Ontario Edition (2023)	***Scottish Atlas of Palliative Care (2016)***	***Global Atlas of Palliative Care (2020)***	***Atlas of Palliative Care in Europe (2019)***	***Atlas of Palliative Care in Latin America (2020)[2]***	**Available Irish data source(s)**
Provision of palliative care in rural/remote areas			Identified pioneering Cardiology service providing palliative care (Y/N)		♦ Public-facing websites ♦ Key informants: public sector agencies/units; care providers ♦ HSE workforce data – NDTP
Availability of ACP resources (Y/N/P)			Identified palliative care protocols specific for Cardiology (Y/N)		
Residential paediatric hospice(s) (Y/N)			European Society for Medical Oncology (ESMO) centre (Y/N)		
Outpatient palliative care program(s) for paediatric populations					
Respite paediatric palliative care (hospice or hospital setting)					
24/7 access to specialist paediatric palliative care team (Y/N)					
Programs and/or initiatives for 'Focused population groups – others': LGBTQ2SIA+; Homeless and Marginally Housed; Prisoners; Recent Immigrants and Refugees (Y/N)					
Programs and/or initiatives to support Informal Caregivers (Y/N)					

Table B6. Service utilisation data: Acute hospitals

Service utilisation - Acute hospital			
Dartmouth Atlas of EOL Inpatient Care (1994-2019)[12]	***Atlas of Variation for palliative and EOL care in England (2018)***	***Canadian Atlas of Palliative Care - Ontario Edition (2023)***	**Available Irish data source(s)**
Hospital Admissions per Decedent During the Last Six Months of Life by HRR[13] (N)	Variation in the proportion of all people who died in hospital by CCG (2015)	Palliative patients who died in hospital (%)	♦ MDS Palliative Care ♦ HIPE ♦ NELS
ICU/CCU Admissions per Decedent During the Last Six Months of Life by HRR (N)	Variation in the proportion of all people admitted into hospital during the last 90 days of their life by CCG	Palliative patients who were discharged 'Home with Support Services' (%)	
ICU/CCU Allowed Charges per Decedent During the Hospitalization in Which Death Occurred by HRR	Variation in the proportion of people who have 3 or more emergency hospital admissions during the last 90 days of life by CCG		
ICU/CCU Allowed Charges per Decedent During the Last Six Months of Life by HRR	Variation in the proportion of hospital admissions ending in death in hospital which are 8 days or longer by CCG		
ICU/CCU Days per Decedent During the Hospitalization In Which Death Occurred by HRR	Variation in proportion of all people who died in hospital that had documented evidence of recognition that they would probably die in the coming hours or days by acute hospital trust site		
ICU/CCU Days per Decedent During the Last Six Months of Life by HRR	Variation in the proportion of all people who had documented evidence that a health professional had recognised during the last episode of care the person was dying and had discussed this with a nominated person(s) important to the dying person by acute hospital trust site		
Inpatient Days per Decedent During the Hospitalization in Which Death Occurred by HRR	Variation in proportion of all people who died in hospital that had documented evidence in the last 24 hours of a holistic assessment of their needs regarding an individual plan of care by acute hospital trust site		
Inpatient Days per Decedent During the Last Six Months of Life by HRR	Variation in provision of face-to-face access to specialist palliative care at least 9am to 5pm, Monday to Sunday by acute hospital trust site		
Inpatient Spending per Decedent During the Hospitalization in Which Death Occurred by HRR (in USD)			

