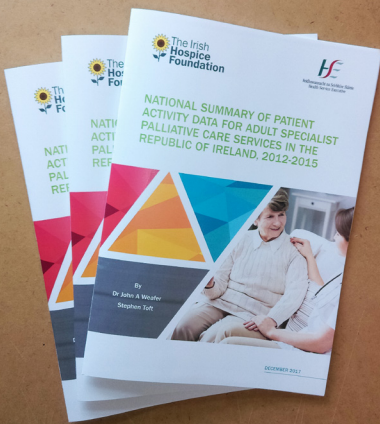


Irish Hospice Foundation

Reflections on the National Summary of Patient Activity Data for Adult Specialist Palliative Care Services in the Republic of Ireland 2012-2015



**February
2018**

Glossary

PALLIATIVE CARE

Palliative care is an approach that improves the quality of life of persons 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 spiritual¹ (WHO, 2016).

SPECIALIST PALLIATIVE CARE SERVICES

Specialist Palliative Care Services (SPC) are those services with palliative care as their core speciality and which are provided by an inter-disciplinary team, under the direction of a consultant physician in palliative medicine.

INPATIENT SPECIALIST PALLIATIVE CARE

There are ten hospices providing SPC inpatient care and one acute hospital with two dedicated SPC beds: Our Lady's Hospice & Care Services Harold's Cross (Dublin) and Our Lady's Hospice & Care Services Blackrock (Dublin); St. Francis Hospice Raheny (Dublin) and St. Francis Hospice Blanchardstown (Dublin); St. Brigid's Hospice (Kildare); Marymount University Hospital and Hospice (Cork); Milford Care Centre (Limerick); Galway Hospice; Northwest Hospice (Sligo); Donegal Hospice (Letterkenny); and Waterford Regional Hospital.

SPECIALIST PALLIATIVE CARE IN THE COMMUNITY

This is care provided to people in their normal place of residence by members of the Specialist Palliative Care Team and is available in every county. It is commonly referred to as 'Home Care'. This care refers to medical and ancillary care given to patients. The service is available in nine locations across the country.

COMMUNITY HEALTHCARE ORGANISATIONS (CHO)

Ireland is divided into nine CHO administrative areas, as follows:

CHO 1: Cavan, Monaghan, Donegal, Sligo, Leitrim.

CHO 2: Galway, Mayo, Roscommon.

CHO 3: Limerick, Clare, North Tipperary, East Limerick.

CHO 4: North Lee, South Lee, North Cork, West Cork, Kerry.

CHO 5: South Tipperary, Carlow, Kilkenny, Waterford, Wexford.

CHO 6: Dun Laoghaire, Dublin South, East Wicklow.

CHO 7: Dublin South City, Dublin South West, Dublin West, Kildare/West Wicklow.

CHO 8: Laois, Offaly, Longford, Westmeath, Louth, Meath.

CHO 9: Dublin North West, Dublin North Central, Dublin North.

¹ WHO. 2016. *WHO Definition of Palliative Care*. [online] accessed on 18 May, 2016. <http://www.who.int/cancer/palliative/definition/en/>

Executive Summary

The Irish Hospice Foundation (IHF) is a national charity which strives for better end of life care for all. This short paper comprises the IHF's reflections on the Minimum Data Set (MDS) from 2012 to mid-2016, which tracks the development of the delivery of specialist palliative care (SPC) in inpatient palliative care units (IPUs) and in the community. Although the present MDS measures service activity (quantity), rather than quality, the IHF believes that the data can help all stakeholders to understand trends over time, as well as to identify gaps in services, and can thus aid both planning and service improvement.

The IHF's analysis shows that:

- More patients are accessing SPC, necessitating the provision of more resources;
- Unequal access to specialist inpatient palliative care units persists;
- Both wait times and access levels to SPC in the community have improved;
- 'Place of Care' data highlights geographic variation and changing trends;
- The provision of SPC services to non-cancer patients is increasing;
- Data on wait times for IPUs is encouraging but it masks inequities in regions with little or no service;
- More data is needed on a range of topics, from location of discharge to bereavement contacts;
- Common coding protocols are needed;
- The 100% response rate is commendable.

While celebrating the many improvements in SPC provision which have taken place in recent years, this paper also includes the IHF's recommendations for improving the effectiveness of SPC. These recommendations are based on the organisation's reflections on the MDS findings and in consideration of other HSE reports. These include a range of suggestions for broadening and strengthening the data collected, as well as, critically, addressing the issues that the data reveal, such as:

- Eliminating funding deficits and any regional disparity in access to inpatient units in line with the new HSE Palliative Care Services, Three Year Development Framework, 2017-2019, as a matter of urgency.
- Eliminating staffing deficits: staffing ratios, originally set in 2001, require updating as part of the Department of Health commitment to update national policy, including workforce planning.
- Updating national policy on access to SPC, to include required number of beds and other services per region.
- Dealing with inequities in the length of time referred patients have to wait for SPC services.
- Resolving disparities in access to SPC for people who do not have cancer.
- Recognising officially the role of SPC inpatient and community services on relieving pressure on acute services, especially in terms of bed management.
- Improving the end of life experience of those who die in hospitals through reporting on the Minimum Dataset in acute hospitals and establishing key performance indicators for this setting.

