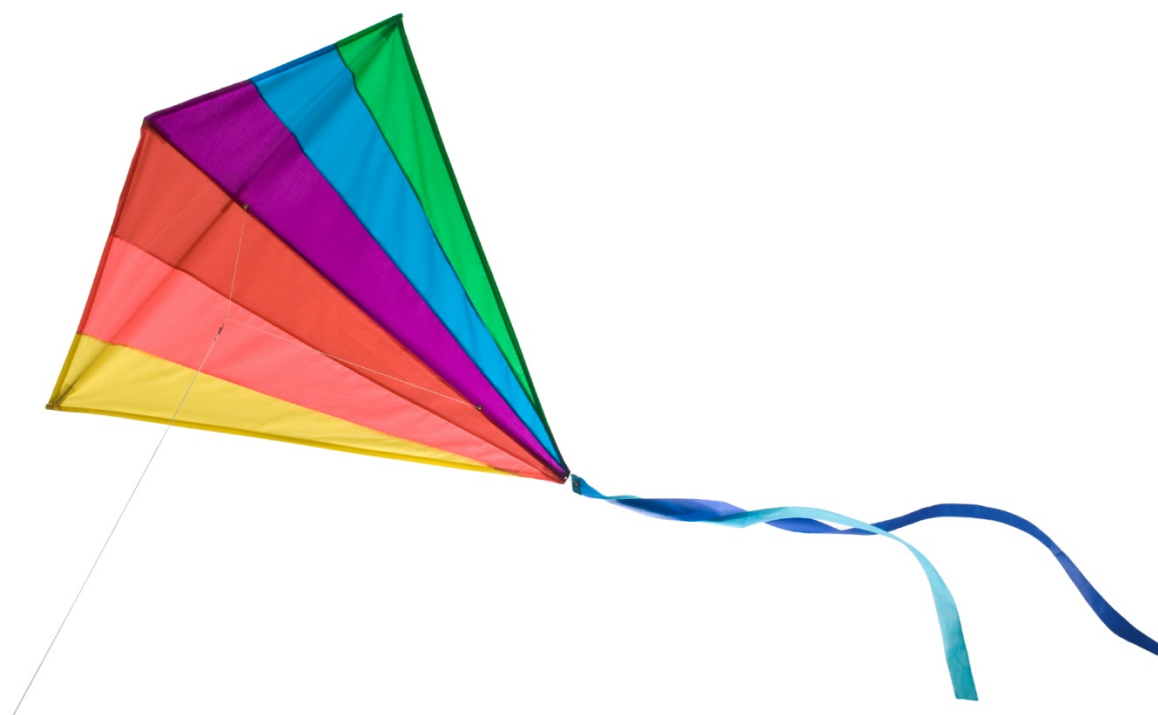


THE  
NATIONAL  
COUNCIL FOR  
PALLIATIVE  
CARE



Public Health  
England

 hospice<sup>UK</sup>



**National Survey of Patient Activity Data  
for Specialist Palliative Care Services  
MDS Summary Report for the year  
2013-2014**

# The MDS: 2008-2014

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## 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. NCPC promotes the extension and improvement of palliative care services for all people with life threatening and life-limiting conditions and promotes 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 to receive publications free of charge and reduced rates at conferences visit [www.ncpc.org.uk](http://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.

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. NEoLCIN plays a vital role in supporting the comprehensive implementation of the strategy. On 1<sup>st</sup> 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](http://www.endoflifecare-intelligence.org.uk)  
Public Health England's website is [www.gov.uk/phe](http://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](http://www.hospiceuk.org)

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*Note on figures: where possible, the number of organisations providing each data item in each year is given in parentheses on each graph. Different organisations return MDS data from year to year, and so any historical trends presented here are subject to the caveat that the profile of services responding may be different from year to year.*

*All tables referenced are available in the accompanying annex document.*

## **Foreword**

I am delighted to be invited to write the foreword for this year's report on the Minimum Data Set for Specialist Palliative Care (MDS). It provides important insight into specialist palliative care services provided for people in England, Wales and Northern Ireland. The MDS has been the key source of data about specialist palliative care for many years, and this year's report – gives an overview of care provided by hospices, hospital palliative care teams, community teams and outpatient clinics.

The findings should be of value to a wide range of audiences and stakeholders, ranging from policy-makers and commissioners of palliative care services, to regulators, to those driving service development and improvement and staff directly giving care. This overview report complements the individual reports provided to each service that submits data to the MDS collection, and should help service providers understand their own services, patient groups and performance and look at these relative to others. The report can be used to inform thinking about service improvement, new models of care and extending reach – important issues for all involved in palliative care as we face increasing levels of need and complexity driven by demographic changes. It is vitally important that both commissioners and service providers consider the palliative care needs of their local populations as a whole, and take active steps to address those needs.

This year the report has a new format presenting the data historically as well as giving details of 2013/14 activity, so that changes and trends over time can be more easily identified.

To take just one example, the data from 2008-2014 show a clear increase in people with diagnoses other than cancer accessing specialist palliative care services, across all settings. Whilst this is an encouraging trend, the rate of change is still slow and there is still great variability between services. These findings are important, but clearly more needs to be done across the sector to increase access for people with conditions other than cancer.

Having good quality data is key to understanding the difference we make and the impact of policy developments and new models of care. As a sector, we need to ask the right questions, collect the right data, ensure the quality of that data, and equip people with the skills and understanding to make good use of the findings. We also need to enable services to examine their performance against others and understand how they might deliver care differently – some of the greatest insights and value can come from such active benchmarking.

There is still a need to improve the quality and use of data in the palliative care sector. I strongly encourage all hospices, hospital palliative care teams and other providers to commit to submitting data to the MDS, as it is only through working together and sharing data in this way that we can achieve the improvements we seek. There are other important developments underway. In England, NHS England and Public Health England are working with providers and stakeholder organisations to develop and pilot a national data collection from specialist palliative care services. This data, collected at individual patient level and including some outcome measures, has the potential to provide a wealth of further information and understanding, particularly about quality of care and people's journeys through different services at the end of life.

**Bee Wee, National Clinical Director for End of Life Care**

### Number of people seen

It is difficult to assess the increase in the number of people seen by specialist palliative care services using MDS data, as different services send data in each year and response rates consequently vary from year to year. However in looking at absolute numbers recorded, all settings have seen an increased number of people over time despite varying response rates:

