

Access to Specialist Palliative Care Services and Place of Death in Ireland

What the data tells us





THE IRISH
HOSPICE
FOUNDATION

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Foreword

How we care for the dying is a fundamental mark of our evolution as a society. For the person who is dying, impeccable assessment of their individual needs and the provision of care appropriate to those needs, for themselves and their caregivers, both through the dying process and afterwards, is the best support we can provide to ensure a good death. This assessment and care is the core role of the healthcare professional providing end-of-life care in the home, hospital or hospice.

However, if society endorses the belief that everyone has the right to access high-quality care at the end of life, then we as a society have a duty to look at society's needs at the level of population health, so that we can, through policy, service planning and community engagement, enable the basic human right of a 'good death' to be fulfilled for every citizen. We also need to plan how we deliver and pay for this care. We echo the belief articulated by Cohen and Deliens, writing on this approach, when they say that: *"Good end of life care is amenable to population based and public sector interventions and has the potential to improve the circumstances of dying on a population scale."*¹

This population health approach was translated into national policy in Ireland in 2001, when a commitment was made to develop specialist palliative care services nationally. Twelve years on, we see from the analysis of data in this report that wide regional variation persists in the provision of hospice beds, resulting in significant inequity in access to services. This is unacceptable – particularly to the estimated 2,500 dying patients who are being denied access to specialist care appropriate to their needs every year.

Furthermore, we know that need will increase. We are expecting a staggering rise in the number of older persons in our population over the next 30 years, with a concurrent rise in 'frail elderly' and in chronic illness, including dementia, and this epidemiological transition requires us to focus on the development of both specialist and more general end-of-life and palliative care services nationally. We need to act *now* to meet the needs of the fast-approaching future.

Compelling international evidence tells us that palliative care is effective not only in terms of its benefits to patients at the end of life, but also because it is cost effective, which means that it has the potential to deliver cost savings to the Irish healthcare system. This is of immense relevance today, when our health service is undergoing seismic change against a backdrop of chronic funding deficits and the challenge of increasing needs.

One way to use resources more effectively is to divert them towards more home care. We know from Irish and international research that about two-thirds of our population want to die in their own home. The reality is that overall, only 26% of people in Ireland achieve this wish, and again, the data in this report reflects wide regional variation. We can see that the provision of specialist palliative home care nurses makes a critical difference in enabling a person to remain at home until death, and in moving forward, hospice home care services must be protected. This report shows that some areas of the country are doing better in this regard than others, and we need to begin to discuss solutions to the issues by sharing the experiences of models of care that appear to be most effective.

¹ A Public Health Perspective on End of Life Care (OUP, 2012)

Specialist palliative care is part of a jigsaw of service provision which looks to meet the needs of those approaching the end of life, wherever they may be. This specialist care is the main focus of this report. We know that not everyone facing the end of life in Ireland will need specialist palliative care, but specialist palliative care services also have a key role to play in supporting community health service providers and all patients in the community who are approaching the end of life and who could benefit greatly from different levels of palliative care. In this way, expertise is spread to where it is most needed.

We do not have all the answers. The data we present is limited in terms of its accuracy and completeness. But we have made a start to what we hope will be a vibrant discussion in health services and departments nationally. We hope that we have sparked a process whereby national datasets relevant to end-of-life care issues will be further mined and explored to answer questions, prompt debate and change mindsets well into the future.

Unless a concerted effort is made to find innovative solutions to the inequity highlighted in this report, through active research and the exploration of funding options, little progress can be made. We welcome the government's recent commitment to assist the HSE to complete a prospective funding model for palliative care as part of the health service reform programme, and we call on decision makers to consider, within this, the development of hospice inpatient units; generalist palliative care services through community and primary care; and palliative care services in the acute hospital setting, as outlined in the HSE's 2009 Five-Year Development Framework for palliative care services. Care at the end of life is important, and the Irish healthcare system needs to actively manage its approach to palliative and end-of-life care, fulfilling the promises made in national policy and frameworks for development.

I would like to thank Eugene Murray, who undertook the core research and original writing of this report; Stephen Toft of the HSE, for his meticulous advice on the data emerging from the HSE's Palliative Care Minimum Data Set, and Dr. Kathy McLoughlin, for her additional commentary, writing and editing, along with a number of individuals who generously agreed to read and input to this report at various point along its journey.

Sharon Foley

Chief Executive Officer

The Irish Hospice Foundation

Executive Summary

The aim of this report is to provide data, analysis and commentary to stimulate discussion on emerging trends in relation to the provision of specialist palliative care in Ireland. The report mines existing data from four key sources – the Health Service Executive’s (HSE) Minimum Data Set for Palliative Care (MDS, 2011); the National Cancer Registry (NCRI, 2010); the Hospital Inpatient Enquiry (HIPE, 2010), and HSE population records (2011) – to compare and contrast administrative regions of the health service² against national averages on a number of key indicators (number of hospice beds, waiting times for first assessment of patient, place of death, etc), and to examine the impact of varying levels of investment in palliative care on access to services and service activity. In particular, the report seeks to explore possible relationships between access to specialist palliative care services and place of death. It is clear from the data emerging from all four sources that there is a marked correlation between the availability or otherwise of hospice/palliative care services and where people die.

In most regions, similar resources are committed to total inpatient beds, combined across all healthcare settings, e.g. acute hospitals, long-stay facilities and hospices. Most regions have approximately 80-90 beds per 10,000 of the population. When we look specifically at hospice beds, however, just two regions – the Mid West and North West – come close to fulfilling government policy by providing one hospice bed per 10,000 of the population, equating to approximately 1% of total inpatient beds. These two regions are almost fully compliant with the recommendations of the *Report of the National Advisory Committee on Palliative Care* (NACPC, 2001), adopted as national policy in 2001. Therefore, the specialist palliative care services of the Mid West (comprising Limerick, Clare and North Tipperary) and North West (Donegal, Sligo and Leitrim) have been used as the ‘benchmark’ in this report.

Sixteen counties of Ireland, on the other hand, have **no** access to hospice beds, undermining the capacity of the HSE, through the Palliative Care Programme, to deliver on its commitment to equity of access to hospice care. The HSE’s 2011 Palliative Care Minimum Data Set shows the impact on patients of this wide regional variation in the provision of hospice beds. Quite clearly, it means that in some areas of the country patients at their most vulnerable are being denied access to services simply because of where they live. The target in the HSE’s 2013 Service Plan that 92% of referrals to hospice beds be fulfilled within seven days is irrelevant to these patients, who cannot be referred to hospice inpatient care at all, because no hospice beds exist.

A comprehensive regional specialist palliative care service requires both an inpatient facility (a hospice) and a home care service working in tandem. In regions with well-resourced palliative care services, where both of these are in place, more than ten times more patients at any point in time are being cared for in their own homes (by hospice home care teams) than in hospice inpatient beds. The average length of stay in home care is almost six months compared to approximately nine days in hospice inpatient services (Voluntary Hospices Group, 2011).

² When the Health Service Executive (HSE) was established, the geographic areas previously under the administration of eight regional Health Boards were replaced by four new administrative regions. Since several key documents referred to in this report pre-date the re-structuring, much of the regional data has been presented in terms of the former Health Boards regions, for ease of reference. In other cases, the data is presented in terms of the current four HSE regions and 32 Local Health Offices (LHOs). See Appendix 1 for details.

Main findings

- This report estimates that because of regional inequity in resource allocation, approximately 2,470 patients are denied admission to hospice beds in Ireland each year. The calculation is based on the rate of access to hospice beds per head of the population in the well-resourced regions of the Mid West and North West.
- While 67% of Irish people express a preference to die at home, in reality only 26% of the circa 28,000 deaths that occur in Ireland each year take place in the home, and 43% occur in hospital. In contrast, 40% of all patients cared for by hospice home care teams die at home.
- Regions which are close to compliance with national policy in the provision of hospice beds show a significant reduction in the number of deaths occurring in acute hospitals. The impact of the unequal availability of hospice services on where people die is illustrated by several examples:
 - ▶ Only 7% of home care patients in the well-resourced hospice services of the Mid West die in acute hospitals, in contrast with 32% in the North East.
 - ▶ The 2010 National Cancer Registry shows that just 21% of all cancer deaths in the Mid West occurred in an acute hospital, compared to 52% in the North East.
 - ▶ The 2010 Hospital Inpatient Enquiry data shows that cancer accounts for just 16% of all deaths in an acute hospital in the Mid West, compared to 29% in similar hospitals in the South East and North East.
- In some regions which provide both hospice inpatient services and home care services (Dublin, Cork and Galway) there appear to be challenges associated with access and waiting times for home care when compared to regions offering home care only. In the latter regions, there are generally more patient admissions and shorter waiting times for home care, and more patients are seen with conditions other than cancer. The Mid West is exceptional in providing both inpatient services *and* speedy access to home care.

Most importantly, this report highlights a range of international research demonstrating that significant savings can be achieved when patients have access to comprehensive hospice inpatient and home care services, with greatly reduced admissions and lengths of stay in expensive acute hospital care.

There has been a consistent commitment by successive governments, the Department of Health and the HSE to deliver equal access to hospice services. The failure to implement national policy in relation to specialist palliative care means that many people who are dying are being denied access to fundamental aspects of end-of-life care. These issues can be addressed without major resource implications, by reconfiguring and standardising the allocation of resources across regions. Reconfiguring existing bed provision so that just 1% of all inpatient beds in healthcare settings are hospice beds will resolve this inequity. The HSE has endorsed this resource re-allocation, and in 2009 outlined an implementation strategy as part of its Five-Year Development Framework for palliative care services (HSE, 2009). This Framework provided for nine new inpatient units and the elimination of deficits in home care teams.

Since then, new hospice inpatient units have been built in Blanchardstown and Cork – but the beds in these units have not been operational to date. It is encouraging that the HSE's Regional Service Plans for 2013 suggest a significant commitment to advancing the implementation of the Five-Year Framework. Included are plans for the opening of 20 additional beds in the new unit in Cork, and commitments to progress the development of hospice inpatient units in Drogheda, Waterford, Tralee and Mayo, along with additional inpatient beds in Galway. No progress has been indicated as regards the inpatient units proposed by the Framework for the Midlands or Wicklow.

While the voluntary sector will contribute significantly to the capital costs of new hospice units, securing the annual revenue required to run them will be very challenging in the current economic climate – yet the implementation of the Five-Year Framework is central to ensuring that people facing the end of life receive appropriate care and can die where they wish, regardless of where they live. A commitment in the government’s recently published document, *Future Health – a Strategic Framework for Reform of the Health Service* (DOH, 2012), offers a potential solution, in that it proposes a new funding model based on a system called ‘prospective funding’, whereby ‘the money follows the patient’. This “*will create incentives that encourage treatment at the lowest level of complexity that is safe, timely, efficient, and is delivered as close to home as possible... This, along with other initiatives such as the introduction of integrated payment systems, will help to support integration between primary, community and hospital care*”. The new strategy states, “*The HSE is currently working on a prospective funding model which will assist in integrating and accounting for palliative care across all funding streams and delivery models... The Department of Health will work with the HSE to complete a prospective funding model for palliative care in 2013.*”

The Irish Hospice Foundation will engage in partnership with all stakeholders to ensure that in the future, all patients with advanced chronic illness who are facing the end of life will have equal access to hospice services. We share the aspirations articulated in *Future Health* and welcome the introduction of the new ‘money follows the patient’ funding model.

Section 1 Introduction

This paper is one of a series of discussion documents from the Irish Hospice Foundation that aim to stimulate thought and debate about specialist palliative care services in Ireland, and to consider the impact of service availability (or otherwise) on issues associated with death and dying for the Irish population. The papers are written using a public health advocacy approach to examine the need for services nationally, and are therefore underpinned by the following principles:

- **Human Rights** – recognising health as a basic human right is the basis for all public health advocacy. ***We believe everyone has the right to a good death and should have access to high-quality care to enable this to happen.***
- **Equity** – advocating for equality of access, participation and outcomes in health and health service utilisation and for the reduction of inequalities in health. ***We believe that areas without access to high-quality palliative care should be a focus for immediate activity.***
- **Democracy** – enabling people, communities and organisations to participate in decision making which impacts on health. ***We believe communities within regions have a role to play in advocacy, health planning and supporting others in their community living with death, dying and loss.***
- **Inclusion** – working in partnership with people, communities and organisations to ensure inclusion across sectors, communities, individuals and representative organisations. ***We believe that using papers such as these, we can stimulate debate on where solutions can be found.***

The specific focus of this paper is to investigate the relationship between access to specialist palliative care services and place of death, through the mining and interpretation of data collated from four key sources:

- The HSE's Palliative Care Minimum Data Set (MDS, 2011)
- The National Cancer Registry (NCRI, 2010)
- The Hospital Inpatient Enquiry (HIPE, 2010)
- HSE national and regional population statistics, 2011.

In exploring the relationship between access to specialist palliative care services and place of death, we highlight a number of key points:

- The pattern toward rapidly declining numbers of people dying in their own homes is in many cases not in line with their preferences and presents a challenge for the health system.
- Hospice/specialist palliative care services have a key role to play in resolving this dilemma, by ensuring that patients with advanced life-limiting illness who have complex symptoms are moved out of the acute care system when it is appropriate to do so, and are supported by comprehensive palliative care services in a range of settings (home, hospice, nursing home) as determined by their clinical needs, personal preferences and family support structures.

- There is demonstrable regional inequity in the provision of hospice/palliative care services in Ireland, impacting on where people die.
- The current inequity in patient access to hospice/palliative care services is not the result of a lack of resources within the health system, but a reflection of the manner in which resources are currently allocated and services organised within each region.
- By managing existing resources more effectively, many more people can be facilitated to be cared for and to die outside of acute hospitals, in their preferred place of care, perhaps without extra expenditure to the state. While it has always been difficult for health systems to transfer resources from one place of care to another, reforms currently proposed for the Irish health system offer opportunities for resource re-allocation. In particular, the Government's proposed model of 'prospective funding', whereby 'the money follows the patient', could provide a sustainable revenue stream for new hospice inpatient beds in areas with a proven deficit in such beds.