Service utilisation - Acute hospital (Cont'd)			
Dartmouth Atlas of EOL Inpatient Care (1994-2019)[12]	***Atlas of Variation for palliative and EOL care in England (2018)***	***Canadian Atlas of Palliative Care - Ontario Edition (2023)***	**Available Irish data source(s)**
Inpatient Spending per Decedent During the Last Six Months of Life by HRR (in USD)			♦ MDS Palliative Care ♦ HIPE ♦ NELS
Percent of Decedents Admitted to ICU/CCU During the Hospitalization in Which Death Occurred by HRR (%)			
Percent of Decedents Spending 7 or More Days in ICU/CCU During the Last Six Months of Life by HRR (%)			
Percent of Medicare Deaths Occurring in Hospital by HRR (%)			
Percent of Medicare Decedents Admitted to ICU/CCU At Least Once During the Last Six Months of Life by HRR (%)			
Percent of Medicare Decedents Hospitalized At Least Once During the Last Six Months of Life by HRR (%)			

Table B7. Service utilisation data: Community-based care settings

Service utilisation - Community-based				
Dartmouth Atlas of EOL Inpatient Care (1994-2019)	***Canadian Atlas of Palliative Care - Ontario Edition (2023)***	***Global Atlas of Palliative Care (2020)***	***Atlas of Palliative Care in Europe (2019)***	**Available Irish data source(s)**
Variation in the number of patients in need of palliative care/support, as recorded on GP disease registers per 100 deaths by CCG	Residents receiving Home Care – Palliative patients (rate per 1,000)	Percentage of Member States providing palliative care for NCD patients through primary health care, home-based care or community-care, by income group	Time before death receiving care at primary level (more than 1 year; between 6 months and 1 year; between 1 month and 6 months; between 1 week and 1 month; NA)	♦ MDS ♦ NELS ♦ CSO – Vital statistics
Variation in the proportion of all people who died in a hospice by CCG			Percentage of palliative care patients identified at primary level (quartiles, %)	
Variation in the proportion of all people that died in a hospice with a recorded cause of death as cancer by STP[14]				
Variation in the proportion of all people who died in their usual place of residence by CCG				
Variation in the proportion of people that died at home by CCG				
Variation in the proportion of people that died in a care home by CCG				
Variation in the proportion of the population who are living in a care home by lower tier local authority				
Variation in the number of care home beds per 100 people living who are aged 75 years or older by CCG				
Variation in the number of nursing home beds per 100 people living who are aged 75 years or older by CCG				
Variation in the proportion of care home residents that died in a care home by CCG				
Variation in the proportion of people who died in a care home who were temporary residents by CCG				

Table B8. Education and Training data

Education/Training					
Canadian Atlas of Palliative Care - Ontario Edition (2023)	***Scottish Atlas of Palliative Care (2016)***	***Global Atlas of Palliative Care (2020)***	***Atlas of Palliative Care in Europe (2019)***	***Atlas of Palliative Care in Latin America (2020)[2]***	**Available Irish data source(s)**
Palliative care training programs for primary health care professionals (physicians, nurses, etc.)	General developments in palliative care education and training initiatives (*descriptive*)	Basic palliative care training for all health professionals and paraprofessionals including physicians, nurses, mental health professionals, clergy, volunteers and therapists (Y/N)	Paediatric Palliative Care components in paediatrics training for medical doctors (Y/N)	Information on each of the following areas: Official accreditation; Postgraduate training; Undergraduate training; Teaching resources (*descriptive*)	♦ HSE - NDTP ♦ Public-facing websites ♦ Key informants: public sector agencies/ units; institutions of higher learning
Mapping of and description of each higher education institution's undergraduate and postgraduate curriculum in palliative care	Specific developments in under-graduate palliative care education initiatives (*descriptive*)	Intermediate training for those routinely working with patients with life-threatening illnesses (Y/N)	Paediatric Palliative Care components in paediatrics training for nurses (Y/N)		
Education program(s) for paediatric palliative care (Y/N)	Specific developments in post-graduate palliative care education initiatives (*descriptive*)	Specialist palliative care training for patients with more complex symptom manage ment needs and for those who will teach palliative care and do research (Y/N)	Paediatric Palliative Care training for neonatologists (Y/N)		
Education programs for Informal Caregivers (Y/N)	Translation of palliative care documents or other materials (*descriptive*)		Palliative care teaching in medical schools (Mandatory; Mandatory combined)		
	Initiatives to develop healthcare professional leadership in palliative care (*descriptive*)		Palliative care teaching in nursing school (Mandatory; Mandatory combined)		
	Officially recognized medical certificatio n (*descriptive*)		Process of specialization in palliative medicine (Y/N)		