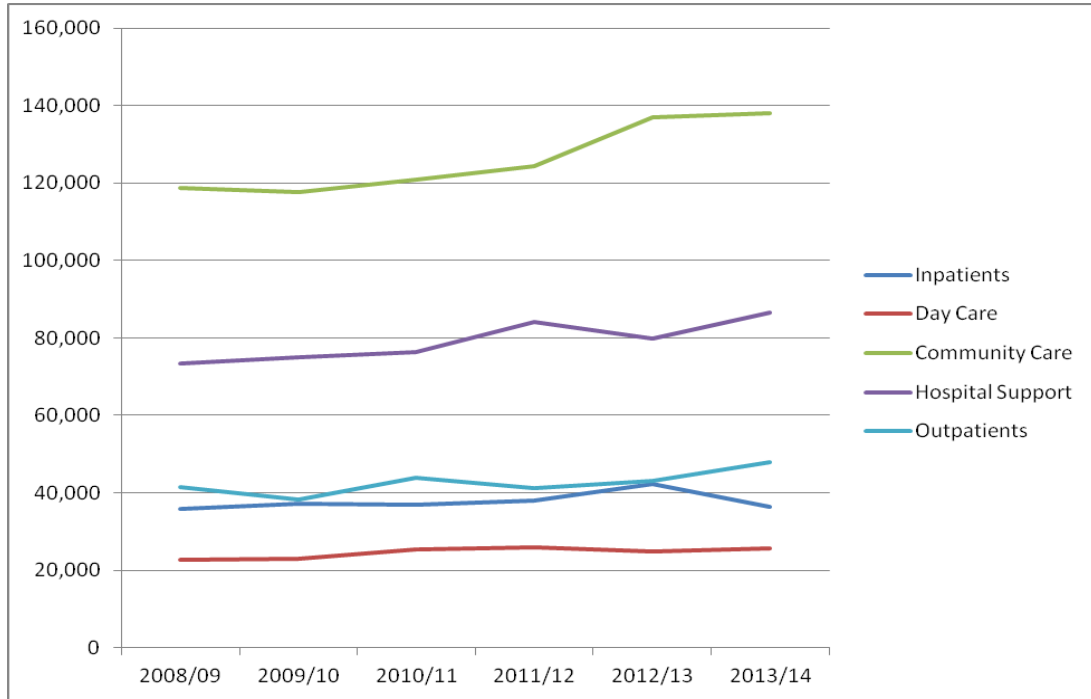
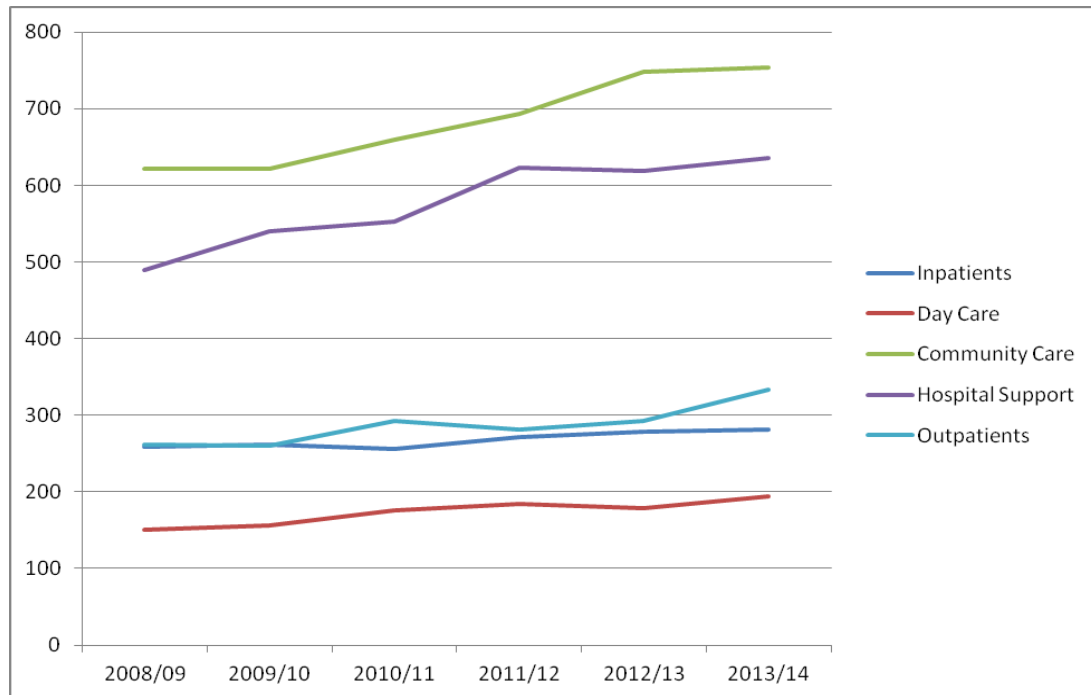


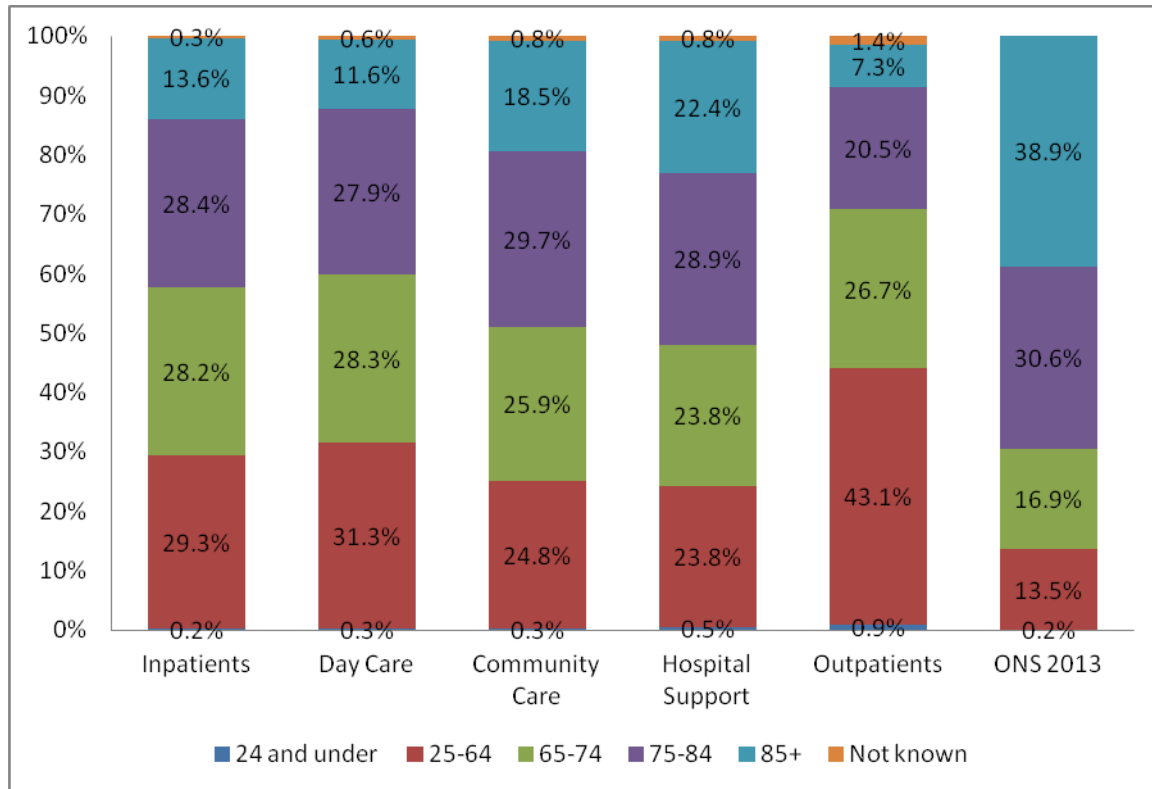
Figure 1.1: total number of patients in each setting, 2008-2014 (Table 2)



**Figure 1.2: mean number of patients seen per service across all settings, 2008-2014 (Table 3)**

To control for varying response rates, the data was standardised to mean patients per service (total patients/number of services responding in each reporting year); an increase can still be seen. The setting that has seen the greatest percentage increase in patient numbers using this standardising methodology is Hospital Support, with a 29.7% increase from 2008/09 to 2013/14, with Day Care close behind with a 29.3% increase. The smallest growth has been in Inpatient settings, where the mean number of patients per service has increased by 8.9% over the same period.

