RESEARCH ARTICLE

Towards universal palliative care in Ireland: Scoping decision-makers' needs for an Atlas of Variation data mapping tool

[version 1; peer review: 1 approved, 1 approved with reservations]

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Abstract

Background

Despite Ireland's longstanding commitment to a national, universal system of palliative and end-of-life care (EoL), prior research has found inequitable variation geographically in provision and access to services, and a need for better data to inform planning in this area. This study investigates data priorities and feasibility of developing an Atlas of Variation data visualisation tool for palliative and end-of-life care in Ireland from the perspective of key stakeholders working across the system.

Methods

Drawing on a review of international atlas methodologies and semi-structured interviews with 17 stakeholders, including policymakers, service providers, service model/delivery experts, and data infrastructure experts, the research identifies key system level barriers and enabling factors to development of an atlas of variation for palliative care/EoL for Ireland.

Findings

Interview participants highlighted fragmentation of data sources, limits to interoperability and harmonisation, regulatory barriers, and an institutional culture that has yet to fully embrace evidence-based service planning and policymaking as key challenges. Existing strong stakeholder networks, analytic capacity, and consistent political will were identified as enablers.

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Any reports and responses or comments on the article can be found at the end of the article.

Conclusions

Foreit and colleagues' Data Demand and Information Use (DDIU) framework frames the discussion of the findings, underscoring the importance of considering non-technical aspects of health information systems, and the cyclical, interdependent nature of the evidence-based decision-making process in palliative care and in healthcare more broadly. The research has important implications for other jurisdictions with similar data infrastructure constraints seeking to use health data visualisation tools to enable more equitable service planning and delivery.

Keywords
Palliative and end-of-life care, health data

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Introduction

Research overview

Ireland published its first national policy on adult palliative care in 2001, effectively instituting a universally accessible system of publicly funded palliative care[1]. The country's palliative care system is thus something of an outlier within the broader healthcare system as Ireland is the only country in Europe without a universal healthcare system, though major initiatives are ongoing to this end under the country's 10-year programme of health reforms, *Sláintecare*[2]. Despite a policy of universal palliative care, there is evidence of persistent inequalities in service coverage and access[3,4]. Significant obstacles to evidence gathering in this area include gaps in current administrative palliative care data collection and interoperability, and in the country's weak health data infrastructure more broadly[5–7]. To facilitate improvements in palliative care service planning and delivery in future, Ireland's updated policy calls for development of an atlas of variation for palliative care[8].

Atlas of variation methodology uses small area geographic analysis to identify warranted and unwarranted variation in specific areas of healthcare provision, access, and health outcomes[9]. Pioneered more than half a century ago by developers of the Dartmouth Atlas Project in the US[10], atlases of variation have since been employed by health systems around the world as a powerful data visualisation tool to guide health service planning and delivery aimed at improving health equity. While atlases of variation have been developed to identify variations in a broad range of healthcare services and outcomes, few atlases of variation exist that focus on palliative and end of life (EoL) care even though access to palliative care is recognised by international health bodies as an essential component of universal healthcare[11].

This paper presents findings from a qualitative study exploring key stakeholders' views on development of an atlas of variation for palliative care for Ireland[12]. Interviews with stakeholders followed a review of the literature on existing atlases of palliative care developed in other jurisdictions. The research identified critical enablers and barriers to development of an atlas of variation, offering important lessons for other countries considering application of atlas of variation and alternative health atlas methodologies. Ultimately, the research found that while atlases of variation are undoubtedly a valuable tool, they are a challenge to realise in countries where the digitalisation and harmonisation of health data is nascent, as in Ireland, and an alternative hybrid approach that utilises both administrative, quantitative data sets and qualitative data may be more appropriate and indeed desirable given stakeholders' data needs and priorities. The study was funded by Ireland's Health Service Executive (HSE) through a collaborative partnership award, with the Lead Knowledge User based in the HSE's National Health Intelligence Unit.

Definition of palliative care

Palliative care is defined as "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"[11]. Access to palliative care is considered an essential component of universal healthcare by the World Health Organization[11]. As such, ensuring access to palliative care is 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 declared equitable access to palliative care an ethical imperative, stating, "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"[13].

