

National Survey of Patient Activity Data for Specialist Palliative Care Services



**Minimum Data Set (MDS)
Summary Report for the year 2014-15**

About the National Council for Palliative Care

The National Council for Palliative Care (NCPC) is the umbrella charity for all those who are involved in providing, commissioning and using palliative care and hospice services in England, Wales & Northern Ireland.

THE
NATIONAL
COUNCIL FOR
PALLIATIVE
CARE

Our vision is that everyone who has palliative care needs or is approaching the end of life, dying or bereaved should receive the high quality care and support they need, where and when they need it. We promote the extension and improvement of palliative care services for all people with life threatening and life-limiting conditions and promote palliative care in health and social care settings across all sectors to government, national and local policy makers. For further information or to subscribe to NCPC visit www.ncpc.org.uk

About The National End of Life Care Intelligence Network

The National End of Life Care Strategy, published in 2008, pledged to commission a National End of Life Care Intelligence Network (NEoLCIN) to improve the collection and analysis of national data about end of life care for adults in England.



Public Health
England

This is with the aim of helping the NHS and its partners commission and deliver high quality end of life care in a way that makes the most efficient use of resources and responds to the wishes of dying people and their families. Established in 2010, NEoLCIN plays a vital role in supporting the comprehensive implementation of the strategy. On 1st April 2013 NEoLCIN became part of Public Health England, an executive agency of the Department of Health.

The NEoLCIN website is www.endoflifecare-intelligence.org.uk
Public Health England's website is www.gov.uk/phe

About Hospice UK

Hospice UK is the national charity for hospice care. We champion and support the work of more than 220 member organisations that provide hospice care across the UK, so that they can deliver the highest quality care to people with terminal or life-limiting conditions and support their families.



Hospice UK supports the breadth, dynamism and flexibility of modern hospice care, by: influencing Government and decision makers; improving quality of care through the sharing of good practice; and providing resources, training, education and grant programmes.

We work collaboratively with our members to support their vital work and to create a stronger voice for hospice care in the UK. We also support the development of hospice and palliative care worldwide. Hospice UK's website is www.hospiceuk.org

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Foreword

It is a pleasure once again to write the foreword for this report on the Minimum Data Set for Specialist Palliative Care (MDS). The MDS remains the only source of data about the specialist palliative care being provided to dying people and those who are important to them, in England, Wales and Northern Ireland. This report summarises important information on the care provided by hospices, hospital palliative care teams and other specialist palliative care services such as individual community teams and outpatient clinics across different settings.

The findings within this report may be useful to a wide range of audiences and stakeholders, including commissioners of palliative care services, regulators, policy makers and those driving service development, improvement, and staff directly giving care. This overview report complements the individual reports provided to each service that submits data to the MDS collection which should help service providers understand their own services, patient groups and performance and look at these relative to others.

The data in this report can be used to inform thinking on improving services, extending access to care and developing new models of care. I urge all hospices, hospital palliative care teams and other providers to commit to collecting and using data to improve quality of care.

Last year for the first time, the MDS report was presented with historical trends to demonstrate change over time. Presenting data in this way allows a greater interpretation nationally and is particularly useful for providers both to monitor trends over time and to use information to support continuous improvement.

I would like to finish by thanking the organisations who have submitted information for the Minimum Data Set, and to the National Council for Palliative Care, Hospice UK and Public Health England, whose work enables the collection and analysis of this data that provides insights into the care of the people and their families who need specialist palliative care in England.

Professor Bee Wee

National Clinical Director for End of Life Care for NHS England

1. Background

The Minimum Data Set (MDS) was developed in 1995 by the National Council for Hospice and Specialist Palliative Care Services (now the National Council for Palliative Care) in association with the Hospice Information Service at St. Christopher's Hospice, London. Twenty years ago, in 1996, its use was commended to the NHS by the Department of Health in Executive Letter 96(85).

The aim of the MDS is to provide good quality, comprehensive data about hospice and specialist palliative care services on a continuing basis. This data can be used on a variety of levels to inform:

- Service management
- Service monitoring and audit
- Development of local palliative and end of life care strategy and service planning
- Commissioning of services
- Development of national policy

The MDS supports the implementation of national initiatives to develop palliative and end of life care in England, Wales and Northern Ireland. For example, the dataset was used to inform the work of the Palliative Care Funding Review, which reported in the summer of 2011.

Full trend analysis, setting by setting, is available in the associated reports which can be found on NCPC's website www.ncpc.org.uk

2. Methods

Data collection

A total of 1,372 specialist palliative care services were invited to take part in the most recent Minimum Data Set survey. Specialist palliative care services are provided both within the NHS and across a wide range of voluntary sector organisations including hospices, both inpatient and community services. The data collected from hospices and across the NHS is aggregated and it includes: the number of people seen by a service; their primary diagnosis, ethnicity and age; length of care/stay; hours of operation; bed availability; location prior to or after care; and location of death. Currently 70% of the MDS activity reported comes from the hospice sector.

Service types included are:

- **Inpatients:** patients who are admitted to a designated specialist palliative care unit
- **Day Care:** service provided by a specialist palliative care day therapy centre
- **Community Care:** service provided by professional members of a specialist palliative care service to patients in their place of residence
- **Hospital Support:** service provided by a specialist palliative care team working in a hospital setting

- **Bereavement Support:** contacts with the bereaved who are relatives or carers of a deceased patient and who need extra support
- **Outpatients:** a patient having an individual appointment to see a specific member of a multi-professional palliative care team (e.g. doctor, social worker, physiotherapist)

Organisations received the MDS data collection forms and guidance in March 2015 and had two months to complete and return their submission. Support was provided to all organisations throughout the data completion period, which was extended until the end of July, in line with previous years. Support included telephone and e-mail follow-up and proactive engagement with organisations to encourage them to make submissions. Once received, data was quality checked, removing any anomalous data from each section (e.g. where a figure appeared to be far higher or lower than a previous submission by that service). No organisational returns were removed completely from analysis.

801 draft service-level reports were generated and sent to all submitting providers in September 2015. Further corrections were then received from providers, and the database was correspondingly updated. Final service-level reports were generated again and sent to providers in November 2015.

It should be noted that the design of the MDS survey does not identify people seen by more than one specialist palliative care service; for example the same individual might receive care from inpatient, day care and community care services. In practice this may be true for many people, and so it is not possible to use MDS data to estimate the total number of people seen by specialist palliative care services in England, Wales and Northern Ireland. The survey can estimate the minimum number of people seen by each type of specialist palliative care service; these are shown in Figure 1.1. The group of services completing MDS varies slightly each year due in part to service changes and therefore response rates may change from year to year. This should be taken into account when interpreting trends.