## Age



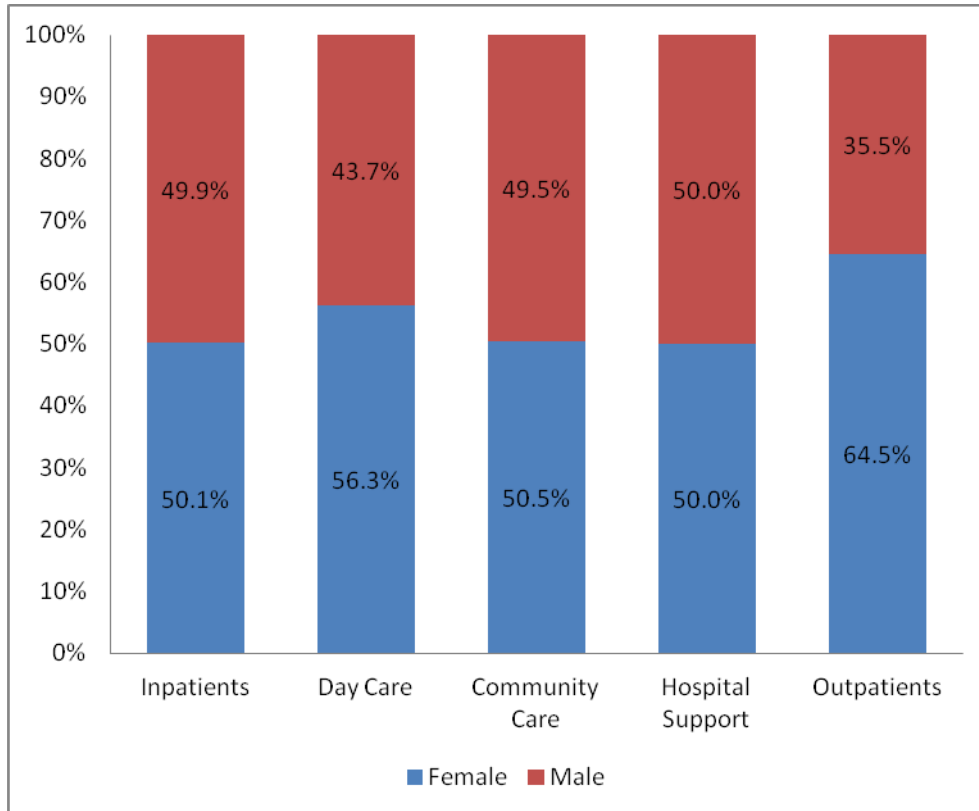
ONS 2013 data covers all deaths registered by the ONS in 2013 for England and Wales, excluding any that would not have reasonably required palliative care i.e. those falling under ICD-10 codes O00-O99, P00-P96, Q00-Q99, R00-R99, U509, and V01-Y89.

**Figure 1.3: proportions of different age groups seen in each setting, 2013/14 (Table 4)**

Looking across settings, the age profile of people accessing each type of service is varied, with Outpatients seeing the greatest proportion of younger people, and Hospital Support seeing the greatest proportion of older people.

By comparing MDS data from 2013/14 to ONS deaths data from 2013, it can be seen that younger people (aged 64 and under) appear to have disproportionate access to specialist palliative care in all settings, accounting for 13.5% of deaths but always at least 23.8% of people accessing any specialist palliative care setting.

## Sex

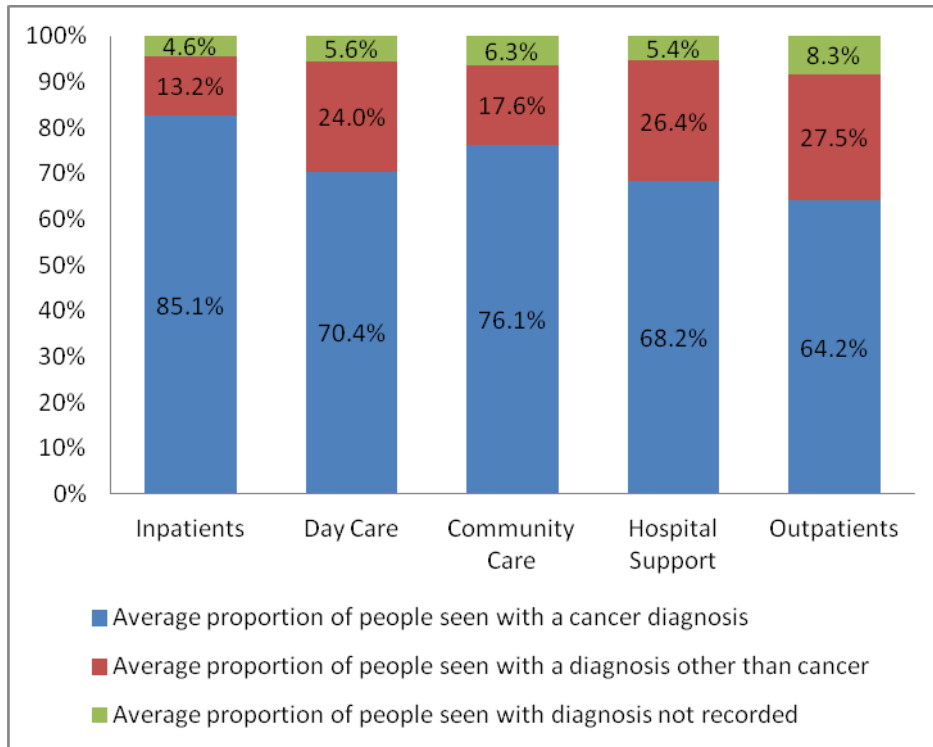


**Figure 1.4: sex of people seen in each setting, 2013/14 (Table 5)**

Inpatients, Community Care and Hospital Support all see a relatively even split of men and women; Day Care and Outpatients both see a higher proportion of women than men. In Outpatients, this is likely to be due to a large number of younger women with breast cancer accessing clinics; in Day Care this data raises a question about the reasons why men are less likely to access support in this setting.



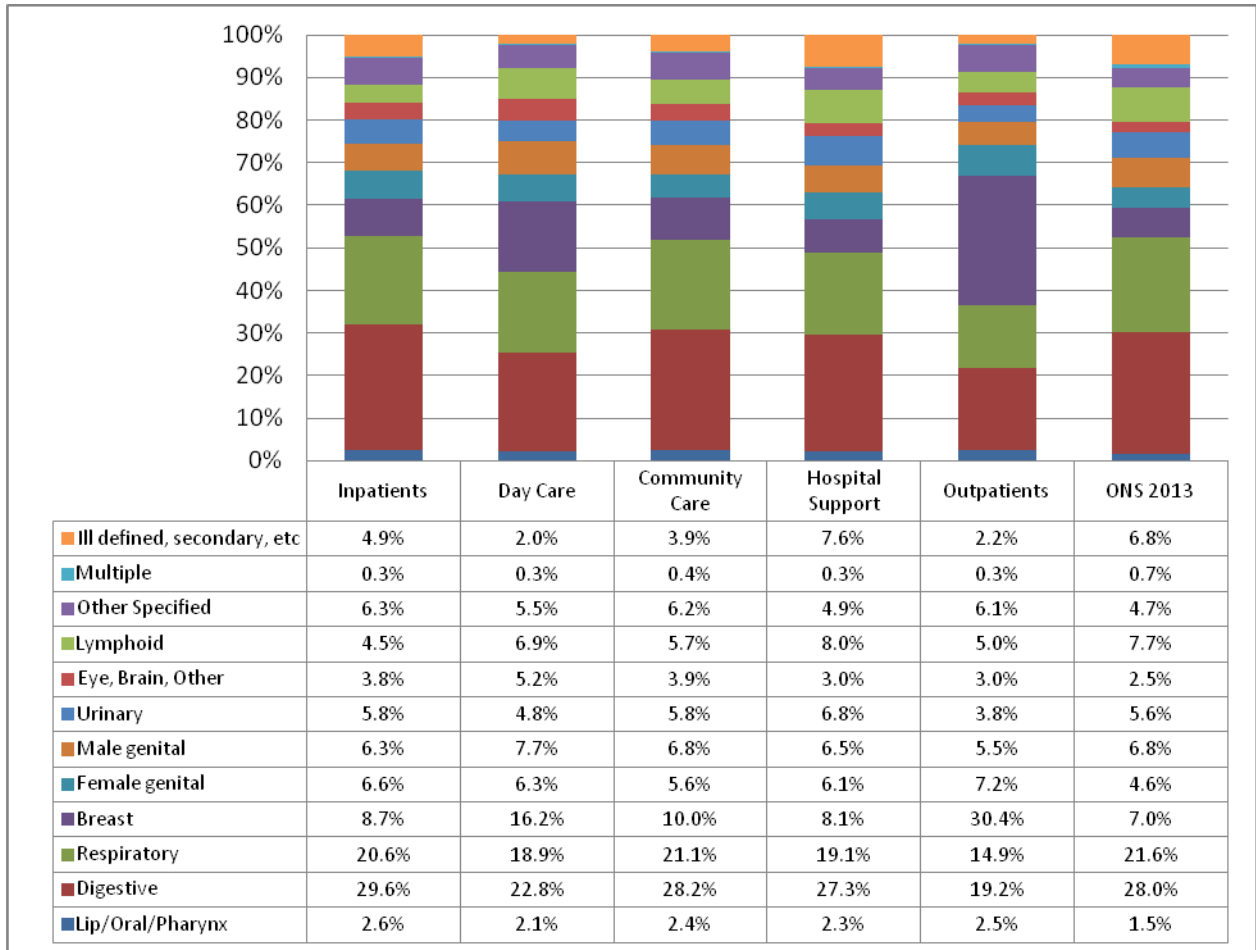
## Diagnoses



**Figure 1.5: proportions of people with different diagnoses seen in specialist palliative care settings, 2013/14 (Table 6)**

There continues to be a disparity in access to specialist palliative care services on the basis of diagnosis. People diagnosed with cancer are far more likely to have access to specialist palliative care compared to those diagnosed with other terminal conditions and this disparity is particularly pronounced in Inpatient settings.