Introduction

The Irish Hospice Foundation (IHF) is a national charity which strives for better end of life care for all. A critical part of care at end of life is provided by specialist palliative care (SPC) provided in acute hospitals, community settings and SPC inpatient units². In 2015, in partnership with the HSE and a project steering group, the IHF commissioned a report on the SPC Minimum Data Set (MDS), now in its sixth full year of collection. The report, available on www.hospicefoundation.ie and www.hse.ie/eng/services/publications/ tracks the development of the delivery of SPC in inpatient units and in the community. The IHF believes that this data can help all stakeholders to understand trends over time, as well as to identify gaps in services, so as to assist both planning and service improvement.

While the report presents an important picture, it should only be seen as a partial one. At present, MDS data is collected from community settings and specialist inpatient units only, although other SPC services will be added in the future³. Furthermore, the MDS data only measures service activity, and so is a measure of service quantity, rather than service quality. While many individual SPC services are concerned with outcome measurement to monitor quality, Ireland does not have national standardised information on either the impact that palliative care services have on patients nor on the health improvements that result from receiving the service. The IHF would very much welcome the development of this kind of outcome data.

Despite these shortcomings, the MDS data provides information which is vital for the further development of SPC services. With enhanced databases, outcome measurement, improved workforce planning and prompt reporting, all aspects of palliative care can continue to improve.

This short paper contains the IHF's informed reflections on the MDS data. It also draws on the Healthcare Pricing Office's Hospital Inpatient Enquiry data (HIPE) and HSE financial data as they apply to SPC. We hope our commentary will prove helpful to both HSE and Department of Health decision-makers, and all others who aim to improve SPC services in Ireland.

This paper covers 2012 to mid-2016. At the time of writing, complete data for 2016 was not available. Half-year data was included at the request of the SPC sector. This reflection paper is best read in conjunction with the full IHF/HSE report⁴, available on hospicefoundation.ie and on hse.ie

² This document understands inpatient units, or IPUs, to be units that provide Level Three (Specialist Palliative Care) services, as defined in the 2001 *Report of the National Advisory Committee on Palliative Care*. While inpatient units are often traditionally called 'hospices' in local communities, they are not always stand-alone hospices and may be a part of an acute hospital setting. In addition, units which may be locally called 'hospices' are not providing care to a Level Three standard. The term 'inpatient unit', therefore, is used throughout this report for all inpatient units providing *inpatient Level Three specialist palliative care*, in line with the HSE use of the term.

³ Data on SPC delivery in acute hospital services, bereavement services and children's palliative care will be available in subsequent MDS reports.

⁴ Weafer, J.A. & Toft, S. 2017. *National Summary of Patient Activity Data for Adult Specialist Palliative Care Services in the Republic of Ireland, 2012-2015*. Dublin: Irish Hospice Foundation.

WHAT THE DATA SAYS

The data illustrates significant achievements within the area of SPC, while highlighting areas which require further attention. It also raises questions about the provision of access to SPC services throughout the country. A disparity of equity in access, whereby everyone is given equal access to the full range of SPC services, is of particular concern.

Key findings are illustrated in the following infographic.

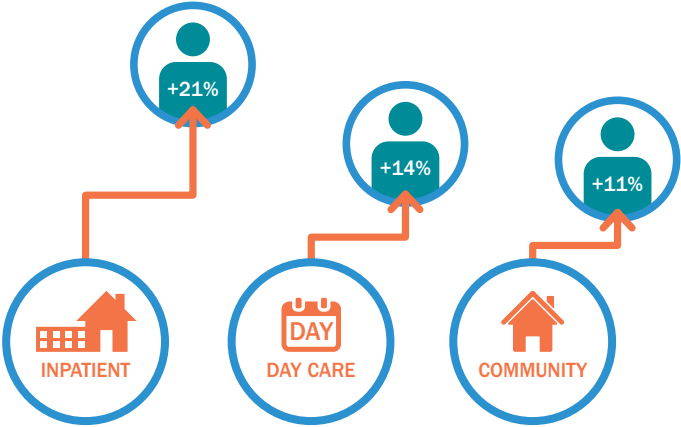
LEVEL OF INPATIENT SERVICE PROVISION BY COUNTY



Source: Palliative Care Services Three Year Development Framework (2017 - 2019), Annex D.