Response rate

The MDS database provides a national resource to identify the numbers and locations of specialist palliative care services. There is no central registry of specialist palliative care services, which sit in both the voluntary and statutory sector. The MDS database is based on the Help the Hospices (now Hospice UK) directory which ceased updating in 2012. Constant steps are taken to ensure that the MDS database is as up to date as possible. For example, the database is regularly checked against lists held by other organisations such as the Care Quality Commission and the National Association for Hospice at Home, and there is monitoring of publications and newsletters such as e-Hospice for announcements about new services.

However, services may merge for the purpose of data submission, see management responsibility change from one organisation to another, or cease operation without notifying NCPC. In addition, where NCPC holds only one contact for an organisation and that person leaves without providing an alternative contact, identifying the person within that organisation who should take on completion of the MDS remains a key priority.

Significant work has been undertaken in the last two years to ensure the MDS database is as up to date as possible as well as increasing engagement with specialist palliative care providers, and consequently the % of services who have never returned data has decreased:

% of services who have never submitted data	Inpatients	Day Care	Community Care	Hospital Support	Bereavement Support	Outpatients
2012/13	14%	17%	37%	36%	36%	37%
2013/14	11%	17%	34%	33%	35%	32%
2014/15	8%	12%	22%	30%	29%	27%
2015/16 (as at July 2016)	4%	7%	19%	25%	26%	24%

Table 1.1: Percentage of services never returning data

With the above caveats about database completeness, Table 1.2 below shows the overall response rate to MDS by service. At an overall organisation level, the response rate was 66% with 286 out of 435 organisations submitting data.

The difference between organisational and service-level response can be explained thus: an organisation may only send data for two services where the database reflects they run four services. This therefore counts as 1 organisational return (1 of 1, 100%) but only a 50% service return (2 of 4). This may be because the data for a particular service is inaccessible to the person sending in returns, because the service no longer exists, or because of resource pressures on completing services meaning they cannot send in complete data. In total, 801 services sent in data in 2014/15.

2014/15 Service setting	Number of services responding				All services on database	Estimated service response rate
	England	N Ireland	Wales	Total		
Inpatient	115	5	8	128	181	70%
Day Care	112	4	10	126	192	66%
Community Care	155	3	12	170	261	64%
Hospital Support	114	6	11	131	230	56%
Bereavement Support	97	3	6	106	245	43%
Outpatients	128	5	7	140	263	52%
Services Responding	721	26	54	801	1,372	66%
All services on database	1,252	45	93	1,372		
Country Response rate (%)	59%	57%	58%	58%		

Table 1.2: Number of services returning data 2014/15

Table 1.3 shows the 2014/15 survey responses were in general fewer in number than previous years. This may have been in part a result of the anticipated roll out of a proposed Specialist Palliative Care Dataset (SPCD)¹. Funding for national roll out of the SPCD has not been made available and therefore MDS currently remains the only nationally collated summary information on the provision of specialist palliative care.

Service setting	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14	2014/15
Inpatient	138	142	144	140	144	129	128
Day Care	152	149	146	141	141	134	125
Community Care	191	189	183	179	183	183	170
Hospital Support	154	145	145	140	127	136	130
Bereavement Support	137	131	134	130	128	115	106
Outpatients	166	155	156	151	151	149	140

Table 1.3: Number of services returning data to MDS surveys 2008/09 to 2014/15

¹ <https://www.gov.uk/government/publications/improving-palliative-care-data-collection-joint-statement-from-phe-and-nhs-england>

Service or Team	NHS Services responding	Voluntary services responding	Total Patients seen	Proportion % of total known services
Inpatient beds	21% (27)	79% (101)	36,164	70%
Outpatient Clinics	38% (53)	62% (87)	43,801	64%
Day Service	17% (21)	83% (104)	15,966	52%
Community Teams	34% (63)	66% (107)	126,047	64%
Hospital Teams	87% (113)	13% (17)	97,385	55%

Table 1.4: Response rate across setting by type and patient attendance. 2014/2015 return

Data Quality

Ensuring consistency and completeness of returns is an essential aspect of working for continuous improvement in data quality. Currently, the basic demographics have not been reported for many patients.

Across all settings age is missing for 5% of cases reported in the survey. This varies by setting; age is unrecorded for 8% of people reported in Hospital Support and 5% for Community Care. For other settings (Inpatient, Day Care and Outpatient) 1.5% of age data is unrecorded.

Similarly, gender is unrecorded for 5% of cases in the survey. In Day Care, Community Care and Hospital Support settings over 5% of data describing gender is unrecorded. The Inpatient (2%) and Outpatient (0.5%) settings are significantly better in this regard.

Diagnosis data is missing for 12% of people reported in the survey. The settings vary from Community Care (14%) to Day Care and Hospital Support (12%), Outpatient (11%) and Inpatient (6%).

3. Who is receiving Specialist Palliative Care services?

Numbers of people seen

The number of people reported as being seen in each setting has remained broadly stable, although Hospital Support services have seen an increase from 74,218 in 2008/09 to 97,783 in 2014/15 despite the number of services reporting dropping from 154 in 2008/09 to 130 in 2014/15.

Community Care has consistently seen more people than other settings – over 125,000 in 2014/15. Table 1.3 in the previous section shows the number of Community Care services responding to MDS was lower in 2014/15 (170) than in 2013/14 (183); this may explain the apparent drop in people seen by Community Care in the most recent survey.