### Diagnosis breakdown: cancer

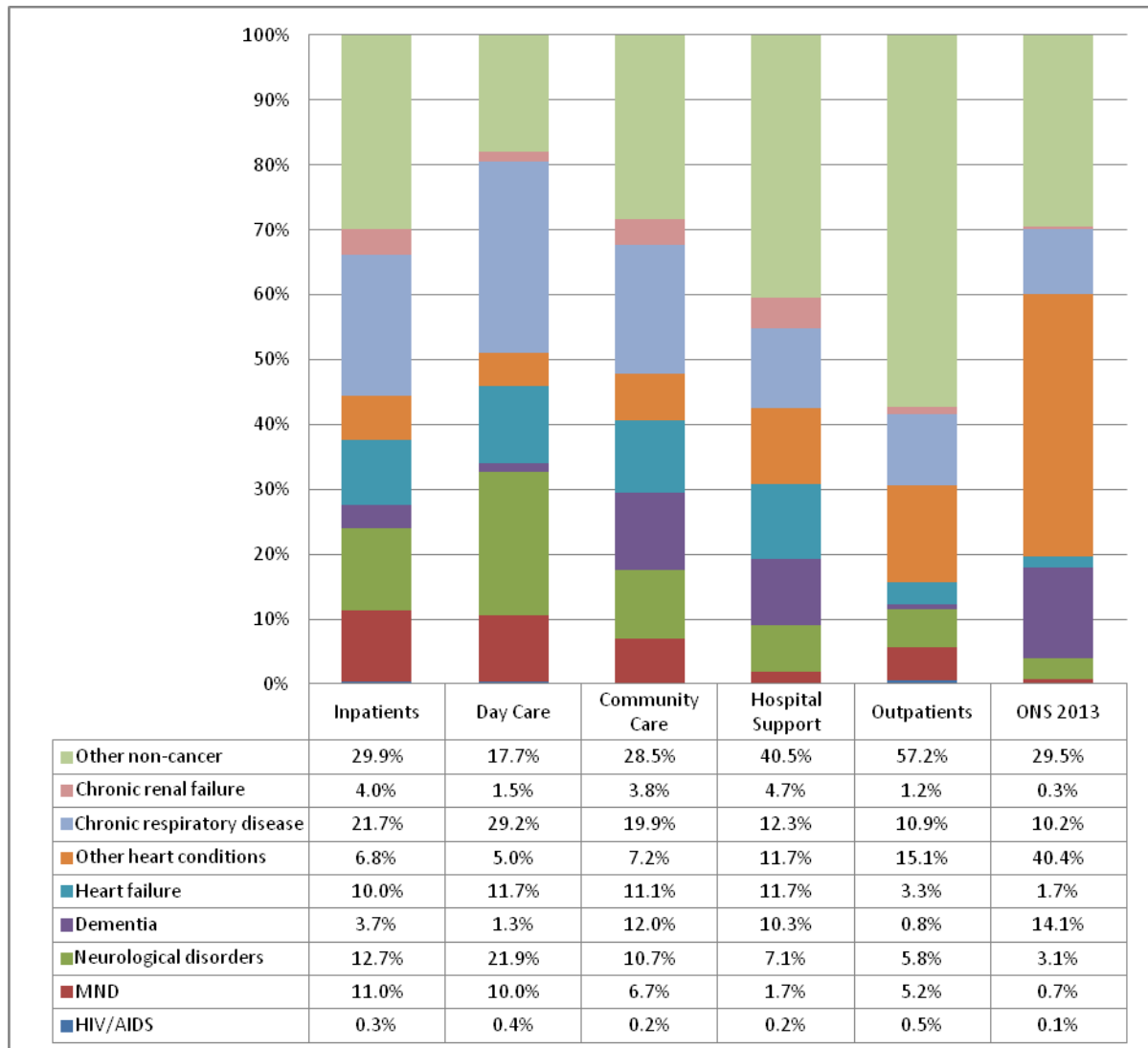


ONS data covers all deaths registered in 2013 under the ICD-10 codes for malignant neoplasms (ICD-10 codes C00-C99).

**Figure 1.6: breakdown of cancer diagnoses seen in each setting and in death registrations, 2013/14 (Table 7)**

Proportions of different cancers seen in each setting do vary slightly, with the most pronounced difference being the representation of breast cancer in Outpatients.

## Diagnosis breakdown: diagnoses other than cancer



\*ONS data covers deaths registered in 2013, minus any deaths due to external causes or neoplasms.

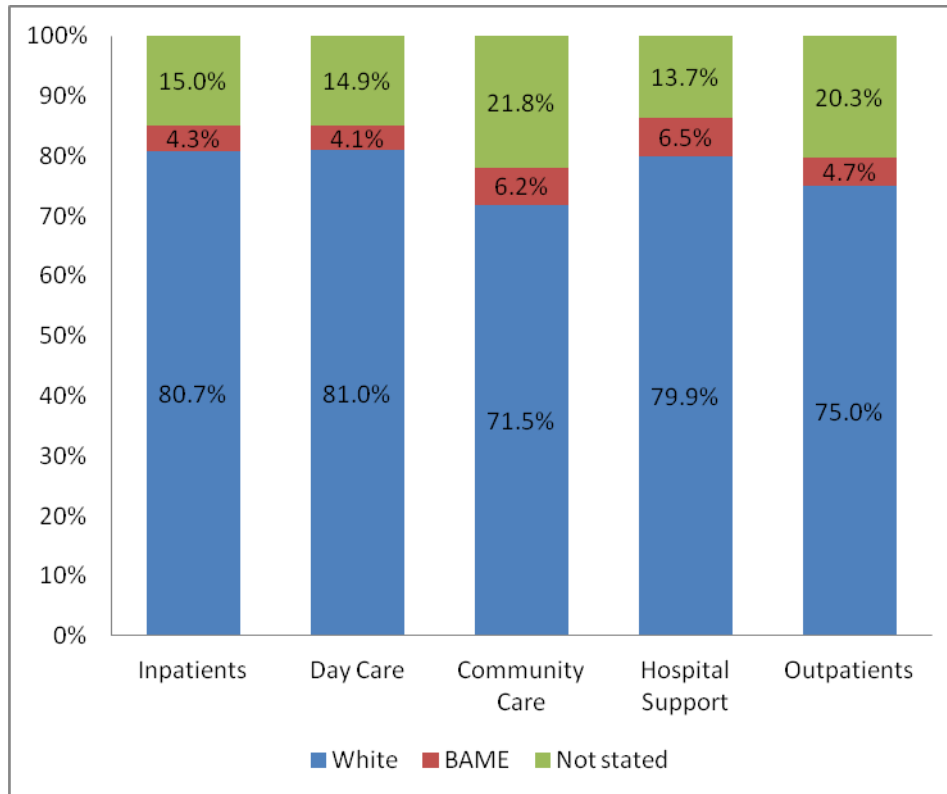
**Figure 1.7: breakdown of diagnoses other than cancer seen in each setting and in death registrations, 2013/14 (Table 8)**

There are some interesting patterns of care in the data on non-cancer diagnoses: for example, the access patterns for people with dementia compared with the incidence of dementia as cause of death in ONS death registration data. Research has shown that people with dementia mentioned on their death certificate are very unlikely to die in hospice settings or at home but instead tend to die in hospital or care homes<sup>1</sup>; this would appear to be reflected in the MDS data with the greatest

<sup>1</sup> 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).

proportions of dementia patients being seen by Hospital Support teams or by Community teams (who may be visiting people in care homes).