Education/Training (Cont'd)					
Canadian Atlas of Palliative Care - Ontario Edition (2023)	***Scottish Atlas of Palliative Care (2016)***	***Global Atlas of Palliative Care (2020)***	***Atlas of Palliative Care in Europe (2019)***	***Atlas of Palliative Care in Latin America (2020)[2]***	**Available Irish data source(s)**
	Status of Palliative Medicine (Full specialty or not)		Type of process of specialization (speciality; sub-specialty; special field of competence)		♦ HSE - NDTP ♦ Public-facing websites ♦ Key informants: public sector agencies/units; institutions of higher learning
			Proportion of medical schools teaching over 20hrs of palliative care, Europe (%)		
			Proportion of medical schools including palliative care mandatory clerkship, Europe (%)		
			Proportion of nursing schools including palliative care mandatory clerkship, Europe (%)		

Table B9. Workforce capacity data

Workforce capacity		
Global Atlas of Palliative Care (2020)	***Atlas of Palliative Care in Europe (2019)***	**Available Irish data source(s)**
Data on workforce capacity issues as barriers to palliative care (*descriptive*)	Staff in LTC facilitates trained in palliative care (quintiles, %)	♦ HSE - NDTP ♦ Public-facing websites ♦ Key informants: public sector agencies/units ; institutions of higher learning; NHI
	Collaboration between palliative care teams and LTRC facilities staff (frequency: always/most of the time/sometimes/very rarely/never)	
	Primary palliative care education in medical schools (Y/N)	
	Primary care palliative care components in residency programme for family doctors/GPs (Y/N)	
	Identified national expert on palliative care provision in Cardiology (Y/N)	

Table B10. Data on resources to support service development, research, innovation

Resources to support service development, research, innovation					
Canadian Atlas of Palliative Care - Ontario Edition (2023)	***Scottish Atlas of Palliative Care (2016)***	***Global Atlas of Palliative Care (2020)***	***Atlas of Palliative Care in Europe (2019)***	***Atlas of Palliative Care in Latin America (2020)[2]***	**Available Irish data source(s)**
Existence of palliative care directory of services (Y/N)	National Association (Y/N)	Information on available resources at global/regional levels to support palliative care policies, programmes and research in LMIC (*descriptive*)	Identified national directories for palliative care services (Y/N)	Information on standards, norms or guidelines, by country (*descriptive*)	♦ Public-facing websites ♦ Key informants: public sector agencies/units; palliative care association(s); institutions of higher learning
Dedicated resources to organize palliative care CPD (continuing professional development) (Y/N)	National Conference (Y/N)		National palliative care associations (Y/N)	Information on national legislation, by country (*descriptive*)	
Palliative care conference/symposia (Y/N)	Scientific Journal (Y/N)		Paediatric representative in national Palliative Care association (Y/N)	Information on national palliative care plan/program, by country (*descriptive*)	
Evidence of palliative care research activities (Y/N)	Research Centres (Y/N)		Palliative care representative in national Paediatrics association (Y/N)	Information on integration with the national healthcare system, by country (*descriptive*)	
Evidence of palliative care quality improvement initiatives (Y/N)	World PC Day initiatives (Y/N)		Number of palliative care publications per year (N)	Information on government resources, by country (*descriptive*)	
	Participants at EAPC Conference (Y/N & Number)		Publications on palliative care provision in LTRC facilities (Y/N)	Information on opioids policy, by country (*descriptive*)	
			Involvement in international research projects on palliative care provision in LTRC facilities (Y/N)	Information on affordability of palliative/EOL care, by country (*descriptive*)	