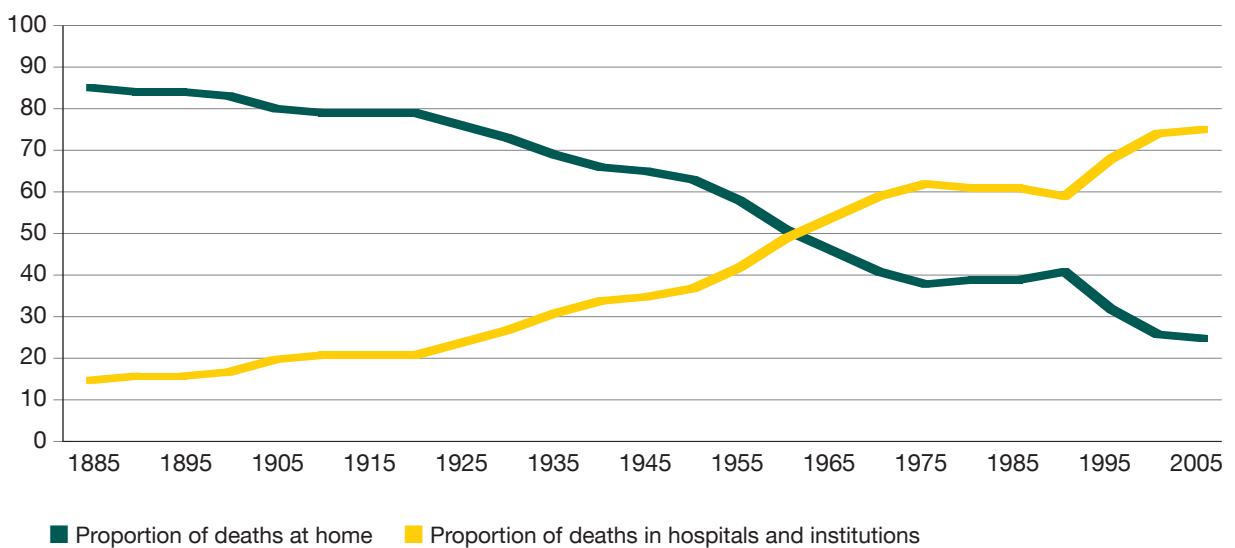
As already stated, the data used in this report has been mined from existing sources, and while every effort has been made to ensure that it is correct, any inaccuracies noted should be reported to the Irish Hospice Foundation.

Since a number of key documents repeatedly referred to in this report relate back to the 'old' health service structures (prior to the establishment of the HSE), much of the regional data has been presented so as to correspond to the eight former Health Board regions, for ease of reference. In some cases, however, the data reflects the four current HSE regions and 32 Local Health Offices (LHOs). See *Appendix 1 for details*.

1.1 Place of care and death in Ireland

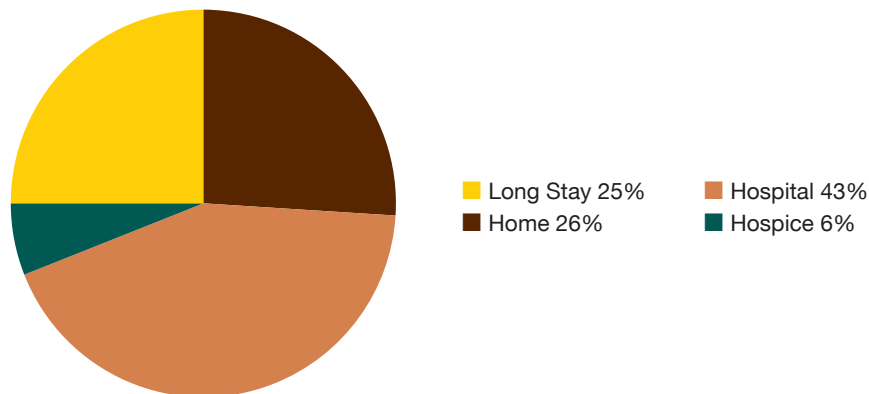
Over the last century, there has been a gradual institutionalisation of end-of-life care and death in Western society. In Ireland, where once it was the norm to die at home, most people now die in hospitals or care facilities, and only about 26% of deaths occur at home (*Fig. 1*).

Figure 1: **Institutionalisation of death in Ireland, 1885-2005** (*McKeown et al., 2010*)



Estimates regarding place of death in Ireland confirm this trend and provide further insights (Fig. 2). Inpatient care settings now account for the place of death of 74% of the Irish population.

Figure 2: **Place of death in Ireland 2010** (McKeown, NYP)



Studies suggest that between 67% (Weafer and Associates, 2004) and 80% (Tiernan et al., 2002) of the Irish population wish to die at home, but despite this, as Fig. 2 shows, only 26% actually do so. There are many possible reasons for this, e.g. people changing their minds as illness progresses, the intensification of their care needs and the likely or perceived burden on family carers, but even allowing for such explanations, there is a significant gap between the number of people who wish to die at home and those who actually achieve this wish. It seems, therefore, that the institutionalisation of care at the end of life and eventual place of death, as highlighted in Figures 1 and 2, does not reflect the wishes of the majority of the Irish population.

Evidence collated from Ireland and the UK suggests that between 22% (McKeown et al., 2010) and 40% (UK National Audit Office, 2008) of deaths in hospitals could have taken place at home, since the patients did not have medical needs requiring hospital treatment and therefore could have been cared for elsewhere. This strongly suggests that more could be done to facilitate people to die where they would wish.

There is a well-documented capacity and funding crisis in the Irish hospital system, and there is compelling data to show that providing end-of-life care in an acute hospital is an expensive option. The HSE's *Acute Hospital Bed Use Review* (PA Consulting, 2007) highlighted the need to transfer resources away from the acute hospital system and toward services in the community. It found that almost 40% of patients in acute hospitals were there unnecessarily, and that unless action were taken, there would be a requirement to build a new acute hospital every year and increase acute bed provision by almost 60% by 2020.

The need to transfer more care to the community setting has been well recognised by government policy, e.g. in the Government's Action Plan for Social Inclusion 2007-16 (Government of Ireland, 2007), health service delivery strategies (HSE, 2010, 2012) and *Future Health: A Strategic Framework for Reform of the Health Services* (DOH, 2012). These all suggest that enabling more people (particularly those with long-term chronic illness) to die at home could be extremely beneficial to overall health service delivery.

In addition to the economic benefits, there are also issues related to the quality of care that patients (and their families) receive at end of life. There is emerging evidence to suggest that *where* people die has an impact on *how* they die, and that those who die at home and in the place they prefer have a better 'quality of dying' than those who do not (McKay et al., 2012; Curtis et al., 2002). However, other studies suggest that the range of services available within the end-of-life care location is of vital importance (UK Office for National Statistics, 2012).

1.2 Role and development of specialist palliative care in Ireland

Palliative 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, 2004). Palliative care can be provided at different locations and at different levels of speciality, based on the needs of the patient and family and on the level of expertise of the staff providing the service, as follows:

- **Level 1 – Palliative Care Approach:** Palliative care principles should be appropriately applied by all health care professionals.
- **Level 2 – General Palliative Care:** At an intermediate level, a proportion of patients and families will benefit from the expertise of health professionals who, although not engaged in full-time palliative care, have had some additional training and experience in palliative care.
- **Level 3 – Specialist Palliative Care:** Specialist palliative care services are those services which are limited, in terms of their core activities, to the provision of palliative care.

Enabling people to die where they choose is an important aim of palliative care (Field, 1997).

The need to provide equitable specialist palliative care services in Ireland has been fully acknowledged since 2001, when the *Report of the National Advisory Committee on Palliative Care* (NACPC, 2001) was published by the Department of Health & Children, and its recommendations were adopted as official government policy. This report stated that each of the eight regional health boards then in existence should have a comprehensive specialist palliative care service to meet the needs of patients and families within its administrative area. Historically, however, there has been uneven development between these administrative areas.

Critically, the report recommended that:

- Palliative care should be available in all care settings: hospice inpatient units, acute general hospitals and the community.
- Services should allow patients to move between care settings.
- Any person in need of palliative care should be able to access it in a timely manner in a setting which is, as far as is reasonably feasible, consistent with their needs or preferences.
- There should be 10 inpatient hospice beds per 100,000 of the population, and at least one inpatient hospice unit per health board area.

- The hospice inpatient unit should act as the ‘hub’ of the specialist palliative care service, facilitating the movement of patients to the most appropriate care setting during the course of their illness.
- Minimum staffing in specialist palliative care should comprise:
 - One nurse per hospice inpatient unit bed
 - 0.5 care attendants per bed
 - One physiotherapist, one occupational therapist and one social worker per 10 beds
 - Two spiritual care chaplains per hospice
 - One pharmacist per hospice
 - At least one consultant in palliative medicine per 160,000 of the population, with at least two consultants in each health board area
 - At least three or more non-consultant doctors per palliative medicine consultant
 - A consultant-led multidisciplinary team in each acute hospital with 150 beds or more (to include nursing and social work, as well as non-consultant doctors)
 - A minimum of one specialist palliative care nurse in the community per 25,000 of the population
 - At least one physiotherapist, one occupational therapist and one social worker in the community per 125,000 of the population.

In 2004, in the absence of any official data and in order to measure progress against national policy, the Irish Hospice Foundation undertook a detailed nationwide study, published under the title, *A Baseline Study on the Provision of Hospice/Specialist Palliative Care Services in Ireland* (IHF/HSE, 2006). This involved an activity-based total costing exercise that enumerated and costed all the members of all multidisciplinary specialist palliative care teams, in all care settings, within each health board area, as at December 2004. The findings highlighted a significant shortfall in funding and in the provision of beds and staff, including:

- Wide disparity between health board areas in the level of expenditure on services, from €1.50 per capita in the Midlands to €31 per capita in the North West.
- Three health board areas, representing 12 counties, with no access to hospice inpatient beds.
- A national deficit of 258 palliative care beds and 744 palliative care staff.
- Regional variations in state funding for home care services, from 100% to 0%.
- No multidisciplinary support (physiotherapist, occupational therapist, social worker) for most home care nursing teams
- Only two of the country’s 22 home care teams available on a 24-hour basis.
- 11 of the country’s 38 acute general hospitals with over 150 beds with no palliative care team.
- Poor access to services for non-cancer patients compared to those with cancer diagnoses.

Officially launching the Baseline Study in March 2006, the then Minister for Health and Children, Mary Harney, acknowledged the need to double the budget for hospice services from €70m to €140m.

An update of the Baseline Study was undertaken in 2007 by the Irish Hospice Foundation and published in 2008. The data showed that little had changed since the original study and highlighted where development needs were greatest nationally.

In April 2008, Minister Harney stated:

“Under the Programme for Government, the Government has committed to removing the regional disparities in the provision and funding of palliative care and to ensuring that the needs of all those who require palliative care are met. The HSE is continuing to work on implementing the Report of the National Advisory Committee on Palliative Care (2001) and is now developing a five-year implementation framework...”

This framework, detailed in the document, *Palliative Care Services – Five-Year/Medium Term Development Framework* (HSE, 2009) was completed with the agreement of all stakeholders and launched in 2009. It included commitments to:

- More than double the number of hospice beds, from 153 to 356.
- Build nine new hospices, in Waterford, Kilkenny, Tralee, Castlebar, Cavan, Drogheda, Wicklow, Blanchardstown and Kildare.
- Provide additional hospice beds in Cork, Galway, Sligo and Letterkenny.
- Double the HSE’s annual budget of €75m for palliative care.
- Action a €250m capital programme, with €90m coming from the voluntary sector.
- Strengthen palliative home care teams to comply with recommended staffing levels nationally, requiring an additional 120 multidisciplinary staff.

It was clear even at the time, however, that no further funding was likely to be made available for service developments, with the Foreword to this key report admitting that: *“...the current economic environment is not conducive to the possibility of further development funding for palliative care services”*.

To date, the majority of the targets contained in the Framework document remain to be reached. As of early 2013, for example, patients in the former health board areas of the Midlands, South East and North East, comprising 12 counties, still have no access to hospice beds. The new hospice unit at Blanchardstown in West Dublin has been completed but awaits revenue funding to enable it to commence offering services to patients. The HSE’s Service Plans for 2013 do indicate that progress is anticipated in the current year. HSE South is to open the 20 additional beds in the newly constructed unit in Cork, and will pursue the development of new hospice units in Waterford and Tralee. HSE West has committed to progressing a new hospice unit for Mayo and additional hospice beds in Galway, and HSE Dublin North East has sanctioned a new hospice unit for Drogheda. There have been no indications from HSE Dublin Mid-Leinster, however, as regards the hospices proposed in the Five-Year Framework for the Midlands and Wicklow.

Given the present extreme financial constraints, it is unclear how these service developments will be achieved – although the Foreword to the Framework document stated that the priorities identified *“...would not be altered despite the need to be aware of the current economic climate, and that the focus for development in palliative care services should be in the context of:*

- *reconfiguration and re-allocation of existing resources/services*
- *increasing and developing capacity within existing resources*
- *developing skills in community care and care of the elderly settings, specifically in relation to palliative care services, and*
- *taking the opportunity afforded by integration to identify ways of enabling the delivery of these agreed national priorities.”*

1.3 Palliative care under the new health service reform agenda

The Irish health service is currently undergoing major reform. As part of the reform process, clinical strategies and programmes have been established to improve and standardise patient care throughout the HSE, by bringing together clinical disciplines and enabling them to develop and share innovative solutions and deliver greater benefits to every service user. The establishment of the National Clinical Programmes is a very positive step for palliative care, and it is anticipated that it will bring a focus to addressing the issues outlined above.

