The Irish Hospice Foundation

Striving for the best care
at end of life for all

ENABLING MORE PEOPLE TO DIE AT HOME:

Making the Case for Quality Indicators as Drivers for Change on Place of Care and Place of Death in Ireland

IHF Perspectives Series: No 3

The Irish Hospice Foundation's Perspectives series aims to spark debate on vital topics in the fields of hospice care, death and dying by commissioning papers from key thinkers and offering our own view of what they propose. Previous Perspectives include:

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Supported by a research paper written by

Dr. Kieran McKeown
Social & Economic Research Consultant

IHF Perspectives Series: No 3
December 2014

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FOREWORD

Most people in Ireland say that they want to die at home. It's a simple vision, yet in the last 60 years it has become rarer, and harder to achieve.

The Irish Hospice Foundation (IHF) believes that a good death at home is within the capabilities of our health services, and should be a true measure of the person-centred values of our society.

Kieran McKeown's research paper *Key Performance Indicators on Place of Care and Place of Death in the Health Service in Ireland*, commissioned by the IHF as part of its ground-breaking Perspectives series, explores whether place of care at the end of life, and place of death, could become part of a wider set of key measures of the effectiveness of the Irish healthcare system.

The paper is an expanded version of one prepared for the Special Delivery Unit (SDU) of the Department of Health, at their request, exploring the best way of providing simple metrics to measure success in meeting the preference of more people to be cared for and die in a home setting, thus reducing the number of patients dying in acute hospitals.

The IHF is publishing the paper, and has added its own commentary, in order to broaden the debate around this most fundamental of wishes.

The IHF recognises that there are a myriad of factors that influence whether a person can die at home. As we age, and as illness progresses, preferences may, of course, change. But people in Ireland consistently and increasingly say that they want to die at home. This can and should become the norm for those who choose it. The fact that quality homecare services at the end of life may be cost-neutral, or even cost-effective, for the health services would be an added bonus.

The IHF hopes that this research paper, and the commentary written by our CEO, Sharon Foley, will be vital reading and food for thought for politicians, health service policymakers, people providing specialist and general health services to those at the end of their lives, and everyone with an interest in the quality of their own dying. We trust that, in common with the other publications in our Perspectives Series, *Enabling More People to Die at Home: Making the Case for Quality Indicators as Drivers for Change on Place of Care and Place of Death in Ireland* will stimulate a vibrant debate, and will ultimately enable more of us to experience a good death. We welcome further engagement on this vital issue.

Jean McKiernan
Chairperson, Irish Hospice Foundation
December 2014

PERSPECTIVE OF THE IHF ON PLACE OF CARE AND PLACE OF DEATH IN IRELAND

> *HOSPICE. The dictionary defines it as a house of rest, a home, and traces its origins to the Latin hospitium meaning hospitality or lodging, which in turn relates it to hospes, a word for a host. And by one of those happy double-takes which are part of every language, hospes was also the Latin word for a guest.*
>
> **Seamus Heaney**, The Whoseday Book [1]

Home, hospitality, hospice. In his introduction to the Whoseday Book, Seamus Heaney, as always, evokes concepts and meanings that get to the heart of who we are, and our deepest wishes.

One of those deepest wishes is the hope for a “good death”. While interpretations of a “good death” may vary, for many Irish people the wish to die at home is a fundamental part of it. In research conducted recently for the Irish Hospice Foundation (IHF), nearly three out of four respondents – 74% of the total – said that they would like to die at home[2], a significant rise from 66% ten years ago[3]. Clearly, the desire to be at home at the end of life is stronger than ever.

When asked “if you had a terminal illness, which of the following would be the most important to you regarding how you spend your final days?” respondents’ top five answers included being surrounded by loved ones, free from pain, having privacy and dignity, being in familiar surroundings and being in a calm and peaceful atmosphere. This is similar to other research conducted by Sue Ryder in the UK. [4] These are the elements of a dignified death and, with the possible exception of pain control, all are most easily achieved at home. Yet, the reality is that at present only about one quarter of those who die each year in Ireland die at home[5]. Place of care at the end of life, and place of death, matter to the Irish Hospice Foundation, and are central to our concerns. The original and sustaining impulse of the hospice movement is to provide hospitable, home-like places where people’s preferences about dying and death can be met. For many this includes a preference to remain in this home-like place until death. The paper proposes a mechanism for checking how well the health service is doing at meeting people’s known preferences to die in a home setting (which may be home or long-stay care) wherever possible.

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[1] Donnelly, M. (Ed) (2000) *The Whoseday Book; a millennium journal.* Dublin : Irish Hospice Foundation

[2] Weafer, J. (2014) *Irish attitudes to death, dying and bereavement 2004-2014*. Dublin: Irish Hospice Foundation

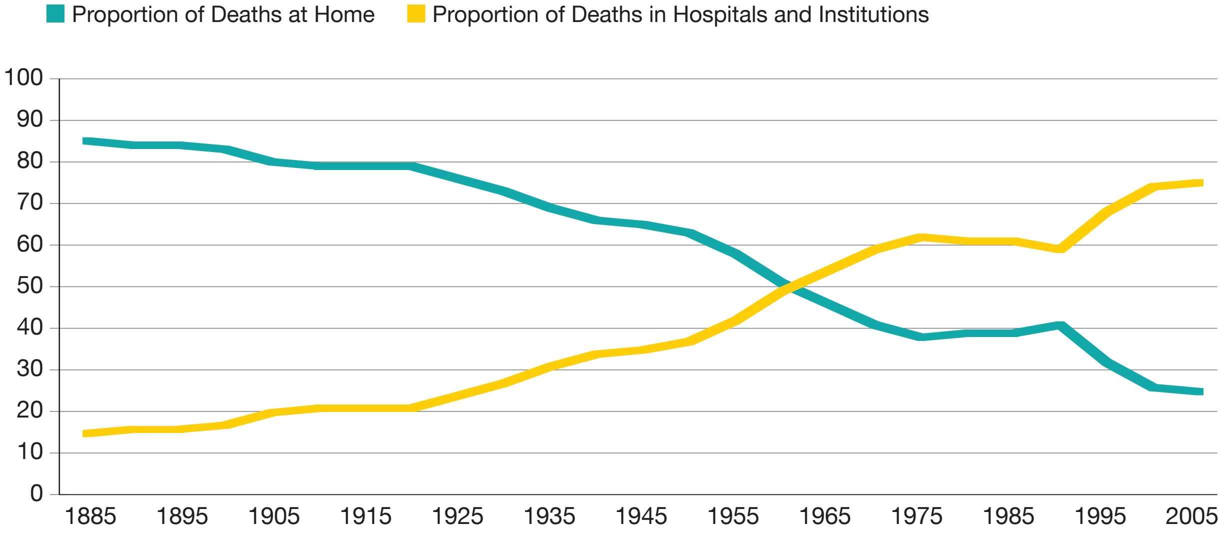
[3] Weafer & Associates (2004) *A nationwide survey of public attitudes and experiences regarding death and dying*. Dublin : Irish Hospice Foundation. [online] Available at http://hospicefoundation.ie/wp-content/uploads/2012/04/Weafer-et-al-2004-A-nationwide-survey-of-public-attitudes-and-experiences-regarding-death-and-dying.pdf Accessed Sept 29 2014

[4] Wood, C.& Salter, J. (DEMOS) (2013) *A time and a place*. London : Sue Ryder [online] Available at http://www.sueryder.org/About-us/Policies-and-campaigns/Our-campaigns/Dying-isnt-working/~/media/Files/About-us/A-Time-and-a-Place-Sue-Ryder.ashx Accessed Sept 29 2014

[5] Central Statistics Office (CSO) (2013) *Vital statistics fourth quarter and yearly summary 2013* Dublin: The Stationary Office. [online] Available at http://www.cso.ie/en/media/csoie/releasespublications/documents/vitalstats/2013/vstats_q42013.pdf Accessed Sept 29 2014

National discussions on place of death are taking place in all developed countries, in specialist services, in nursing homes and hospitals, and among the general public. Many authors have discussed the increasing medicalisation of dying (see Fig. 1 below) and the gradual trend over the past century towards increasing deaths in the hospital setting[6]. A US doctor's blog, describing a conversation with a patient, outlines the everyday dilemma, "While some patients may not be as assertive about their needs as [name], their desire is nonetheless just as strong. It's easy to understand their motivation. Too many institutional residential facilities feel sterile, lack privacy and, worse yet, do not meet our basic quality standards. However, the draw is much stronger than that. It's about the familiar, it's about memory, and it's about where and with whom we feel most safe[7]."

Fig 1. **Place of death in Ireland 1885-2005 (McKeown et al)**



Unfortunately, we know that this is true for too many people living in Ireland. Discussions about returning home to die occur daily in every Irish hospital. When asked about their preferences, most Irish people say they want to die at home, in their own bed, surrounded by the people they love.

The Irish Hospice Foundation believes that more can be done to enable more people to die at home. In other countries, including England and Scotland, indicators relating to "place of care at the end of life" and "place of death" are increasingly used as ways of enabling and measuring success in achieving this important priority for patients and their families[8]. We think that Ireland should explore this approach and do whatever it takes to make it possible for people to fulfil their wish to die at home.

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[6] McKeown, K., Haase, T., Pratschke, J., Twomey, S., Donovan, H., & Engling, F. (2010) *Dying in Hospital in Ireland: An Assessment of the Quality of Care in the Last Week of Life, Report 5, Final Synthesis Report.* Dublin: Irish Hospice Foundation. [online] http://hospicefoundation.ie/wp-content/uploads/2012/04/FINAL_National_Audit_of_End_of_Life_Care_in_Hospitals_Report_5.pdf Accessed Oct 1 2014

[7] Tulsky, J. (2014) 'All the comforts' *Duke Magazine* July 18 [online] http://dukemagazine.duke.edu/article/all-the-comforts Accessed Sept 29

[8] Hunt, K., Shlomo, N. & Addington-Hall, J. (2014) End-of-life care and achieving preferences for place of death in England: Results of a population based survey using the VOICES-SF questionnaire. *Palliative Medicine* Vol. 25 (5) pp 412-421

1.1 Why is dying at home so important?

The IHF believes that enabling people to fulfil their wish to die at home is not just a matter of effective health services and flexible, responsive, people-centred systems. It is fundamental to the very basis of humanity in an evolved society. Allowing choice and dignity in end of life care, and in the experience of dying, is a strong indication of how we care for Irish society as a whole. Ireland's legendary "people focus" lies at the heart of who we are, and there can be no clearer demonstration of our caring and concern than to enable people to have as "good" a death as possible. And that, increasingly, means being supported and enabled to die at home.

The IHF knows that this will take commitment, effort, will and drive. To make it happen, Irish health services need to find ways to transfer care from hospitals to communities and into homes. Commitment is needed from the political level right down to families themselves having those critical conversations. The IHF has produced this publication as a way of informing the debate and helping it to take root.

Dr McKeown's paper explores ways of using indicators to measure success in helping those facing death to achieve their wish of dying at home. There are many ways of doing this: place of death, place of care in last six months, preference for place of care and ability to meet this preference[9] . At the end of the day, for IHF, how this is measured is less important than the fulfilment of a real commitment to provide for people's preferences at the end of life.

The IHF believes that the location in which people die in Ireland is important. We know that this topic can evoke strong opinions and reactions. As a national charity striving to promote better care at end of life in every care setting, including in people's own homes, we have worked to create better environments for end of life in hospitals, care homes and through community services. Services are evolving: whereas in years past hospices were the only "specialised" place of care for people who were dying, now every county has its own hospice homecare team. But the outcomes vary throughout Ireland, suggesting that more can be done to enable more people to die at home.

The IHF believes that now is the time to explore the underlying factors associated with facilitating more patients to die at home. Issues related to the measurement and implementation of such measures do not always lend themselves to clear answers. Dying at home is an aspiration for many, but in the reality of inconsistent home and community supports, the quality of a home death may be poor, and therefore not in the best interests of the patient and their family. The Irish Hospice Foundation believes that this is not inevitable, and that Ireland can and must do better.

This is a debate we need to have as a society. We need to consider what more can be done to allow more people to die at home if that is their wish. We need to reflect on whether a focus on "place of death" as an outcome measure or quality indicator (QI) is ethical, consider any appropriate alternatives and learn from international experience.

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[9] De Roo M., Miccinesi G., Onwuteaka-Philipsen B., Van Den Noortgate, N., Van den Block, L., Bonacchi, A., Donker, G., Alonso, J., Moreels, S., Deliens, L. & Francke, A. (2014) Actual and Preferred Place of Death of Home-Dwelling Patients in Four European Countries: Making Sense of Quality Indicators *PLoS ONE* Vol. 9 (4) [online] http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0093762 Accessed Oct 1 2014

1.2 Achieving system change through measuring quality

Measuring performance links strategic intent with quantifiable actions and outcomes. Quality indicators are like dials on the dashboard of a car. They provide elementary signals about how the engine is working and, if something is wrong, a warning sign ensues, highlighting that some remedial action may need to be taken.

Dr. McKeown's paper proposes that kind of quality indicator. Ireland is now in its second decade of health service transformation. This is an appropriate time to look at the baseline situation, so that progress can be tracked as further transformation proceeds. In the previous decade of transformation the proportion of people dying at home remained relatively unchanged. A focus now on a specific national QI may represent a way of helping to make sure that change happens in the decade ahead.

In Ireland, data on "place of death" is collected through a death certificate which, like a birth certificate, is one of the most robust and reliable forms of data collection in the country, backed by statute. It is easily accessed through the CSO. Some changes to the classification of care settings would be needed to make this data useful in the context of a national QI, but this can be achieved without difficulty. Data on "preference for place of care at end of life" or "place of care in last six months of life" is more challenging, as this data is not yet routinely collected in Ireland. It will require the establishment of new data collections routes, but this is not an insurmountable challenge.

It is likely that any or all of this range of metrics would be collected annually. As such, they would not lend themselves to the monthly monitoring procedures associated with current HSE key performance indicators (KPIs). Consequently, the IHF proposes that any quality indicator on place of death and/or place of care at the end of life should be a national QI, measured annually and reported for each geographical area of the health service including region, hospital catchment area, Local Health Office, and Primary Care Network region.

By themselves, QIs can be blunt tools. Positive organisational attitudes and staff involvement are critical to ensuring the QI is adopted in the first instance and then actively used to transform delivery of care. System change will depend on a participative approach at a number of levels, one that actively seeks to understand patient need and test ways to realistically achieve greater care and deaths in the home setting. Locating QIs on place of care at the end of life, and place of death, in the context of a national aspiration, would help to provide the leverage for such thinking to begin.

What influences place of care and place of death?

Where we die is not just a matter of personal preference. It also clearly depends on what supports are in place to allow us to die at home – at peace and with good care. Factors that increase the likelihood of dying at home include the presence of a carer, the nature of the illness itself and the symptoms associated with it, socio-economic and demographic status and, of course, the availability of quality local services[10].

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[10] Social Care Institute for Excellence (SCIE) (2013) *Dying well at home: the case for integrated working. SCIE Guide 48.* London: Social Care Institute for Excellence. [Online] Available at http://www.scie.org.uk/publications/guides/guide48/files/guide48.pdf.Accessed Oct 1 2014

Notwithstanding the wide range of influences on home death, the Irish Hospice Foundation believes that more can be done to facilitate people at end of life to be cared for and to die in their home setting if that is their wish. For example, we know that services can:

- provide rapid access to palliative care and support at all times of the day and night
- provide facilities and supports for rapid discharge from hospital for dying patients, including the provision of necessary community services without delay
- operate effective methods of communication between mainstream and out-of-hours services, thus preventing unnecessary emergency hospital admissions
- improve the capacity of primary care services to support GPs, public health nurses and other community care providers to provide good generalist palliative care
- improve recognition of people as being in the last year of life, or at the end stage of their disease or condition, referring them as early as possible to palliative care services
- support hospice homecare teams to fulfil local community needs.

Exemplar projects throughout Ireland have already highlighted how the percentage of people dying at home can increase. These include hospice homecare services, daycare programmes for non-malignant diseases and Milford Care Centre's Hospice at Home Service[11]. Recently published HSE national discharge guidance for patients who wish to die at home provide a framework for discharging patients quickly but it is too early to see the impact of this initiative.

1.3 Ethical considerations and challenges

Much needs to be considered before a national QI on place of death/place of care at the end of life can be introduced in Ireland. For example, we need to be sure that the proposed QI is valid, reliable, supported by evidence and/or expert consensus, is acceptable, feasible, sensitive, specific, relevant, balanced, tested and safe, avoids duplication and provides timely data. Dr McKeown discusses many of these factors in his paper.

In addition, it is important to balance the merits and potential dangers of promoting and developing health and social services to support care and dying at home. Dr Joan McCarthy has developed a ground-breaking ethical framework within which ethical issues concerning end of life can be explored[12]. Together with the traditional ethical principles of beneficence (do good) and non-maleficence (do no harm), the values she explores include:

- the sanctity of life: the fact of being alive is itself deeply valued
- quality of life: the fact of having positive experiences and avoiding negative experiences is considered deeply morally significant
- autonomy: respecting someone's preferences in relation to where, how and when they die is, a core part of ethical thinking but is also increasingly, considered to be a contested notion[13].

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[11] McKay, E., Taylor, A., Armstrong, C., Gallagher, M., Bailey, M., Graham, M. & Ward, J. (2011) An Evaluation of the Hospice at Home Service Delivered by Milford Care Centre 2009/2011 Limerick: Milford Care Centre and University of Limerick. [online] Available at http://www.milfordcarecentre.ie/media/ideabubble/MIL-1115/docs/final_copy_hah_report_8-2-12.pdf Accessed Oct 14 2014

[12] McCarthy, J., Donnelly, M., Dooley, D., Campbell, L., Smith, D., O'Neill, C., Quinlan, C. & Weafer, J. (2010) *The complete framework for End-of-Life care*. Dublin : Irish Hospice Foundation. [online] Available at http://hospicefoundation.ie/publications/ethics/. Accessed Oct 1 2014

[13] ibid

While these may be the components of ethical care, the IHF recognises that other factors may also have a significant influence. For example, obligations concerning fitness to practise, and competing demands of legal rights to care, have to be balanced against a caregiver's natural desire to look after their loved one. Health professionals have legitimate concerns about openness to accusations of negligence and possible litigation. In Ireland we need to find workable solutions to these dilemmas.

A critical element for good end of life care is the "respectful opportunity for the patient's voice to be heard concerning their dying".[14] Autonomy is defined as the capacity for self-determination, which is manifested in the person's ability to make choices about their life. The preference for place of care and dying is a fundamental aspect of patient autonomy. The moral principle of autonomy requires that, in a healthcare context, health professionals recognise and support the values, priorities and preferences of patients. This means that the needs and wishes of the dying person, and not just those of their family, must be taken into account.

However, autonomy is not an absolute right: the right to autonomy is limited by the legitimate autonomy and welfare claims of others. Health professionals may constrain autonomous choices by deciding to limit treatment options where they might pose a harm or disadvantage to others, or where a patient is insisting on a treatment which is deemed futile. So, for example, a person may wish to be cared for and ultimately die at home, but such is their healthcare needs, combined with the lack of appropriate services at home and in the community, that the health professional makes a judgment to retain the person in a hospital setting. In doing so, the healthcare professional is considering the principle of beneficence, obliging them to "do good" and to be actively concerned for the interests of patients and the promotion of patient wellbeing.

The principle of beneficence places pain relief and symptom management among the most important objectives in caring for patients living with advanced life-limiting illness. Lack of adequate pain management causes harm to the patient – suffering, worry, depression, anxiety. Consequently, facilitating people to be at home must be balanced with the capacity of the healthcare system to meet people's needs safely, enabling healthcare staff to act in accordance with the principle of non-maleficence – to "do no harm" – particularly in relation to pain and symptom management. This is where the presence of strong community and hospice homecare services make the critical difference: their presence can give people excellent care in their own homes.

The IHF therefore believes that a national QI on place of death/place of care at the end of life should be balanced with the appropriate levels of home-based and community-based services. Pain relief can be provided in the home to the same high standard as in the very best specialist palliative care (SPC) service. There are many quality service improvement initiatives in place all around Ireland which can be adapted to enhance the provision of homecare at end of life. Achieving more deaths at home will require investment in community and home care services – quality care is a prerequisite for more home deaths. We just need the will to do it.

Aligned to the principle of beneficence is the understanding that dying at home might be better for patients. Some research has shown that the quality of death may be better in a homecare setting and that patients who die at home, or in another freely-chosen place, have a better quality of dying compared to those who do not. However the evidence is not consistent as there are inequities in access to support services and unmet needs amongst patients and carers[15].

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[14] ibid

[15] Higginson, I., Sarmento, V., Calanzani, N., Benalia, H. & Gomes, B. (2013) Dying at home – is it better: A narrative appraisal of the state of the science. *Palliative Medicine* Vol. 27 (10) pp 918-924

However, the potentially positive benefits for people who die in the setting of their preference (choice, comfort, familiar surroundings, access to loved ones etc.) are fundamental to an ethical health service, alongside the other system-wide benefits of more home deaths discussed later in this commentary.

1.4 Seeing Place of Care and Death in the Wider Context of Health Service Performance

The ethical backdrop to the debate on “place of death/place of care at the end of life” as a national QI serves as a framework within which to understand the concerns expressed about its possible place in the Irish healthcare system. It is clearly no-one’s intention to reduce reliance on acute services in favour of a poorer quality service in the home setting.

Ireland needs to take a 360° perspective of care and patient need. As the HSE has noted, many factors influence expressed choice including age, diagnosis, treatment options, culture, urban or rural setting, location of hospital and family circumstances[16]. Stage of disease also contributes to place of death. No national QI on place of death/place of care at end of life could be taken alone as a reliable measurement of health service performance. The purpose of such a QI would be that data regarding place of death could inform and drive system-wide change and encourage more effort to facilitate home deaths where appropriate. **The IHF wants to make sure that the debate takes place and that place of care and death is used to inform analysis of overall health service performance**. The proposal for KPIs on place of care and death is a modest one and in many other countries it is taken for granted as part of their health information systems. Health atlases, which map spatial variations in health services, are now a feature of all developed healthcare systems, including Ireland. We sincerely believe that all concerns, for an Irish equivalent, can be mitigated through a balanced discussion on the proposed national QI, in tandem with a policy commitment to galvanise high-quality service provision in the community, increase home deaths and truly honour people’s choice of place of care and death.

The IHF acknowledges that not all research about homecare at the end of life is in agreement, and that dying at home is not possible or desirable for everyone. Specialist palliative care is available in hospitals and other in-patient facilities, and it is important that a national QI on place of death/place of care at the end of life is not interpreted as a reflection on the quality of care provided[17]. Hospital care could be exemplary, and care in a home setting could be very poor if appropriate care and support are not in place.

The IHF recognises the risk that a national QI on home deaths could be implemented without increased resources for homecare. Quality homecare plays a key role in facilitating people’s choice to die at home, and has the potential to increase this up to 40% from the present level of 26%. This finding is replicated internationally.[18]

The IHF’s considered view is that any initiative to increase the proportion of deaths in the home setting must be accompanied by a transfer of resources from the acute sector to community-based services.

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[16] Health Service Executive (HSE) (2013) Written response to Sharon Foley CEO Irish Hospice Foundation to a request to review an original version of the KPI paper.

[17] Paddy, M. (2011) Influence of location on a good death. *Nursing Standard* 26(1) pp 33-36.[online] Available at http://rcnpublishing.com/doi/pdfplus/10.7748/ns2011.09.26.1.33.c8693. Accessed Oct 1 2014

[18] Riolfi, M., Buja, A., Zanardo, C., Marangon, C., Manno, P. & Baldo, V. (2014) Effectiveness of palliative home-care services in reducing hospital admissions and determinants of hospitalization for terminally ill patients followed up by a palliative home-care team: A retrospective cohort study. *Palliative Medicine* Vol. 28 (5) pp 403-411

1.5 Seeing Place of Care and Death in wider context of Hospice Movement

While there are undoubtedly challenges to be surmounted in the introduction of a national QI, the potential benefits make it compelling. Enabling people to die at home is an important issue for the hospice movement worldwide:

> "Meeting patients' preferences and creating home-like environments has been a major concern for hospice and palliative care since its inception. During the 20th century, in many countries, hospital deaths increased and home deaths reduced. Despite the fact that this trend has been halted or reversed in some countries (notably the United States, Canada and, more recently, the United Kingdom) in the last 5–20 years, a home death is still a distant reality for the majority, even though evidence shows it is the most commonly preferred place to die".[19]

Doing more to achieve death at home

Increasing the proportion of people dying at home is an outcome measure associated with high quality care, but this does not imply that those who died elsewhere only received "second-best" care or that a service "failed" in not getting a patient home to die. People at the end of life are admitted to in-patient facilities for valid reasons, and it is some people's preferred place of care and death[20]. Not everyone can die at home, or even wants to die at home. So a measure concerned with place of death is not an indicator of the success or failure of acute services, palliative care services or any other part of a hospital system (such as an elderly care unit). Instead, it is a measure of how the *entire* health care system is managing the care of those patients at most risk of dying and, by extension, vulnerable patients in the health care system as a whole. By actively recognising those people who may be nearing death, and by actively looking to see if they are in the best place of care in relation to their needs and wishes, hospitals could be improving quality for patients and responding to their specific requirements. A national QI therefore merits investigation, not only as an effort to grant people's preferences, but also as a way to enhance patient experience and the health service's approach to the provision of care at end of life.

In 2013, the IHF undertook a survey of bereaved relatives as part of a pilot study using an audit and review system which it developed for supporting quality improvement in all care settings where people die[21]. The case below, in which a 75-year old bereaved daughter describes the death of her 101-year old mother, is not unusual, and shows the need for improvement in the current system.

> "Staff at the hospital were excellent to my mother but she did not need to be in the hospital most of the 5 months, but we could not afford full time care which at nearly 102 years of age my mother then required. I want the HSE to have the fair deal applied to her own home as well as nursing homes but although we had fair deal approval my mother died after a chest infection while waiting on a place. I got a call this month from [the] CNU to say they had a place - 4 months after she had died. I am very upset that my mother had to spend her last days in hospital as she was not very ill but as I was the only carer at 75 years I could not do full time care with an 84 year old husband. However I was grateful for the hospital's care."

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[19] Higginson, et al (2013: 918)

[20] Macleod, U. (2011) Place of death – is home always best? *British Journal of Hospital Medicine* Vol. 72 (8) pp 441-443

[21] McKeown, K., Lovegrove, M. & McLoughlin, K. (2013) *Audit and Review System for End-of-Life Care: Master Documents for Pilot Study.* Dublin: Irish Hospice Foundation.

At the same time, geographical variations in the proportion of people who die in hospital in different counties in Ireland, and even within areas of the same county, are hard to justify in terms of the needs and expressed preferences of patients. A national QI would offer a way of monitoring unwarranted and unnecessary variation and would ensure that action is taken to correct it.