## ***Ethnicity***

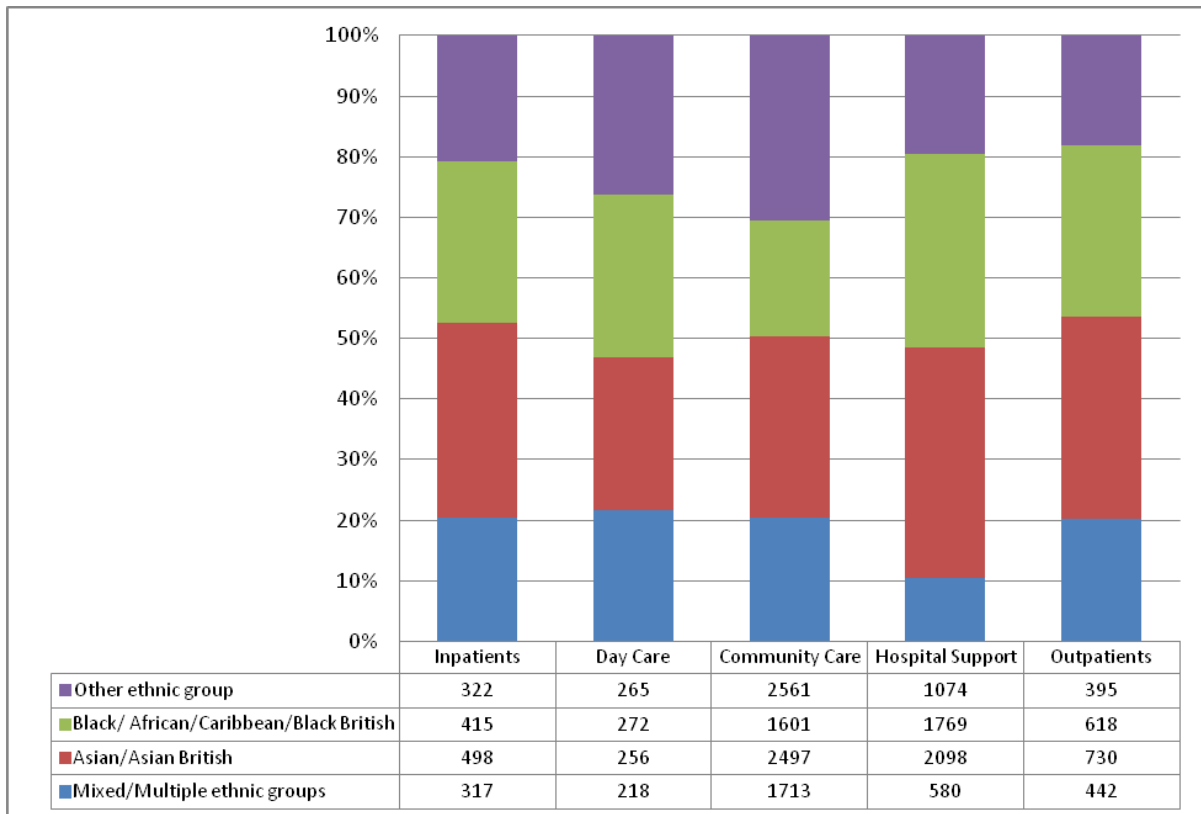


**Figure 1.8: proportion of people from different ethnic backgrounds seen in each setting, 2013/14 (Table 10)**

Hospital Support and Community Care see the greatest proportion of non-white people in their services, but this is still below the expected level of access. Inequality in access to services on the basis of ethnicity continues to be an issue for specialist palliative care and has been so for many years<sup>2</sup>.

The quality of ethnicity data remains a concern, with a large amount of ethnicity data not being collected across all settings. Feedback from provider organisations suggest that for some services, this information is not routinely collected but instead is provided as part of the referral received from GPs, suggesting the part of the problem with recording accurate ethnicity data lies within primary care. However, specialist palliative care organisations could still remedy this by collecting more detailed ethnicity data to replace incomplete information from referrals.

<sup>2</sup> National Council for Palliative Care, 1995. *Opening Doors: Improving Access to Hospice and Specialist Palliative Care Services by Members of the Black and Ethnic Minority Communities*; National Council for Palliative Care, 2001. *Wider Horizons: Care of the Dying in a Multicultural Society*.



**Figure 1.9: BAME groups accessing specialist palliative care settings, 2013/14 (Table 11)**

Even where ethnicity data is being collected, often a high proportion of people are recorded as 'Other' or 'Mixed Other'. The proportion of people recorded as being in these groups on MDS returns far exceeds the proportion of these groups found in the population, suggesting this data may not be entirely accurate.

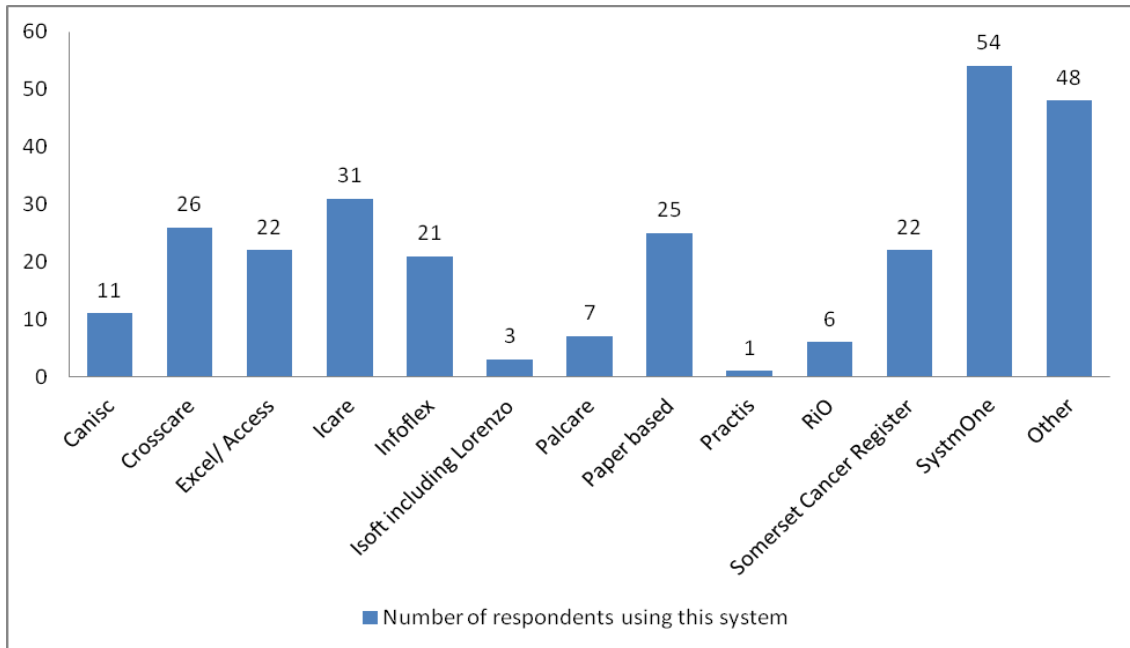
As ethnicity is not a measure captured on death certificates, it is difficult to compare provision with prospective need, although we will look further into how this may be done using census data on the BAME population aged over 65 as a proxy measure for need. Researchers have also previously used country of birth as a proxy for ethnicity<sup>3</sup> but this is acknowledged as a potentially flawed approach.

<sup>3</sup> Koffman, J., Ho, Y. K., Davies, J., Gao, W., and Higginson, I. J., 2014. *Does ethnicity affect where people with cancer die? A population-based 10 year study*. PLoS One, 9(4).