Table B11. Other: Medication data

Other – Medication				
Scottish Atlas of Palliative Care (2016)	***Global Atlas of Palliative Care (2020)***	***Atlas of Palliative Care in Europe (2019)***	***Atlas of Palliative Care in Latin America (2020)[2]***	**Available Irish data source(s)**
Is there a standard process for the prescription and acquisition of opioids in Scotland? (Y/N) (Describe the standard process)	Morphine use worldwide (Mg/Capita)	Consumption of strong opioids, excluding methadone (mg/capita)	Collaboration between prescribers and regulators of opioid analgesics (Very good/Good/Moderate/Bad)	Key informants *International Narcotics Control Board (INCB)*
What are the restrictions on opioid prescriptions in Scotland? (descriptive)	Morphine equivalent total opioid use worldwide (excluding methadone) (mg/capita)	Levels of opioids consumption by quartiles, morphine equivalent (mg/capita/year)	Opioid distribution Morphine - equivalent (mg/capita)	
What specialties can prescribe opioids in your country? (descriptive)		All general physicians and Family Doctors allowed to prescribe opioids (Y/N)		
Is codeine available in a variety of strengths, formulations and as an ingredient in multi-ingredient preparation(s)? (Y/N)		All specialists allowed to prescribe opioids (Y/N)		
Availability of following medications (Y/N): Hydrocodone, Morphine, Hydromorphone, Oxycodon, Meperidine, Fentanyl, Sufentanil, Methadone, Levorphanol, Oxymorphone, Transdermal Fentanyl, Diamorphine		Only some specialists allowed to prescribe opioids (Y/N)		
		Only palliative care physicians allowed to prescribe opioids (Y/N)		

Table B12. Other: Data on lived experience

Other – Lived experience	
Global Atlas of Palliative Care (2020)	**Available Irish data source(s)**
Individual service user vignettes, by country	♦ NELS ♦ Key informants: AIIHPC/Voices4Care

Table B13. Data on sociocultural factors

Other – Sociocultural	
Scottish Atlas of Palliative Care (2016)	**Available Irish data source(s)**
Change in public awareness or perception of hospice and palliative care (descriptive)	♦ Public-facing websites ♦ Key informants

Table B14. Other: Data on community/voluntary sector resources

Other – Community/Voluntary sector			
Canadian Atlas of Palliative Care - Ontario Edition (2023)	***Atlas of Palliative Care in Europe (2019)***	***Atlas of Palliative Care in Latin America (2020)[2]***	**Available Irish data source(s)**
Volunteer opportunities in palliative care (Y/N)	Palliative care volunteers across Europe, by country (<100; 100-500; 500-1,000; >1,000)	Teams of volunteers in hospitals providing palliative care (paediatric; adult; mixed) (N)	♦ Public-facing websites ♦ Key informants: public sector agencies/units; care providers; palliative care association(s); volunteer ass ociation(s)
Volunteer training activities in palliative care (Y/N)	Training programmes in palliative care or curricula for volunteers (Y/N)		
Compassionate Communities (Y/N)	Data collection systems to track volunteers' activity (Y/N)		
	Compassionate Communities (Y/N)		
	Volunteer representation in national palliative care association (Y/N)		
	Government funding for palliative care volunteering activities (Y/N)		

Appendix C. Recruitment documents for interviews with key informants

Document C1. Participant Information Leaflet

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Scoping decision-makers' needs for a National Palliative Care Atlas of Variation for Ireland (NPCAVI)

Participant Information Leaflet

Study Title	Scoping decision-makers' needs for a National Palliative Care Atlas of Variation for Ireland (NPCAVI)
Research Site	Trinity College Dublin
Principal Investigator and Co-Investigator	Principal Investigator: Dr. Bridget Johnston Research Assistant Professor Centre for Health Policy and Management, Trinity College Dublin bjohnst@tcd.ie (01) 896 2201 Co-Investigator: Dr. Katharine Schulmann Research Fellow Centre for Health Policy and Management Trinity College Dublin kschulma@tcd.ie
Study Organiser/ Sponsor	Health Service Executive of Ireland
Data Controller	Trinity College Dublin
Data Protection Officer (Research Data)	Data Protection Officer Secretary's Office Trinity College Dublin Dublin 2

Introductory Statement

We would like to invite you to take part in a research study that is being carried out by Dr. Bridget Johnston and Dr. Katharine Schulmann at Trinity College Dublin.