The aim of the HSE's Palliative Care Programme is to ensure that patients with life-limiting conditions and their families can easily access a level of palliative care service that is appropriate to their needs, regardless of care setting or the nature of their diagnosis. While it does not have the operational control to mandate service developments, the Programme can set the strategic direction for future service development. In 2012, it articulated four clear objectives, as follows:

- Improve planning for palliative care services to ensure optimal resource utilisation.
- Strengthen specialist palliative care services to improve access and quality of care.
- Strengthen generalist palliative care services in order to strengthen access and quality of care.
- Improve partnerships in care to improve continuity and quality of care.

The Programme's 2012 briefing notes included the following as an action under the second objective:

“Expansion of the provision of specialist palliative care services to provide new services where there are identified gaps: There is significant regional variation in the availability of palliative care beds, and in the number of staff within hospital and community specialist palliative care teams. The provision of specialist palliative care services in the majority of LHOs is not proportional to need and this must be addressed as a matter of priority in order to ensure that there is sufficient specialist palliative care capacity to provide care for patients who are currently receiving inappropriate or sub-optimal care in acute and community care settings”.

It was not stated, however, how this would be achieved.

As reform gets under way, the HSE is challenged by the economic situation. In *Future Health – a Strategic Framework for Reform of the Health Service* (DOH, 2012), it is acknowledged that palliative care can be delivered in diverse locations and will need *“to be considered within all of the funding mechanisms now being contemplated and across all service delivery models. The HSE is currently working on a prospective funding model which will assist in integrating and accounting for palliative care across all funding streams and delivery models.”* The proposed funding model is based on the principle that ‘the money follows the patient’. This prospective funding model could address the inequity in access to hospice/specialist palliative care services by covering the cost of inpatient hospice treatment in the services approved in the Five-Year Development Framework, and facilitating the opening and ongoing support of the 203 new hospice beds provided for in that document.

1.4 Projections of future service need

In Ireland, approximately 28,000 people die each year (CSO, 2011). Most of these people do not need specialist palliative care – although they may well benefit from some level of palliative care ‘support’ (NACPC, 2001). The vast majority of those who access specialist palliative care services have a diagnosis of cancer (MDS, 2011). Cancer accounts for a quarter of all deaths in Ireland (CSO, 2011). Approximately 60-70% of patients with advanced cancer have multiple symptoms such as pain, breathlessness and lymphoedema; they may also be dealing with the complex emotional and spiritual issues that can often accompany a life-limiting illness (NACPC, 2001). Multiple symptoms such as these can be considered an indicator of likely need for specialist palliative care, delivered either in a specialist inpatient unit (a hospice) or in another setting, with the support of a specialist palliative care team.

It has been anticipated that both the prevalence and the incidence of cancer will almost double between 1998 and 2020 (NCRI, 2006). The current cancer survival rate indicates that 50% of those diagnosed are alive five years later (ICS, 2012). While some cancers are being cured, the reality is that most cancer treatments prolong life rather than cure. Therefore, it is likely that there will be a concurrent increase in the demand for specialist palliative care services.

By the year 2016 – even before allowing for the impact of an aging population on cancer incidence – it is estimated that approximately 6,500 people each year dying from cancer will have a need for specialist palliative care (NACPC, 2001). New treatments will reduce mortality, but in many cases these will also extend the period during which palliative care will be required, while a rising population over the age of 65 is likely to also increase demand.

It is also important to consider the future palliative care needs of people with life-limiting conditions other than cancer. The *Report of the National Advisory Committee on Palliative Care* (NACPC, 2001) estimated that approximately 6,900 deaths per year in a population of one million are due to progressive non-malignant disease. One-fifth of the people represented by this figure would be expected to have symptom severity comparable to the top one-third of cancer patients. Extrapolating from these figures, it has been estimated that in Ireland at least 5,000 people each year with a life-limiting condition other than cancer would have a recognised period where they would be likely to benefit from specialist palliative care. The joint Irish Hospice Foundation/HSE report, *Palliative Care for All* (2010), highlighted the need for palliative care services to be available to people living with non-malignant conditions, and noted the potential implications of fulfilling this need:

“Since 2001, palliative care reports and policy have predicted that the inclusion of people with non-malignant diseases within SPC [Specialist Palliative Care] services would increase demand ... by 80%.”

Access to palliative care services for people with non-cancer conditions varies across Ireland, with some services seeing a higher proportion of such patients than others. The report continues:

“These reports state that the desired level of activity within SPC for these patients would be 25%. Irish data available in 2006 indicates that the level of service delivery in this area is between 5% and 10%”.

By 2011, 21% of all patients of palliative home care services in Ireland had a non-cancer diagnosis; however, this ranged from 35% in Sligo/Leitrim to % in South Tipperary. The findings of *Palliative Care for All* have been widely disseminated and have contributed to a raised appreciation at all levels of the need for change. Awareness is growing of the role that specialist palliative care can play in meeting the needs of people dying from a wide range of neurological, cardiac, respiratory and other conditions, and demand for services will continue to grow.

1.5 So where are we now?

Combining the above figures, and taking into account population projections, we can conclude that by 2016, over 12,500 people dying annually in Ireland from both cancer and non-cancer conditions would benefit from specialist palliative care. Also, while the majority of the circa 28,000 people who die each year will not require **specialist** palliative care, professionals in the field have a vital role to play in advising and educating healthcare staff providing **generalist** palliative care in the community, e.g. primary care teams. This need too will continue to grow.

There is also a growing momentum towards the theory and practice of health-promoting palliative care, and it is anticipated that the expertise of staff working in palliative care will have a critical role to play in enabling the general public and communities to openly discuss end-of-life care, dying, death and loss, and to support people living with life-limiting illness and/or experiencing bereavement (McLoughlin, 2012; Kellehear, 1999).

The 2001 national policy on palliative care is now more than 11 years old. As the health service undergoes a new round of re-organisation, an updated strategy and implementation plan would be useful to build on the HSE's Five Year Development Framework, harness the power of the National Clinical Programmes and the proposed prospective funding model to deliver change, and take account of the latest developments in our knowledge regarding palliative care. That said, much of the 2001 policy and the 2009 Framework remain valid and remain to be implemented. Of on-going concern are the regions identified by both the original Baseline Study and its 2007 update as providing little choice in specialist palliative care services: the Midlands, the North East and the South East. Therefore it is timely to consider the data available on access to and uptake of hospice/specialist palliative care services nationally and to determine any patterns arising and themes emerging for discussion.

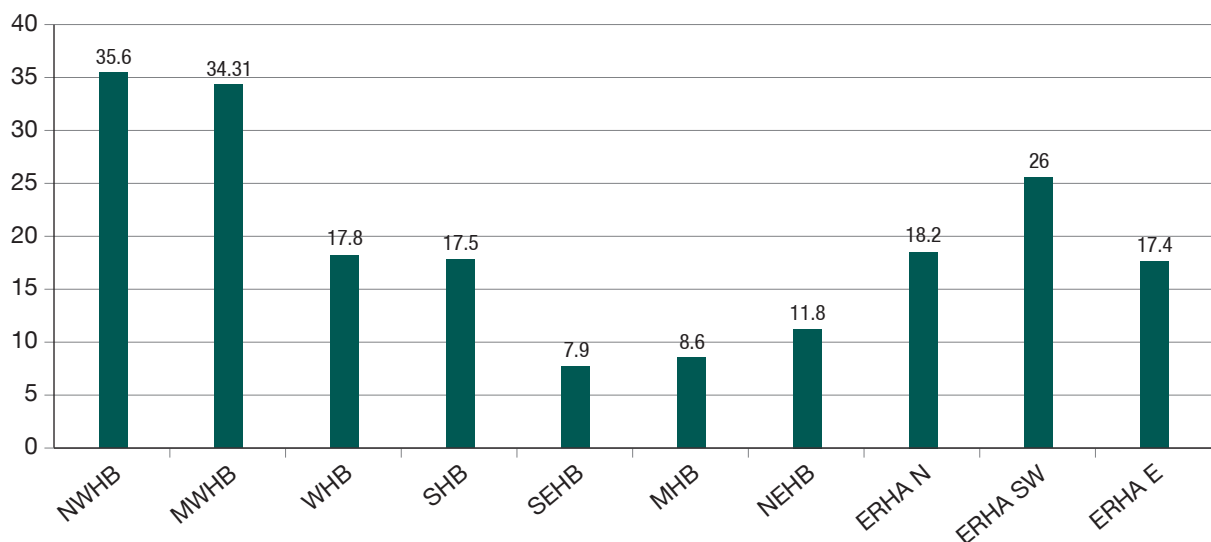
Section 2 Palliative care: access and service activity

Using a range of data sources, we now explore access to and activity in palliative care services in detail. The data analysed is based on published, historical data from four key sources, as described in Section 1. The analysis is intended to stimulate debate, and as data collection systems develop and are refined, it is likely that data accuracy and comparability over time will improve.

2.1 Funding

In order to develop palliative care services to the level recommended by government policy, funding must be available to services in the different regions. In the update (IHF, 2008) to the original Baseline Study, the IHF explored funding for specialist palliative care (Fig. 3). At that time there was very significant variation in state spending on specialist palliative care across Ireland, from over €34 and €35 respectively per capita in the former Mid Western and North Western Health Board areas to only €7.9 in the South East. The current economic restrictions, in place since 2008, have effectively limited further investment in specialist palliative care services. The Mid West and North West therefore stand out and are very similar in benefiting from a reasonably good level of resourcing, especially when compared to the three areas of the North East, Midlands and South East, which are the least well provided for.

Figure 3: Per capita state spending (€) on hospice care, by former health board area (IHF, 2008)



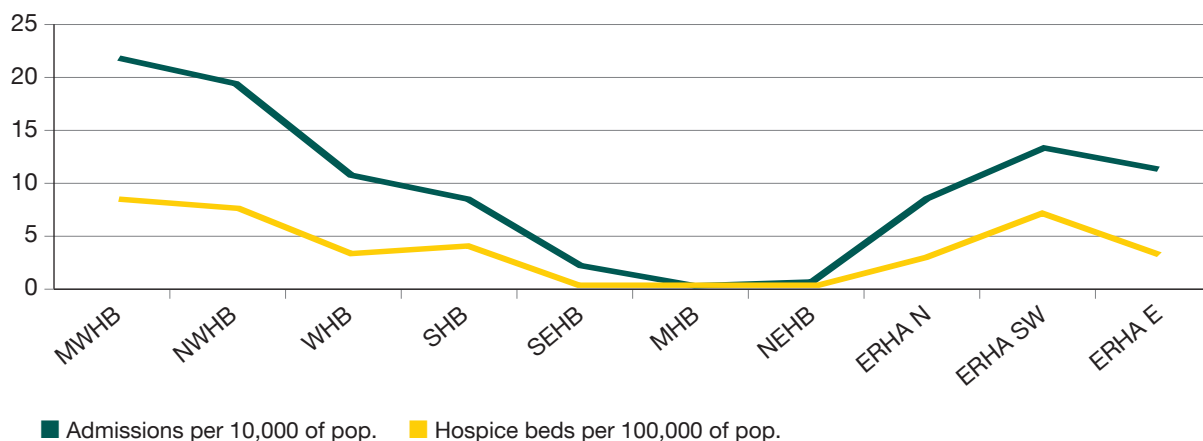
See Appendix 1 for note on abbreviations used for health boards.

In 2011, the HSE allocated a budget of €78 million to specialist palliative care. It is not clear where all the funding was spent – a total of €4.559m is unaccounted for against regional service plans. As of September 2012, the HSE was unable to provide accurate data on the exact spend on palliative care services, because of differing financial systems in operation between regions. We acknowledge that there has been additional expenditure on generalist palliative care – in the areas, for example, of services for older people, acute medicine and community services. Of high concern, however, is the spend on *specialist* palliative care (specialist staffing and service developments across regions), since this determines the level of services that patients – particularly those with complex medical needs – have access to at end of life. We have no reason to believe that the inequity in service provision identified by the research undertaken in 2004 and 2007 for the two Baseline Studies has decreased over time. If anything, this will have increased against increased financial constraints.

2.2 Access to hospice inpatient beds

Figures provided by the Voluntary Hospices Group and the HSE show that in 2011, there were 155 specialist palliative care beds nationally (this excludes two beds out of the acute bed complement in Waterford Regional Hospital that are notionally designated for specialist palliative care but are not identified beds). This figure represents 10 beds per 292,224 of the population. Fig. 4 shows that in 2011, no former health board area reached the national target of 10 beds per 100,000 of population. Bed numbers varied between 0 and 8.3 per 100,000 of the population.

Figure 4: Number of hospice beds per 100,000 of population; and admissions to hospice inpatient units per 10,000 of population, by former health board area (MDS, 2011, and IHF, 2012)



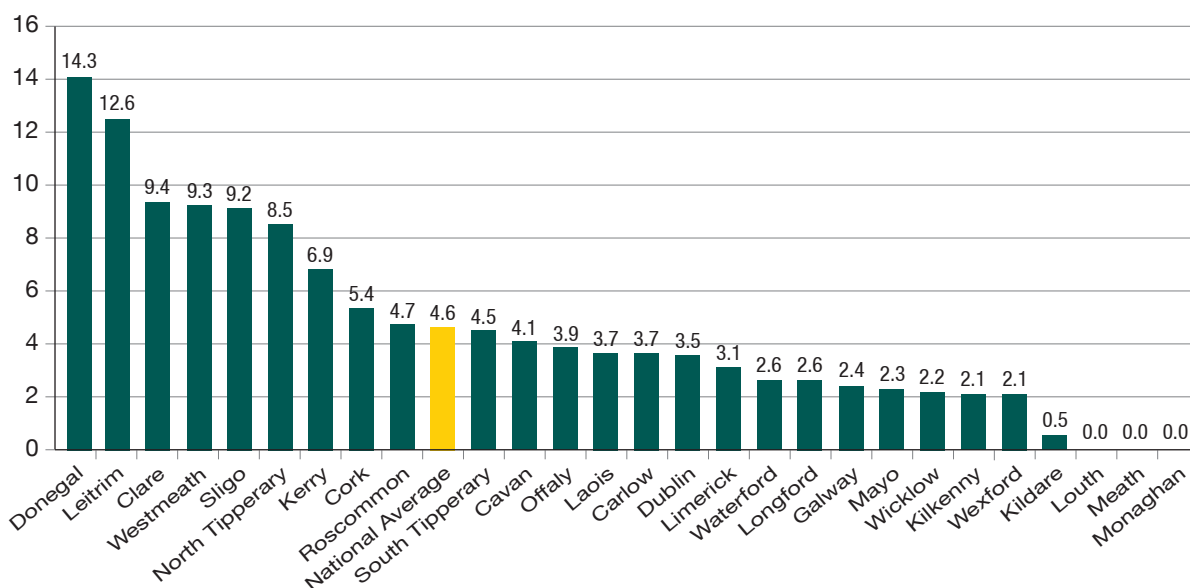
Not surprisingly, the data shows that former health board areas with a higher number of hospice beds have more admissions per 10,000 of the population. For example, there are over 21.4 admissions per 10,000 of population in the Mid West, compared to 0.1 in the Midlands, 0.3 in the North East and 2 in the South East – the three regions which have no hospice inpatient unit. While a small number of patients from these three regions may be gaining admittance to a hospice outside of their area of residence, the significant inequity in access to hospice beds for the vast majority is clear.