1.6 Cost benefits

In Ireland, as elsewhere, the place where people are cared for at the end of life, and where they ultimately die, is assuming greater importance, not just because of the imperative to align health services with people's preferences, but also because the escalating cost of hospital care is no longer sustainable. In response to this, and accelerated by the recession in Europe and the US since 2008, many countries are reducing their expenditure on health services, especially hospitals. Ireland is no exception. While hospitals should and will remain central to any developed healthcare system, offering the most advanced available forms of treatment, it is increasingly accepted that hospitals should be used only by those whose acute care needs cannot be treated elsewhere. At present, one of the unintended consequences of the overuse of acute care hospitals is that those with life-threatening illnesses who cannot be treated elsewhere have to wait longer to be admitted, and this causes unnecessary suffering, while also making their condition more difficult (and more expensive) to treat. The declared purpose of health service reform in Ireland is to "move us away from the current hospital-centric model of care towards a new model of integrated care which treats patients at the lowest level of complexity that is safe, timely, efficient, and as close to home as possible".[22]

Over 500 people die each week in Ireland. Of these, over 200 die in hospital. A national audit of care during the last week of life in 2008-9 showed that the care provided in and by Irish hospitals is as good as that in hospitals in the UK, the US, and France[23]. This finding is reassuring about the quality of care in Irish hospitals and is consistent with other studies which show that Ireland compares well with other countries in terms of its end of life care (Martin-Moreno et al., 2009[24]; Bjornberg et al., 2009[25]). But other factors, such as quality of experience, must also be considered.

Every government is challenged to improve the quality of care for patients at all stages of life while also reducing healthcare costs – specifically those associated with acute care. The Institute of Healthcare Improvement (IHI) describes this as the "triple aim" of:

- improving the patient's experience of care (including quality and satisfaction)
- improving the health of populations
- reducing the per capita cost of healthcare.[26]

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[22] Department of Health (2012) *Future Health: A Strategic Framework for Reform of the Health Service 2012-2015.* Dublin : Department of Health. [online] Available at http://lenus.ie/hse/bitstream/10147/253172/1/FutureHealth.pdf Accessed Oct 1 2014

[23] McKeown et al, 2010

[24] Martin-Moreno, J. & Centeno, C (2009) Bringing palliative care on to the European agenda. *European Journal of Palliative Care* Vol. 16 (2) p.57 [online] Available at http://www.eapcnet.eu/LinkClick.aspx?fileticket=eqKvw70E66A%3D&tabid=38. Accessed Oct 1 2014

[25] Björnberg, A., Garrofé, B., & Lindblad, S. (2009). *Euro Health Consumer Index 2009 Report*. Health Consumer Powerhouse. [online] Available at http://www.healthpowerhouse.com/files/Report%20EHCI%202009%20091005%20final%20with%20cover.pdf Accessed Oct 1 2014

[26] Institute of Health Improvement (IHI) (2014) *The IHI triple aim initiative*. [online] Available at http://www.ihi.org/Engage/Initiatives/TripleAim/pages/default.aspx. Accessed Oct 1 2014

A key way to improve patient experience while simultaneously driving down costs is to transfer appropriate elements of care into the community and home setting. Dr. McKeown's paper notes that "inappropriate use of hospitals is a significant source of inefficiency and inequity in the health service, although evidence on the cost effectiveness of home care by comparison with usual care is inconclusive". Some early work completed by the CEO Group of the Voluntary Hospices in Ireland shows that homecare at the end of life not only takes patients out of the acute setting but only adds under €700 to the total cost of patient care in the community – a monumental cost saving on the cost of acute care.[27]

The IHF National End of Life Audit report[28] showed that patients who die in Ireland's acute hospitals spend at least twice as long there before dying compared with other countries such as the UK[29] the US[30] and the OECD generally[31]. This raises questions about whether this reflects the case-mix of patients or, more likely, the overall management of hospitals and health services generally.

The audit also found that at least a fifth of those who die in hospital – over 40 per week – could have died at home if sufficient supports had been available. This finding raises significant concerns. Firstly, as this commentary has stressed, people prefer to die at home but are more likely to die in hospital. This means that their preference to be cared for and die at home is going unmet. Secondly, for well over a decade it has been national health policy to deliver health and social care, wherever possible, in the homes and communities where people live. If this policy was fully implemented, there would be an increase in end of life care and deaths at home. This suggests that the policy has not been implemented or is not working as intended.

An initiative which has great potential to influence positive system change is the Rapid Discharge Pathway (RDP[32]), which is currently being implemented across the health system. Recognising that enabling people to die where they choose is an important aim of palliative care, the RDP provides a guidance framework for healthcare professionals when end of life care at home is considered a priority. This work needs support at a national level so that its implementation is consistent throughout the health service and we look forward to seeing the impact this has on statistics regarding place of death in the future.

Achieving system change which facilitates more people to die at home should have implications for reducing acute healthcare costs whilst requiring an increase, most likely to a lesser degree, in funding for community and home-based care. The IHF believes that it is time to grasp this nettle, and to establish the likely level of financial saving through careful research on the costs and outcomes of care in different settings, adjusted for different types of patient need.

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[27] Voluntary Hospice Group (2012) Service Provision for Specialist Palliative Care in Ireland: A Briefing Paper. Submission to National Director Palliative Care, Health Service Executive.

[28] McKeown et al, 2010

[29] Abel, J., Rich, A., Griffin, T. & Purdy, S. (2009) End-of-life care in hospital: a descriptive study of all inpatient deaths in 1 year. *Palliative Medicine* Vol. 23 (7) pp 616-22

[30] Martin L., Nelson E., Lloyd R. & Nolan T. (2007) *Whole System Measures. IHI Innovation Series white paper*. Cambridge, Massachusetts: Institute for Healthcare Improvement. [online] Available at http://www.ihi.org/resources/Pages/IHIWhitePapers/WholeSystemMeasuresWhitePaper.aspx Accessed Oct 7 2014

[31] OECD (2013) *Health at a Glance 2013: OECD Indicators*. OECD Publishing. [online] Available at http://www.oecd.org/els/health-systems/Health-at-a-Glance-2013.pdf. Accessed Oct 2 2014

[32] National Clinical Programme for Palliative Care (2013) *National rapid discharge guidance for patients who wish to die at home.* Dublin: Health Service Executive. [online] Available at http://www.hse.ie/eng/about/Who/clinical/natclinprog/palliativecareprogramme/Resources/Rapid.pdf. Accessed Oct 2 2014

Where to from here?

Introduce national quality indicators

The Irish Hospice Foundation supports Dr McKeown's conclusion that, notwithstanding the data collection and other challenges, both place of care at the end of life and place of death are sound QIs and should be adopted by the Irish healthcare system. The IHF sees this as far more than an additional form of data collection since these QIs offer an indication of how well the health services are meeting the deepest wishes of people approaching the end of life, reflecting the humanity and aspirations of Irish society as a whole.

Dr McKeown proposes that the Department of Health in partnership with the HSE should set up a project group to consider QIs relevant to end of life, specifically including place of death and place of care at the end of life, or in the context of the consideration of outcome measures for the entire system, under those being considered for Healthy Ireland or for acute hospital services. Mindful of the profound implications of these measures, the IHF advocates that the potential QIs should be considered as national quality indicators for Irish society and the health services as a whole. We ask for discussions to be prioritised and time-targeted, with a view to implementation as soon as possible. The IHF is happy to support and facilitate debate on this vital topic.

THE IHF THEREFORE RECOMMENDS THAT:

The Department of Health, in partnership with the HSE, should establish a project group to consider key influences for care at home at the end of life and the introduction of performance measures relevant to end of life care and place of death as national quality indicators for Irish society and the health services as a whole.

Strengthen the services which enable people to die at home

The IHF is particularly concerned about regional disparities in home deaths between those areas supported by an in-patient hospice unit and the 16 counties which have none. One effect of the presence of a hospice in Ireland is the transfer of patients from hospital to hospice, thus facilitating the provision of the most appropriate specialised care to those with complex palliative care needs, in line with national policy. Conversely, the absence of a hospice means that people who need specialised care and who cannot die at home die in hospital[33].

The IHF is concerned about what this implies about access to appropriate quality care for people at the end of life. Intriguingly, however, the data presented by Dr. McKeown also suggests that, in areas without a hospice, patients are more likely to die at home. The finding raises the question of what more can be done in those areas with a hospice to facilitate a higher proportion of home deaths. It may be that those areas without hospices have better developed homecare teams, or other reasons may be at play, such as urban/rural differences in allocation of community supports. We need to find out.

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[33] Murray, E. (2013) *Access to specialist palliative care services and place of death in Ireland; What the data tells us. Irish Hospice Foundation, perspectives series no. 2*. Dublin: Irish Hospice Foundation. [online] Available at http://hospicefoundation.ie/wp-content/uploads/2013/06/Access-to-specialist-palliative-care-services-place-of-death-in-Ireland.pdf. Accessed Oct 2 2014

Increasing the proportion of home deaths needs to be driven by a strong strategy, as well as innovative practice, such as that provided by Milford Care Centre's Hospice at Home service (see page 57). Across the country a critical support for deaths at home is hospice homecare. All counties have a team in place, and their impact on home deaths is notable: where patients are under the care of a hospice homecare team, the percentage of home deaths rises from 26% to 41%.[34] Equally significant is the fact that two of the areas without hospices – South East and North East – have a higher proportion of deaths at home than any of the areas with hospices.

In the current fiscal circumstances, small-scale services such as hospice homecare – often involving teams of less than 10 nurses – are vulnerable to staff attrition and cutbacks. The IHF wants hospice homecare services to be protected, supported and grown. We need better access to current verified data on the level of homecare nurses, so that services can be monitored effectively. Many areas provide the requisite number of nurses for their population but it is likely that some areas are understaffed and that actual and potential demand for their services is going unmet.

Update policy on palliative care

At present all planning for palliative and end of life care services, is based on the 2001 report of the National Advisory Committee on Palliative Care[35]. Following his consideration of the impact of health service facilities on place of death, Dr McKeown suggests that it is time to reassess the appropriate level of SPC provision in different parts of the country. For example, he shows that areas such as the South East, Midlands and North East – conventionally designated as "under-resourced" in terms of SPC services by virtue of not having a hospice – have much higher proportions of patients dying in their usual place of residence than other SPC services. At the same time, the absence of a hospice in the South East, and similar areas, also means that this option is not available for those patients who may have a need or preference for a hospice. In light of this analysis, Dr McKeown suggests that some re-framing is required of the paradigm used to assess the appropriate level of SPC provision in different parts of the country by taking account of "the outcomes and costs associated with different service configurations (hospital, home, long-stay, hospice) in order to form a rounded assessment of what constitutes best value for populations and patients in terms of end-of-life care."

The IHF believes that it is vital to examine service provision across all care settings, including homecare. The National Palliative Care Policy is now 13 years old. While much remains valid and visionary, it needs to be updated and refreshed in light of current national policy for the health services and a renewed focus on the outcomes which services are expected to deliver for the resources available, including meeting people's preferences to be cared for and die in a home setting.' It also needs a renewed implementation imperative. Much of the vision to address inequities, as outlined in the 2009 Framework[36], designed to bring the 2001 policy to life, remains unfulfilled, with people in 16 counties still denied access to hospice beds. Service specifics (for example, the requirement for one specialist palliative care bed per 10,000 of population) have been useful for service planning, but they now need to be updated to reflect the current delivery of both general and specialist palliative care services, the real and potential requirement for hospice homecare, the possibility of delivering more care in the home setting and the achievement of national equity.

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[34] Ibid

[35] Department of Health & Children (2001) *Report of the National Advisory Committee on Palliative Care.* [online] Available at http://lenus.ie/hse/bitstream/10147/42522/1/1890.pdf Accessed Oct 6 2014

[36] Health Service Executive (2009) *Palliative Care Services - Five year/medium term development framework*. [online] Available at http://www.hse.ie/eng/services/Publications/corporate/palcareframework.pdf. Accessed Oct 2 2014

The IHF believes that it is time to address questions such as the following: What more can be done to enable people to die at home? Is it possible to replicate and scale up the examples of great practice and experience in other parts of the country? Over time, the IHF will continue to explore these issues. We believe a realistic review of service requirement is now required, particularly in relation to hospice homecare.

THE IHF THEREFORE RECOMMENDS THAT:

The HSE and the Department of Health should update the 2001 report of the National Advisory Committee on Palliative Care with specific consideration to the immediate and medium term commitments for development of palliative care services and a review of the necessary requirement of specialist palliative care staff and inpatient beds in hospital and community.

CSO is the definitive national data-set on all deaths in Ireland, including place of death. It is based on the official registration of every death. There are three limitations with this data-set, particularly from a QI perspective. First, data on place of death is normally published about two years after the death has occurred; for example, data on place of death in 2011 was published in October 2013 (CSO, 2013). Second, the CSO classification of place of death is outdated and – apart from deaths at home – does not correspond in any meaningful way to where people die or may be cared for at the end of life[37]. Third, the data is available at county level but cannot be presented, without a great deal of re-coding and re-analysis, for HSE administrative areas such as Local Health Offices (LHOs) or Primary Care Networks (PCNs) or in time Hospital Groups.

THE IHF THEREFORE RECOMMENDS THAT:

The CSO develop a more systematic solution to the problems concerning timeliness of data on place of death, classification of place of death and reconciliation with HSE administrative areas.

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[37] The four CSO categories for place of death are: (i) General & Special Hospitals & Nursing Homes (ii) Mental Hospitals (iii) Local Authority Institutions (iv) Domiciliary.

CONCLUSION

The Irish Hospice Foundation fervently believes that ensuring people can fulfil their wish to die at home is a mark of a civilised, person-centred, caring society, the kind of country in which we all want to live and die. Discussing this topic is not always easy, but it is vital and essential. The IHF intends this commentary to open discussions with politicians and policymakers and to stimulate debate amongst service providers and the general public.

In presenting our views, the Irish Hospice Foundation is calling on the Government to adopt place of care at the end of life and place of death as part of a wider set of quality indicators, not just of the healthcare system but for Irish society as a whole. By driving system change in the health services, we can bring about the conditions for the "good death" that we all hope for and deserve.

We ask you, the reader, to help us make that happen.

Sharon Foley
CEO, Irish Hospice Foundation
December 2014

RESEARCH PAPER

Key Performance Indicators on Place of Care & Place of Death in the Health Service in Ireland

Report written by

Kieran McKeown
Social & Economic Research Consultant
www.kieranmckeown.ie

October 2014

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EXECUTIVE SUMMARY

The paper makes the case for using place of care and death as Key Performance Indicators (KPIs) to measure some of the outcomes of health and social services at end of life. In conjunction with other indicators, it is proposed that this is a useful way of assessing how well these services are responding to the needs and preferences of people.

Most KPIs in the health sector focus on inputs (such as financial resources, staff, buildings, equipment) and outputs (patients, procedures, admissions, discharges). The development of KPIs to measure outcomes is somewhat rarer but also more challenging; arguably it has never been more important.

What is a KPI?

A Key Performance Indicator (KPI) is simply a way of measuring performance in order to improve it. To be effective, therefore, a KPI needs to be SMART: Simple, Measurable, Appropriate, Reliable and Timely. But it also needs to be intelligent in the sense that it is a valid pointer – since an indicator is only a pointer – to some deeper experience which is valued by everyone.

What would these KPIs look like?

A KPI is normally measured as the proportion of people in a particular category and requires a numerator and a denominator. The numerator for a KPI on place of care could be the total bed-days spent by a patient in hospital during the last six months of life; the denominator would be the total bed-days a patient could have spent in hospital of during the last six months of life (182 days maximum). Other indicators on place of care during the last six months of life could include: number of days a patient spent in intensive care; number of times a patient was admitted to hospital; number of times a patient was admitted through Emergency Department; number of deaths in Emergency Department.

A KPI on place of death could be measured by the total number of deaths in hospital during the last twelve months (the numerator) divided by the total number of deaths (the denominator). Data on both KPIs could be aggregated for each health service area including region, hospital catchment area, Local Health Office, and Primary Care Network.

Naturally, there is more to assessing the outcomes of health and social services than simply measuring the place where one is cared for or dies. That is why place of care and death should complement, not replace, other quality indicators for the structure, process and outcomes of care. In other words, place of care and death should be seen as part of a wider set of measurements on what contributes to good care and a good death. That is why the proposed KPIs are just an additional set of data to help improve decisions about whether the right care is being delivered in the right place at the right time.

Why use place of care and death as a KPIs?

There are a number of reasons why place of care and death merit consideration as KPIs for measuring outcomes of health services at end of life. First, most people in Ireland and across Europe prefer to die at home, including those who are terminally ill, but most will actually die in hospital. This implies that people's preferences to be cared for and die at home may not be facilitated by the health system. In Ireland, for example, about three quarters of the population would prefer to die at home but only a quarter actually die there.

Second, although there is limited comparative data on the quality of care in different settings, a national audit of end-of-life care in Ireland found that some aspects of care which are unique to acute hospitals, notably admissions through an Emergency Department, were predictors of poor quality care. Being admitted to acute hospital is not always the best option.

Third, a substantial proportion of those who die in hospital in Ireland could die at home if appropriate supports were available. That is a robust finding based on the opinions of doctors, nurses and relatives in the 2008/9 national audit of end-of-life care.

Fourth, inappropriate use of hospitals is a significant source of inefficiency and inequity in the health service. Inappropriate in this context refers to the use of hospitals for treatment and care that could be provided in another less expensive setting. Given that the average length of stay of patients who die in hospital is about 24 days – compared to an average length of stay for all patients of 6 days - the implications of reducing these hospital deaths could be substantial in terms of using resources more efficiently and equitably.

Fifth, a KPI on place of care and death is consistent with national policy for the health services. National health policy in Ireland for well over a decade – and even longer - is underpinned by the idea that health services should be delivered, to the greatest extent possible, in the communities and homes where people live, and should avoid unnecessary admissions to acute hospitals and other institutions. This is also the policy of the Government (2011-present) which has reiterated a commitment to 'reforming our model of delivering healthcare so that more care is delivered in the community' and 'move us away from the current hospital-centric model of care towards a new model of integrated care which treats patients at the lowest level of complexity that is safe, timely, efficient, and as close to home as possible.'

Are there precedents for using place of care and place of death as KPIs?

There are precedents for using place of care and place of death as KPIs for some of the outcomes of health services at end of life. In Scotland, for example, place of care is one of the main indicators used for monitoring its 2008 end of life strategy and is measured as the percentage of last six months of life spent at home or in a community setting; or the inverse of this which is the percentage of last six months of life spent in acute hospital. In England, place of death is the main KPI which has been used to assess the outcome of its end of life care strategy since 2008. This is measured as the proportion of all registered deaths at home, in care home, or in hospital in each area.

What data exists on place of death in Ireland?

There are four main national sources of data on place of care and death in Ireland: (1) CSO (Central Statistics Office) data on deaths (ii) HIPE (Hospital In-Patient Enquiry) data on the activities of acute hospitals and (iii) Minimum Dataset (MDS) on Specialist Palliative Care (SPC); (iv) National Cancer Registry (NCR). If place of care and death are to become part of a set of KPIs for measuring the outcomes of end-of-life care, consideration will need to be given to the way this data is currently collected, coded and analysed so that it can be used to produce timely information to measure and assess performance.

Is there a difference between place of death in Ireland and internationally?

Broadly speaking, there are four places where deaths occur: hospital, home, long-stay and hospice. In Ireland, as in other developed countries, more people die in hospital than anywhere else. More than four in ten deaths (43%) occur in hospitals with most of the remainder divided almost equally between those that die at home (26%) and those that die in long-stay places of care (25%); a small minority die in hospice (6%). Internationally, Ireland has a significantly higher proportion of deaths occurring in hospitals (43%) compared to the US (36%) but lower than most European countries except the Netherlands (34%), based on the countries for which comparable data is available.

The fact that there are wide differences between countries in the outcomes of their health services, as measured by place of death, suggests that decisions about which patients can die at home or in hospital are made differently in different countries. This illustrates that what is an ‘appropriate’ place of care for a patient can be quite different from one setting to another. It also indicates that a wide spectrum of possibilities exist for organising end-of-life care services by showing what **is** done in different settings, and therefore what **can** be done once it has been decided what **should** be done.

The variability between and within countries, and even within counties in Ireland, in the place of care and death also raises the question: is this variability warranted in the sense that it can be justified by corresponding variation in the needs and preferences of patients? This seems unlikely in a country the size of Ireland and leads to the suggestion that some patients, from say Dublin or Galway who die in acute hospital, would probably die at home or in long-stay care if they lived in Leitrim, Limerick or Donegal. Similarly the scale of variation in deaths at home between counties leads one to ask why, for example, is it possible for 34% of deaths to take place at home in Donegal, yet about half that proportion (18%) die at home in Dublin? Addressing that question and its implications in terms of meeting the needs and preferences of patients in a cost effective manner is important and timely given that acute hospital care is one of the most expensive forms of care available.

Why is there so much variation in place of death?

Three broad sets of factors are normally used to explain variations in place of care and death between and within countries. The first are personal and socio-demographic factors including patient preferences. The second are disease-related factors such as symptoms, functional impairment, disease trajectory and associated burden of care. The third are environmental factors such as healthcare policy and provision, the patient’s social supports, and wider factors such as societal expectations.

Looking closer at the environmental factors, US evidence in particular has shown that the concentration of hospital resources (beds, doctors, nurses, etc) influences the likelihood of dying in hospital. In European studies, availability of alternatives to hospital (long-stay, home care, hospice) has been highlighted as an influence on the likelihood of dying in hospital; although this has also been found in a US study. A common factor influencing place of death across many contexts is the role of policies to promote care at or closer to home, including the clinical culture and practice of promoting patient choice and autonomy.

Do SPC services improve the chances of people dying at home?

SPC services are delivered through Home Care Teams (HCTs) and In-Patient Units (IPUs, also known as hospices) as well as in hospitals. It is well-documented that there are disparities in the size and composition of SPC services throughout the country. These disparities provide a natural experiment to assess, using the Minimum Dataset (MDS) for SPC, how regional and county differences in SPC services may impact on a KPI to increase care and dying at home or reduce deaths in hospital.

The overall effect of SPC services, as delivered through HCTs, is to increase the proportion of deaths at home and reduce the proportion of deaths in hospital. Patients who died with the support of HCTs in 2011 were less likely to die in hospital and more likely to die at home. This implies that HCTs have an important role to play in advancing the outcome of increasing deaths at home or closer to home and reducing deaths in hospital.

When SPC services are compared between areas with and without a hospice, it shows that one effect of a hospice in Ireland is to transfer patients from hospital to hospice. This is consistent with the acknowledged role of hospices in providing specialised care to patients with complex palliative care needs. Conversely, the absence of a hospice may mean that patients who cannot die at home but who need specialised care then die in hospital which, depending on the quality of hospital care in those areas, may raise questions about whether the area has the appropriate mix of services for end-of-life care. The data also suggests that, in areas without a hospice, patients are more likely to die in their usual place of residence, which may be either home or a long-stay place of care.

These findings suggest that some re-framing might be helpful of the conventional paradigm used to assess the appropriate level of SPC provision in different parts of the country, based on the report of the 2001 National Advisory Committee on Palliative Care. For example, areas such as the South East, Midlands and North East are conventionally designated as ‘under-resourced’ in terms of SPC services – by virtue of not having a hospice - yet they have much higher proportions of patients dying in their usual place of residence compared to any other SPC service. At the same time, the absence of a hospice in the South East, and similar areas, also means that this option is not available for those patients who may have complex palliative care needs or prefer a hospice setting.

Given that hospice is an approach to care and not just a place of care, as the World Health Organisation has made clear in its definition of palliative care, the aspiration of the Hospice Friendly Hospitals programme (2007-2012) was to make every acute hospital in Ireland a hospice-friendly place to be cared for and die. This aspiration remains relevant given that, compared to every other place of care, acute hospitals are likely to remain the place where most people will continue to be cared for and die at the end of life. In weighing up these considerations, account needs to be taken of the outcomes and costs associated with different service configurations (hospital, home, long-stay, hospice) in order to form a rounded assessment of what constitutes best value for populations and patients in terms of end-of-life care. In light of that evidence, it may then be possible to specify more precisely the combination of SPC services – and health services generally - which simultaneously support more care in the patient's usual place of residence and less in acute hospital.

What is needed to implement these KPIs?

A substantial amount of work still remains to be done to implement these KPIs, particularly in terms of setting up data systems that can deliver accurate and timely reports. For that reason, a project group needs to be set up which is inclusive of all data-holders relevant to these KPIs as well as those with strategic responsibilities for overall management of outcomes in the health service.

Concluding Comment

The proposal contained in this paper, to adopt KPIs for monitoring the place where people are cared for and die, is timely and useful in the context of the reconfiguration of health services in Ireland. The proposal is consistent with the overall thrust of health policy which aims to provide more health care in the homes and communities where people live while also aiming to reduce the inappropriate use of hospitals. As such, this is not a radical proposal nor, from an international perspective, is it particularly innovative since similar KPIs have been implemented in Scotland and England for a number of years. A project group is now required to prepare the proposal for implementation and address the challenges of improving data collection systems to meet the need for timely, accurate and appropriate data.

SECTION 1 - INTRODUCTION

The purpose of health services is to keep people well while also providing treatment and care when they are unwell. In that sense, health services are a means to an end, not an end in themselves. The outcome which health services seek to achieve is the well-being of each individual and the entire population so that people enjoy the best possible quality of life[38]. That is also the outcome of services at end of life, including palliative care services: 'The goal of palliative care is the highest possible quality of life for both patient and family.'[39]

The importance of framing health services in terms of the outcomes they are expected to achieve is increasingly recognised, and not just in health services. In the economy, for example, it is now recognised that measuring well-being is an important indicator of progress that is not captured by traditional output data such as GNP[40]. Similarly in health services, progress is measured not just by the amount of services, or the amount of money spent on them, but also by the outcomes they produce in terms of health and well-being[41]. This paper extends that thinking to health services at end-of-life including palliative care where it is still relatively rare to find any mention of outcomes[42].

Taking outcomes seriously is not easy however, particularly from the perspective of measurement. It is normally much easier to measure the inputs of health services (such as financial resources, staff, physical capital) and its outputs (patients, procedures, admissions, discharges, waiting times) but much more difficult to measure the outcome of these services. That is why there are numerous key performance indicators (KPIs) for measuring the inputs and outputs of health services but relatively few(er) for measuring outcomes.

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[38] This understanding of outcome is informed by the WHO definition of health: 'Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.' (World Health Organisation, 1946: Preamble).

[39] National Advisory Committee on Palliative Care, 2001:10.