Before you decide whether you wish to take part, please take time to read this information leaflet carefully.

If there is anything which is not clear, or if you would like more information, please ask the research team. You should understand the benefits and any risks of taking part in this study so that you can make a decision that is right for you.

Do I have to take part?

No. Participation in this study is entirely voluntary. You can change your mind about taking part in the study any time you like. Even if the study has started, you can still opt out. You do not have to give us a reason for opting out and there are no consequences for doing so.

This leaflet has five parts:

Part 1 – The Study

Part 2 – Data Protection

Part 3 – Approval, Organising and Funding

Part 4 – Further Information

Part 5 – Next steps

Part 1 - The Study

Why is this study being done?

This research is being done to inform the development and implementation of an Atlas of Variation for Palliative and End-of-life (EOL) care in Ireland, a data tool used for identifying geographical variations in access to and availability of services. To achieve this aim, interviews with people with expertise in the planning and provision of palliative care services, and in health and social care data infrastructure more generally, are being carried out. These interviews will help identify priorities and issues of feasibility for development of an Atlas of Variation for Ireland.

Why have I been invited to take part?

You have been invited because of your professional expertise in the planning and/or provision of palliative and EOL care services, or because of your expertise in health and social care data infrastructure more broadly.

What does taking part involve?

- Taking part will involve a one-to-one interview, conducted either in-person or virtually [using Microsoft Teams or Zoom], according to your preference.
- The date and time of the interview will be scheduled at your convenience and will last no more than 1.5 hours.

- The interview will be carried out by Dr. Bridget Johnston or Dr. Katharine Schulmann.
- With your consent, the interview will be audio recorded for the purposes of analysis. If you would like to review the interview transcript, please inform the research team within 10 working days and they will provide you with a copy.
- If you decide to take part, a member of the research team will first discuss this information leaflet and consent form with you. You will be asked to sign and return the consent form to the research team, and you will be given a copy of your signed consent form and this leaflet to keep.

What are the possible benefits of taking part?

Participating in the study provides you with the opportunity to share your expertise related to palliative care/EOL services in Ireland, and what future priorities in this area should be. While this may be something that makes you feel engaged and your expertise valued, there will not be any additional benefits from participating.

Are there any possible disadvantages or risks from taking part?

We have taken great care to ensure that the confidentiality of the information you provide is maintained. However, we cannot guarantee that a data breach will not happen. We have provided further information on how we safeguard and manage your data in the sections below. Of note, we wish to reassure you that your data will not be used in automated decision making or profiling.

What will happen to the results of the study?

The findings will be published in a technical brief for the Health Service Executive. The findings will also be published in open access scientific journal(s), as well as presented at meeting(s) for policy makers and other stakeholders.

You will NOT be identifiable in the write-up of the study findings.

Part 2 - Data Protection

What information about me (personal data) will be used for this study?

We will keep the following data about you: your name and your institutional email address, and your employer/affiliated organisation.

Who will access my personal data?

Only members of the research team based in Trinity College Dublin will have access to the personal information you provide.

How is the information kept confidential and secure?

Your privacy is important to us. We will file information that might identify you, such as your name, in a separate document from the interview transcript, and this personal information will be kept securely in a password-protected database. This database will be stored in a secure and dedicated Trinity College Dublin OneDrive cloud-based folder accessible only to the research team. The research team will only access these data using encrypted devices approved by Trinity College Dublin.