2.3 Access to palliative care support beds

Palliative care support beds are non-specialist beds, generally located in community hospitals or nursing homes, which provide an alternative to admission to an acute hospital. Previously these beds were referred to as ‘intermediate’ or ‘Level 2’ palliative care beds. In some regions, patients availing of these beds have the active support of the community specialist palliative care nursing team; however, their medical care normally falls under the remit of a G.P. or medical officer rather than a consultant in palliative medicine. There are at least one or two such beds in most areas, generally used for respite care or to treat patients with non-complex symptoms, and while not an alternative to hospice inpatient beds, they can be used for end-of-life care where no hospice beds are available or when patients wish to remain located within their own community, close to family and friends. They are included here for this reason, and because their usage as palliative care support beds requires the support of specialist palliative care professionals.

Data provided by the HSE in 2011 suggests that nationally there are 4.6 palliative care support beds per 100,000 of the population. As Fig. 5 shows, however, the variation in their availability across the country is extremely marked, resulting in very unequal access to them for people facing death and requiring palliative care support. Because these beds are used to enable people to be cared for within their local community, the data is presented by county. Of particular concern is the absence of *any* such beds in counties Kildare, Louth, Meath and Monaghan. While patients in Kildare have access to a specialist inpatient unit within the county (St Brigid’s), dying patients in the three other counties have no access to any type of palliative care support bed.³

Figure 5: No. of palliative care support beds per 100,000 of population, by county (HSE, 2011)



The data does not provide information on the level of occupancy of these beds, which can also vary from region to region – for example, where a bed is reserved for end-of-life care, it may not be in continuous use and may therefore actually be deemed to be under-utilised in one region as compared with another. Furthermore, the designation of these beds can change over short periods, so that it is likely that the 2011 data is already out of date. The Irish Hospice Foundation is pleased to support the HSE’s Clinical Care Programme in completing a more in-depth examination of the function and use of these beds.

³ A review of the use of palliative care support beds, funded by the Irish Hospice Foundation, is currently under way through the HSE’s Palliative Care Clinical Programme.

2.4 Access to hospice home care

The 2001 NACPC report recommended at least one home care nurse per 25,000 of the population; however, studies have highlighted regional variations in staffing levels. The updated Baseline Study (IHF, 2008) showed that some counties have fewer than one home care nurse per 25,000 of population, while in others, staffing levels exceed the recommendation. The regions where staffing levels are exceeded are generally those that include large rural areas, where staff report that it would not be possible to provide a seven-day service with the minimum number of nurses recommended by the NACPC.

Access to home care is clearly impacted by staffing levels that fall below the recommendations; however, it may also be affected by other factors that may vary between services, such as admission criteria and pre-admission assessment processes. It is particularly interesting to note that the number of home care nurses falls short of the recommendation in some of the regions where there are inpatient hospice units.

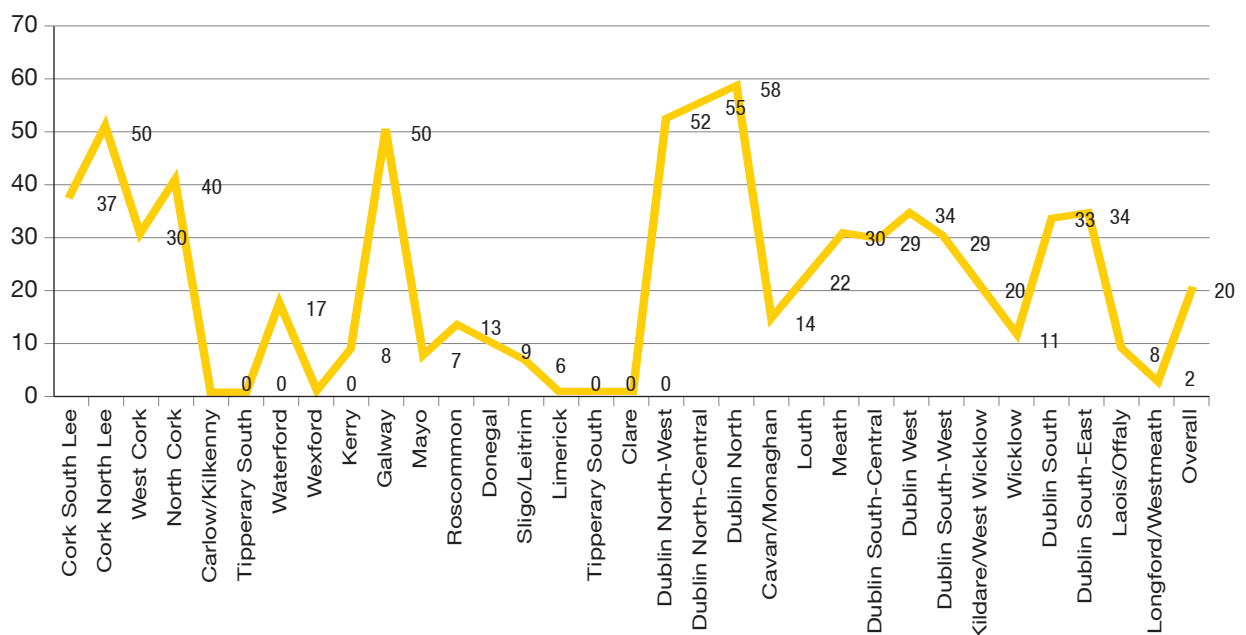
2.5 Service activity in hospice home care

The Palliative Care Minimum Data Set now in use by the HSE collects data on hospice home care teams. Over time this will enable service activity levels to be examined and compared regionally against national patterns. Already, the data for 2011 (the first complete year for which national data is available) points to regional variations against some key indicators which are explored below. It is possible to discern some interesting correlations between specific aspects of service activity and the presence of an inpatient hospice.

2.5.1 Waiting times for home care

On average, 80% of hospice home care patients are first seen in their place of residence within seven days of referral. There is significant variation across the country, however, with between 0% and 58% of patients waiting more than seven days for a first visit, depending on where they live (Fig. 6).

Figure 6: **Percentage of patients waiting more than seven days for a first visit by a home care team, by Local Health Office (MDS, 2011)**

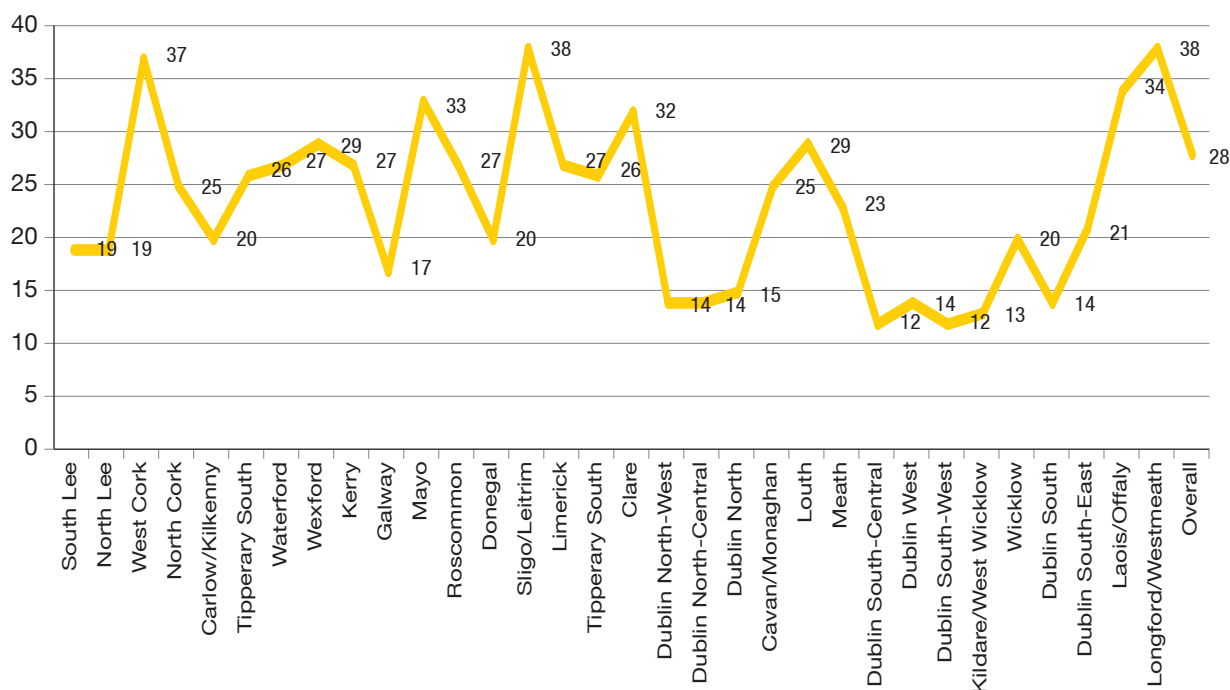


The Local Health Office (LHO) areas where waiting times are considerably higher than the national average – Dublin (particularly Dublin North), Cork and Galway – were identified by the second Baseline Study (IHF, 2008) as having fewer than the recommended number of home care nurses. The data suggests that in areas where there is a hospice inpatient unit, waiting times for home care following initial referral may be longer. This raises the question of whether adequate resources are being provided in these areas to cover the operational costs of the inpatient unit *and* allow the home care service to eliminate undue waiting times.

2.5.2 Number of patients in home care

There are wide variations in the number of patients admitted to home care across LHO areas (Fig. 7). The national average is 27.6 patients per 10,000 of population each year. Dublin, Galway and Cork, however – which all have hospice inpatient units – have fewer than this. It may be that some patients admitted to home care in the less resourced regions are in fact in need of hospice inpatient care, which is not available locally – this would at least partially explain the higher numbers of admissions in these areas.

Figure 7: **New patient admissions to home care per 10,000 of population, by Local Health Office (MDS, 2011)**



2.5.3 Diagnosis of patients in home care

On average nationally, 20.8% of patients receiving palliative home care have been diagnosed with a condition other than cancer. However, this is subject to regional variation. For example, 35% of patients in the LHO area of Longford/Westmeath have a non-malignant diagnosis, compared to 4.9% in Dublin North West and 0% in Tipperary South. The data also suggests that the percentage of patients of home care services with a non-malignant diagnosis is higher in areas which have no hospice inpatient unit than in areas where an inpatient facility is in place.

2.6 Access to palliative care in acute hospitals

The NACPC report (2001) recommended (pp 80-81) that: “*All acute general hospitals should have a consultant-led specialist palliative care service, offering advice and support to health care professionals in the hospital.*” It proposed that: “*The specialist palliative care team [...] should consist of at least a consultant in palliative medicine, a specialist palliative care nurse, a social worker ...*”

The first report of the *National Audit of End-of-Life Care in Hospitals in Ireland, 2008/9* (McKeown et al, 2010) found that only a quarter of acute hospitals met this government-approved standard of having a full specialist palliative care team. The Audit noted that this uneven distribution more than likely reflects supply-led considerations and prioritisations – with some hospitals appearing to seek and be able to secure palliative care resources, while others do not – rather than any objective measure of need, such as the number of deaths in the hospital.

The National Audit revealed that a majority of hospital patients who died did not receive specialist palliative care. The percentage that did was reported as varying from 22% (according to doctors) to 32% (according to nurses) in the sample of 1,000 random deaths. In over a quarter of cases where patients did not receive specialist palliative care, doctors and nurses were uncertain if they would have benefited from it. This suggests that there may be some difference in understanding between doctors and nurses – and also within these two groups – as to the precise role and function of specialist palliative care, which may have an impact on referral. The finding was echoed in a study by McLoughlin (2012), which highlighted a lack of knowledge regarding palliative care and negative attitudes towards referral to palliative care services. We welcome the future MDS data on palliative care in acute hospitals, which will provide further information for analysis.

Section 3 Exploring relationships: access to palliative care and impact on place of death

While acknowledging that patient preferences may change as death approaches, we have noted earlier that a clear majority of Irish people would prefer to die at home. Examining where people actually die provides an indication of the number who were able to access services that enabled them to stay at home (assuming such a service was required). We would therefore expect that the number of patients who die at home in a given region tells us something about the availability of palliative care services there.