[40] This perspective has been articulated by an international commission on how to measure economic progress: 'The time is ripe for our measurement system to shift from measuring economic production to measuring people's well-being. … . Emphasising well-being is important because there appears to be an increasing gap between the information contained in aggregate GDP data and what counts for common people's well-being. This means working towards the development of a statistical system that complements measures of market activity by measures centred on people's well-being and by measures that capture sustainability.' (Commission on the Measurement of Economic Performance and Social Progress, 2009:12-15). In keeping with this, the Minister for Finance announced in the Budget Speech on 7th December 2010 that: 'The Government has committed to the introduction of a new national performance indicator to allow a variety of quality of life measurements to be assessed and reported on a regular basis, complementing traditional economic data. This will be used to guide policy development. It will allow the public to assess the progress being made across a range of indicators.' (Minister for Finance, 2010).

[41] Referring to the US health system, one commentator observed: 'The current delivery system is not organized around value for patients. … First, measurement and dissemination of health outcomes should become mandatory for every provider and every medical condition. … . Outcomes of care are inherently multidimensional, including not only survival but also the degree of health or recovery achieved, the time needed for recovery, the discomfort of care, and the sustainability of recovery. … . We need to measure true health outcomes rather than relying solely on process measures.' (Porter, 2009).

[42] For example, it is difficult to find any mention of outcomes, at least by that name, in any of the key documents which are publicly available on end-of-life and palliative care in Ireland.

This paper proposes that place of care and place of death are appropriate KPIs for measuring outcomes of health services at end of life. In conjunction with other indicators, it is a useful way of assessing how well health services are responding to the needs and preferences of people.

A KPI is normally measured as the proportion of people in a particular category based on a numerator and a denominator. The numerator for a KPI on place of care could be the total bed-days spent by a patient in hospital during the last six months of life; the denominator would be the total bed-days a patient could have spent in hospital of during the last six months of life (182 days maximum). Other indicators on place of care during the last six months of life, which could be developed as KPIs, could include: number of days a patient spent in intensive care; number of times a patient was admitted to hospital; number of times a patient was admitted through Emergency Department; number of deaths in Emergency Department.

A KPI on place of death could be measured by the total number of deaths in hospital during the last twelve months (the numerator) divided by the total number of deaths (the denominator). Data on both KPIs could be aggregated for each health service area including region, hospital catchment area, Local Health Office, and Primary Care Network.

The paper sets out the thinking behind this proposal and the evidence supporting it. We begin by explaining the purpose of KPIs and why they work best when they are smart and intelligent (Section 2). We then offer reasons why the proposed KPIs are appropriate and timely for Ireland (Section 3) and why it follows a precedent set by other countries notably Scotland and England (Section 4). The proposed KPIs require data on place of care and death, and we review the main data sources in Ireland on this topic, including the challenges which arise from using this data to make the KPIs operational (Section 5). In order to illustrate the value of these KPIs we present an overview of place of death in Ireland – hospital, home, long-stay, hospice - and set it in an international context (Sections 6). This is followed by more detailed analysis of deaths in hospital (Section 7) and at home (Section 8). We also review deaths which are supported by Specialist Palliative Care Services (SPC) since these represent a significant minority of all deaths in Ireland and offer a useful illustration of variations in place of care and death within this service (Section 9). Finally, in the concluding section, we summarise the arguments and evidence in favour of adopting the proposed KPIs (Section 10).

SECTION 2 - FINDING A KPI THAT IS SMART AND INTELLIGENT

It is useful to begin by stating that the purpose of a KPI is to improve performance. That is why they need to be SMART: Simple, Measurable, Appropriate, Reliable and Timely. In other words, if a KPI is designed to enhance performance, it is necessary to have a clear understanding why that particular area of performance is important, what standard of performance is being sought, and what might enhance that performance.

KPIs also need to be intelligent. This aspect is prompted by an observation attributed to the physicist Albert Einstein: 'Not everything that is important can be measured, and not everything that can be measured is important'. That observation is relevant here because any proposed KPI for end-of-life care must be able to point validly – since an indicator is only a pointer – to some deeper experience which is valued by everyone. In this instance, that deeper experience could be described as quality of life and involves living life as fully as each person wishes, irrespective of whether the end of life is thought to be close or distant. Measuring quality of life therefore is the underlying goal of the proposed KPI, just as promoting quality of life is also the goal of national health strategy[43], national palliative care strategy[44], and the strategic framework for the reform of the health service[45].

Building on this understanding, there is a good deal of evidence that place of care and death may be useful proxies for some of the outcomes of care at end of life and, to the extent that they accord with people's preferences of where they want to die, an indicator of a 'good death'[46].

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[43] The vision informing Ireland's 2001 Health Strategy states: 'A health system that supports and empowers you, your family and community to achieve your full health potential. A health system that is there when you need it, that is fair, and that you can trust. A health system that encourages you to have your say, listens to you, and ensures that your views are taken into account.' (Department of Health and Children, 2001a:8).

[44] 'In essence, palliative care is primarily concerned with quality of life; it is dedicated to a form of active treatment that is designed to ensure that patients are enabled and encouraged to live their lives to the greatest possible extent, in the manner and in the setting of their choice' (National Advisory Committee on Palliative Care, 2001:3; see also 10-11; 22; 34; 58; 86; 113).

[45] 'The overall purpose of the health service is to improve the health and wellbeing of people in Ireland' (Department of Health, 2012a:6; 2012b:13).

[46] See, for example, Gomes, Calanzani, Gysels, Hall, and Higginson 2013; Gomes, Higginson, Calanzani, Cohen, Deliens, Daveson, 2012; Gomes, Calanzani, Higginson, 2011a, 2011b; Houttekier, et al, 2009; 2010; Cohen, et al, 2006; 2008. A recent study observed that the patient's preferred place of care and preferred place of death are not static categories and are not easy to measure: 'Discussing 'preferred place of care' with patients is an easier communication issue than discussing 'preferred place of death'. Many patients and their families are unwilling or unable to contemplate the hour of their death. It is difficult for patients to anticipate how they will be feeling when they reach the final stage of their illness. For these reasons (and because health care professionals often find it stressful to talk directly about death) discussions frequently centre on location of care rather than place of death. … . Although large numbers of hospitalized patients may initially report that their preferred place of care is at home, caution must be exercised to ensure that this also reflects their preferred place of death. In our own practice [large London teaching hospital] a greater attention to distinguishing between these two concepts has identified a significant proportion of patients who prefer to stay in hospital when they enter the terminal phase. While every effort should continue to be made to facilitate the desire of patients to die at home, care must be taken not to neglect the wishes of patients who prefer to die in hospital.' (Gerard, et al, 2011).

Naturally, place of care and death do not replace other quality indicators on the structure and process of care, nor are they the only possible outcome indicators. That is why place of care and death need to be seen as part of a wider set of measurements on what contributes to good care and a good death[47]. For example, in England where place of death is the main outcome indicator for its End of Life Care Strategy[48], a good death is understood as: (i) being treated as an individual with dignity and respect; (ii) being without pain and other symptoms; (iii) being in familiar surroundings; and (iv) being in the company of close family and/or friends[49]. Place of care and death reflects some of these dimensions but other indicators are necessary to provide a fuller picture of the structure, process and outcome of care.

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[47] 'The use of place of death as an outcome measure to judge the quality and quantity of service provision is based on the supposition that these determine outcome: in reality, the characteristics of the patient and their family, and of the illness itself, may also play a significant role. Some hospital admissions may be both appropriate and unavoidable because of complex, difficult-to-control symptoms. Patients may prefer hospital because of quality relationships they have developed over previous admissions. Furthermore, the relationship between place of death and patient and family experience is complex, as it is not just location that matters but how that location impacts on the needs and preferences of the patient as well as their family and friends.' (Hunt, Shlomo and Addington-Hall, 2014:413).

[48] Department of Health, 2008.

[49] Department of Health, 2008:9.

SECTION 3 - SOME REASONS FOR USING PLACE OF CARE AND DEATH AS KPIS

The first reason why place of death merits consideration as an outcome of health services at end of life is that most people in Ireland[50], England[51], and Europe[52] prefer to die at home, including those who are terminally ill, but most will actually die in hospital[53]. Over the decade 2004-2014, the preference for dying at home among Ireland's population increased (from 67% to 74%) while the preference for dying in hospital fell (from 10% to 5%); by contrast, the proportion dying at home has remained largely unchanged since at least 2000 (at around 25%). Significantly, the preference to die at home is even stronger among doctors and nurses than among the general population[54]. This implies that people's preferences to be cared for and die at home may not be facilitated by the health system[55].

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[50] A national survey of 1,000 adults in Ireland (89% response rate) in 2014 found that 74% preferred to die at home; 15% preferred to die in hospice; 5% preferred to die in hospital; 3% preferred to die in long-stay; and the remaining 3% were a combination of 'other' and 'don't know' (Weafer, 2014). A similar survey in Irealnd in 2004 found that 67% preferred to die at home; 10% preferred to die in hospital; 10% preferred to die in hospice; 5% preferred to die in long-stay; and the remaining 8% were a combination of 'other' and 'don't know' (Weafer, 2004).

[51] A similar survey in England, Wales and Scotland was carried out in 2003 and found, compared to Ireland, a weaker preference for dying at home (56%) but a stronger preference for dying in a hospice (24%) (Higginson, 2003). A 2010 update of the English survey found that the preference for dying at home strengthened (63%) but so also did the preference for dying in a hospice (29%) (Gomes, Calanzani and Higginson, 2011a and 2011b; Gomes, Calanzani, Gysels, Hall and Higginson, 2013). A more recent survey in England, based on a sample of bereaved relatives (n=473), found that just over a third (36%) of their deceased relatives had expressed a preference of where they would like to die and, of those expressing a preference, nearly three quarters (74%) expressed a preferencce to die at home (Hunt, Shlomo and Addintgon-Hall, 2014:414).Very few (1%) were reported to have changed their mind (Ibid). Although just under half died in their preferred place (49%), the majority of bereaved relatives felt their relative had died in the right place (90%) (Ibid).

[52] A recent European survey in seven countries on preferences for place of death if the person faced advanced cancer found that 'At least two-thirds of people prefer a home death in all but one country studied. The strong association with personal values suggests keeping home care at the heart of cancer EoLC.' (Gomes, Higginson, Calanzani, Cohen, Deliens, Daveson, et al, 2012)

[53] 'Most cancer patients (50-70%) prefer a home death but this is not the reality of their expeirnece; in the UK, 59% of all deaths occur in hospitals, a further 17% in care homes, and only 18% at home. … For those with conditions other than cancer, the proportions dying at home differ markedly according to condition, with only 12% of deaths ffrom respiratory and neurological causes occurring at home, and almost all dementia deaths occurring in care homes (55%) or hospital (39%)' (Murtagh, et al, 2012:18). A study of all cancer deaths in England between 1993 and 2010 concluded that 'hospital remained the most common PoD [place of death] throughout the study period (48.0%)' (Gao, Ho, Verne, Glickman, Higginson, et al. 2013:1).

[54] As part of the National Audit of End-of-Life Care 2008/9, a survey of 2,358 ward staff and 1,858 hospital staff revealed a much higher preference to die at home among both ward staff (81%) and hospital staff (77%); correspondingly, the proportion preferring to die in hospital (6%) was smaller than in the national population (10%) (McKeown, Haase and Twomey, 2010c). This is consistent with the results of a survey of 1,899 ICU doctors, nurses and patients in six European countries, who were asked where they would rather be if they had a terminal illness with only a short time to live; the results showed that more doctors and nurses would prefer to be at home or in a hospice and more patients and families preferred to be in an ICU (Sprung, Carmel, Sjokvist, et al., 2007; see also Sprung, Cohen, Sjokvist, et al., 2003). The same study also revealed that physicians provide more extensive treatment to seriously ill patients than they would choose for themselves, possibly indicating a public demand for life-prolonging interventions that may have little prospect of success.

[55] A recent review observed that: 'At present, in many countries of the world, most people have their wishes for home death unfulfilled. Despite efforts and policies to enable more to die at home only a minority of deaths take place at home' (Gomes, Calanzani, Curiale, McCrone and Higginson, 2013:9; Gomes, Calanzani, Gysels, Hall and Higginson, 2013). In the US, a more varied pattern is reported: 'In some regions of the United States, and in some hospitals, patients with short life expectancies receive relatively high levels of comfort-focused, palliative services and are less likely to die in a hospital or in a hospital's intensive care unit. In other places, such patients are more likely to spend their last days in the hospital, often in intensive care units, receiving uncomfortable treatments - such as using a breathing tube connected to a ventilator - that are unlikely to prolong or enhance the quality of life. In some cases intense care may be driven by patient preferences, but commonly it is not.' (Morden, Chang, Jacobson, Berke, Bynum, Murray and Goodman, 2012:786; see also Tolle, et al, 1999).

In Ireland, for example, about three quarters of the population would prefer to die at home but only a quarter actually die there. It is recognised that preferences can change as end of life approaches but the preference to be cared for and die at home tends to remain strong and stable[56].

Second, although there is limited comparative data on the quality of care in different settings[57], the national audit of end-of-life care in Ireland in 2008/9 found that some aspects of care which are unique to acute hospitals, notably admissions through an Emergency Department, were predictors of poor quality care[58]. At the same time, the overall quality of care in Irish hospitals was found to be good and as good as one finds in hospitals in the UK, the US, and France[59]. Equally, there is growing evidence on the benefits of home-based palliative care[60] but there is insufficient evidence on whether dying at home is better than dying in hospital for patients and families[61].

The third reason why place of death is important is that a substantial proportion of those who die in hospital in Ireland could die at home if appropriate supports were available. That was a clear finding of the national audit of end-of-life care in Ireland in 2008/9, based on the views of nurses, doctors and relatives[62]. In addition to being generally contrary to patient preferences, this suggests that dying at home may be unnecessary for a significant proportion of patients.

Fourth, inappropriate use of hospitals is a significant source of inefficiency and inequity in the health service, although evidence on the cost effectiveness of home care by comparison with usual care is inconclusive[63]. Inappropriate in this context refers to the use of hospitals for treatment and care which could be provided in another less expensive setting. As indicated, some patents who die in hospital could probably die at home.

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[56] 'Many studies have researched preferences for both place of care and place of death in cancer in different populations and contexts and with different questions. Place of care and place of death are not the same, but preferences are associated. … . Longitudinal studies of place of death preferences in patients approaching the end of life have shown that some patients shift their preference away from home and towards inpatient hospice or other inpatient setting. Nonetheless, even in these studies, home remained the preference for the majority, with some variation probably due to how the question was asked. Recent work has suggested that for many, preferences are stable.' (Higginson, Sarmento, Calanzani, Benalia and Gomes, 2013:920).

[57] One study, based on a sample of 40 respondents who had the experience of a relative dying of cancer in both a hospital and a hospice in England found that: 'In comparison to hospital care, from the perspective of bereaved relatives, hospice in-patient care provided better pain control, better communication with patients and families, and better medical, nursing and personal care, which treated the patient with more dignity'. (Addington-Hall and O'Callaghan, 2009:190).

[58] 'The majority of acute hospital patients in the audit were admitted through A&E (84%). … . The biggest impact is on the overall acceptability of death and results in patients admitted through A&E having a less acceptable death, when compared to other patients … . In addition, these patients have more negative experience of symptoms … and poorer symptom management … . For relatives, emergency admissions are associated with a reduced sense of family support' (McKeown, Haase, Pratschke, Twomey, Donovan and Engling, 2010:94).

[59] McKeown, Haase, Pratschke, Twomey, Donovan, and Engling, 2010. See also Martin-Moreno, Harris, Gorgojo, Clark, Normand, Centeno, 2008; Bjornberg, Cebolla Garrofe, and Lindblad, 2009.

[60] 'Evidence from systematic reviews suggests home palliative care results in higher caregivers' and patients' satisfaction, reduced length of stay in hospitals and greater odds of dying at home. However, work is still needed to understand which components of the intervention provide the highest benefit.' (Higginson, Sarmento, Calanzani, Benalia and Gomes, 2013:919).

[61] 'We still do not know whether dying at home is better than dying in hospital for patients and families. There is some evidence suggesting that psychological, social and holistic measures of the patient's well-being in the last weeks or days of life may be better for patients dying at home. However, the findings regarding symptoms and family outcomes are not consistent enough to support that dying at home is better, worse or similar to dying in institutional settings.' (Higginson, Sarmento, Calanzani, Benalia and Gomes, 2013:921).

[62] In the National Audit of End-of-Life Care, nearly a quarter of patients are described as being suitable to die at home by nurses (22%), doctors (22%) and relatives (24%) (McKeown, Haase, Pratschke, Twomey, Donovan and Engling, 2010:125). This is somewhat similar to another study in Ireland where doctors and nurses assessed that 18% of patients who died in a hospice or hospital could have died at home (Tiernan, Connor, Kearney and Siorain, 2002).

[63] Even if the cost of home care was the same as the cost of hospital care, this could be justified by the fact that it also fulfils the desire of many people to live at home in the last days of their life (see Gomes, Calanzani, Curiale, McCrone and Higginson, 2013:37).

Given that the average length of stay of patients who die in hospital is 24 days[64] – compared to an average length of stay for all patients of 5 days[65] - the implications of reducing these hospital deaths could be substantial in terms of using resources more efficiently and equitably. If other sources of inefficiency and inequity are taken into account – such as delayed discharges and inappropriate admissions – then the impact on reducing waiting times for people who need essential treatments in acute hospitals could be substantial[66].

Fifth, a KPI on place of care and death is consistent with national policy for health services. National health policy in Ireland since 2001 – and even earlier - is underpinned by the idea that health services should be delivered, to the greatest extent possible, in the communities and homes where people live, and should avoid unnecessary admissions to hospitals and other institutions[67]. Other health-related strategies - notably the Primary Care Strategy[68] and HSE strategies including the Transformation Programme[69], the Corporate Plan (2008-2011)[70], the policy framework for tackling chronic disease[71], and the National Strategy for Service User Involvement[72] - all affirm the importance of community-based and home-based health services.

This consensus is continued in the programme of the Government (2011-present) which reiterates a commitment to 'reforming our model of delivering healthcare so that more care is delivered in the community' and 'the integration of care in all settings is key to efficient healthcare delivery in which the right care is delivered in the right place'[73]. The strategic framework for the current reform of health services is designed to 'move us away from the current hospital-centric model of care towards a new model of integrated care which treats patients at the lowest level of complexity that is safe, timely, efficient, and as close to home as possible.'[74]

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[64] This is based on the national baseline audit of end-of-life care in Ireland in 2008/9 (McKeown, Haase, Pratschke, Twomey, Donovan and Engling, 2010:189).

[65] This is based on the 2012 annual report of HIPE, Activity in Acute Public Hospitals in Ireland, (ESRI, 2013, Table 3.14, p.88).

[66] Delayed discharges from acute hospitals are defined as 'patients who have completed the acute phase of their care and are medically fit for discharge' (HSE, 2014). In 2012, the number of bed-days lost through delayed discharges in Ireland's acute hospitals (243,673) was higher than in 2008 (223,704) or 2009 (144,565), when the issue was examined by the Expert Group on Resource Allocation and Financing in the Health Sector (2010; see also Brick, Nolan, O'Reilly, and Smith, 2010a; 2010b; 2010c; 2012). The practical implication of delayed discharge is that fewer patients are treated, creating delays for patients waiting for essential treatments. Given that the average length of stay in hospital in 2012 was about 6 days, the effect of delayed discharges is estimated as equivalent to an additional 40,612 inpatients who could have been treated in 2012 if there were no delayed discharges. This is higher than in 2009 when an estimated additional 24,000 inpatients could have been treated (Ibid).

[67] A core principle of Ireland's 2001 Health Strategy is that 'appropriate care is delivered in the appropriate setting' so that people get 'the right care in the right place at the right time' (Department of Health and Children, 2001a:81).

[68] Department of Health and Children, 2001b.

[69] HSE's Transformation Programme (2007-2010) was launched in December 2006, stating: 'change is not an option – it is a necessity. … . We must radically change the way we organise our services and the way we deliver these services' (HSE Transformation Programme, 2006:5). The Transformation Programme had six transformation priorities, the first two of which state: 'Develop integrated services across all stages of the care journey' and 'Configure Primary, Community and Continuing Care services so that they deliver optimal and cost effective results' (HSE Transformation Programme, 2006:11).

[70] The HSE Corporate Plan (2007:16-17) states: 'There is considerable evidence that indicates the need for a reconfiguration of Irish healthcare delivery which includes changes in the current hospital structures and a move towards enhanced healthcare services based in the community. At an operational level the biggest challenge facing us is the speed with which reliance on hospitals can be reduced and capacity to deliver care within the community setting by building a fully integrated and responsive local health and personal social service, so that people are confident that the vast majority of their health needs can be provided outside hospitals. As community-based services are strengthened, the barriers that currently exist between hospital care and community care will begin to dissolve and the gap between the two services will disappear. The traditional role of the hospital will also change.'

[71] Department of Health and Children, 2008a.

[72] Department of Health and Children, 2008b.

[73] Department of Taoiseach, 2011:32 and 38.

[74] Department of Health, 2012b:iii.

Referring specifically to services for older people, the Department of Health's Statement of Strategy states the purpose of these services as follows: 'To enhance the quality of life of older people, maintain their full potential, support them in their homes and communities, provide access to respite care and day care and, when required, provide access to appropriate quality long-term residential care.'[75]

Despite limited progress towards implementing national health policy over the past decade, there is growing recognition, triggered by demographic and fiscal pressures, that the balance of health services still needs to shift more decisively in favour of settings that are closer to home or at home and away from hospital-type settings. This awareness is prompted by the fact that Ireland's population is both growing and ageing which, in turn, is creating a demand for healthcare services, particularly associated with chronic diseases among older people[76]. These demands cannot be met without radically altering the balance between acute and community health services and linking both in a more integrated way[77]. This is the rationale behind the current reform of health services: 'The current hospital-centric model of care cannot deliver the quality of care required by our people at a price which the country can afford.'[78]

The development of KPIs to increase end-of-life care at home and reduce deaths in hospital poses challenges which are not ordinarily encountered, at least not to the same degree, by other hospital-related KPIs (such as waiting times, day case rates, etc). The main challenge for an acute hospital is that its ability to improve performance on this KPI may be limited by the way other parts of the system operate – such as primary care services, long-stay homes, hospices - over which it currently has little or no leverage. This is not an argument against this type of KPI – indeed it may be an argument in favour of it – but the system-level requirements associated with any proposed KPI would need to be considered if it is to become a meaningful motivator of performance and a robust indicator of improvement[79]. In other words, the success of the proposed KPIs may need to be supported by corresponding KPIs for the other places of care and death. The evidence presented below confirms why this is necessary.

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[75] Department of Health, 2012a:18.

[76] For a review of population ageing and its implications for health and social services, see McKeown, Pratschke and Haase, 2014.

[77] It is estimated that between 2009 and 2021, the proportion aged 65+ in Ireland will increase from 11% to 15% while those aged 85+ will increase from 1% to 2% (Layte, 2009a). Based on this projection, the authors conclude: 'The increased demand for health care likely to stem from demographic and epidemiological change in the Irish population is significant. Even if national finances improve substantially, the current way in which care is delivered will be unsustainable within any reasonable budget given the nature of demographic change. This demands a reconfiguration and intensification in the use of health care resources and improvements in levels of efficiency. … . A transition to a healthcare system focused more on care in the community than acute public hospitals will require development of both primary and long-stay services, as well as social care services, if it is not to lead to severe degradation in the level and quality of service' (Layte, 2009b:62-3). This scenario is not unique to Ireland but applies to almost all developed countries: 'The increase in the ageing population, with correspondingly higher levels of co-morbidity, will likely mitigate against home deaths and in favour of hospital deaths, unless innovative approaches can be developed to support those with complex co-morbidities in the community' (Murtagh, 2012:23 and 219).

[78] Department of Health, 2012b:18.

[79] The importance of a system approach was underlined in a recent report on variations across England in the balance of hospital and community care for older people which concluded that: 'the key to improvement lies in changing ways of working across a system rather than piecemeal initiatives. A set of unaligned projects will not produce system-wide results. This is a challenging message in the context of the significant organisational upheavals under way, but it confirms evidence from other sources that organisations need to prioritise 'whole system' approaches and working if they are to deliver the long-term policy aspiration of a real shift from hospital to community-based care.' (Imison, Poteliakhoff and Thompson 2012:19).

SECTION 4 - IS THERE A PRECEDENT FOR USING PLACE OF DEATH AS A KPI?

For over 20 years, the Dartmouth Atlas of Health Care in the US has been showing how the place where one lives makes a difference to the type of health service one receives[80]. A consistent finding is that people living in areas with more hospital beds are more likely to be admitted to hospital compared to people in areas with fewer hospital beds[81]. This suggests that healthcare is 'supply sensitive' - the more provided the more used - and gives rise to variations which cannot be explained solely in terms of people's health needs and preferences, and frequently does not result in corresponding differences in outcome. This body of research has given rise to the concept of 'unwarranted variation' in use of health services while the health atlas provides an instrument for making it transparent[82]. It has also given rise to a growing body of research on organisational and regional variation in health care resources, utilisation, and outcomes[83], including variations in place of death[84] Many countries[85], including Ireland, are developing health atlases to map variations in health services, including variations in end-of-life care[86]. These developments illustrate that place is important for many types of healthcare services and not just care at end of life. Moreover, given that more people tend to die in acute hospital than in other places[87], and given that this is still the most expensive form of care[88], interest in the place where people are cared for and die is likely to remain a topic of considerable interest for the foreseeable future.

Against this background we now show, using the examples of Scotland and England, that there is a precedent for using place of care and place of death as KPIs for the outcomes of health services at end of life.

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[80] www.dartmouthatlas.org

[81] Goodman, Esty, Fisher and Chang, 2011

[82] Unwarranted variation has been defined as: 'Variation in the utilization of health care services that cannot be explained by variation in patient illness or patient preferences' (Wennberg, 2010; See also: www.dartmouthatlas.org). By contrast, some variation is warranted when different populations have different levels of need (RightCare, 2011:17). Significant improvements in health services, including greater value from the use of healthcare resources, can be obtained by mapping and then reducing unwarranted variations in health services.

[83] A recent literature review identified more than 6,000 research papers which have been published on medical practice variations (Stukel, 2011). See also Wennberg International Collaborative, 2010; 2011.

[84] A recent systematic review of research on place of death for patients with non-malignant conditions identified over 10,000 relevant articles although only 2% met the quality standards for inclusion in the review (Murtagh, et al, 2012).

[85] See, for example, the NHS Atlas of Variation in Healthcare (RightCare, 2011).

[86] National End of Life Care Intelligence Network, 2010; 2011; 2012a; 2012b.

[87] 'Hospital death remains the most common occurrence in developed countries' (Murtagh, et al, 2012:25).