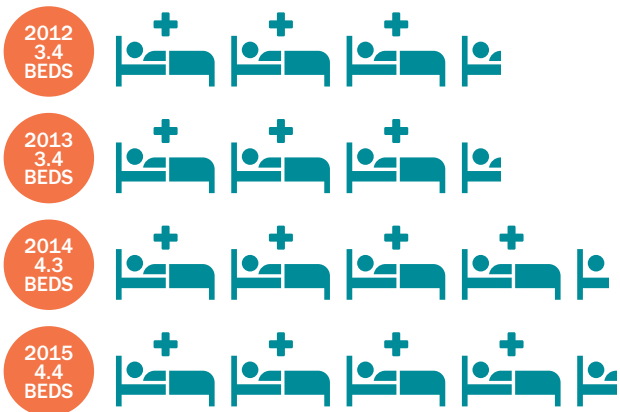
*Units are planned for Cavan/Monaghan, Louth and the Midlands, and a unit in Carlow/Kilkenny is under consideration.

INCREASE IN PATIENTS RECEIVING PALLIATIVE CARE 2012-2015



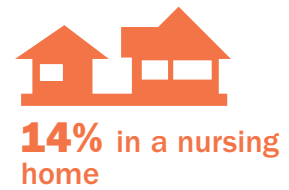
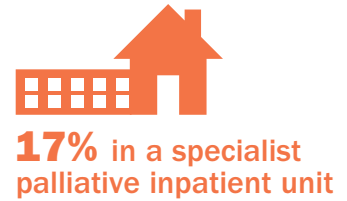
Source: National Survey of Patient Activity Data for Specialist Palliative Care Services in the Republic of Ireland, 2012-2015, Table 2.

SPECIALIST PALLIATIVE CARE INPATIENT BEDS PER 100,000 PEOPLE 2012-2015



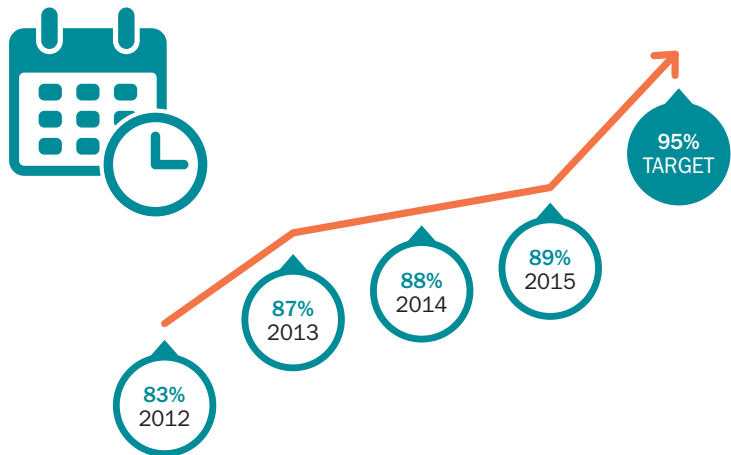
Source: National Survey of Patient Activity Data for Specialist Palliative Care Services in the Republic of Ireland, 2012-2015, Table 3.

WHERE SPECIALIST PALLIATIVE CARE COMMUNITY PATIENTS DIE 2015



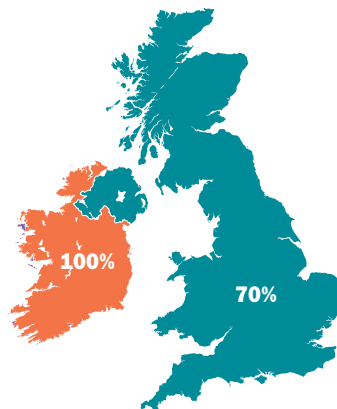
Source: National Survey of Patient Activity Data for Specialist Palliative Care Services in the Republic of Ireland, 2012-2015, Table 20.

PATIENTS WAITING SEVEN DAYS OR LESS FOR PALLIATIVE COMMUNITY CARE



Source: National Survey of Patient Activity Data for Specialist Palliative Care Services in the Republic of Ireland, 2012-2015, Table 15.

RESPONSE RATE FOR NATIONAL SURVEY OF PATIENT ACTIVITY DATA FOR SPECIALIST PALLIATIVE CARE SERVICES



Source: National Survey of Patient Activity Data for Specialist Palliative Care Services in the Republic of Ireland, 2012-2015, Background.

What the data shows

1. As more patients access SPC, more resources will be needed

Every palliative care service reported an increase in new patients between 2012 and 2015⁵. The increase was highest for inpatient units (+21%), although more patients also accessed community care (+11%) and day care services (+14%). The extended reach of palliative care across most healthcare settings is to be commended. The growth in demand will necessitate increased resources if quality and patient focus are to be maintained.