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[14]. 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 and are funded primarily by the public sector. 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 in the world to publish a national policy on palliative care[1]. As mentioned earlier, an update to the 2001 policy, focused on addressing inequalities in access and capacity issues in the sector, was published in 2024[8].

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[3,4], with specialist services historically concentrated in the most populous cities of Dublin, Cork and Limerick. 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[4,8].

Palliative care services in Ireland are organised into three levels, structured by level of healthcare providers' specialisation: 1) Level one – Palliative care approach: all healthcare professionals should be aware of, and appropriately apply, palliative care principles; 2) Level two – Generalist palliative care: healthcare professionals not engaged full time in palliative care but have some relevant training; 3) Level three – Specialist palliative care: healthcare professionals whose core activity is providing palliative care (see Figure 1). Specialist palliative care units, referred to as hospices, act as hubs for specialist palliative care delivery in their respective geographic regions. 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

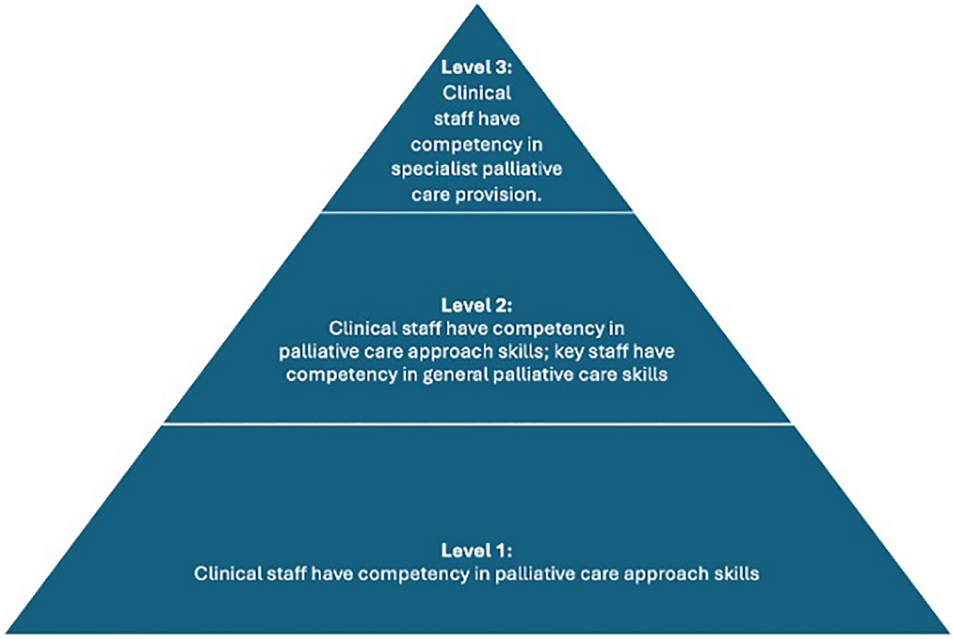

Figure 1. Palliative care expertise and specialisation levels in Ireland's model of integrated palliative care. Source: Adapted from Department of Health[8], Figure 2, p.14.

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. According to the national policy, all three levels of palliative care should be accessible to all individuals with palliative care needs, with access determined by the level of care need, irrespective of a person's ability to pay or place of residence[8].

Atlas methodologies applied in other jurisdictions to map aspects of palliative care

Atlas of variation methodology was pioneered by researchers at the Dartmouth Atlas Project in the US[10]. The key to the Dartmouth Atlas of Health Care, an active study to this day, is the application of small area analysis. In small area analysis, the unit of analyses are small, specific geographic areas used to identify variations in access to healthcare[9]. Explaining the significance of this methodology, Bronner and Goodman write, "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"[10].

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[9].

Since development of the Dartmouth Atlas, which includes a series of indicators or 'rates' on EoL as part of the larger atlas, several other atlases of palliative and EoL care have been published internationally. These include atlases that set out to compare data on palliative and EoL 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[15,16].

Over the past decade, the ATLANTES Global Observatory of Palliative Care based at the University of Navarra in Spain and a WHO Collaborating Centre for the Global Monitoring of Palliative Care Development since 2022, has collaborated with regional associations of palliative care and country level stakeholders to develop editions of the European Atlas of Palliative Care[17,18], the Latin American Atlas of Palliative Care[19,20], the Atlas of Palliative Care in the Eastern Mediterranean

Region[21,22], and the Atlas of Palliative Care in Africa[23]. The ATLANTES group's methodology 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[24].