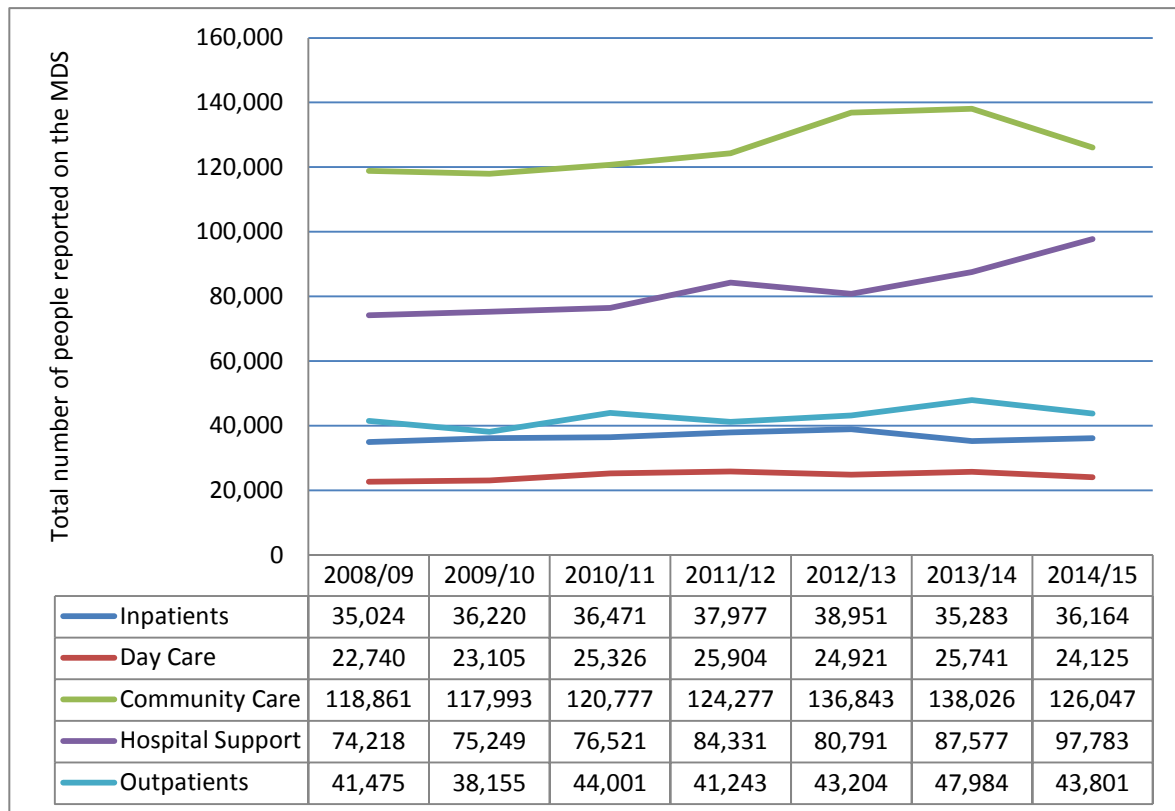


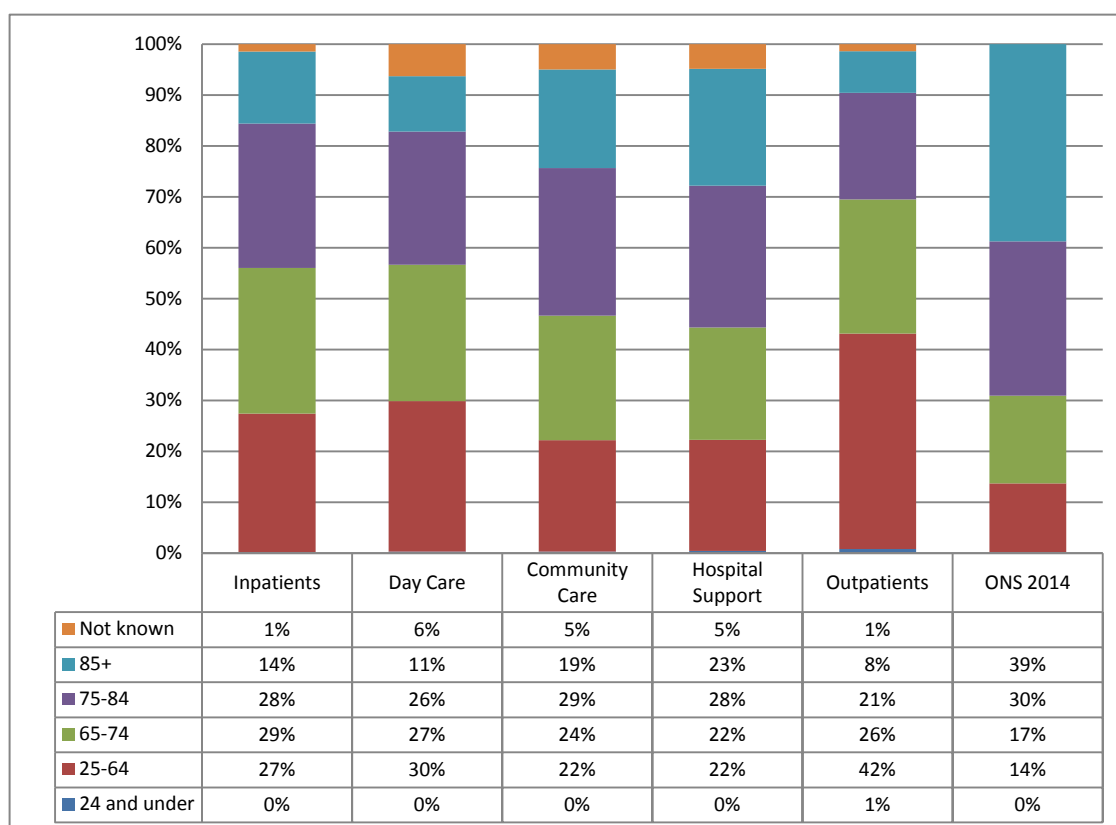
Figure 1.1: Total number of patients seen in each setting

Ethnicity

All specialist palliative care service providers are urged to ensure they prioritise data collection including people’s ethnicity. Inequalities in access to end of life care, including by ethnicity, are a significant issue and specialist palliative care services can help address this through robust data collection. Ethnicity data collection is still incomplete in every setting, with the poorest quality data found in Community and Outpatients settings (22% of ethnicity unrecorded).