Changes in work practices (such as an increased emphasis on community) and demographic changes (such as population ageing) will increase demand further in the future. Now is the time to update national policy on SPC in order to ensure that demand can be met. We understand the Department of Health is committed to updating national policy under the recently published Three-Year Palliative Care Development Framework⁶.

2. Unequal access to specialist inpatient palliative care services persists

The National Palliative Care Policy (2001)⁷ recommended a ratio of 10 inpatient unit beds per 100,000 population. According to the MDS data, no region has achieved this target. There is a wide range in the ratio of inpatient beds per 100,000 population across the country, from a high of 7.4 in CHO 3 (Clare, Limerick, North Tipp) to an unacceptable 0.4 in CHO 5 (South East). Inpatient units under construction/expansion in Kerry, Mayo, Waterford, Wicklow, Kildare and Galway will go some way to improving the situation.

Critically, there are still no inpatient beds in CHO 8 (Midlands and North East), and although a commitment is noted in the Three Year Framework⁸, there are no clear plans to rectify this situation, despite the intention for development being agreed in national policy in 2001, in 2009 and again in 2017. The persistence of such severe inequity in access to inpatient SPC beds is unacceptable.

3. Staffing ratios, set in 2001, require updating

The SPC model of care has evolved since 2001. The growing trend in discharges from inpatient units into the community shows a greater emphasis on enabling patients to live in their preferred place of care – often their own home. This is in line with Government policy to provide more care in the community⁹.

The shift in emphasis towards community necessitates a change in service provision. People are able to die comfortably at home only if their carers can receive appropriate support. The staffing ratios outlined in the 2001 policy need to be updated, enabling more care to be delivered through SPC in the community. The HSE three-year development framework for palliative care services¹⁰, makes this recommendation. This work needs to become a priority as soon as possible.

⁵ National Survey of Patient Activity Data for Specialist Palliative Care Services in the Republic of Ireland 2012-2015, Table 2.

⁶ HSE. 2017. *Palliative Care Services Three Year Development Framework (2017 – 2019)*. Dublin: Health Service Executive.

⁷ Department of Health & Children. 2001. *Report of the National Advisory Committee on Palliative Care*. Dublin: Department of Health & Children.

⁸ HSE, op. cit.

⁹ For example, the Programme for Government 2016 prioritises 'a decisive shift of the Health Service to Primary Care with the delivery of enhanced Primary Care in every Community'. Also, the Sláintecare Report, produced by the Oireachtas Select Committee on the Future of Healthcare, want to see all aspects of healthcare accessible 'as close to home as possible'.

¹⁰ HSE Primary Care Division (2017) *Palliative Care Services: Three Year Development Framework (2017 – 2019)*. Dublin: Health Service Executive.

4. Big improvement has occurred in wait time and access to SPC in the community

Access to SPC in the community (palliative homecare) has improved greatly in recent years, with 88% of patients being seen within seven days in 2015, up from 83% in 2012. Increased resources provided last year should help to achieve the HSE's 2016 key performance indicator (KPI) of 95% of patients who are referred to SPC being seen within seven days. Seven of the nine CHO regions have already achieved the target.

However, there is still disparity between CHOs about the number of community visits as well as the availability of both health professionals and SPC community nurse specialists in each CHO. Without accurate staffing numbers or in-depth information on localised practice, it is impossible to comment on this data, since trends could be the result of many possible variations in service, such as:

- Differences in staffing ratios: with staff shortages and attrition, employment embargos and maternity leave, are there enough staff to meet community demands to the required standard?
- Differences in service definition: is it service over seven days or five days; what is regarded as the 'first visit'; do different diagnoses result in different approaches?
- Differences in coding: is each of the CHOs coding cases in the same way; when does wait time start?
- Differences in support arrangements and type of service being provided by different professionals.

The forthcoming National Clinical Programme for Palliative Care Model of Care¹¹ from the National Clinical Programme for Palliative Care, should help to standardise practices in SPC nationally, on a seven-day basis. At present, not all services are provided on this basis, and there is no comparison of service outcomes. While this area is notoriously difficult to measure, it seems reasonable to say that greater geographical equity and consistency of service are needed.

These issues need to be explored with a view to addressing deficits and ensuring that patients get timely and consistent access to services. Furthermore, as stated earlier, a national policy on staffing ratios for all healthcare professionals in the community needs to be established, using the National Clinical Programme for Palliative Care Model of Care as a reference for quality.

The Seven-Day metric itself requires further consideration. The HSE's KPI requires that 95% of patients referred to homecare are to be seen within seven days. This is a welcome starting point, but it may require a more nuanced approach to ensure that it is reflecting varying levels of urgency. In addition, it would be useful to include the number of people who receive SPC in residential care settings.