[88] Research findings remain inconclusive on the cost of care in different settings and whether community care is necessarily cheaper than acute care. However, the latest synthesis of research in England concluded that, 'with all the acknowledged limitations and caveats', community care is cheaper than acute care: 'the midpoint of the estimated inpatient EoLC [end of life care] costs is £3,065.50 and the midpoint of the estimated community care EoLC costs is £2,107.50, giving an estimated potential saving of £958.' (National End of Life Care Programme, 2012:18).

4.1 Place of Death as KPI in Scotland

In Scotland, the end of life strategy – called Living and Dying Well[89] – is being implemented as part of its Government's wider Healthcare Quality Strategy[90]. The measurement framework for the Healthcare Quality Strategy distinguishes three levels of measurement: (i) Level 1 indicators for longer-term national outcomes, one of which is place of care at end of life; (ii) Level 2 indicators for improvements in healthy life expectancy, efficiency, access to services, and treatments appropriate to need; (iii) Level 3 indicators for other measures to improve quality and performance management and reporting[91].

The specific Level 1 indicator that is relevant to end-of-life is the percentage of the last six months of life spent at home or in a community setting. The rationale for this KPI is explained as follows: 'For an individual, the preferred place of care can change as their condition and/or family circumstances change over time, making this very difficult to measure and track. Alternatively, the number of anticipatory care plans (APCS) and electronic palliative care summaries (ePCS) could be used as an indicator of how many people have a planned approach to end of life care. … . However, these measures capture process and not outcomes for an individual … . Percentage of time in the last year of life spent at home or in a community setting and not spent in an acute hospital may be the best alternative measure currently available. The last six months of life was chosen as this is the period when most hospital admissions occur compared to the last 12 months of life and the period when clinicians would tend to plan end-of-life care if the patient was not expected to live longer than 6 months.'[92]

Building on this work, four KPIs have been proposed for palliative and end-of-life care services in all care settings in Scotland[93]. These are: (i) identifying people with palliative and end-of-life care needs, based on the number of patients listed with a general practice and who are on a palliative care register; (ii) assessment and care planning to meet patients' palliative and end-of-life care needs, based on patients on the palliative care register with an electronic palliative care summary; (iii) accessing the anticipatory care plan (ACP) in all unscheduled care settings, based on the number of individuals who have had their electronic palliative care summary accessed at least once in an unscheduled care setting in the past 12 months; and (iv) place of care at end-of-life, based on total bed days spent in an acute hospital setting in the 6 months before death.

This last indicator is the same as Level 1 indicator described in the previous paragraph. The numerator for this KPI is: 'Total bed days spent in an acute hospital setting in the 6 months before death for those people who died within a specified year'[94]. The denominator for this KPI is: 'Total number of bed days that an individual could have spent in an acute hospital setting in the last 6 months of life (187.5 days).'[95]

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[89] Scottish Government, 2008; 2011a.

[90] Scottish Government, 2010.

[91] Scottish Government, 2010:34-38; 2011b:3.

[92] Scottish Government, 2011b:53.

[93] Healthcare Improvement Scotland, 2012. Healthcare Improvement Scotland has key responsibility to help NHSScotland and independent healthcare providers to deliver high quality, evidence-based, safe, effective and person-centred care, and scrutinise services to provide public assurance about the quality and safety of that care.

[94] Healthcare Improvement Scotland, 2012:12.

[95] Healthcare Improvement Scotland, 2012:12.

4.2 Place of Death as KPI in England

In England, place of death is the main KPI to assess the outcome of its End of Life Care Strategy[96]. The fourth annual report on the End of Life Care Strategy states: 'Deaths in usual place of residence (DiUPR) – the main marker of progress for the Strategy as well as the first Key Performance Indicator for our Quality, Innovation, Productivity and Prevention (QIPP) workstream - are continuing their steady rise, accompanied by a drop in deaths in hospital. I can report that, nationally, 42.4% of people are now dying at home or in a care home. While this does not necessarily capture individual patient choice it is nonetheless a good proxy.'[97] Progress on this KPI is tracked on a quarterly basis using mortality data from the Office for National Statistics[98], equivalent of the Central Statistics Office in Ireland. The numerators for this KPI are: deaths at home (defined as the person's home address and not a communal establishment)[99]; deaths in care home (defined as NHS or private nursing home, private or Local Authority residential home or specialist nursing home)[100]; and deaths in hospital (defined as NHS or non-NHS acute or community hospitals / units but not psychiatric hospitals)[101]. The denominator for this KPI is all deaths from all causes registered in a year.

The End of Life Care Strategy in England recognises that place of death is not the only relevant outcome indicator and does not replace KPIs on the structure and process of care. For that reason, the strategy team in England is developing two additional KPIs to measure outcome: (i) number of hospital admissions of 8 days or more which end in death; and (ii) number of emergency admissions in the final year of life[102]. These are currently at the pilot-testing stage.

These examples from Scotland and England indicate that there is a precedent for using place of care and death as KPIs for the outcome of end-of-life services. They also illustrate two different ways in which these KPIs can be measured. Scotland has opted for a more composite measure that combines *place* with the *time* spent in that place during the last six months. England has a somewhat more static measure of place – where the death occurred - but this is complemented by measures of both hospital admissions and emergency admissions. In practice, the choice of KPI is determined not just by its appropriateness to the outcome but also by the availability of data to measure it on a regular basis. Similar considerations will also apply if these KPIs are adopted in Ireland.

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[96] Department of Health, 2008.

[97] Department of Health, 2012:8. Note that QIPP is the transformational programme for the NHS. The Department of Health website states: 'QIPP – Quality, Innovation, Productivity and Prevention – is a large scale transformational programme for the NHS, involving all NHS staff, clinicians, patients and the voluntary sector. It will improve the quality of care the NHS delivers while making up to £20billion of efficiency savings by 2014-15, which will be reinvested in frontline care.' (www.dh.gov.uk)

[98] Department of Health, 2012:12-13.

[99] National End of life care Intelligence Network, 2011.

[100] National End of life care Intelligence Network, 2011.

[101] National End of life care Intelligence Network, 2011.

[102] Department of Health, 2012:12-13.

SECTION 5 - DATA ON PLACE OF DEATH IN IRELAND

There are four main national sources of data on place of death in Ireland: (1) CSO (Central Statistics Office) data on deaths (ii) HIPE (Hospital In-Patient Enquiry) data on the activities of acute hospitals and (iii) Minimum Dataset (MDS) on Specialist Palliative Care (SPC); (iv) National Cancer Registry (NCR). Here is a brief description of each.

5.1 CSO data on deaths

CSO is the definitive national data-set on all deaths in Ireland, including place of death. It is based on the official registration of every death. There are three limitations with this data-set, particularly from a KPI perspective. First, data on place of death is normally published about two years after the death has occurred; for example, data on place of death in 2011 was published in October 2013[103]. Second, the CSO classification of place of death is outdated and – apart from deaths at home – does not correspond in any meaningful way to where people die or may be cared for at the end of life. The four CSO categories for place of death are: (i) General & Special Hospitals & Nursing Homes (ii) Mental Hospitals (iii) Local Authority Institutions (iv) Domiciliary. Third, the data is available at county level but cannot be presented, without a great deal of re-coding and re-analysis, for HSE administrative areas such as Local Health Offices (LHOs) or Primary Care Networks (PCNs). In order to overcome these difficulties, the Vital Statistics Section of the CSO has responded positively to requests for special analysis of the data at ED (Electoral District) level and this has been done in the case of Cork and Donegal. However, it is not sustainable for the CSO to respond to individual requests in this way without a more systematic solution to the problem.

5.2 HIPE data on activities of acute hospitals

HIPE is the definitive national data source on the activity of 57 hospitals in Ireland[104]. The data reported here is based on deaths in Ireland's 37 acute hospitals, referred to as HIPE37, since these are the main acute hospitals in the country. One of the limitations of HIPE data is that it does not include deaths in Emergency Departments (ED) which occur before the patient is admitted since, technically speaking, these are not 'in-patients'.

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[103] CSO Annual Report on Vital Statistics 2011, 2013.

[104] Data is published in an Annual Report on the activity in acute public hospitals in Ireland as recorded through HIPE (ESRI, 2013).

The 2008/9 baseline audit of end-of-life care in Ireland found that 12% of deaths in the participating hospitals occurred in ED and were therefore outside the HIPE system[105]. The data presented here has been adjusted to take account of this. We have also extracted HIPE data on deaths by county, including whether the patient died inside or outside the county, in order to arrive at a correct estimate of the number of acute hospital deaths by county.

5.3 Minimum Dataset on Specialist Palliative Care

The Minimum Dataset on Specialist Palliative Care (SPC) produced its first national dataset for 2010 and covers care provided by In-Patient Units (IPUs, also referred to as hospices) and Home Care Teams (HCTs). This dataset is still in process of development and additional modules will cover acute hospitals (from 2014), day care, and bereavement services.

5.4 National Cancer Registry

The Irish National Cancer Registry (NCR) began full registration of all cancers in Ireland in January 1994, including all deaths due to cancer as well as deaths of all patients, from whatever cause, who have been registered as having cancer. The registry obtains data on patients with cancer from a variety of sources, primarily via qualified tumour registration officers (TRO) who are employed by the NCR and based in hospitals around the country. In addition, the NCR uses HIPE to identify cases that have not had a histological verification of the diagnosis, or for which the registry failed to identify a pathology report. Finally, the NCR cross-checks its data against CSO data on deaths and unmatched cases are followed up. Given that the main focus of this report is on place of death for **all** deaths we did not analyse the NCR data[106].

5.5 Implications

The four datasets just described are normally analysed in isolation but here we try to draw three of them together – CSO, HIPE, MDS - to form a more unified picture of how the healthcare system influences the place where people are cared for and eventually die. The analysis in subsequent sections is anchored in the CSO data since this is definitive on the number of deaths, cause of death, county of death, and place of death, at least for those for whom there is a home address which can be coded. By linking this to HIPE37 data it is then possible to calculate the proportion of persons who died in acute hospital in each county. Finally, linking the SPC data to the CSO data allows us to estimate the proportion of deaths supported by SPC, the cause of those deaths, and the place where the deaths occurred.

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[105] This is based on an audit of resources and facilities for end-of-life care in 24 acute hospitals based on 2008 data. At that time, these hospitals covered a major part of the acute hospital sector in Ireland in terms of number of patients (72%), deaths (71%), staff (73%), and bed-capacity (74%). The audit found that 12% of deaths in these acute hospitals occurred in the Emergency Department. These deaths are not recorded in the HIPE system because, technically speaking, they occurred before admission and the HIPE system only covers admissions (McKeown, Haase and Twomey, 2010a). Further analysis of the audit revealed that patients who died in a cancer or geriatric ward and who had a cancer diagnosis were much less likely to be admitted through ED compared to all other patients. The influence of ward practices – and the clinical practices of the associated specialties – is indicated by the fact that patients who died in cancer or geriatric wards 'were nearly five times more likely to be admitted through OPDs/DCs [Out-Patient Departments / Day Centres] compared to other wards, when all other influences have been taken into account' (McKeown, 2010:13). Similarly, the influence of diagnosis – and associated clinical practices – is indicated by the fact that 'Patients whose primary diagnosis on last admission to hospital was cancer – a reasonable proxy for the cause of death – are about four times more likely to be admitted through OPDs/CDs compared to ED patients, when all other influences have been taken into account.' (Ibid).

[106] A previous study sponsored by the Irish Hospice Foundation analysed NCR data (Murray, McLoughlin, and Foley, 2013).

Given the purpose of this paper – to clarify how place of care and death could be useful KPIs for measuring some of the outcomes of health services at end of life – we review data on deaths in hospital and at home since this is the most accessible national data. In addition, we analyse deaths supported by SPC services since this represents an important subset of mainly cancer deaths. Throughout the analysis, there is a presumption that the preferred scenario involves a higher proportion of deaths at home – or 'usual place of residence' which refers to both home and long-stay places of care combined - and a lower proportion of deaths in hospital since this is consistent with the evidence on people's preferences and with national health policy. We leave aside, for the time being, the question of what might be an appropriate KPI for deaths in hospice given that these constitute a relatively small proportion of all deaths (6%) while the expressed preference of people in Ireland to die at home (74%) far outweighs their preference to die in hospice (15%) or hospital (5%)[107].

It is worth noting that the data reviewed in subsequent sections of the paper is far from being exhaustive in terms of either the data that could be extracted from these datasets or the analysis that could be undertaken. However extracting and merging these datasets is not easy for a range of conceptual and technical reasons[108]. In view of that, the analysis is based only on the data that is more readily accessible and of immediate relevance for developing KPIs on the outcomes of end-of-life services. However, in our conclusion we suggest that if place of care and death are to become KPIs for measuring some outcomes of end-of-life care, this will require substantial improvements in the way this data is currently collected, coded and analysed.

We now present an overview of where deaths occur in Ireland with comparative data from selected European countries and the US.

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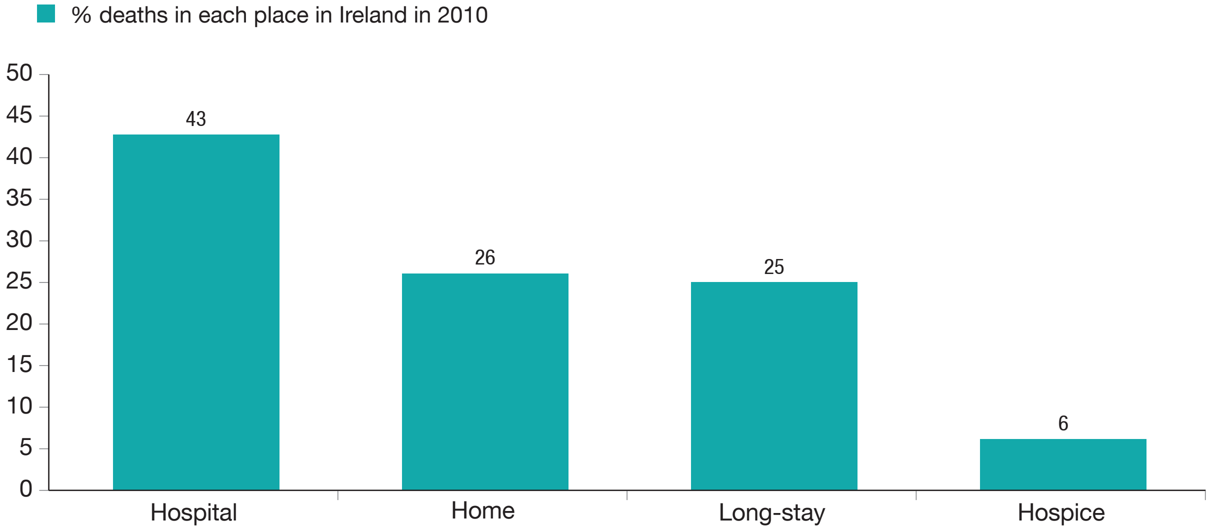
[107] Weafer, 2014.

[108] Some of the difficulties have been highlighted in a recent report on how geographical information is collected and used in Ireland, particularly but not exclusively in the health services: 'The vast majority of administrative boundaries in the Republic of Ireland are derived from aggregates of EDs [Electoral Divisions]. Unfortunately, however, this is not the case for the HSE, and a significant number of HSE boundaries cross ED boundaries. This has led to many anomalies e.g. the need to support two sets of boundaries for LHOs. The first of these boundaries is an approximation based on EDs for which census data are available; these are referred to as 'statistical LHO boundaries'. The second is based on actual LHO boundaries. EDs are not a satisfactory long-term solution as they were originally drafted in the 1870s to secure areas of approximately equal rateable value and correspond to nothing in particular on the ground. In urban areas in particular, EDs are far too large to be of practical value for health service planning purposes. … . Another fundamental problem arises in relation to the different geographies used by the various routine data systems being operated in Ireland. Most of these systems use county boundaries; for example, this is the case for the registration of births and deaths and for much of HIPE. HIPE uses postal areas in Dublin to determine boundaries – an approach to defining boundaries that is not used in other State information. NPIRS [National Psychiatric In-patient Reporting System] uses HSE mental health catchment areas, which are close to, but not identical to, LHO boundaries. The PCRS [Primary Care Reimbursement Service] uses the old Health Board areas. Budgetary reports, although generated within the former Health Board structures, use LHO boundaries, as does much of the internal activity reporting system e.g. Healthstat. … . Each of the sets of boundaries described above is costly to maintain, and the different boundaries are not mutually compatible. In particular, there is no simple way for data recorded at county level to be converted to LHO-level data. It is important to emphasise that these costs affect every single user of health data in Ireland, including the HSE, Department of Health and Children, researchers, local authorities and the private sector - each of which has to invest resources in managing these various boundaries.' (Staines, et al, 2010a:9-10; 2010b). On a more hopeful note, the authors report that: 'The Ordinance Survey of Ireland (OSI) and the Central Statistics Office (CSO) have worked with Martin Charlton, National Centre for Geocomputation, National University of Ireland Maynooth to develop a new set of output areas. It is hoped that Small Area Population Statistics (SAPS) from the 2011 Census will be published for these areas, in addition to the customary EDs nationwide and Enumeration Areas (EAs) in cities. On average, the new output areas are much smaller and more consistent in population size than EDs. … . Each output area is designed to contain a minimum of 65 households. More typically, however, output areas contain about 120 households. It is envisaged that the boundaries will remain fixed into the future, in order to facilitate temporal comparisons.' (Ibid).

SECTION 6 - PLACE OF DEATH: IRELAND IN INTERNATIONAL CONTEXT

Broadly speaking, there are four places where deaths occur: hospital, home, long-stay and hospice. Figure 1 shows that in Ireland, as in other developed countries, more people die in hospital than anywhere else. More than four in ten deaths (43%) occur in hospitals with most of the remainder divided almost equally between those that die at home (26%) and those that die in long-stay places of care (25%); a small minority die in hospice (6%).

Figure 1 **Place of Death in Ireland, 2010**



Source: Table A1 Place of Death in Ireland, 2010, Appendix One below.

Internationally, as Figure 2 reveals, Ireland has a significantly higher proportion of deaths occurring in hospitals (43%) compared to the US (36%)[109] but lower than most European countries except the Netherlands (34%), based on the countries for which comparable data was found.

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[109] The US is also a significant point of comparison with Ireland since it reduced the proportion of deaths in hospital by 13 percentage points over an 18-year period between 1989 (49%) and 2007 (36%).

Figure 2 **Deaths in Hospital in Selected Countries in Selected Years**

Sources:

1. Cohen, J., Bilsen, J., Addington-Hall, J., Lofmark, R., Miccinesi, G., Kaasa, S., Onwuteaka-Philipsen, B., Deliens, J., 2008. 'Population-based study of dying in hospital in six European countries', Palliative Medicine, 22: 702-710. Data refers to 2003.
2. National Center for Health Statistics. Health US, 2010, With Special Feature on Death and Dying, 2011 www.cdc.gov/nchs. Data refers to 2007.
3. HIPE. Data refers to 2010.

Turning to deaths which occur at home, and based on 2003 data for each country (the year for which we have comparable data), Figure 3 shows that Ireland holds an intermediate position (with 25% dying at home) between Italy (where 33% of deaths occur at home) and Norway (where 16% of deaths occur at home). England had 18% of deaths at home in 2003 but more recent data indicates that the proportion of deaths occurring at home in England in 2010 has risen to 21%[110] while in Ireland it has risen to 26%[111].

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[110] Gomes, Calanzani, Higginson, 2011a; 2011b.

[111] CSO Annual Report on Vital Statistics 2009.

Figure 3 **Deaths Occurring at Home in Selected Countries**

Sources:

1. Cohen, J., Houttekier, D., Addington-Hall, J., Bilsen, J., 2010. 'Which Patients With Cancer Die at Home? A Study of Six European Countries Using Death Certificate Data', Journal of Clinical Oncology, March 29.
2. National Center for Health Statistics. Health US, 2010, With Special Feature on Death and Dying, 2011 www.cdc.gov/nchs. Data refers to 2007.
3. CSO Annual Report on Vital Statistics 2003, 2005.

*Note: In England, ONS data for 2010 indicate 21% die at home (Gomes, B, Calanzani, N., Higginson, IJ., 2011a; 2011b. 'Reversal of the British trends in place of death: Time series analysis 2004–2010', Palliative Medicine 0(0) 1-6). In Ireland, CSO data for 2009 indicate that 26% die at home.

This data shows that there are wide differences between countries in the outcomes of their health services as measured by place of death. Specifically, it shows that decisions about which patients can die at home or in hospital are made differently in different countries, illustrating that what is an 'appropriate' place of care for a patient can be quite different from one setting to another[112]. This indicates that a wide spectrum of possibilities exist for organising end-of-life care services by showing what **is** done in different settings, and therefore what **can** be done once it has been decided what **should** be done.

The growing body of international research on place of death has identified three broad sets of factors to explain variations in place of death between and within countries[113]. The first are personal and socio-demographic factors including patient preferences[114]. The second are illness-related factors such as symptoms, functional impairment, disease trajectory and burden[115].

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[112] In a different way, this was also illustrated in 2008/9 national audit of end-of-life care in hospitals which found only moderate agreement between doctors, nurses and relatives in terms of which patients were deemed suitable to die at home. The audit showed that nearly a quarter of patients were assessed as being suitable to die at home by nurses (22%), doctors (22%) and relatives (24%) However, when the assessments of nurses, doctors and relatives were compared on a case-by-case basis, we found that all three agreed in only 29% of cases, while nurses and doctors agreed in only 48% of cases (McKeown, Haase, Pratschke, Twomey, Donovan and Engling, 2010:94).

[113] Gomes and Higginson, 2006; Murtagh, et al, 2012.

[114] A systematic review of research on place of death for patients with non-malignant conditions found that: 'Those more likely to live alone (single or widowed) are less likely to die at home, and more likely to die in care homes, while those who are married are more likely to experience a home death' (Murtagh, et al, 2012:20).

[115] A systematic review of research on place of death for patients with non-malignant conditions found that: 'Illnesses where there is a longer trajectory of functional impairment (even if severe) are associated with increased home death (possibly because of the time available for planning and preparation)' (Murtagh, et al, 2012:20).

The third are environmental factors such as healthcare policy and provision, the patient's social supports, and wider factors such as societal expectations[116].

6.1 Explaining Variations in Place of Death

Looking closer at the environmental factors, since these are 'the most important group in influencing death at home'[117], US evidence in particular has shown that the concentration of hospital resources (beds, doctors, nurses, etc) influences the likelihood of dying in hospital[118]. In European studies, availability of alternatives to hospital (long-stay, home care, hospice) has been highlighted as an influence on the likelihood of dying in hospital[119]; this has also been found in a US study[120]. A common factor influencing place of death across many contexts is the role of policies to promote deaths at or closer to home, including the clinical culture and practice of promoting patient choice and autonomy[121].

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[116] A systematic review of research on place of death for patients with non-malignant conditions found that: 'Increased availability of hospital beds is consistently associated with reduced likelihood of home death and greater likelihood of hospital death, although the effect is small. Greater palliative care provision (across conditions) reduces the chance of hospital death. … . Across all conditions, considerations of carer/family burden (as well as personal considerations) are a major influence on the preferences of those with advanced disease' (Murtagh, et al, 2012:21).

[117] Higginson, Sarmento, Calanzani, Benalia and Gomes, 2013:921.

[118] This is based on a US study of variations in end-of-life care for Medicare beneficiaries with severe chronic illness (Goodman, Esty, Fisher and Chang, 2011). The authors of this study offer the following explanation for the observed association between hospital resources and deaths in hospital: 'This phenomenon, which we have labeled supply-sensitive care, results from uncertainty about how best to treat patients with chronic diseases and the tendency of clinicians to use the resources available to them (e.g., hospital beds, ICU beds, physician FTEs), whether the capacity is low or high. For example, when a patient's chronic condition worsens, it sometimes seems easier and safer to clinicians to treat the patient in the hospital, even though it may be reasonable to start outpatient treatment and monitor the patient's condition in clinic or by phone. If more hospital beds are available in an area, local care patterns unconsciously adapt to this higher capacity, and patients are more likely to be admitted. Similarly, research has shown that when ICU beds are readily available, more patients who are less severely ill will be admitted, and they will stay longer. Yet greater use of the hospital or ICU as a site of care does not lead to better outcomes on average. Although it is possible that some of the differences across hospitals may be explained by differences in patients' preferences for care, studies show that regional variation in patient preferences overall explains very little of the variation in the intensity of end-of-life care.' (Goodman, Esty, Fisher and Chang, 2011:3).

[119] A study of hospital deaths in six European countries suggested the following explanation: 'Our research in Europe seems to indicate that availability of hospital beds plays only a minor role in explaining European country differences. Availability of alternatives to hospital for older people (i.e., number of care home beds) explained differences between countries to a larger extent. The relatively low availability of care home beds in Wales and Flanders, compared with the Netherlands, could to a considerable extent explain the higher probability of hospital deaths in those places. However, the case of Sweden, with a low number of hospital beds and a high number of care home beds but a high probability of hospital death illustrates that this factor cannot fully explain country variation. Possibly other factors such as cross-national differences in reimbursement policies and possibilities for complex home care may play a role, but this cannot be confirmed by our data.' (Cohen, Bilsen, Addington-Hall, Lofmark, Miccinesi, Kaasa, Onwuteaka-Philipsen and Deliens, 2008:707-708).

[120] This study focused specifically on why the state of Oregon has one of the lowest proportions of deaths in hospital (Tolle, et al, 1999:681 and 684): 'Throughout the United States, use and availability of acute care hospital beds have been confirmed to be the principal determining factors in location of death. Within that constraint, however, the availability of other resources and services both facilitates the process of arranging for patients to die outside the hospital and improves satisfaction with the quality of terminal care. … . It is hard to know which came first: restrictions on in-hospital bed availability that drove the creation of alternative resources or the availability of these resources and services that led to decreased demand for in-hospital beds and, in turn, encouraged planners and administrators to shrink the in-hospital bed supply. Dying out of the hospital may be more feasible in Oregon than in some other states. Oregon has an extensive network of services to support dying patients and their families at home and in nursing homes. Wishing to die in a setting that is not institutional and having that wish become a reality require not only advance planning but also appropriate resources. Unless strong community resources are available to support patients and their families, as in Oregon, hospital admission at the end of life may be the patient's only realistic alternative. We acknowledge that in states with large inner-city cores of poverty, out-of-hospital care and other support for dying patients can be far more challenging to provide.'

[121] This factor has been used as part of the explanation for the much lower proportion of cancer deaths in hospital in Netherlands compared to its other European neighbours: 'The Netherlands is known to value candor, which stimulates open communication between patient and physician, as does the relationship between Dutch people and their general practitioners. Dutch government policies are clearly directed at care at home, or at least outside hospitals, with well-organized possibilities for home care and nursing home care, and comprehensive palliative care in the Netherlands has always been strongly focused on the home and the family. Many other countries have developed palliative care predominantly in hospitals and also give a less powerful gate-keeping role to primary care.' (Cohen, Houttekier, Addington-Hall, Bilsen, 2010:5; see also Alonso-Babarro, et al, 2011:1165).