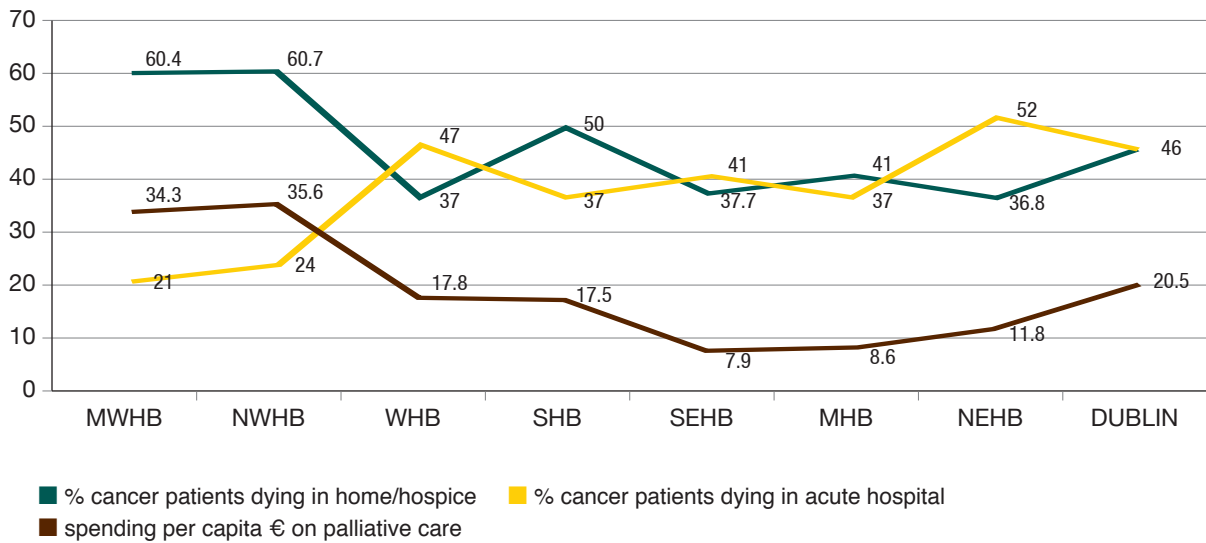
All areas of Ireland have access to hospice home care teams. Therefore the data on home care from the HSE's Palliative Care Minimum Data Set (2011), combined with 2010 data from the National Cancer Registry, provides vital information on the number of people facilitated to die at home, along with an insight into their care. It also allows us to identify trends and possible correlations with other data relating to service availability.

3.1 Place of death of cancer patients

Data from the 2011 Palliative Care Minimum Data Set enables us to estimate that on average, cancer patients account for 91.2% of admissions to hospice inpatient units and 79.2% of admissions to hospice home care services nationally. Information on cancer deaths is therefore highly relevant in exploring the possible correlation between access to specialist palliative care services and place of death – even if it does not provide the full picture.

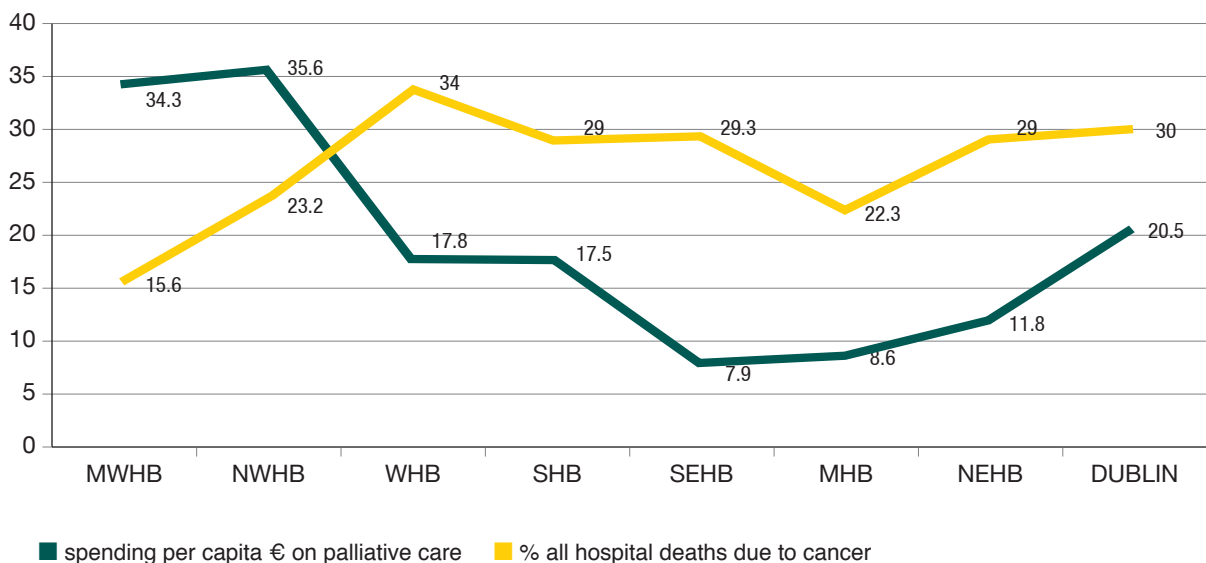
Data from the National Cancer Registry (2010) tells us that nationally, an average of 45% of people with a diagnosis of cancer die either at home or in a hospice, while 38% die in an acute hospital. It also highlights regional variation. In Fig. 8, we see that in the Mid West – where state spending on specialist palliative care is over €34 per capita – 60.4% of people who died from cancer died at home or in a hospice (compared to 45% nationally), while 21% died in an acute hospital. By contrast, in the North East, where spending on specialist palliative care is only €11.8 per capita, just 36.8% of those who died from cancer died at home or in a hospice, while 52% died in an acute hospital.

Figure 8: Percentage of cancer patients dying at home/in a hospice or in an acute hospital (NCRI, 2010), and per capita spending on specialist palliative care (IHF, 2008), by former health board region



In examining acute hospital data (HIPE, 2010 – Fig. 9), we find that of *all* deaths that occur in hospital, the percentage due to cancer is generally lower in regions where spending on palliative care is in line with national policy. For example, in the Mid West, 15.6% of all deaths in acute hospitals were cancer deaths compared to 29% in both the North East and the South East. The high figure for the West (34%) may be explained by a combination of a deficit in hospice beds and a lack of integration between acute services and palliative care services in the region. (The Minimum Data Set shows a relatively low level of admissions to hospice beds from acute hospitals in Galway, compared to other regions with access to hospice beds). In Dublin, too, the figure for cancer deaths as a percentage of all hospital deaths appears to be relatively high, but this may be at least partly due to the migration of cancer patients from the regions to hospitals designated as Specialist Cancer Centres in Dublin. This merits further investigation.

Figure 9: Cancer deaths as a percentage of all hospital deaths (HIPE, 2010) and spending per capita on palliative care (IHF, 2008), by former health board region

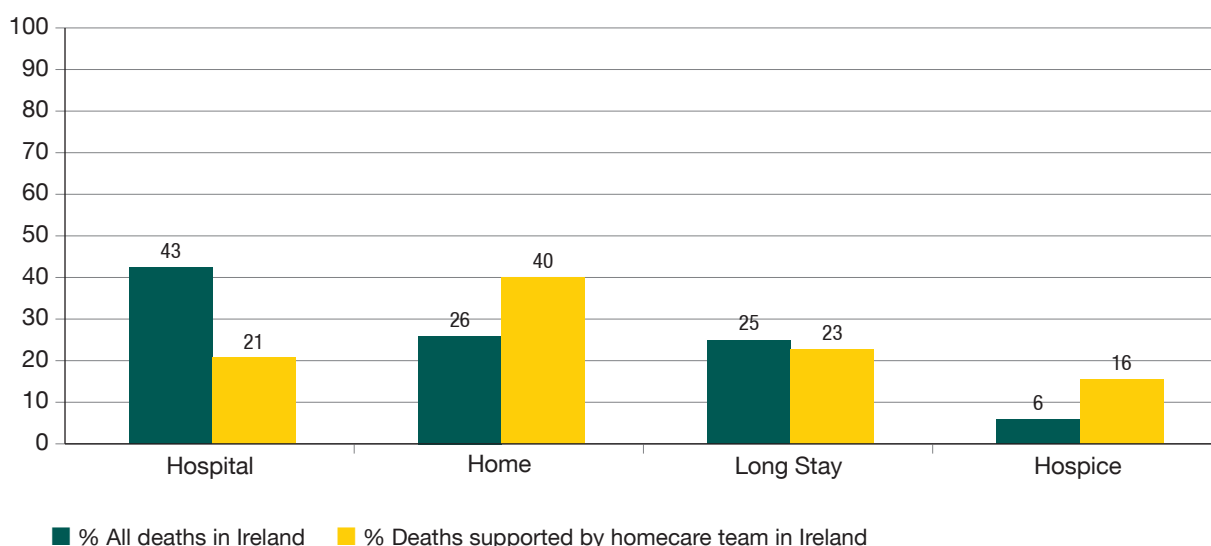


It would be interesting to explore in future studies if differences in spending on palliative care are reflected by differences in patients' and families' experience of the quality of care they receive at end of life, as well as in value for money.

3.2 Place of death of hospice home care patients

The fact that a patient is under the care of a hospice home care service does not *necessarily* mean that that patient will actually die at home – but access to home care certainly has a bearing on place of death. We have already seen that an estimated 26% of all deaths in Ireland take place at home. Fig. 10 shows that where hospice home care services are involved, however, the figure rises to 40%. The percentage of all deaths taking place in hospital was estimated at 43% - but hospice home care reduces this to 21%.

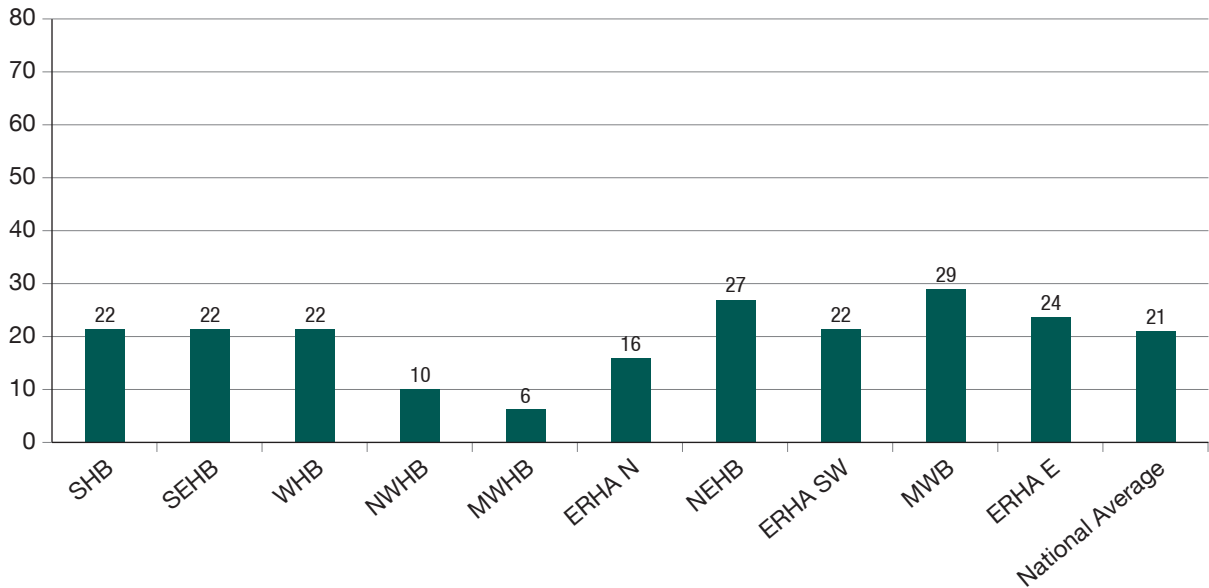
Figure 10: **Place of death in Ireland, by care setting: All deaths (%) compared with deaths supported by hospice home care teams (MDS, 2011 and CSO, 2011)**



If the home care service is attached to an inpatient hospice, then the patient may be admitted to the hospice as death approaches or symptom management becomes more complex (59% of admissions to hospice beds come from home care, primary care or long-stay care services; while 41% come from acute hospitals). Analysis of the data suggests that there is minimal variation between home care services across the country as regards the proportion of patients who die at home, the average being 40%, indicating that consistency of outcome is being achieved.

Nationally, the proportion of home care patients dying in an acute hospital averages 21% (Fig. 10). The data in Fig. 11, however, suggests that a significantly higher percentage die in acute hospitals in areas without a hospice inpatient unit – e.g. the Midlands (29%) and the North East (27%) – than in areas where an inpatient unit is in place, such as the Mid West (6%) or the North West (10%). The pattern appears to be contradicted by the Dublin area, where, despite access to an inpatient unit, between 19% and 24% of home care patients die in acute hospitals – but this likely reflects a particular pattern of care occurring in Dublin, probably related to the availability of acute beds and specialist teaching hospitals, including Specialist Cancer Centres. This requires further exploration.

Figure 11: **Percentage of home care patients dying in an acute hospital** (MDS, 2011)



Given that the percentage of home care patients dying at home across the country is relatively equal, the data in Fig. 11 appears to show that where keeping the patient at home is not feasible and there is no inpatient hospice unit in a region, the home care team have no choice but to look for admission to an acute hospital. The availability of acute hospital beds in a region (e.g. Dublin) may also be a major influence in determining where palliative care patients die.

The provision of hospice beds is not a substitute for home care; it is rather a service for patients with complex symptoms or end-of-life care needs requiring inpatient admission. At any point in time, in regions with well-resourced hospice services, there are almost ten times more patients being cared for in their homes, by hospice home care teams, than in hospice beds. The average length of stay in home care is almost six months, compared to nine days for hospice inpatient stays. The presence of a hospice inpatient unit as the hub of a comprehensive specialist palliative care service, as recommended by the NACPC report (2001), enables patients to remain mostly at home, accessing a hospice inpatient bed only when the need arises.

Section 4 Impact of regional inequity in the resourcing of palliative care services: The North East, Midlands and South East

Earlier sections of this paper have highlighted the regional inequity that exists in access to palliative care in Ireland and at the implications for patients, particularly in relation to place of death. We now look in more detail at the impact on patients of the poor resourcing of palliative care services specifically in the former health board areas of the North East, Midlands and South East, and compare these with the best-resourced areas – the Mid West and North West – which are used as a benchmark. Focusing on the former three areas is not to suggest that other areas of Ireland are adequately resourced – in fact, in *no* area (not even the Mid West or North West) do staffing levels in palliative care services, for example, conform with national policy. Colour coding has been used to distinguish between well-resourced and poorly-resourced regions.