Overall, around 42% of community SPC patients die in their own homes. The percentage of community palliative care patients dying in acute hospitals dropped from 19% in 2012 to 16% in 2015. This ratio varies widely across regions¹², from a low in 2015 of 5% in CHO 3 (Limerick, Clare, North Tipperary) to over 19% in CHO 6 (Dublin South East, Dun Laoghaire, Wicklow), CHO 7 (Dublin South, Dublin South West, Kildare, West Wicklow) and CHO 8 (Midlands, North East). These findings concur with our report 'Enabling More People to Die at Home'¹³ which recommended introducing 'place of death' as a national quality indicator as well as strengthening the services that enable people to die at home.

¹¹ In development as part of the HSE's National Clinical Programme for Palliative Care.

¹² Unpublished data provided to IHF.

¹³ IHF. 2014. *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. Dublin: Irish Hospice Foundation. [online] accessed on 30 May, 2016. <http://hospicefoundation.ie/wp-content/uploads/2014/12/Enabling-More-People-to-Die-at-Home1.pdf>

5. Place of care prior to admission to inpatient unit

Between 2012 and 2015, over half of new patients to inpatient units came there from their usual place of residence (own home or nursing home). Encouragingly, at over 2,600 in 2015, the rate of admittance from an acute hospital rose to 47% (from 44% in 2012). This is in stark contrast to the UK, where only 28% of people admitted to inpatient units come from acute hospitals¹⁴. The high rate of referral from acute hospitals demonstrates the importance of inpatient units in meeting patient preferences, as well as alleviating the pressures faced by the hospital sector. This key role should receive due recognition and support in policy on acute hospital services.

Not all people approaching end of life need SPC in an inpatient unit. Information is, therefore, also needed on achievement of the rapid discharge protocol, fast-tracking to Fair Deal packages (to residential care settings) and for homecare packages for those approaching end of life.

Not all patients can be discharged from the acute hospital setting. Recent data from HIPE show that, in 2016, nearly 200,000 bed days were occupied by over 11,000 patients who died in an acute hospital, with an average length of stay of nearly 18 days. This means that, over a year, the equivalent of 545 acute hospital beds are occupied on a full-time basis by patients nearing end of life – the size of a large Level 4 acute hospital. Also of interest to this issue is data from Scotland, where recent census and mortality studies showed that almost 30% of hospital inpatients had died by the time of 12-month follow-up and that, of these, 9.3% died during the index (taken at the time of the census) admission, and this accounted for 1,001 (32.3%) of all 3,098 deaths within the 12-month follow-up period. This clearly shows that death and dying are a core part of acute hospitals' work and so need to be planned for accordingly. To this end, we look forward to the addition of acute hospital setting data to the MDS. This will show how many of acute patients receive SPC at the end of their life. The further development of initiatives such as the IHF/HSE Hospice Friendly Hospitals programme and programmes of support in emergency departments can ensure that end of life, palliative and bereavement care become central to the everyday business of acute hospitals.

The move, by the HSE, to include a KPI measurement for the rapid discharge protocol, as well as the HSE decision to include metrics concerning aspects of palliative care provision in acute hospitals in their 2018 statistics, are both very welcome¹⁵. As previously recommended by the IHF, a KPI on dying at home and in acute hospitals would also be useful¹⁶.

7. The provision of SPC services to non-cancer patients is increasing

The proportion of new non-cancer patients receiving SPC inpatient care rose from 11% to 14% from 2012 to 2015. It is reassuring to see non-cancer patients gain access to inpatient units in a similar proportion to the UK. The level of access, however, to inpatient units for those with diseases other than cancer varies throughout Ireland, demonstrating differences in referral patterns and inequity in provision. Greater equity is needed since people, no matter what their diagnoses, should be able to expect equal access to SPC, no matter where they live.

¹⁴ NCPC / PHE / Hospice UK (2015) *National Survey of Patient Activity Data for Specialist Palliative Care Services MDS Inpatients Report for the year 2013-2014*. London: NCPC, Public Health England & Hospice UK. [online] accessed on 30 May, 2016. <http://www.ncpc.org.uk/sites/default/files/MDS-2013-14-Inpatients-report.pdf>

¹⁵ HSE National Clinical Programme for Palliative Care Clinical Strategy & Programmes Directorate. 2016. *National Rapid Discharge Guidance for Patients Who Wish To Die At Home*. Dublin: Health Service Executive. [online] accessed on 25 September, 2017. <http://hse.ie/eng/about/Who/cspd/ncps/palliative-care/resources/rapid-discharge-guidance/>

¹⁶ McKeown, K. (2014) 'Key Performance Indicators on Place of Care & Place of Death in the Health Service in Ireland' in IHF *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* (pp.18-79). Dublin: Irish Hospice Foundation.

The proportion of non-cancer patients in receipt of SPC in the community is increasing each year. In 2015, 29% of new patients in the community had a non-cancer diagnosis¹⁷. The equivalent UK community rate (18%) is substantially lower. This may mean that Irish community settings offer greater identification and recognition of the SPC needs of those with diseases other than cancer, but further investigation would be required.