In addition to explaining the sources of variation in place of death, these factors could also be seen as the main set of levers which are available to policy-makers and practitioners to increase deaths at home and reduce deaths in hospital. In other words, if KPIs are to improve performance, then a system-wide approach is required – both nationally and locally – to facilitate each part of the system to reduce deaths in hospital and increase deaths at home. Without a system-wide approach – involving community services (especially Home Care Teams), hospitals, long-stay homes and hospices - it is questionable if setting KPIs alone will change performance.

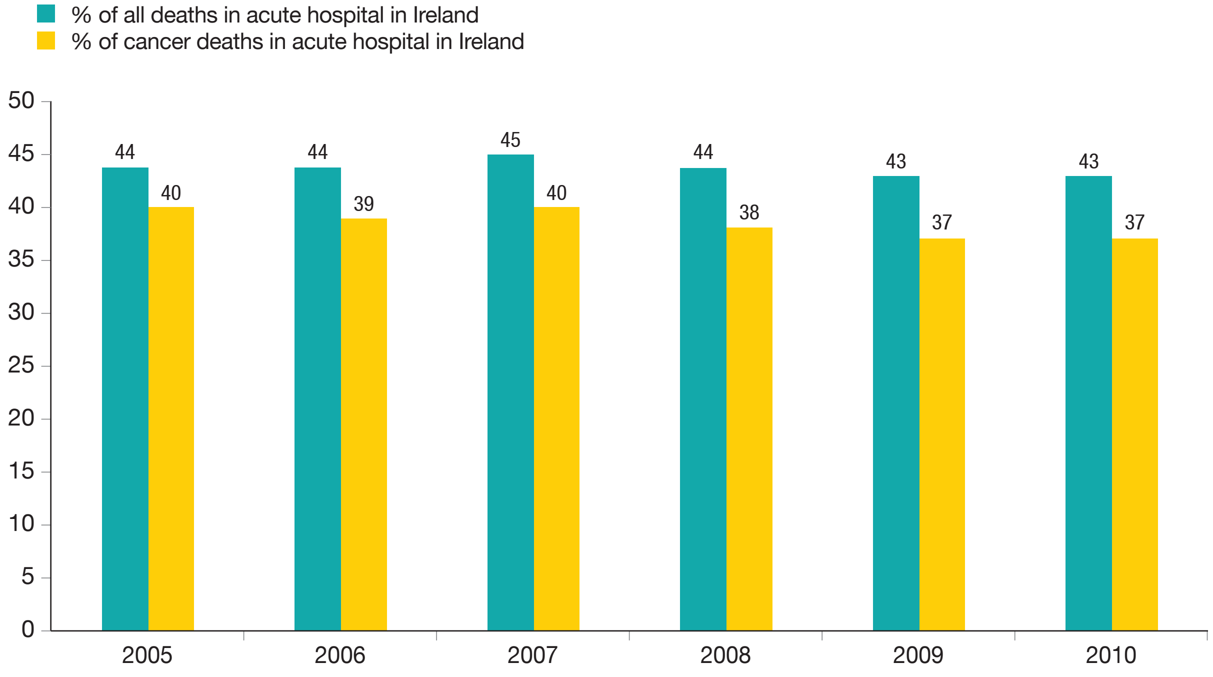
SECTION 7 - DEATHS IN HOSPITAL IN IRELAND

Deaths in hospitals in Ireland, the 37 acute hospitals in the HIPE system (HIPE37), accounted for 43% of all deaths in 2010 (Figure 4). This pattern has been relatively steady between 2005 and 2010, the years for which HIPE37 data has been extracted. Between 2005 and 2008, the proportion of deaths in HIPE37 hospitals was 44%, falling in 2009 and 2010 to 43%. From a European perspective, as indicated earlier, Ireland has a higher proportion of deaths in hospital compared to Netherlands (34%) but well below Sweden (63%). Ireland also has a higher proportion of deaths in hospital compared to the US (36%).

Figure 4 also shows that cancer deaths are consistently less likely to occur in hospital compared to all deaths. In 2010, for example, 43% of all deaths occurred in hospital compared to 37% of cancer deaths. The reason for this difference is due largely to the influence of Specialist Palliative Care Services (SPC), the majority of whose patients have cancer (85%). The analysis in the next section (Section 8) reveals that SPC services are associated with a reduction in hospital deaths (in areas where there is a hospice) and an increase in home deaths (in areas where there is no hospice).

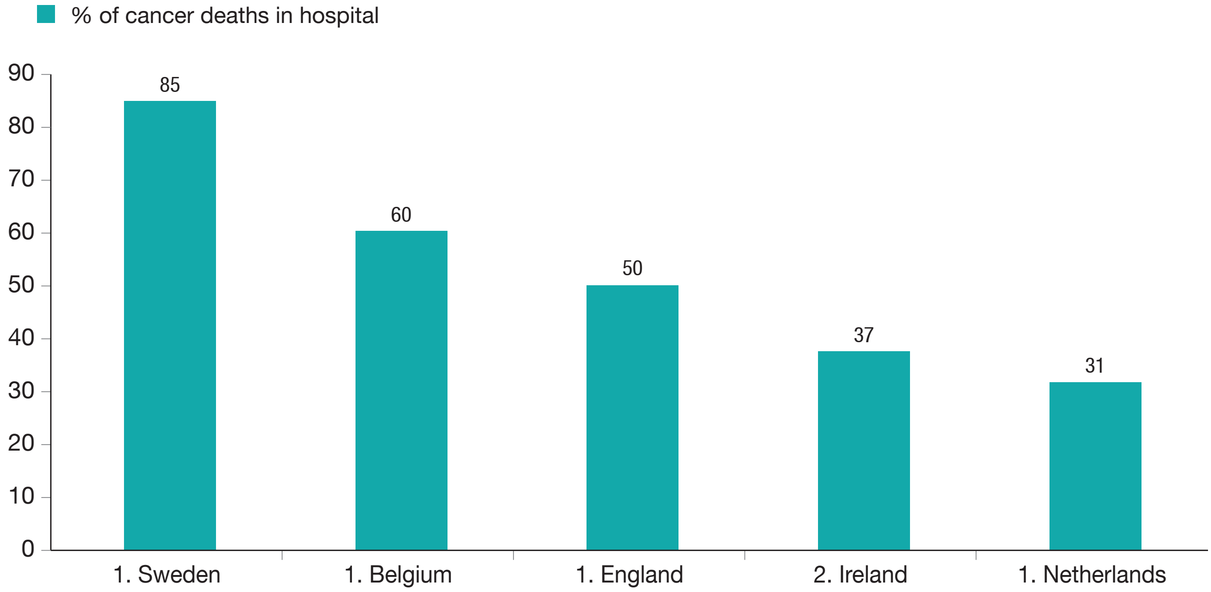
Within Europe there is also significant variation in the proportion of deaths from cancer which occur in hospital. Figure 5 shows that there is a 54-percentage point difference between the proportion of cancer deaths in hospital in Sweden (85%) and Netherlands (31%).

Figure 4 **Deaths in Hospital in Ireland, 2005-2010**



Source: HIPE data, 2009.

Figure 5 **Cancer Deaths in Hospital in Selected Countries**



Sources:

1. Cohen, J., Bilsen, J., Addington-Hall, J., Lofmark, R., Miccinesi, G., Kaasa, S., Onwuteaka-Philipsen, B., Deliens, J., 2008. 'Population-based study of dying in hospital in six European countries', Palliative Medicine, 22: 702-710. Data refers to 2003.
2. HIPE and CSO data for 2009

In Ireland, there is significant variation across the country in the proportion of deaths in hospital. Figure 6 shows that this varies from the lowest in Leitrim (31%) to the highest in Roscommon (53%), a range of 22 percentage points; this is based on all deaths *from* each county in HIPE37 whether they occur *inside or outside that county*. In a comparative context, variation in the proportion of deaths in hospital in Ireland is somewhat less than in England where there is a 28 percentage point difference between areas with the lowest (42%) and highest (70%) per cent of deaths in hospital[122]. It is also slightly less than the variation in the US, based on deaths of Medicare beneficiaries, where there is a 26 percentage point difference between areas with the lowest (20%) and highest (46%) per cent of deaths in hospital[123]. In making these comparisons, however, it is worth remembering that the per cent of deaths in hospital is sensitive to both the definition of 'hospital' used and the size of the area for which it is measured. England and the US, for example, are much larger countries than Ireland and a larger range of variation might be expected.

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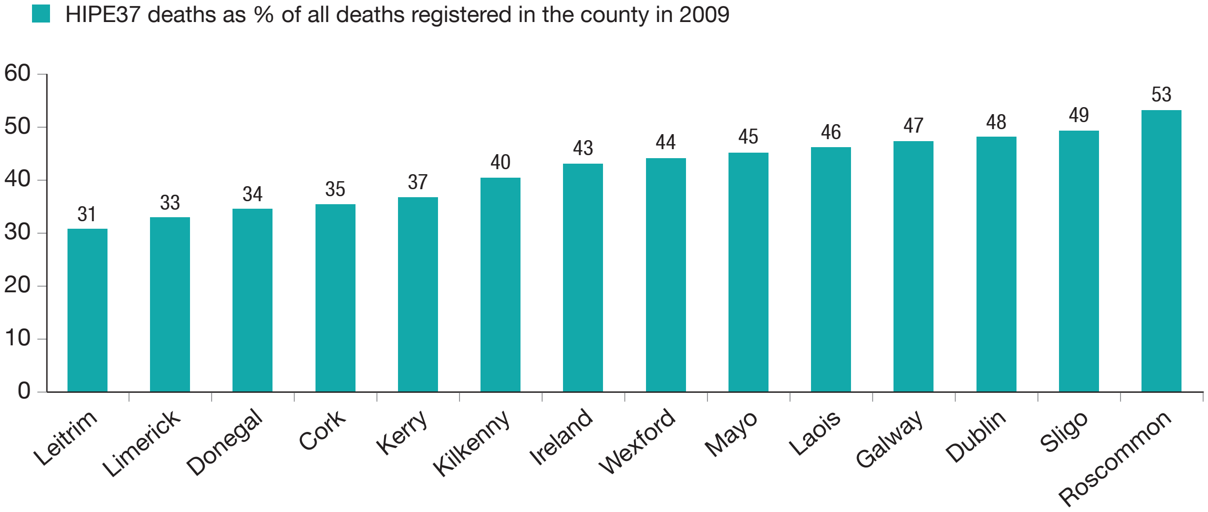
[122] National End of Life Care Intelligence Network, 2012a.

[123] Goodman, Esty, Fisher and Chang, 2011.

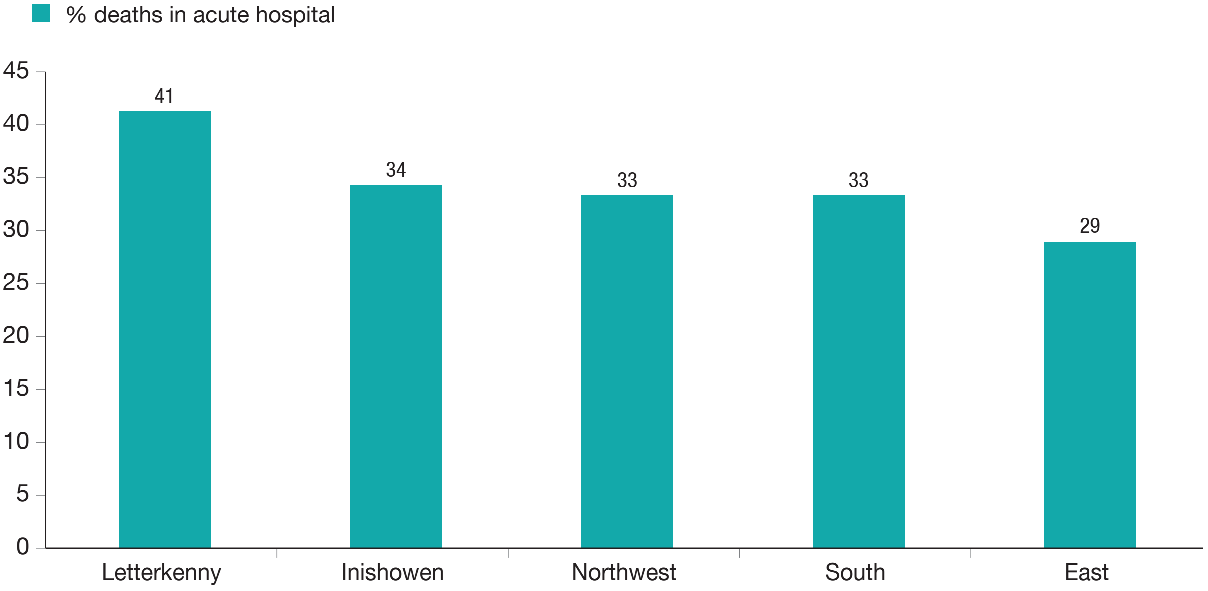
Figure 6 **Deaths in HIPE37 Hospitals in Different Counties of Ireland, 2009**



Source: HIPE data 2009; and CSO data 2009.

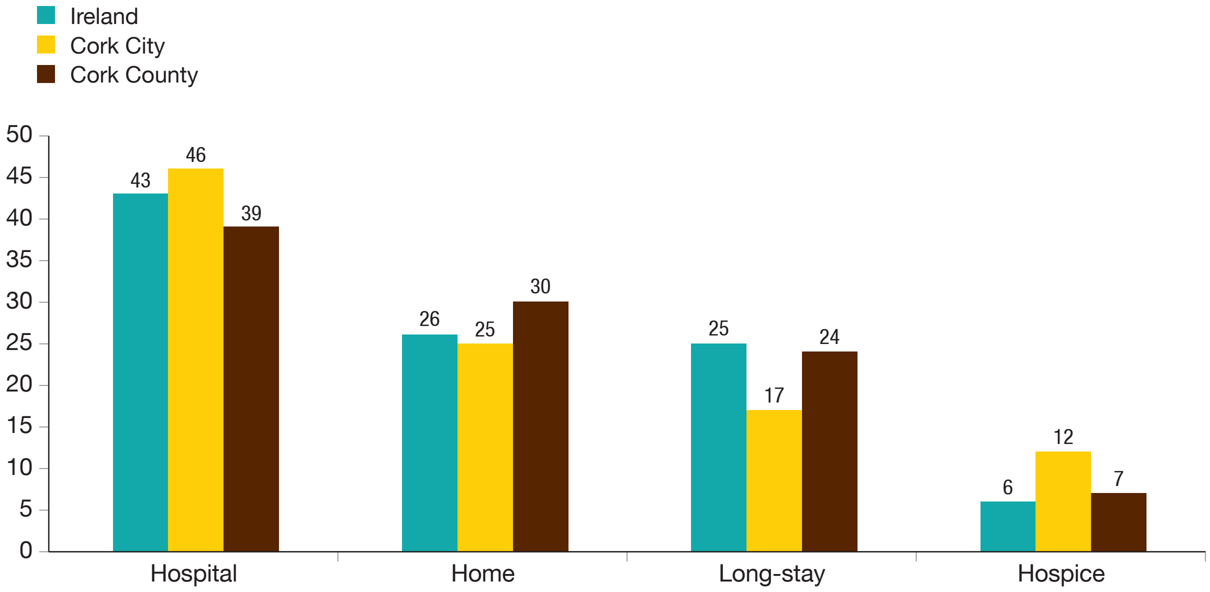
Further analysis reveals considerable within-county variation in Ireland in the proportion of people who die in an acute hospital, and further illustrates that the chances of dying in an acute hospital vary depending on where a person lives. This is illustrated in Figure 7 which shows significant variations between the five Primary Care Networks (PCN) in County Donegal. The proportion of acute hospital deaths is highest in Letterkenny PCN (41%) and lowest in East PCN (29%), a difference of 12 percentage points. All other PCNs have fewer deaths, by at least seven percentage points, compared to Letterkenny PCN where the only acute hospital and hospice in the county is located. Similarly in Cork, as illustrated in Figure 8, there is a difference in the proportion of deaths in acute hospital according to whether the person lived in Cork City (46% of all deaths) or Cork County (39% of all deaths) while, correspondingly, the proportion who die in their usual place of residence (home plus long-stay care) is much higher in the county (54%) than in the city (42%).

Figure 7 **Deaths in Hospital in Each Primary Care Network in Donegal, 2009**



Source: Special tabulations based on CSO data for 2009.

Figure 8 **Place of Death in Cork City, Cork County and Ireland, 2009**



Source: CSO, 2012. Special Tabulations.

7.1 Is this variability warranted?

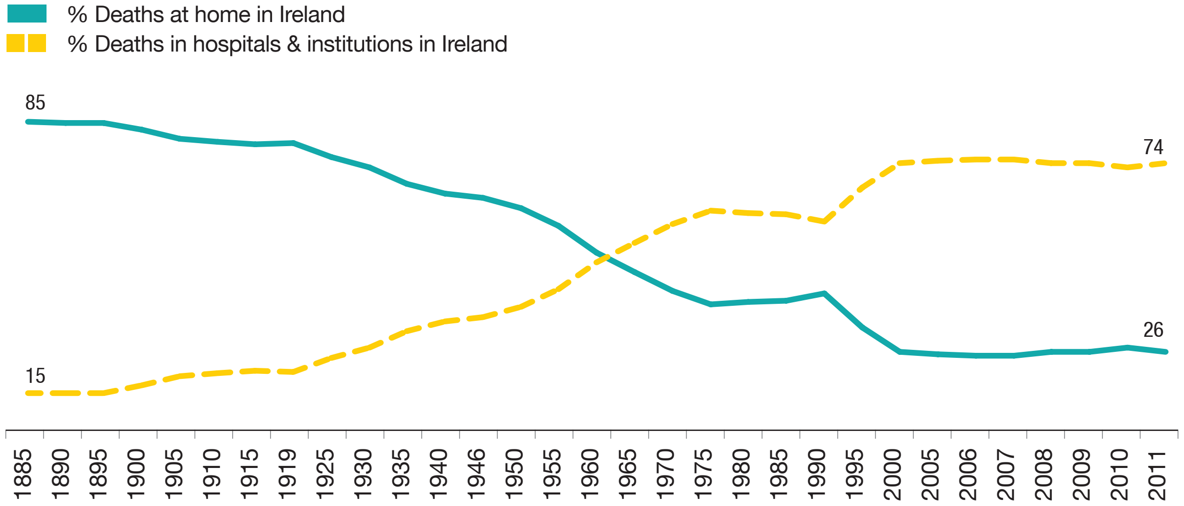
The variability in acute hospital deaths across Ireland raises the question: is this variability warranted? More specifically, does variability in the chances of dying in hospital correspond to the needs and preferences of populations and patients? If it is conceded that at least some of the variation is unwarranted – on the simple assumption that patient needs and preferences are unlikely to vary so widely across the country or within counties – then it must also be conceded that some patients from, say Dublin or Galway who die in acute hospital would, if they lived in Leitrim, Limerick or Donegal, die elsewhere (possibly home or long-stay). It is not possible, within the confines of this paper, to systematically analyse the reasons for the inter-county variation in the proportion of deaths in acute hospital in different parts of Ireland. However, it seems likely that a significant source of variability lies in the availability of hospital resources and how these are managed; it is also likely that availability of alternatives of hospital care such as primary care (including supports in the home) and intermediate care (notably long-stay facilities in community hospitals and nursing homes) are also an influence. The implications of this in terms of meeting the needs and preferences of patients in the most cost effective manner possible are considerable given that acute hospital care is one of the most expensive forms of care available.

These findings make the case for a KPI which aims to reduce deaths in hospital. The first leg of the case is that there has been no change in the proportion of deaths in hospital since 2005 and perhaps longer (Figure 4). This, in turn, suggests that there may be no effective incentive in the system to bring about this type of change. The second leg of the case is that there is significant variation between counties – and even within counties - in the proportion of deaths in hospital which raises questions about efficiency and equity of the use of health care resources (Figures 6 and 7).

SECTION 8 - DEATHS AT HOME IN IRELAND

A quarter of deaths in Ireland (26%) took place at home in 2011. It was not always so, as Figure 9 illustrates. Taking a broader time perspective, over 125 years ago (in 1885) the vast majority of people in Ireland (85%) died at home. Even 50 years ago (in 1960) half of all deaths (51%) occurred at home. Since then, there have been two significant periods of decline in the proportion of deaths at home: a decline of 10 percentage points during the 1960s and a further decline of 15 percentage points during the 1990s. Both of these decades were associated with substantial economic growth and a sustained expansion of hospital facilities and services.[124]

Figure 9 **Deaths at Home in Ireland, 1885-2011**



Source: CSO Annual Reports on Vital Statistics, 1885-2011.

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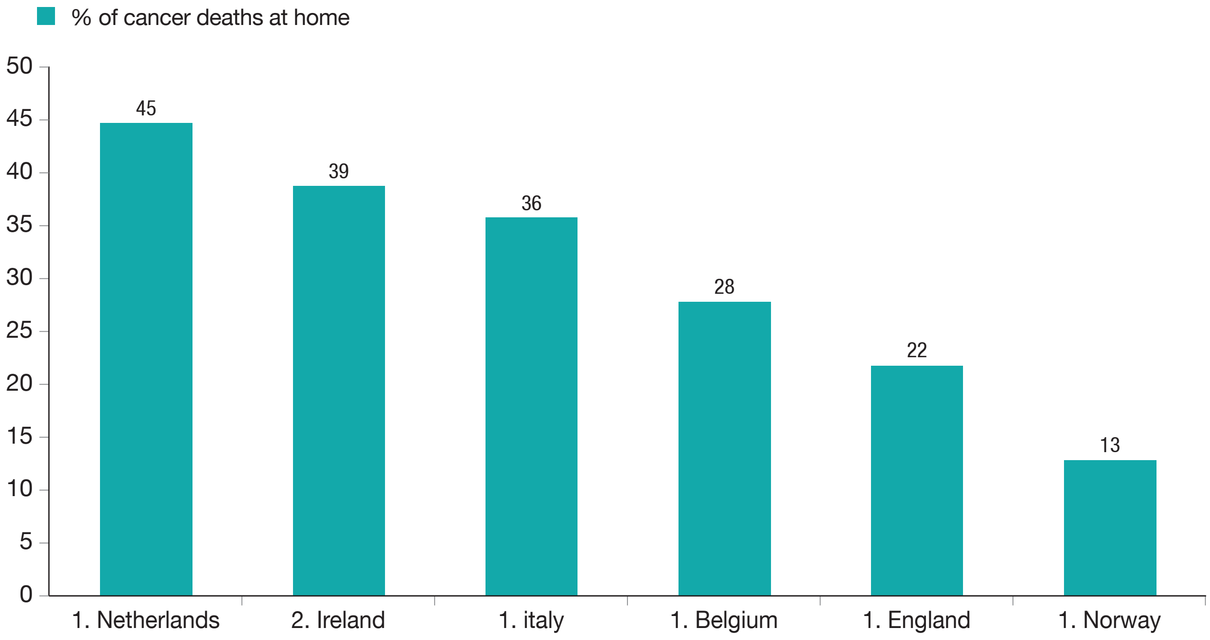
[124] It almost goes without saying that deaths can only occur in hospital if there are hospital beds and relatively easy access to them and that has been the case in the Irish health system for the past 80 years. Over a period of approximately 30 years (1930-1960), largely due to funding from the Irish Hospitals' Sweepstake, Ireland built more hospital beds per head of population than almost any other country, including those with much greater income and wealth. That was done without any clear plan or evidence about current or likely future demand for hospital beds. The outcome of this process has been described by one historian as 'the curse of the Irish Hospitals' Sweepstake' who summarised the situation in Ireland the 1960s as follows: 'By the mid-1960s Ireland had over 20,000 acute-care hospital beds; that represented 7.2 beds per 1,000 of population, a figure exceeded only by Sweden and Luxembourg, and substantially higher than England and Wales, at 4.3 per 1000, Northern Ireland 5.5, or the United States 4.9. Minister for Health Erskine Childers reminded the inaugural meeting of the National Health Council in February 1971 that 'we have the highest proportion of hospital beds to population in Western Europe'. To fill these beds, the rate of hospital admissions was growing. In 1964 the rate of hospital admissions in Ireland was 100 per 1,000 of the population; in 1951 that figure had been 60 per 1,000. Despite the high rate of hospital admissions, Irish patients spent more days in hospital – an average of 20 days in 1960 (the figures exclude long-stay institutions) and fewer patients were treated annually per hospital bed: 16 patients per bed, compared with 19 in Sweden, 22 in England and Wales and 30 in the USA. All of this suggests that there were too many hospital beds. … . It is no great surprise therefore that by the 1960s approximately 70 per cent of health spending went on hospitals (this includes long-stay hospitals). It is worth noting that in 1960 public expenditure on health accounted for 2.9 per cent of Irish GNP – a higher percentage than France (2.6%), Belgium (2.0%), and The Netherlands (1.8%), and only fractionally lower than Germany and Denmark both at 3 per cent. While GNP per capita in Ireland was much lower than in the comparator countries, this suggests that, while state funding for GP, home-care, drugs and other non-hospital services was low, funding for the hospital sector was not inadequate – whether that money was well spent is another question.' (Daly, 2012:2- 9). In 2011, Ireland had 4.9 beds per 100 population, the same as the OECD average; it spent 9.5% of GDP on health also the same as the OECD (OECD, 2012)

A noteworthy feature of Figure 9 is the absence of almost any change in the proportion of deaths at home in Ireland over the past decade. This could be seen as remarkable in light of the unprecedented reorganisation of health services which occurred during this period, all within a policy focus of shifting the balance of services towards primary and community care. If the proportion of deaths at home is taken as a KPI of change towards providing care closer to home or at home, then it is difficult to avoid the conclusion that this policy has still to be fully implemented. Whatever the reasons, this evidence provides a rationale for using the proportion of deaths at home as a KPI for measuring the extent to which the balance of health services is being tipped more in favour of primary and community care.

Internationally, home deaths in Ireland (25%) hold an intermediate position between Italy (where 33% of deaths occur at home) and Norway (where 16% of deaths occur at home). However, when deaths from cancer are considered in Figure 10, based on countries for which we have comparable data, Ireland has a higher proportion of deaths at home (39%) compared to most other European countries, except Netherlands (45%). The data for Ireland is based on the Minimum Dataset for Specialist Palliative Care which accounted for nearly three quarters (72%) of all cancer deaths in 2010.