Age of service users

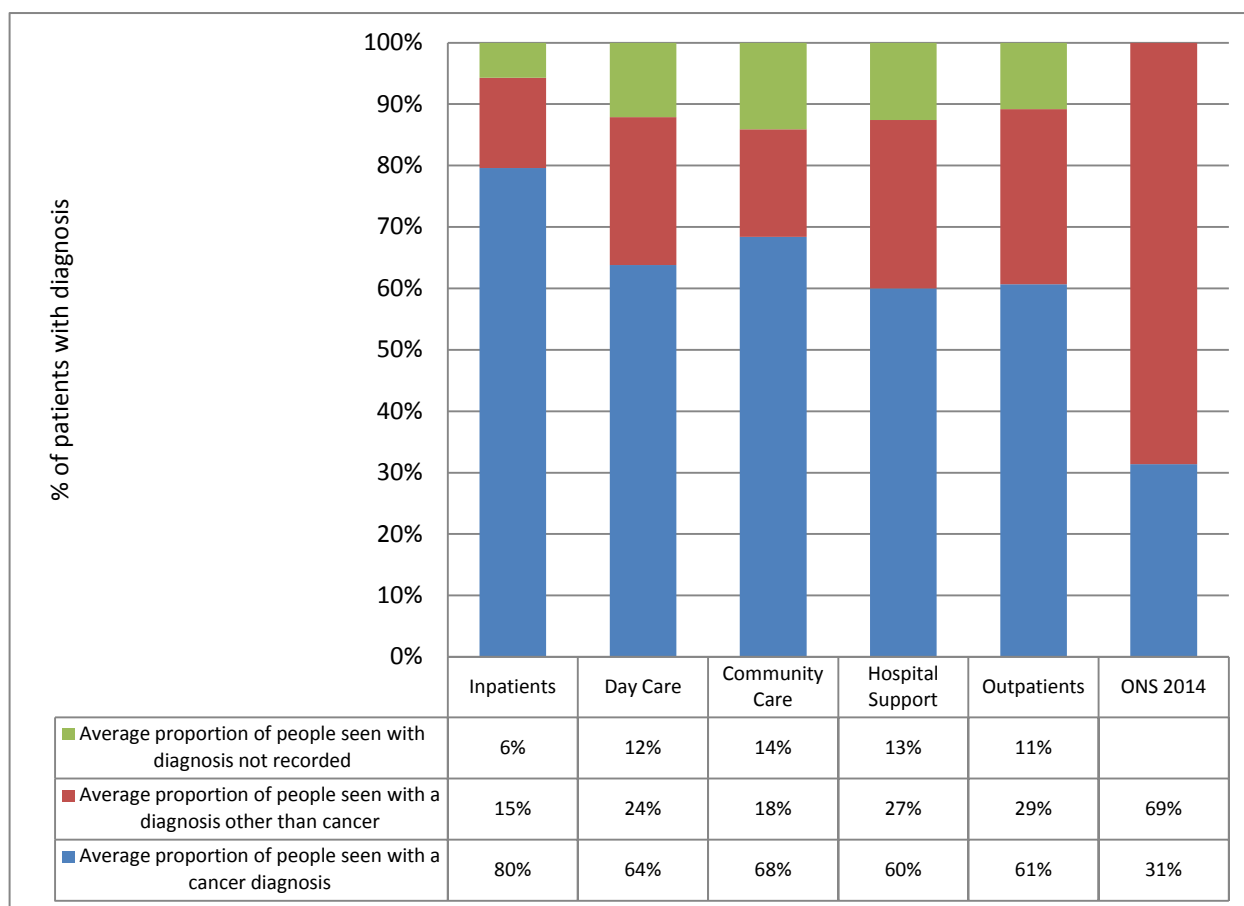
There are differences in the age profile of people accessing each type of service. Figure 1.2 shows that Outpatients see the greatest proportion of people aged under 65 (43%), and Hospital Support seeing the greatest proportion of people aged 75+ (51%). Figure 1.2 shows a comparison of the age profiles of each setting to the age profile of all deaths recorded by ONS (excluding any deaths that are unlikely to have received palliative care – see the note underneath figures 1.2-1.3 for more details).



ONS 2014 data covers all deaths registered by the ONS in 2014 for England and Wales, excluding any that are unlikely to have received palliative care i.e. those falling under ICD-10 codes O00-O99, P00-P96, Q00-Q99, R00-R99, U509, and V01-Y89.

Figure 1.2: Age distribution of people seen in each setting

Diagnosis



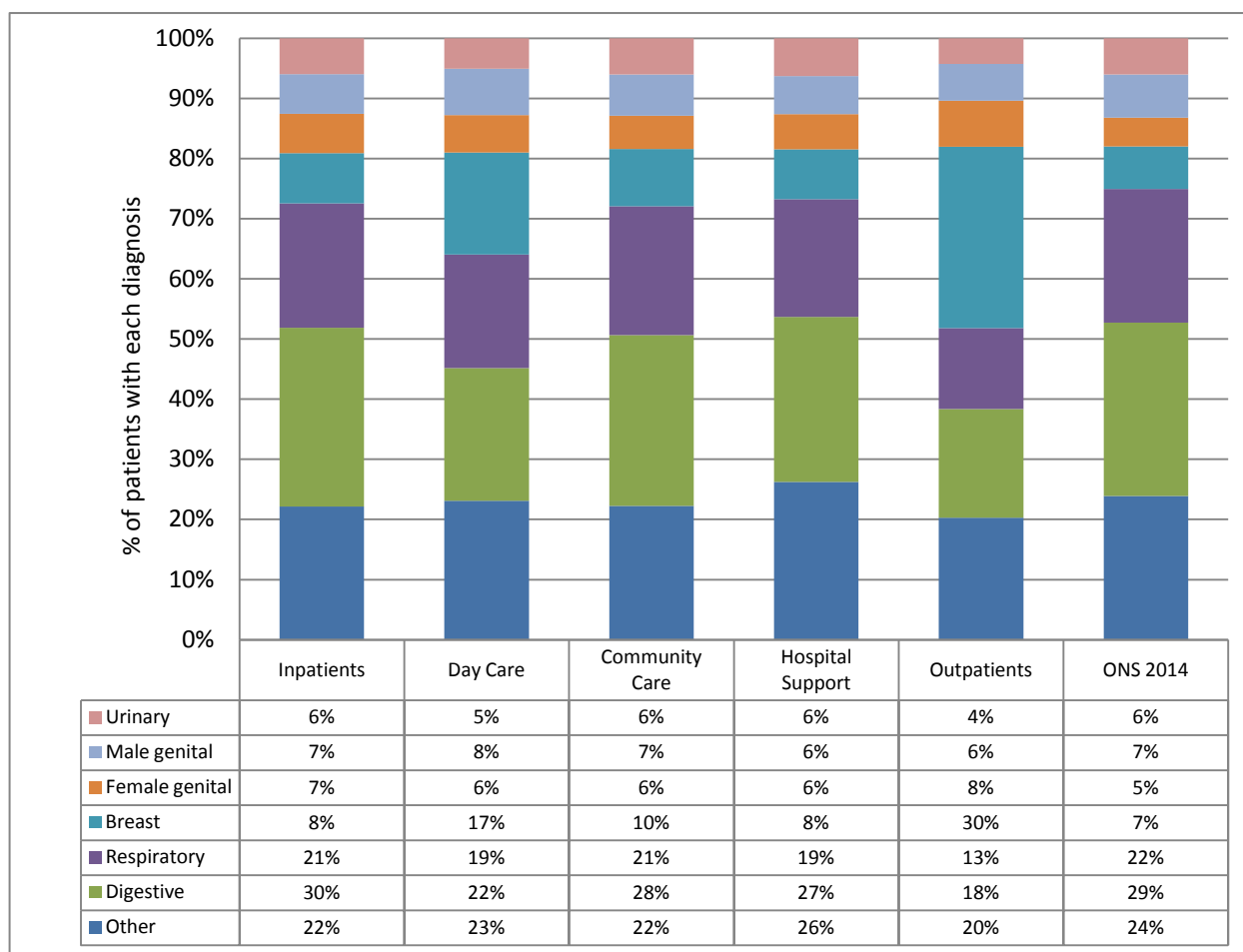
ONS data covers all deaths registered in 2014 in England and Wales; cancer includes the ICD-10 codes for malignant neoplasms (ICD-10 codes C00-C99); non-cancer excludes any deaths due to external causes or neoplasms (ICD-10 codes C00-C99, O00-O99, P00-P96, R00-R99, U509, V01-Y89).