8. Encouraging data on wait times for inpatient care mask inequities in areas with little or no service

It is encouraging to note that the vast majority (98%) of patients referred to inpatient units¹⁸ were admitted to an inpatient unit within seven days¹⁹, and that 88.5% of patients referred for community services were seen in seven days also.

The figures relating to inpatient units need to be treated with caution, in that they do not signify the level of inpatient care on offer. CHO 8 (Midlands) accurately reports 'Not Applicable' due to the absence of inpatient unit beds in this region. However, the 100% achievement of all patients being seen in the inpatient unit in CHO 5 (South East region) and 98% in CHO 1 (North West region), relates to two SPC inpatient beds in CHO 5, and eight in Sligo, eight in Donegal, but none in Cavan / Monaghan or in Leitrim. The overall figures, as they stand, do not provide a true picture of actual referral on the ground and, to that extent, such reporting may give an incorrect overall picture. It is essential that MDS data reflect *real* access to *actual* services and whether they are meeting demand; for this metric, it might be more useful if this data was reported by individual institutions and in actual days. For example, how many institutions achieve access within three days? How many patients in each get access within one week? How many are triaged from point of referral? How many patients who are referred decide not to avail of a place or defer access to services? The reasons for longer delays could then be queried and addressed. Measurements such as these, which form part of the current HSE review of MDS metrics, are greatly needed, and can be used to support improvements in service delivery.

9. Location of discharge

It is useful to know that, in 2015, almost one-third (31%) of patients, having been seen in an inpatient unit, went home once their symptoms were managed. This is important in the context of patients' usual wish to remain at home. It may also be illuminating information about the timeliness of referral (since the sickest patients are least likely to be able to return home). This would warrant further exploration with a view to earlier referral to inpatient units, so as to allow the option of returning home with adequate supports.

10. Data on nursing homes

The data on nursing homes warrants further investigation; in 2015, approximately 14% of community SPC patients died in a private nursing home, with a further 5% dying in an intermediate bed in a community setting. This indicates that a level of SPC is being provided in nursing homes by SPC community teams. Only 1% of patients from an inpatient unit, however, are discharged into a private nursing home²⁰ and private nursing homes are not listed as a place of care prior to entry into an inpatient palliative care unit²¹, most likely as percentages are so low. These trends warrant further investigation as it may indicate problems in assessing nursing home beds for patients who could be discharged from inpatient units.

¹⁷ National Survey of Patient Activity Data for Specialist Palliative Care Services in the Republic of Ireland 2012-2015, Table 17.

¹⁸ This is called the 'seven-day wait time' and is the percentage of patients seen within seven days of referral to a service.

¹⁹ National Survey of Patient Activity Data for Specialist Palliative Care Services in the Republic of Ireland 2012-2015, Table 4.

²⁰ *ibid*, Table 11.

²¹ *ibid*, Table 8.

11. Outstanding measures and common coding protocols

The critical issue of unmet urgent need is not reflected in the MDS data. It is important to know about patients who are referred to a service but who die before it can be provided. These may be patients in acute care who die before they can be admitted to an inpatient unit or go home to access community services. Alternatively, they may be people in the community with complex symptoms, who receive inadequate care and die before reaching SPC teams, in addition to those who were not referred at all. None of these people are currently counted.

The UK MDS database includes the following, which would be useful in an Irish context:

- bereavement contacts (this is under development);
- disaggregation of non-cancer diagnoses;
- access to Day Care (at present, Irish MDS data on this issue is scant, and several CHOs do not provide Day Care services).

Night nursing is often critical for enabling patients to stay in their own homes. The night nursing service²² currently funded primarily by charities, should be integrated with the community SPC service and included in MDS metrics.

A final issue concerns some uncertainty regarding coding, despite best efforts to standardise this. Continuous refinement of protocols by providers and the HSE would assist and standardise data collection and reporting.

12. Regional differences in the allocation of the palliative care budget

The graph below, showing the HSE spend on Palliative Care per head of population, is extrapolated from the HSE Management Data Report December 2016²³ which shows actual spend in Palliative Care²⁴ and the 2016 Census population data.

While the data is presented for 2016, it reflects trends seen by IHF in other years. The graph illustrates enduring inequity in SPC budget allocation across regions. CHO 3 has almost reached the recommended estimate under the NACPC report²⁵, with CHO 9 still falling short by nine beds. Plans are in place to develop services in Waterford (CHO 5), Galway (CHO 2), Wicklow and Dublin (CHOs 6 and 7), Kerry (CHO 4), Mayo (CHO 2) and Sligo (CHO 1). In CHO 8 (Laois, Offaly, Longford, Westmeath, Louth and Meath), budget allocated is very low and services are significantly under-developed.