Similarly, the consent form containing your name will be kept securely in a password-protected database if in electronic form, or, if in hard copy, in a locked cabinet in the Centre for Health Policy and Management in Trinity College. Only the research team will have access to the database and to the locked cabinet.

The research team are governed by a professional code of ethics to maintain your confidentiality. Both members of the research team have completed Data Protection Training and have received ethics approval for this study from the School of Medicine, Trinity College Dublin Research Ethics Committee.

How long will my personal data be needed?

The database with participants' names, employers and email addresses will be retained for 10 years to allow for publication timeframes and in case of requests to validate or verify data, in line with the RCUK Code of Good Research Conduct. After 10 years, the data will be securely deleted.

Your consent form will be retained for a period of 10 years following completion of the study, in case of DPO audit and in line with the RCUK Code of Good Research Conduct. After 10 years, the data will be securely deleted.

The audio recording of your interview will only be retained until it has been transcribed and the content verified by both members of the research team, in line with the RCUK Code of Good Research Conduct. The data will then be securely deleted.

The codebook assigning pseudonyms to participant names will be retained for 10 years following completion of the study in case of DPO audit, in line with the RCUK Code of Good Research Conduct. The data will then be securely deleted.

The pseudonymised transcript will be retained for 10 years to allow for publication timeframes and in case of requests to validate or verify data, in line with the RCUK Code of Good Research Conduct. After 10 years, the data will be securely deleted.

What is the lawful (legal) basis to use my personal data?

The lawful basis for the processing of your personal data is Article 6(1)(e) and Article 9(2)(j) of the EU's General Data Protection Regulation (GDPR).

We will only use your personal data for this research project, which we hope will improve the planning and delivery of palliative and EOL care services in Ireland. We will also ask for your consent as a requirement of Irish law (Health Research Regulations), but we do not rely on this as our legal basis under GDPR.

What are my rights under Data Protection law?

You are entitled to:

- object to our use of your personal data or any further use;
- request access to your personal data and to receive a copy of it;
- request inaccurate personal data be corrected or deleted;
- request restriction of our use of your personal data;
- request deletion of your personal data.

By law you can exercise the above rights in relation to your personal data, unless the request would make it impossible or very difficult to conduct the research. Once analysis of all interview data has been completed, we may not be able to delete data as it would impact on the results.

You can exercise these rights by contacting either member of the research team: Dr. Bridget Johnston [bjohnst@tcd.ie] or Dr. Katharine Schulmann [kschulma@tcd.ie].

Alternatively, you can contact the Trinity College Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: www.dataprotection.ie .

Part 3 - Approval, Organising and Funding

Has this study been approved by a research ethics committee?

Yes, this study has been approved by the Research Ethics Committee (REC) of the School of Medicine, Trinity College Dublin. Approval was granted on 23 March 2024. A report will be provided to the REC on completion of the study.

Who is organising and funding this study?

This study is being funded by Ireland's Health Service Executive. They will be provided with an anonymised report at the end of the study. They will not access any personal data.

Will I be paid for taking part?

No, we are not paying you to take part in the study. We do, however, greatly appreciate your time and contribution to this research.

Part 4 - Further Information

What happens if I change my mind?

Your participation in this study is voluntary and you can change your mind before, during, and even after the interview. Please note, however, that we will not be able to remove your pseudonymised interview data once the data analysis phase of the study has been completed.

You do not have to give a reason for changing your mind and there are absolutely no consequences should you choose to do so.

If you would like to withdraw from the study, please contact Dr. Bridget Johnston [bjohnst@tcd.ie] or Dr. Katharine Schulmann [kschulma@tcd.ie] and they will arrange this for you.

We will not contact you again.

Who should I contact for information or concerns?