The Worldwide Hospice Palliative Care Association, in collaboration with the WHO, published its second edition of the Global Atlas of Palliative Care in 2020[25,26], 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 in the US[27,28], Canada[16], England[29], and Scotland[30]. Notably, developers of the Canadian and Scottish atlases cite the ATLANTES Global Observatory's methodology as a reference point for selecting which domains to cover, adapting the methodology to meet their own aims and country contexts. The England Atlas most closely follows the approach of the Dartmouth Atlas, taking advantage of the availability of and access to large scale, administrative population-based healthcare data to guide the selection of its domains/indicators and populate them[29].

In reviewing the literature, an important definitional and methodological distinction emerged 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 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[10]. To achieve its aims, atlases of variation employ large administrative data sets to populate quantitative indicators that are regularly updated and fed into an online, interactive atlas. Only the US atlas[27] and the England atlas[29] 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, atlases adopting a broader interpretation of the term 'variation' have also been developed. These atlases' methodologies tend to apply larger geographical units of analysis, combine multiple existing data sets, and sometimes involve bespoke data collection instruments to compare aspects of palliative/EoL care in their respective jurisdictions. The regional atlases compiled by the ATLANTES group, 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 utilisation or health data, they map variation across domains and quantitative and qualitative indicators down to the county level, presented in an online, interactive tool.

There is also considerable diversity in terms of the domains and indicators included in the atlases reviewed. Table 1 above provides an overview of the domains included in seven atlases identified in our review. In each instance, the type of information captured by each of the atlases follows on from stated aims and objectives, which in turn are influenced by matters of feasibility, foremost the availability and accessibility of data, and resourcing. 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[25,26].

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

Methods

This qualitative study involved 17 semi-structured interviews with key stakeholders working across the palliative care system in Ireland (see Table 2). A review of international evidence and data mapping of available palliative care data in Ireland informed the topic guide for the semi-structured interviews with participants (see Supplemental File 1). Individuals with expertise in palliative care policy, the service delivery model, representatives of palliative care provider organisations, and data specialists with expertise in health information systems/data infrastructure related to palliative care were purposively sampled to participate in the interviews (see Table 2). Interviews were carried out with the aim of gaining participants' views on data priorities, barriers and facilitators, and feasibility

Table 1. Comparison of exemplar international atlases, by the data domains they include.

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.

Table 2. Interview participants, by area of expertise and institutional affiliation.

Interview No.	Area of expertise	Institutional Affiliation
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
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

of development of an atlas of variation for palliative care for Ireland. Having obtained participants' informed 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 both inductive and deductive codes[31].

The study was guided by an advisory group whose members convened and provided guidance and feedback to the research team at three critical junctures over the course of the project. The eight members of the advisory group were chosen for their expertise as clinicians, researchers, and managers with experience in the provision, organisation, or evaluation of palliative care services in Ireland. The project's Lead Knowledge User, Consultant in Public Health Medicine with the National Health Intelligence Unit, HSE, and the National Lead for Palliative Care, HSE, co-chaired the advisory group and served as gatekeepers in the recruitment of interview participants.

Research ethics approval for this study was granted by the Centre for Health Policy and Management/Centre for Global Health Research Ethics Committee, Trinity College Dublin, on March 20, 2024 [Ref Number: 3215]. Informed, written consent was collected from all individuals participating in the study. Data management processes complied fully with GDPR regulations.

Results

The interviews provide valuable insight into what palliative care decisionmakers consider important information to capture in an atlas of variation, and the key considerations, systemic barriers and enablers to developing an atlas. Five core thematic areas emerged from the analysis of the interview data addressing: Broad consensus on data priorities with a need for systematic co-production approach to defining atlas domains and indicators going forward; Integration and harmonisation of palliative care data, and by extension, of palliative/EoL care services; Resources and capacity; Governance; and 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.

Broad consensus on 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 Ireland's public healthcare system; and 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.

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[1] in Ireland—was seen by more than one interviewee as a major barrier to integrating data.

[1] 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/)

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 must be aligned with the health system's sub-national structures. In Ireland, these are in first order the six newly formed Health Regions, and within each of these, 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 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-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.