Figure 1.3: Distribution of cancer / non-cancer diagnoses of people seen in specialist palliative care settings

In every setting the majority of people seen have a cancer diagnosis. Figure 1.3 shows almost 80% of people accessing Inpatient care were diagnosed with cancer and at least 60% of people seen in each of the other settings. All settings are seeing proportionately more cancer patients than the 31% of all deaths that are recorded as being caused by cancer (ONS).

Hospital Support sees the greatest number of non-cancer diagnoses (26,778) corresponding to 6% of all deaths from causes other than cancer reported by the ONS in 2014 (475,511).

Diagnosis breakdown: cancer

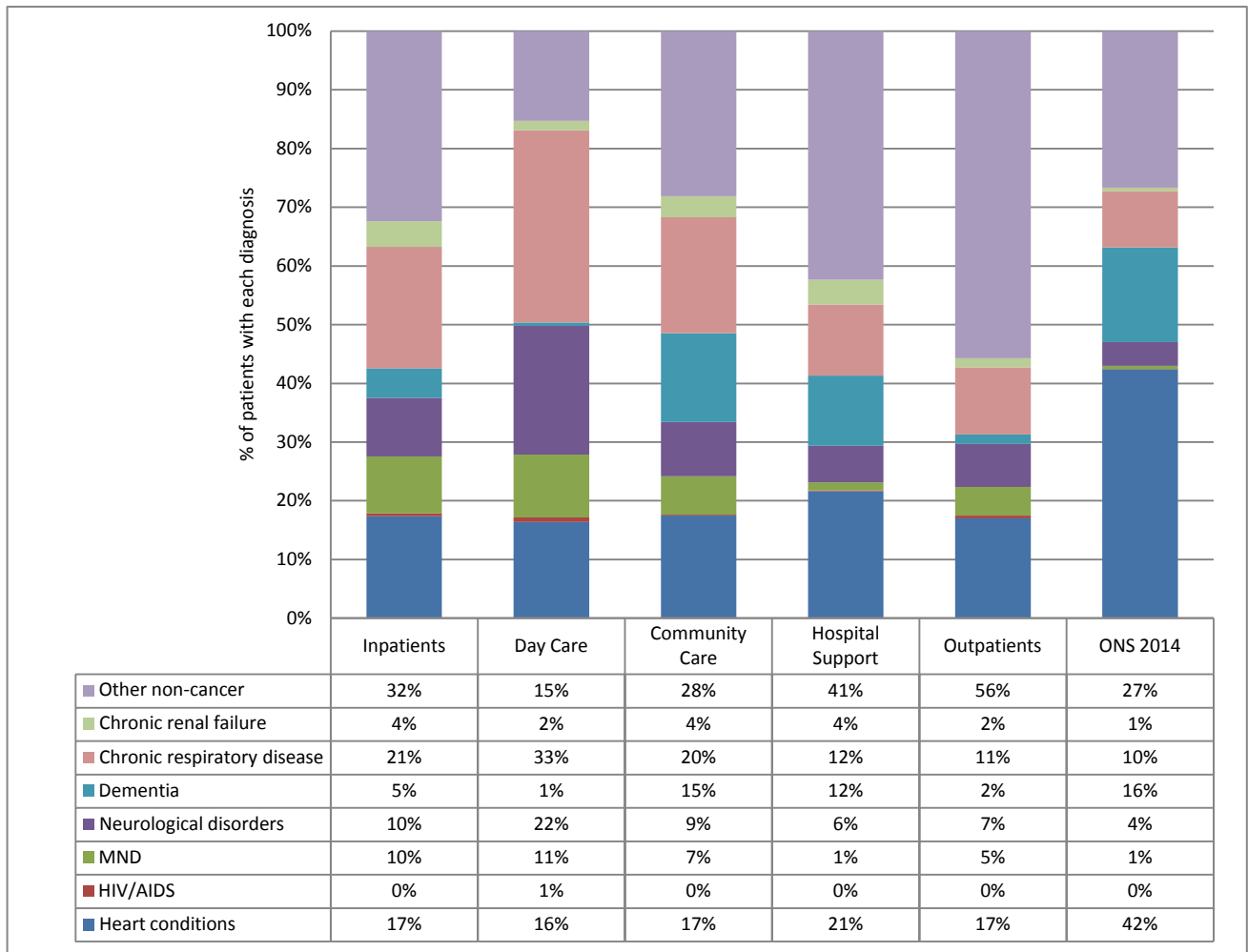


ONS data covers all deaths registered in 2014 under the ICD-10 codes for malignant neoplasms in England and Wales (ICD-10 codes C00-C99).

Figure 1.4: Distribution of cancer diagnoses seen in each setting and in death registrations

Proportions of different cancers seen in each setting vary slightly, but Figure 1.4 shows they broadly follow the distribution of cancer causes of death recorded in 2014 (ONS, England and Wales), the most pronounced difference being the large proportion (30%) of people seen in Outpatients who have a diagnosis of breast cancer.

Diagnosis breakdown: diagnoses other than cancer



*ONS data covers deaths registered in 2014, minus any deaths due to external causes or neoplasms (ICD-10 codes C00-C99, O00-O99, P00-P96, R00-R99, U509, V01-Y89).