## IT systems

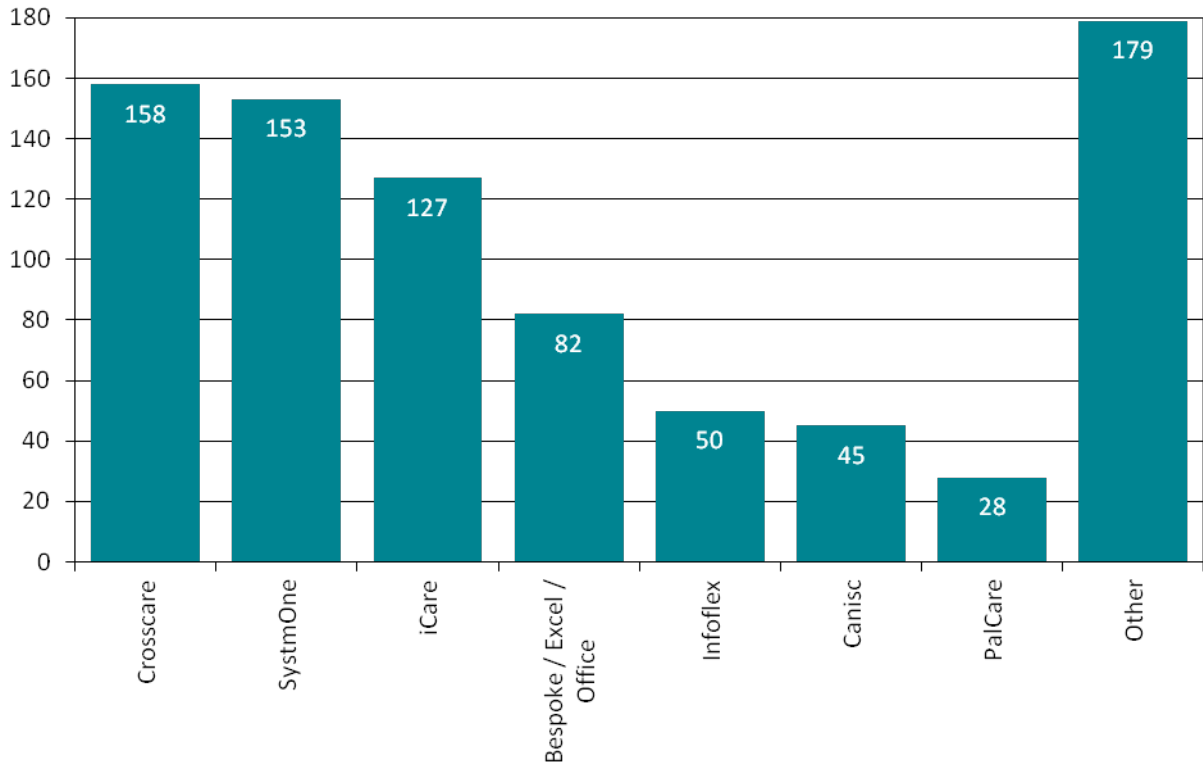
There continues to be a high amount of variety in the systems used to record data across specialist palliative care services.

In November 2014, NCPC carried out an IT survey of all 513 providers held on the MDS database and received a total of 208 responses (42%). From the IT survey, a large number of respondents were using SystmOne as their primary database. A large number of services also continued to use paper records alongside any electronic system.



**Figure 1.10: responses to NCPC IT survey question: Do you have a clinical information system for storing patient records? Which system do you use? (If you use more than one system, please select all that you use.)**

In addition to the information gathered from this survey, all services returning data are asked to list their IT system on their MDS forms. Different services responded to the survey and to the MDS, giving slightly different pictures of the systems in use in specialist palliative care.



**Figure 1.11: IT systems used by services in organisations responding to the MDS, 2013/14**

### ***Data quality***

As in all years of the MDS to date, data quality issues have caused some problems in interpreting the data. As far as possible, anomalous data has been removed from past and current years of the MDS to try and ensure comparisons are as reliable as possible. However, as good quality data becomes more of a priority for the sector in order to improve care, gain funding, and prove effectiveness, it is imperative that data collection and reporting be improved.

We are aware that certain clinical systems are easier to report from than others, and that a significant minority of services have no clinical database at all. We also recognise that for many services, there is no dedicated resource for reporting and data analysis, and so the MDS returns are completed by members of clinical or administrative staff who may only encounter this data once a year and may struggle therefore to complete the forms as accurately as possible, or in a timely fashion.

## Response rates

Response rates continue to vary between settings. Bereavement Support has the lowest response rate by far, and investigation is ongoing as to how the bereavement data aspect of the MDS can be improved to make this a more meaningful part of the dataset. For most settings with the exception of Hospital Support, the majority of responses come from independently-run hospices, emphasising how much specialist palliative care is delivered outside the NHS.

Table 1a: response rates by setting, organisation type and management type, 2013/14

2013/14	Hospice		Hospital		Clinic	Community		NHS Trust	Health Centre	Total services responding
	Managed by NHS	Managed by Independent	Managed by NHS	Managed by Independent	Managed by NHS	Managed by NHS	Managed by Independent	Managed by NHS	Managed by NHS	
Inpatients	12	104	13							129
Day Care	13	110	9	2						134
Community Care	23	116	24	3	4	8	1		4	183
Hospital Support	11	24	96	2	1	1		1		136
Outpatients	13	91	43	1				1		149
Bereavement Support	9	93	11	1	1					115