4.1 Access to hospice inpatient beds

Although national policy specifies that there should be 10 hospice inpatient beds per 100,000 of population – one bed for every 10,000 people (NACPC, 2001) – we have seen in Fig. 4 (Section 2, p.19) that the North East, Midlands and South East (uniquely) have no hospice unit and therefore no access to inpatient hospice beds.⁴ This compares with the Mid West and North West, where there are 8.3 and 7.5 beds respectively per 100,000 of the population. If the provision of hospice beds in the Midlands, North East and South East were in line with national policy, we estimate that approximately 1,150 patients would access these beds every year in the hospice inpatient units proposed, in the HSE's 2009 Five-Year Development Framework for specialist palliative care services, for Waterford, Kilkenny, Tullamore, Drogheda and Cavan.

4.2 Access to palliative care support beds

The data in Fig. 5 (Section 2, p.20), which shows the number of palliative care support beds per 100,000 of population on a county-by-county basis, translates to a total of 56 beds in the (combined) former health board areas of the Mid West and North West. These serve a total population of approximately 638,948. In the combined areas of the Midlands, North East and South East, there are 32 palliative care support beds for a population of approximately 1,219,393. These figures equate to one bed per 11,000 of population in the combined Mid West and North West areas, as against one bed per 38,000 of population in the combined Midlands, North East and South East, again indicating wide discrepancies in access.

4.3 Access to funding and expenditure

According to the updated Baseline Study (IHF, 2008), state spending on hospice/specialist palliative care averages over €30 per capita in the Mid West and North West, and less than €11 per capita in the North East, Midlands and South East (Fig. 3, Section 2). Although there are no hospice inpatient beds in the North East, there is a well-developed multidisciplinary home care team which is over 90% funded by the state compared to less than 60% state funding in the Midlands and South East. The South East and the Midlands are therefore the most disadvantaged regions overall in terms of service resourcing.

⁴ This excludes two designated for use in Waterford Regional Hospital – see Section 2.2, p.19

Let us now look at hospice/specialist palliative care beds in the wider context of the provision **and cost** of inpatient beds in *all* healthcare settings within the different regions.

Table 1 below looks at inpatient beds in acute hospitals, community hospitals, hospices and private nursing homes. It also looks at the cost of beds, both in each type of institution and in total. The data has been sourced from the National Hospitals Office, Department of Health and Voluntary Hospices Group. While this data can change depending on how costs are assigned (and it is clear that these costs do change over time), what is interesting is the consistent finding that **the provision of hospice beds has no bearing on the overall cost of beds in a region**. The variation between regions arises primarily from the cost of acute hospital beds. The total cost of inpatient beds (all institution types) is actually €1m less in the Mid West, which has 30 hospice beds, than in the South East, which has none.

Table 1: **No. and cost of inpatient beds in all care settings, by former health board area**

Institution type	Total no. beds	Cost	Total beds per 10,000 of pop.	Cost of beds (all) per 10,000 of pop.
North Western Health Board – Population: 259,621				
Acute hospital	629	€229m	24.2	€8.82m
Community hospital [<i>Fair Deal</i>]	747	€52m	28.8	€2.00m
Private nursing home [agreed price under <i>Fair Deal</i>]	933	€41m	35.9	€1.58m
Hospice (includes 2 beds in N.I.)	18	€5m	0.7	€0.19m
Total	2,327	€327m	89.6	€12.60m
Mid Western Health Board – Population: 379,327				
Acute hospital	740	€270m	19.5	€7.12m
Community hospital [<i>As above</i>]	610	€43m	16.1	€1.13m
Private nursing home [<i>As above</i>]	2,029	€90m	53.5	€2.37m
Hospice	30	€9m	0.8	€0.24m
Total	3,409	€412m	89.9	€10.86m
Midland Health Board – Population: 282,410				
Acute hospital	511	€186.5m	18.1	€6.60m
Community hospital [<i>As above</i>]	538	€38m	19.1	€1.35m
Private nursing home [<i>As above</i>]	1,207	€53m	42.7	€1.88m
Hospice	0	€0m	0	€0m
Total	2,256	€277.5m	79.9	€9.83m
South Eastern Health Board – Population: 497,578				
Acute hospital	1,081	€394m	22.5	€8.22m
Community hospital [<i>As above</i>]	1,041	€73m	21.7	€1.52m
Private nursing home [<i>As above</i>]	2,247	€99m	46.9	€2.06m
Hospice	0	€0m	0	0
Total	4,369	€566m	91.1	€11.80m
North Eastern Health Board – Population: 439,405				
Acute hospital	819	298	18.6	€6.78m
Community hospital [<i>As above</i>]	644	45	14.7	€1.02m
Private nursing home [<i>As above</i>]	1,895	84	43.1	€1.91m
Hospice	0	0	0	€0m
Total	3,358	427	76.4	€9.72m

Sources (2011): National Hospitals Office (acute hospitals); Department of Health (community and private nursing home beds under the *Fair Deal* scheme) and Voluntary Hospices Group (hospice beds).

From the table, we can see that the total number of inpatient beds in each former health board area is just under 100 beds per 10,000 of population (the figure ranges from 76 to 91.) It is national policy that there should be one hospice bed per 10,000 of population (NACPC, 2001). A simple calculation shows that **the number of hospice inpatient beds required to fulfil national policy therefore equates to just around 1% of total inpatient beds**. While the North East and Mid West meet or are close to meeting this target, the data highlights the enduring failure to provide hospice inpatient beds in the North East, Midlands and South East.

It should be noted that the proximity to Dublin of some counties in the North East and Midlands probably means that there is significant usage by patients from these areas of beds in specialist acute hospitals in Dublin. This warrants further investigation.

4.4 Access to hospice home care

Tables 2-6 below look in detail at hospice home care service activity in the areas under scrutiny. The data on the number of home care nurses comes from our own research with local sources rather than from any official source, so while every effort has been made to ensure its accuracy, it should be treated with caution.

As already noted, home care services in areas where palliative care is under-resourced actually compare very favourably with the better-resourced areas under some indicators of patient access. We find, for example, that in the North East, Midlands and South East, the number of home care nurses per 10,000 of population is generally higher than the national average. Services in these areas are also above the national average in the number of patients seen; percentage of patients with conditions other than cancer; access waiting times; care visits per patients; visits per nurse and patients per nurse.

4.4.1 The Mid West

The Mid West (Table 2) has the most developed 'hospice at home' service in the country. The consultant-led specialist palliative care service includes 16.5 clinical nurse specialists and a full multidisciplinary team, including care assistants, registered general nurses, physiotherapists, occupational therapists, pastoral care workers and social workers.

This service has reduced the percentage of patients dying in acute hospital to about 6% (MDS, 2011). Clearly this demonstrates that active management of home care patients, the effective allocation of resources to home care and the availability of hospice inpatient beds can significantly impact on the rate of deaths in the acute setting.

Table 2: Palliative home care services in the former Mid Western Health Board area, by LHO

Mid Western Health Board			
	Local Health Office*		
	Clare	Tipperary North	Limerick
Population, 2011	103,364	106,332	169,631
New patients per 10,000 of population <i>National average: 21.4</i>	17.0	19.2	23.9
Admissions per 10,000 of population <i>National average: 27.6</i>	32.0	25.7	26.9
% of patients with non-cancer diagnosis <i>National average: 20.8%</i>	21.6%	17.2%	22.7%
No. nurses <i>Approx. pop. per nurse **</i>	3 (34,400)	3 (35,400)	10.5 (16,100)
Average no. visits per patient <i>National average : 3.5</i>	4.5	3.6	3.7
Percentage waiting over 7 days <i>National average 20.2%</i>	0%	0%	0%

Source: MDS, 2011, and HSE population statistics, 2011.

* Home care teams' catchment areas do not always correspond exactly to LHOs, and nurses from one area may provide services to neighbouring LHOs, e.g. Clinical Nurse Specialists based in Limerick also see patients in Clare and Tipperary North.

** National policy recommends one home care nurse per 25,000 of population

4.4.2 The North West

In the North West (Table 3), the home care team is reasonably well resourced, with a total of 12.5 specialist palliative care nurses. The data illustrates a varying pattern of care across Local Health Offices in the region. Donegal seems to compare unfavourably with Sligo/Leitrim across a number of measures, including waiting times and access for patients with diagnoses other than cancer. However, Donegal is a more rural county, and appears to provide three times the number of visits per patient.

Table 3: Palliative home care services in the former North Western Health Board area, by LHO

North Western Health Board		
	Local Health Office*	
	Donegal	Sligo/Leitrim
Population, 2011	164,023	95,598
New patients per 10,000 of population <i>National average: 21.4</i>	15.0	27.1
Admissions per 10,000 of population <i>National average: 27.6</i>	19.8	37.8
% of patients with non-cancer diagnosis <i>National average: 20.8%</i>	14.6%	35.1%
No. nurses <i>Approx. pop. per nurse **</i>	7 (23,400)	5.5 (17,300)
Average no. visits per patient <i>National average: 3.5</i>	4.3	1.4
Percentage waiting over 7 days <i>National average: 20.2%</i>	8.5%	6.2%

Source: MDS, 2011, and HSE population statistics, 2011.

* Home care teams' catchment areas do not always correspond exactly to LHOs

** National policy recommends one home care nurse per 25,000 of population

4.4.3 The North East

Table 4 shows that the North East has a reasonably well-resourced home care team and that service activity compares well against national indicators. Meath LHO has fewer admissions per head of population and slightly longer waiting times for access to the service.

Table 4: Palliative home care services in the former North Eastern Health Board area, by LHO

North Eastern Health Board			
	Local Health Office*		
	Cavan/Monaghan	Louth	Meath
Population, 2011	129,427	122,098	187,880
New patients per 10,000 of population <i>National average: 21.4</i>	18.7	18.6	18.7
Admissions per 10,000 of population <i>National average: 27.6</i>	25.4	28.6	23.4
% of patients with non-cancer diagnosis <i>National average: 20.8%</i>	24.8%	19.4%	30.4%
No. nurses <i>Approx. pop. per nurse **</i>	6 (21,600)	7.2 (17,000)	7.5 (25,100)
Average no. visits per patient <i>National average: 3.5</i>	3.2	3.9	3.4
Percentage waiting over 7 days <i>National average: 20.2%</i>	13.6%	22.5%	30.1%

Source: MDS, 2011, and HSE population statistics, 2011.

* Home care teams' catchment areas do not always correspond exactly to LHOs.

** National policy recommends one home care nurse per 25,000 of population

4.4.4 The South East

In the South East (Table 5) Waterford appears to have a higher percentage of patients waiting more than seven days for admission than other LHO areas, but the figure is still below the national average. Carlow/Kilkenny and South Tipperary home care teams appear to cater for very few patients with conditions other than cancer.

Table 5: Palliative home care services in the former South Eastern Health Board area, by LHO

South Eastern Health Board				
	Carlow/ Kilkenny	Local Health Office*		
		Tipperary South	Wexford	Waterford
Population, 2011	130,315	98,105	145,320	123,838
New patients per 10,000 of pop. <i>National average: 21.4</i>	15.3	15.6	20.4	20.2
Admissions per 10,000 of pop. <i>National average: 27.6</i>	20.5	26.4	18.8	27.1
% of patients with non-cancer diagnosis <i>National average: 20.8%</i>	3%	0%	13.9%	18.4%
No. nurses <i>Approx. pop. per nurse **</i>	4 (32,600)	4.85 (20,200)	6 (24,200)	4 (31,000)
Average no. visits per patient <i>National average: 3.5</i>	3.4	4.2	3.2	3.7
Percentage waiting over 7 days <i>National average: 20.2%</i>	0%	0%	0%	16.8%

Source: MDS, 2011, and HSE population statistics, 2011.

* Home care teams' catchment areas do not always correspond exactly to LHOs.

** National policy recommends one home care nurse per 25,000 of population

4.4.5 The Midlands

The Midlands (Table 6) performs well across all indicators of home care and has the highest proportion of patients with conditions other than cancer. This is achieved in spite of the fact that its home care service is only 50% state-funded and it is the only region with just one consultant in palliative medicine. The Midlands' acute hospital palliative care service is also the most under-resourced in the country, with just one consultant and no specialist palliative care nurse or other palliative care professionals,

Table 6: Palliative home care services in the former Midland Health Board area, by LHO

Midland Health Board		
	Local Health Office*	
	Laois/Offaly	Longford/Westmeath
Population, 2011	157,246	125,164
New patients per 10,000 of population <i>National average: 21.4</i>	29.6	29.3
Admissions per 10,000 of population <i>National average: 27.6</i>	34.4	38
% of patients with non-cancer diagnosis <i>National average: 20.8%</i>	31.4%	35.0%
No. nurses Approx. pop. per nurse **	6.2 (25,400)	8.4 (14,900)
Average no. visits per patient <i>National average: 3.5</i>	3.8	3.8
Percentage waiting over 7 days <i>National average: 20.2%</i>	7.7	2.2

Source: MDS, 2011, and HSE population statistics, 2011.

* Home care teams' catchment areas do not always correspond exactly to LHOs

** National policy recommends one home care nurse per 25,000 of population

4.5 Impact on place of death

Figs. 8 and 9 in Section 3 (p.25) have clearly shown the link between the resourcing of palliative care and place of death. In 2010, over 60% of people who died from cancer in the well-resourced Mid West and North West regions died at home or in a hospice, compared to 36.8% in the North East; 37.7% in the South East and 41% in the Midlands.