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]

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 analysing, gathering and you know, making sure it's accurate." [14, Service provider, Voluntary Hospice Group]

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.

Discussion

The findings demonstrate a strong appetite in the palliative care system at senior level for additional data collection and improved integration and accessibility of existing datasets. Alongside a clear desire for data that enables identification of geographic variation across need, access, and use of palliative care, the findings point to features of the palliative care and wider healthcare system that are limiting the realisation of stakeholders' data needs. These challenges are consistent with concerns raised by other studies on the state of Irish palliative care data, such as data fragmentation, data access issues, variability in data quality, and the need for a cultural shift towards valuing data as evidence to improve services and inform

policy[4–6]. Crucially, the research also points to a number of enablers to realising an atlas, including strong, existing stakeholder networks that could be leveraged to achieve consensus on the aims, governance, and data measures of a future atlas for palliative care.

MEASURE Evaluation's data demand and information use (DDIU) in health decision-making conceptual framework (see Figure 2) provides a useful lens for understanding the challenges and opportunities in developing a national palliative care atlas (of variation) for Ireland[32]. The central assumption underpinning the framework is that the primary purpose of health information systems is to inform better decisions—whether at the policy, planning, or service delivery level. In other words, the ultimate value of health data lies not in its collection or storage for the sake of it, but in its *use* with the aim of improving population health outcomes. The framework identifies four core elements of health information systems—data demand, data collection and analysis, information availability, and information use.

Data demand refers to the extent to which decision-makers actively seek information to support planning, policy, or service improvement. Demand can be latent or explicit, and is often influenced by institutional culture, leadership expectations, and previous experiences with data use. A strong data demand environment is one where stakeholders ask questions that data can answer, and where information is seen as essential rather than optional. *Data Collection and Analysis* involves the generation, organisation, and interpretation of data. It includes not only the technical processes of data gathering and cleaning, but also the analytical capacity to transform raw data into usable insights. Effective data systems require standardised definitions, interoperability between sources, and adequate human resources to ensure that data are reliable and meaningful. *Information Availability* must be timely, accessible, and presented in formats that decision-makers can use. Availability includes both technical access (e.g. user-friendly platforms, data visualisation tools) and interpretive access—ensuring that those who need the information can understand and apply it. Information that is difficult to access, overly complex, or buried in reports may technically exist but is functionally unavailable. *Information Use* refers to the actual application of information in decision-making processes. This includes routine use in planning, budgeting, service redesign, or advocacy. Information use is influenced by institutional processes, leadership, trust in data sources, and whether the data are perceived as relevant and credible. Even when all earlier components are in place, information may still not be used if these enabling conditions are absent. These four elements operate as a continuous process or cycle. Demand for information drives data collection; data collection supports availability; and available information, if used effectively, can create further demand. Weakness in any single element can undermine the entire system. Therefore, improving health data systems requires attention not just to technical solutions, but to the organisational, cultural, and political context in which data are made available and used. The next paragraphs reflect on the research findings in the context of the DDIU framework.

Data demand

The majority of interview participants expressed a clear and shared demand for better data on palliative and end-of-life care, particularly around service capacity, population need, and care outcomes. They articulated specific priorities for what should be captured—emphasising both specialist and generalist palliative care delivered across different care settings, and the importance of disaggregating data by (small) geographical area and care setting. Most participants also expressed a desire for a co-produced, policy-relevant tool, reflecting active information-seeking behaviour, a key indicator of strong data demand as defined in the DDIU framework.

At the same time, some variability in how participants understood the purpose and aims of an atlas for palliative/EoL suggests that this demand still needs to be further consolidated