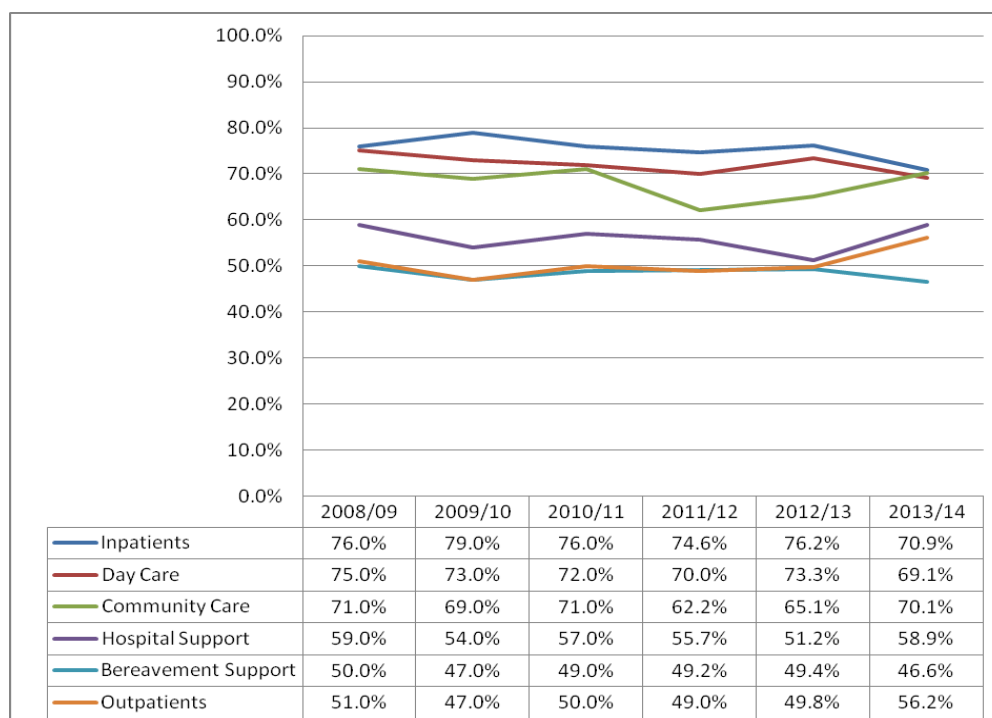
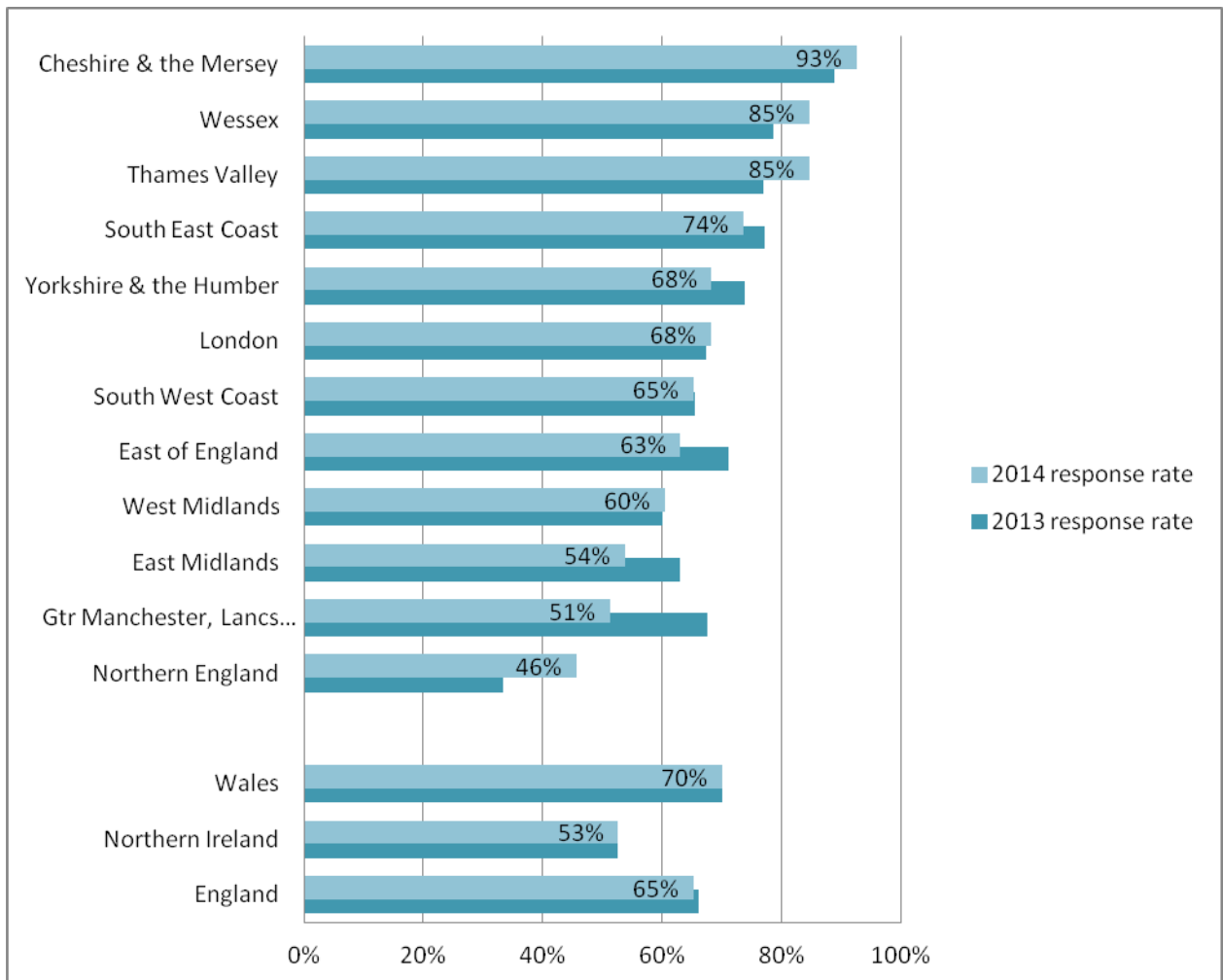


Figure 1.12: trend in response rates since the MDS revision in 2008/09



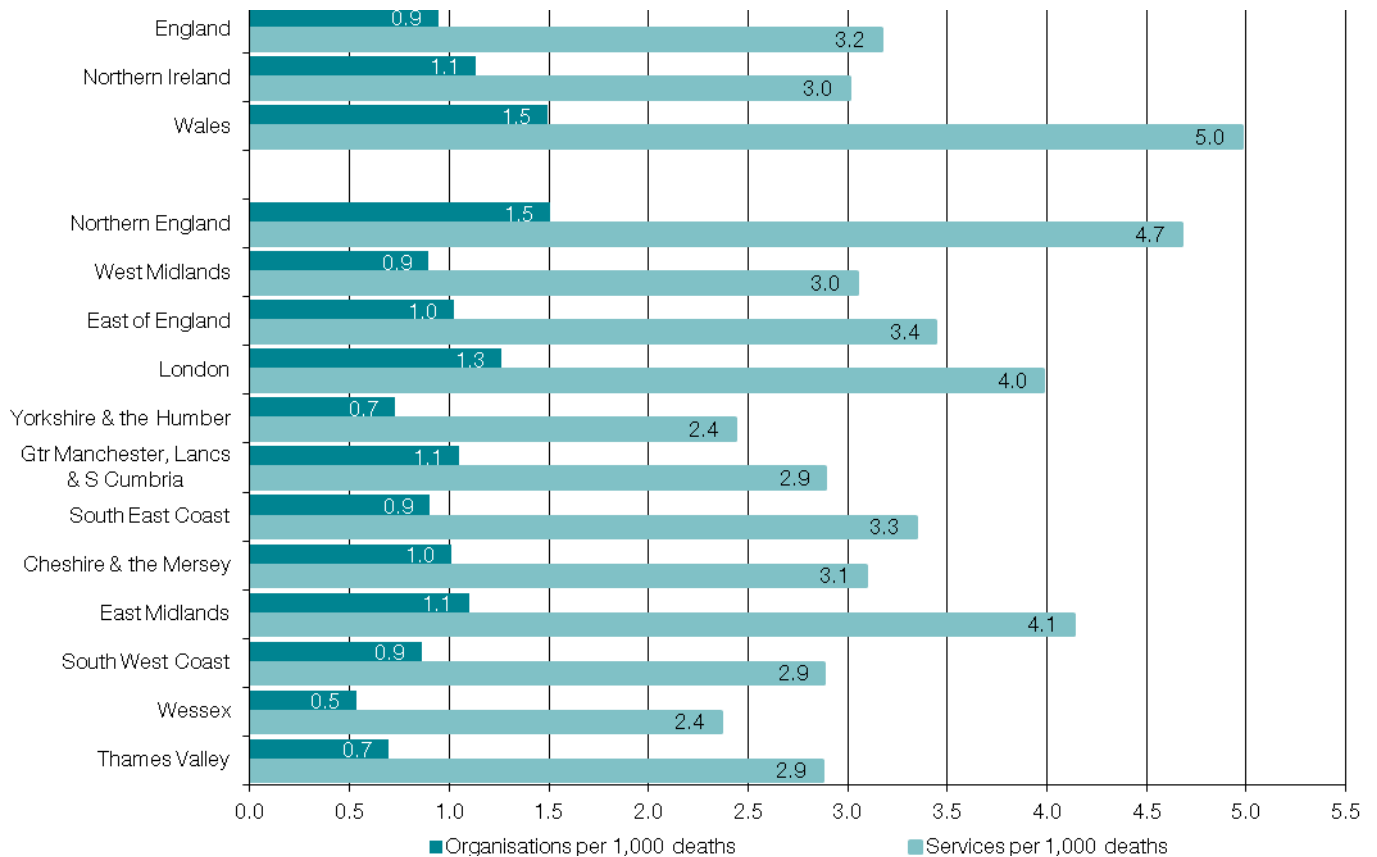
It should be noted that there have been improvements in response rates for the Community, Hospital Support and Outpatient settings for this year, although there is still more work to be done to increase response rates in every setting.



**Figure 1.13: regional variation in response rates to the MDS in 2012/13 and 2013/14**

There is significant regional variation in likelihood to respond; Northern England continues to be the area with the lowest response rate, although this year's 46% is up on last year's 33%. The reasons behind varied response rates in different areas is unclear and will be subject to further investigation as part of the ongoing MDS review.

## Service provision



This includes historical data from non-responding services. Death data are from [ONS Mortality Statistics: Deaths Registered by Area of Usual Residence, 2013 Registrations, Table 1b](#).