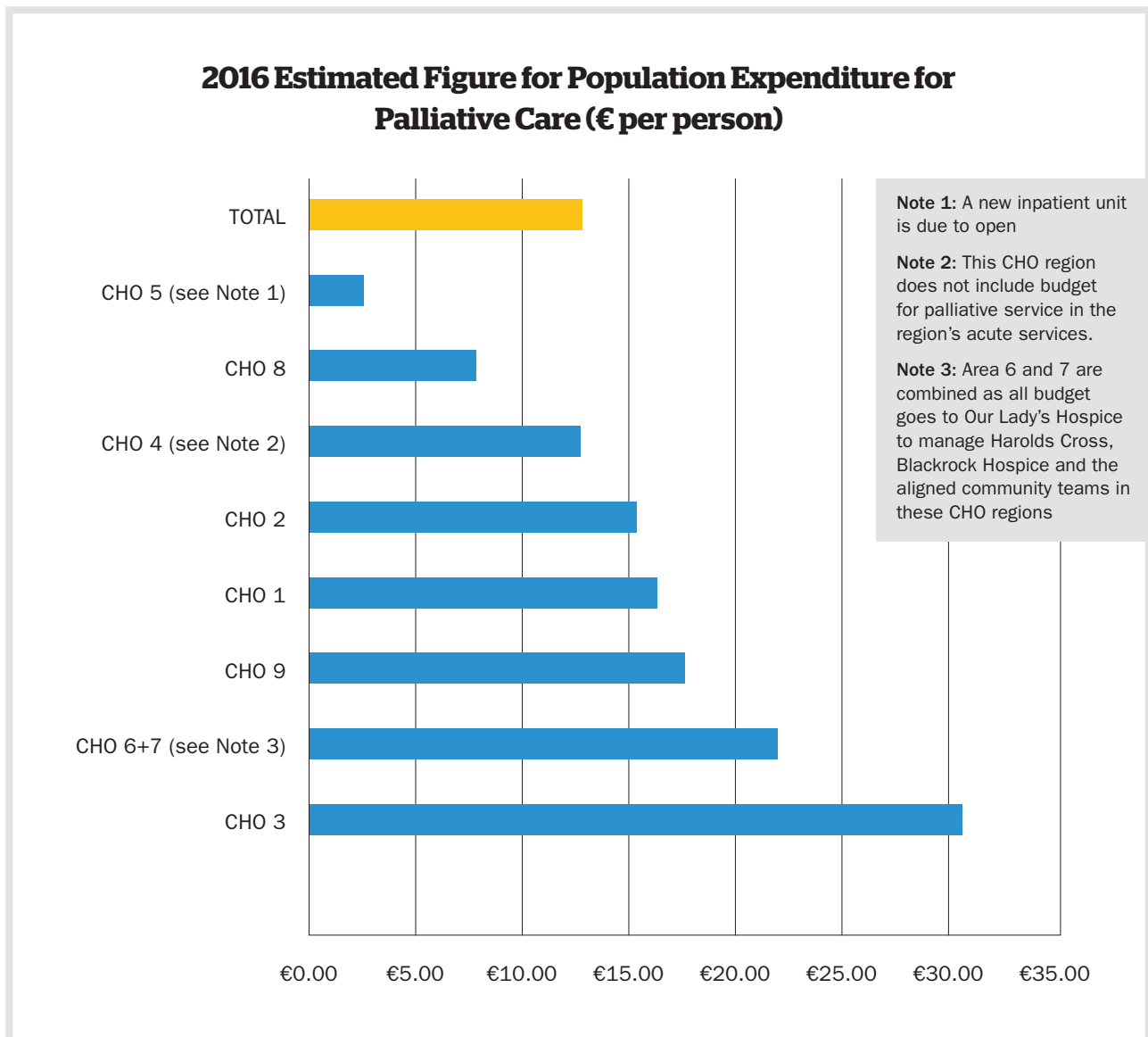
It should be noted that this does not reflect other sources of income that support these services, such as voluntary fundraising contributions.

²² The night nursing service is comprised of the IHF's *Nurses for Nightcare* service (for people with diseases other than cancer; in 2016, it reached more than 500 people) and with the Irish Cancer Society's night nursing service (for people with cancer).

²³ HSE's Performance Assurance Report (PAR). [online] accessed on 25 September, 2017. <http://www.hse.ie/eng/services/publications/performance-reports/>

²⁴ There are caveats in the data, in that some areas also include an allocation for chronic illness and there are variations in how budgets are allocated, with some areas being more reliant on charitable fundraising to fund homecare teams.

²⁵ Department of Health & Children. 2001. *Report of the National Advisory Committee on Palliative Care*. Dublin: Department of Health & Children.