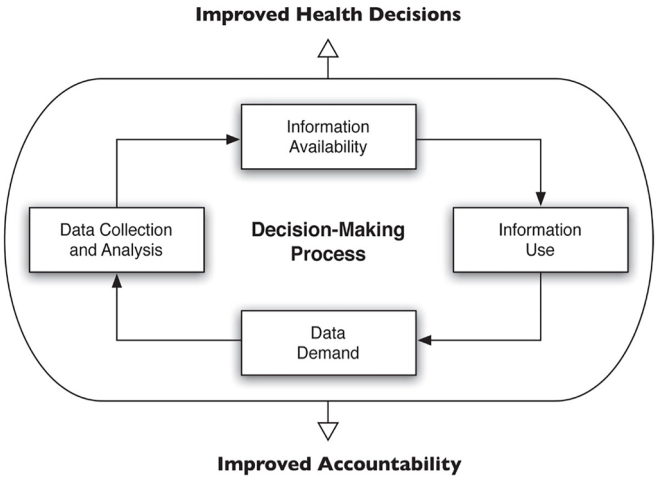

Figure 2. Data demand and information use in the evidence-based decision-making cycle. Source: Foreit, Moreland & LaFond[32], p. 3.

and formalised through structured engagement processes and consensus-building. This finding mirrors broader observations about the culture of evidence use in Irish policymaking, where despite increased commitment to evidence-informed policy, uneven demand for high-quality data persists[33].

Data collection and analysis

While participants agreed that significant relevant data are already being collected, they described a system hampered by fragmentation, poor interoperability, and inconsistent definitions—particularly across community and hospital care settings. The lack of routine use of the IHI was repeatedly cited as a significant constraint. These findings strongly echo Kelly and colleagues'[5] research, which demonstrated the persistent barriers to using administrative health datasets for palliative and end-of-life care research in Ireland, including incomplete capture of care episodes, inadequate metadata, and a lack of linkage across care settings.

Ireland's government has recognised many of these structural barriers and is moving to improve its health information infrastructure. Ongoing initiatives under the government's Digital for Care 2024–2030 strategy, such as the implementation of the Individual Health Identifier (IHI), the proposed Health Information Bill, and the development of the National Electronic Health Record[34] aim to create a more integrated, interoperable system for health data. While these reforms are at varying stages of implementation, they represent important foundations for enabling more comprehensive, linked palliative and end-of-life care data in the future.

Participants recognised that meaningful analysis would require investment not only in technical infrastructure but also in the human capacity to process and interpret linked data. This mirrors findings from the wider Irish health information system literature calling for investment to deepen health information expertise and analytical capacity[7].

Information availability

Participants were mostly in agreement that data collected and analysed as part of an atlas must be accessible, meaningful, and actionable. Some noted, however, that although many relevant datasets exist, they are often inaccessible to certain key stakeholders, or too technical for planning and operational decision-making. The importance of embedding outputs from a future atlas within Ireland's health system structures—specifically, the six new HSE Health Regions and their sub-structures—was noted as a practical step towards making information more locally relevant and usable. In recent years, the ATLANTES Global Observatory of Palliative Care has prioritised global, open access to the data underpinning their regional atlases, which in some instances has involved an explicit trade-off between access and inclusion of certain types of data[24].

Recent comparative international research by Hurley and colleagues[35] underscores the importance of this concern beyond just Ireland. Their review of 16 countries revealed that even where routine palliative care data are collected, they often fail to systematically capture critical domains such as service transitions, equity of access, and patient-reported outcomes—areas that the participants in this study explicitly prioritised. Without careful consideration of information availability and interpretability, an atlas risks reproducing existing data gaps.

Information use

Participants were clear that the ultimate value of an atlas of variation lies in its use as a decision-support tool. Several described current decision-making processes as still overly influenced by local lobbying or historical precedent, rather than systematically informed by data. This finding is consistent with prior analyses of evidence use in Irish policymaking, where political priorities and a tendency to short-termism have outweighed the systematic use of evidence in shaping decisions.

A well-governed atlas, updated and interpreted regularly, was seen by participants as a potential mechanism to shift decision-making dynamics—helping to guide service development and support more consistent, needs-based planning. However, many also recognised that data alone is not sufficient. For the atlas to be used, it must be seen as independent, credible, and embedded within the roles and responsibilities of those in decision-making positions. This finding reflects a broader understanding in health systems research that technical tools must be nested within institutional and cultural changes to be effective[36].

Conclusions

Our analysis illustrates both the promise and the complexity of developing a palliative care atlas of variation in Ireland. While there is clear demand for data and strong support for its use in decision-making, challenges remain in ensuring consistent data collection, integration, and availability. As noted in other research done to date on the Irish health information system, structural and infrastructural issues continue to limit the health system's capacity to generate and use meaningful palliative care data. A national atlas has the potential to address some of these barriers—but only if it is developed with sustained investment, clear governance, and ongoing stakeholder engagement.