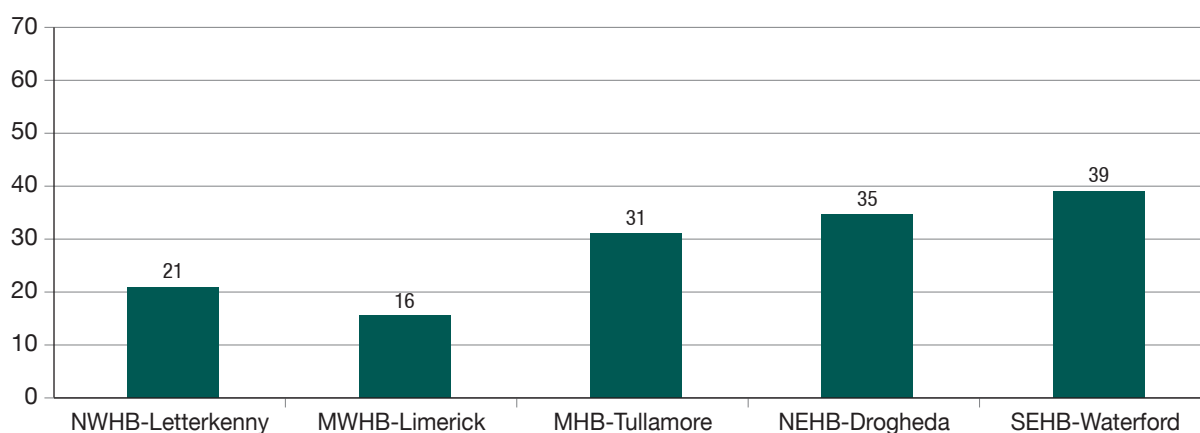
4.5.1 Deaths in hospital

Fig. 8 also showed that in the Mid West, just 21% of cancer deaths took place in an acute hospital, compared with 52% in the North East, 41% in the South East and 37% in the Midlands. The figure for the North West was 24%. This reflects our earlier point that the lack of an inpatient unit in a region means that for patients whose symptoms cannot be managed at home, the only option is admission to an acute hospital.

The Hospital Inpatient Enquiry data (2010) supports this finding: Fig. 9 shows that cancer deaths tend to make up a higher proportion of overall deaths in acute hospitals in areas where there no hospice beds.⁵ The same pattern emerged in Figure 11, when we looked at the percentage of hospice home care patients dying in an acute hospital, using data from the Palliative Care Minimum Data Set. A significantly higher percentage die in acute hospitals in areas which do not have access to a hospice inpatient unit – e.g. the Midlands (29%) and the North East (27%) – compared to areas where an inpatient unit is in place, such as the Mid West (6%) or the North West (10%).

If we look at specific leading hospitals in the regions under discussion, again we see (Fig. 12) that the figure for cancer deaths as a percentage of all deaths is notably higher in areas where palliative care services are inadequately resourced. In Limerick University Hospital and Letterkenny Hospital, just 16% and 21% respectively of all deaths in 2010 were cancer deaths. By contrast, cancer deaths accounted for 31%, 35% and 39% respectively of all deaths in the hospitals in Tullamore, Drogheda and Waterford. The figure for Waterford was more than double that for Limerick.

Figure 12: **Cancer deaths as a percentage of all deaths in leading regional hospitals (HIPE, 2010)**



This data clearly demonstrates the impact on place of death of the under-resourcing of specialist palliative care services. Many of these cancer patients who died in hospital could probably have been cared for in a more appropriate setting.

⁵ The figures for the North West and Midlands seem to rather contradict the general trend, but this may be at least partly attributable to the fact that people sometimes travel beyond their own region to be cared for and to die in hospitals in other regions. This is worth further exploration.



Section 5 Discussion

The aim of this report has been to stimulate discussion on emerging trends in the provision of specialist palliative care in Ireland. Existing data sources have been mined to examine the impact of varying levels of palliative care investment on access to services in different parts of the country, and to compare and contrast specific regions against national averages. In particular the report has sought to explore possible relationships between access to specialist palliative care services and place of death. We are now beginning to build a picture of service resourcing and outcomes in Ireland. Over time this picture will become more robust and will deepen our understanding of the role that investment in palliative care can play in the effective and efficient management of our health services. More importantly we can track its impact on patient access to a range of services and therefore on patient choice at end of life.

Quantitative data, gathered in a systematic way, has the power to change hearts and minds. By building on our knowledge, we can demonstrate the cost-effectiveness of palliative care across all care settings. However, quantitative data has its obvious limitations. In particular, the data tells us nothing about quality of care. Equally, numbers alone – for example, patient numbers – should be interpreted with caution. A home care service in one area may see fewer patients per nurse than a service in another, but rather than pointing to inefficiencies, this may reflect a more rural area of coverage or variations in work practices. In a palliative care approach, time and quality of care are essential.

5.1 So why does it matter?

Tracking patients' place of care and death against investment in palliative care services matters for a variety of reasons.

5.1.1. Value of the hospice approach: to patients, to the health system

Firstly, and most importantly, the Irish Hospice Foundation, along with a wide range of service providers, fundamentally believes in the hospice approach to death and dying. By this we mean a positive approach which emphasises quality of life and looks to relieve suffering, whether physical, emotional, psychosocial or spiritual, and to support families through bereavement. This belief was validated in Ireland in 2001, when a commitment to develop specialist palliative care services nationally was enshrined in government policy.

Over four in ten deaths occur in acute hospital settings. While our acute hospitals provide excellent curative treatment, the reality is that they are also places where people die – and dying patients need a special type of care and comfort. Hospitals are often poorly equipped to provide the environment and culture of care that are most conducive to a 'good' death. Indeed, this reality was the driving force behind the establishment of the IHF's Hospice Friendly Hospitals (HFH) Programme, which is working to effect change in end-of-life care in the acute hospital setting.

A National Audit of End-of-Life Care in Hospitals undertaken by the HFH Programme in 2008/09 found up to one quarter of the 1,000 hospital deaths examined could have been facilitated to occur at home, and that deaths in A&E are less acceptable to both families and healthcare staff (12% of all hospital deaths occur in A&E). In collaboration with the HSE's Palliative Care Programme, the HFH Programme has gone on to develop an end-of-life care audit and review system, a concept supported by HIQA. This is currently being piloted to examine the quality of care provided in the last week of life to patients who die at home, in a hospice, in an acute hospital, community nursing unit or private nursing home. The findings, combined with the HSE's Palliative Care Minimum Data Set, will build a better picture of the 'quality of death' experience in healthcare settings and will further deepen our knowledge of end-of-life care in Ireland from a population health perspective.

Specialist palliative care services offer a support system to other care providers, allowing patients with complex conditions who are facing the end of life to be managed and cared for according to their needs. Hospice inpatient units have developed to meet these needs and to provide a rounded, holistic service to patients and their families which simply cannot be provided in an acute hospital setting. They also allow more patients be discharged or to be cared for at home, as shown by the data on hospice home care teams. For example, Milford Care Centre in Limerick has 30 hospice beds (28 of which are currently open), with a median length of stay per patient of nine days (MDS, 2011). Fifty percent of patients who go into the hospice for complex symptom control or respite are discharged home again. At any one time, Milford has over 300 patients in home care, with an average length of stay of around 145 days. These patients also use the hospice's day-care service and outpatient clinics.

International studies show that hospice care saves money by reducing admissions and lengths of stay in expensive acute care settings. However, while the evidence suggests that palliative care provides good economic value to health systems, this is clearly not the main reason to invest in services. We established at the outset that a population health approach was being adopted in this report, and we believe that access to effective palliative care in the most appropriate setting is a human rights issue. Higginson and Foley (2009), two leading palliative care clinicians in the UK, have argued that *"Palliative care should and must be given on the grounds of higher quality care, and the argument that palliative care should be given because it is cheaper is highly dangerous. No care anywhere at all is probably cheapest. But compared with other forms of care, there is evidence now emerging that not only is palliative care effective, producing quantifiable benefits in terms of pain and symptom relief, it also is cost-effective, providing savings in real terms for the health care system"* (p.1). How we care for the dying is fundamentally an ethical issue. As a society, we need to make the right decisions and take the right actions.

5.1.2. More can be done to allow patients to die at home

Secondly, we believe that more can be done to facilitate more people to die at home. The overwhelming shift towards dying in institutional care over the last century has been illustrated in Section 1 (Fig. 1), where we also noted that while 67% of Irish people surveyed (Weafer & Associates, 2004) expressed a preference to die at home, only 26% actually do so. Clearly, the wishes of many are not being fulfilled. We are therefore challenged to provide people with greater choice as to where they are cared for at the end of life and where they ultimately die, and in particular, to facilitate their wish – where it exists and is feasible – to remain at home. The wide regional variation in place of death in Ireland, as highlighted in this report, shows that some areas are closer to achieving this than others, suggesting that solutions can be found within an Irish context. The data shows, for example, that in some regions the percentage of cancer deaths occurring in acute hospitals is being reduced, with a corresponding increase in deaths in the home or in a hospice. This illustrates that more can be done to provide more appropriate care settings for people approaching the end of life.

The Mid West and North West have very good access to hospice services and much lower percentages of cancer patients dying in acute hospitals. Patients approaching death in the ‘resource-poor’ regions of the South East, Midlands and North East suffer significant inequity in access to hospice services, with a consequential higher proportion of cancer deaths in acute hospitals. There is no hospice inpatient unit in the South East (encompassing Carlow, Kilkenny, Wexford and Waterford, with a total population of 500,000); the North East (Louth, Meath, Cavan and Monaghan – population: 440,000); or the Midlands (Laois, Offaly, Longford and Westmeath – population: 280,000). The patient experience in these regions is remarkably different to that of people living in areas which have comprehensive palliative care services: the Mid West (population 380,000) and the North West (population 260,000). If access to hospice beds were equal across all five regions, an additional 1,100 patients would benefit from hospice inpatient admission every year.

The HSE’s capacity to deliver on its commitment to provide a consistent quality of palliative care service, as outlined by the Palliative Care Programme, is greatly compromised in the 16 counties that have no access to hospice beds.

5.1.3 Healthcare costs increase towards the end of life

We believe that the Irish healthcare system needs to actively manage its approach to palliative and end-of-life care. Healthcare costs rapidly escalate towards the end of life. The following is a summary of some of the international evidence:

- The healthcare budgets of most countries are skewed towards spending on care in the last year of life. Given that less than 1% of a country’s population die every year, it is estimated that up to 30% of all hospital expenditure goes towards caring for people in the last year of life (e.g. Gray, 2004).
- Working with an estimate that between 10% and 12% of the total healthcare budget is spent on caring for people in the last year of life (Polder et al., 2006), this would amount to more than €1.3 billion of Ireland’s current total health budget of over €13 billion.
- Spending on the last month of life is the highest. Between 25% and 33% of the average person’s lifetime health services consumption occurs in the last year of life. This can be roughly estimated at €70,000, out of a lifetime average spend of €300,000. About 40% (€28,000) of this ‘last-year’ expenditure happens in the last month of life (Ezekeil, 2002).
- All of the studies show that proximity to death, rather than age, results in very high use of health service resources (Raitano, 2006).
- The cost of dying in an acute hospital is far greater than in other healthcare settings. For example, in one study which examined 30,000 elderly patients with heart failure who died between 2000 and 2006 in Alberta, researchers found that when heart failure patients die in an acute hospital the cost is more than double that than when they die elsewhere, such as at home or in a palliative care facility. This finding is not surprising – acute hospitals are designed to cater for patients with acute medical needs, and such medical interventions are likely to be cost intensive (Kaul et al, 2011).

There is little comparable evidence for an Irish context, and indeed, this is an area which requires much greater attention. We understand that it is being explored by the HSE’s Palliative Care Programme, and Professor Charles Normand of Trinity College Dublin is currently conducting an international economic evaluation of palliative care in which Ireland is a participating country. This evaluation includes a systematic review of economic evidence.

5.1.4 Hospice services can provide real savings for the healthcare system

Once again we do not have reliable information to track the cost of palliative care in an Irish context, and this is an area in which research is urgently required. While approximately €78 million is provided by the state to specialist palliative care services⁶, where care is provided through a hospice inpatient unit local voluntary fundraising significantly augments this investment. It is therefore likely that overall investment is higher, and the fact that local hospices are able to increase their funding in this way shows the added value the voluntary hospice movement brings to the healthcare system. Through our work with that movement over the years, we understand that individual hospices have contributed significant voluntary funding to the cost of specialist palliative care in Ireland.

Internationally there is compelling evidence to indicate that hospice programmes can provide real savings to healthcare systems. When people enter hospice programmes they are cared for and die mostly at home or in a hospice, use fewer acute hospital services and live longer in greater comfort and dignity. They also consume at least 25% fewer medical resources than those who access 'usual care' (e.g. Emanuel, 1996). Cost savings also extend to hospitals that have palliative care units within the hospital. Several studies have reported lower use of acute care beds, aggressive therapies and intensive care units by patients under the care of specialist palliative care teams. A study in Richmond, Virginia, concluded that patients admitted to the hospital's palliative care unit had 57% lower care costs than patients with life-limiting illnesses who did not access the service (Smith et al, 2003). If 10% of Ireland's total healthcare budget of around €13.4 billion is spent on the care of people in their last year of life (see 5.1.3., p.37), then state spending on hospice/specialist palliative care, at under €75m, is less than 5% of this 'last year of life' spend, or 0.55% of the total health spend.

There is a natural logic to the argument that reducing the number of patients who die in an acute hospital setting by facilitating them to be cared for in other, more appropriate settings, will free up acute hospital resources. It could be argued that in reality it is likely that these resources will then be used for other patients, so that no budget reductions will be realised – but it may still yield improved efficiencies. The current agenda of the Department of Health's Special Delivery Unit⁷ is to achieve better quality, access and financial balance across the healthcare system. Specialist palliative care services have a role to play in achieving this. By ensuring that patients are cared for in the most appropriate setting for their needs, including specialist inpatient care needs, acute care resources can be diverted to patients who actually need them. More of these patients could be admitted through emergency medicine departments and waiting times for admissions reduced. We do not have all the answers, but from the perspectives of both service quality and cost, better management of death in the acute hospital setting offers opportunities for better resource utilisation.

5.1.5 Hospice services may be very cost effective in themselves

There is compelling evidence that investment in comprehensive specialist palliative care services across all care settings (hospital, home, inpatient hospice and daycare) yields significant savings. In particular, such investment reduces lengths of stay in hospital and the use of expensive medical interventions. It also enables patients to spend more time at home.