If you have any concerns or questions, you can contact:

Principal Investigator: Dr. Bridget Johnston

bjohnst@tcd.ie

(01) 896 2201

If you have any questions in relation to your rights under data protection law, you can contact the Data Protection Officer, Trinity College Dublin: Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: www.dataprotection.ie

Under GDPR, if you are not satisfied with how your data is being processed, you have the right to raise a concern with the Office of the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland. Website: www.dataprotection.ie

Part 5 - Next Steps

Will I be contacted again?

If you would like to take part in this study, we ask that you reply to us by email: Dr. Bridget Johnston [bjohnst@tcd.ie] or Dr. Katharine Schulmann [kschulma@tcd.ie].

We will also ask you to sign the Consent Form, which we have attached as separate document.

Thank you

Thank you very much for taking the time to read this Participant Information Leaflet.

You will be given a copy of this leaflet and the signed Consent Form to keep. Please retain these in case they are needed for future reference.

Document C2. Informed Consent Form

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Scoping decision-makers' needs for a National Palliative Care Atlas of Variation for Ireland (NPCAVI)

Informed Consent Form

STUDY: Scoping decision-makers' needs for a National Palliative Care Atlas of Variation for Ireland (NPCAVI)

Recruitment Site: Trinity College Dublin

There are two sections in this form.

Section 1 contains statements of understanding and asks you to tick each if you understand. Please ask any questions you may have when reading each of the statements.

Section 2 asks for your informed consent. Please select either 'yes' or 'no' to indicate your choice.

Thank you for participating.

The end of this form is for the researchers to complete.

1. General Understanding	Tick
I confirm that I have read and understood the Participant Information Leaflet for the above study. The information has been fully explained to me and I have been able to ask questions, all of which have been answered to my satisfaction.	
I understand that taking part in this study is entirely voluntary. I understand that not taking part will have no negative impact on me.	
I understand that I can leave this study at any time without giving a reason. I understand that leaving this study will have no negative impact on me, now or in the future.	
I understand that I will not be paid for taking part in this study or receive any benefits from any products developed as a result of this research study.	
I know how to contact the research team if I need to.	

By ticking each box above and choosing my options below and signing this document I agree to participate in the NPCAVI study as described in the Participant Information Leaflet.	
2. Consent	**Tick**
I agree to take part in this research study, involving a one-to-one interview with a member of the research team, having been fully informed of the risks and benefits in the Participant Information Leaflet provided to me.	Yes ☐ No ☐
I agree to the use of information about me (personal data) including my name, email address, employer, and information recorded during the interview being used by the research team for this research study as described in the Participant Information Leaflet.	Yes ☐ No ☐

Participant Name (Block Capitals) Participant Signature Date

Witness Name (Block Capitals) Witness Signature Date

To be completed by the Principal Investigator or nominee.

I, the undersigned, have taken the time to fully explain to the above participant the nature and purpose of this study in a way that they could understand.

I have explained the risks and possible benefits involved. I have invited them to ask questions on any aspect of the study that concerned them.

I have given a copy of the participant information leaflet and consent form to the participant with contact details of the study team.

Researcher name _____

Title and qualifications _____

Signature _____

Date _____

Copies to be created and retained: 1 for Participant, 1 for PI.

Document C3. Invitation letter to potential participants

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Scoping decision-makers' needs for a National Palliative Care Atlas of Variation for Ireland (NPCAVI)

Invitation to participate in Key Informant Interviews

Dear ,

I am the Principal Investigator on a Health Service Executive Research Award funded project entitled, 'Scoping decision-makers' needs for a National Palliative Care Atlas of Variation for Ireland (NPCAVI).'

This project lays the groundwork for future development of an Atlas of Variation for palliative/EOL care in Ireland by drawing on international best practice and stakeholder input from within Ireland. In order to gather input from relevant stakeholders, we are conducting interviews with people with expertise in the planning and provision of palliative care services, and with expertise in health and social care data infrastructure more generally. These interviews will help identify priorities and issues of feasibility for development of an Atlas of Variation for Ireland.