Figure 1.5: Distribution of diagnoses other than cancer seen in each setting and in death registrations

The most often seen non-cancer diagnoses in specialist palliative care are chronic respiratory disease, heart conditions, motor neurone disease (MND) and neurological disorders.

4. Other key findings

Location of people prior to admission to Inpatient specialist palliative care

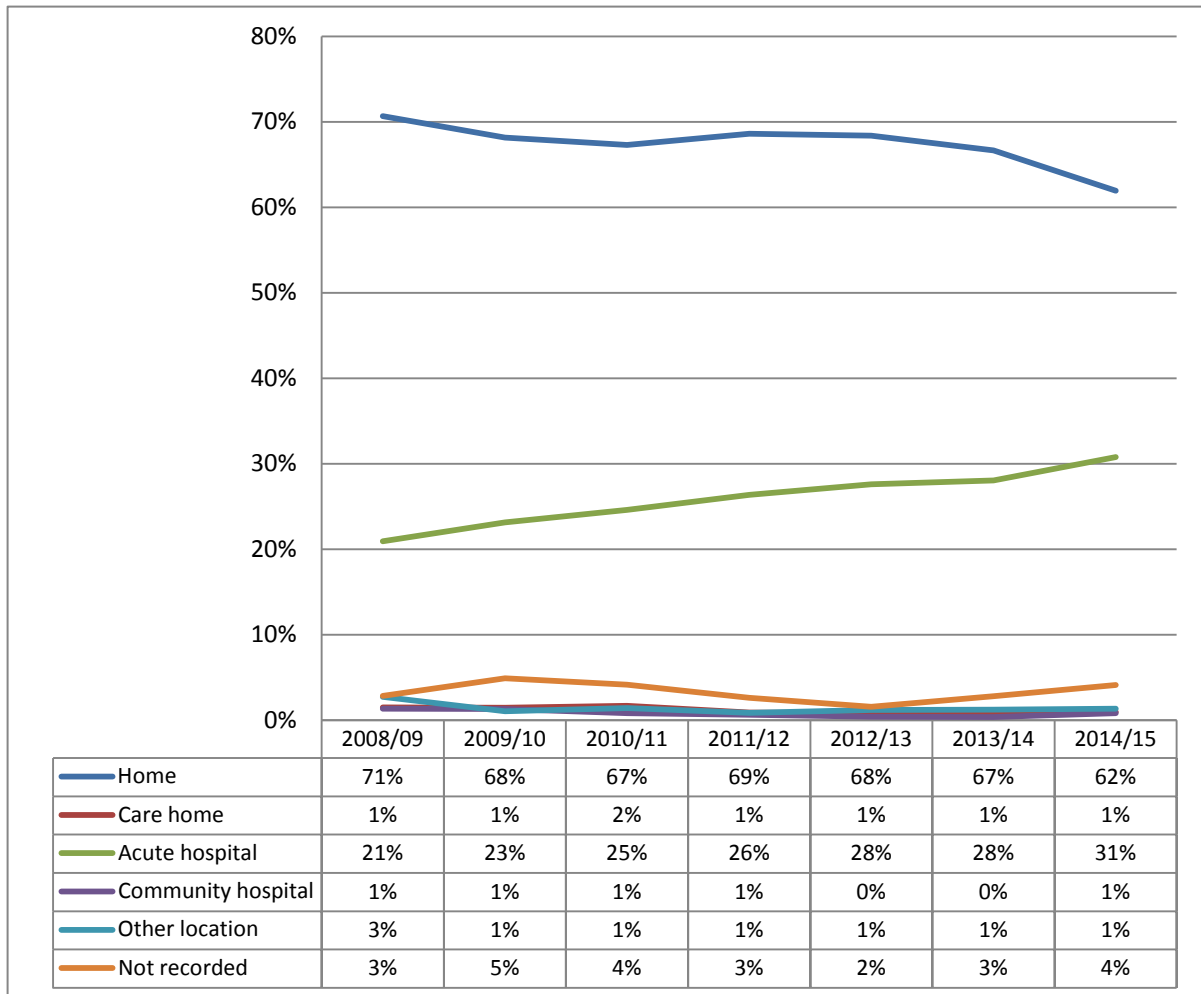


Figure 1.6: Location of people prior to Inpatient admission

There has been a steady increase in the proportion of people admitted into specialist palliative care services who were admitted from hospital and a corresponding reduction in those admitted from home. In 2008/09 21% (8,418) of these admissions came from hospital, but in 2014/15 this has risen to over 30% (12,629).

Specialist palliative care inpatient services are seeing an increasing percentage of people whose stay ends in death