Ethics and consent

Research ethics approval for this study was granted by the Centre for Health Policy and Management/Centre for Global Health Research Ethics Committee, Trinity College Dublin, on March 20, 2024 [Ref Number: 3215]. Informed, written consent was collected from all individuals participating in the study. Data management processes complied fully with GDPR regulations.

Data availability

The qualitative dataset generated and analysed during the current study has not been made publicly available due to

ethical restrictions. The data consist of interviews with a small number of individuals directly involved in policy and service delivery in Ireland, making full anonymisation impractical. The dataset contains potentially identifiable and sensitive information that could compromise participant confidentiality. Therefore, the authors did not deem it appropriate to share the raw qualitative data collected as part of this study (interview transcripts), and did not obtain ethical consent to do so. If readers have questions about the data, they can contact the corresponding author by email: schulmak@tcd.ie. Select quotes may be made available upon reasonable request to the corresponding author.

Acknowledgments

The authors would like to thank the Health Service Executive for funding this research. They are especially grateful to the project's Lead Knowledge User, co-chairs and members of the project advisory group, and all of the interview participants working across Ireland's palliative care service who contributed their time and expertise to this research.

References

1. Department of Health and Children: **Report of the National Advisory Committee on Palliative Care.** Dublin: Department of Health and Children, 2001.
Reference Source
2. Committee on the Future of Healthcare: **Sláintecare report.** Dublin: Houses of the Oireachtas, 2017.
Reference Source
3. Johnston BM, May P, McCauley R, *et al.*: **Out-of-hours specialist and generalist palliative care provision: an evidence review.** Dublin: Health Research Board, 2019.
Reference Source
4. Johnston BM, Ní Chéileachair F, Burke S, *et al.*: **Review of the implementation of the 2001 report of the National Advisory Committee on Palliative Care as it relates to adult palliative care.** Dublin: Department of Health, 2022.
Reference Source
5. Kelly M, O'Brien KM, Hannigan A: **Using administrative health data for Palliative and End of Life Care research in Ireland: potential and challenges [version 2; peer review: 2 approved].** *HRB Open Res.* 2021; **4**: 17.
PubMed Abstract | Publisher Full Text | Free Full Text
6. Matthews S, Pierce M, O'Brien Green S, *et al.*: **Dying and death in Ireland: what do we routinely measure, how can we improve?** Dublin: Irish Hospice Foundation, 2021.
Reference Source
7. Walsh B, Mac Domhnaill C, Mohan G: **Developments in healthcare information systems in Ireland and internationally, ESRI Survey and Statistical Report Series No.105.** Dublin: Economic and Social Research Institute, 2021.
Reference Source
8. Department of Health: **National Adult Palliative Care Policy.** Dublin: Department of Health, 2024.
Reference Source
9. Bronner KK, Goodman DC: **The Dartmouth Atlas of Health Care – bringing health care analyses to health systems, policymakers, and the public.** *Res Health Serv Reg.* 2022; **1**(1): 6.
PubMed Abstract | Publisher Full Text | Free Full Text
10. Wennberg J, Gittelsohn A: **Small area variations in health care delivery: a population-based health information system can guide planning and regulatory decision-making.** *Science.* 1973; **182**(4117): 1102–1108.
PubMed Abstract | Publisher Full Text
11. WHO: **Palliative care fact sheet**. 2020.
Reference Source
12. Schulmann K, Johnston BM: **Scoping decision makers' needs for a National Palliative Care Atlas for Ireland.** Dublin: Trinity College Dublin, 2024.
Reference Source
13. WHO: **Resolution WHA67.19: strengthening of palliative care as a component of comprehensive care throughout the life course.** Geneva: Sixty-seventh World Health Assembly, 2014.
Reference Source
14. HSE: **Palliative care services: five year/medium term development framework.** Dublin: Health Service Executive, 2009.