Figure 10 **Deaths from Cancer Occurring at Home in Selected Countries**



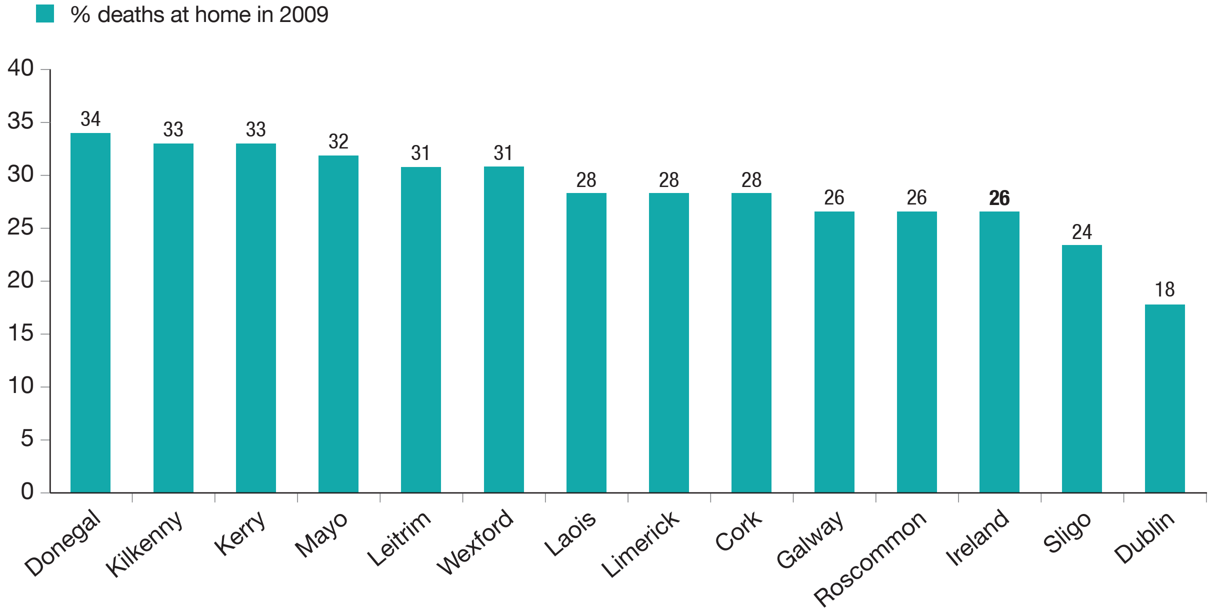
Sources:

1. Cohen, J., Houttekier, D., Addington-Hall, J., Bilsen, J., 2010. 'Which Patients With Cancer Die at Home? A Study of Six European Countries Using Death Certificate Data', Journal of Clinical Oncology, March 29. Data refers to 2003.
2. Minimum Dataset for Specialist Palliative Care, 2010.

Across the different counties of Ireland, there is significant variation in the proportion of deaths at home, as Figure 11 reveals. People in Dublin are least likely to die at home (18%) while people in Donegal are most likely (34%), a difference of 16 percentage. In other words, nearly twice the proportion of people in Donegal die at home compared to Dublin.

The difference between the proportion of deaths at home (18%) and in hospital (48%) is greatest in Dublin (a difference of 30 percentage points) and suggests that the likelihood of dying at home may be inversely related to access to hospitals since Dublin has greater access to hospitals and fewer deaths at home compared to any other part of the country, assuming population and patient profiles are broadly the same in Dublin as elsewhere. As already indicated, the association between the location of hospital resources and where people are cared for and die has been observed elsewhere, most notably in a US study on variations in end-of-life care for Medicare beneficiaries with severe chronic illness.[125] However this relationship does not apply uniformly throughout the country since, for example, the difference between the proportion of deaths at home and in hospital is less in Galway (a difference of 21 percentage points) and Cork (a difference of 7 percentage points), yet both places have 'Level 4' university hospitals.

Figure 11 **Deaths at Home in Selected Counties of Ireland, 2009**



Source: CSO Vital Statistics 2009.

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[125] The authors of this study offer the following explanation for the observed association between hospital resources and deaths in hospital: 'This phenomenon, which we have labeled supply-sensitive care, results from uncertainty about how best to treat patients with chronic diseases and the tendency of clinicians to use the resources available to them (e.g., hospital beds, ICU beds, physician FTEs), whether the capacity is low or high. For example, when a patient's chronic condition worsens, it sometimes seems easier and safer to clinicians to treat the patient in the hospital, even though it may be reasonable to start outpatient treatment and monitor the patient's condition in clinic or by phone. If more hospital beds are available in an area, local care patterns unconsciously adapt to this higher capacity, and patients are more likely to be admitted. Similarly, research has shown that when ICU beds are readily available, more patients who are less severely ill will be admitted, and they will stay longer. Yet greater use of the hospital or ICU as a site of care does not lead to better outcomes on average. Although it is possible that some of the differences across hospitals may be explained by differences in patients' preferences for care, studies show that regional variation in patient preferences overall explains very little of the variation in the intensity of end-of-life care.' (Goodman, Esty, Fisher and Chang, 2011:3).

8.1 Is this variability warranted?

The variability in home deaths across the country raises the same question that was raised with acute hospital deaths: is this variability warranted? It seems reasonable to assume that at least some amount, perhaps a substantial amount, of this variability is unwarranted since population and patient needs and preferences are unlikely to vary so widely from one county to another. In light of that, it is reasonable to ask why, if it is possible for 34% of deaths to take place at home in Donegal, why is it that about half that proportion (18%) die at home in Dublin? In addition to the expressed preference of a majority of people to die at home rather than in hospital, the possibility that a substantial proportion of deaths in Dublin could take place at home has implications for the use of scarce resources such as beds in hospitals, as already indicated (Section 3). This again confirms why KPIs on place of care and death at end of life could be valuable not just as a way of monitoring progress towards delivering care at or close to home, but also as a way of tracking if resources are being used efficiently and equitably[126].

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[126] The results of research at The Dartmouth Institute for Health Policy and Clinical Practice, which produces The Dartmouth Atlas of Health Care merit reflection in this context even though they are based on a different health system (US) and have a particular focus on mainly older patients (Medicare beneficiaries). Its website poses and answers the following question: '*The Atlas is often cited as a source for the estimate that 30% of the nation's spending is unnecessary — what is the evidence?* The Dartmouth approach was to ask how much might be saved if all regions could safely reduce care to the level observed in low-spending regions with equal quality; we find estimates ranging from 20-30%, but view these as an underestimate given the potential savings even in low cost regions. At least three other groups have come to 30% waste estimates: the New England Healthcare Institute, McKinsey, and Thomson Reuters.' (www.dartmouthatlas.org).

SECTION 9 - DEATHS SUPPORTED BY SPC SERVICES

Specialist Palliative Care (SPC) services have a particular focus on the quality of life of people with life-limiting illnesses and aim ‘to ensure that patients are enabled and encouraged to live their lives to the greatest possible extent, in the manner and in the setting of their choice’[127]. For that reason, it is appropriate to examine the impact of these services in the context of KPIs to increase the proportion of care and deaths at home and reduce the corresponding proportions in hospital.

SPC services are delivered through Home Care Teams (HCTs), In-Patient Units (IPUs also known as hospices), and in hospitals. In 2010 and 2011, about eight out of ten deaths in SPC services were supported by HCTs with the remaining two out of ten supported by IPUs, bearing in mind that some deaths were supported by both. In other words, the predominant focus of SPC services is on patients at home or their usual place of residence. SPC services are involved in a significant minority of all deaths (25%) but a majority of cancer deaths (72%) though the proportion of deaths in hospice is small (6%).

It is well-documented that there are disparities in the size and composition of SPC services throughout the country. For example, there are eight hospices in Ireland but some areas have none – notably Midlands, North East and South East[128]. Similarly, there are disparities in home care teams[129]. These disparities provide a natural experiment to assess how regional and county differences in SPC services may impact on the likelihood of being cared for and dying at home or in hospital. For that reason, we analyse the data by comparing place of death for patients supported by Home Care Teams in areas with a hospice and those without a hospice, but first compare both for all deaths in Ireland.

The overall effect of SPC services is illustrated in Figure 12. This shows, similar to a previous report[130], that the effect of HCTs is to increase the proportion of deaths at home and reduce the proportion of deaths in hospital. Patients who died with the support of HCTs in 2011 were less likely to die in hospital (20% compared to 43% for all patients) and more likely to die at home (42% compared to 26% for all patients). This implies that HCTs have an important role to play in providing palliative and end-of-life care at home or closer to home while reducing deaths in hospital.

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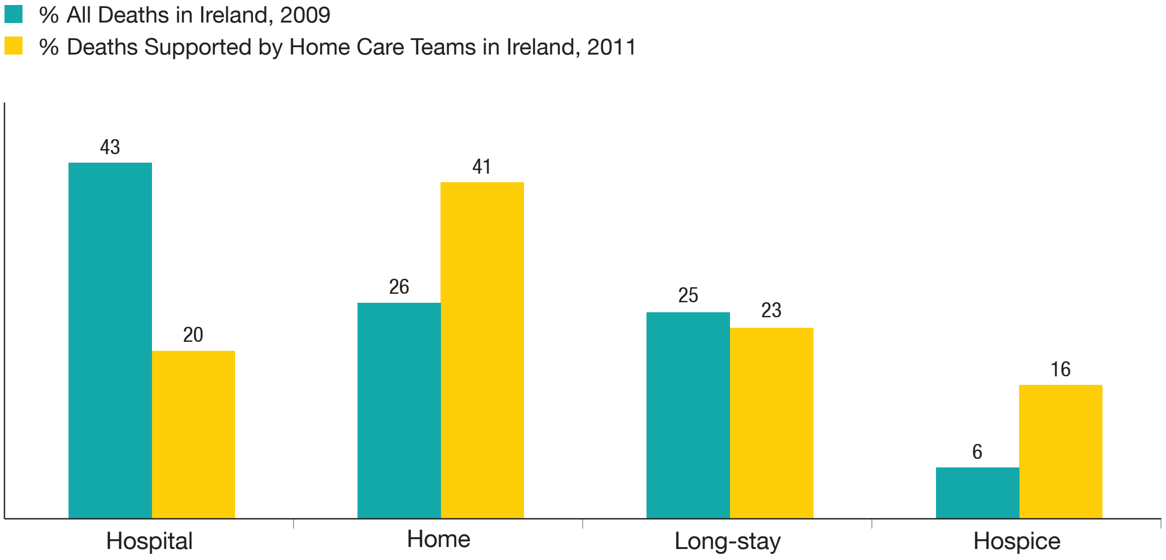
[127] National Advisory Committee on Palliative Care, 2001:3.

[128] A baseline study of SPC services was carried out in 2004 and concluded that: ‘The NACPC [National Advisory Committee on Palliative Care] report recommended that there should be 8-10 inpatient beds for every 100,000 of population, with at least one inpatient unit in each of the ten health board areas. While seven health board areas have inpatient units, the remaining three (the Midlands, the North-East and the South-East), covering 12 counties, have none. Even those health board areas with existing inpatient units are experiencing hospice bed deficits. Several counties or areas where there are inpatient units in neighbouring counties have an identified need for satellite units, e.g. Cavan, Kerry, Mayo/Roscommon, Wicklow, Kildare and Dublin West.’ (Murray, Sweeney, Smyth and Connolly, 2006:13).

[129] ‘The Baseline Study indicates a high level of diversity in specialist palliative care teams in the community. The report of the NACPC outlines an interdisciplinary consultant-led team based in, or with formal links to, the specialist palliative care unit. Only one former health board approaches a fully compliant service. Services are not consultant-led in the main. Most services are ‘nurse only’. Some services have medical and or social work input. Key staffing deficits are identified in the areas of physiotherapy, occupational therapy and social work.’ (Murray, Sweeney, Smyth and Connolly, 2006:13).

[130] Murray, McLoughlin, and Foley, 2013.

Figure 12 **Place of Death for All Deaths and SPC Deaths Supported by Home Care Teams**



Sources: Minimum Dataset for Specialist Palliative Care, 2011; Figure 1 above.

From a comparative perspective, the place of death of patients in receipt of palliative care in Ireland is similar to the US, particularly with respect of patients dying in their ‘usual place of residence’ (home and long-stay). In the US in 2010, for example, 67% of palliative care patients were cared for and died in their usual place of residence compared to 64% in Ireland (41% at home and 23% in long-stay). The main difference is that the US has a higher proportion of deaths in hospice (22% compared to 16% in Ireland) and, correspondingly, a lower proportion of deaths in hospital (11% compared to 20% in Ireland)[131].

9.1 Place of SPC Deaths in Areas with and without Hospice

When SPC services are compared between areas with and without a hospice, as in Figure 13, this allows a more nuanced assessment of how SPC services may influence where people are cared for and die. It shows that areas with a hospice are associated with significantly less deaths in hospital (15%) compared to areas without a hospice (26%). However, areas without a hospice are more likely to have patients who die in their usual place of residence - home and long-stay (71%) - compared to areas with a hospice (58%), a difference of 13 percentage points in both 2010 and 2011.

Understandably, areas with a hospice have a higher proportion of deaths in hospice and this, in conjunction with the fact that these areas also have a lower proportion of deaths in hospital, suggests that the effect of a hospice in Ireland is to transfer patients from hospital to hospice. This is consistent with the acknowledged role of hospices in providing specialised care to patients with complex palliative care needs. Conversely, the absence of a hospice may mean that patients who cannot die at home but who need specialised care then die in hospital which, depending on the quality of hospital care in those areas, may raise questions about whether the area has the appropriate mix of services for end-of-life care. The data also suggests that, in areas without a hospice, patients are more likely to die in their usual place of residence, which may be either home or a long-stay place of care.

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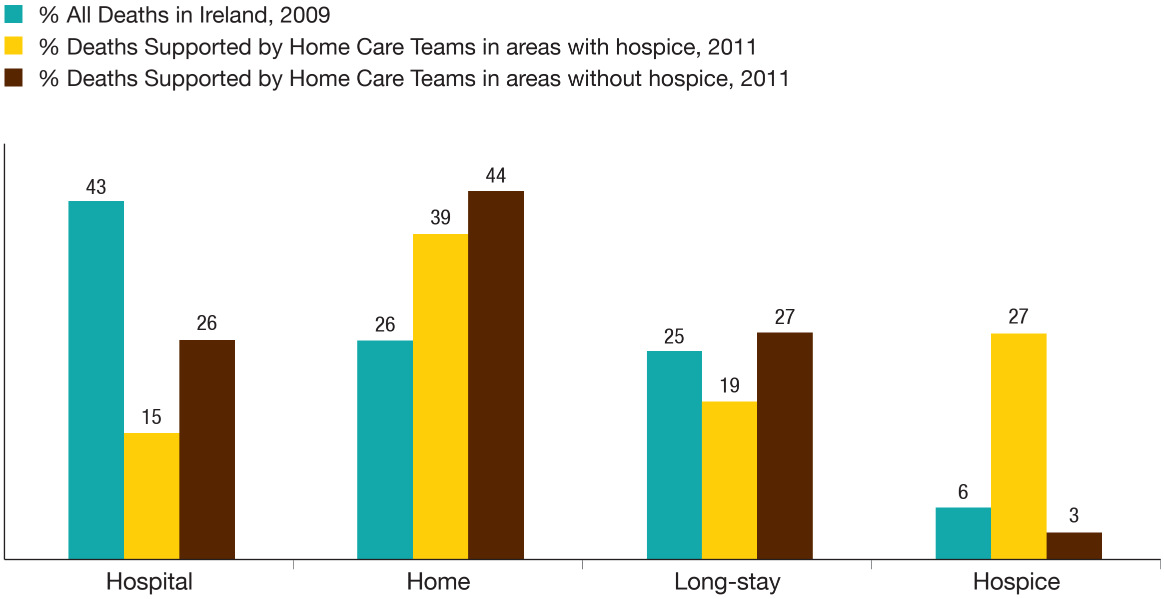
[131] National Hospice and Palliative Care Organisation, 2012:6.

Figure 13 **Place of SPC Deaths in Areas With and Without Hospices, 2011**



Source: Minimum Dataset for Specialist Palliative Care, 2011; CSO data 2010.

9.2 SPC Deaths at Home in Areas with and without Hospices

These over-arching differences between areas with and without hospices also conceal significant variation between and within both sets of areas. This is illustrated by the variation in home deaths. Figure 14 shows that in 2011 this ranged from 31% in Dublin South to 48% in the South East[132], a difference of 17 percentage points. This variation may reflect differences in the quantity and configuration of services between areas as well as different approaches by HCTs to supporting deaths at home.

Whatever the reasons, it is clear that the likelihood of dying at home varies greatly from one HCT to another. Such wide variation in outcome suggests that there may not be a standardised approach to facilitating deaths at home by HCTs. Equally significant is the fact that two of the areas without hospices – South East and North East – have a higher proportion of deaths at home than any of the areas with hospices.

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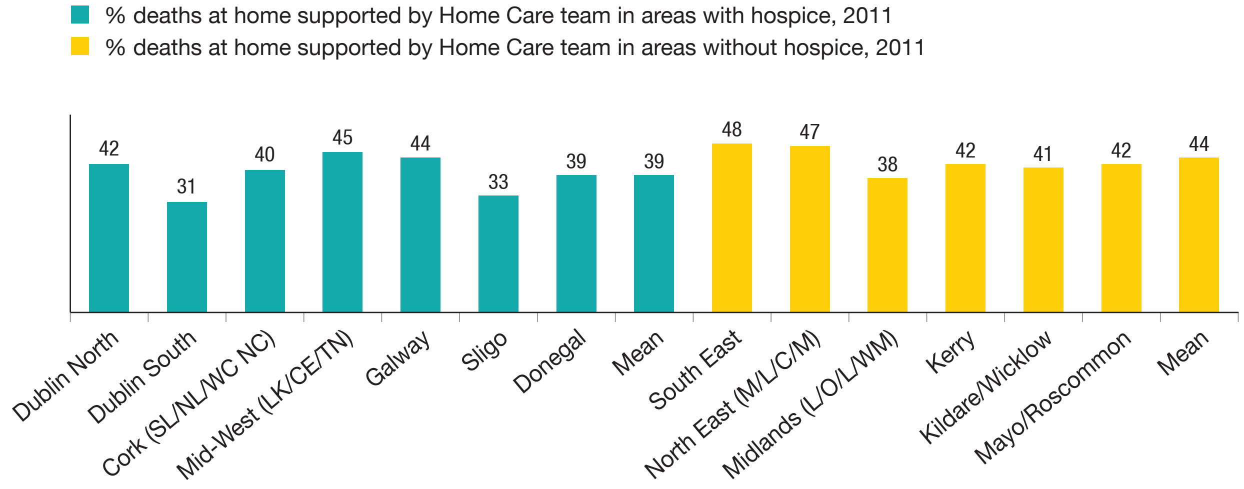
[132] Note that the Carlow / Kilkenny figures have been excluded since there is some doubt about their accuracy.

Figure 14 **SPC Deaths at Home in Areas with and without Hospices, 2011**



Source: Minimum Dataset for specialist Palliative Care, 2011; Table A1.

9.3 SPC Deaths in Usual Place of Residence in Areas with and without Hospices

Figure 15 shows significant variation in the proportion of patients who die in their 'usual place of residence', a term which refers to both home and long-stay places of care because it is the place where the person lived permanently prior to death. In England, as already indicated, this concept has been adopted as an outcome indicator for the end-of-life strategy. It is useful therefore to examine how HCTs impact on the patient's usual place of residence. On average, HCTs in areas without a hospice supported a higher proportion of deaths in long-stay in 2011 (71%) compared to HCTs in areas with a hospice (58%), a difference of 13 percentage points. This is exactly the same difference as in 2010 and suggests that this is probably a genuine difference between HCTs.

All but one of the HCTs without a hospice had at least 65% of deaths in the usual place of residence in 2011 whereas only one area with a hospice (Mid-West) achieved this level, possibly because of its recently developed 'hospice at home' service[133]. This suggests that not having a hospice in an area facilitates a higher proportion of deaths in the patient's usual place of residence. Of equal note is the huge variation between HCTs in the proportion of patients supported to die in their usual place of residence from the lowest (47% in Dublin South) to the highest (76% in South East), a difference of 29 percentage points. From a patients' perspective, this clearly indicates that the likelihood of dying in their usual place of residence depends on where one lives since it seems unlikely that patient needs and preferences would vary so widely from one part of the country to another.

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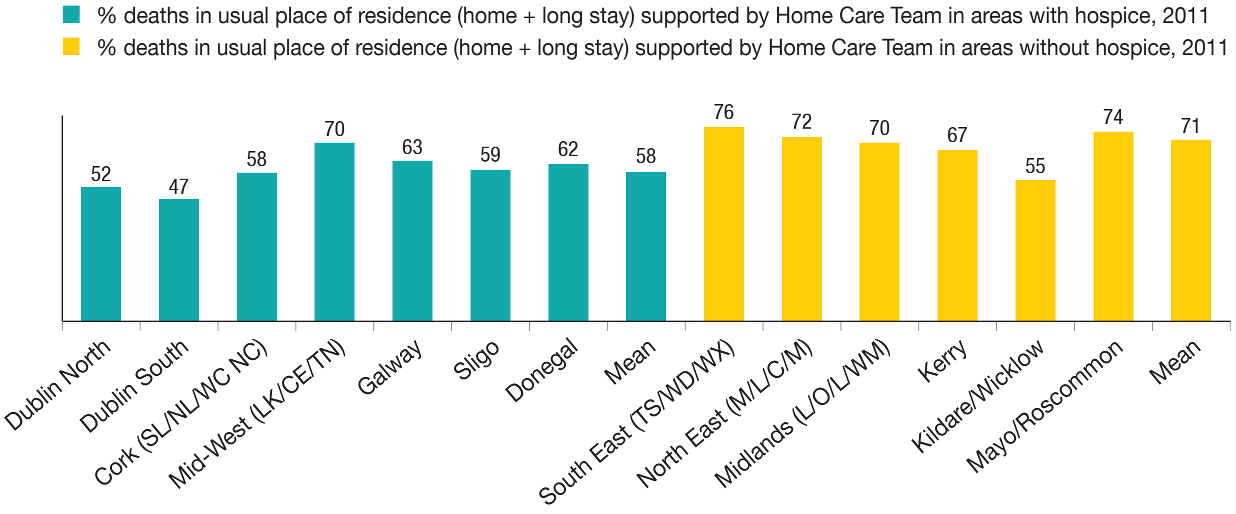
[133] McKay, et al, 2011.

Figure 15 **SPC Deaths in Usual Place of Residence in Areas with and without Hospices**

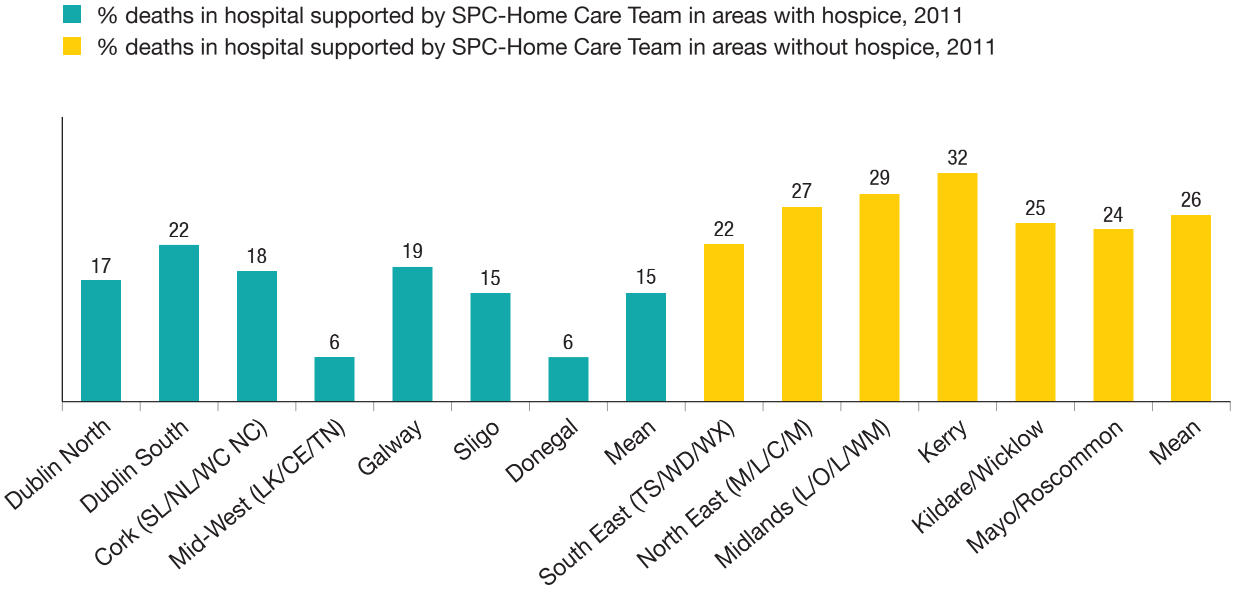


Source: Minimum Dataset for specialist Palliative Care, 2011; Table A1.

9.4 SPC Deaths in Hospital in Areas with and without Hospices

Figure 16 shows substantial variation in the proportion of hospital deaths supported by HCTs in 2011. More patients are supported by HCTs to die in hospital in areas without a hospice (26%) compared to areas with a hospice (15%), and a difference of 11 percentage points. This is almost identical to the pattern in 2010. This difference is to be expected since it reflects the fact that patients are supported to die in a hospice in those areas which have a hospice whereas, in areas without a hospice, patients are supported to die in hospital.

Figure 16 **SPC Deaths in Hospital in Areas with and without Hospices**



Source: Minimum Dataset for specialist Palliative Care, 2011.

As in previous sections, these findings suggest that where a person dies is shaped more by the quantity and configuration of health services in the area – including whether or not the SPC service has a hospice - rather than by patient needs and preferences; otherwise it would be difficult to explain why there is so much geographical variation in place of death for cancer patients who make up 72% of SPC patients. Given the specific aspiration of SPC services to meet the needs of patients 'in the manner and in the setting of their choice'[134], the extent of geographical variation suggests that this aspiration is not being met. By extension, it suggests that much of the variation is unwarranted in the sense that 'cannot be explained by variation in patient illness or patient preferences'[135].

The findings draw particular attention to the different outcomes of SPC services in areas with and without hospices. In areas with a hospice, SPC services are associated with significantly fewer deaths in hospital while areas without a hospice are associated with more patients dying in their usual place of residence. In other words, the presence of a hospice is associated with a positive effect on one KPI (namely reducing care and deaths in hospital) while its absence is associated with a positive effect on another KPI (namely increasing care and deaths in the patient's usual place of residence).

9.5 Implications of Variations in Place of Death in SPC Services

The analysis of SPC services, based on the Minimum Dataset on Specialist Palliative Care Services, reveals that areas with a hospice have a higher proportion of deaths in hospice and this, in conjunction with the fact that these areas also have a lower proportion of deaths in hospital, suggests that the effect of a hospice in Ireland is to transfer patients from hospital to hospice. This is consistent with the acknowledged role of hospices in providing specialised care to patients with complex palliative care needs. Conversely, the absence of a hospice may mean that patients who cannot die at home but who need specialised care then die in hospital which, depending on the quality of hospital care in those areas, may raise questions about whether the area has the appropriate mix of services for end-of-life care. The data also suggests that, in areas without a hospice, patients are more likely to die in their usual place of residence, which may be either home or a long-stay place of care.