⁶ This includes other services designated as being for older persons.

⁷ The Special Delivery Unit (SDU) was established to unblock access to acute services by improving the flow of patients through the system. The SDU is focusing initially on emergency departments and is working to support hospitals in addressing excessive waiting times for admission to hospital. The SDU is working closely with key teams in the HSE and the National Treatment Purchase Fund, building on initiatives already under way, including the Clinical Programmes. The SDU will provide a performance management function for the Irish hospital system and will drive down waiting times. (*Department of Health, 2012*)

Many international studies indicate savings when patients access hospice programmes. They also show improved length of life, better symptom control, and patient and carer satisfaction. Studies in the US, Spain and Canada show the impact on the cost of care of regional palliative care programmes:

- In the US, hospice care saved Medicare (the agency providing medical insurance for those aged 65 and older) an average of 25% compared to the cost of providing for other patients with incurable life-limiting conditions, who accessed the non-hospice option (Taylor et al., 2007).
- In the Barcelona region the use of hospital resources by patients with incurable life-limiting illness fell by 61% following the implementation of a palliative care programme. Deaths in the home increased from 31% to 42%. Lengths of hospital stays were reduced by 25% and the use of emergency hospital rooms was reduced by 42% (Gomez et al., 2006).
- Paz-Ruiz et al., (2009) stated that: “*decreasing the number of hospital admissions, shortening the lengths of hospital stay, diminishing the frequency of emergency room consultations, shifting the use of acute hospital beds to palliative care beds for treating advanced disease inpatients, and substantially improving the use of opioids in the community are major determinants of the palliative care program’s success.*”
- In the 1990’s, a study in an Illinois veterans’ hospital demonstrated that a palliative care programme delivered savings of 18% and greatly improved patient and carer satisfaction. Some 171 patients receiving end-of-life care were split into two groups, with about half entering a palliative care programme. Those in the palliative care programme consumed 47% fewer hospital resources (Hughes et al., 1992).
- A study in an academic medical centre in San Francisco compared a group of patients in palliative care and a group in ‘usual care’. The palliative care group had an average 50% shorter length of stay, and daily care costs were lower by 33%, resulting in annual savings of \$2.2 million (Ciemens et al., 2007).
- A study of eight regionally dispersed US hospitals found that: “*palliative care consultation was associated with a reduction in direct hospital costs of almost \$1,700 per admission (\$174 per day) for live discharges and of almost \$5,000 per admission (\$374 per day) for patients who died.*” (Morrison et al., 2008).
- A study in New York of patients in two urban hospitals found significant savings in end-of-life care costs for palliative care recipients. Savings were \$239 or 20% per patient per day, with a 42% lower likelihood of intensive care admission. (Penrod et al., 2006)

We know that some of this evidence is replicated (if somewhat hidden) in an Irish context. In the first instance, much of the cost of home care is borne by family members so if more care can be provided in the home, this has the potential to impact significantly on health care costs. It is estimated that the total average cost per patient receiving specialist palliative home care support is €686. The average length of stay in home care in the Mid West specialist palliative care service was around 145 days – almost six months (Voluntary Hospices Group, 2011). Compare this to the cost of a bed in an acute hospital, which is approximately €1,000 a day or €7,000 a week (National Hospitals Office, 2011), and where the mean length of stay for a final admission is 22.5 days (HIPE, 2009), equating to a cost of approximately €22,500⁸. The cost savings can immediately be seen.

⁸ This is the cost of the final stay in hospital and does not take account of any previous admissions in the last six months of life.

We do need better Irish data and a deeper understanding of the true cost of care at the end of life. **It seems, however, that patients who are under the care of a palliative care team live longer, with greater comfort and dignity, and that overall the services do not cost any more than acute interventions.** Hospice care avoids inappropriate aggressive therapies in favour of the active total care of patients in the final stage of life, and allows many to be cared for in the home setting.

These findings are not new to the HSE, which has recognised for many years that specialist services must be developed, ideally through a reconfiguration of existing services. In May 2010, a presentation to the Board of the HSE from its own National Director of Performance and Financial Management stated:

“A comprehensive palliative care service can prove to be cost effective, with savings accrued through reduced acute and emergency bed usage and higher satisfaction of patients and family.... the deficit of Specialist Palliative Care beds in certain areas of the country is a hindrance to the continued focus and development of Specialist Palliative Care in the community. The requirement for these beds is, in percentage terms, very low compared to the existing bed stock.”

The advantages to adopting a comprehensive end-of-life care service model are:

- *Decreased acute hospital utilisation*
- *Reduced emergency admissions*
- *Reducing length of stay in hospital with usage of appropriate care*
- *Reduced costs”.*

The HSE's Acute Medicine Programme (2010) and Palliative Care Programme are both concerned to ensure that non-curative end-of-life care is provided in the appropriate setting. One of the major objectives of both programmes is to ensure that fewer people die in acute hospitals. The Palliative Care Programme's 2012 briefing document (HSE, 2012) stated that its aim was to support local implementation of best practice, and its objective is to *“ensure that patients with life-limiting conditions and families can easily access a level of palliative care service that is appropriate to their needs regardless of care setting or diagnosis.”*

5.1.6 Government policy is not being realised and significant inequity remains

Responding to national policy, which is based on the recommendations of the *Report of the National Advisory Committee on Palliative Care* (NACPC, 2001), the HSE's Five-Year Development Framework (HSE, 2009) set out the investment necessary to address the gaps in palliative care service provision. The Framework provided for nine new inpatient units and the elimination of deficits in home care teams. The reality is that only 1% of inpatient bed stock will be required for palliative care – this is not an excessive investment. With only two of the proposed new inpatient units built to date (and their beds not yet operational), the commitments in the HSE's 2013 Service Plans – including the intention to progress the development of four more inpatient units – are welcome. Achieving progress on the priorities laid down in the national policy and the Framework will be very challenging, however, given the current economic crisis. Of particular concern are those areas of Ireland which have least developed the full range of palliative care services in line with national policy. It is clear once again that the healthcare system is struggling to address the inequity in access to specialist palliative care services across the country.

There is also a need to address inequity in the provision of non-specialist palliative care support beds across the country. Of particular concern is the paucity of support beds in the North Eastern region. As already noted, the Irish Hospice Foundation is working with the HSE to examine the use of these beds.

5.1.7 Hospice home care must be protected

Perhaps one of the most interesting findings to emerge from this data mining study concerns hospice home care. Patient and family experiences of access to home care vary greatly across the country. In Cork and parts of the greater Dublin area (the Northern and South-Western areas of the former Eastern Regional Health Authority), where inpatient hospice units are in place, fewer patients are admitted to home care and waiting times are longer than in some areas where there is no hospice. Also, for patients with conditions other than cancer, admission to home care is below average in most LHOs within these areas. In comparison, in areas *without* an inpatient unit, such as the Midlands, there is greater access to hospice home care for all patients. This can be explained by the fact that in areas without a hospice, home care is often the *only* palliative care option available, and development funding allocated to specialist palliative care can only be invested in home care. However, we have also noted that a patient's access to home care during the course of illness does not automatically mean that they will die at home. In the North East, for example, where there is no inpatient hospice, 27% of patients of home care services die in hospital, compared to 6% in the Mid West, which benefits from the full range of services that only the presence of an inpatient unit can provide.

Of critical importance is the finding that access to hospice home care plays a vital role in determining whether a patient can remain at home. While only 26% of all deaths in Ireland occur in the home, 40% of patients cared for by home care teams die at home. Given that these will often be the patients with the most complex care needs, this is a great tribute to hospice home care teams across the country. This finding is consistent nationwide regardless of whether there is an inpatient unit in the region or not. It is clear that hospice home care teams are vital in enabling people to die in their preferred place of care. Anecdotal findings from home care teams across the country tell of a continual struggle to maintain staff numbers, with teams heavily impacted by staff embargoes and no capacity to be able to recruit replacement staff for periods of leave. This will heavily impact on a team's ability to see patients within seven days, and on the overall numbers of patients seen within a given period. Hospice home care teams need to be supported, strengthened and protected.

5.1.8 Change can be delivered even with restricted resources

The data used in this report consistently show a strong correlation between the under-development of hospice/palliative care services and where people die. The report has noted that the failure to implement national policy has meant that people who are dying are being denied access to fundamental aspects of end-of-life care and choice as regards where they die. We believe that the future development of palliative care services can be addressed without major resource implications, by standardising and reconfiguring the allocation of resources across regions. The HSE has endorsed this reconfiguration in the Five-Year Development Framework for palliative care services (HSE, 2009), which remains a national priority for action as this report goes to print in 2013. The proposed new model of prospective funding for palliative care services (DOH, 2012), based on the principles of 'equity of access' and 'the money follows the patient', offers hope to those facing the end of life, and a potential solution to facilitate the implementation of the Five-Year Framework within the current economic climate.

In the first paper published as part of the Irish Hospice Foundation's *Perspectives* series (IHF, 2013), we declared our belief in the strategic importance of palliative care in the health system, and outlined a vision for the future. The reform of the health service offers a strategic opportunity to ensure the best possible outcomes for people with palliative care needs. However, to achieve better care for these patients will require development at a number of levels, and any new directions or structures for palliative care will need to be underpinned by the following clear principles:

- **Strategic leadership at the highest level** of the health service – this will be essential to drive the development of comprehensive palliative care services as a core government commitment.
- The **integrated provision of palliative care** to all patients in every healthcare setting, including – where clinically feasible and in keeping with the patient's wishes – in the home.
- To ensure the seamless delivery of services across all of the HSE's new Directorates, a **mechanism for coordinating responsibility for palliative care**.

The specialist palliative care unit is designed to act as a 'hub' of the service and to support teams providing palliative care in the community, day care centres, hospitals and public and private nursing homes. Unless a real effort is made to develop innovative solutions to the current inequity issue, with a commitment to actively explore funding options, little progress can be made. The IHF is currently funding a development project in the Midlands to assist in achieving this level of detailed planning. Other regions should be facilitated to replicate this process.

We endorse the objective of the HSE's Palliative Care Programme to ensure that patients receive the right care at the right time and in the right place (HSE, 2012). Palliative care services provided in Ireland must be evidence-based and of a high quality, and should be accessible to patients and families in a timely manner, respecting their right to choice according to their needs. In addition to planning for future service development and reconfiguration, we must ensure that we protect the services that are currently in place and agree the development of robust quality measurement systems.

In summary

The data analysed in this report clearly shows that patients at their most vulnerable are being denied access to services because of where they live. There is clear evidence that the availability of hospice beds reduces hospital admissions and enables more people to be discharged from hospital settings to their preferred place of care – the home or a hospice inpatient bed. The hospice inpatient unit provides home care, day care, outpatient clinics, respite care and access to multidisciplinary specialist services. The inpatient service will not only meet the preferred care needs of patients but will also be more cost-effective than current services.

A comprehensive specialist palliative care service requires both an inpatient facility and a home care service working in tandem. At any point in time, in regions with well-resourced hospice beds, there are approximately ten times more patients being cared for in their homes, by hospice home care teams, than there are in hospice beds. The average length of stay in home care is almost six months compared to a mean length of stay of nine days in hospice inpatient units.

The 2011 Programme for Government commits the Government to introducing a system of universal health insurance driven by the principle of "equality of access" and a process whereby "the money follows the patient".

The Programme states that:

“...the separation of purchaser-provider functions will enable the development of a money follows the patient system of purchase of care... The HSE’s function of purchasing care for uninsured patients will be given to a Hospital Care Purchase Agency which will combine with the National Treatment Purchase Fund to purchase care for the uninsured over this transition period.”

In November 2012, the Government’s newly published health service reform strategy, *Future Health – a Strategic Framework for Reform of the Health Service*, outlined details of the proposed new funding model for patient care. The ‘money follows the patient’ (DOH, 2012) model will cover all patients with chronic illnesses, mental and physical disability, and those needing long-term care. A similar model for palliative care patients would enable the voluntary sector to fill the gaps in the provision of palliative care inpatient services. This is sometimes referred to as ‘prospective funding’. The HSE’s Palliative Care Programme and *Future Health* have a commitment to “develop a model of prospective funding”. There is a related workstream in the Palliative Care Programme on the “expansion of the provision of specialist palliative care services to provide new services where there are identified gaps.” It is hoped that these developments may facilitate the implementation of the HSE’s 2009 Five-Year Development Framework for palliative care services. This remains a key priority.

The HSE’s 2013 Service Plan makes a commitment that 92% of referrals to hospice beds will be met within seven days. Unfortunately, in areas where there are no hospice beds, there can be no referrals. The proposed new system of funding healthcare services presents a real opportunity for the reconfiguration of end-of-life care services and for ensuring consistency in meeting commitments to patients.

No one should have to face death or bereavement without the care and support they need. We need to ensure that regardless of where people live in Ireland, they may face the end of life with dignity, comfort and choice. We can do this by addressing, with our partners and the public, the critical matters outlined in this report.

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Appendix 1 Administrative regions of the health service

When the Health Service Executive was established, the geographic areas corresponding to the eight regional health boards then in existence were replaced by four new administrative regions. Since several key documents referred to in this report relate back to the 'old' structures, much of the regional data has been presented in terms of the former Health Boards regions, for ease of reference. In other cases, it is presented in terms of the four current HSE regions and 32 Local Health Offices (LHOs)

Former health boards, with abbreviations used in this report

The North Western Health Board	(NWHB)
The Mid Western Health Board	(MWHB)
The Western Health Board	(WHB)
The Southern Health Board	(SHB)
The South Eastern Health Board	(SEHB)
The Midland Health Board	(MHB)
The North Eastern Health Board	(NEHB)
The Eastern Regional Health Authority	(ERHA), covering the greater Dublin area and its hinterland, and further subdivided into the: <ul style="list-style-type: none">- Northern Area (ERHA N.)- South West Area (ERHA SW.)- East Coast Area (ERHA E.)

Current HSE administrative regions

- HSE Dublin/Mid-Leinster
- HSE Dublin North East
- HSE South
- HSE West



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