Reference Source
15. Herx L, Pereira J, Clark R, *et al.*: **The Canadian Atlas of Palliative Care: British Columbia edition.** Pallium Canada, 2024.
Reference Source
16. Pallium Canada: **Canadian Atlas of Palliative Care**. 2025; [Accessed April 14, 2025].
Reference Source
17. Centeno C, Lynch T, Donea O, *et al.*: **EAPC Atlas of Palliative Care in Europe 2013 – full edition.** Milan: European Association of Palliative Care Press, 2013.
Reference Source
18. Arias-Casais N, Garralda E, Rhee J, *et al.*: **EAPC Atlas of Palliative Care in Europe 2019.** Vilvoorde: European Association of Palliative Care Press, 2019.
Reference Source
19. Pastrana T, De Lima L, Sánchez-Cárdenas M, *et al.*: **Atlas of Palliative Care in Latin America 2020, 2nd Edition [Atlas de Cuidados Paliativos en Latinoamérica 2020, 2ª ed.].** Houston: International Association for Hospice and Palliative Care Press, 2021.
Reference Source
20. Pastrana T, De Lima L, Wenk R, *et al.*: **Atlas of Palliative Care in Latin America, 1st Edition [Atlas de Cuidados Paliativos de Latinoamérica, 1a edición]2013).** Houston: International Association for Hospice and Palliative Care Press, 2013.
Reference Source
21. Osman H, Rihan A, Garralda E, *et al.*: **Atlas of palliative care in the Eastern mediterranean region**. Houston: International Association for Hospice & Palliative Care Press, 2017.
Reference Source
22. WHO: **Assessing palliative care in the Eastern mediterranean region 2021**. Cairo: WHO Regional Office for the Eastern Mediterranean, 2023.
Reference Source
23. Rhee JY, Luyirika E, Namisango E, *et al.*: **APCA atlas of palliative care in Africa**. IAHPC Press, 2017.
Reference Source
24. Tripodoro V, Pons JJ, Bastos F, *et al.*: **From static snapshots to dynamic panoramas: the evolution and future vision of palliative care atlas in cross-national perspectives.** *Res Health Serv Reg.* 2024; **3**(1): 5.
PubMed Abstract | Publisher Full Text | Free Full Text
25. Connor S, Sepulveda Bermedo MC, (Eds.): **Global atlas of palliative care at the end of life**. Worldwide Palliative Care Alliance (WPCA), World Health Organization (WHO), 2014.
Reference Source
26. Connor S, (Ed.): **Global atlas of palliative care, 2nd Edition.** Worldwide Hospice Palliative Care Alliance (WHPCA), World Health Organization (WHO), 2020.
Reference Source
27. Dartmouth Atlas Project: **Dartmouth atlas of healthcare: end of life care**. 2024.
Reference Source
28. Goodman D, Esty A, Fisher E, *et al.*: **A report of the Dartmouth atlas project: trends and variation in end-of-life care for medicare beneficiaries with severe chronic illness**. The Dartmouth Atlas Project, 2011.
Reference Source
29. Public Health England: **Atlas of variation for palliative and end of life care in England: reducing unwarranted variation to improve health outcomes and value**. London: Public Health England (PHE) Publications, 2018.
30. Inbadas H, Gillies M, Clark D: **Scottish atlas of palliative care**. Dumfries: The University of Glasgow, 2016.
Reference Source
31. Braun V, Clarke V: **Using thematic analysis in psychology.** *Qual Res Psychol.* 2006; **3**(2): 77–101.
Publisher Full Text
32. Foreit K, Moreland S, LaFond A: **Data demand and information use in the health sector, conceptual framework**. Chapel Hill, NC: MEASURE Evaluation, 2006.
Reference Source

33. Ruane F: **Chapter 5: Introducing evidence into policy making in Ireland**. J. Hogan & M. P. Murphy (Eds.). *Policy analysis in Ireland*. Bristol: Bristol University Press, 2021.
Publisher Full Text

34. Department of Health: **Digital for care: a digital health framework for Ireland 2024–2030**. Dublin: Department of Health, 2024.
Reference Source

35. Hurley E, May P, Matthews S, *et al.*: **What gets measured in palliative care? A review and synthesis of routine data collection in 16 countries.** *Health Policy Open.* 2025; **8**: 100141.
PubMed Abstract | **Publisher Full Text** | **Free Full Text**

36. Nutley T: **Improving data use in decision making: an intervention to strengthen health systems**. MEASURE Evaluation, 2012.
Reference Source

Open Peer Review

Current Peer Review Status: ✔ ?