**Figure 1.14: geographical variation in service provision, 2013/14**

Service provision continues to vary considerably between regions. The overall number of services on the MDS database has decreased from 1,511 in 2011/12 to 1,482 in 2012/13 to 1,372 in 2013/14. This is partly due to an ongoing audit of the database, and partly due to organisations requesting to merge their returns, but further work on service provision might be apposite, to ensure that this is not a reflection of reduced services which will then impact on people's ability to access specialist palliative care.

## ***This year's review***

The ongoing review of the MDS has resulted in a number of changes. In last year's MDS report, a number of issues were listed that would be addressed by the review.

<b>Issue</b>	<b>Proposed solution from last year's MDS report</b>	<b>Action taken in 2014/15</b>
<p>The current picture of palliative care drawn by the MDS is incomplete. Analysis of past response rates has shown that 23% of organisations surveyed have sent in no data since the MDS was revised in 2008, and almost 10% of organisations have sent in no data at all since at least 2000. The data we do receive is of variable quality, making any kind of historical reporting a challenge.</p>	<p>Work will be undertaken to find out how we can support organisations with their responses to ensure we are collecting as much data of as high a quality as possible. The data cleansing process next year will be more stringent, and we will be seeking to understand the data submitted to us as fully as possible.</p> <p>We will consult with organisations who don't return the MDS, to see if there is anything we can do to support them in sending in data, as often the constraint is that reporting is too time-consuming or difficult, rather than the data not being collected. We will also be auditing our records of service provision, to make sure we aren't asking for data from services that organisations no longer run.</p>	<p>Discussions are ongoing with many organisations who submit to the MDS about the obstacles that prevent them from recording accurate data or creating accurate reports. Many of these obstacles are due to resourcing challenges, or to a perceived lack of importance of data. There is more work to be done to position data collection and reporting as a useful tool for care improvement.</p> <p>Internally, the data cleansing process has been improved for the 2013/14 collection and will be improved again in 2014/15. Inbuilt checks will be coded into the Excel forms to highlight issues with the data prior to submission, and more manual checks will be done once data is submitted and in a more timely manner, to ensure data is checked and updated as quickly as possible. As part of our commitment to better quality data, it will no longer be possible for organisation to submit data on a Word form.</p> <p>Most organisations who replied to our inquiries about why they don't submit MDS data indicated that they had other data reporting burdens that were more critical, such as reporting to their commissioners. We will look at how we can more closely align MDS data with the data requirements of commissioners.</p>

<b>Issue</b>	<b>Proposed solution from last year's MDS report</b>	<b>Action taken in 2014/15</b>
<p>Limited historical analysis of the MDS data is provided on a regular basis. This is due to both the varying quality of the data, and the inconsistency of returns. Different organisations return data each year, making it difficult to track whether changes in service provision are due to changes in practice, or simply an artefact of returns from organisations with different profiles of activity.</p>	<p>We plan to issue a sub-report later in 2014, analysing historical data only from services that have consistently sent in returns since the MDS was revised in 2008. We hope this will illustrate some trends within palliative care that are difficult to track in the usual national report. This report will be checked against the complete dataset where possible, in the hope that it will provide a representative sample of trends in the sector.</p>	<p>The sub-report was drafted but not published owing to uncertainty around how representative the data was, and whether it would add value to the sector as a whole to have a report covering only selected organisations; the work done on the sub-report was used to inform the new design for the national MDS report which includes a large volume of trend data. More cleansing has been done on the data to keep this trend reporting as reliable as possible, and where necessary, organisations submitting anomalous data have been excluded from the analysis to ensure data quality is as high as possible.</p>

<b>Issue</b>	<b>Proposed solution from last year's MDS report</b>	<b>Action taken in 2014/15</b>
<p>Another part of the data quality issue is that organisations may be interpreting the data definitions differently, leading to inconsistent comparisons across services. In addition, our service definitions do not necessarily fit the ways in which organisations work with patients, meaning the MDS does not capture the specialist palliative care sector as fully as it might.</p>	<p>NCPC will revisit the guidance that accompanies the data submission forms to ensure that service and data definitions are as clear as possible, in the hope this will improve the quality of the data received. We will also be looking at working with the many IT providers across the sector to see if reporting can be made easier for organisations.</p> <p>Work will also be carried out with organisations to understand whether there should be any changes to the data we collect, or how we report on it. This work will particularly focus on the Bereavement Support data and how we can better capture activity in this area.</p>	<p>The guidance for the existing forms has been redrafted for the 2014/15 collection.</p> <p>Consultation with the sector has resulted in the removal of several items from the MDS forms where data received was unreliable, defined differently between services, or unable to be reported on in any meaningful way. Our hope is that this lessens the data burden for services and makes returning data quicker and easier.</p> <p>We have talked with several IT providers but still have further work to do in this area.</p> <p>The Bereavement Support form has had minimal revision at this time, but work is ongoing into how a more complete bereavement dataset could be collected.</p> <p>For 2015/16, there will also be the addition of a new form to collect data about wider work done by specialist palliative care organisations, such as support given to carers, training and support for generalist staff, or outreach to groups who currently under-access specialist palliative care services. We hope this will give us a wider picture of all the work done by specialist palliative care, rather than focussing on medical data.</p>

<b>Issue</b>	<b>Proposed solution from last year's MDS report</b>	<b>Action taken in 2014/15</b>
<p>The individual reports produced from the MDS could be more useful, more insightful, and more detailed. The national report could likewise be refreshed.</p>	<p>The reports we provide to individual organisations and at national level have followed a consistent format for several years, and we will be looking at how we can update and improve them with a particular focus on providing individual services with historical information about their activity, so they can see any changes in the use of their services.</p> <p>We also hope to look at joining MDS data with other datasets to contextualise national reporting, and collecting case studies from organisations about how they've used data or where they've changed practice which has had effects visible in MDS data.</p>	<p>The individual reports have been significantly updated this year to include service-level historical data, to provide comparisons against figures of all patients seen in a year rather than just newly referred patients, and to add new fields of data to make use of more of the data submitted as part of the MDS.</p> <p>The national report has likewise been redesigned to be presented in a modular format, and with more historical data. This is in the hope of making it a more accessible document. Case studies have been included where possible to give an idea of the stories behind the submitted data. Where possible, MDS data has been linked to previously published reports and academic research, to give greater context to the findings.</p> <p>The data tables and graphs from the previous version of the national MDS report will still be available on request.</p>
<p>NCPC has access to a great deal of data on the specialist palliative care sector, which is not currently used for anything but the MDS report, and could be used for benchmarking, sharing of best practice, service improvement, and better understanding of the sector as a whole.</p>	<p>NCPC and Help the Hospices are to work together on ways the MDS data can be used to support and inform hospices, and to encourage individual organisations to make more use of their individually collected data.</p>	<p>NCPC and Hospice UK (previously Help the Hospices) have had initial discussions about providing the sector with a data dashboard that would allow comparison between services. Separately, work has been ongoing with individual services to try and encourage better quality data collection and to give ideas about how data could be used to improve care and demonstrate impact. There is still more work to be done in this area though.</p>

<b>Issue</b>	<b>Proposed solution from last year's MDS report</b>	<b>Action taken in 2014/15</b>
Individual-level data would allow more detailed analysis of the activity of specialist palliative care services, and the inclusion of an outcomes measure would allow assessment of patient experience with a view towards service improvement.	NCPC, Public Health England and Help the Hospices will be working together to scope the possibility of collecting individual-level data as a replacement to the current aggregate MDS, including an outcomes measure. We will also work with the Palliative Care Funding team on individual-level data collection.	Work is ongoing for Public Health England to develop and pilot an individual-level data collection in England. This work is aligned with the Palliative Care Funding work, in order to minimise the burden of data collection on services.

In addition to the review work detailed above:

- A survey was carried out looking at the sector's IT capacity.
- Internal work has been going on to audit the directory of services used as the basis for the MDS, to ensure we are surveying all organisations currently providing specialist palliative care, although there is more work to do on this.
- We plan to release short briefings of MDS data that give a quick overview of the position of the sector in 2013/14 and that are easy to understand.
- We also hope to produce more in-depth reports looking at particular aspects of the data, such as regional variations in access to specialist palliative care by people of BAME origin, or condition-specific summaries across all settings.