The purpose of this research is to identify and learn from excellent examples of Atlases of Variation in use in other countries, to map current data availability and priorities for data infrastructure in the area of palliative/EOL care in Ireland moving forward, and ultimately to formulate recommendations to support development and implementation of the Atlas of Variation for Palliative and End of Life Care in Ireland.

The research project will apply a multi methods approach, including a scoping review, data mapping, and as mentioned above, semi-structured interviews with key informants to gather evidence.

This letter is to kindly request an interview with you given your relevant experience and expertise [in the field of palliative/EOL care *OR* health information systems].

Should you agree to take part in this study, your explicit consent will be required. Myself or my colleague in this piece of research, Dr Katharine Schulmann, will visit you at your office or another place convenient to you. Alternatively, if you prefer, the interview may also be conducted virtually. The interview should take about one hour and would constitute your full

participation in the study. I will record the interview which will be transcribed with encrypted software.

Participation in this research is entirely voluntary. You can choose not to participate without giving me a reason and there are no consequences for doing so. You may also withdraw your consent to participate at any time. Furthermore, your participation will remain anonymous and confidential, meaning that no one outside of the research team will know that you have chosen to participate, and your responses will not be shared or identified as your own.

I have included with this letter more information about the study as well as a consent form which I would ask you to sign if you choose to participate in the study.

Many thanks for taking the time to consider this request and hoping you agree to participate.

If you have any questions or wish to contact me, please do so at bjohnst@tcd.ie.

Thank you for considering participating in this study.

Kind regards,

Dr Bridget Johnston (Principal Investigator)

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Document C4. Interview topic guide

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Scoping decision-makers' needs for a National Palliative Care Atlas of Variation for Ireland (NPCAVI)

Interview Topic Guide

Aim: Semi-structured interviews with key informants to explore priorities and feasibility of data collection to inform future development of an Atlas of Variation for palliative/EOL care for Ireland.

Questions will be adapted depending on the specific expertise of the participant; however, our core questions include:

a) Can you please describe your professional background and your experience/trajectory in the field of palliative/EOL care *OR* health and social care data infrastructure?

    i. Can you please detail your current role/position within your organisation?

b) What do you consider to be the priorities in terms of data collection for an Atlas of Variation for Ireland?

c) What, if any, do you consider to be the gaps in current data availability and/or harmonisation that would need to be addressed in order for an Atlas of Variation to be realised?

    i. What, in your view are the facilitators/barriers to feasibility in these areas?

d) In your view, what would be required at the policy level in terms of data infrastructure/health information systems in order to realise an Atlas of Variation in Ireland?

    i. What, in your view are the facilitators/barriers to policymaking in this area, if any?

e) In your view, what would be required in terms of additional resources and capacity to realise an Atlas of Variation?

    i. What, in your view are the facilitators/barriers in this regard, if any?

f) What are your views on the feasibility of developing and implementing an Atlas of Variation in Ireland?

g) Is there something you would like to add that we have not discussed?

Appendix D. Project Advisory Group

Paul Kavanagh (Co-chair)	Consultant, National Health Intelligence Unit, HSE
Maurice Dillon (Co-chair)	National Lead for Palliative Care, National Strategy and Planning Office for Palliative Care, HSE
Brendan Kennelly	Member, All-Ireland Institute of Hospice and Palliative Care Voices4Care
Val O'Reilly	Consultant in Palliative Medicine, Milford Care Centre and University Hospital Limerick
Kerrie McLaverty	CEO, LauraLynn Children's Hospice
Fiona Kiely	Consultant in Palliative Medicine, Marymount University Hospital and Hospice
Mary Browne	Consultant in Public Health, Clinical Lead QPS Education, HSE
Rory Egan	Assistant Principal Officer, Older Persons Strategy Unit, DOH
Martina O'Reilly	Programme Manager, National Clinical Programmes for Palliative Care, and Office NCAGL Older Persons, HSE
Catherine Regan	Director of Nursing, Donegal Hospice