Version 1

Reviewer Report 04 November 2025

https://doi.org/10.21956/hrbopenres.15564.r50269

?

Ailish Hannigan
University of Limerick, Limerick, Ireland

This paper addresses an important area of research and explores the potential of an underused methodology (atlas of variation).

Comments:
Title
The title uses decision-makers - elsewhere in the paper key informants or stakeholders are used. It would be useful to standardise terminology. Does **needs** capture the type of information collected?

Introduction
The research overview section introduces concepts that have yet to be defined and summarises the findings of the research before we get to the Methods section. There is also some duplication of content. It may work better to start with the definition of palliative care and remove the overview from the introduction.

The introduction mentions a literature review/our review. It isn't clear whether the review and its findings are background context for this study or part of this study. For example, how was the literature review conducted? Is it published or available? How were the domains identified in Table 1? Some of these domains need more explanation e.g. resources and services.

The introduction ends without an overall aim and specific objectives for this paper, and these would be helpful to frame the Methods, Results and Discussion.

Methods
The Methods section is brief, and it would be helpful to use a reporting tool for qualitative research to guide the information provided e.g. were all the interviews conducted by the same person, were they online or in-person, how long were they, how many members of the research team conducted the analysis, reflexivity, etc. Gatekeepers are mentioned but it would be useful to know more about recruitment – how people were asked and when.

The authors reference Braun & Clarke and their recent paper may be useful
(Braun, et al., 2025) - ref 1
There is no public representation in the list of participants despite the growing evidence of the role of patient and public involvement in palliative care research and also as stakeholders for the sharing of data.
(Bedenik, et al., 2025) - ref 2.

Is there a link available to the supplemental file with the topic guide?

Results
Again, sometimes the people interviewed are called participants and sometimes key informants – it would be useful to standardise terminology.

The findings section of the abstract suggests the results are organised into barriers and facilitators, but this isn't followed through in the Results section. It may be useful to consider barriers and facilitators for each of the themes that emerged.

Discussion
A justification for the choice of framework for the Discussion would be useful – has it been used in the context of palliative care data?
Adding strengths and limitations of this research and future research would strengthen the discussion.

References
1. Braun V, Clarke V: Reporting guidelines for qualitative research: a values-based approach. *Qualitative Research in Psychology*. 2025; **22** (2): 399-438 Publisher Full Text
2. Bedenik T, Geaney F, Foley B, Flynn R, et al.: If it wasn't for us, there would be no data: stakeholders' perspectives on patient involvement in the use of health data in Ireland. *Research Involvement and Engagement*. 2025; **11** (1). Publisher Full Text

Is the work clearly and accurately presented and does it cite the current literature?
Yes

Is the study design appropriate and is the work technically sound?
Yes

Are sufficient details of methods and analysis provided to allow replication by others?
Partly

If applicable, is the statistical analysis and its interpretation appropriate?
Not applicable

Are all the source data underlying the results available to ensure full reproducibility?
No

Are the conclusions drawn adequately supported by the results?

Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Health information systems; secondary data analysis

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Reviewer Report 22 September 2025

https://doi.org/10.21956/hrbopenres.15564.r49506

Shih-Chun Lin
Kaohsiung Medical University, Kaohsiung, Taiwan

1. This is a well-structured and organized piece of work.
2. The background and aim sections are clear, but there are several abbreviations throughout the text that may hinder reader comprehension. It is important to include the full names for terms such as GDPR, WTE, and GIS.
3. In the methods section, the data collection sites and the timing of the interviews are not mentioned. Additionally, it would be helpful to state the number of participants at the beginning of the results section.
4. The discussion provides good insights into the challenges in developing a national palliative care atlas of variation for Ireland; however, it lacks a discussion on the potential limitations of the study.
5. The conclusions drawn are appropriate.

Is the work clearly and accurately presented and does it cite the current literature?
Yes

Is the study design appropriate and is the work technically sound?
Yes

Are sufficient details of methods and analysis provided to allow replication by others?
Partly

If applicable, is the statistical analysis and its interpretation appropriate?
Yes

Are all the source data underlying the results available to ensure full reproducibility?

Yes

Are the conclusions drawn adequately supported by the results?
Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Pediatric palliative nursing

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.