13. 100% response rates offer robust data

The 100% response rate to the *National Survey of Patient Activity Data for Specialist Palliative Care Services in the Republic of Ireland, 2012-2015* is much higher than that achieved in the UK (around 70%). This is a very positive reflection on the sector, demonstrating its commitment and guaranteeing robust data. We commend Irish SPC services, and encourage their continued commitment.

At present, the HSE, along with SPC providers, is reviewing the MDS data metrics, with a view to honing and refining the measures used, and to developing outcome data. IHF welcomes this development, which can only strengthen understanding and delivery of SPC. We hope that the review will be completed swiftly, so that more MDS data can become available for public analysis.

Recommendations

The IHF welcomes the release of patient activity data for adult specialist palliative care services and, based on its analysis of the data, makes the following recommendations:

1. Reporting

- Respondents should be encouraged to maintain the 100% response rate.
- As well as publishing monthly performance reports on the main measurements, the HSE should:
 - complete its review of measurements in a short timeframe
 - ensure a prompt release of data
 - report annually to the public on the data findings
 - articulate clearly how service developments are linked to, and influenced by, evidence provided by MDS data
 - adapt the MDS so that, over time, the universal health identifier can track access by individual patients across settings.
- The HSE should develop ways of gathering standardised outcome data for SPC services. Quality, impact and outcomes are essential measurements of service viability and success.
- Data should be collected on the volume and type of SPC care provided in all residential care settings.
- As well as introducing data collection on this topic in the acute setting, the HSE should consider:
 - introducing national and regional/site-specific metrics on dying in acute hospitals and at home (available through CSO datasets)
 - developing an indicator on the use of the Rapid Discharge protocol²⁶
 - developing indicators which will trigger mechanisms for fast-tracking access to homecare packages and Fair Deal for patients with palliative care needs.

2. Service gaps and disparity

- As part of the timely implementation of the HSE Three-Year Development Framework, immediate support should be provided to achieve national inpatient bed policy ratios, the enduring disparity in access to SPC inpatient units should be rectified as a matter of urgency. This is of particular concern in CHO 8 (Midlands and North East) where development plans remain unclear.
- As the volume of new patients continues to increase, there is a need for a commensurate increase in staffing and resources. Staffing deficits need to be rectified, with priority given to areas without an inpatient unit. Workforce planning and budgetary projections for both inpatient unit and community/homecare services should respond to increased service use, using the forthcoming SPC model of care as guidance.
- Each CHO should be resourced to reach the same level of provision. In particular, funding deficits for CHO 8 should be addressed as a matter of urgency. Those with strong services, however, should not be effectively penalised for their relative success.

²⁶ Integrated Care Guidance: A practical guide to discharge and transfer from hospital [online] accessed on 25 September, 2017. <http://www.hse.ie/eng/about/Who/qualityandpatientsafety/safepatientcare/integratedcareguidance/Integrated%20Care%20Guidance.pdf>

3. Policy on service provision

- National policy on access to SPC, especially inpatient unit and community services, should be updated as part of the proposed revision of the Report of the National Advisory Committee on Palliative Care. As part of this, clear policy guidance is also needed on workforce numbers.

4. Wait times

- Those areas which do not achieve the target of 95% of referred patients seen within seven days should explore reasons for this and find solutions, so as to ensure equity of practice and access. These solutions will move services towards standardised provision throughout the country. Greater examination of the data needs to explore differences in access.
- The current practice of reporting wait times by CHO area masks the inequalities that occur in particular counties. As more nuanced metrics would be required to highlight this, metrics highlighting the role of individual institutions are required.
- HSE indicators for inpatient units and community SPC services should reflect the differing urgency of patients' SPC needs.

5. Role recognition

- While it is acknowledged in the Three-Year Development Framework that SPC inpatient and community services relieve pressure on acute services (especially in terms of bed management), this must now be realised in the planning, resourcing and development of services. This will enhance quality and choice, and ensure focus on those with the most complex symptoms.

6. End of life in acute hospitals

- As stated in the Three-Year Development Framework, there is a need to develop, resource and support the Hospice Friendly Hospitals programme in order to provide appropriate services to the substantial cohort of people who die in acute hospitals.

7. SPC for patients with non-cancer diagnoses

- Despite the optimism of the Three-Year Development Framework, the existing disparities of access between cancer patients and non-cancer patients, and differences in referral patterns, need continued examination by the clinical care programme, and solutions to counteract those disparities need to be implemented.

The MDS offers very useful information on activity levels across all SPC services. This first composite national report of activity reveals interesting trends and it demonstrates that activity in the sector is rising each year. This increase in activity will require more resources if demand is to be met.

Further development of the MDS dataset, timely release of the data and further development of outcome measures in relation to the new model of care will help to measure quality, as well as activity.

IHF commends all those who have championed this project, and who continue to strengthen it.

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