In assessing the implications of this finding, a number of considerations need to be taken into account. First, people in areas without a hospice may not have the opportunity to die in their preferred place of care, bearing in mind that 15% of the Irish population expressed a preference to die in hospice when surveyed in 2014, up from 10% in 2004[136]. Second, the absence of a hospice may mean that patients who cannot die at home but who need specialised care then die in hospital which, depending on the quality of hospital care, may not be the best possible end-of-life care. Third, a majority of people (74%) prefer to die at home[137] and this is slightly more likely to happen in areas without hospices; if a broader KPI is considered - dying in 'usual place of residence' (home and long-stay) - then this is much more likely in areas without a hospice. Fourth, observed variations in outcomes of SPC services cannot be dissociated from wider system-level variations in health services within each area, including how those services are managed.

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[134] National Advisory Committee on Palliative Care, 2001:3.

[135] Wennberg, 2010.

[136] Weafer, 2014.

[137] Weafer, 2014.

This means that the implications of implementing current policy - to ‘move us away from the current hospital-centric model of care towards a new model of integrated care which treats patients at the lowest level of complexity that is safe, timely, efficient, and as close to home as possible.’[138] - will need to address these wider system issues. Fifth, the economic value of outcomes associated with SPC services in each area is unknown, where economic value is defined as the relationship between outcomes and cost[139]. Addressing this unknown – arguably one of the biggest knowledge-gaps in the management of all health services in Ireland - would involve examining the resource implications of providing end-of-life care in different settings (hospital, home, long-stay, hospice) and the associated variations in quality of care.

These considerations suggest that the conventional paradigm used to assess the appropriate level of SPC provision in different parts of the country, based on the report of the 2001 National Advisory Committee on Palliative Care, may need to be re-framed. For example, areas such as the South East, Midlands and North East are conventionally designated as ‘under-resourced’ in terms of SPC services – by virtue of not having a hospice - yet they have much higher proportions of their patients dying in their usual place of residence compared to any other SPC service. In the South East, for example, the SPC service has the highest proportion of patients dying in their usual place of residence (76%) and the same proportion of deaths in hospital (22%) compared to the Dublin (22%) which has a number of SPC inpatient units but a much smaller proportion of patients dying in their usual place of residence (47-52%). At the same time, the absence of a hospice in the South East, and similar areas, also means that this option is not available for those patients who may have a need or preference for a hospice.

Given that hospice is an approach to care and not just a place of care, as the World Health Organisation has made clear in its definition of palliative care[140], the aspiration of the Hospice Friendly Hospitals programme (2007-2012)[141] was to make every acute hospital in Ireland a hospice-friendly place to be cared for and die. This aspiration remains relevant given that, compared to every other place of care, acute hospitals are likely to remain the place where most people will continue to die, even if the proposed KPIs are implemented. In weighing up these considerations, account needs to be taken of the outcomes and costs associated with different service configurations (hospital, home, long-stay, hospice) in order to form a rounded assessment of what constitutes best value for populations and patients in terms of end-of-life care. In light of that evidence, it may then be possible to specify more precisely the combination of SPC services – and health services generally - which simultaneously support more care and deaths in usual place of residence and correspondingly less care and deaths in acute hospital.

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[138] Department of Health, 2012b:iii.

[139] ‘Value in any field must be defined around the customer, not the supplier. Value must also be measured by outputs, not inputs. Hence it is patient health results that matter, not the volume of services delivered. But results are achieved at some cost. Therefore the proper objective is the value of health care delivery, or the patient health outcomes relative to the total cost (inputs) of attaining those outcomes. Efficiency, then, is subsumed in the concept of value. So are other objectives like safety, which is one aspect of outcomes.’ (Porter, 2010).

[140] The World Health Organization defined palliative care in 2004 as ‘an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual’ (World Health Organization. 2004).

[141] The Hospice Friendly Hospitals Programme was launched in 2007, with the aim of developing and promoting a culture of care for those facing death in hospitals that would draw on the principles of hospice care. More details at www.hospicefoundation.ie

SECTION 10 - CONCLUSIONS

This paper shows the potential usefulness of KPIs on place of care and place of death in order to monitor one aspect of the outcomes of health services at the end-of-life. Unlike most KPIs in the health sector, which focus on the inputs to health services (such as financial resources, staff, physical capital) and its outputs (patients, procedures, admissions, discharges), the development of KPIs to measure outcomes is somewhat rarer but also more challenging.

What would these KPIs look like?

A KPI is normally measured as the proportion of people in a particular category based on a numerator and a denominator. The numerator for a KPI on place of care could be the total bed-days spent by a patient in hospital during the last six months of life; the denominator would be the total bed-days a patient could have spent in hospital of during the last six months of life (182 days maximum). Other indicators on place of care during the last six months of life, which could be developed as KPIs, could include: number of days a patient spent in intensive care; number of times a patient was admitted to hospital; number of times a patient was admitted through Emergency Department; number of deaths in Emergency Department.

A KPI on place of death could be measured by the total number of deaths in hospital during the last twelve months (the numerator) divided by the total number of deaths (the denominator). Data on both KPIs could be aggregated for each health service area including region, hospital catchment area, Local Health Office, and Primary Care Network.

It is recognised that place of care and death does not replace other quality indicators on the structure, process and outcome of care, nor is it the only possible outcome indicator. That is why these KPIs need to be seen as part of a wider set of measurements on what contributes to good care and a good death, as it is in Scotland and England where these KPIs are also used.

The case for adopting these KPIs rests in part on the fact that a majority of people in Ireland (about three quarters) express a preference to die at home but only a minority (about a quarter) actually die at home. In addition to preferences, the case rests on three further considerations:

(i) there has been no change in the proportion of deaths at home for over a decade despite unprecedented reorganisation of health services during that period with a view to shifting the balance of services towards primary care;

(ii) there is significant variation between counties in Ireland – and even within counties - in the proportion of deaths at home and in hospital which points to the possibility of unwarranted variation within the health system;

(iii) there is significant variation within specific services – notably Specialist Palliative Care services - in the proportion of deaths at home and in hospital which also points to opportunities for reflecting on how to ensure the best alignment of these services with the wider goals of health policy.

Given that the purpose of a KPI is to improve performance in line with policy goals, our analysis also draws attention to the way in which performance on these KPIs must linked to the wider configuration of health services in each area. This suggests the need for a system-wide approach to KPIs – both nationally and locally – if they are to be effective as an instrument for monitoring the implementation of national health policy. Without a system-wide approach – involving community services (especially SPC Home Care Teams), acute hospitals, long-stay homes and hospices - it is questionable if setting KPIs alone will change performance.

A substantial amount of work remains to bring these KPIs to implementation stage, particularly in terms of setting up data systems that can deliver accurate and timely reports on these KPIs. For that reason, a project group needs to be set up which is inclusive of all data-holders relevant to this KPI as well as those with strategic responsibilities for overall management of outcomes in the health service. Some of the data challenges associated with these KPIs have already been referred to, such as the need to improve data coding on place of death and the area where the deceased lived, both in HIPE (where deaths in Emergency Department are currently excluded) and the CSO (where coding of place of death and area where the deceased lived needs improvement). These challenges are made all the greater by the absence of unique patient identifiers or the use of postal codes to geo-code the addresses of patients. In addition, the project group will need to address the fact that: (i) hospitals in the Dublin region do not have a clear catchment area unlike other parts of the country; and (ii) there are differences in the catchment areas and patient profiles of different hospitals. These challenges are not insurmountable since further data analysis could clarify the effective catchment areas of hospitals or groups of hospitals in the Dublin region; it would also be possible to adjust KPIs to take account of patient profiles in different hospitals and of deaths in hospital from outside its catchment area.

10.1 Concluding Comment

The proposal contained in this paper, to adopt KPIs for monitoring the place where people are cared for and die, is timely and useful in the context of the reconfiguration of health services in Ireland. The proposal is consistent with the overall thrust of health policy which aims to provide more health care in the homes and communities where people live while also reducing the inappropriate use of hospitals. As such, this is not a radical proposal nor, from an international perspective, is it particularly innovative since similar KPIs have been implemented in Scotland and England for a number of years. A project group is now required to prepare the proposal for implementation and address the challenges of improving data collection systems to meet the need for timely, accurate and appropriate data on these KPIs.

APPENDIX

Table A1 Place of Death in Ireland, 2010

Place of Death	N	%	*Status*	*Notes*
Hospital	11,714	43	*Estimated*	*1*
Home	7,052	26	*Estimated*	*2*
Long-stay	6,831	25	*Estimated*	*3*
Hospice	1,525	6	*Actual*	*4*
Total	**27,122**	**100**	*Estimated*	*2*

Notes

1. HIPE (Hospital In-Patient Enquiry) is the definitive national data source on the activity of 57 hospitals in Ireland. The data reported here is based on deaths in Ireland's 37 acute hospitals, referred to as HIPE37. HIPE data does not include deaths in Emergency Departments (ED) which occur before the patient is admitted. This has been estimated at 12% of all acute hospital deaths, based on the 2008/9 baseline audit of end-of-life care in Ireland[142]. The data has been adjusted to take this into account.
2. Derived from two sources: (i) CSO Report on Vital Statistics 2009, published in May 2012; and (ii) CSO Vital Statistics and Yearly Summary 2010, published in June 2011. The data reported here on the total number of deaths is based on 'deaths registered' for 2010; based on previous years, this is equivalent to 99% of all deaths (see Table A3). The data on deaths at home is based on the per cent of deaths at home in 2009 (26%). This is the latest year for which there is data on place of death and includes those who may have died at a residence that is different to the person's home address – apart from acute hospitals, hospices or long-stay places of care - or may be a public place.
3. 'Long-stay' is an umbrella term covering nursing homes, community hospitals, and other places of care or custody, excluding acute hospitals and hospices. The figures reported here are estimates based on the residual number of deaths, after the known number of deaths elsewhere (home, acute hospital, hospice) have been excluded from the total number of deaths.
4. The Minimum Dataset on Specialist Palliative Care (SPC) produced its first national dataset for 2010 and covers care provided by Hospices (In-Patient Units) and SPC Home Care Teams. The data reported here is based on deaths in Hospices (In-Patient Units).

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[142] McKeown, Haase and Twomey, 2010a.

Table A2 Deaths at Home in Ireland, 1885-2009

Year	Deaths at home		Deaths in hospitals & institutions		Total Deaths	
	N	%	N	%	N	%
1885	76,676	85	14,036	15	90,712	100
1890	72,307	84	13,543	16	85,850	100
1895	71,075	84	13,320	16	84,395	100
1900	72,322	83	15,284	17	87,606	100
1905	60,277	80	14,794	20	75,071	100
1910	59,456	79	15,438	21	74,894	100
1915	60,028	79	16,123	21	76,151	100
1919	62,197	79	16,415	21	78,612	100
1925	32,957	76	10,693	24	43,650	100
1930	30,407	73	11,295	27	41,702	100
1935	28,541	69	13,002	31	41,543	100
1940	27,747	66	14,138	34	41,885	100
1946	26,998	65	14,459	35	41,457	100
1950	23,625	63	14,116	37	37,741	100
1955	21,367	58	15,394	42	36,761	100
1960	16,743	51	15,917	49	32,660	100
1965	15,285	46	17,737	54	33,022	100
1970	13,977	41	19,709	59	33,686	100
1975	12,613	38	20,560	62	33,173	100
1980	12,946	39	20,526	61	33,472	100
1985	12,961	39	20,252	61	33,213	100
1990	12,468	41	18,002	59	30,470	100
1995	10,382	32	21,877	68	32,259	100
2000	8,147	26	23,244	74	31,391	100
2005	7,166	25	21,094	75	28,260	100
2006	7,219	25	21,269	75	28,488	100
2007	7,102	25	21,012	75	28,117	100
2008	7,242	26	21,032	74	28,274	100
2009	7,412	26	20,968	74	28,380	100

Source: CSO, Annual Reports on Vital Statistics 1885-2009.

Table A3 Deaths at Home and in Hospital (HIPE-37) by County, 2009

County	All Deaths (i)	Deaths at Home (i)	% Deaths at Home	HIPE37 Deaths (ii)	Add 12% to HIPE37 (iii)	Adjusted HIPE37	Adjusted HIPE37 as % of All Deaths
Carlow	370	116	31	140	17	157	42
Cavan	492	148	30	202	24	226	46
Clare	790	208	26	255	31	286	36
Cork	3186	890	28	984	118	1102	35
Donegal	1085	370	34	334	40	374	34
Dublin	7314	1298	18	3103	372	3475	48
Galway	1468	389	26	622	75	697	47
Kerry	1137	372	33	372	45	417	37
Kildare	899	227	25	411	49	460	51
Kilkenny	573	188	33	206	25	231	40
Laois	404	114	28	167	20	187	46
Leitrim	280	86	31	77	9	86	31
Limerick	1363	381	28	402	48	450	33
Longford	299	87	29	98	12	110	37
Louth	761	183	24	355	43	398	52
Mayo	1029	327	32	415	50	465	45
Meath	808	232	29	374	45	419	52
Monaghan	441	135	31	195	23	218	50
Offaly	472	151	32	178	21	199	42
Roscommon	521	137	26	248	30	278	53
Sligo	459	108	24	202	24	226	49
Tipperary North	598	198	33	185	22	207	35
Tipperary South	596	170	29	238	29	267	45
Waterford	778	243	31	329	39	368	47
Westmeath	517	165	32	202	24	226	44
Wexford	959	293	31	378	45	423	44
Wicklow	781	196	25	285	34	319	41
Total	**28,380**	**7412**	**26**	**10,957**	**1,315**	**12,272**	**43**

Sources: (i) CSO, Annual Report on Vital Statistics 2009. (ii) HIPE, 2009. (iii) HIPE data does not include deaths in Emergency Departments (ED) which occur before the patient is admitted. This has been estimated at 12% of all acute hospital deaths, based on the 2008/9 baseline audit of end-of-life care in Ireland[144].

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[144] McKeown, Haase and Twomey, 2010a.

Table A4 Deaths (All, Cancer, Non-Cancer) in HIPE-37 Hospitals, 2005-2010

All Deaths	**2005**	**2006**	**2007**	**2008**	**2009**	**2010**
CSO Deaths Registered	27,441	27,479	28,050	28,192	28,898	27,122
CSO Deaths	28,260	28,488	28,117	28,274	28,380	-
CSO Registered as % of CSO Deaths	97.10%	96.50%	99.80%	99.70%	100%	-
HIPE-37 Deaths	10,978	11,107	11,371	11,212	10,993	10,459
Add 12% for ED Deaths	1,317	1,333	1,365	1,345	1,319	1,255
Adjusted HIPE-37 Deaths	12,295	12,440	12,736	12,557	12,312	11,714
Adjusted HIPE-37 Deaths as % all CSO deaths	*43.5%*	*43.7%*	*45.3%*	*44.4%*	*42.6%*	*43.2%*
CSO deaths at home	25.4%	25.3%	25.2%	25.6%	26.1%	-
Cancer Deaths						
CSO Cancer Deaths Registered	7,614	7,868	7,844	8,203	8,396	7,971
CSO Cancer Deaths	7,749	8,066	7,917	8,199	8,336	-
CSO Cancer % of CSO Deaths	27.4%	28.3%	28.2%	29.0%	29.4%	29.4%
HIPE-37 Cancer Deaths	3,091	3,173	3,172	3,125	3,086	2,957
HIPE-37 Cancer Deaths as % of CSO Cancer Deaths	*39.9%*	*39.3%*	*40.1%*	*38.1%*	*36.8%*	*37.1%*
Non-Cancer Deaths						
CSO Non-Cancer Deaths Registered	19,827	19,611	20,206	19,989	20,502	19,151
CSO Non-Cancer Deaths	20,511	20,422	20,200	20,075	20,044	-
HIPE-37 Non-Cancer Deaths	7,887	7,934	8,199	8,087	7,907	7,502
Add 12% for ED Deaths	*1,317*	*1,333*	*1,365*	*1,345*	*1,319*	*1,255*
Adjusted HIPE-37 *Non-Cancer* Deaths	*9,204*	*9,267*	*9,564*	*9,432*	*9,226*	*8,757*
Adjusted HIPE-37 Non-Cancer Deaths as % all CSO deaths	*32.6%*	*32.5%*	*34.0%*	*33.4%*	*31.9%*	*32.3%*
Adjusted HIPE-37 Non-Cancer as % CSO Non-Cancer Deaths	*44.9%*	*45.4%*	*47.3%*	*47.0%*	*45.0%*	*45.7%*

Sources: CSO and HIPE, 2005-2010.

Table A5 Place of Death in Each Primary Care Network in Donegal and Ireland, 2009

Place of Death	*Inishowen*		*East*		*Letterkenny*		*Northwest*		*South*		*Donegal*		*Ireland*	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Acute Hospital	70	33.8	60	28.7	73	40.6	65	33.3	81	32.7	349	33.6	12,171	43
• *Letterkenny*	65	31.4	51	24.4	64	35.6	58	29.7	47	19.0	285	27.4		
• *Sligo*		0		0		0		0	28	11	28	3		
• *Other*	5	2.4	9	4.3	9	5.0	7	3.6	6	2.4	36	3.5		
Home / Other	75	36.2	77	36.8	60	33.3	62	31.8	63	25.4	337	32.4	7,412	26
Long-Stay	49	23.7	52	24.9	27	15.0	57	29.2	91	36.7	276	26.6	7,095	25
• *Community Hospital*	34	16.4	43	20.6	16	8.9	42	21.5	65	26.2	200	19.2		
• *Nursing & long-stay home*	15	7.2	9	4.3	11	6.1	15	7.7	26	10.5	76	7.3		
Hospice	13	6.3	20	9.6	20	11.1	11	5.6	13	5.2	77	7.4	1,702	6
• *Donegal*	12	5.8	20	9.6	20	11.1	11	5.6	9	3.6	72	6.9		
• *Other*	1	0.5		0.0		0.0		0.0	4	1.6	5	0.5		
Total Deaths	207	100	209	100	180	100	195	100	248	100	1039	100	28,380	100
Hospital - Mean Distance	37.5		16.7		10.1		35.2		52.3		31.7			
Hospital - Median Distance	39.1		18		7.1		36.7		50.3		30.6			
Hospice - Mean Distance	36.9		16.8		9.9		35.5		52.9		31.7			
Hospice - Median Distance	38.5		18.2		6.7		37.1		50.9		30.6			

Source: Special tabulations prepared by CSO based on 2009 data on deaths in Donegal. There were 1083 deaths in Donegal in 2009. Of these, 1039 had an address in Donegal which could be coded to one of the primary care networks in Donegal.

Table A6 Minimum Dataset Specialist Palliative Care: Deaths in 2010

Category	SPC-IPU Inpatient Unit	SPC-HCT Home Care	IPU +HCT* N	Total %
All SPC Deaths	1,525	6,191	6,733	100.0%
All CSO Deaths	-	-	27,122	100.0%
SPC as % of All CSO Deaths,	-	-	-	24.8%
% SPC Cancer Deaths	93%	83%	-	-
SPC Cancer Deaths	1,418	4,323	5,741	85.0%
SPC Non-Cancer Deaths	107	885	992	15.0%
All SPC Deaths	-	-	6,733	100.0%
All CSO Cancer Deaths	-	-	7,971	
SPC as % of CSO Cancer Deaths	-	-	-	72.0%
All CSO Non-Cancer Deaths	-	-	19,151	100.0%
SPC as % of CSO Non-Cancer Deaths	-	-	-	5.2%
All SPC Deaths: Place of Death				
SPC Deaths in hospital	0	1,288	1,288	19.1%
SPC Deaths in hospice	1,525	-	1,525	22.6%
SPC Deaths in long-stay	0	1,309	1,309	19.4%
SPC Deaths in home	0	2,611	2,611	38.8%
Total SPC Deaths	1,525	5,208	6,733	100%

Source: Minimum Dataset Specialist Palliative Care, 2010.

*This excludes patients (983) cared for by the SPC Home Care Team (HCT) but who died in the SPC In-Patient Unit (IPU)

Table A7 Minimum Dataset Specialist Palliative Care – Home Care Teams (HCT): Deaths in Areas with Hospices, 2010

	Donegal		**Cork**		**Galway**		**Mid-West L/C/NT**		**Dublin**		**Sligo S/L**		**Total: Areas with Hospices**		**Ireland: Areas with & without Hospices**	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
All SPC-HCT Deaths	225	100	704	100	277	100	645	100	1,253	100	203	100	3,307	100	6,191	100
% SPC-HCT Cancer Deaths	89%	-	85%	-	87%	-	83%	-	88%	-	76%	-	86%	-	83%	-
Cancer Deaths	200	89	598	85	241	87	535	83	1,103	88	154	76	2,832	86	5,139	83
Non-Cancer Deaths	25	11	106	15	36	13	110	17	150	12	49	24	475	14	1,052	17
SPC-HCT *Place of Death*																
SPC-HCT Deaths: Hospital	22	9.8	111	15.8	51	18.4	60	9.3	274	21.9	23	11.3	541	16.4	1,288	20.8
SPC-HCT Deaths: Hospice	67	29.8	180	25.6	60	21.7	186	28.8	343	27.4	51	25.1	887	26.8	983	15.9
SPC-HCT Deaths: Long-stay	38	16.9	113	16.1	46	16.6	130	20.2	166	13.2	54	26.6	547	16.5	1,309	21.1
SPC-HCT Deaths: Home	98	43.6	300	42.6	120	43.3	269	41.7	470	37.5	75	36.9	1,332	40.3	2,611	42.2
Total	225	100	704	100	277	100	645	100	1,253	100	203	100	3,307	100	6,191	100

Source: Minimum Dataset Specialist Palliative Care, 2010.

Table A8 Minimum Dataset Specialist Palliative Care – Home Care Teams (HCT): Deaths in Areas without Hospices, 2010

	South East W/W/ST*		**North East M/L/C/M**		**Midlands L/OL/WM**		**Mayo / Roscommon**		**Kerry**		**Kildare / Wicklow**		**Total: Areas without Hospices**		**Total: Areas with Hospices**		**Ireland: Areas with & without Hospices**	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
All SPC - HCT Deaths	608	100	653	100	556	100	404	100	264	100	258	100	2,743	100	3,307	100	6,191	100
% SPC-HCT Cancer Deaths	87%	-	75%	-	66%	-	74%	-	85%	-	93%	-	78%	-	86%	-	83%	-
Cancer Deaths	531	87	488	75	366	66	299	74	224	85	241	93	2,149	78	2,832	86	5,139	83
Non-Cancer Deaths	77	13	165	25	190	34	105	26	40	15	17	7	594	22	475	14	1,052	17
SPC-HCT *Place of Death*																		
SPC-HCT Deaths: Hospital	142	23.4	199	30.5	154	27.7	97	24.0	79	29.9	66	25.6	737	26.9	541	16.4	1,288	20.8
SPC-HCT Deaths: Hospice	8	1.3	7	1.1	12	2.2	10	2.5	17	6.4	38	14.7	92	3.4	887	26.8	983	15.9
SPC-HCT Deaths: Long-stay	170	28.0	150	23.0	170	30.6	129	31.9	64	24.2	58	22.5	741	27.0	547	16.5	1,309	21.1
SPC-HCT Deaths: Home	288	47.4	297	45.5	220	39.6	168	41.6	104	39.4	96	37.2	1,173	42.8	1,332	40.3	2,611	42.2
Total	**608**	**100**	**653**	**100**	**556**	**100**	**404**	**100**	**264**	**100**	**258**	**100**	**2.743**	**100**	**3,307**	**100**	**6,191**	**100**

Source: Minimum Dataset Specialist Palliative Care, 2010. *Excludes Carlow / Kilkenny because data deemed unreliable

FULL REFERENCE LIST

Abel, J., Rich, A., Griffin, T. & Purdy, S. (2009) End-of-life care in hospital: a descriptive study of all inpatient deaths in 1 year. *Palliative Medicine* Vol. 23 (7) pp 616-22

Addington-Hall, J. & O'Callaghan, A. (2009) A comparison of the quality of care provided to cancer patients in the UK in the last three months of life in in-patient hospices compared to hospitals, from the perspective of bereaved relatives: results from a survey using the VOICES questionnaire. *Palliative Medicine* Vol. 23 (3) pp.190-197

Alonso-Babarro, A., Bruera, E., Varela-Cerdeira, M., Boya-Cristia, M., Madero, R., Torres-Vigil, I., Javier De Castro, and Gonza´lez-Baro´n, M. (2011) Can this patient be discharged home? factors associated with at-home death among patients with cancer*. Journal of Clinical Oncology*, Vol. 29 (9) 1159-1167

Björnberg, A., Garrofé, B. & Lindblad, S. (2009) *Euro health consumer index 2009 report.* Health Consumer Powerhouse. [online] Available at http://www.healthpowerhouse.com/files/Report%20EHCI%202009%20091005%20final%20with%20cover.pdf Accessed Oct 1 2014

Brick, A., Nolan, A., O'Reilly, J. & Smith, S. (2010)(a) *Resource Allocation, Financing and Sustainability in Health Care Evidence for the Expert Group on Resource Allocation and Financing in the Health Sector (Volume I).* Dublin: The Economic and Social Research Institute. [online] Available at http://www.esri.ie/UserFiles/publications/BKMNEXT167V1.pdf Accessed Oct 10 2014

Brick, A., Nolan, A., O'Reilly, J. & Smith, S. (2010)(b) *Resource Allocation, Financing and Sustainability in Health Care: Evidence for the Expert Group on Resource Allocation and Financing in the Health Sector (Volume 2)*. Dublin: The Economic and Social Research Institute. [Online] Available at http://www.esri.ie/UserFiles/publications/BKMNEXT167V2.pdf Accessed Oct 10 2014

Brick, A., Nolan, A., O'Reilly, J. & Smith, S. (2010) (c) Resource Allocation, Financing and Sustainability in the Health Sector' *Quarterly Economic Commentary*, Autumn. Dublin: The Economic and Social Research Institute. [online] Available at http://www.esri.ie/UserFiles/publications/RB20100103/RB20100301.pdf Accessed Oct 2014

Brick, A., Nolan, A., O'Reilly, J. & Smith, S. (2012) Conflicting Financial Incentives in the Irish Health-Care System. *The Economic and Social Review* Vol. 43 (2) pp. 273–301

Central Statistics Office (CSO) (2014) *Vital statistics fourth quarter and yearly summary 2013* Dublin: The Stationary Office. [online] Available at http://www.cso.ie/en/media/csoie/releasespublications/documents/vitalstats/2013/vstats_q42013.pdf Accessed Sept 29 2014