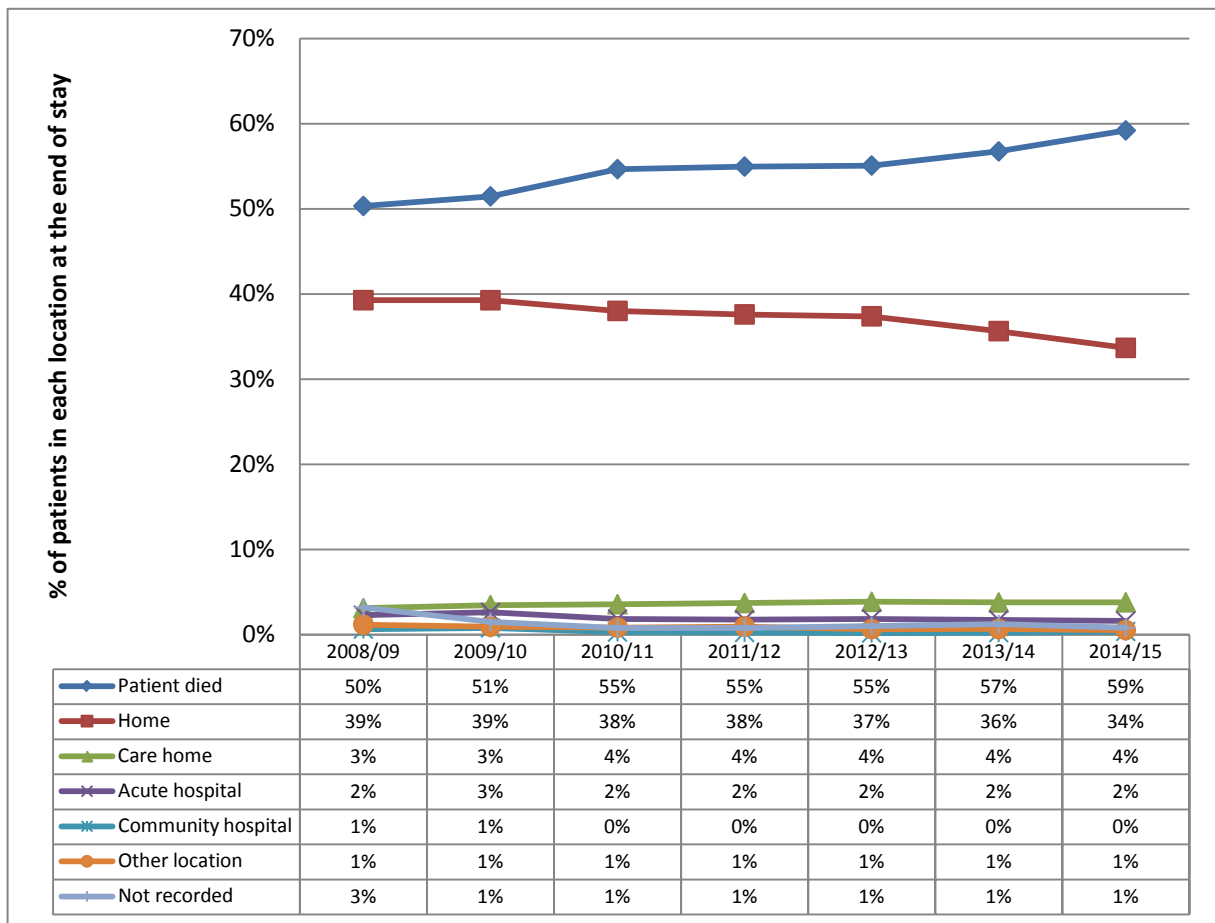


Figure 1.7: Destination of people after discharge from Inpatient unit

There has been a steady increase in the proportion of people whose stay in inpatient specialist palliative care services ends with their death. In 2008/09 50% (20,351) of these admissions ended in death, but in 2014/15 this has risen to over 59% (24,225).

Hospital Support services are seeing an increasing percentage of people who die in hospital

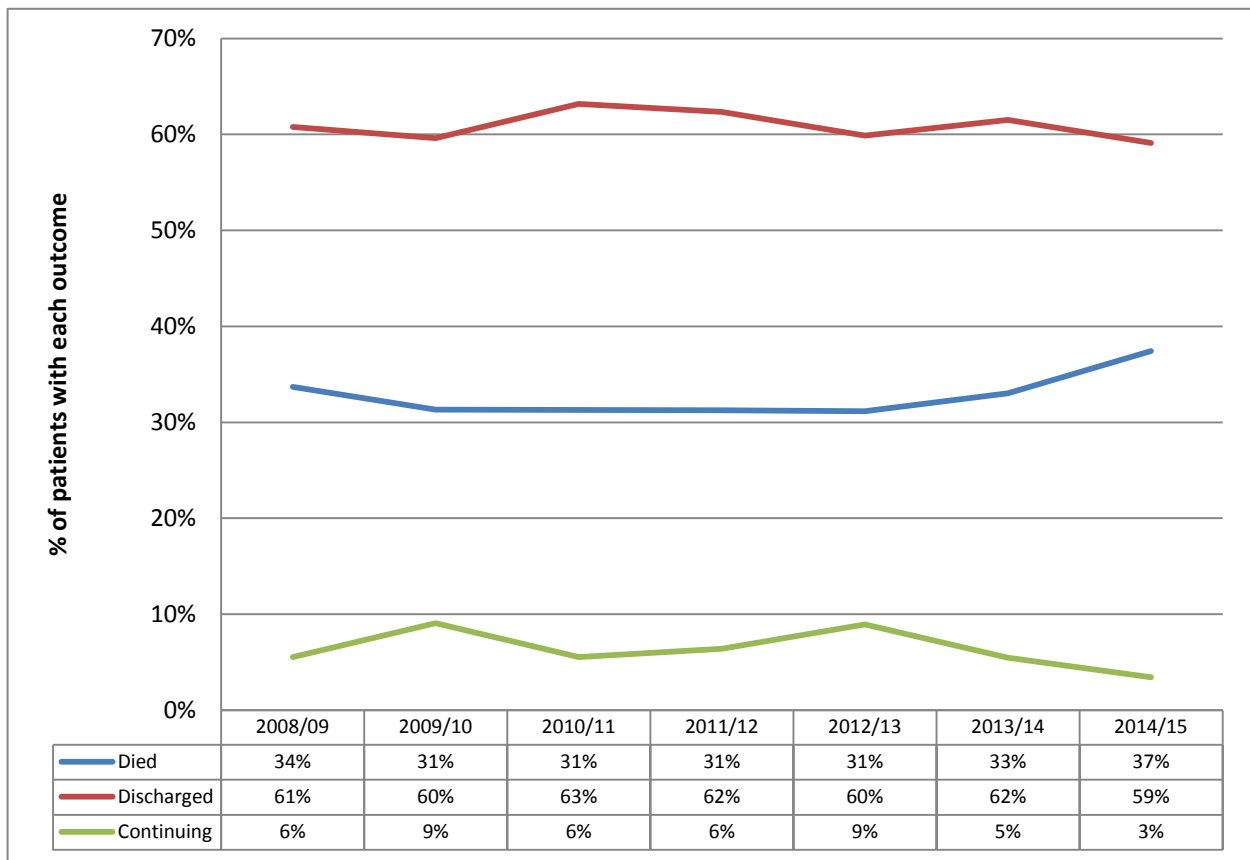


Figure 1.8: End of stay outcome for Hospital Support patients

The past few years has seen an increase in the proportion of Hospital Support referrals that end in death. In 2008/09, 33.7% of stays ended in death, while in 2014/15 37.4% of stays ended in death.

5. Commentary and key findings from each activity report

Reach of specialist palliative and hospice care

- Each year approximately 500,000 people die in England and Wales and it is estimated that approximately 75% (375,000) of those who die need palliative care². This survey indicates that at least one third of the people who die each year are seen by specialist palliative care Community Care services and at least a quarter are seen by Hospital Support services.

Older people and palliative care

- People aged under 65 years appear to be disproportionately represented in all specialist palliative care settings, accounting for 14% of deaths but always at least 22% of people accessing any specialist palliative care setting. The observation that proportionately the oldest people are less likely to access palliative care than younger people has been made before³; “The barriers to accessing palliative care for older people in hospitals are attitudinal barriers, lack of resources for both specialist and generalist palliative care, difficulties in switching from a curative or interventionist approach, and confusion over roles and responsibilities, in particular, a lack of clarity regarding the role of the geriatrician in providing palliative care.”⁴
- Older people are more likely than younger people to be residents of care homes. The care and support available in the care home environment, including through Community Care services, may reduce the need for admission to Inpatient specialist palliative care services and in part explain the under-representation of older people seen by specialist palliative care services. However, a review of equity in provision of palliative care⁶ found evidence that the palliative care needs of older people may not be identified effectively in practice.

Community specialist palliative care teams – including hospice at home teams

- 81% of patients supported by Community Specialist Palliative care teams die out of hospital, compared to the national average of 52%. Community palliative teams who returned MDS data in 2014/15 saw 126,047 people, 68,877 of whom died (28.1% of all deaths recorded by the ONS in England and Wales in 2014/15). A significantly high proportion of people seen by hospice and NHS community palliative care teams died at home or in a hospice, compared to those who died in a hospital.

² T Hughes-Hallett, A. Craft, C Davies Palliative Care Funding Review: Finding the right care and support for all (2011) https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215107/dh_133105.pdf

³ Equity in the provision of palliative and end of life care in the UK (2015) Marie Curie

⁴ Dixon J, King D, Matosevic T, Clark C, Knapp K (2015) Equity in the provision of palliative care in the UK: review of evidence. Personal Social Services Research Unit, London School of Economics and Political Science, London.

Diagnosis and specialist palliative care

- Of the approximately 150,000 people who in total died from cancer (ONS, 2014), the survey suggests over half were seen by Community Care based specialist palliative care and over a third were seen by Hospital Support. Community Care see more people than any other setting, and with comparison to mortality data the survey suggests that at least 80% of all breast cancer patients are seen by Community Care.
- This survey serves as a reminder that access to specialist palliative care for patients with a non-cancer diagnosis remains a challenge; improvements are happening but are slow. 29% of people who died in 2014 died of cancer, yet cancer accounts for at least 60% of diagnoses seen in any specialist palliative care setting. This is in line with other research e.g. Marie Curie⁵ have reported that 1) two-thirds of people with cancer who died were on the palliative care register compared with 20% of people with non-malignant conditions: and 2) just 20% of people diagnosed with dementia or organ failure (heart, lung, liver or kidney) either requested or were identified for specialist palliative care at the end of life in Scotland.
- Of note however is that the number of patients seen with a non-cancer diagnosis has doubled over the last 6 years to 28% in the hospital setting and in out-patient clinics in hospital and hospice.

Admissions to specialist palliative care beds/hospices

- Most people admitted to Inpatient specialist palliative care units are admitted from their home, but the number admitted from acute or community hospitals has been increasing over recent years. Admissions from home made up 71% of total admissions in 2008/09 and 62% of admissions in 2014/15, while admissions from an acute or community hospital made up 22% and 32% of all admissions in those years respectively. This change could be driven by more people whose condition is less complex being enabled to stay at home and avoid admission to a specialist unit - freeing up specialist Inpatient beds for people who have greater need of intensive care and who are likely to have been admitted to hospital for symptom control before being transferred to a specialist unit.

Deaths and discharges in specialist palliative beds/hospices

- In 2008/09, 50% of Inpatient stays ended in death, but in 2014/15 this had risen to 59%. The reason for this change could be the same as that offered above i.e. that more people are being enabled to stay in their own home and those admitted to specialist units are increasingly complex in their care needs. If this is the case then the increase in the proportion of admissions ending in death is linked to the increasing proportion of deaths from hospital. The current design of the MDS means that it is not possible to break down the

⁵ Equity in the provision of palliative and end of life care in the UK (2015) Marie Curie

data to investigate this question. However, organisations submitting Inpatient returns to the MDS could look at their own patient records to assess whether this is the case in their own data, and in doing so may gain greater insights about the people they are supporting in their caseload.

Hospital palliative teams

- Hospital Support services are seeing an increasing percentage of stays ending in death. In 2008/09, 33.7% of stays ended in death, while in 2014/15 37.5% of stays ended in death. This may mean that people with more complex conditions are being admitted to hospital, or it may reflect a difficulty in discharging people home due to a lack of community care.

Dementia and specialist palliative care

- Research has shown that people with dementia mentioned on their death certificate are unlikely to die in hospice settings or at home but instead tend to die in hospital or care homes⁶; this survey shows that of the specialist palliative care settings Hospital Support teams and Community teams (who may be visiting people at home or in care homes) see the greatest proportions of dementia patients at 12% for Hospital Support and 15% for Community Care. However, the MDS collects only primary diagnosis and so dementia comorbidities may be present but unreported.

6. Definitions

- **Inpatients:** patients who are admitted to a specialist palliative care unit or hospice.
- **Day Care:** service provided by a specialist palliative care day therapy centre.
- **Community Care:** service provided by professional members of a specialist palliative care service to patients in their place of residence. This includes hospice at home teams.
- **Hospital Support:** service provided by a specialist palliative care team working in a hospital setting.
- **Bereavement Support:** contacts with the bereaved who are relatives, friends or carers of a deceased patient and who need extra support.
- **Outpatients:** a patient having an individual appointment to see a specific member of a multi-professional palliative care team (e.g. doctor, social worker, specialist nurse, physiotherapist).

⁶ Sleeman, K., Ho, Y.K., Gai, W., and Higginson, I.J., 2014. *Reversal of English trend towards hospital death in dementia: a population-based study of place of death and associated individual and regional factors, 2001-2010*. BMC Neurology, 14(59).

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Author

Jocelyn Hinds

Data and Intelligence Manager, The National Council for Palliative Care

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Claire Henry

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Susanna Shouls

Associate, The National Council for Palliative Care

Dr Julia Verne

Clinical Lead - National End of Life Care Intelligence Network, Public Health England

Andy Pring

Principal Analyst, National End of Life Care Intelligence Network, Public Health England

Nicola Bowtell

Analytical Programme Manager, National End of Life Care Intelligence Network, Public Health England

Katie Lindsey

Programme Manager, National End of Life Care Intelligence Network, Public Health England (until Dec 2015)

Dr Ros Taylor

Clinical Director, Hospice UK

Professor Bee Wee

National Clinical Director of End of Life Care

The National Council for Palliative Care

4th Floor

34-44 Britannia Street

London

WC1X 9JG

Tel: 020 7697 1520

Fax: 020 7697 1530

enquiries@ncpc.org.uk

www.ncpc.org.uk

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