Central Statistics Office (CSO) (2013) *Vital statistics fourth quarter and yearly summary 2012* Dublin: The Stationary Office. [online] Available at http://www.cso.ie/en/media/csoie/releasespublications/documents/vitalstats/2012/vstats_q42012.pdf Accessed Oct 10 2014

Central Statistics Office (2013) *Report on vital statistics 2011*. Dublin: Stationery Office. [online] Available at http://www.cso.ie/en/media/csoie/releasespublications/documents/vitalstats/2011/annual report2011.pdf Accessed Oct 10 2014

Central Statistics Office (2012) *Report on vital statistics 2009*. Dublin: Stationery Office. [online] Available at http://www.cso.ie/en/media/csoie/releasespublications/documents/vitalstats/2009/annual report2009.pdf Accessed Oct 10 2014

Central Statistics Office (2005) *Report on vital statistics 2003*. Dublin: Stationery Office. [online] Available at http://www.cso.ie/en/media/csoie/releasespublications/documents/vitalstats/2003/annual report_2003.pdf Accessed Oct 10 2014

Cohen, J., Bilsen, J., Addington-Hall, J., Lofmark, R., Miccinesi, G., Kaasa, S., Onwuteaka-Philipsen B. & Deliens, L. (2008) Population-based study of dying in hospital in six European countries. *Palliative Medicine* Vol. 22 (6) pp 702-710

Cohen, J., Houttekier, D., Addington-Hall, J., Bilsen, J. (2010) Which patients with cancer die at home? A study of six European countries using death certificate data. *Journal of Clinical oncology* Vol. 28 (13) pp 2267 – 2273

Daly, M. (2012) *The curse of the Irish Hospitals' Sweepstake: A hospital system, not a health system*. Working Papers in History and Policy, No 2, Dublin: School of History and Archives, University College Dublin. [Online] Available at http://historyhub.ie/the-curse-of-the-irish-hospitals-sweepstake Accessed Oct 10 2014

De Roo M., Miccinesi G., Onwuteaka-Philipsen B., Van Den Noortgate, N., Van den Block, L., Bonacchi, A., Donker, G., Alonso, J., Moreels, S., Deliens, L. & Francke, A. (2014) Actual and preferred place of death of home-dwelling patients in four European countries: Making sense of quality indicators *PLoS ONE* Vol. 9 (4) [online] http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0093762 Accessed Oct 1 2014

Department of Health (2012) *Future Health: A Strategic Framework for Reform of the Health Service 2012-2015*. Dublin: Department of Health. [online] Available at http://lenus.ie/hse/bitstream/10147/253172/1/FutureHealth.pdf Accessed Oct 1 2014

Department of Health & Children (2001)(a) *Report of the National Advisory Committee on Palliative Care.* [online] Available at http://lenus.ie/hse/bitstream/10147/42522/1/1890.pdf Accessed Oct 6 2014

Department of Health and Children (2001)(b) *Quality and fairness: A health system for you, Health Strategy.* Dublin: The Stationary Office [online] Available at http://www.lenus.ie/hse/bitstream/10147/46392/1/1317.pdf Accessed Oct 10 2014

Department of Health and Children (2001)(c) *Primary Care Strategy: A New Direction.* Dublin: Stationery Office. [online] Available at http://www.lenus.ie/hse/bitstream/10147/46389/1/1245.pdf Accessed Oct 10 2014

Department of Health and Children (2008)(a) *Tackling chronic disease: A policy framework for the management of chronic disease*. Dublin: Department of Health and Children. Available at http://www.lenus.ie/hse/bitstream/10147/45895/1/9558.pdf Accessed Oct 13 2014

Department of Health and Children 2008(b) *National strategy for service user involvement in the Irish Health Service 2008-2013.* Dublin: Department of Health and Children and Health Services Executive. Available at http://www.lenus.ie/hse/bitstream/10147/45923/1/9606.pdf Accessed Oct 13 2014

Department of Health (2008) *End of Life Care Strategy: Promoting high quality care for all adults at the end of life.* London: Department of Health. [online] Available at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf Accessed Oct 13 2014

Department of Health & Children (2010) *Report of the expert group on resource allocation and Financing in the Health Sector* Dublin: Government Publications. [online] Available at http://health.gov.ie/wp-content/uploads/2014/03/resource_allocation_report_hiRes.pdf Accessed Oct 13 2014

Department of Health (2012) *End of Life Care Strategy: Fourth Annual Report.* London: Department of Health. [Online]Available at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136486/End-of-Life-Care-Strategy-Fourth-Annual-report-web-version-v2.pdf Accessed Oct 13 2014

Department of Health (2012)(a) *Statement of Strategy 2011-2014.* Dublin: Department of Health. [online] Available at http://health.gov.ie/wp-content/uploads/2014/03/Statement_of_Strategy_2011-2014.pdf Accessed Oct 13 2014

Department of Health (2012) *Future Health: A strategic framework for reform of the health service 2012 – 2015*. Dublin: Department of Health. [online] Available at http://www.lenus.ie/hse/bitstream/10147/253172/1/FutureHealth.pdf Accessed Oct 13 2014

Department of Taoiseach (2011) *Programme for Government 2011-2016.* Dublin: Department of Taoiseach. [online] Available at http://www.taoiseach.gov.ie/eng/Work_Of_The_Department/Programme_for_Government/Programme_for_Government_2011-2016.pdf Accessed Oct 13 2014

Donnelly, M. (Ed) (2000) *The Whoseday Book; a millennium journal*. Dublin : Irish Hospice Foundation

Economic and Social Research Institute (ESRI) (2013) *Activity in Acute Public Hospitals in Ireland, 2012 Annual Report.* Dublin: Economic & Social Research Institute. [online] Available at http://www.esri.ie/__uuid/dbadf914-7da3-4bd0-bede-2e878b56f78b/AR_2012_FINAL.pdf Accessed Oct 13 2014

Gao, W., Ho, Y., Verne, J., Glickman, M., Higginson, I. (2013) Changing patterns in place of cancer death in England: A population-based study. *PLoS Med* Vol. 10 (3) pp 1-10 [online] Available at http://www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.1001410 Accessed Oct 13 2014

Gerrard, R., Campbell, J., Minton, O., Moback, B., Skinner, C., McGowan, C., Stone, P. (2011) Achieving the preferred place of care for hospitalized patients at the end of life. *Palliative Medicine* Vol. 25 (4) pp 333-336

Gomes B., Calanzani N., Curiale V, McCrone P, Higginson I. (2013) Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. *Cochrane Database of Systematic Reviews* Issue 6 [Online] Available at http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD007760.pub2/pdf

Gomes B, Calanzani N, Gysels, M., Hall, S., & Higginson I. (2013) Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliative Care* Vol. 12 (7) [online] Available at http://www.biomedcentral.com/1472-684X/12/7 Accessed Oct 13 2014

Gomes B, Higginson I., Calanzani N, Cohen, J., Deliens, L., Daveson, B., Bechinger-English, D., Bausewein, C., Ferreira, P., Toscani, F., Meñaca, A., Gysels, M., Ceulemans, L., Simon, S., Pasman, H., Albers, G., Hall, S., Murtagh, F., Haugen,D., Downing, J., Koffman, J., Pettenati, F., Finetti, S., Antunes, B & Harding, R. on behalf of PRISMA (2012) Preferences for place of death if faced with advanced cancer: a population survey in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain. *Annals of Oncology* Vol. 23(8) pp 2006-2015

Gomes, B., Calanzani, N. & Higginson, I. (2012) Reversal of the British trends in place of death: Time series analysis 2004–2010. *Palliative Medicine* Vol. 26(2) 102-107.

Gomes, B. & Higginson, I. (2006) Factors influencing death at home in terminally ill patients with cancer: Systematic review. *British Medical Journal* 332:515

Gomes, B., Calanzani, N. & Higginson, I. (2011) *Local preferences and place of death in regions within England 2010.* London: Cicely Saunders Institute. [online] Available at http://www.csi.kcl.ac.uk/files/Local%20preferences%20and%20place%20of%20death%20in%20regions%20within%20England.pdf Accessed Oct 13 2014

Goodman D., Esty, A., Fisher, E. & Chang, C. (2011) *Trends and variation in End-of-Life Care for Medicare beneficiaries with severe chronic illness: Report of the Dartmouth Atlas Project.* [online] Available at http://www.dartmouthatlas.org/downloads/reports/EOL_Trend_Report_0411.pdf Accessed Oct 13 2014

Goodman D., Fisher, E., and Chang, C. (2011) *After Hospitalization: A Dartmouth Atlas report on post-acute care for Medicare beneficiaries: Report of the Dartmouth Atlas Project*. [online] Available at http://www.dartmouthatlas.org/downloads/reports/Post_discharge_events_092811.pdf Accessed Oct 13 2014

Health Service Executive (2009) *Palliative Care Services - Five year/medium term development framework*. [online] Available at http://www.hse.ie/eng/services/Publications/corporate/palcareframework.pdf Accessed Oct 2 2014

Healthcare Improvement Scotland (2013) *Palliative and end of life care indicators.* Edinburgh: Healthcare Improvement Scotland. [online] Available at http://www.healthcareimprovementscotland.org/our_work/person-centred_care/palliative_care/palliative_care_indicators.aspx

Higginson, I., Sarmento, V., Calanzani, N., Benalia, H. & Gomes, B. (2013) Dying at home – is it better: A narrative appraisal of the state of the science. *Palliative Medicine* Vol. 27 (10) pp 918-924

Higginson, I. (2003) *Priorities and preferences for end of life care in England, Wales and Scotland.* The Cicely Saunders Foundation, Scottish Partnership for Palliative Care

Houttekier, D., Cohen, J., Bilsen, J., Deboosere, P., Verduyckt, P. & Deliens, L. (2009) Determinants of the Place of Death in the Brussels Metropolitan Region. *Journal of Pain and Symptom Management.* Vol. 37 (6) pp 996 -1006

Houttekier, D., Cohen, J., Bilsen, J., Addington-Hall, J., Onwuteaka-Philipsen, B. & Deliens, L. (2010) Place of death of older persons with Dementia: A study in five European countries. *Journal of The American Geriatrics Society* Vol. 58 (4) pp.751-756.

Health Service Executive (2007) *Corporate Plan (2008-2011).* Cork : Health Service Executive. [online] Available at http://www.hse.ie/eng/services/Publications/corporate/Corporate_Plan_2008_-_2011.pdf Accessed Oct 14 2014

Health Service Executive (2006) *Transformation Programme (2007-2010)*. Dublin: Health Service Executive. [online] Available at http://www.hse.ie/eng/services/Publications/corporate/transformation.pdf Accessed Oct 14 2014

Health Service Executive (2014) *Delayed Discharges: National Report*. Dublin: Health Service Executive

Hunt, K., Shlomo, N. & Addington-Hall, J. (2014) End-of-life care and achieving preferences for place of death in England: Results of a population based survey using the VOICES-SF questionnaire. *Palliative Medicine* Vol. 25 (5) pp 412-421

Imison, C., Poteliakhoff, E., Thompson, J.(2012) *Older people and emergency bed use: Exploring variation.* London: The King's Fund. Available at http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/older-people-and-emergency-bed-use-aug-2012.pdf Accessed Oct 13 2014

Institute of Health Improvement (IHI) (2014) *The IHI triple aim initiative*. [online] Available at http://www.ihi.org/Engage/Initiatives/TripleAim/pages/default.aspx Accessed Oct 1 2014

Langford, S. (2007) Delivering integrated policy and services for children. *Journal of the Statistical and Social Inquiry Society of Ireland.* Vol XXXVI, pp.205-260. Available at http://www.tara.tcd.ie/handle/2262/24099 Accessed Oct 14 2014

Layte, R., 2009 Coping with population change in Ireland: The implications for healthcare *Quarterly Economic Commentary,* Winter 2009 4/3. Dublin: Economic and Social Research Institute. [online] Available at http://www.esri.ie/__uuid/8483ed5e-4994-4242-80f7-322642316fee/RB20090403.pdf Accessed Oct 14 2014

Layte, R., (Ed) (2009) *Projecting the Impact of Demographic Change on the Demand for and Delivery of Healthcare in Ireland.* ESRI Research Series No. 13. Dublin: Economic and Social Research Institute. [online] Available at https://www.esri.ie/UserFiles/publications/20091023164031/RS013.pdf

Macleod, U. (2011) Place of death – is home always best? *British Journal of Hospital Medicine* Vol. 72 (8) pp 441-443

Martin L., Nelson E., Lloyd R. & Nolan T. (2007). *Whole System Measures*. *IHI Innovation Series white paper*. Cambridge, Massachusetts: Institute for Healthcare Improvement.

Martin-Moreno, J. & Centeno, C. (2009) Bringing palliative care on to the European agenda. *European Journal of Palliative Care* Vol. 16 (2) p 57. [online] Available at http://www.eapcnet.eu/LinkClick.aspx?fileticket=eqKvw70E66A%3D&tabid=38 Accessed Oct 1 2014

Martin-Moreno, J., Harris, M., Gorgojo, L., Clark, D., Normand, C., Centeno, C. (2009) Transforming research into action: Palliative Care in the European Union. *Eurohealth* Vol. 15 (2) PP 23-25 [Online] Available at http://www.lse.ac.uk/LSEHealthAndSocialCare/pdf/Martin-Moreno%20v15n2.pdf Accessed Oct 14 2014

McCarthy, J., Donnelly, M., Dooley, D., Campbell, L., Smith, D., O'Neill, C., Quinlan, C. & Weafer, J. (2010) *The complete framework for End-of-Life care*. Dublin: Irish Hospice Foundation. [online] Available at http://hospicefoundation.ie/publications/ethics/ Accessed Oct 1 2014

McKay, E., Taylor, A., Armstrong, C., Gallagher, M., Bailey, M., Graham, M. & Ward, J. (2011) *An Evaluation of the Hospice at Home Service Delivered by Milford Care Centre 2009/2011* Limerick: Milford Care Centre and University of Limerick. [online] Available at http://www.milfordcarecentre.ie/media/ideabubble/MIL-1115/docs/final_copy_hah_report_8-2-12.pdf Accessed Oct 14 2014

McKeown, K., Haase, T., Pratschke, J., Twomey, S., Donovan, H., and Engling, F. (2010) *Dying in Hospital in Ireland: An Assessment of the Quality of Care in the Last Week of Life, Report 5, Final Synthesis Report*. Dublin: Irish Hospice Foundation. [online] Available at http://hospicefoundation.ie/wp-content/uploads/2013/04/FINAL_National_Audit_of_End_of_Life_Care_in_Hospitals_Report_5.pdf Accessed Oct 2 2014

McKeown, K. (2010) *National Audit of End-of-Life Care in Hospitals in Ireland, 2008/9 – How Does the Route of Admission to Acute Hospitals Affect End-of-Life Care Outcomes?* Unpublished Report for the Hospice Friendly Hospitals Programme.

McKeown, K., Haase, T., & Twomey, S., 2010 (a*) Resources and Facilities for End-of-Life Care in Irish Hospitals, National Audit Report 1.* Dublin: Irish Hospice Foundation. [Online] Available at http://hospicefoundation.ie/wp-content/uploads/2013/04/Report-1.pdf Accessed Oct 14 2014

McKeown, K., Haase, T., & Twomey, S.(2010)(b) *Dying in Hospital in Ireland: Nurse and Doctor Perspectives, National Audit Report 2.* Dublin: Irish Hospice Foundation. [online] Available at http://hospicefoundation.ie/wp-content/uploads/2013/04/Audit2.pdf Accessed Oct 14 2014

McKeown, K., Haase, T. & Twomey, S. (2010)(c) *Dying in Hospital in Ireland: Family Perspectives, National Audit Report 3.* Dublin: Irish Hospice Foundation. [online] Available at http://hospicefoundation.ie/wp-content/uploads/2013/04/Audit-report-3.pdf Accessed Oct 14 2014

McKeown, K., Haase, T., & Twomey, S. (2010)(d) *The Culture of End-of-Life Care in Hospital in Ireland, National Audit Report 4.*, Dublin: Irish Hospice Foundation. [Online] Available at http://hospicefoundation.ie/wp-content/uploads/2013/04/Audit-Report-4.pdf Accessed Oct 14 2014

McKeown, K., Pratschke, J.& Haase T. (2014) *Individual needs collective responses: The potential of social enterprise to provide supports & services for older people: Assessment of national business case*. Dublin: Fourth Age Trust. [Online] Available at http://kieranmckeown.ie/wp-content/uploads/2014/01/69.-Individual-Needs-Collective-Responses.-National-Business-Case-for-Social-Enterprise-Older-People-231213-L.pdf Accessed Oct 14 2014

Minister for Finance (2009) Financial Statement of Minister for Finance, Mr. Brian Lenihan, T.D., 9 December 2009. [online] Available at http://www.budget.gov.ie/Budgets/2010/FinancialStatement.aspx Accessed Oct 14 2014

Morden, N., Chang, C., Jacobson, J., Berke, E., Bynum, J., Murray, K. & Goodman, D. (2012) End-of-life care for medicare beneficiaries with cancer is highly intensive overall and varies widely. *Health Affairs* Vol. 31(4) pp.786-796.

Murray, E. (2013) *Access to specialist palliative care services and place of death in Ireland; What the data tells us. Irish Hospice Foundation, perspectives series no. 2*. Dublin: Irish Hospice Foundation. [online] Available at http://hospicefoundation.ie/wp-content/uploads/2013/06/Access-to-specialist-palliative-care-services-place-of-death-in-Ireland.pdf Accessed Oct 2 2014

Murray, E., Sweeney, C., Smyth, C. & Connolly, E. (2006) *A Baseline Study on the Provision of Hospice / Specialist Palliative Care Services in Ireland.* Dublin: The Irish Hospice Foundation. [Online] Available at http://www.lenus.ie/hse/bitstream/10147/43228/1/8208.pdf Accessed Oct 14 2014

Murtagh F, Bausewein C, Petkova H, Sleeman K, Dodd R, Gysels, M., Johnston, B., Murray, S., Banerjee, S., Shipman, C., Hansford, P., Wakefield, D., Gomes, B., & Higginson, I. (2012) Understanding place of death for patients with non malignant conditions: a systematic literature review. Final report. NIHR Service Delivery and Organisation Programme.

National Center for Health Statistics (2011) *Health United States, 2010: With Special Feature on Death and Dying.* Hyattsville, MD: National Centre for health statistics [Online] Available at http://www.cdc.gov/nchs/data/hus/hus10.pdf Accessed Oct 14 2014

National Clinical Programme for Palliative Care (2013) *National rapid discharge guidance for patients who wish to die at home.* Dublin : Health Service Executive. [online] Available at http://www.hse.ie/eng/about/Who/clinical/natclinprog/palliativecareprogramme/Resources/Rapid.pdf Accessed Oct 2 2014

National End of Life Care Intelligence Network (2010) *Variations in Place of Death in England: Inequalities or appropriate consequences of age, gender and cause of death?* [Online] Available at http://www.endoflifecare-intelligence.org.uk/ Accessed Oct 14 2014

National End of life care Intelligence Network (2011) Metadata for End of Life Care Place of Death with Cause of Death Profile. [Online] Available at http://www.endoflifecare-intelligence.org.uk/end_of_life_care_profiles/ccg_profiles Accessed Oct 14 2014

National End of Life Care Intelligence Network (2012) *Deprivation and death: Variation in place and cause of death.* [Online] Available at http://www.endoflifecare-intelligence.org.uk/resources/publications/deprivation_and_death Accessed Oct 14 2014

National End of Life Care Programme (2012) *Reviewing end of life care costing information to inform the QIPP End of Life Care.* [Online] Available at http://www.thewholesystem.co.uk/wp-content/uploads/2014/07/EoLC_QIPP_Costings_Report.pdf Accessed Oct 14 2014

National Hospice and Palliative Care Organisation (2012) *NHPCO Facts and Figures: Hospice Care in America, 2011 Edition*. Alexandria, VA: National Hospice and Palliative Care Organization. [Online] Available at http://www.nhpco.org/sites/default/files/public/Statistics_Research/2011_Facts_Figures.pdf Accessed Oct 14 2014

OECD (2013) *Health at a Glance 2013: OECD Indicators*. Paris: OECD Publishing. [online] Available at http://www.oecd.org/els/health-systems/Health-at-a-Glance-2013.pdf Accessed Oct 2 2014

OECD (2012) *Health at a Glance 2011: OECD Indicators.* Paris: OECD. Available at http://www.oecd.org/els/health-systems/49105858.pdf Accessed Oct 2 2014

Paddy, M. (2011) Influence of location on a good death. *Nursing Standard* 26(1) pp 33-36 [online] Available at http://rcnpublishing.com/doi/pdfplus/10.7748/ns2011.09.26.1.33.c8693 Accessed Oct 1 2014

Porter, M. (2009) A Strategy for Health Care Reform - Toward a Value-Based System. *The New England Journal of Medicine* Vol. 361 (2) pp 109-112.

RightCare (2011) *The NHS Atlas of Variation in Healthcare: Reducing unwarranted variation to increase value and improve quality.* [online] Available at http://www.rightcare.nhs.uk/atlas/qipp_nhsAtlas-LOW_261110c.pdf Accessed Oct 14 20014

Riolfi, M., Buja, A., Zanardo, C., Marangon, C., Manno, P. & Baldo, V. (2014) Effectiveness of palliative home-care services in reducing hospital admissions and determinants of hospitalization for terminally ill patients followed up by a palliative home-care team: A retrospective cohort study. *Palliative Medicine* Vol. 28 (5) pp 403-411

Scottish Government (2011) *Report on the Development of the Outcome Indicators for the Healthcare Quality Strategy for Scotland by the Quality Measures Technical Group.* Edinburgh: Scottish Government. [Online] Available at http://www.scotland.gov.uk/Resource/Doc/924/0118740.pdf Accessed Oct 14 2014

Scottish Government (2008) *Living and Dying Well: A National Action Plan for Palliative and End of Life Care in Scotland.* Edinburgh: Scottish Government. [Online] Available at http://www.scotland.gov.uk/resource/doc/239823/0066155.pdf Accessed Oct 14 2014

Scottish Government (2010) *The Healthcare Quality Strategy for NHSScotland.* Edinburgh: Scottish Government. [Online] Available at http://www.scotland.gov.uk/Resource/Doc/311667/0098354.pdf Accessed Oct 14 2014

Scottish Government (2011) *Living and Dying Well: Building on Progress*. Edinburgh: Scottish Government. [Online]Available at http://www.scotland.gov.uk/Resource/Doc/340076/0112559.pdf Accessed Oct 14 2014

Social Care Institute for Excellence (SCIE) (2013) *Dying well at home: the case for integrated working; SCIE Guide 48.* London: Social Care Institute for Excellence. [Online] Available at http://www.scie.org.uk/publications/guides/guide48/files/guide48.pdf Accessed Oct 1 2014

Sprung, C., Carmel, S., Sjokvist, P., Baras, M., Cohen, S., Maia, P., Beishuizen, A., Nalos, D., Novak, I., Svantesson M., Benbenishty J. & Henderson B. (2007) Attitudes of European doctors, nurses, patients and families regarding end of life decisions; The ETHICATT Study*. Intensive Care Medicine* Vol. 33 (1) pp 104-110.

Sprung, CL., Cohen, SL., Sjokvist, P., Baras, M., Bulow, H., Hovilehto, S., Ledoux, D., Lippert, A., Maia, P., Phelan, D., Schobersberger, W., Wennberg, E. & Woodcock, T. (2003) End-of-life practices in European intensive care units. The Ethicus study. *JAMA* Vol. 290 (6) pp 790-797.

Staines, A. (2010)(a) *Towards the Development of a Resource Allocation Model for Primary, Continuing and Community Care in the Health Services, Volume 1, Executive Summary*. Dublin: Dublin City University. [Online] Available at http://www.dcu.ie/news/2010/jan/ResourceAllocationDCUreport.pdf Accessed Oct 14 2014

Staines, A. (2010) (b) *Towards the Development of a Resource Allocation Model for Primary, Continuing and Community Care in the Health Services, Volume 2, Technical Report.* Dublin: Dublin City University. [Online] Available at http://doras.dcu.ie/15131/1/ram-volume2-technical-report.pdf Accessed Oct 14 2014

Stukel, T. (2011) 'Medical practice variations: Recent progress in research and *analysis' The Wennberg International Collaborative; Report of the Second Annual Conference.* London School of Economics and Political Science, September 14–16, 2011. [online] Available at http://wennbergcollaborative.org/uploads/documents/WIC2011Report.pdf Accessed Oct 15 2014

Tiernan, E., Connor, M., Kearney, P. & O' Siorain, L. (2002) A prospective study of preferred versus actual place of death among patients referred to a palliative care home-care service. *Irish Medical Journal*, Vol. 95 (8) pp.232-235.

Tolle, S., Rosenfeld, A., Virginia P., Tilden, V. & Park, Y. (1999) Oregon's Low In-Hospital Death Rates: What Determines Where People Die and Satisfaction with Decisions on Place of Death?*' Annals of Internal Medicine*, Vol. 130 (8) pp 681-685.

Tulsky, J. (2014) 'All the comforts' *Duke Magazine* July 18 [online] http://dukemagazine.duke.edu/article/all-the-comforts Accessed Sept 29

Weafer & Associates (2004) *A nationwide survey of public attitudes and experiences regarding death and dying*. Dublin : Irish Hospice Foundation. [online] Available at http://hospicefoundation.ie/wp-content/uploads/2012/04/Weafer-et-al-2004-A-nationwide-survey-of-public-attitudes-and-experiences-regarding-death-and-dying.pdf Accessed Sept 29 2014

Weafer, J. (2014) *Irish attitudes to death, dying and bereavement 2004-2014*. Dublin: Irish Hospice Foundation

Wennberg International Collaborative (2010) *Report of the First Annual Conference, London School of Economics and Political Science, September 14–15, 2010*. [Online] Available at http://wennbergcollaborative.org/uploads/documents/WIC2010Report.pdf Accessed Oct 15 2014

Wennberg J. (2010) *Tracking medicine; A researcher's quest to understand healthcare* Oxford: Oxford University Press.

Wood, C. & Salter, J. (2013) *A time and a place; What people want at the end of life.* London: Sue Ryder [online] Available at http://www.sueryder.org/About-us/Policies-and-campaigns/Our-campaigns/Dying-isnt-working/~/media/Files/About-us/A-Time-and-a-Place-Sue-Ryder.ash Accessed Sept 29 2014

World Health Organization (1946) *Constitution of the World Health Organization* [Online] Available at http://www.who.int/about/definition/en/print.html

World Health Organization (2004) Definition of Palliative Care. [Online] Available at http://www.who.int/cancer/palliative/definition/en/

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Hospice
Foundation

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The Irish Hospice Foundation
Morrison Chambers
32 Nassau Street, Dublin 2, Ireland

Telephone: + 353 (0) 1 679 3188
Fax: +353 (0) 1 673 0040
Email: info@hospicefoundation.ie

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www.hospicefoundation.ie